

Dear Sir/Madam:

On behalf of the Massachusetts Act Early State Autism Team, we are pleased to provide you with the autism screening kit, *Considering Culture in Autism Screening*, to assist you in your role as a Massachusetts pediatric clinician or community health center provider.

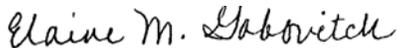
This free screening kit holds key information about culturally competent screening and referral practices to detect autism and other developmental concerns in children from immigrant families or from families whose primary language is not English. It is designed to strengthen provider knowledge and confidence when working with families from diverse backgrounds, and to increase the likelihood that *all* children in Massachusetts, regardless of cultural or linguistic barriers, will gain access to high-quality, routine autism screening.

Please print and share these reproducible materials widely with colleagues and staff. The kit is available in a downloadable electronic version that is free to the public at www.MAActEarly.org. Inside the kit, you will find:

- The clinician guide, *Considering Culture in Autism Screening*, complete with practical tips and case examples of screening in four cultures: Chinese, Haitian-Creole, Spanish, and Vietnamese (unstapled for easy printing)
- *Referral Information at a Glance* with listings of developmental evaluation centers in MA
- *Resources* with national listings of government, special, and disability-specific resources
- *Pediatric Developmental Screening Flowchart* to assist providers through the process (CDC)
- *Fact sheets* on screening, Autism Spectrum Disorders, and Asperger Syndrome (CDC)
- *Track Your Child's Developmental Milestones* brochures in English and Spanish (CDC)
- *Modified Checklist for Autism in Toddlers (M-CHAT)* * screening tool (Robins et al.) with instructions, a scoring guide, the brief 23-question M-CHAT screening tool (in English with translations in Chinese, Haitian-Creole, Spanish and Vietnamese), and the critically important M-CHAT Follow-up Interview
- A feedback survey (also available at www.MAActEarly.org).

The Massachusetts Act Early campaign aims to educate parents and professionals about childhood development, including early warning signs of autism and other developmental disorders, and encourages developmental screening and intervention. To learn more about our efforts, please visit our web site at www.MAActEarly.org or contact me at the email address below. Our state team is honored to share the enclosed screening kit with our colleagues and hope that it will lead to improved developmental outcomes for all children in Massachusetts.

All the best,



Elaine M. Gabovitch, MPA

MA Act Early State Team Leader and CDC Ambassador | Elaine.Gabovitch@umassmed.edu

* More M-CHAT translations are available at <http://www.mchatscreen.com>

Considering Culture in Autism Screening was developed through collaboration between the Massachusetts Act Early State Autism Team, pediatric developmental specialists, primary care clinicians practicing in neighborhood health centers with diverse populations, and community liaisons. The project was funded by the Association of Maternal and Child Health Programs (AMCHP) as part of the national "Learn the Signs. Act Early." program run by the Centers for Disease Control and Prevention's (CDC) National Center on Birth Defects and Developmental Disabilities (NCBDDD) in collaboration with the Association of University Centers on Disability (AUCD).



Massachusetts Act Early Campaign Brief

Massachusetts Act Early is the state campaign for the national "Learn the Signs. Act Early." program run by the Centers for Disease Control and Prevention's (CDC) National Center on Birth Defects and Developmental Disabilities (NCBDDD), in collaboration with the Association of University Centers on Disability (AUCD).

The campaign aims to educate parents and professionals about childhood development, including early warning signs of autism and other developmental disorders, and encourages developmental screening and intervention. The MA state team has set the following as its goals:

1. Develop affordable and feasible outreach plan to increase public awareness (e.g., disseminating free CDC Act Early materials in settings such as childcare, education, early intervention, medical offices, community centers, etc.)
2. Increase training for health care, early childhood and educational professionals;
3. Shorten the wait times between screening, diagnosis and intervention by
 - a. promoting early intervention (EI) adoption and implementation of a second level screening process;
 - b. coordinating interaction between EI and diagnosticians to streamline referrals to diagnostic centers
4. Develop and disseminate a culturally competent autism screening kit for pediatric offices and community health centers.

MA Act Early has 40-60 state team members, with an executive steering committee and three task forces. Since November 2010, MA Act Early has held three statewide summit meetings and five webinar/conference calls. State team members represent parents, university centers of excellence, health care organizations, public health, early education, day care, elementary and secondary education, disability agencies, family support agencies, advocacy groups, and research centers.

For more information about the MA Act Early State Autism Team, please contact:

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Considering Culture in Autism Screening

Massachusetts Act Early



www.MAActEarly.org
www.cdc.gov/actearly
1-800-CDC-INFO



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MA Act Early Culturally Competent Autism Screening Kit

Promoting the early identification of autism spectrum disorders across culturally and linguistically diverse populations.

Massachusetts has a diverse population and “one size” does not always fit all when it comes to monitoring healthy development. Even though effective autism screening requires your full range of clinical skills and resources, screening families from diverse backgrounds may take an expanded set of knowledge and skills.

The Massachusetts Act Early State Autism Team, along with pediatric developmental specialists, primary care clinicians practicing in neighborhood health centers with diverse populations, and community members, collaborated to learn the challenges and provide clinicians who screen with tips for promoting the identification of autism spectrum disorders (ASDs) and other developmental disabilities for children from immigrant families or from families whose primary language is not English. Our team interviewed a variety of experienced clinicians and community members who shared their thoughts about what works well in ASD screening for children from families from these diverse backgrounds.

Included in this screening kit, you will find:

- Clinician Tips for Culturally & Linguistically Competent Autism Screening
- Modified Checklist for Autism in Toddlers (M-CHAT) screening tool in English and in four translations: Chinese, Haitian Creole, Spanish, and Vietnamese. (Please note that there are a number of autism screening tools available. The M-CHAT is enclosed in this screening since it is free to the public, offered in many translations, and provides a follow-up interview to reduce false positive rates. More information at: www.tinyurl.com/m-chat-autism-tool.)
- An assortment of CDC “Learn the Signs. Act Early.” materials for use in your practice.
- Resource and referral information may be found on the “Referral Information at a Glance” sheet.

We hope that this resource will prove valuable in helping navigate the ASD screening and referral process with all children and their families.

For more information, please contact Elaine Gabovitch, MA Act Early Ambassador & State Team Leader at: Elaine.Gabovitch@umassmed.edu.

Thank you to the following contributors

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More information at:

- www.MAActEarly.org
- www.cdc.gov/actearly

Clinician Tips

THINK PROCESS

Culturally & Linguistically Competent Autism Screening

Screening for ASDs is the first step of an ongoing process of identification. It is especially critical for clinicians to understand this when working with families from diverse backgrounds, particularly when their primary language is not English or when they have different views on child development since it may require more persistent follow up in such circumstances to keep families engaged.

Getting started

- Explain to the family that you routinely screen and observe young children for healthy development.
- Ask general questions about the child's communication skills and social interactions, but it is also important to ask specific questions about how their child is doing by using a screening tool.
- It is equally important to ask questions about the family's understanding of and expectations for child development. This could provide a wealth of information and set the stage for mutual communication about child development in general and the child's development specifically.
- Remember that in some families, questions about a child's skills may go unanswered since they may feel intrusive. Some families may view screening as "looking for trouble" or feel that things clinicians think are problems are not an issue. Still for other families, their responses may shed light on their ability, background or resources. Thus, communicating slowly and clearly while listening carefully and fully engaging families produces the best results.

Following up

- Even if screening results are negative, it is still important to repeat the screening test at the next visit or sooner, if warranted.
- If you or the family have significant concerns, then referral to a specialist for additional evaluation may be the next step, even if screening results are negative.
- It can sometimes take multiple conversations, even several visits, to discuss concerns with families and work towards referral.

More information at:

- www.MAActEarly.org
- www.cdc.gov/actearly

Rising to the Challenge

- Approximately 1 in 110 children have an autism spectrum disorder.
- The American Academy of Pediatrics (AAP) recommends ongoing surveillance and ASD-specific screening at 18 and 24 months or whenever there is concern.
- Autism screening tools, such as the M-CHAT, are more accurate when used in conjunction with clinical judgment.
- Children with autism from minority backgrounds are often diagnosed at a later age than other children
- The concepts of screening, early identification and early intervention may be unfamiliar for families from diverse backgrounds. For many families, these concepts are culturally bound and they may perceive that their children will be stigmatized in their communities by participating in these practices.

→Remember that all ASD screening tools must be used in their entirety to obtain valid results. For the M-CHAT, this includes conducting the follow-up interview—a critically important final step in the process. It can be found at:

www.tinyurl.com/m-chat-follow-up

Clinician Tips

THINK PROCESS

More than Translation

Because terms used in screening tools may have somewhat different meanings once translated, consider whether parents understand the screening questions in addition to having other possible primary language barriers. Consider literacy level, as well as language. Interpreters (who are proficient in the language) and cultural liaisons (who are proficient in distinct cultural issues) can assist greatly since written screening tools may be difficult for some families to complete, and for clinicians to interpret. When working with families from diverse backgrounds, having thorough and clear conversations about the screening questions is critical to be certain that families understand and answer questions accurately.

→ It is important to consider that some terms may not exist in a target language. In addition to translation, it may be equally important to develop new materials in the target language as well.

→ For some screening tools, follow-up questions are a formal part of the assessment (e.g., the follow-up interview in English for the M-CHAT - see page 3.)

Ask

Communicating concerns about a child's development in a different language or across cultures can sometimes be tricky. While having a general understanding about the cultural group you serve may help in anticipating particular reactions or issues, clinicians must avoid stereotyping. Each family is distinct, irrespective of racial or cultural identity. When discussing screening concerns, miscommunication can often be avoided by starting with the families' perspective.

Ask:

"Do you have any concerns about your child's development?"

"What do you think is the cause of this concern?"

(This is an invitation for the parents to tell you what they are thinking).

Clinicians should express their concerns only after the family's perspective has been shared, but they should also be mindful that families may not see a concern, especially if they are first-time parents. Targeted questions about the child's behavior, communication, play, and interactions with other children and adults help clinicians probe further.

When the issue is a failed (positive) screening test, it is important to emphasize that it identifies only that a child is at higher risk for ASDs, but is not a diagnosis. Be careful about

using the word "autism" if families do not ask you about it specifically. If they do, it is critical to ask:

"What have you heard about autism?"

"What does the term "autism" mean to you?"

Reassure parents that when a child has problems with talking, interacting, or behavior, there are many things that can help a young child develop these skills.

Don't Go It Alone

Whether you work with interpreters, cultural liaisons, nurses, community agencies, social workers, or others, enlist their collaboration in supporting the family through the referral process. Identifying an available person in your practice or community with cultural and linguistic knowledge, and professional experience in ASDs, can make a positive difference to families in a successful identification and intervention process.

NEXT STEPS: Referral for Further Evaluation

- Contact the evaluation specialist (e.g., developmental pediatrician, pediatric neurologist) and/or referral agency directly to discuss any unique needs the family may have.
- Call to remind the family when and why the evaluation will be done.
- Discuss the family's comfort with speaking and understanding English and offer an in-person interpreter to assist at all visits, making sure that the interpreter is available free of charge.
- Schedule a follow up visit for one or two weeks after the specialty evaluation to talk through what happened at the visit.
- Reinforce that such an assessment is part of standard care since the concepts of screening, early identification and early intervention may be unfamiliar for families from diverse backgrounds. For many families, these concepts are culturally bound and they may perceive that their children will be stigmatized in their communities by participating in these practices.

→ In some cultures, the word "research" or "evaluation" may be met with mistrust. Take time to explain.

More information at:

- www.MAActEarly.org
- www.cdc.gov/actearly

Clinician Tips

UNIQUE CONSIDERATIONS

Our experts highlighted unique considerations in the screening and referral process when working with culturally and linguistically diverse populations from immigrant backgrounds and/or whose primary languages are not English. These tips may help you find a new approach if your typical process meets with challenges.

Awareness

- Be aware that discussions about a problem, concern, or potential diagnosis such as autism can be anxiety provoking and confusing for most parents, and even more so if language and cultural barriers are layered on.
- Some families may not have seen children with ASDs included in their communities or in their countries of origin.
- Media campaigns around ASD awareness may not reach many of these populations.

→Have you ever considered that most media campaigns are typically in English?

Surveillance

- Recognize that children's behavior in the office may reflect cultural norms and may not be a true reflection of a disorder. When in doubt, explore further.
- Conversely, some behaviors seen in ASDs may be viewed as culturally appropriate or even desired behavior.

→Did you know that in certain cultures, eye contact with adults is discouraged as an inappropriate, even rude, behavior? Active children may be regarded as undisciplined. Parents may be embarrassed by such behaviors. On the other hand, playing alone may be interpreted as being independent and may be highly valued. Having no friends may be a good thing to avoid problems with other children.

Screening Administration

- Introduce the screening tool as an important way to catch concerns so you and the family can address them early if necessary.
- Go over the screening tool with the family during or after completion if at all possible.
- Use of translated screening tools and an interpreter will increase the accuracy of the results, even for fluent English speakers.
- When clinicians are not aware of diverse cultural beliefs and practices, cultural liaisons can provide insight to increase sensitivity to such differences.

→Note that there are different levels of fluency in a second language. Families can be fluent in ordinary interactions, but not have the level of fluency to understand new and complex material. There should always be a choice for families about interpreters and translated materials.

Communicating concerns and screening results

- Ask first about the family's concerns, if any, when discussing screening results.
- Finding common ground between your concerns and families' perceptions may take time and possibly multiple visits. Building a trusting relationship with families is key.
- Keep the conversation going, looking for shared interests and building on those over whatever time the family needs.

→In some cultures, even talking about autism may be viewed as stigmatizing, brought on by perceived supernatural forces, or "bad luck."

Referral for diagnostic evaluation and services

- Check to make sure your referrals offer appropriate linguistic and cultural resources. Help families with the legwork.
- Make sure they know the date and time of the visit, have a way to get there, and have a contact number to call with questions.
- When needed, use community supports to help connect families to professional referrals.

→It's important to have a system in place in your practice to coordinate families for referral appointments.

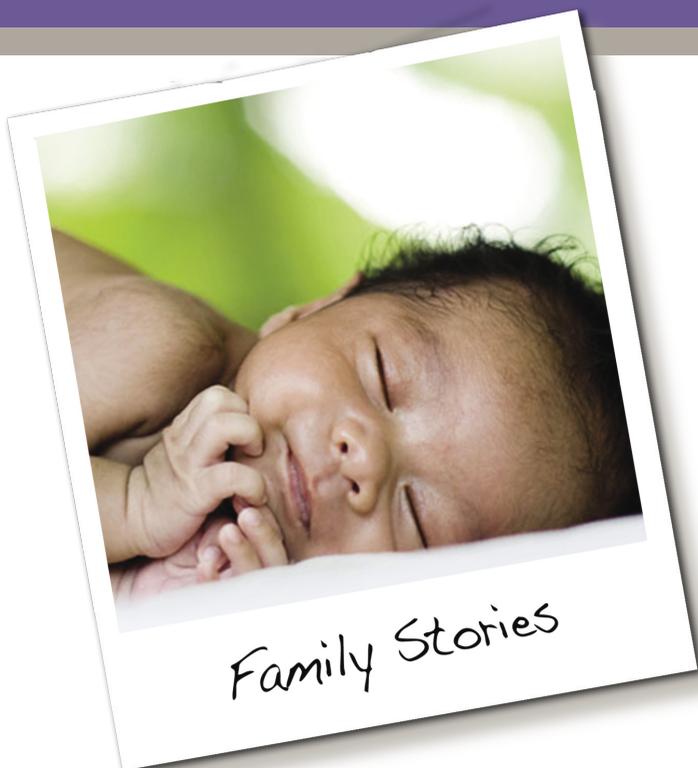
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Clinician Tips

PUTTING IT ALL TOGETHER



Ming's Story

Ming is a 30-month-old who comes to you for a well-child visit with his mother and grandparents. His mother speaks English fairly well, but the family primarily speaks Cantonese. They are proud that he knows many letters of the alphabet already, but he only uses six single words in Chinese and English. Ming has fleeting eye contact and does not involve you or his family while playing with toys in the office. His mother is given an M-CHAT translated into Chinese. She leaves many answers blank, and states that she has no concerns about Ming's development. She admits that she wants Ming to be ready for preschool in a few months. You use this concern to suggest an Early Intervention (E.I.) referral but the family would prefer not to have someone come to their home so you work with your local E.I. to provide an alternative setting. You also schedule another visit two weeks later with both parents with a Cantonese interpreter to review the M-CHAT.

At the next visit, you learn that Ming's parents notice that his language is delayed. The M-CHAT reveals delays with pointing and play. You recommend a developmental evaluation to support Ming's language skills. His parents agree to the subspecialty evaluation, and schedule a follow up visit

one week after the specialty evaluation. Ming is diagnosed with ASD, and begins to receive intensive early intervention. The developmental pediatrician also refers the family to a family autism center. They tell you on follow-up that they had been suspecting autism, however they were worried about the label and share that one translation of autism in Chinese means "closed doors." On subsequent follow-up, Ming shows consistent progress and his family feels more supported.

François' Story

François' mother, who recently emigrated from Haiti, has brought her firstborn two-year-old son to visit you today. She describes him as having been a quiet infant who had more vocabulary at 15 months, but now speaks only in single, non-recognizable words. François has episodes of uncontrollable agitation and has been labeled "Ti Moun Dezod" (undisciplined child) at home, and "Ti moun mal eleve" (a poorly raised child) outside of the family. François' father has started spanking in order to control his outbursts. Although late-talking runs in the family, François' aunt has expressed concern over his loss of language, peculiar hand mannerisms, and repetitive lining up of cars, and has suggested that François' condition may be due to supernatural causes. His "Gran Ma" has requested that the family take one year to raise François in prayer to make sure all bad spirits leave the house and François in peace. In the meantime, she is treating him with a daily homemade remedy of one cup of water soaked overnight in mortar (Dlo pilon) to stimulate speech.

François' mother comes to the clinic with concerns about his loss of language and possible deafness. You ask a Creole interpreter to help her fill out the M-CHAT screening tool. She endorses three critical items. You explain that those items indicate that François needs further evaluation by a developmental pediatrician who will rule out or in a specific diagnosis. You tell his mother that such developmental concerns are more common in children than previously thought, and that much can be done to help François and the family. You refer François to the local E.I. provider and help to arrange a visit with the developmental pediatrician.

More information at:

■ www.MAActEarly.org ■ www.cdc.gov/actearly

Clinician Tips

PUTTING IT ALL TOGETHER



Maria's Story

Maria is a healthy, two-year-old second-born daughter of a family who emigrated from the Dominican Republic only one year ago. She comes in today for her second well-child visit accompanied by her mother who speaks only Spanish. Her mother completes the M-CHAT in Spanish, and endorses three critical items, with six failed items overall. Maria does not have words yet. You notice the child staring at the lights, flapping her arms, and not turning when you call her name. Rather than playing with a doll in your office, she flips it several times over. In reviewing the items her mother endorsed on the M-CHAT and her behavior at home, you are highly concerned that she has classic autism.

You review the M-CHAT with Maria's mother. You ask, "Will you tell me more about these comments?" to start the conversation. If her mother had not conveyed worries, you would have expressed your perspective. But instead, you agree with the M-CHAT responses that you observe (such as not responding to her name as you would expect) and ask what she makes of this behavior. By combining your observations with her comments, you communicate a joint approach to viewing Maria's development. You stimulate

more conversation by stating, "I'm worried these are signs of a developmental concern, but I want to know how you as a parent see this." You acknowledge her perspective while sharing yours. Finally, you introduce the idea that sometimes language delays are part of a larger picture such as autism, meaning both language and social interactions are involved, and that further evaluation with a specialist could help figure that out. You ask if she has heard of autism, and if she knows any children affected. While explaining that the questions she answered and your visit observation are part of screening and don't mean you are diagnosing autism, you want to be sure you understand the correct nature of her development.

Maria's mother is given material about ASDs written in Spanish. She agrees to have her evaluated by E.I. and you make an appointment for them to come back to see you in two weeks. A Spanish-speaking nurse spends more time with the family, and they call E.I. together. Maria's mother returns in two weeks, and she and her husband have many questions. They looked up autism on the Internet and are very concerned. You join them in their concern and support the plan for an E.I. evaluation. Additional referral to a developmental specialist is appealing to the family, and you arrange that as well.

Key points to consider for families from diverse backgrounds

- The family may not have the familiarity with autism that many English-speakers have. They may not have known of any children in their native country with autism or developmental disabilities.
- Expectations for language development and other skills of independence may differ in their culture. It may be considered "normal" for two year olds to lack language or more elaborate play.
- Based on their experiences with schools and health care in their native country, the parent may have limited or negative expectations of what U.S. systems can offer.
- Many parents of children diagnosed with autism have concerns about their child prior to age two.
- At age two, if a child has a language delay, an autism screening should be done and close follow up will be needed, even if the screening is negative and a referral for further evaluation is not necessary at that time. The next well-child visit will not be until one year later and valuable intervention time may be lost. Schedule a visit within four weeks to reassess.

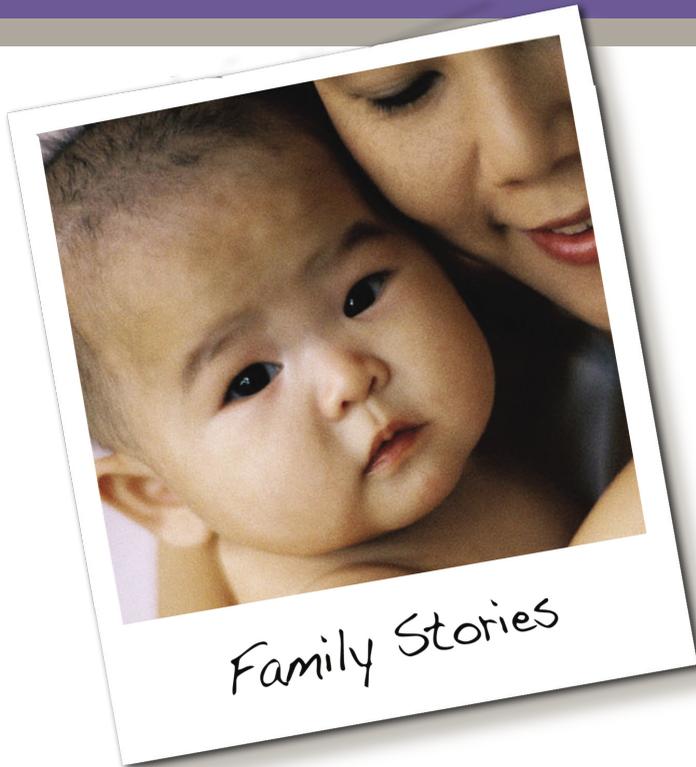
More information at:

- www.MAActEarly.org
- www.cdc.gov/actearly

CULTURALLY COMPETENT AUTISM SCREENING KIT | 7

Clinician Tips

PUTTING IT ALL TOGETHER



Daniel's Story

On a busy Monday afternoon, you walk into the exam room to greet your new patient, three year-old Daniel and his family. Daniel's mother speaks only Vietnamese so you call the telephone interpretation line because you do not have an in-house interpreter available. Through the interpreter, Daniel's mother reports that she is worried because Daniel only uses three to four words and has "bad" behavior like temper tantrums and not listening. He also sleeps poorly and is a picky eater.

His mother shares that she has been concerned about Daniel since before he turned two. He is very different from his two older sisters. She shared her concerns with their previous primary care clinician at his 24-month well-child visit, but was told that boys often talk later than girls, he was hearing both Vietnamese and English at home (through television and his sisters), and she needed to be more consistent with discipline. Daniel, his sisters, and mother live with her parents who also believe that Daniel is a boy and will talk later, especially because he has two sisters who are more than willing to speak for him. His mother feels there is something more going on and has decided to see you after her friend told her how you helped them find a special education classroom for their preschooler with a developmental delay.

You observe Daniel and are concerned that he does not use any words and wanders around the exam room without purpose. You want to complete an M-CHAT with the family but don't have a Vietnamese copy. You then remember it is available online and download a copy that his mother completes. She endorses three critical items and you review these with the telephone interpreter who confirms that these are accurate responses. You revisit his mother's concerns and support her sense that Daniel needs a more detailed evaluation which she requests you help arrange with a developmental pediatrician. You also connect her with her local school system since at age three, Daniel is now eligible for school-based services.

Questions to ask families

- What is causing the most concern now?
- What kind of things do you think would help your child develop these areas (such as: language, play skills, social engagement, etc.)?
- Did they have Early Intervention in your country? What would happen there to kids whose development was behind?
- What do you think is causing these concerns?
- What would you like to happen as a result of this visit?

Practice points

- A parent may not respond immediately to your offer of early intervention and specialist evaluation. Some may need several more visits to get to the point of understanding and readiness necessary to enable further assessment and treatment.
- Providing written information in the family's native language will give them an opportunity to process what you have said in their own time frame. Following up with native speakers or staff from the family's culture may provide another level of support as well.
- If you or the child's family has persistent concerns about development, refer for further evaluation.

Referral Information AT A GLANCE

MASSACHUSETTS ACT EARLY PROGRAM

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A free, downloadable version of the entire MA Act Early Culturally Competent Autism Screening Kit is available at:
www.MAActEarly.org

CDC LEARN THE SIGNS. ACT EARLY. PROGRAM

- Free, downloadable CDC “Learn the Signs. Act Early.” materials in multiple languages.
www.cdc.gov/ncbddd/actearly/downloads.html#lang

FOR FURTHER EVALUATION

The list below provides contact information for some of the centers in Massachusetts where clinicians can refer patients and families for further diagnostic evaluation and information. Program specifics vary by location so it may be helpful to discuss the needs of a family directly with the program when making a referral.

- Baystate Medical Center, Springfield
Pediatric Psychology 413-794-5075
Pediatric Neurology 413-794-0814
Developmental Pediatrics 413-794-0904
www.baystatehealth.com
- Boston Medical Center, Boston
Developmental and Behavioral Pediatrics Clinic 617-414-4260
Pediatric Neurology 617-414-4501
www.bmc.org/pediatrics-developmentalbehavioral.htm
- Children’s Hospital, Boston
Developmental Medicine Center 617-355-7971
Neurology 617-355-6388
Deaf and Hard of Hearing Program 781-216-2215
(if child has hearing loss and possibly ASD)

(Other sites located in Brockton, Lexington, Peabody, Waltham, Weymouth & Wilmington)
www.tinyurl.com/childrensbostdbmed
- Franciscan Hospital For Children, Boston 617-254-3800
www.franciscanhospital.org/Home/ProgramsServices/page.aspx/996
- Harvard Vanguard Medical Associates, Burlington 781-221-2800
Developmental Consultation Service
www.harvardvanguard.org
- Mass General Hospital, Boston 617-726-3402
Pediatric Neurology
www.massgeneral.org/children/specialtiesandservices/neurology/default.aspx

- MGH Lurie Center for Autism, Lexington 781-860-1700
www.tinyurl.com/lurieautismcenter
- National Autism Center Clinic, Randolph 877-313-3833
www.nationalautismcenter.org/service/
- Reliant Medical Group, Worcester 800-283-2556
www.reliantmedicalgroup.org
- St. Anne’s Hospital, Fall River 508-235-5285
Autism Clinic Team
www.stewardhealth.org/St-Annes-Hospital
- Tufts Floating Hospital for Children
Center for Children with Special Needs, Boston
Little Kids Clinic (Boston) 617-636-7242
Zero to Three Clinic (Chelmsford) 978-937-6362
(Other sites located in Metrowest and Woburn)
www.floatinghospital.org/OurServices/CCSNDevelopmentalBehavioralPediatrics/
- UMass Memorial Medical Center, Worcester
Developmental and Behavioral Pediatrics 508-856-3030
Neurology 508-856-5965
www.umassmemorial.org/MedicalCenterip.cfm

MASSACHUSETTS STATE SERVICES

- Department of Public Health, 800-905-8437
Early Intervention Program
www.mass.gov/dph/earlyintervention
- Department of Developmental Services 617-727-5608
Autism Division
www.mass.gov/dds

ADDITIONAL CULTURALLY COMPETENT RESOURCES

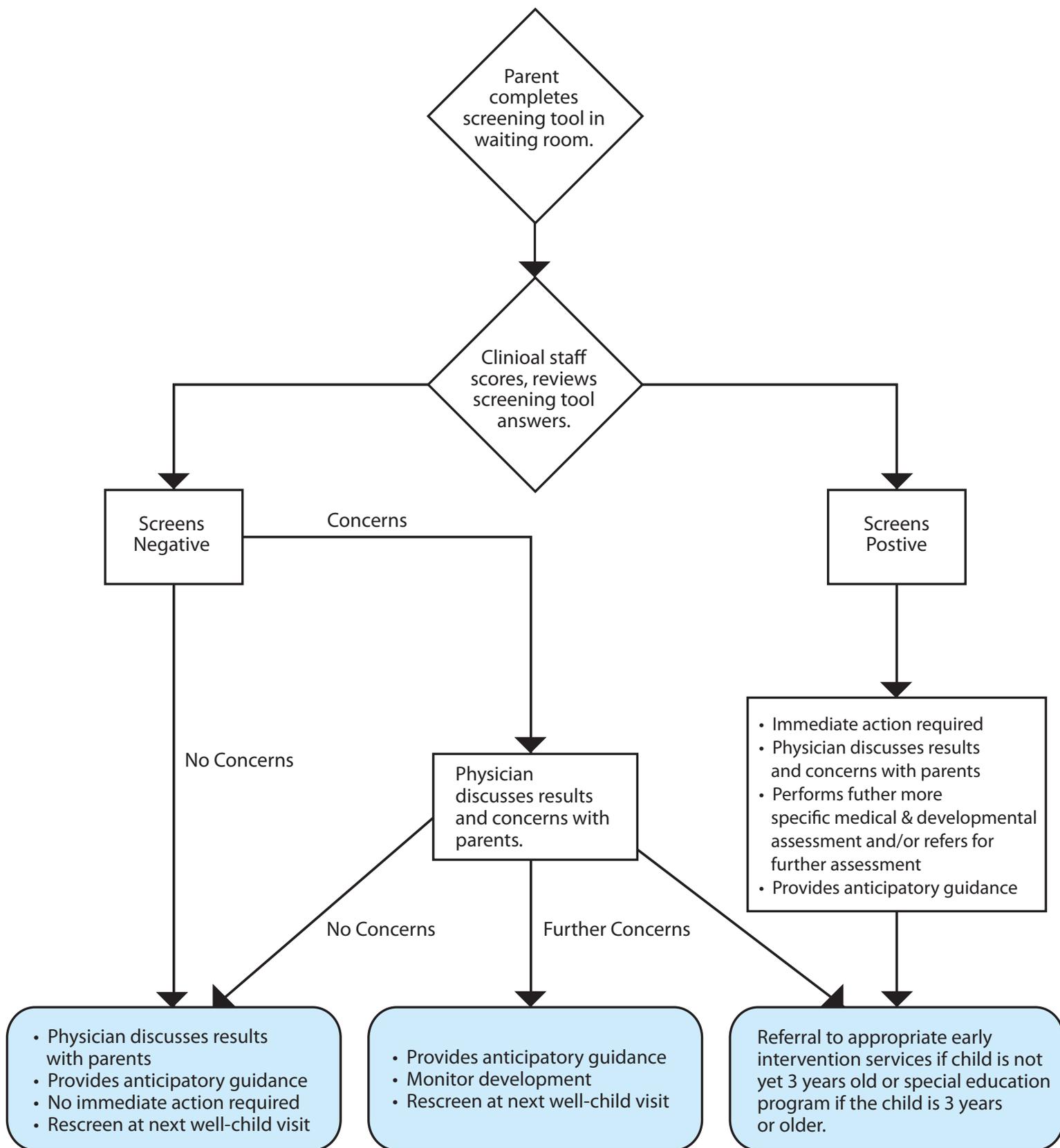
- Autism Consortium 617-432-6961
Free downloadable parent information packet on autism spectrum disorders and treatment. Available in English, Spanish, Portuguese, Chinese, Vietnamese and Haitian Creole
www.autismconsortium.org/empowering-families/parent-information-packet.html
- National Center on Cultural Competence 800-788-2066
A range of culturally and linguistically competent strategies and approaches are described at this web site for professional and organizations to practice.
<http://nccc.georgetown.edu/>

→ This list is not exhaustive and inclusion in it does not signify an endorsement. Information about these agencies and providers is widely available on the Web.

More information at:

- www.MAActEarly.org ■ www.cdc.gov/actearly

Pediatric Developmental Screening Flowchart



Sample Delineation of Pediatric Staff Roles for Developmental Screening

Shaded areas indicate which activities are the responsibilities of each staff member. Items in orange are the primary responsibility of the pediatrician.

<i>Activity</i>	<u>Staff</u>	Pediatrician	Head Nurses	Office Manager	Other Nurses	Office Staff
Establish the developmental screening and referral system within the practice – agree on screening protocol and encourage support from office staff.		■	■	■		
Participate in AAP training on the importance of early childhood development, early intervention, the screeners, appropriate referrals, and billing information.		■	■	■		
After individual training, train other staff members (e.g., nurses) in the practice who will be scoring the tool.		■			■	
Screen children at designated well-child visit, or if there is a concern.		■	■	■	■	
Evaluate their developmental status. Identify children with and at risk for developmental problems.		■				
Provide feedback to parents.		■				
Advise parents on development and behavior.		■				
Initiate appropriate further assessment, referrals/interventions.		■				
Recognize the manifestations of stressors in parenting, evaluate the risks involved and determine necessary referrals/interventions.		■				
Score screening tools.*			■		■	■
Distribute patient materials.					■	
Maintain and update referral lists.					■	
Enter data into the web-based data system, if available.					■	
Medical records staff: maintain system.					■	
Secretarial staff: copy or order tools, maintain inventory of all necessary supplies.					■	
Receptionists: serve as a resource for parents (e.g., explain tool, ask if the parent needs assistance in filling it out).					■	■

*Scoring could be automated.

Instructions and Permissions for Use of the M-CHAT

The Modified Checklist for Autism in Toddlers (M-CHAT; Robins, Fein, & Barton, 1999) is available for free download for clinical, research, and educational purposes. There are two authorized websites: the M-CHAT and supplemental materials can be downloaded from or from Dr. Robins' website, at www2.gsu.edu/~wwwpsy/faculty/robins.htm

Users should be aware that the M-CHAT continues to be studied, and may be revised in the future. Any revisions will be posted to the two websites noted above.

Furthermore, the M-CHAT is a copyrighted instrument, and use of the M-CHAT must follow these guidelines:

- (1) Reprints/reproductions of the M-CHAT must include the copyright at the bottom (© 1999 Robins, Fein, & Barton). No modifications can be made to items or instructions without permission from the authors.
- (2) The M-CHAT must be used in its entirety. There is no evidence that using a subset of items will be valid.
- (3) Parties interested in reproducing the M-CHAT in print (e.g., a book or journal article) or electronically (e.g., as part of digital medical records or software packages) must contact Diana Robins to request permission (drobins@gsu.edu).

Instructions for Use

The M-CHAT is validated for screening toddlers between 16 and 30 months of age, to assess risk for autism spectrum disorders (ASD). The M-CHAT can be administered and scored as part of a well-child check-up, and also can be used by specialists or other professionals to assess risk for ASD. The primary goal of the M-CHAT was to maximize sensitivity, meaning to detect as many cases of ASD as possible. Therefore, there is a high false positive rate, meaning that not all children who score at risk for ASD will be diagnosed with ASD. To address this, we have developed a structured follow-up interview for use in conjunction with the M-CHAT; it is available at the two websites listed above. Users should be aware that even with the follow-up questions, a significant number of the children who fail the M-CHAT will not be diagnosed with an ASD; however, these children are at risk for other developmental disorders or delays, and therefore, evaluation is warranted for any child who fails the screening.

The M-CHAT can be scored in less than two minutes. Scoring instructions can be downloaded from www2.gsu.edu/~wwwpsy/faculty/robins.htm. We also have developed a scoring template, which is available on these websites; when printed on an overhead transparency and laid over the completed M-CHAT, it facilitates scoring. Please note that minor differences in printers may cause your scoring template not to line up exactly with the printed M-CHAT.

Children who fail more than 3 items total or 2 critical items (particularly if these scores remain elevated after the follow-up interview) should be referred for diagnostic evaluation by a specialist trained to evaluate ASD in very young children. In addition, children for whom there are physician, parent, or other professional's concerns about ASD should be referred for evaluation, given that it is unlikely for any screening instrument to have 100% sensitivity.

M-CHAT

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 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/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 small toys (e.g. cars or blocks) 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

Modified Checklist for Autism in Toddlers (M-CHAT)*

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*The full text may be obtained through the Journal of Autism and Developmental Disorders, April 2001

PLEASE NOTE: The M-CHAT was not designed to be scored by the person taking it. In the validation sample, the authors of the M-CHAT scored all checklists. If parents are concerned, they should contact their child's physician.

Abstract

Autism, a severe disorder of development, is difficult to detect in very young children. However, children who receive early intervention have improved long-term prognoses. The Modified Checklist for Autism in Toddlers (M-CHAT), consisting of 23 yes/no items, was used to screen 1,293 children. Of the 58 children given a diagnostic/developmental evaluation, 39 were diagnosed with a disorder on the autism spectrum. Six items pertaining to social relatedness and communication were found to have the best discriminability between children diagnosed with and without autism/PDD. Cutoff scores were created for the best items and the total checklist. Results indicate that the M-CHAT is a promising instrument for the early detection of autism.

Background

The M-CHAT is an expanded American version of the original CHAT from the U.K (Baron-Cohen et al., 1992; 1996). The M-CHAT has 23 questions using the original nine from the CHAT as its basis. The goal of the ongoing M-CHAT research is to demonstrate adequate psychometric properties of the M-CHAT (sensitivity, specificity, positive and negative predictive power). The M-CHAT is available for clinical and research use, with the following caveats:

1. Clinical use should proceed with caution, given that the current scoring system is designed to maximize sensitivity (i.e., identify as many children with autism spectrum disorders as possible), which results in a number of false positive cases (i.e., children who will not be diagnosed with an autism spectrum disorder, although they fail the M-CHAT). Once cross-validation of the M-CHAT is complete, the scoring may be revised.
2. The M-CHAT is not designed to detect all possible developmental disorders. Any parents who have concerns about their child should see their child's physician, regardless on the child's score on the M-CHAT.

M-CHAT research is ongoing at the University of Connecticut and Georgia State University. The follow-up study of the initial sample is expected to be published in the near future. This research is supported by funding from the National Institute of Child Health and Development, the Maternal and Child Health Bureau, and the National Alliance for Autism Research. For more information, please contact Diana Robins at drobins@gsu.edu or Deborah Fein at Deborah.fein@uconn.edu.

M-CHAT Scoring Instructions

A child fails the checklist when 2 or more critical items are failed OR when any three items are failed. Yes/no answers convert to pass/fail responses. Below are listed the failed responses for each item on the M-CHAT. Bold capitalized items are CRITICAL items.

Not all children who fail the checklist will meet criteria for a diagnosis on the autism spectrum. However, children who fail the checklist should be evaluated in more depth by the physician or referred for a developmental evaluation with a specialist.

1. No	6. No	11. Yes	16. No	21. No
2. NO	7. NO	12. No	17. No	22. Yes
3. No	8. No	13. NO	18. Yes	23. No
4. No	9. NO	14. NO	19. No	
5. No	10. No	15. NO	20. Yes	

修正的幼兒自閉症檢查表 (M-CHAT)

請按照你孩子平常的狀況回答下列問題。儘量每個問題都回答。如果那種行為很少出現（例如：你看過一、兩次），請以孩子沒有做過來作答。

- | | | |
|--|---|---|
| 1. 你的孩子喜歡你搖他或是把他放在你的膝蓋上等等之類的事嗎？ | 是 | 否 |
| 2. 你的孩子對其他孩子有興趣嗎？ | 是 | 否 |
| 3. 你的孩子喜歡爬東西，像上樓梯嗎？ | 是 | 否 |
| 4. 你的孩子喜歡玩捉迷藏嗎？ | 是 | 否 |
| 5. 你的孩子會假裝，例如，講電話或照顧洋娃娃，或假裝其他事情嗎？ | 是 | 否 |
| 6. 你的孩子曾用食指指著東西，要求要某樣東西嗎？ | 是 | 否 |
| 7. 你的孩子曾用食指指著東西，表示對某樣東西有興趣嗎？ | 是 | 否 |
| 8. 你的孩子會正確玩小玩具（例如車子或積木），而不是只把它們放在嘴裡、隨便亂動或是把它們丟掉？ | 是 | 否 |
| 9. 你的孩子曾經拿東西給你（家長）看嗎？ | 是 | 否 |
| 10. 你的孩子會注意看著你的眼睛超過一、兩秒鐘嗎？ | 是 | 否 |
| 11. 你的孩子曾對聲音過分敏感嗎？（例如摀住耳朵） | 是 | 否 |
| 12. 你的孩子看著你的臉或是你的微笑時會以微笑回應嗎？ | 是 | 否 |
| 13. 你的孩子會模仿你嗎？（例如：你扮個鬼臉，你的孩子會模仿嗎？） | 是 | 否 |
| 14. 你的孩子聽到別人叫他／她的名字時，他／她會回應嗎？ | 是 | 否 |
| 15. 如果你指著房間另一頭的玩具，你的孩子會看那個玩具嗎？ | 是 | 否 |
| 16. 你的孩子走路嗎？ | 是 | 否 |
| 17. 你的孩子會看你正在看的東西嗎？ | 是 | 否 |
| 18. 你的孩子會在他／她的臉附近做出一些不尋常的手指頭動作嗎？ | 是 | 否 |
| 19. 你的孩子會設法吸引你看他／她自己的活動嗎？ | 是 | 否 |
| 20. 你是否曾經懷疑你的孩子聽力有問題？ | 是 | 否 |
| 21. 你的孩子能理解別人說的話嗎？ | 是 | 否 |
| 22. 你的孩子有時候會兩眼失焦或是沒有目的地逛來逛去嗎？ | 是 | 否 |
| 23. 你的孩子碰到不熟悉的事物時會看著你的臉，看看你的反應嗎？ | 是 | 否 |

修正的幼兒自閉症檢查表（M-CHAT）計分說明

關鍵性項目中有兩項或兩項以上的答案為未通過，或是所有項目當中有任何三項的答案為未通過，該名兒童就被評定為未通過。是／否的答案轉換為通過／未通過。下列為M-CHAT上所有項目未通過的答案。粗體字的項目為關鍵性項目。檢查表判定為未通過的兒童並非全都達到自閉症範圍診斷的標準。然而，未通過檢查表的兒童應該由醫師做更進一步的評估，或是交由專家做發展評估。

1.否	6.否	11.是	16.否	21.否
2.否	7.否	12.否	17.否	22.是
3.否	8.否	13.否	18.是	23.否
4.否	9.否	14.否	19.否	
5.否	10.否	15.否	20.是	

M-CHAT

Tanpri ranpli fòm sa a ki konsènan jan pitit ou a konn aji. Tanpri eseye reponn chak grenn kesyon. Si konpòtman an konn rive raman (kidonk, ou konn wè li yonn oubyen de fwa konsa), reponn konmsi timoun nan pa te janm gen konpòtman sa a ditou.

- | | | |
|--|----|-----|
| 1. Èske pitit ou an renmen lè w'ap bèse'l, oswa lè w'ap balanse li sou jenou ou, elatriye | Wi | Non |
| 2. Èske pitit ou an konn enterese (renmen jwe) ak lòt timoun parèy li? | Wi | Non |
| 3. Èske pitit ou an konn renmen grenpe pou li monte sou bagay, tankou eskalye? | Wi | Non |
| 4. Èske pitit ou an konn renmen jwe koukou/apa li, kach kach liben/lago kache | Wi | Non |
| 5. Èske pitit ou konn pretann jwet, komsi l'ap pale nan telefòn, oubyen l'ap okipe pope-li, oubyen l'ap fè lòt bagay kèlkonk? | Wi | Non |
| 6. Èske pitit ou an janm lonje dwèt li pou li vize yon bagay l'ap mande? | Wi | Non |
| 7. Èske pitit ou an janm lonje dwèt li pou li vize, epi montre yon bagay ki enterese li? | Wi | Non |
| 8. Èske pitit ou an konn jwe byen ak ti jwèt piti (tankou ti machin, oubyen ti blòk an bwa) san li pa foure yo nan bouch li, vire yo, tounen yo, oubyen lage yo atè? | Wi | Non |
| 9. Èske pitit ou an janm pote bagay devan ou (kòm paran) pou li montre ou? | Wi | Non |
| 10. Èske pitit ou an konn gade ou nan je, pou plis ke yonn ou de segonn? | Wi | Non |
| 11. Èske pitit ou an janm parèt tankou li trò sansiv pou li tande bri (kidonk, li konn bouche zòrèy li)? | Wi | Non |
| 12. Èske pitit ou an konn souri lè l'ap gade figi ou, oubyen lè li wè w'ap souri ba li? | Wi | Non |
| 13. Èske pitit ou an konn imite ou? (kidonk, si ou fè yon grimas, li fè you grimas tou?) | Wi | Non |
| 14. Èske pitit ou an reponn lè ou rele non'l? | Wi | Non |
| 15. Si ou lonje dwèt ou sou yon jwèt nan chanm nan, èske pitit ou an ap voye je'l sou li? | Wi | Non |
| 16. Èske pitit ou an mache? | Wi | Non |
| 17. Èske pitit ou an gade bagay li wè w'ap gade? | Wi | Non |
| 18. Èske pitit ou an fè mouvman ki dwòl ak dwèt li, tou pre bò figi li? | Wi | Non |
| 19. Èske pitit ou an konn eseye atire atansyon ou pou fè ou gade aktivite l'ap fè? | Wi | Non |
| 20. Èske ou janm mande tèt ou, si pitit ou an soud? | Wi | Non |
| 21. Èske pitit ou an konprann sa moun di? | Wi | Non |
| 22. Pafwa, èske pitit ou an konn fikse je li sou anyen, (pitit la nan lalin) tankou je li yo ap flannen nan levid? | Wi | Non |
| 23. Èske pitit ou an konn gade figi ou pou li wè ki reyaksyon ou, lè li devan yon bagay (ou byen you sitiyasyon) li pa twò rekonèt? | Wi | Non |

M-CHAT: Evaluación del desarrollo de niños en edad de caminar

Por favor conteste acerca de como su niño (a) es **usualmente**. Por favor trata de contestar cada pregunta. Si el comportamiento de su niño no ocurre con frecuencia, conteste como si no lo hiciera.

- | | | |
|---|----|----|
| 1. ¿Disfruta su niño (a) cuando lo balancean o hacen saltar sobre su rodilla? | Sí | No |
| 2. ¿Se interesa su niño (a) en otros niños? | Sí | No |
| 3. ¿Le gusta a su niño (a) subirse a las cosas, por ejemplo subir las escaleras? | Sí | No |
| 4. ¿Disfruta su niño (a) jugando "peek-a-boo" o "hide and seek" (a las escondidas)? | Sí | No |
| 5. ¿Le gusta a su niño (a) jugar a pretendar, como por ejemplo, pretende que habla por teléfono, que cuida sus muñecas, o pretende otras cosas? | Sí | No |
| 6. ¿Utiliza su niño (a) su dedo índice para señalar algo, o para preguntar alguna cosa? | Sí | No |
| 7. ¿Usa su niño (a) su dedo índice para señalar o indicar interés en algo? | Sí | No |
| 8. ¿Puede su niño (a) jugar bien con juguetes pequeños (como carros o cubos) sin llevárselos a la boca, manipularlos o dejarlos caer)? | Sí | No |
| 9. ¿Le trae su niño (a) a usted (padre o madre) objetos o cosas, con el propósito de mostrarle algo alguna vez? | Sí | No |
| 10. ¿Lo mira su niño (a) directamente a los ojos por mas de uno o dos segundos? | Sí | No |
| 11. ¿Parece su niño (a) ser demasiado sensitivo al ruido? (por ejemplo, se tapa los oídos)? | Sí | No |
| 12. ¿Sonríe su niño (a) en respuesta a su cara o a su sonrisa? | Sí | No |
| 13. ¿Lo imita su niño (a)? Por ejemplo, si usted le hace una mueca, su niño (a) trata de imitarlo? | Sí | No |
| 14. ¿Responde su niño (a) a su nombre cuando lo(a) llaman? | Sí | No |
| 15. ¿Si usted señala a un juguete que está al otro lado de la habitación a su niño (a), lo mira? | Sí | No |
| 16. ¿Camina su niño (a)? | Sí | No |
| 17. ¿Presta su niño (a) atención a las cosas que usted está mirando? | Sí | No |
| 18. ¿Hace su niño (a) movimientos raros con los dedos cerca de su cara? | Sí | No |
| 19. ¿Trata su niño (a) de llamar su atención (de sus padres) a las actividades que estada llevando a cabo? | Sí | No |
| 20. ¿Se ha preguntado alguna vez si su niño (a) es sordo (a)? | Sí | No |
| 21. ¿Comprende su niño (a) lo que otras dicen? | Sí | No |
| 22. ¿Ha notado si su niño (a) se queda con una Mirada fija en nada, o si camina algunas veces sin sentido? | Sí | No |
| 23. ¿Su niño le mira a su cara para chequear su reacción cuando esta en una situación diferente? | Sí | No |

M CHAT

Xin hãy cho điểm dựa trên các câu hỏi phỏng vấn ở trên trang này. Các câu hỏi tiêu chuẩn được in **ĐẬM** và những câu hỏi nghịch, nghĩa là với câu hỏi này câu trả lời “Có” ám chỉ nguy cơ bị tự kỷ (11, 18, 20, 22), được ghi chú bằng chữ **(CÂU NGHỊCH)**.

1.	Con bạn có thích được lắc lư hoặc nâng lên hạ xuống trên đầu gối của bạn không ?	Có	Không
2.	Con bạn có chú ý đến các trẻ khác không ?	Có	Không
3.	Con bạn có thích leo trèo không ? Như leo lên cầu thang chẳng hạn ?	Có	Không
4.	Con bạn có thích chơi trốn tìm/ cúc ngào không ?	Có	Không
5.	Con bạn có bao giờ chơi giả vờ như vờ gọi điện thoại hoặc săn sóc búp bê hoặc giả vờ làm cái gì đó không ?	Có	Không
6.	Con bạn có bao giờ dùng ngón tay trỏ của bé để chỉ vào một thứ gì đó để đòi (vòi) không ?	Có	Không
7.	Con bạn có bao giờ dùng ngón tay trỏ của bé để chỉ một thứ gì đó để tỏ sự quan tâm không ?	Có	Không
8.	Con bạn có biết cách chơi với các đồ chơi nhỏ như xe, các khối đồ chơi v.v.. (mà không chỉ bỏ đồ chơi vào miệng, nghịch vớ vẩn hoặc thả rơi đồ chơi)?	Có	Không
9.	Con bạn có bao giờ đem một vật gì đó đến cho bạn để chỉ cho bạn về vật đó không ?	Có	Không
10.	Con bạn có bao giờ nhìn vào mắt bạn hơn một hoặc hai giây không ?	Có	Không
11.	Con bạn có bao giờ tỏ vẻ quá nhạy cảm với tiếng động không ? (Ví dụ bịt tai lại)	Có	Không
	(CÂU NGHỊCH)		
12.	Con bạn có bao giờ cười khi thấy mặt bạn hoặc khi bạn cười với bé không ?	Có	Không
13.	Con bạn có bắt chước bạn không ? (Ví dụ bạn làm bộ nhăn mặt, con bạn có sẽ bắt chước bạn không ?)	Có	Không
14.	Con bạn có đáp ứng với tên của bé khi bạn gọi không ?	Có	Không
15.	Nếu bạn chỉ một thứ đồ chơi nào đó ở trong phòng, bé có nhìn vào nó không ?	Có	Không
16.	Con bạn có đi được không ?	Có	Không
17.	Con bạn có nhìn vào vật mà bạn đang nhìn không ?	Có	Không
18.	Con bạn có làm những cử động ngón tay bất thường gần mặt của bé không ?	Có	Không
	(CÂU NGHỊCH)		
19.	Con bạn có cố bắt bạn phải chú ý vào các hoạt động của bé không?	Có	Không
20.	Có khi nào bạn băn khoăn là con mình có thể bị điếc không?	Có	Không
	(CÂU NGHỊCH)		
21.	Con bạn có hiểu những điều người khác nói không ?	Có	Không
22.	Con bạn có bao giờ nhìn chăm chăm vào một vật gì đó hoặc đi thơ thẩn mà không có mục đích gì hết không ?	Có	Không
	(CÂU NGHỊCH)		
23.	Con bạn có nhìn vào mặt bạn để xem phản ứng của bạn khi đối diện với một vật nào đó không quen thuộc với bé không?	Có	Không

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ĐIỂM TIÊU CHUẨN: _____

TỔNG ĐIỂM: _____



Massachusetts Act Early Campaign

IMPORTANT FINAL SCREENING STEP

Modified Checklist for Autism in Toddlers (M-CHAT) Follow-Up Interview

The M-CHAT must be used in its entirety to obtain valid results. This includes conducting the follow-up interview – a critically important final step in the process. The M-CHAT Follow-Up Interview can be downloaded *free of charge* from:

<http://www.mchatscreen.com>

For more information, please contact Deborah Fein (deborah.fein@uconn.edu) or Diana Robins (drobins@gsu.edu).

Reference to use if you cite the M-CHAT FUI in research:

Robins, D.L., Fein, D., & Barton, M.L. (1999). Follow-up Interview for the Modified Checklist for Autism in Toddlers (M-CHAT FUI). Self-published.

May be used for research or clinical purposes, but please do not post on a website; instead you may post a link to www.mchatscreen.com

