

Case Worksheet for Learners

Case Goal

Screening for ASD in families from culturally and linguistically diverse (CLD) backgrounds can be challenging not only due to language differences, but also because of differing cultural expectations about child development, and understanding of ASD and its treatment.

Key Learning Points of this Case

1. *Know the steps for eliciting concerns and conducting developmental surveillance and screening with families from culturally and linguistically diverse (CLD) backgrounds.*

a. Describe some important techniques that a physician should include when asking about a family's expectations for their child's development. _____

b. Explain how to conduct surveillance in a culturally and linguistically competent context. _____

c. Identify the potential barriers commonly encountered when using either developmental and/or autism screening tools with CLD families. _____

2. *Know how to discuss the outcomes of developmental and/or autism screening with CLD families.*

a. Describe how to communicate normal and abnormal screening results using a culturally competent approach. _____

b. Share the rationale and potential barriers for conducting timely follow up with families after positive or negative screening. _____

c. Define the role of a cultural liaison. _____

Considering Culture in Autism Screening

3. Understand how to discuss autism with CLD families.

- a. Name some challenges related to language and/or culture with using the word “autism”. _____

- b. Explain how to work effectively with interpreters in translating the word and concept of “autism” for families.

- c. Describe culturally competent diagnostic evaluation and treatment approaches. _____

- d. Identify potential culture specific barriers to diagnosis and treatment access. _____

- e. List 3 resources to refer CLD families to when concerns are raised about autism. _____

Post Learning Exercise

Read:

Lin, S.C., Yu, S.M., & Harwood, R.L. (2012). Autism spectrum disorders and developmental disabilities in children from immigrant families in the United States. *Pediatrics*, 130, S 191.

McGee J. (n.d.). *Understanding and Using the “Toolkit Guidelines for Culturally Appropriate Translation.”* (Part 11, Section 5). McGee & Evers Consulting, Inc. for U.S. Department of Health and Human Services Centers for Medicare & Medicaid Services (CMS). Retrieved from www.tinyurl.com/cultural-translation-toolkit.

Case Study 1: Part I

You are having a busy clinic day and you see your next patient is Mario, a healthy, two-year-old boy here with his parents for a well-child visit. You saw Mario once before when he was 15 months, but unfortunately the family missed his 18-month visit as it is hard for his parents to take time off from their jobs and transportation can be challenging. Mario's parents speak only Spanish having emigrated from Guatemala one year ago. With the exception of basic phrases, you do not speak Spanish, but an interpreter has been booked.

You and the interpreter enter the room together. While you are greeting his mother, you notice Mario staring at the lights and not turning when his mother calls his name. He doesn't seem to use eye contact as his mother is talking with him. You begin the visit by asking if she has any concerns about her son that she would like to discuss today with the interpreter's help. Mario's mother tells you then that she is not sure if Mario's language is what it should be for his age. She reports that Mario babbles and has one word. She also questions if Mario's language is delayed because she only speaks Spanish to him and he is exposed to English on TV.

Case Study 1 Authors

- **Stephanie Blenner**, MD, Boston Medical Center, Boston University School of Medicine
- **Roula Choueiri**, MD, Center for Children with Special Needs (CCSN), Floating Hospital for Children, Tufts Medical Center

Case Study 1: Part II

When Mario's parents checked in at the front desk, his mother was given an **M-CHAT-R** (the revised version of the original M-CHAT) as part of the visit paperwork. When you are reviewing the paperwork, you notice that the **M-CHAT-R** she was given was in English and you see she has left it blank. You apologize that she was provided a copy in English and get her a translated copy in Spanish. You let her know through the interpreter that she can complete the questions while you check Mario's height, weight, and complete his physical exam next to her. Mario has difficulty understanding that he needs to stand on the scale even with the interpreter's help with language translation. Mario has few vocalizations and you cannot recognize babbling, though he uses "mama" for his mother. You ask his father to hold him on his lap so you can continue the exam. Mario is irritable when you try to touch him or measure his head circumference and avoids eye contact. He does not seem to like to be touched, and he does not look back at his father. During the exam, you notice that he tenses up and hand flaps, though you are able to complete it.

Meanwhile Mario's mother fills out the **M-CHAT-R** in Spanish and answers appropriately to almost all questions. In fact, Mario only has "failed" two questions from the **M-CHAT-R**: "Have you ever wondered if your child is deaf?" and "Does your child respond when you call his name?" You sit down and go over the questions with her with the interpreter. As you clarify Mario's mother's answers to the questions with the help of the interpreter, you soon notice that she may not know enough about what they really mean. You describe in more detail what some of the questions are asking and provide examples. You soon notice though that the interpreter is having difficulties translating some of your questions and you also learn that she is from Spain.

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- **Stephanie Blenner**, MD, Boston Medical Center, Boston University School of Medicine
- **Roula Choueiri**, MD, Center for Children with Special Needs (CCSN), Floating Hospital for Children, Tufts Medical Center

Case Study 1: Part III - Epilogue

After using the **M-CHAT-R** and obtaining additional details about Mario's current communication, social skills and play skills, the actual total score turns out to be 8. Based on the revised algorithm, you do not need to complete the follow-up interview, but do need to refer Mario immediately to his local Early Intervention provider and to a local diagnostic specialist for a full developmental evaluation to investigate possible developmental delays and Autism Spectrum Disorder. You discuss your concerns with the family, recommending that Mario have an additional medical evaluation to assess his development on any flagged responses indicating a concern. You ask if you can contact the local Early Intervention program on their behalf so that Mario may start to receive help with developing communication skills. You schedule a follow-up appointment at your office at the family's earliest possible availability with an early evening appointment slot that you keep expressly for urgent appointments needing further discussion and follow-up. You emphasize to the family the importance of coming back for this appointment, even if only one parent can come due to their work schedules.

After Mario's family leaves and you finish clinic for the day, you reflect on how this visit went and think about how you will further review Mario's screening test results and recommended referrals with his parents when you meet, since based on your clinical observations, you strongly suspect that Mario has ASD. One of the nurse practitioners in your clinic is from Guatemala, so you ask for her perspective on what to consider from a cultural standpoint when you see Mario's family again to further discuss next steps: specifically, the referral to Early Intervention, obtaining a comprehensive developmental evaluation for Mario, and most importantly, how to best discuss the topic of ASD in a culturally competent manner.

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- **Stephanie Blenner**, MD, Boston Medical Center, Boston University School of Medicine
- **Roula Choueiri**, MD, Center for Children with Special Needs (CCSN), Floating Hospital for Children, Tufts Medical Center

Case Study 2: Part I

Your next patient is François who comes with his mother who is originally from Haiti. She has brought her firstborn two-year-old son to visit you today at the suggestion of her local daycare provider. Assisted by a Haitian-Creole speaking cultural liaison from your practice, 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

Case Study 2 Authors

- **Kathleen Braden**, MD, Eunice Kennedy Shriver Center, University of Massachusetts Medical School, LEND Program
- **Elaine Gabovitch**, MPA, Eunice Kennedy Shriver Center, University of Massachusetts Medical School, LEND Program
- **Nicole Prudent**, MD, Boston Medical Center, Boston University School of Medicine

Case Study 2: Part II

François' aunt has suggested that his condition may be due to supernatural causes. His "Gran Ma" has requested that the family take one year to raise him 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.

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- **Kathleen Braden**, MD, Eunice Kennedy Shriver Center, University of Massachusetts Medical School, LEND Program
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- **Nicole Prudent**, MD, Boston Medical Center, Boston University School of Medicine

Case Study 2: Part III

After you hear François' mother's story about his development, you ask the Haitian-Creole cultural liaison to help her fill out the M-CHAT screening tool by reading the questions to her in Haitian-Creole and recording her answers since she is unable to read. The results and follow-up interview report a "failure" of five critical items. You explain that those items indicate that François needs further evaluation by a developmental-behavioral pediatrician who will rule out or rule in a specific diagnosis.

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- **Kathleen Braden**, MD, Eunice Kennedy Shriver Center, University of Massachusetts Medical School, LEND Program
- **Elaine Gabovitch**, MPA, Eunice Kennedy Shriver Center, University of Massachusetts Medical School, LEND Program
- **Nicole Prudent**, MD, Boston Medical Center, Boston University School of Medicine

Case Study 2: Part IV

After discussing that you would like to refer Francois to a developmental-behavioral pediatrician for further evaluation, Francois' mother expresses a sudden and strong hesitation and resistance to proceeding further, so you ask a few more questions to understand why. Eventually she nervously shares that her tourist visa expired more than a year ago. She came to the U.S. on an approved visa when she was six months pregnant to visit her extended family, gave birth to François while here, and never returned to Haiti, hoping to create a better life for her young son by living and working in the U.S. She has taken him to see you today at the urging of her son's daycare provider regarding his behavior, but now has a new concern: fear of further exposure of her undocumented status leading to possible deportation and separation from her son and family members by needing to see yet one more unfamiliar provider.

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- **Kathleen Braden**, MD, Eunice Kennedy Shriver Center, University of Massachusetts Medical School, LEND Program
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- **Nicole Prudent**, MD, Boston Medical Center, Boston University School of Medicine

Case Study 2 Part V - Epilogue

With a little more time and discussion, you are able to reassure François' mother to seek evaluation for her son. You are glad that his daycare provider had the training and the insight to encourage his mother to see you for his check-up. You help to arrange a visit with a local developmental-behavioral pediatrician and make a referral to a nearby Early Intervention provider. The cultural liaison will follow up with the family to assist them with scheduling the evaluation appointment and will also help arrange transportation for them. The cultural liaison will refer François' family to the local Early Intervention office, an important community partner in delivering culturally competent family-centered care and evidence-based interventions. This type of follow-through is a well-established part of your practice for non-English-speaking families.

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- **Kathleen Braden**, MD, Eunice Kennedy Shriver Center, University of Massachusetts Medical School, LEND Program
- **Elaine Gabovitch**, MPA, Eunice Kennedy Shriver Center, University of Massachusetts Medical School, LEND Program
- **Nicole Prudent**, MD, Boston Medical Center, Boston University School of Medicine

Handout I: Cultural & Linguistic Differences in Autism Identification

Prevalence

A 2014 report summarized data from 2010 from 11 sites collected by the Center for Disease Control and Prevention's (CDC) *Autism and Developmental Disabilities Monitoring Network*, an active surveillance system that tracks ASD trends.¹ The overall prevalence for Autism Spectrum Disorder (ASD) in this study was found to be 1 in 68 based on DSM-IV TR criteria among 8 year olds. Non-Hispanic white children were approximately 30% more likely to be identified with ASD than non-Hispanic black children and were almost 50% more likely to be identified than Hispanic children.

Average age of diagnosis

The majority of children identified as having ASD in the CDC study had a developmental concern noted by 36 months of age. The median age of first evaluation for ASD was 38 months in white children, 40 months in black children and 43 months in Hispanic children.

Presenting concerns

By self-report, more pediatric clinicians reported difficulty identifying ASD signs and symptoms in children from families who are Latino, or African American or whose family's primary language was Spanish, than in white children or children whose family's primary language is English (Zuckerman, 2013). This may be, in part, because children from other culturally and linguistically diverse (CLD) backgrounds may have different presenting concerns or their families may not be concerned at all.

Most common concerns

The most common reason children are identified as being at risk for ASD is due to reported expressive language delay. However, this may or may not be perceived to be a problem by some families.

For example, if parents speak a primary language other than English, they may attribute their child's language delays to being exposed to multiple languages between the home, siblings, childcare and the media.

It would be important to reinforce with families that speaking two or more languages does not necessarily put a child at risk for language delays and disorders. Furthermore, it is not a reason to stop speaking the parents' primary language at home.

¹ Centers for Disease Control and Prevention. (2014b). Prevalence of autism spectrum disorder among children aged 8 years—Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2010. *MMWR Surveillance Summaries*, 63:1-21.

Considering Culture in Autism Screening

However, identification of a language disorder in dual language-speaking children is more complex than in children from single language households and requires physicians to pay special attention to parent report and use specialized and alternative assessment measures to distinguish delayed language from a developmental concern.²

Lack of concern

Signs of ASD also occur in a cultural context and may not be seen as concerning in some cultures. This is particularly true of several core symptoms like *language delay, decreased eye contact, lack of pointing, or diminished bids for adult attention*.

As an example, in cultures where children are expected to show deference to adults, being quiet, not demanding attention and not speaking as much as other children their age may not be seen as problems and potentially could be seen even as desirable.

Reluctance to share concerns

Finally, parents may be reluctant to share their knowledge or to voice any concerns about their child's development because in some cultures this can be seen as potentially stigmatizing and as inviting problems, or may bring up broader issues around the trust of and the feeling of being able to communicate with medical professionals. Parents may also fear immigration issues that might lead to exposure and eventual deportation or separation from their child and family.

² Paradis, J., Genesee, F., & Crago, M. (2014). What are some myths about dual language development? Brookes Publishing. Retrieved from: <http://archive.brookespublishing.com/author-interviews/paradis-70588-interview.htm>.

Handout II: Considering Culture in Autism Screening Guide

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

MA ACT EARLY SCREENING KIT DEVELOPMENT TEAM

- Stephanie Blenner, MD
Boston Medical Center
- Kathleen Braden, MD
University of Massachusetts Medical School/E.K. Shriver Center
- Roula Choueiri, MD
Tufts Floating Hospital for Children, Center for Children with Special Needs
- Elaine Gabovitch, MPA
University of Massachusetts Medical School/E.K. Shriver Center
- David Helm, PhD
Children’s Hospital Boston/Institute for Community Inclusion
- Tracy Osbahr, MA
Massachusetts Department of Public Health
- Nicole Prudent, MD
Boston Medical Center
- Alison Schonwald, MD
Children’s Hospital Boston
- Jason Travers, PhD, BCBA-D
University of Massachusetts Amherst

GREATER BOSTON COMMUNITY HEALTH CENTERS PARTNERS

- Dorchester House
Cultural liaison: Bich Phuong Do
- Haitian Health Institute
Cultural liaison: Marie K. Foureau
- Harvard Street Community Health Center
Cultural liaison: Soukaina Adolphe, MD
- Mattapan Community Health Center
Cultural liaison: Tarma Johnson, RN
- Martha Eliot Health Center
- Tufts Floating Hospital for Children Asian Clinic
Cultural Liaison: Sue Ponte, NP

NATIONAL CENTER FOR CULTURAL COMPETENCE PARTNERS

- Tawara Goode, MA, Director
- Suzanne Bronheim, PhD, Director
SUID Project & Senior Policy Associate
- Wendy Jones, M.Ed., MSW Director
Children & Youth with Special Health Care Needs Project

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- Simeon Damas, Boston Medical Center
- Kelly Hurley, UMass Medical School
- Teresita Ramos Dunne, parent, advocate, Shriver Center LEND fellow
- Diana L. Robins, PhD, Georgia State University, M-CHAT author

More information at:

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

Clinician Tips

THINK PROCESS

Culturally & Linguistically Competent Autism Screening

Screening for ASD 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 68 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 or M-CHAT-R/F 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 or M-CHAT-R/F, this includes conducting the follow-up interview—a critically important final step in the process. It can be found at: www.mchatscreen.com

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 ASD, 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 ASD, 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 ASD 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 ASD 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
- www.cdc.gov/actearly

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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 ASD 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.

Handout III: Working with Interpreters & Cultural Liaisons

*Understanding how to effectively work with **interpreters** and **cultural “liaisons”** or “**brokers**” can improve your ability to provide care for diverse families. Keeping in mind that there are myriad cultures and languages; sometimes finding these professionals can be challenging.*

Interpreters

Interpretation

Interpretation is the oral restating in one language of what has been said in another language. Interpreted information should accurately convey the tone, level and meaning of the information given in the original language. (Source: National Center for Cultural Competence)

Preparation

Though not always possible, it is ideal to *meet with the interpreter prior to entering the clinic room* to assure s/he is comfortable translating the content and vocabulary that will be discussed during the encounter and to clarify any questions s/he may have.

- This is especially important when discussing issues like ASD that may involve less commonly used terms.
- Keep in mind as well that the word “autism” may not exist in the interpreter’s and family’s language.
- Confirm the interpreter’s essential role to uphold the family’s confidentiality.

Methods to consider

There is a range of ways that professional interpretation can be provided including through an in-person interpreter, telephone service, or video techniques.

Tips for working with an interpreter:

- Introduce the interpreter and the family to each other.
- You should ask the family’s permission to use an interpreter and explain that you feel it will be helpful for their child’s care. Keep in mind that if the family speaks English as a second language and has been in the U.S. for several year, an interpreter may not be appropriate for their needs.
- Effectively position the interpreter in the clinic room. Typically this is next to the parent so that you can maintain your body orientation and eye contact with the parent even when using the interpreter.
- Ideally, the interpreter should be physically positioned at the same level as the person or people you are speaking with (i.e., seated if the parent is seated, standing if the parent is standing) to minimize any perceived power differential.
- During the encounter, it is important to direct your questions to the parent, not the interpreter.
- Minimize the use of ad-hoc interpreters, such as family members or untrained bilingual staff, when possible. This can frequently contribute to misunderstandings and misinformation.
- Never put another child in the family in the position of being an interpreter given the nature of medical discussions.
- Continually gauge the effectiveness of the interaction between you, the family, and the interpreter.
- Attend to the family’s demeanor, emotional expression, and level of engagement.
- Make certain both parties understand that they can ask questions at any point if things are not clear or either is unsure of something being discussed.

Finding the right interpreter for the family’s and your needs

Interpreters are proficient in language translation, but not necessarily sensitive to cultural interpretation and may not always be able to help in the clarification of cultural norms, for example:

- A Spanish-speaking person from Spain probably would have a different cultural perspective than a Spanish-speaking person from Latin America.

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- Certain Latino and Asian cultures may consider pointing and eye contact to be impolite, but this may not be true in the interpreter's culture, thus s/he may miss this subtle difference in the translation.
- Interpreters and families may come from very different socio-economic backgrounds as well, making sensitivity to such differences very important.

Other important points to consider:

- a. Interpreters may not be particularly specialized in the medical terms used about child development
- b. Certain terms may be difficult to translate into the family's primary language or may not even exist in that language (i.e., some languages do not have a word for autism).

Thus, it is important to understand the culture of the family and of the interpreter, to be able to translate these important medical and developmental terms in the most appropriate way.

Follow up visits

It is important to have an interpreter available for the follow-up visit; however, assistance from the interpreter alone may not be enough because:

- a. Some interpreters only translate language but may not understand or help interpret the cultural perspective for the family, especially if they are from a different country/cultural background or have a different level of acculturation.
- b. General medical interpreters may not be familiar with many of the terms used to describe child development.
- c. Most importantly, an interpreter may not know how to translate "Autism Spectrum Disorder" in a family's native language, or such translation may not exist in some languages. In this case, a fuller description of the condition should be used.
- d. Thus, it is important to clarify the translation and description of important terms you will use during your follow-up visit beforehand with the interpreter.

Cultural liaisons or brokers

Cultural liaisons or cultural brokers

Cultural liaisons or brokers function much the same way as interpreters but also have the knowledge of the values, beliefs and practices of a cultural group or community and specific organizations and systems with which they have learned to navigate effectively, either for themselves, their families, and/or their communities. Cultural brokers can play a key role in informing organizations about the most culturally appropriate ways of joining with families and communities from different backgrounds. (Source: *Family Voices, Inc.*)

In addition to the skill set required for an interpreter, a cultural liaison is an individual from the same culture as the family – whether a colleague, another healthcare professional, or clinic staff – who can provide valuable insights on a family's cultural perceptions of the different screening questions, their understanding of child development in general, and their expectations of their child's development. The cultural liaison can facilitate follow-up steps resulting from screening by contacting specialty clinics on the family's behalf to book evaluation appointments, to arrange transportation to help families access these services, and other important steps to keep families engaged. Most importantly, this additional person could support and help both the pediatric provider and the family with difficult conversations, such as approaching the topic of the risk for ASD, etc.

The potential cultural and linguistic barriers to diagnosis and treatment that a cultural liaison might assist with include family and community perspectives, concerns about maternal blame and stigma surrounding disability, as well as immigrant status worries about deportation and separation from one's child and family.

Handout IV: M-CHAT-R/F

Modified Checklist for Autism in Toddlers, Revised with Follow-Up

(M-CHAT-R/F)TM

Acknowledgement: We thank Joaquin Fuentes, M.D. for his work in developing the flow chart format used in this document.

For more information, please see www.mchatscreen.com
or contact Diana Robins at DianaLRobins@gmail.com

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Permissions for Use of the M-CHAT-R/F™

The Modified Checklist for Autism in Toddlers, Revised with Follow-Up (M-CHAT-R/F; Robins, Fein, & Barton, 2009) is a 2-stage parent-report screening tool to assess risk for Autism Spectrum Disorder (ASD). The M-CHAT-R/F is available for free download for clinical, research, and educational purposes. Download of the M-CHAT-R/F and related material is authorized from www.mchatscreen.com.

The M-CHAT-R/F is a copyrighted instrument, and use of the M-CHAT-R/F must follow these guidelines:

- (1) Reprints/reproductions of the M-CHAT-R must include the copyright at the bottom (© 2009 Robins, Fein, & Barton). No modifications can be made to items, instructions, or item order without permission from the authors.
- (2) The M-CHAT-R must be used in its entirety. Evidence indicates that any subsets of items do not demonstrate adequate psychometric properties.
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- (4) If you are part of a medical practice, and you want to incorporate the first stage M-CHAT-R questions into your own practice's electronic medical record (EMR), you are welcome to do so. However, if you ever want to distribute your EMR page outside of your practice, please contact Diana Robins to request a licensing agreement.

Instructions for Use

The M-CHAT-R can be administered and scored as part of a well-child care visit, and also can be used by specialists or other professionals to assess risk for ASD. The primary goal of the M-CHAT-R is 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 will be diagnosed with ASD. To address this, we have developed the Follow-Up questions (M-CHAT-R/F). Users should be aware that even with the Follow-Up, a significant number of the children who screen positive on the M-CHAT-R will not be diagnosed with ASD; however, these children are at high risk for other developmental disorders or delays, and therefore, evaluation is warranted for any child who screens positive. The M-CHAT-R can be scored in less than two minutes. Scoring instructions can be downloaded from <http://www.mchatscreen.com>. Associated documents will be available for download as well.

Scoring Algorithm

For all items except 2, 5, and 12, the response "NO" indicates ASD risk; for items 2, 5, and 12, "YES" indicates ASD risk. The following algorithm maximizes psychometric properties of the M-CHAT-R:

- LOW-RISK:** **Total Score is 0-2;** if child is younger than 24 months, screen again after second birthday. No further action required unless surveillance indicates risk for ASD.
- MEDIUM-RISK:** **Total Score is 3-7;** Administer the Follow-Up (second stage of M-CHAT-R/F) to get additional information about at-risk responses. If M-CHAT-R/F score remains at 2 or higher, the child has screened positive. Action required: refer child for diagnostic evaluation and eligibility evaluation for early intervention. If score on Follow-Up is 0-1, child has screened negative. No further action required unless surveillance indicates risk for ASD. Child should be rescreened at future well-child visits.
- HIGH-RISK:** **Total Score is 8-20;** It is acceptable to bypass the Follow-Up and refer immediately for diagnostic evaluation and eligibility evaluation for early intervention.

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M-CHAT-R™

Please answer these questions about your child. Keep in mind how your child usually behaves. If you have seen your child do the behavior a few times, but he or she does not usually do it, then please answer **no**. Please circle **yes** or **no** for every question. Thank you very much.

1. If you point at something across the room, does your child look at it? (FOR EXAMPLE , if you point at a toy or an animal, does your child look at the toy or animal?)	Yes	No
2. Have you ever wondered if your child might be deaf?	Yes	No
3. Does your child play pretend or make-believe? (FOR EXAMPLE , pretend to drink from an empty cup, pretend to talk on a phone, or pretend to feed a doll or stuffed animal?)	Yes	No
4. Does your child like climbing on things? (FOR EXAMPLE , furniture, playground equipment, or stairs)	Yes	No
5. Does your child make <u>unusual</u> finger movements near his or her eyes? (FOR EXAMPLE , does your child wiggle his or her fingers close to his or her eyes?)	Yes	No
6. Does your child point with one finger to ask for something or to get help? (FOR EXAMPLE , pointing to a snack or toy that is out of reach)	Yes	No
7. Does your child point with one finger to show you something interesting? (FOR EXAMPLE , pointing to an airplane in the sky or a big truck in the road)	Yes	No
8. Is your child interested in other children? (FOR EXAMPLE , does your child watch other children, smile at them, or go to them?)	Yes	No
9. Does your child show you things by bringing them to you or holding them up for you to see – not to get help, but just to share? (FOR EXAMPLE , showing you a flower, a stuffed animal, or a toy truck)	Yes	No
10. Does your child respond when you call his or her name? (FOR EXAMPLE , does he or she look up, talk or babble, or stop what he or she is doing when you call his or her name?)	Yes	No
11. When you smile at your child, does he or she smile back at you?	Yes	No
12. Does your child get upset by everyday noises? (FOR EXAMPLE , does your child scream or cry to noise such as a vacuum cleaner or loud music?)	Yes	No
13. Does your child walk?	Yes	No
14. Does your child look you in the eye when you are talking to him or her, playing with him or her, or dressing him or her?	Yes	No
15. Does your child try to copy what you do? (FOR EXAMPLE , wave bye-bye, clap, or make a funny noise when you do)	Yes	No
16. If you turn your head to look at something, does your child look around to see what you are looking at?	Yes	No
17. Does your child try to get you to watch him or her? (FOR EXAMPLE , does your child look at you for praise, or say “look” or “watch me”?)	Yes	No
18. Does your child understand when you tell him or her to do something? (FOR EXAMPLE , if you don’t point, can your child understand “put the book on the chair” or “bring me the blanket”?)	Yes	No
19. If something new happens, does your child look at your face to see how you feel about it? (FOR EXAMPLE , if he or she hears a strange or funny noise, or sees a new toy, will he or she look at your face?)	Yes	No
20. Does your child like movement activities? (FOR EXAMPLE , being swung or bounced on your knee)	Yes	No

M-CHAT-R Follow-Up (M-CHAT-R/F)TM

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The Modified Checklist for Autism in Toddlers, Revised, with Follow-Up (M-CHAT-R/F; Robins, Fein, & Barton, 2009) is designed to accompany the M-CHAT-R. The M-CHAT-R/F may be downloaded from www.mchatscreen.com.

The M-CHAT-R/F is a copyrighted instrument, and use of this instrument is limited by the authors and copyright holders. The M-CHAT-R and M-CHAT-R/F may be used for clinical, research, and educational purposes. Although we are making the tool available free of charge for these uses, this is copyrighted material and it is not open source. Anyone interested in using the M-CHAT-R/F in any commercial or electronic products must contact Diana L. Robins at DianaLRobins@gmail.com to request permission.

Instructions for Use

The M-CHAT-R/F is designed to be used with the M-CHAT-R; the M-CHAT-R is valid for screening toddlers between 16 and 30 months of age, to assess risk for autism spectrum disorder (ASD). Users should be aware that even with the Follow-Up, a significant number of the children who fail the M-CHAT-R will not be diagnosed with ASD; however, these children are at risk for other developmental disorders or delays, and therefore, follow-up is warranted for any child who screens positive.

Once a parent has completed the M-CHAT-R, score the instrument according to the instructions. If the child screens positive, select the Follow-Up items based on which items the child failed on the M-CHAT-R; only those items that were originally failed need to be administered for a complete interview.

Each page of the interview corresponds to one item from the M-CHAT-R. Follow the flowchart format, asking questions until a PASS or FAIL is scored. Please note that parents may report “maybe” in response to questions during the interview. When a parent reports “maybe,” ask whether most often the answer is “yes” or “no” and continue the interview according to that response. In places where there is room to report an “other” response, the interviewer must use his/her judgment to determine whether it is a passing response or not.

Score the responses to each item on the M-CHAT-R/F Scoring Sheet (which contains the same items as the M-CHAT-R, but Yes/No has been replaced by Pass/Fail). The interview is considered to be a screen positive if the child fails any two items on the Follow-Up. If a child screens positive on the M-CHAT-R/F, it is strongly recommended that the child is referred for early intervention and diagnostic testing as soon as possible. Please note that if the healthcare provider or parent has concerns about ASDs, children should be referred for evaluation regardless of the score on the M-CHAT-R or M-CHAT-R/F.

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M-CHAT-R Follow-Up™ Scoring Sheet

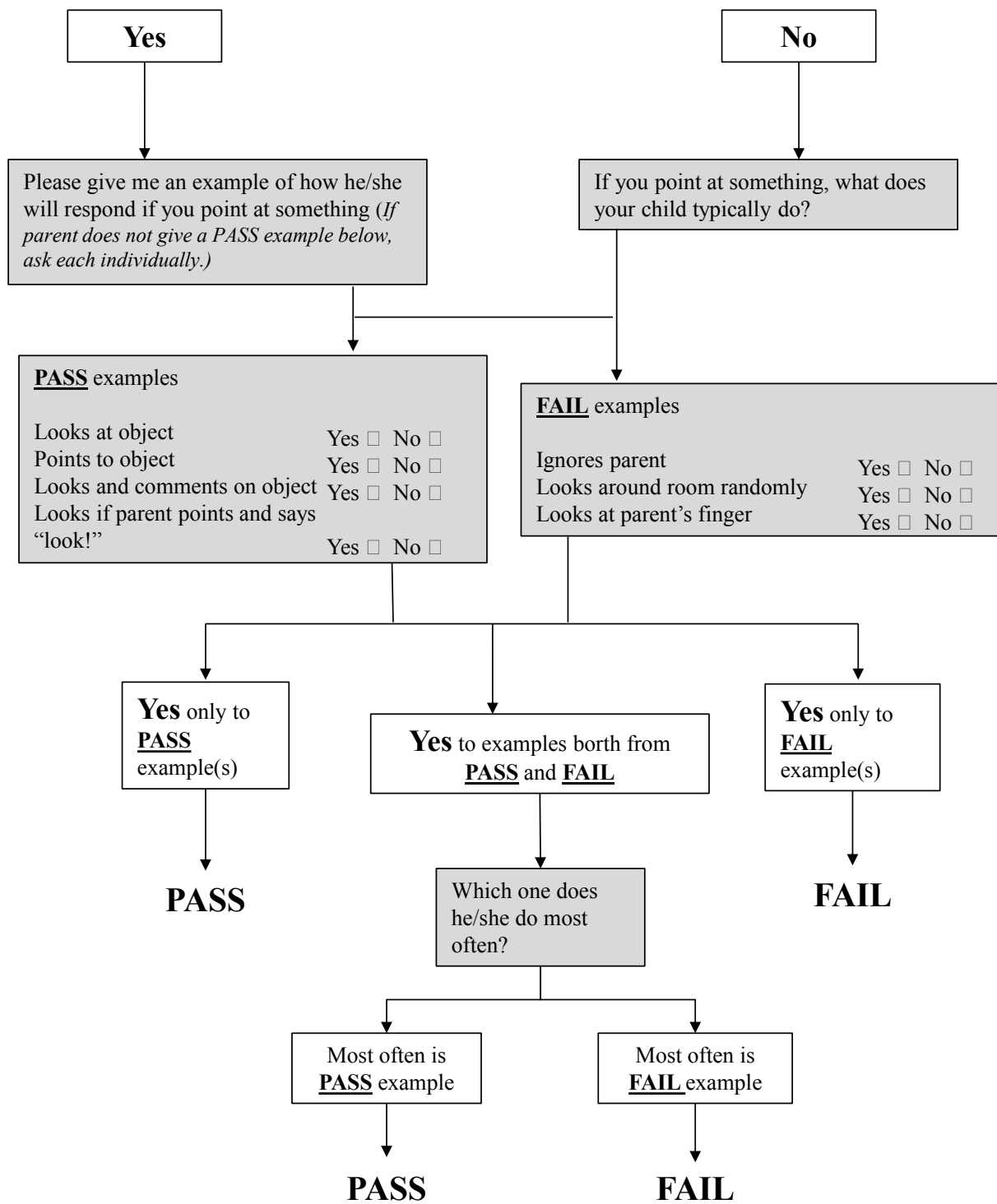
Please note: Yes/No has been replaced with Pass/Fail

1. If you point at something across the room, does your child look at it? (FOR EXAMPLE, if you point at a toy or an animal, does your child look at the toy or animal?)	Pass	Fail
2. Have you ever wondered if your child might be deaf?	Pass	Fail
3. Does your child play pretend or make-believe? (FOR EXAMPLE, pretend to drink from an empty cup, pretend to talk on a phone, or pretend to feed a doll or stuffed animal)	Pass	Fail
4. Does your child like climbing on things? (FOR EXAMPLE, furniture, playground equipment, or stairs)	Pass	Fail
5. Does your child make <u>unusual</u> finger movements near his or her eyes? (FOR EXAMPLE, does your child wiggle his or her fingers close to his or her eyes?)	Pass	Fail
6. Does your child point with one finger to ask for something or to get help? (FOR EXAMPLE, pointing to a snack or toy that is out of reach)	Pass	Fail
7. Does your child point with one finger to show you something interesting? (FOR EXAMPLE, pointing to an airplane in the sky or a big truck in the road)	Pass	Fail
8. Is your child interested in other children? (FOR EXAMPLE, does your child watch other children, smile at them, or go to them?)	Pass	Fail
9. Does your child show you things by bringing them to you or holding them up for you to see – not to get help, but just to share? (FOR EXAMPLE, showing you a flower, a stuffed animal, or a toy truck)	Pass	Fail
10. Does your child respond when you call his or her name? (FOR EXAMPLE, does he or she look up, talk or babble, or stop what he or she is doing when you call his or her name?)	Pass	Fail
11. When you smile at your child, does he or she smile back at you?	Pass	Fail
12. Does your child get upset by everyday noises? (FOR EXAMPLE, a vacuum cleaner or loud music)	Pass	Fail
13. Does your child walk?	Pass	Fail
14. Does your child look you in the eye when you are talking to him or her, playing with him or her, or dressing him or her?	Pass	Fail
15. Does your child try to copy what you do? (FOR EXAMPLE, wave bye-bye, clap, or make a funny noise when you do)	Pass	Fail
16. If you turn your head to look at something, does your child look around to see what you are looking at?	Pass	Fail
17. Does your child try to get you to watch him or her? (FOR EXAMPLE, does your child look at you for praise, or say “look” or “watch me”)	Pass	Fail
18. Does your child understand when you tell him or her to do something? (FOR EXAMPLE, if you don’t point, can your child understand “put the book on the chair” or “bring me the blanket”)	Pass	Fail
19. If something new happens, does your child look at your face to see how you feel about it? (FOR EXAMPLE, if he or she hears a strange or funny noise, or sees a new toy, will he or she look at your face?)	Pass	Fail
20. Does your child like movement activities? (FOR EXAMPLE, being swung or bounced on your knee)	Pass	Fail

Total Score: _____

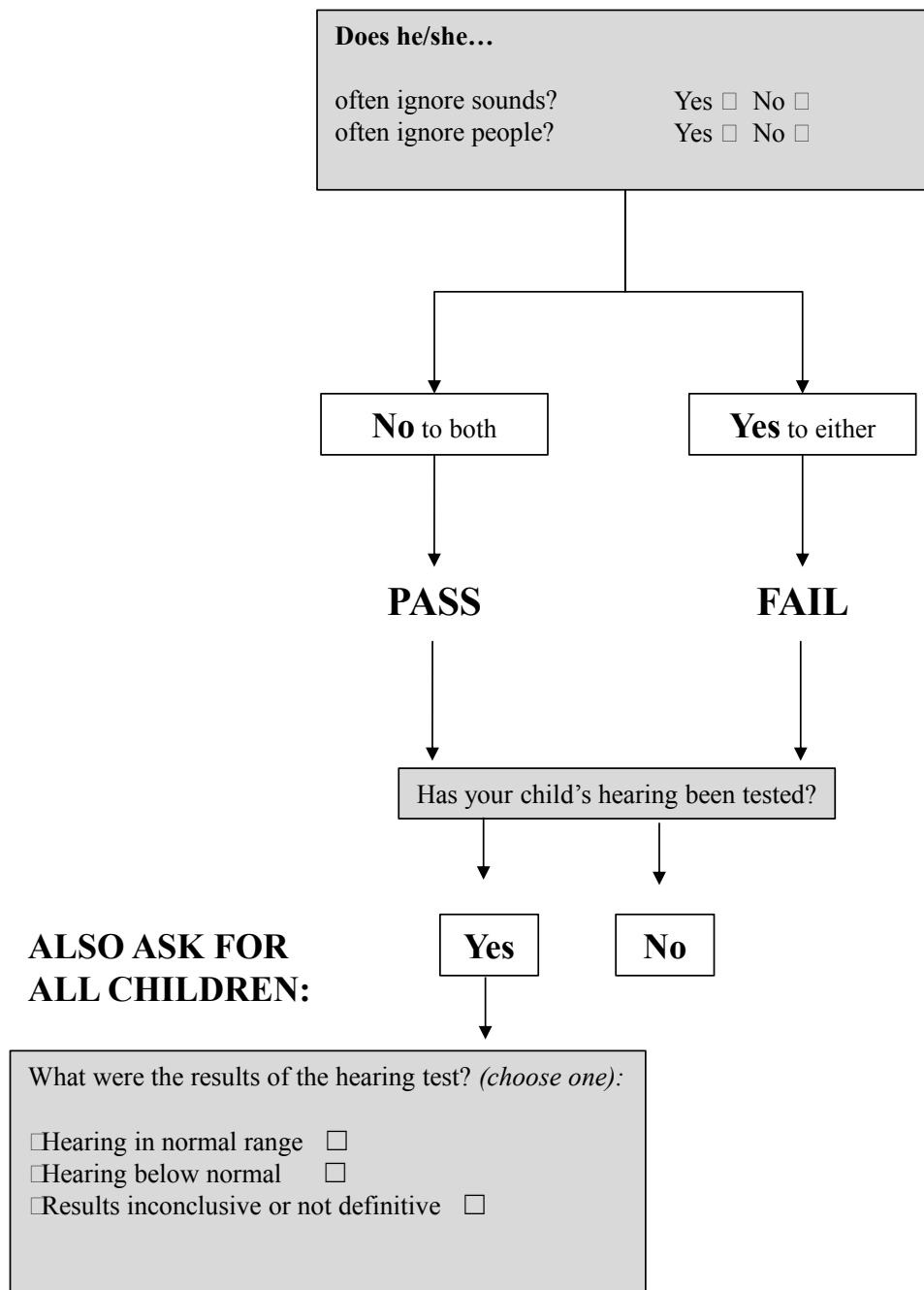
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1. If you point at something across the room, does _____ look at it?



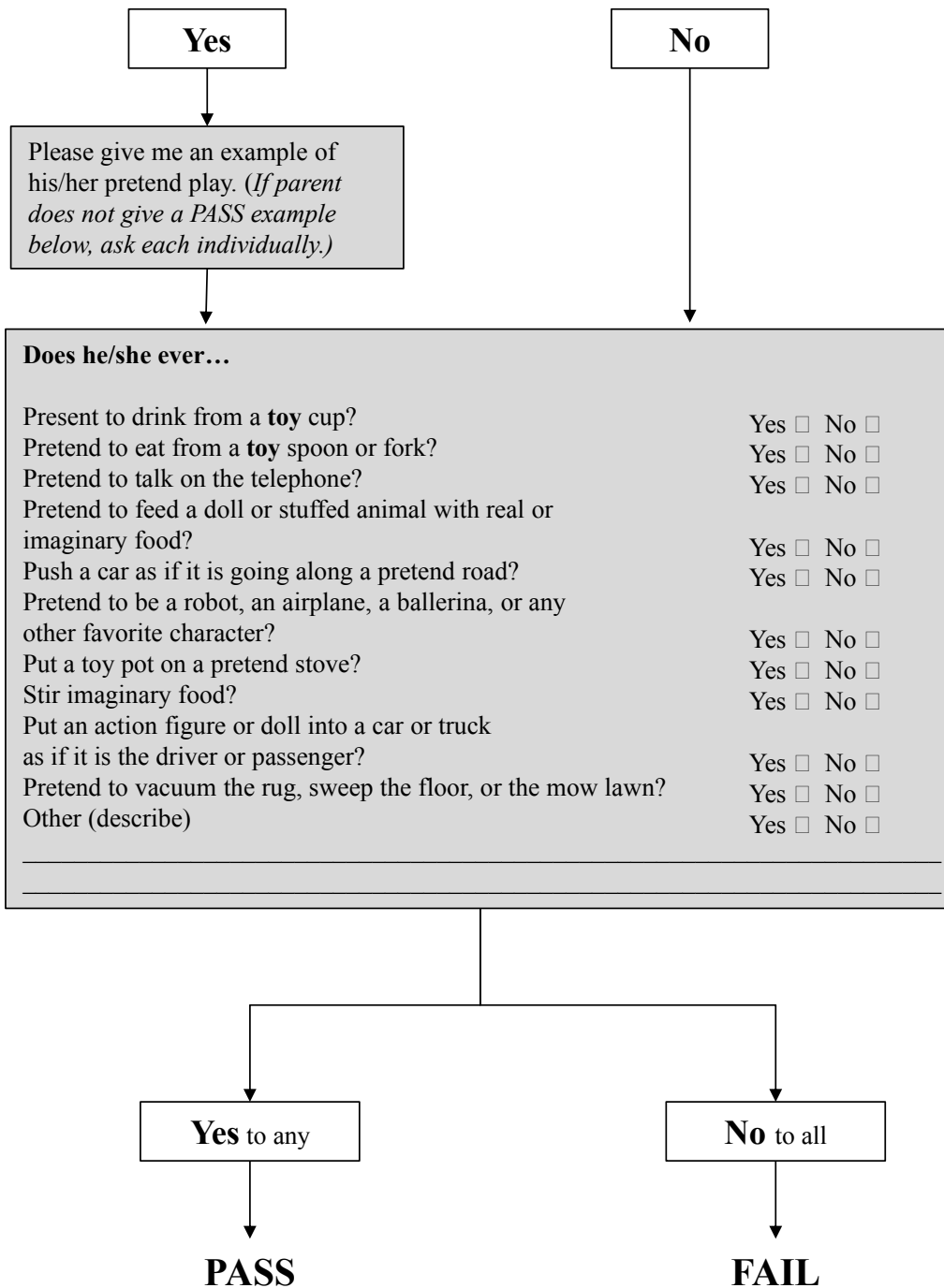
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2. You reported that you have wondered if your child is deaf. What led you to wonder that?



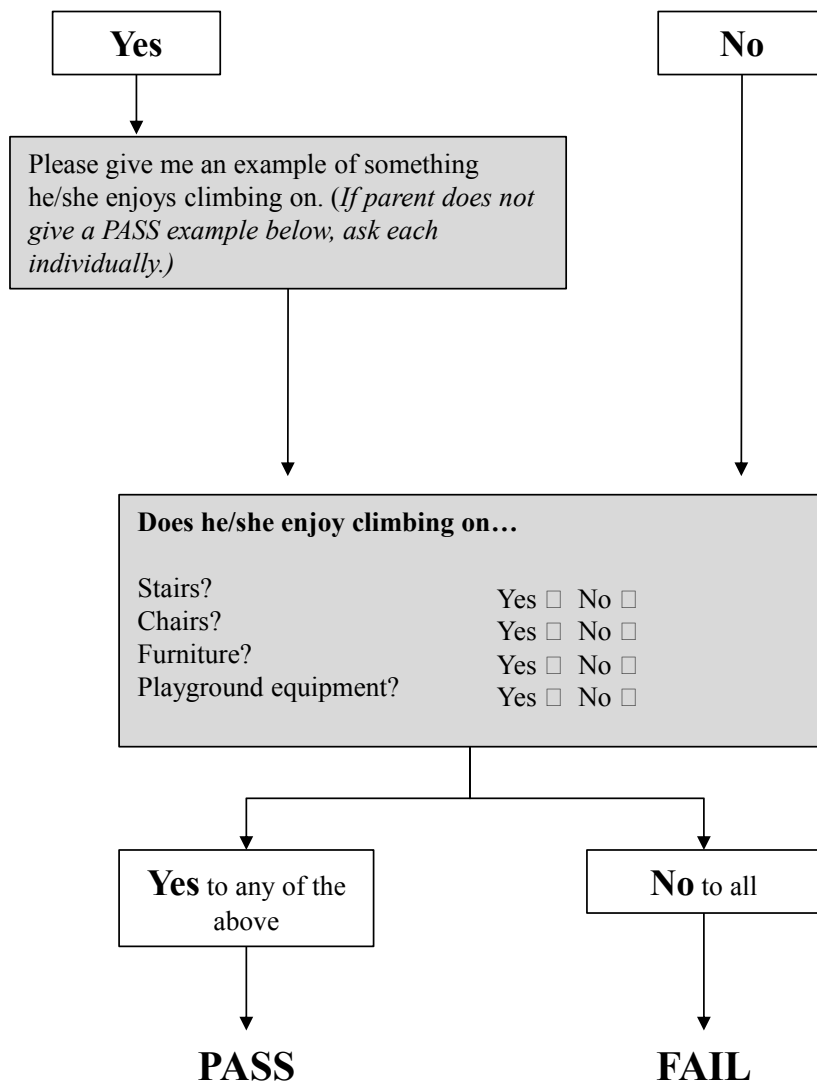
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3. Does _____ play pretend or make- believe



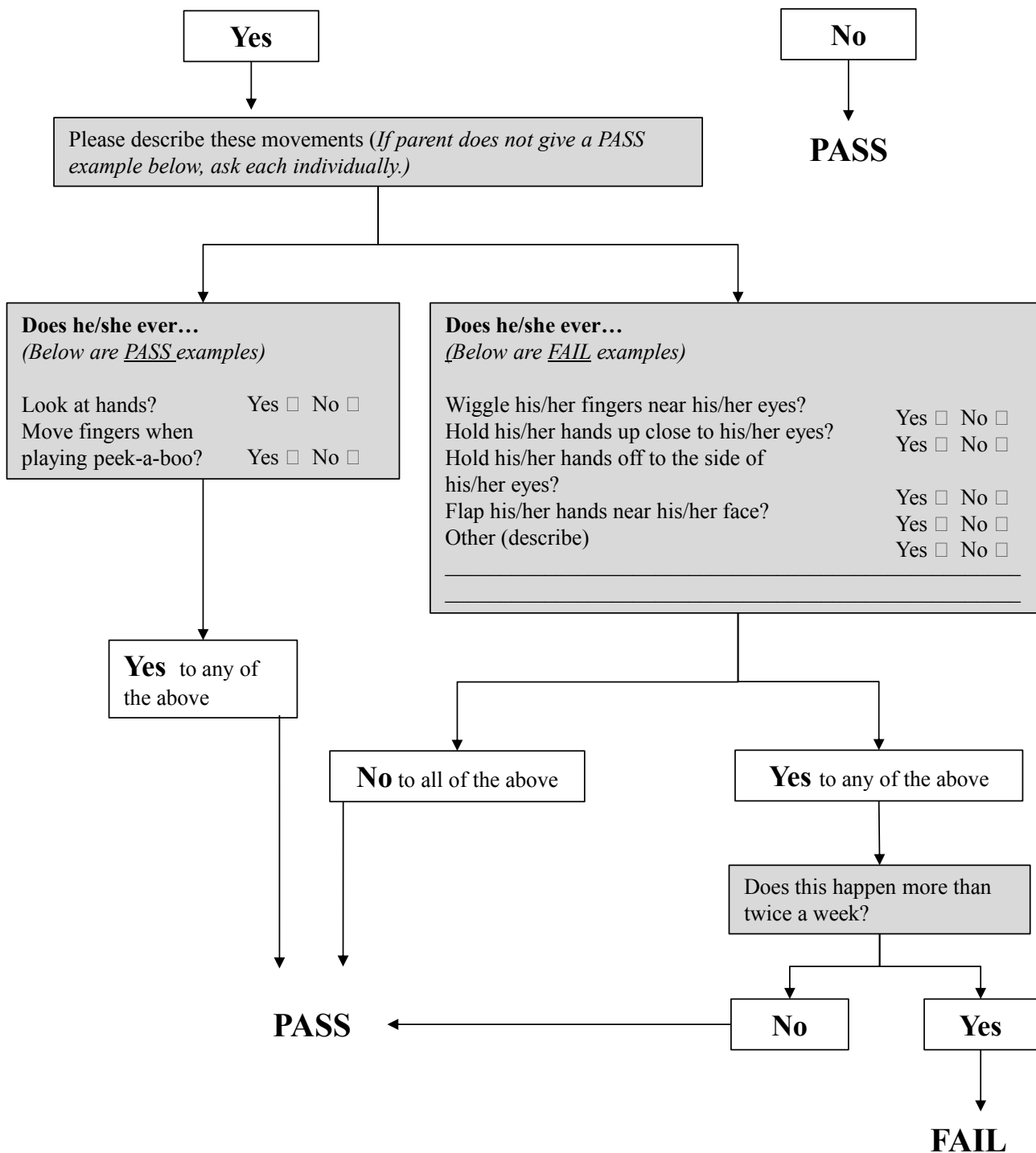
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4. Does _____ like climbing on things?



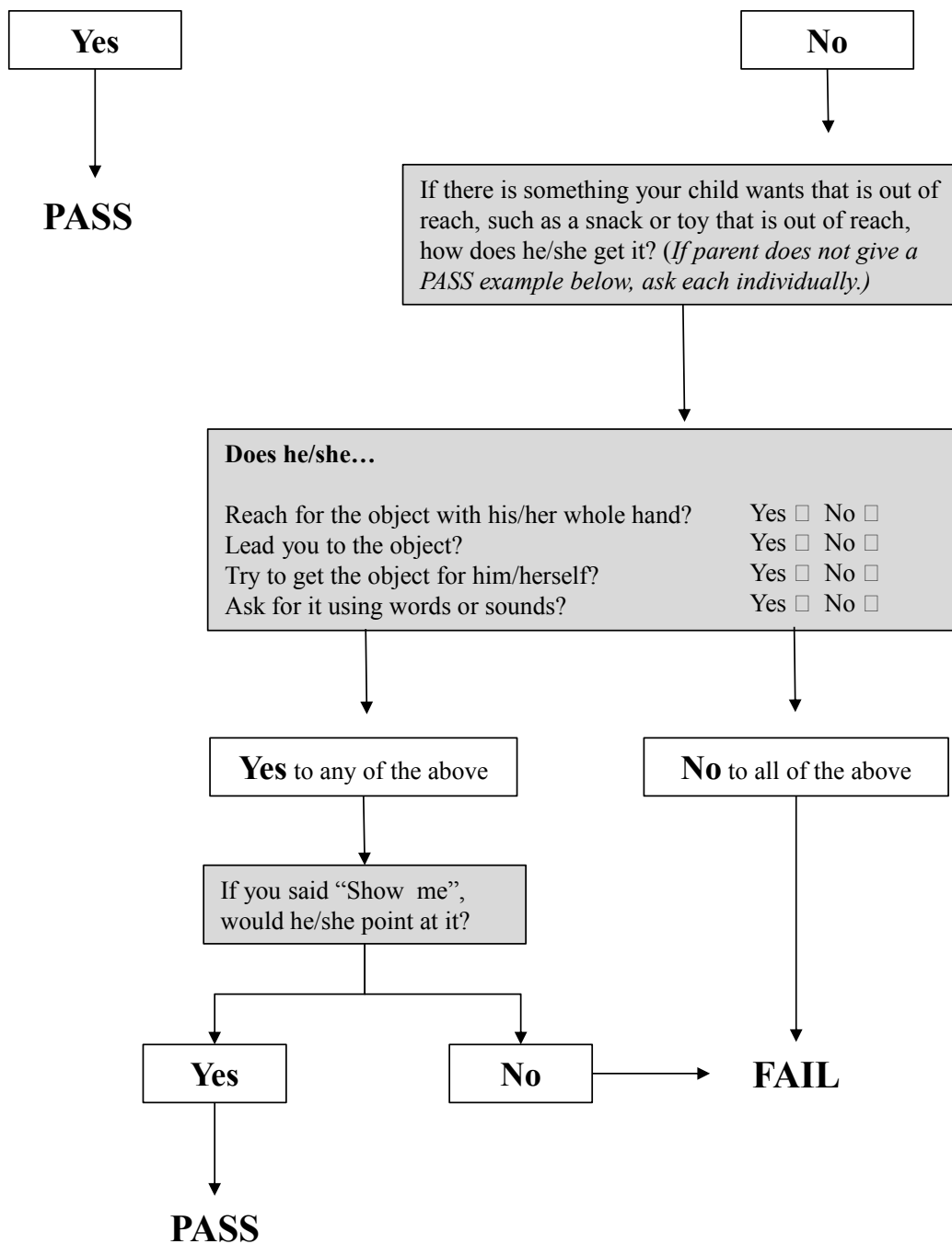
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5. Does _____ make unusual finger movements near his/her eyes?



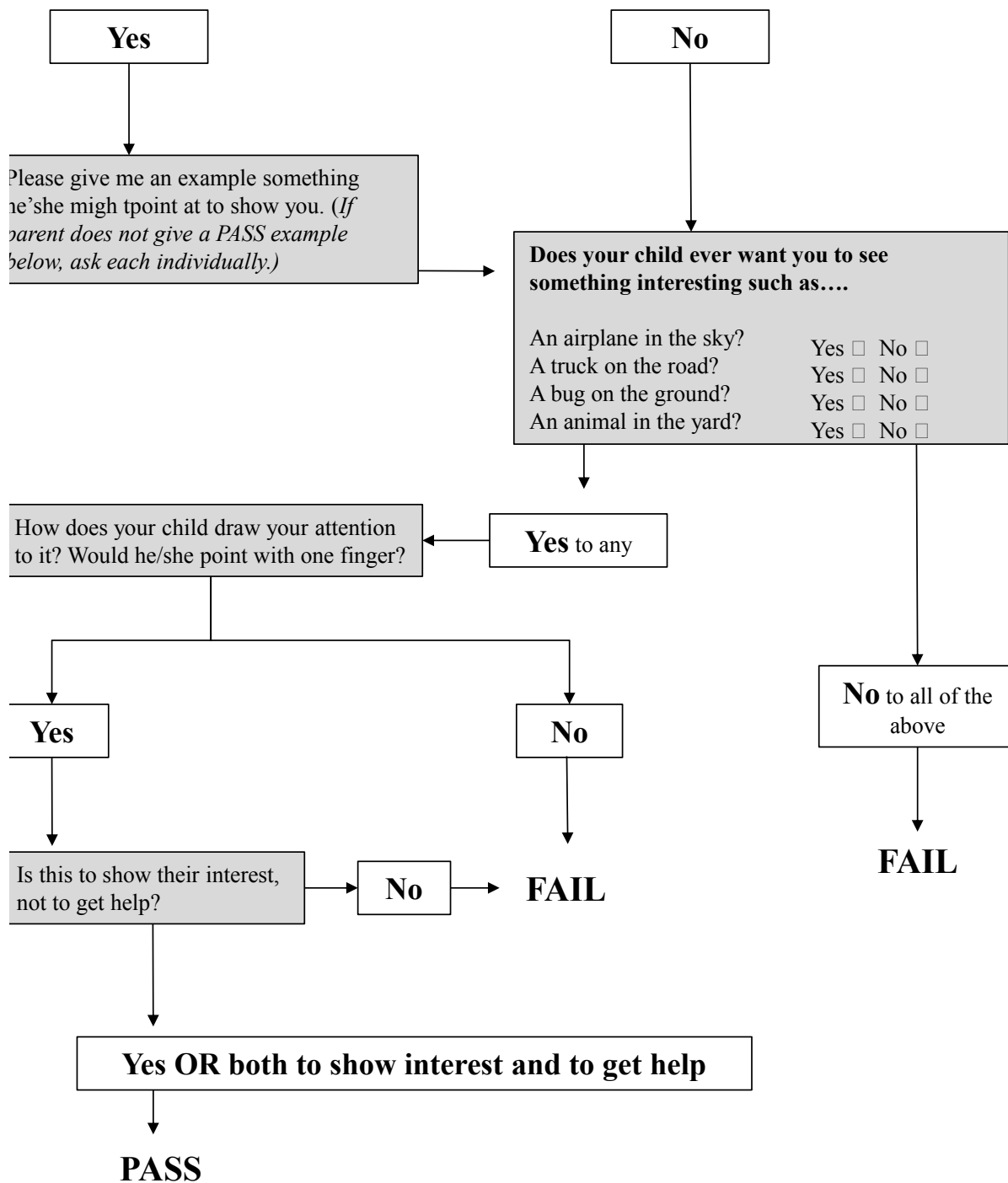
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6. Does your child point with one finger to ask for something or to get help?



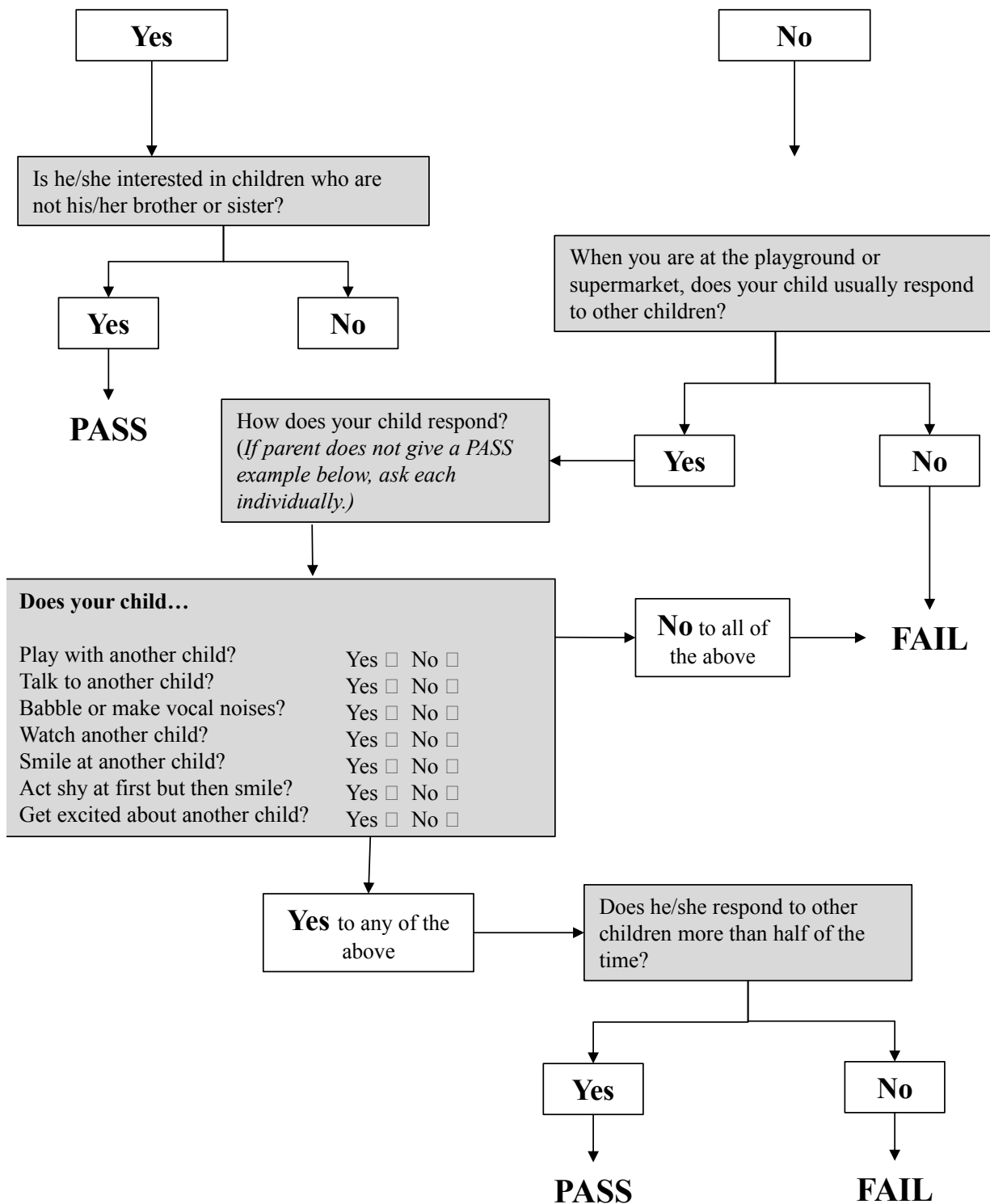
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7. * If the interviewer just asked #6, begin here: We just talked about pointing to *ask* for something, ASK ALL → Does your child point with one finger just to show you something interesting?



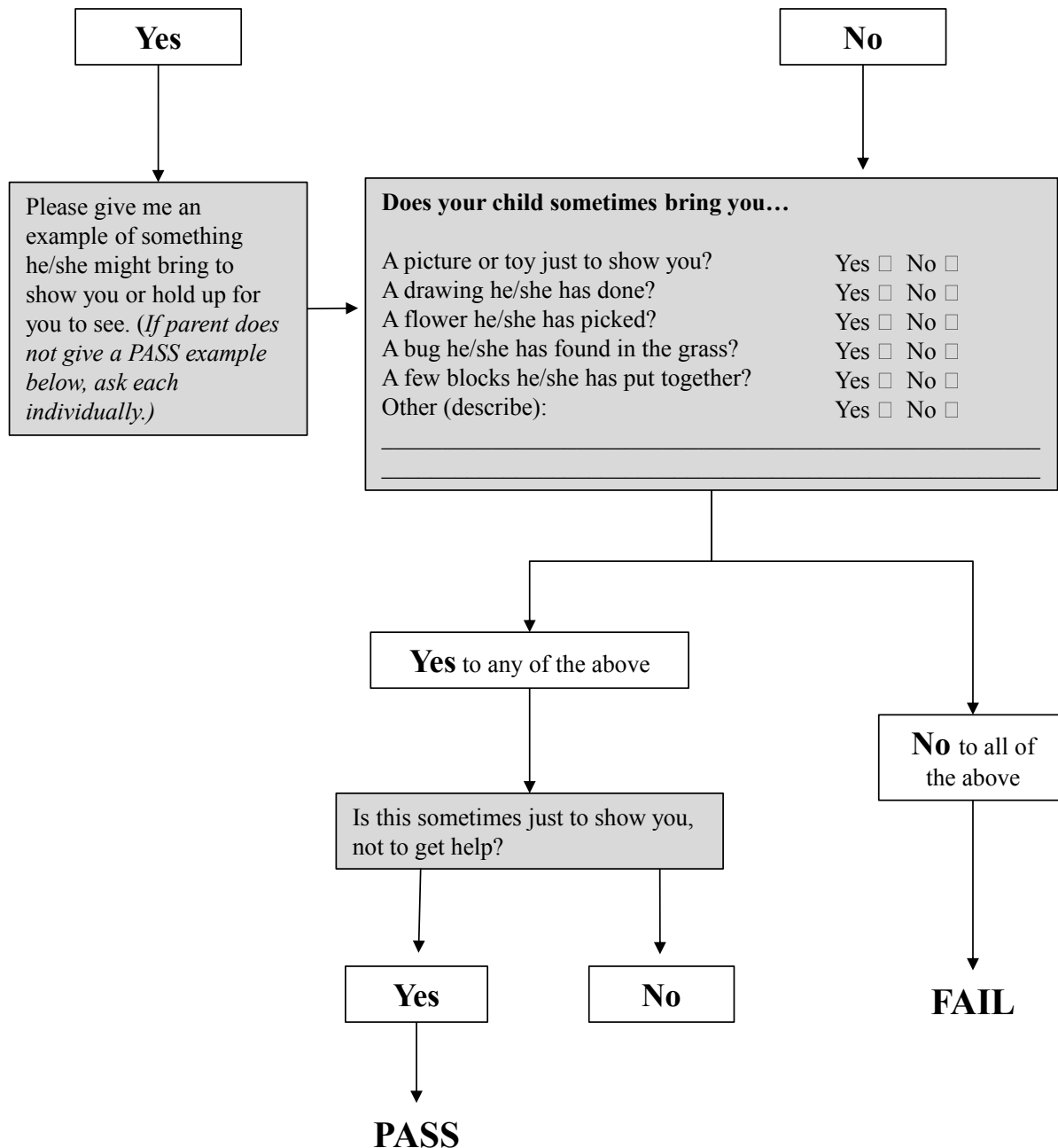
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8. Is _____ interested in other children?



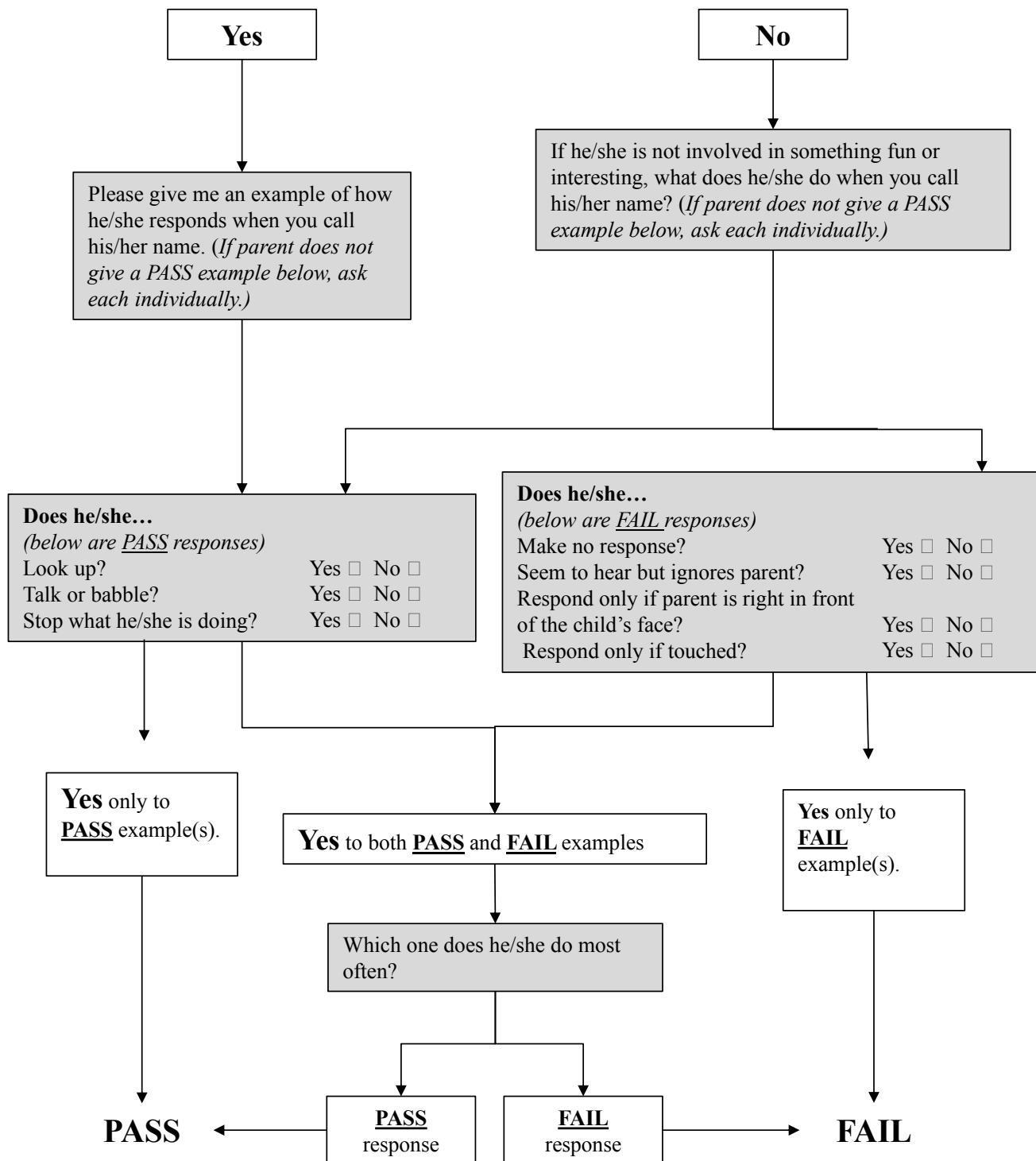
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9. Does _____ show you things by bringing them to you or holding them up for you to see? Not just to get help, but to share?



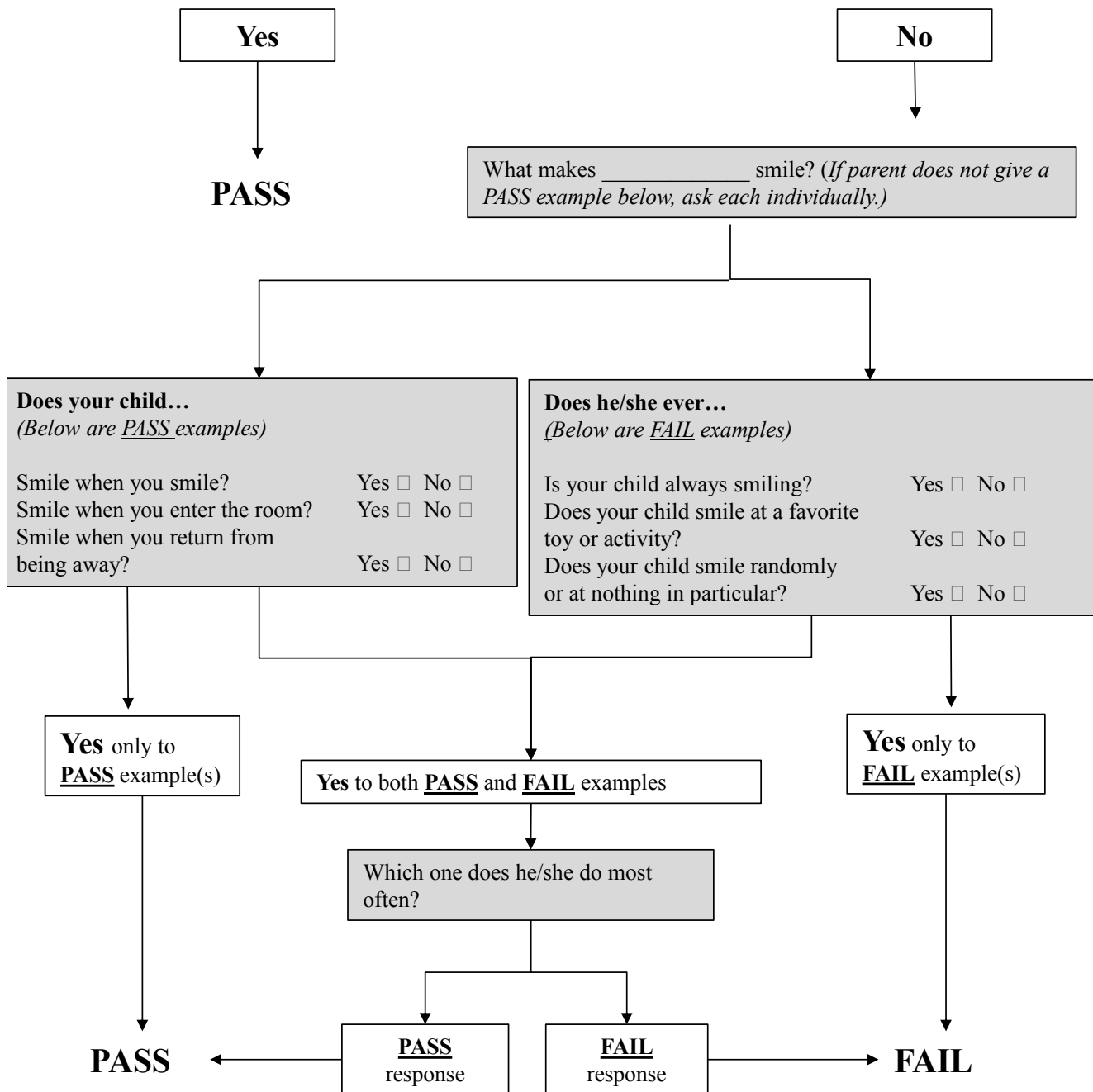
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10. Does _____ respond when you call his/her name?

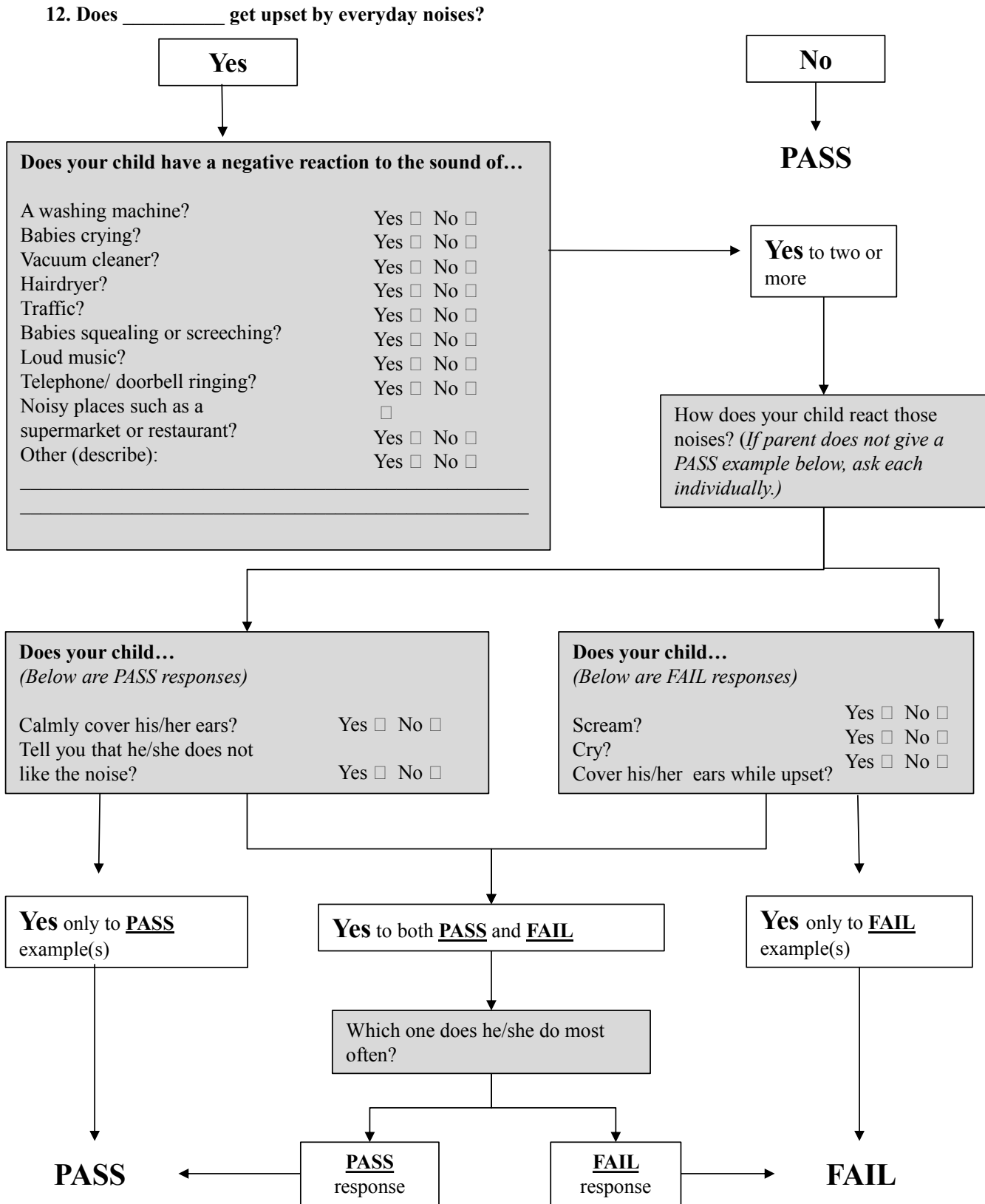


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11. When you smile at _____, does he/she smile back at you?

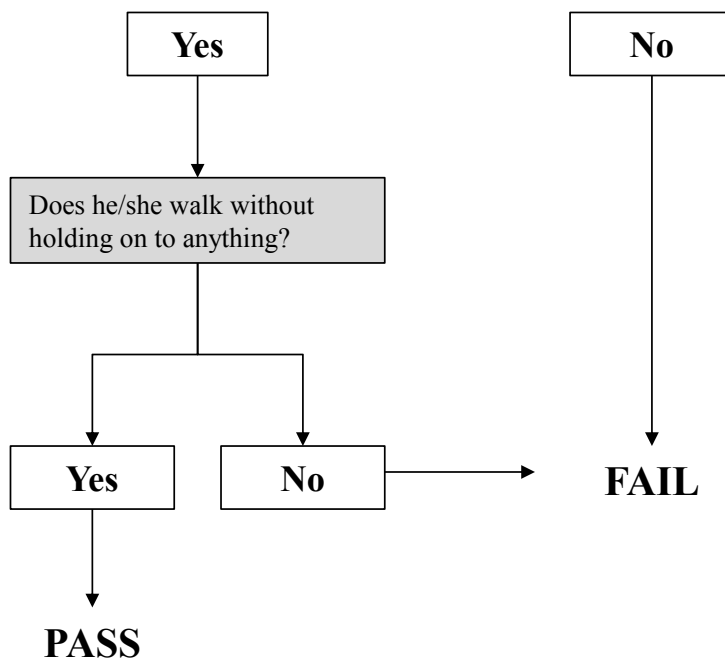


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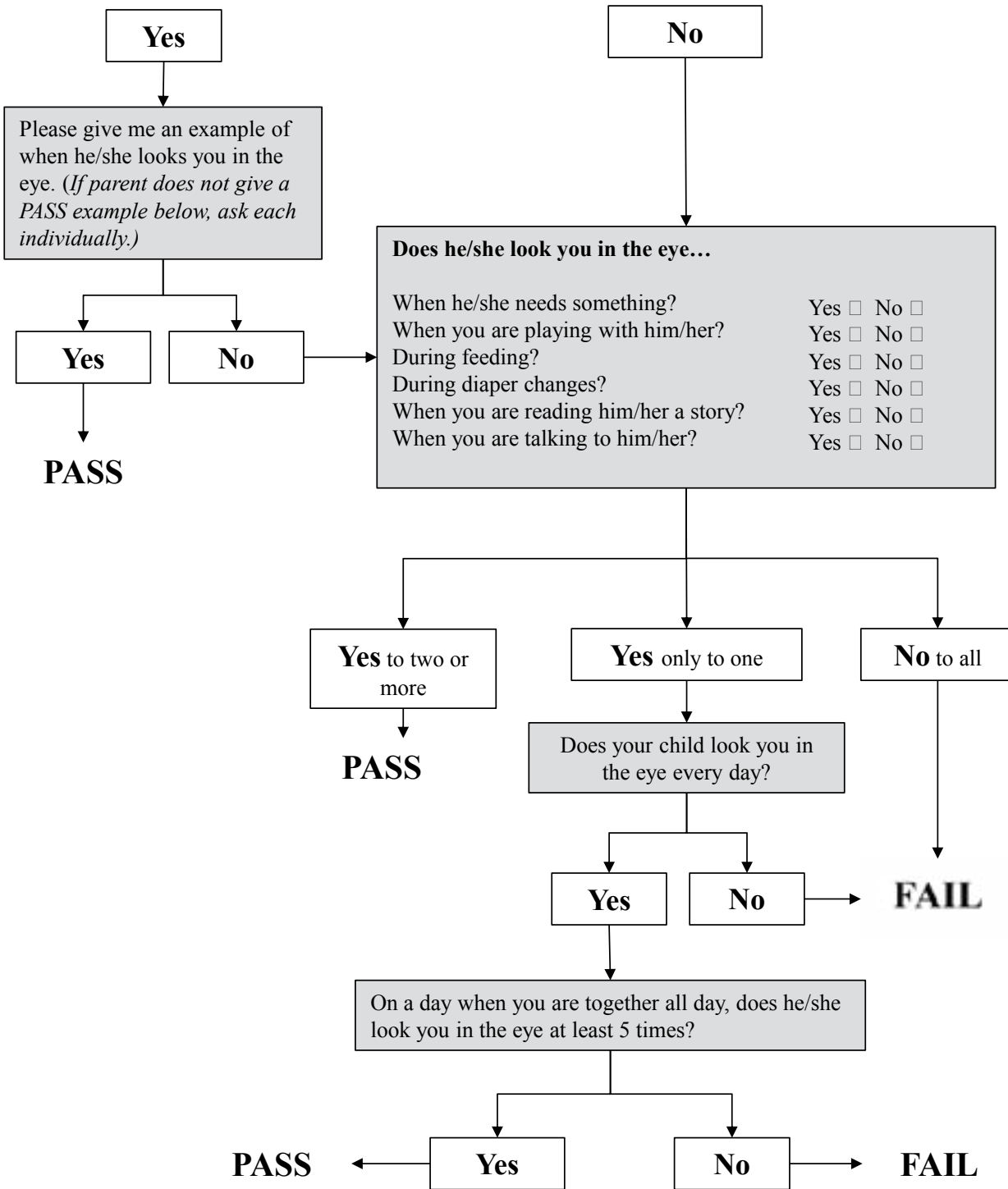
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13. Does _____ walk?



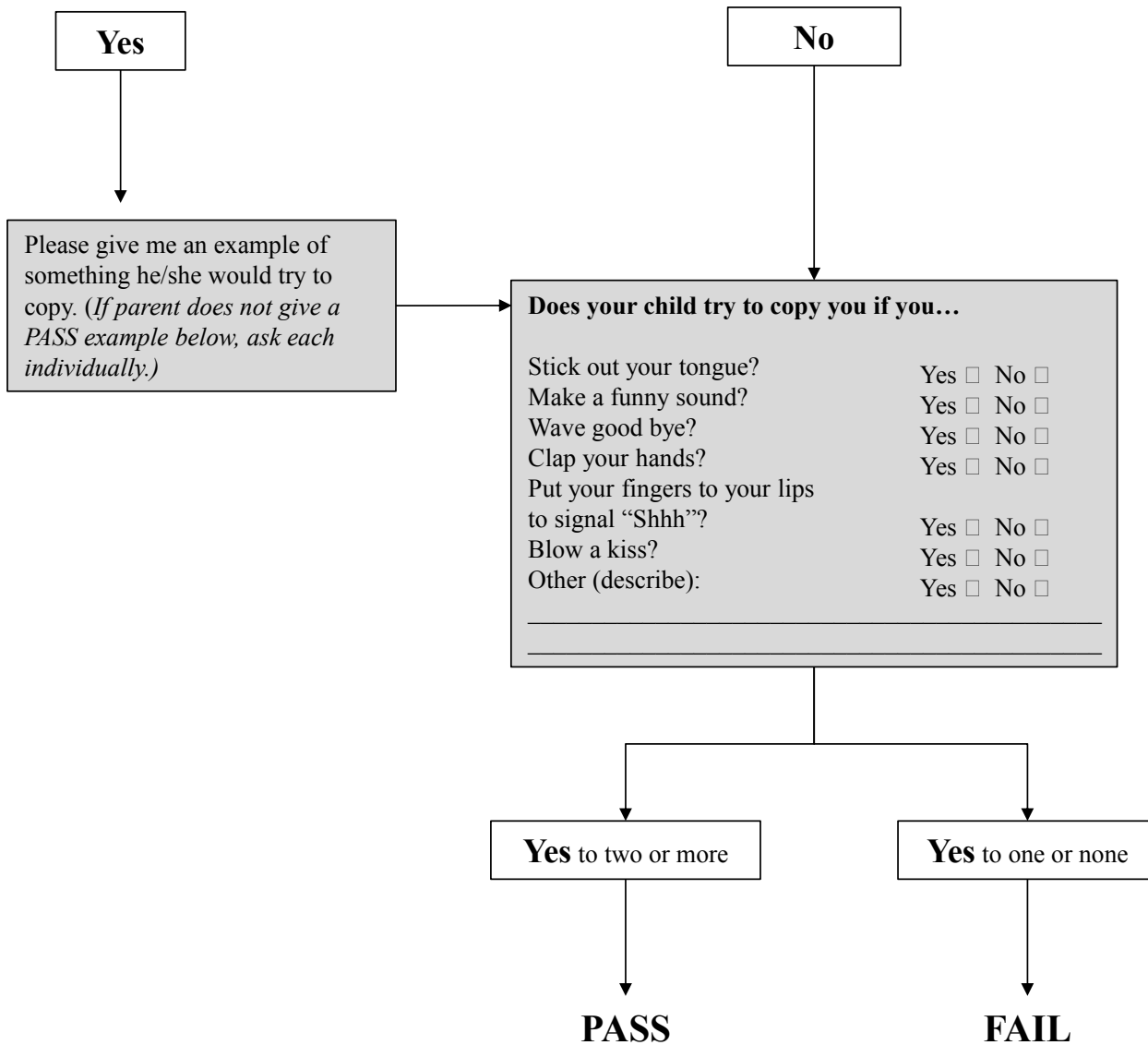
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14. Does _____ look you in the eye when you are talking to him/her, playing with him/her, or changing him/her?



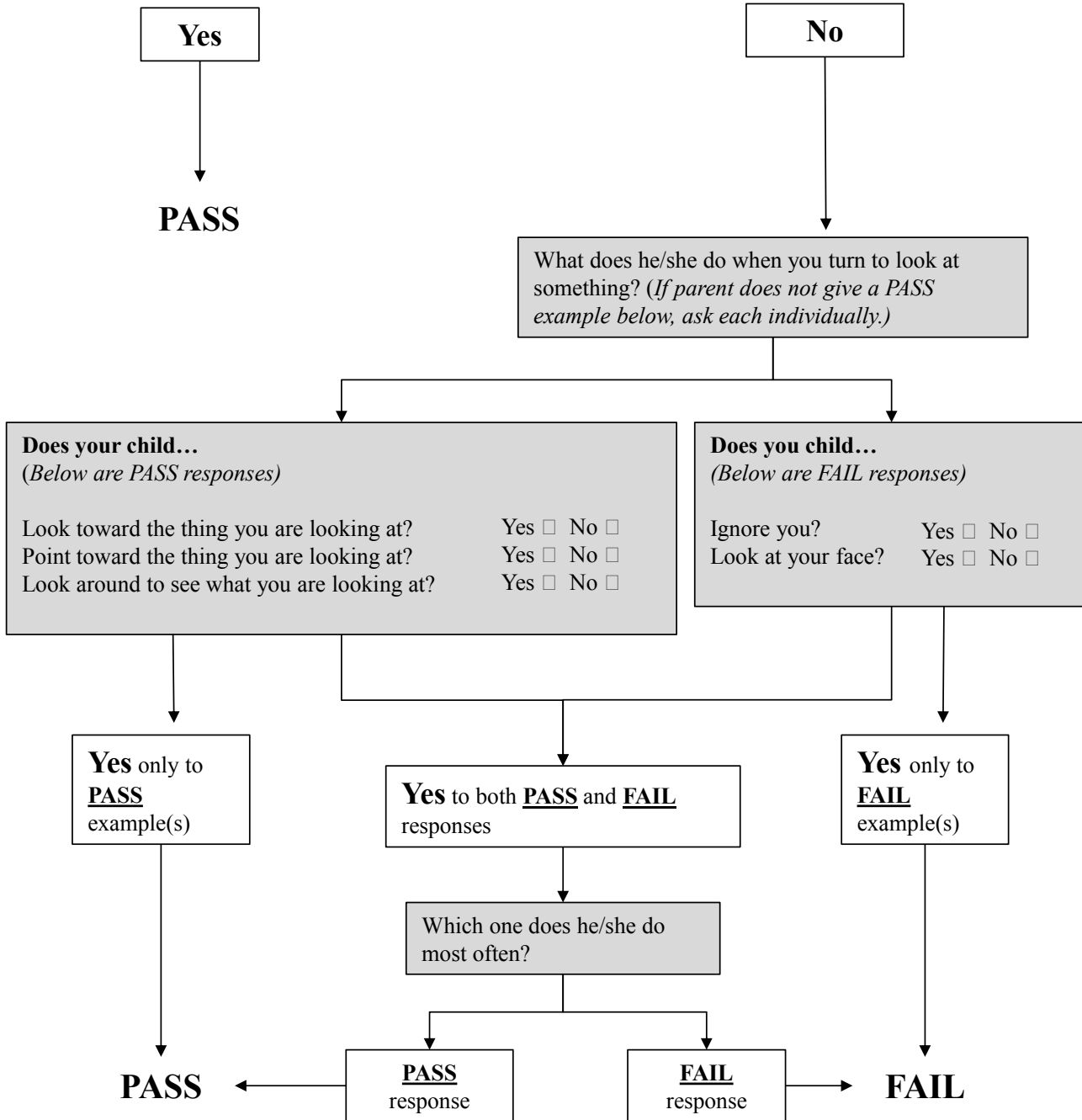
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15. Does _____ try to copy what you do?



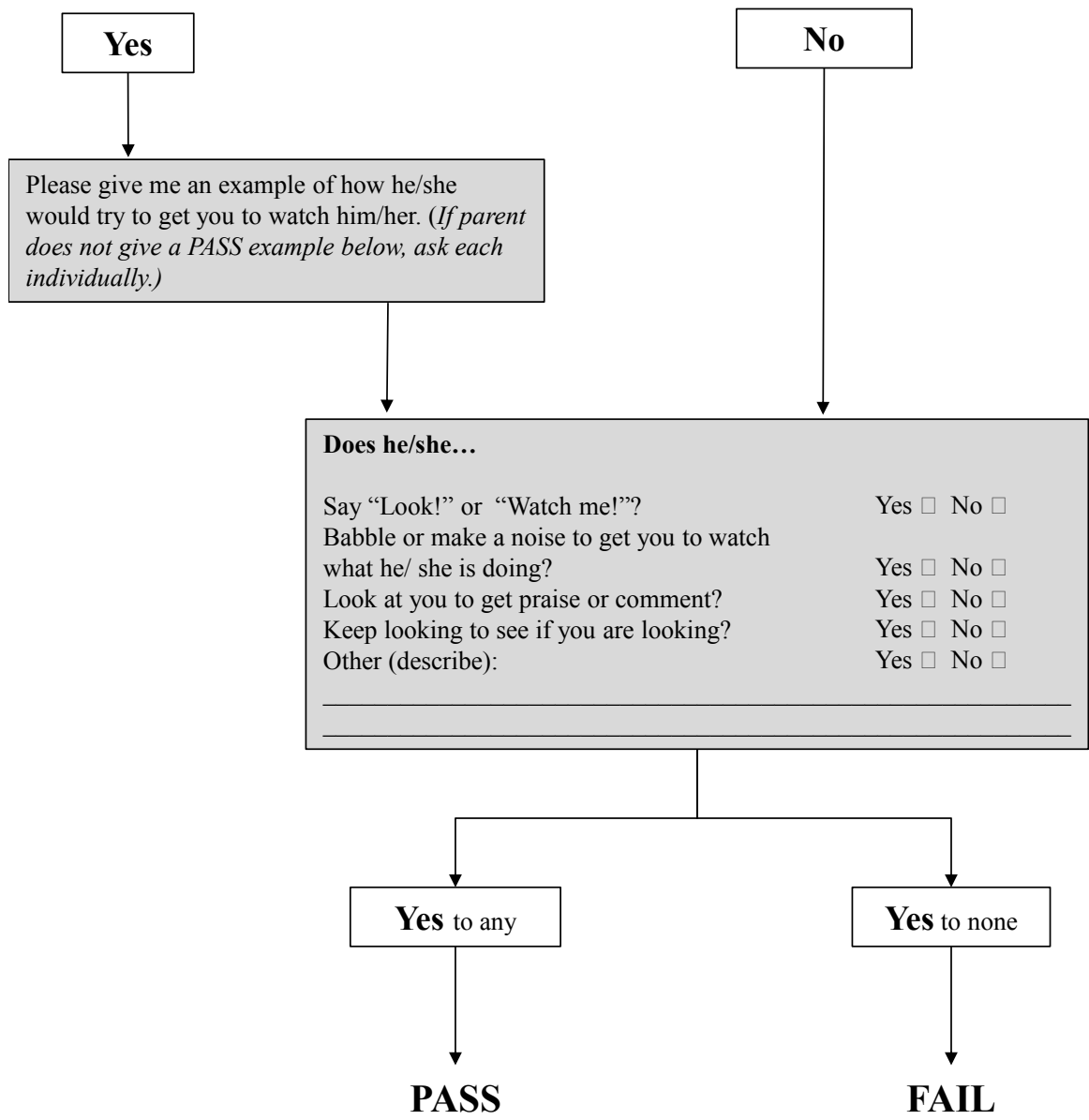
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16. If you turn your head to look at something, does _____ look around to see what you are looking at?



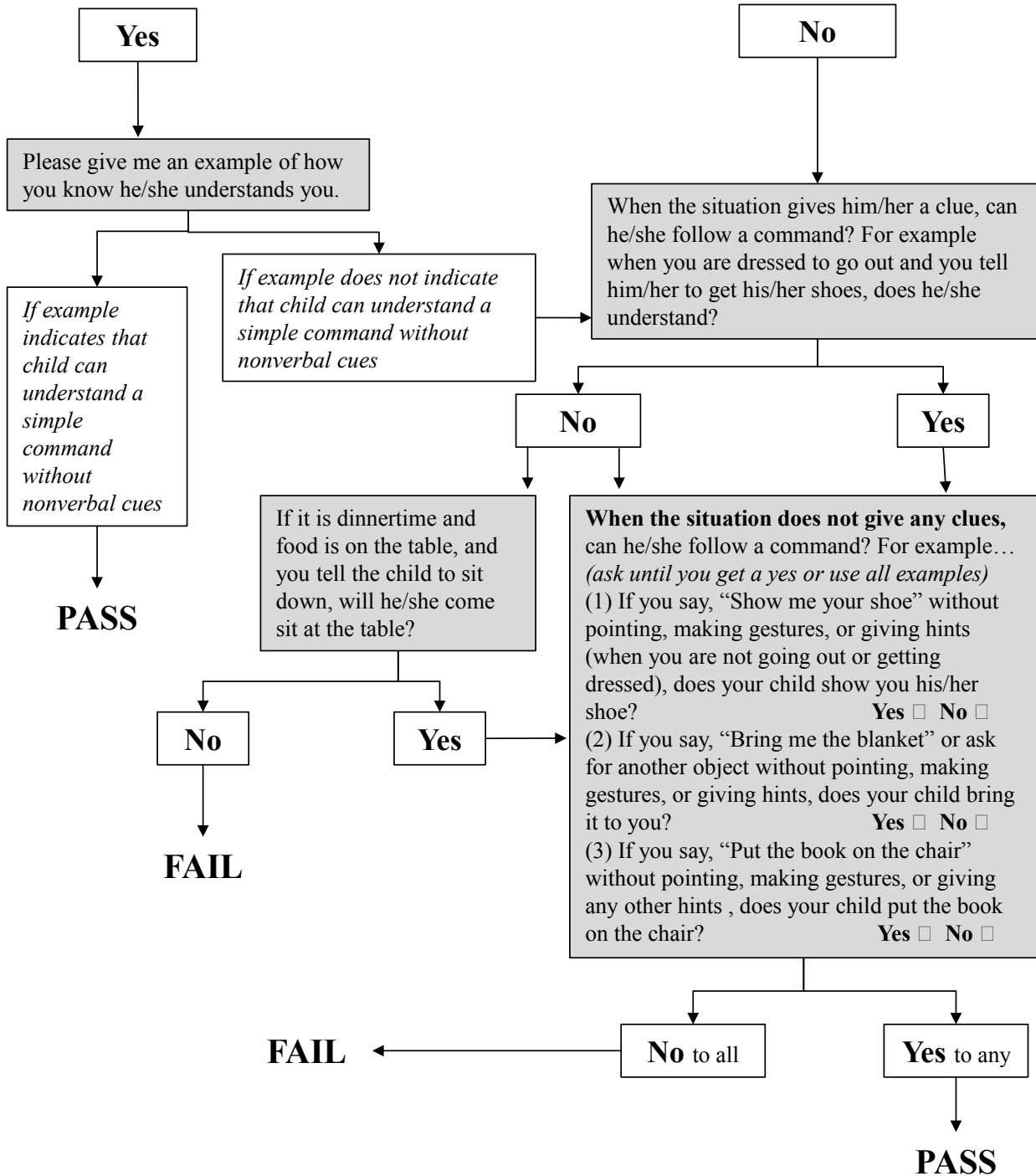
Considering Culture in Autism Screening

17. Does _____ try to get you to watch him/her?



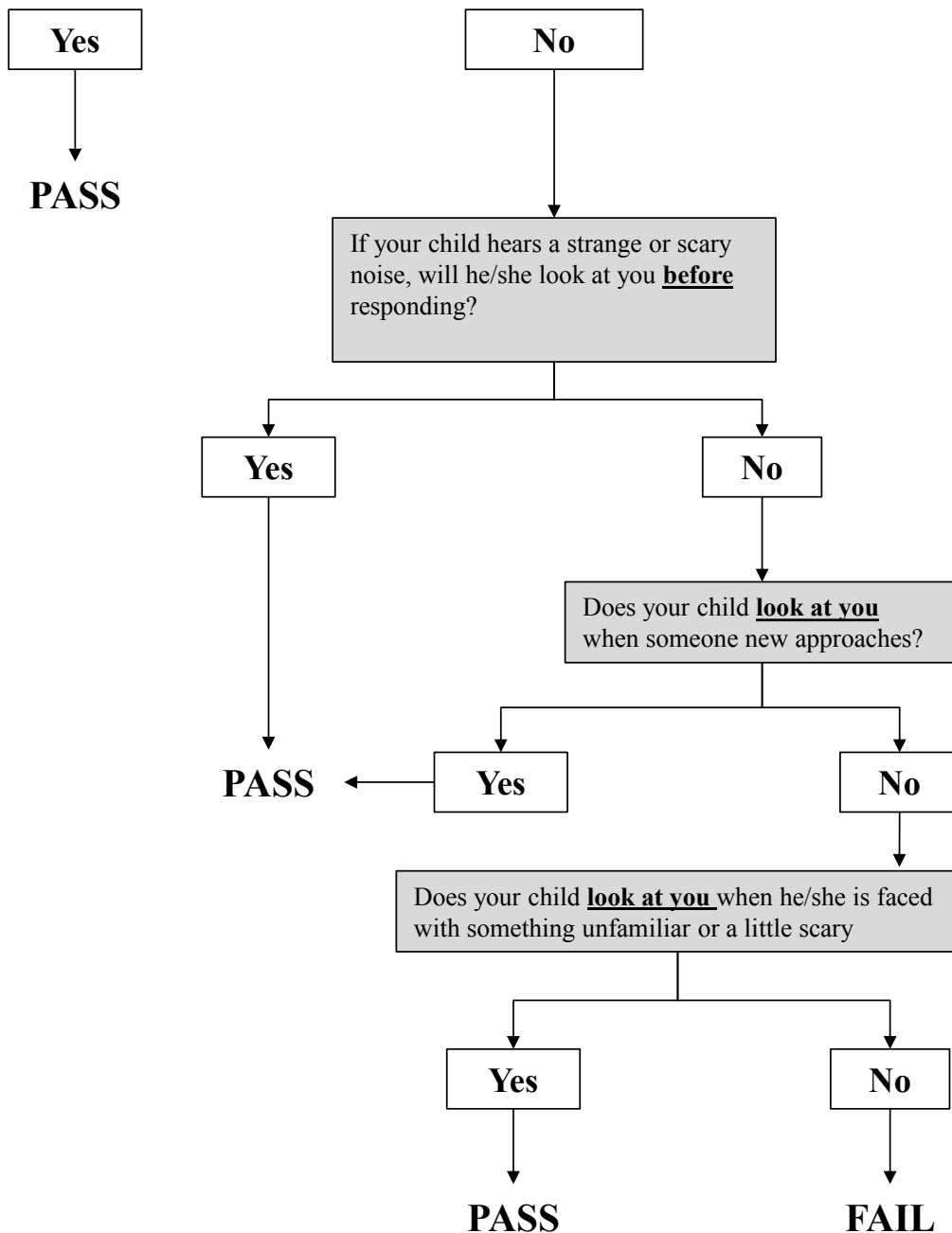
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18. Does _____ understand when you tell him/her to do something?



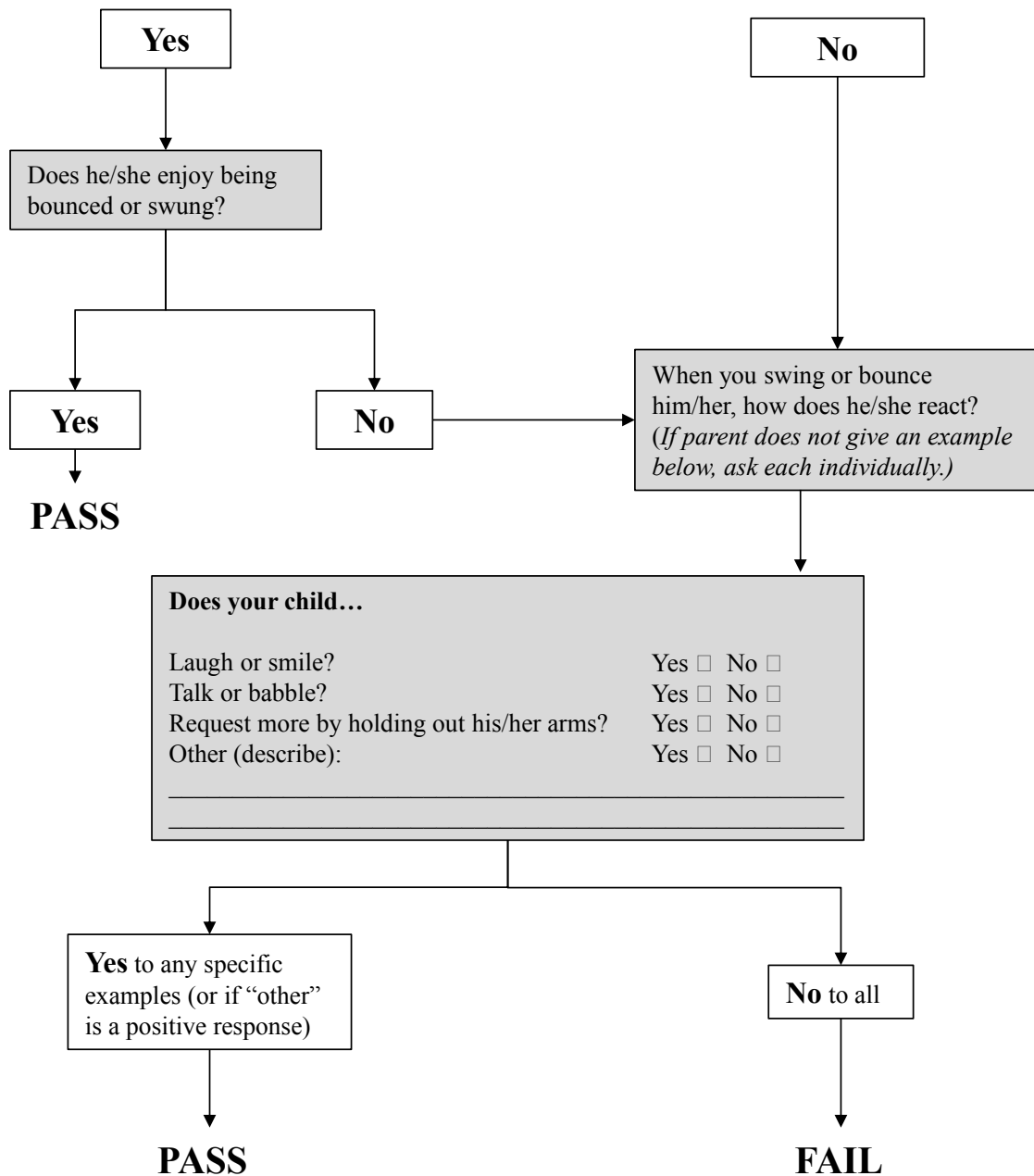
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19. If something new happens, does _____ look at your face to see how you feel about it?



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20. Does _____ like movement activities?



Handout V: Cultural Considerations for Screening & Follow-Up

There are a number of developmental and autism screening tools available in multiple languages that capture delays and disorders in children from families with limited English proficiency (LEP). Routinely screening for autism and other developmental concerns at all recommended well-child visit ages with validated, translated screening tools will increase early identification of those young children at risk for these disorders, regardless of their background. It is important to use these translated tools and know the follow-up steps necessary to improve accurate detection of developmental concerns.

Routine developmental and autism screening practices reduce disparities

Several studies have found that screening is less consistent and occurs later for children from ethnic minorities and low SES backgrounds than it is for middle class, non-minority children. Incorporating routine screening into pediatric practice helps reduce such disparities. Get to know your local community and have screening tools available in all languages commonly spoken in your area (see “Handout VI: Cultural Competence Resources”). By doing so, you will increase children’s and family’s access to early identification and intervention in the event that developmental disorders, such as autism, are detected.

- In a 2013-2014 survey of pediatric providers conducted by the Massachusetts Act Early state team, 20% of respondents reported they do not screen if the family does not speak English.
- In a 2013 study of Latino families by Zuckerman et al., only 29% of primary care practices offered the Spanish version of screening tools to Latino families.
- Formal screening practices increase sensitivity and may reduce ethnic and SES disparities in early identification of ASD (Sices et al, 2003).

M-CHAT and M-CHAT-R/F screening tools

The M-CHAT-R/F (2014) is the latest version of the original M-CHAT screening tool (2000). Although the original M-CHAT has been translated into a number of languages, the updated **M-CHAT-R** questionnaire is still early in its acquisition of new translations, and more can be expected over time. If a translation does not yet exist for the revised version, the original version’s translations provide a high level of accuracy, but only if used in conjunction with the follow-up interview (M-CHAT-R/F) since it has variable utility in different cultural and linguistic settings with the questionnaire alone.

- Translations for both the M-CHAT and M-CHAT-R/F can be downloaded from http://www2.gsu.edu/~psydlr/M-CHAT/Official_M-CHAT_Website.html.

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- The M-CHAT has been studied in several countries: China (Wong et al, 2004), Arab countries (Seif et al, 2008), Portugal (Losapio, 2008), Sri Lanka (Perera, 2009), Thailand (Pintunan, 2009), Japan (Inada et al, 2011), Mexico (Albores-Gallo, 2012), Korea (Kim et al, 2013), Latin America and Spain (Zuckerman, 2013), and others, though more research is needed.
- Cultural interpretation of screening tools is important as well. For example, Spanish M-CHAT and M-CHAT-R/F versions exist for Spanish from Spain (SS) and for Spanish from the Western Hemisphere (WHS) or Latin American culture. Both require consideration when selecting tools.
- The M-CHAT and M-CHAT-R/F have not been standardized in other languages. Thus, the follow-up interview, while time-consuming, is an essential component, since it eliminates most population differences in screening outcomes.
- The M-CHAT authors request translators to translate and back-translate until the tool is accurately translated back into English. For more information, please read “Toolkit Guidelines for Culturally Appropriate Translation” written by the U.S. Department of Health and Human Services Centers for Medicare & Medicaid Services at <http://tinyurl.com/translation-toolkit>.

Administering translated screening tools is not enough

Do not assume it is enough to provide a parent with a translated version of the M-CHAT-R/F screening tool. There is a higher rate of missed questions or false positives in screening results from Latino parents than from white parents. This is probably secondary to the misinterpretation of the questions asked.

Although a family may have difficulty understanding questions from an autism screening tool, the following questions from the previous version of the M-CHAT and current MCHAT-R/F were found to lead to confusion for some Latino families:

<i>Original M-CHAT Question</i>	<i>M-CHAT-R/F Question</i>
Q11: Does your child ever seem oversensitive to noise? (e.g., plugging ears)	Q12: Does your child get upset by everyday noises? (FOR EXAMPLE, does your child scream or cry to noise such as a vacuum cleaner or loud music?)
Q18: Does your child make unusual finger movements near his/her face?	Q5: Does your child make <u>unusual</u> finger movements near his or her eyes? (FOR EXAMPLE, does your child wiggle his or her fingers close to his or her eyes?)
Q20: Have you ever wondered if your child is deaf?	Q2: Have you ever wondered if your child might be deaf?

To clear up any confusion, it may be helpful to go over each question with families and explain each to them, if warranted. In addition, the follow-up interview is an essential step to ensuring clarity and accuracy in the tool’s administration.

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Post screening follow-up and next steps

It is important to set aside more time than is left in the remainder of the well-child visit to go over the results of the ASD screening test. Many clinicians use time slots at the end of their day or at the end of a session for such discussions so that they do not feel rushed with a family. Consider if you also need an interpreter or a cultural liaison (CL) to help translate this important conversation. You could then schedule a follow-up visit with the family and the interpreter or CL at the earliest possible available date for the family, even if only one parent can come. At that time with the family and interpreter/CL present, you will discuss your concerns, the M-CHAT-R/F results, and the follow-up referrals in more detail, answer any questions, and insure logistical supports are in place for them to be able to follow through with the referrals.

An effective approach to open the conversation about screening results:

1. Begin the conversation by using the parent's perspective as your starting point and reviewing the child's strengths.
2. Speak slowly & calmly.
3. Listen.
4. Discuss results with empathy and follow guidelines for any feedback.
5. Maintain eye contact when culturally appropriate, and direct your body positioning towards the family, NOT towards the interpreter or CL.
6. Whenever possible, you want to tie in your own concerns with those raised by the parent (e.g., "When we first sat down, I know you mentioned that you were concerned about your child's not speaking. I am too, and I'd like to see what more we can learn from specialists who have more experience and expertise in this area").
7. Be clear, expressing your concerns at this time.
8. Be specific in your use of examples (e.g., describing exactly what you have seen, as well as using parental report and/or M-CHAT-R/F questions to guide this conversation).
9. Discuss the results of the M-CHAT R/F, but also provide referrals and explain what they are for and what each specialist or program will do.
10. Convey logistical information, such as how to contact the referral clinic, and you may also need to insure that the family has appropriate transportation to get to the assessment visit.
11. Share your concerns with the child's parents around development and ask their permission to begin working on arranging additional evaluations.
12. Use these as the reasons you feel a child would benefit from a more comprehensive evaluation.
13. Depending on the perspective that the family has shared thus far, you can decide how much to include about the possibility of ASD, recognizing that there could be implications either way.
14. You should conclude by reinforcing to the parent that you hope to be considered their "partner."
15. Let them know you will follow their child closely and assist in whatever ways you can to ensure that both he and his family are getting the care and support that they need.

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Other points to consider when giving any feedback:

- a. Provide time for questions (i.e., pause often, keep the language and medical terms you use simple).
- b. Identify a cultural liaison if/when available to help explain and support the clinician and family in discussing and following up on screening results, the family's reaction, and their questions and referrals.
- c. Clarify parents' expectations and explain to them what the screening tool does and what it does not do.
- d. Discuss with families if they have concerns about their child's development and if they think their child has delays or differences in his or her development. If so, ask what they think might be causing those delays.
- e. Clarify with the interpreter and/or the cultural liaison the equivalent term or definition of "autism spectrum disorder" in that particular language and culture.
- f. Always consider your clinical impression and clinical judgment of this particular family and child and let that guide your approach.
- g. Use simplified medical language and avoid jargon or confusing terminology; never use acronyms.
- h. Allow time for questions; don't try to include all that you know about ASD risks or screening tools since too much or overly sophisticated information can be overwhelming for many families.
- i. Inquire about the family's understanding and check for your own understanding in turn by rephrasing what they tell you to accurately clarify their perspective.
- j. Provide the family with informative materials translated in their primary language.
- k. Provide a contact person for follow-up with questions. It would be ideal if this person were a cultural liaison. It is critical that the family leaves with a firm plan and the phone of the contact person to call if support is needed.
- l. Provide a close follow up to check in on the evaluation, results and recommendations.

Handout VI: Cultural Competence Resources

Health care clinics that serve culturally and linguistically diverse (CLD) populations offer an extraordinary opportunity to reduce health care disparities and increase access to services for children and families. Along with this opportunity come certain challenges such as barriers related to language and customs. To have meaningful conversations and interactions with patients' families and to provide a high quality of care to their children, cultural competence is critical.

We all hail from different cultures. When trying to understand the perspectives of people from a variety of cultures, it is best to reflect on one's own background first. With this approach as the starting point, it can help heighten awareness and bridge understanding between cultures.

Key recommendations for pediatric providers to bear in mind when working with CLD families include:

- Although getting to know specific cultures is important, it is even more important to know an individual family's cultural health beliefs, behaviors and social context to better understand your patient's needs.
- Avoid cultural generalizations that might hinder meaningful conversations and relationships with patients.
- Get to know the community in which your clinic is situated; take into account and show respect for individual and collective values that are based on the cultures represented in your area.

Where to begin:

The **National Center for Cultural Competence** (NCCC - see links below) serves to increase the capacity of health care and mental health care programs to design, implement, and evaluate culturally and linguistically competent service delivery systems to address growing diversity, persistent disparities, and to promote health and mental health equity. Their web site offers a wealth of assessment tools, guides, frameworks and information at the individual or organization level to enhance the delivery of high quality services to culturally and linguistically diverse individuals and underserved communities.

Foundations of Cultural Competence:
<http://nccc.georgetown.edu/foundations/index.html>

Self-Assessment Checklist:
<http://tinyurl.com/georgetown-checklist>

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Get to know the history and demographics of the families you serve by compiling your own “fact sheet”:

<i>What to know</i>	<i>Where to look</i>
U.S. Census Bureau State and County Quick Facts: education, socioeconomic status, urban/rural designations, race & ethnicity, family constellation, etc.	<ul style="list-style-type: none">• www.census.gov
Languages spoken in your area	<ul style="list-style-type: none">• http://tinyurl.com/census-lang
Language spoken at home	<ul style="list-style-type: none">• http://tinyurl.com/socdemopop
State level data on the size, composition, and socioeconomic characteristics of foreign-born populations	<ul style="list-style-type: none">• http://tinyurl.com/migrationinformation
Yearbook of Immigration Statistics: Immigrants coming to the U.S. (by state) and immigration status	<ul style="list-style-type: none">• http://tinyurl.com/uscis-yearbookstats
Local immigrant centers for specific populations	<ul style="list-style-type: none">• Foreign Embassy and Consulate Offices: www.state.gov/s/cpr/rls/• Or ask the Office of Social Workers at your local hospital
Medical assistance programs for immigrants by state	<ul style="list-style-type: none">• http://nilc.org/document.html?id=159
13-volume series, <i>The Rehabilitation Provider's Guide to Cultures of the Foreign-Born</i> , information about how disability & rehabilitation are viewed in each culture.	<ul style="list-style-type: none">• http://cirrie.buffalo.edu/culture/monographs/

Cultural Resources

Guides to working with translators

A Guide to Working with Professional Translators. Source: Carolina Association of Translators & Interpreters (CATI) . <http://www.catiweb.org/working.htm>

Translation Getting It Right. American Translators Association. http://www.atanet.org/publications/getting_it_right.php

Cultural liaisons and brokers

Growing Your Capacity to Engage Diverse Communities by Working with Community Liaisons and Cultural Brokers. Source: Family Voices. http://www.familyvoices.org/admin/work_diversity/files/CommunityBrokers_04-27-2009.pdf

Phrasebooks

Phrasebooks for Selected Refugee Populations -19 free downloadable translations. Source: Cultural Orientation Resource Center. <http://www.culturalorientation.net/resources-for-refugees/phrasebooks>

Other resources

Diversity and Cultural Competence. Source: Family Voices. <http://www.familyvoices.org/work/diversity>

School Success for Haitian Children with Autism: A Parent Training Manual to Overcome Culture, Language and Other Barriers. (2014). Boston, MA: Mass Advocates for Children.

http://www.massadvocates.org/documents/MAC_HMANUALFINAL_2014.pdf

Handout VII: Immigration Fact Sheet

Information about immigrant status is highly complex, ever-changing, and may vary depending upon individual circumstance. If you wish to understand more about a particular family you are serving, it may require researching a family's status using the most valid, primary sources of information, such as the U.S.CIS official web site at www.uscis.gov and/or seeking legal advice with an immigrant expert. For our purposes, we will provide a general overview.

Some immigrant status categories that clinicians should be aware of include:

- Citizens from Immigrant Families
 - Native born citizens are born in the U.S. or its territories. The vast majority of children in immigrant families fit this status, including François.
 - Naturalized citizens originally emigrate to the U.S. and apply to become naturalized citizens after living
- Lawful Permanent Residents (LPRs) (i.e., Green Card Holders)
 - Lawful permanent residents have permission to live and work permanently in the U.S.
 - Naturalized citizens originally emigrate to the U.S. and apply to become naturalized citizens after living
- Immigration Statuses Other than LPR
 - Non-immigrant status
 - Admitted to the U.S. for a limited period of time and for a specific purpose
- Undocumented Immigrants
 - Undocumented immigrants are foreign-born and lack the right to be in the U.S. because either a) they entered without inspection (“entered without inspection” “EWI”) (and did not subsequently obtain any right to remain) or b) they stayed beyond the expiration date of a visa or other status making them “out of status” or “overstayed” status. Francois’ mother demonstrates an example of an “overstayed” status.

Common concerns and tips for addressing them:

- Quality of services in U.S. not available in home country
 - A common story among immigrant families involves when a parent comes to the U.S. on a tourist visa, similar to Francois’ mother and ends up staying in the country due to a child’s needs because of a lack of appropriate health care in one’s home country. The parent fears what will happen to the child if they lose their health care in the U.S. due to deportation as it is often irreplaceable.
- Confusion about eligibility
 - Immigration and welfare laws are complex. Confusion about eligibility rules originates from differences in eligibility criteria for various state and federal programs. Many eligible immigrants do not understand this system and wrongly assume that they should not seek services. Some eligibility workers have mistakenly turned away eligible immigrants.
 - Tips:
 - Emphasize that a lawfully-present child or adult will still be eligible even when other family members are not.
 - Language is important. Use terms like “eligibility” and “non-eligibility.” Avoid the term “undocumented.” Another term that does not imply criminal activity is “unlawfully present.”
 - Identify community advocates who understand immigrant eligibility.
 - Seek valid expert answers to questions your patient’s families may raise. Never assume that someone is either eligible or ineligible.

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- Privacy and confidentiality
 - Parents may wonder whether they will be reported to immigration authorities if they, their child, or other family members are undocumented.
 - The Affordable Care Act and its regulations include strong protections for personally identifiable information, with information about applicants and non-applicants used only to determine eligibility for health insurance.
 - It is perfectly safe for an ineligible family member to apply for a member who is eligible.
 - Information about applicants obtained for health insurance eligibility will not be used by Immigration and Customs Enforcement/Department of Homeland Security (ICE/DHS) for immigration enforcement.
 - Tips:
 - Understand the subtleties of being “undocumented” or “unlawfully present.” As clinicians, you should be aware that based on immigration status, an individual should avoid putting themselves in compromising circumstances that would jeopardize their ability to stay in the U.S. (e.g., domestic violence, other crimes).
 - Provide the family with multiple reassurances about your agreement to privacy and confidentiality in working with them because in your role as a clinician, you are a child advocate trying to provide health care to a child and your role is not to report families to immigration authorities.
- Public charge
 - One major concern of many undocumented parents is how accessing certain public benefits such as Medicaid or food stamps will affect their chances of applying for a green card or becoming a citizen if one is considered a “public charge.” A “public charge” is a person who depends exclusively on cash benefits such as SSI or TANF for financial support. Depending on one’s migratory status, a person can be refused admission to the U.S. or the opportunity to become a lawful permanent resident if government authorities believe the individual will not be able to support him or herself without these benefits in the future. Removal based on public charge is very rare.
IMPORTANT: Children who are citizens and recipients of cash assistant benefits will not hurt or affect their parents’ migratory status.
 - Tip:
 - To allay these fears, keep credible fact sheets available about eligibility for benefits and public charge in English and multiple languages. The National Immigration Law Center at www.nilc.org has many helpful immigrant fact sheets for families on this and other immigration topics
- Hostility and discrimination
 - Some CLD families come from countries where they may have experienced persecution and discrimination based on race, ethnicity, and national origin, including language spoken. You can assure them that in the U.S., these practices are prohibited by civil rights laws.
 - Immigration enforcement authorities cannot enter into private areas of public facilities such as medical clinics without consent or a warrant.
 - Tips:
 - Create a safe and trusted environment for seeking services in your clinic
 - Provide free, competent interpretation services
 - Provide translated documents in as many languages as possible
 - Train all staff and volunteers who provide assistance to immigrant families
 - Reach out to organizations trusted by immigrant communities
 - Identify appropriate referrals in the community, if needed, or cultural and linguistic community experts

Handout VIII: Immigration Resources

Migratory status affects the access to and quality of critical services for children with disabilities and their families. Often fear, misconceptions, lack of knowledge, and inevitable language barriers increase the difficulty of navigating an already challenging system of health and human service agencies. The following resources can familiarize providers about immigration in order to understand some of families' barriers when trying to get services for their children.

Immigration Resources

U.S. Citizenship and Immigration Services (USCIS) is the government agency that oversees lawful immigration to the United States. USCIS will secure America's promise as a nation of immigrants by providing accurate and useful information to their customers, granting immigration and citizenship benefits, promoting an awareness and understanding of citizenship, and ensuring the integrity of the U.S. immigration system. <http://www.uscis.gov/>

The **National Immigration Law Center** (NILC) engages in policy analysis, litigation, education and advocacy, to achieve this vision. NILC plays a critical role within the movement for racial, economic and social justice for low-income immigrants. They have a variety of informative fact sheets and printable materials in several languages. Includes the "Quick Guide to Immigrant Eligibility for ACA": www.nilc.org/document.html?id=844. www.nilc.org

The **National Immigration Project of the National Lawyers Guild** (NIPNLG) is a national non-profit that provides legal and technical support to immigrant communities, legal practitioners, and all advocates seeking to advance the rights of noncitizens. www.nationalimmigrationproject.org/index.htm

Massachusetts Resources

Catholic Charities of the Archdiocese of Boston is one of the largest providers of social services in Massachusetts and offers nearly 90 programs and services in 27 locations around Eastern Massachusetts. From Lawrence to Brockton and Natick to Boston, their service sites throughout Eastern Massachusetts serve people of all faiths. www.ccab.org/refugee.html

The **Irish International Immigrant Center** (IIIC) has supported Irish immigrants since 1989 and has grown into a multiservice center for people from 120 countries helping them find their place in our multicultural society. <http://iiicenter.org>

The **Massachusetts Immigrant and Refugee Advocacy Coalition** (MIRA) is the largest organization in New England promoting the rights and integration of immigrants and refugees. www.miracoalition.org

The **Refugee & Immigrant Assistance Center** (RIAC), formerly known as the Somali Women and Children's Association, is a community-based, grassroots organization dedicated to promoting educational and socio-economic development in the Massachusetts refugee and immigrant community. RIAC has offices in Jamaica Plain, Lynn, and Worcester. www.riacboston.org

A Quick Guide to Immigrant Eligibility for ACA and Key Federal Means-tested Programs

JANUARY 29, 2013

FOR MORE DETAILED INFORMATION: immigrant eligibility for federal programs, www.nilc.org/table_ovrw_fedprogs.html; medical assistance programs, www.nilc.org/document.html?id=159; state-funded food assistance, www.nilc.org/state_food.html; state-funded TANF replacements, www.nilc.org/guide_tanf.html; state-funded SSI replacements, www.nilc.org/document.html?id=475.

Handout IX: Quick Guide to Immigrant Eligibility for ACA

PROGRAM	LAWFUL PERMANENT RESIDENTS (age 18 and over)	LAWFUL PERMANENT RESIDENTS (under age 18)	LAWFUL PERMANENT RESIDENTS (pregnant women)	REFUGEES, ASYLEES, VICTIMS OF TRAFFICKING, OTHERS ¹	LAWFULLY PRESENT INDIVIDUALS	UNDOCUMENTED IMMIGRANTS (including children and pregnant women)
If entered the U.S. on or after August 22, 1996:						
ACA – Health Care Reform Subsidies (premium tax credits and cost-sharing reductions)	Eligible	Eligible	Eligible	Eligible	Eligible	Not eligible Also not eligible for full-priced health insurance in the Exchange marketplace
SNAP	Not eligible until after 5-year waiting period or have credit for 40 quarters of work	Eligible	Not eligible until after 5-year waiting period or have credit for 40 quarters of work	Eligible	Not eligible	Not eligible
MEDICAID	Not eligible until after 5-year waiting period ²	State option ³ to provide without a 5-year waiting period ²	State option to provide without a 5-year waiting period ²	Eligible ⁴	State option for children under 21 and pregnant women only	Eligible only for emergency Medicaid
CHIP	Not eligible until after 5-year waiting period	State option to provide without a 5-year waiting period	State option to provide without a 5-year waiting period	Eligible	State option for children under 21 and pregnant women	Not eligible
TANF	Not eligible until after 5-year waiting period ⁵	Not eligible until after 5 year waiting period ⁵	Not eligible until after 5-year waiting period ⁵	Eligible ⁴	Not eligible	Not eligible
SSI	Not eligible until after 5-year waiting period and have credit for 40 quarters of work or meet another exception	Not eligible until after 5-year waiting period and have credit for 40 quarters of work or meet another exception	Not eligible until after 5-year waiting period and have credit for 40 quarters of work	Only eligible during first 7 years after status is granted	Not eligible	Not eligible

¹ Also includes Cuban/Haitian entrants, Amerasian immigrants, Iraqi or Afghan special immigrants, and individuals granted withholding of deportation or removal.

² In a few states, remain ineligible after 5 years unless have credit for 40 quarters of work history or are a veteran, active duty military, or his or her spouse/child.

³ Eligible if receiving federal foster care.

⁴ A few states terminate Medicaid to humanitarian immigrants after a 7-year period, and/or TANF after a 5-year period.

⁵ At least a dozen states use their maintenance of effort funds to provide TANF without a waiting period.

Handout X: Glossary

The following terms appear in alphabetical order and define frequent terms or concepts presented in the Considering Culture in Autism Screening training module. While there may be many definitions for any of the terms below, we have chosen those that closely reflect our purposes. We have shared and credited the sources with each definition and provided their web links for more information.

Community liaison

Trusted individuals, who may or may not live in a certain community, yet have knowledge of a community's strengths, preferences and needs. Community liaisons may act as relationship brokers providing information and linkages between individuals, families and communities and the organizations and systems that seek to provide information and supports.

Source: Family Voices, Inc.

http://www.familyvoices.org/admin/work_diversity/files/CommunityBrokers_04-27-2009.pdf

Cultural competence

Cultural competence is a set of values, behaviors, attitudes, and practices within a system, organization, program, or among individuals and which enables them to work effectively cross culturally. Further, it refers to the ability to honor and respect the beliefs, language, interpersonal styles and behaviors of individuals and families receiving services, as well as staff who are providing such services. Striving to achieve cultural competence is a dynamic, ongoing, developmental process that requires a long-term commitment. *Source: U.S. Department of Health and Human Services, Health Services and Resources Administration.*

<http://www.familyvoices.org/news/latest?id=0317>

Cultural liaison or broker

Cultural liaisons or brokers function much the same way as community liaisons (above) but also have the knowledge of the values, beliefs and practices of a cultural group or community and specific organizations and systems with which they have learned to navigate effectively, either for themselves, their families, and/or their communities. Cultural brokers can play a key role in informing organizations about the most culturally appropriate ways of joining with families and communities from different backgrounds. *Source: Family Voices, Inc.*

http://www.familyvoices.org/admin/work_diversity/files/CommunityBrokers_04-27-2009.pdf

Immigrant

According to the Department of Homeland Security, an immigrant is defined as a "permanent resident alien: An alien admitted to the United States as a lawful permanent resident. Permanent residents are also commonly referred to as immigrants; however, the Immigration and Nationality Act (INA) broadly defines an immigrant as any alien in the United States, except one legally admitted under specific nonimmigrant categories. An illegal alien who entered the United States without inspection, for example, would be strictly defined as an immigrant under the INA but is not a permanent resident alien. Lawful permanent residents are legally accorded the privilege of residing permanently in the United States." *Source: Department of Homeland Security.*

<http://www.dhs.gov/definition-terms#15>

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Interpretation

Interpretation is the oral restating in one language of what has been said in another language. Interpreted information should accurately convey the tone, level and meaning of the information given in the original language. *Source: National Center for Cultural Competence.*

<http://nccc.georgetown.edu/features/language.html>

Linguistic competence

The capacity of an organization and its personnel to communicate effectively, and convey information in a manner that is easily understood by diverse audiences including persons of limited English proficiency, those who have low literacy skills or are not literate, individuals with disabilities, and those who are deaf or hard of hearing. Linguistic competency requires organizational and provider capacity to respond effectively to the health and mental health literacy needs of populations served. The organization must have policy, structures, practices, procedures, and dedicated resources to support this capacity. *Source: National Center for Cultural Competence.*

<http://nccc.georgetown.edu/documents/Definition%20of%20Linguistic%20Competence.pdf>

Linguistic isolation

Households in which no one over age 14 speaks English very well. *Source: U.S. Census Bureau.*

<http://www.census.gov/population/cen2000/phc-t20/tab02.pdf>

Limited English Proficiency (LEP)

Individuals who do not speak English as their primary language and who have a limited ability to read, write, speak, or understand English are considered limited English proficient, or “LEP.” In other words, LEP individuals speak very little or no English. *Source: National Conference of State Legislators, Children’s Policy Initiative.*

http://www.vdh.virginia.gov/ohpp/clasact/documents/clasact/language/Language_Access.pdf

Public charge

The term “public charge” is used in immigration law to describe a person who depends exclusively on cash benefits to support him or herself. *Source: National Immigration Law Center.*

www.nilc.org

Refugee

A refugee is someone who owing to a well-founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group, or political opinion, is outside the country of his nationality, and is unable to or, owing to such fear, is unwilling to avail himself of the protection of that country. *Source: Cultural Orientation Resource Center.*

<http://www.culturalorientation.net/learning/about-refugees>

Translation

Typically refers to the written conversions of written materials from one language to another.

Source: Cultural Orientation Resource Center.

<http://nccc.georgetown.edu/features/language.html>

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