Considering Culture in Autism Screening: Lessons Learned by the MA Act Early Team

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Background and Objective

• Non-English and non-Caucasian children are diagnosed with autism spectrum disorders (ASD) and other developmental disorders at later ages, and with lower prevalence than their counterparts.
• The Massachusetts Act Early state team sought to address this gap so that at-risk families from diverse backgrounds receive more effective autism screening.

Methods

Providers and cultural liaisons from four Greater Boston community health centers (CHCs) with large immigrant populations shared their successes, challenges, and recommendations for screening based on their experiences with families of the following backgrounds:

• Chinese
• Haitian-Creole
• Spanish
• Vietnamese

Drafts were reviewed with representatives of key stakeholders and experts in the field:

• Cultural liaisons
• National Center on Cultural Competence
• Autism Consortium resource specialist

Results

The “Considering Culture in Autism Screening” kit was developed to be used by providers to reduce cultural/linguistic disparities by providing culturally competent and timely screening, diagnosis, and referral to care.

The kit is available free online at www.MAActEarly.org

The kit contains:
1. Screening guide
2. Resource sheets (referrals, roles, facts)
3. Modified Checklist for Autism in Toddlers (M-CHAT) in English, Spanish, Chinese, Vietnamese, Haitian-Creole
4. M-CHAT instructions

Uniqueness of Each Family

• Communicating developmental concerns in a different language or across cultures can sometimes be tricky.
• Each family is distinct.
• 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?”

Discuss “autism” with care. If families ask, first inquire:
• “What does the term “autism” mean to you?”

For many families, these concepts are culturally bound; they may worry about stigma in their communities.

Implications for Referrals and Treatment

• Is a cultural liaison available?
• Can you offer information in the native language?
• Try to contact the referral agency directly.
• Schedule frequent follow-ups.
• Include the family in developing the treatment plan.

Encourage practice that respects and honors every family’s culture and language.

Future Directions

• National workshops using case examples
• Online distance learning curriculum
• Developing further understanding of other cultures
• Public service announcements in various languages
• Partnering with key stakeholders