

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.

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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:

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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.

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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.

More information at:

- www.MAActEarly.org
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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

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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

- Act Early Ambassador & State Team Leader
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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

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