



First Concern to Action Tool Kit



AUTISM SPEAKS® EARLY ACCESS TO CARE INITIATIVE



The First Concern to Action Tool Kit

is designed to provide you with specific resources and tools to help guide you on the journey from your first concern regarding your child's development to action. If you have a concern about how your child is communicating, interacting or behaving, you are probably wondering what to do next.

This kit can help you sort that out.

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 tool kit 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

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!

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.

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 the opportunity and assistance 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 a pediatrician, family doctor, community health care worker, specialist or a trusted, knowledgeable professional in your community.

2. Be prepared 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. Prepare in advance for your visit with your health care provider.

3. Start the intervention process right away. Your child can receive a free evaluation without a formal diagnosis by contacting Early Intervention services through your state. You can find the contact information on the Autism Speaks website.

4. Contact the Autism Speaks Autism Response Team for assistance.

Call: 1-888-288-4762 (In Spanish: 1-888-772-9050)

Email: familyservices@autismspeaks.org

Text: ART to 30644

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, he or she should be evaluated for autism. 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.

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 advances 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 following list 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 [cdc.gov/milestones.com](https://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 three-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 four 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 him or her 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 (one is provided at the end of this tool kit) 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 autismspeaks.org/what-autism/video-glossary to learn more.



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 are 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 him or her. Bring the M-CHAT-R and any notes with you at the visit so he or she can more fully understand your concerns.



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 these “well child visits.” 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. Under the Affordable Care Act, many types of health insurance must cover free autism screening at 18 months and 24 months of age. 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 delays. 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.

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. The Modified Checklist of Autism in Toddlers (M-CHAT-R) is one of the AAP's recommended tools. The M-CHAT-R™ 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-R is called a "screener" because it is designed to identify those children who need to be referred for a full evaluation. There is a possibility that your child may screen positive on the M-CHAT-R 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-R 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-R screener indicates your child has some signs of autism, it will be important to complete the second step of the screening, the M-CHAT-R 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 your state or local Early Intervention agency. 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 obtain an evaluation by public Early Intervention and public education offices. The contact information for these offices changes depending on where you live and can be found on the [Autism Speaks website](#).
- You can obtain a developmental health assessment by a pediatrician, psychologist, neurologist or other specialist. This may or may not be covered by insurance, so be sure to check with your insurance provider. Get a referral from your primary care provider to be safe.
- You may also be referred to a private 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, 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 regarding your concerns about your child’s development.

The coordinator will also review your family’s 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 a parent, are an important member 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 public education department are provided at no cost to parents. They are funded by the state and federal government. In terms of services for your child, whether or not you will have to pay for certain services 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 Early Intervention representative 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 will 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 that you 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 observations 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 is said and 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 autismspeaks.org/resource-guide.

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 engaged social interaction. Research has shown that improved joint attention during infancy is an important part of later communication skills.

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 he or she is 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.

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

The first time you hear “autism” will likely be a devastating moment. The more you read and understand about autism, 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 have been seen in the past or may be part of current symptoms.

Step 1: Act early

If your child has been recently diagnosed with autism, you are probably feeling very overwhelmed. But there are many 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 first 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:

Call: 1-888-288-4762 (in Spanish: 1-888-772-9050)

Email: familyservices@autismspeaks.org

Text 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 Interventions 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 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 perspectives of your child and your 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](#).

Step 3: Monitor progress

Develop a plan with your Early Intervention specialist focused on your child's current level of skill 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 therapies is that they are 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 services?

Some of the strategies or skills that are taught in the clinic by your child's therapist may be able to be repeated at 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 atacf.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 others
7. Using predictable routines and predictable spaces for your child



Section V: Other Things to Know



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 worth pursuing.

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 that lead to impairments in their ability to effectively communicate – and limit 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 their bodies 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. This will be helpful in obtaining an accurate diagnosis and documenting progress.

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, people with autism are able 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 autismspeaks.org for more helpful tips, tools and resources for you and your family.

Information to Bring to Your Health Care Provider

Answer the questions below to help you discuss your concerns. You should also fill out the M-CHAT-R 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 he/she has concerns about your child? If so, what has he/she 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 Revised (M-CHAT-R)

The M-CHAT-R is validated for screening toddlers between 16 and 30 months of age, to assess risk for autism spectrum disorders (ASD). The AAP has endorsed its use at 18 and 24 months of age. This completed form should be brought to your health care provider.

The questions can be scored in less than 2 minutes using instructions found on www.mchatscreen.com.

A trained professional can discuss the responses and guide you to find the right resources. These 20 questions should be accompanied by a follow-up interview which will clarify some of the responses.

How to Score the M-CHAT-R

Please score 1 point if you answered “NO” to all questions EXCEPT 2, 5, and 12 or if you answered “YES” to questions 2, 5, or 12.

If your total score is 0 – 2, and your child is younger than 24 months, screen again after second birthday.

If your total score is 3 or higher, your child needs a follow-up interview with your provider or health care professional.

Even if your total score is less than 3, and you still have concerns about your child, bring this completed form and your questions to your provider for a more in-depth evaluation or referral.

Please fill out the following about how your child **usually** is. Please try to answer every question. If the behavior is rare (e.g., you’ve seen it once or twice), please answer as if he or she 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 or her 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 |

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-R, or Modified Checklist for Autism in Toddlers. The M-CHAT-R is a screening tool endorsed by the American Academy of Pediatrics (AAP) to be administered at 18 and 24 months.

Because no screening tool is perfect, research recommends that the original 23 questions include an M-CHAT-R Follow-Up Interview. As a screener, it identifies some indication of autism and the interview 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 M-CHAT-R Follow-Up Interview can be found at 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.

**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

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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 cdc.gov/actearly.

NATIONAL CENTER ON BIRTH DEFECTS AND DEVELOPMENTAL DISABILITIES

Learn the Signs. Act Early.





Autism Speaks is dedicated to promoting solutions, across the spectrum and throughout the life span, for the needs of individuals with autism and their families. We do this through advocacy and support; increasing understanding and acceptance of people with autism; and advancing research into cause and better interventions for autism spectrum disorder and related conditions.

**To find resources, join a fundraising walk or make a donation,
go to www.AutismSpeaks.org.**