# Addressing Cultural Barriers in Autism Screening: Lessons Learned from the 2015 SPHARC Peer-to-Peer Exchange

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## Background

Recent data from the CDC indicate that approximately 1 in 68 children have an autism spectrum disorder (ASD). The American Academy of Pediatrics recommends ongoing surveillance and ASD-specific screening at 18 and 24 months or whenever there is concern. Autism screening tools, such as the M-CHAT, are more accurate when used in conjunction with clinical judgment.

Children with ASD and developmental disorders (DD) from diverse cultural and linguistic backgrounds remain significantly less likely to be identified for evaluation and services and are also diagnosed at later ages than children from English-speaking families. The concepts of screening, early identification and early intervention may be unfamiliar to 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.

## SPHARC Peer-to-Peer Exchange

Since 2008, AMCHP's State Public Health Resource Center (SPHARC) has conducted the Peer-to-Peer Exchange Programs as a mechanism for states to learn from one other about building systems of care for children and youth with autism, share lessons learned and best practices, and develop plans of action for moving ahead. In 2015, SPHARC partnered with Massachusetts Act Early to expand its Spring 2015 Summit meeting into a two-day event about *Considering Culture in Autism Screening and Systems of Care*. The Peer-to-Peer Exchange was designed to develop skills and build the capacity of State Autism Grantees and focused on the sharing of programs, strategies and lessons learned to address cultural and linguistic gaps in screening, evaluation, and referral to intervention services. Seven states participated in the exchange (CT, IA, ME, MA, MN, NH and VA), which was held at the Boston Children's Museum.

The exchange included training on the *Considering Culture in Autism Screening* curriculum and facilitated discussions based on problem solving cultural and linguistic challenges and brainstorming solutions.
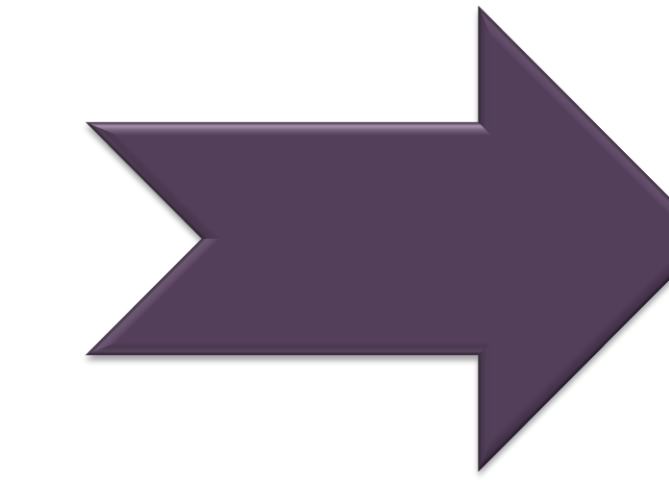
### Learn more at:

http://www.amchp.org/SPHARC

http://www.maactearly.org

**AMCHP**
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**Massachusetts Act Early**

## CONSIDERING CULTURE: LESSONS LEARNED

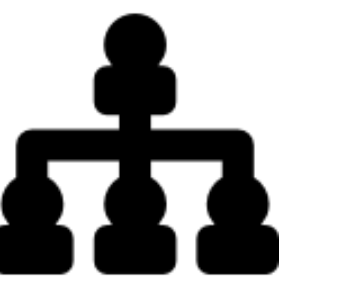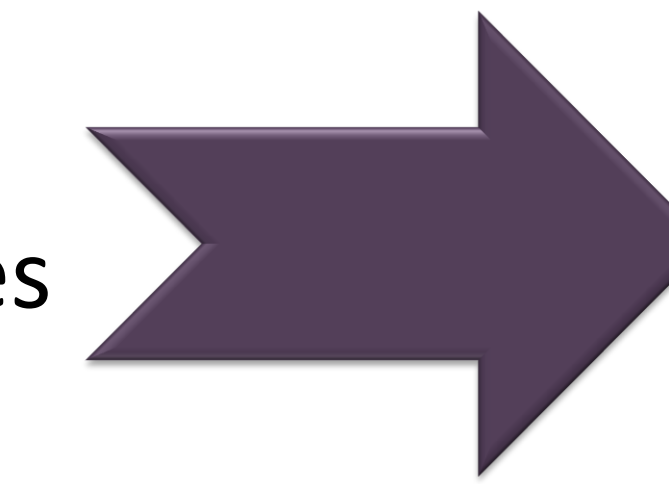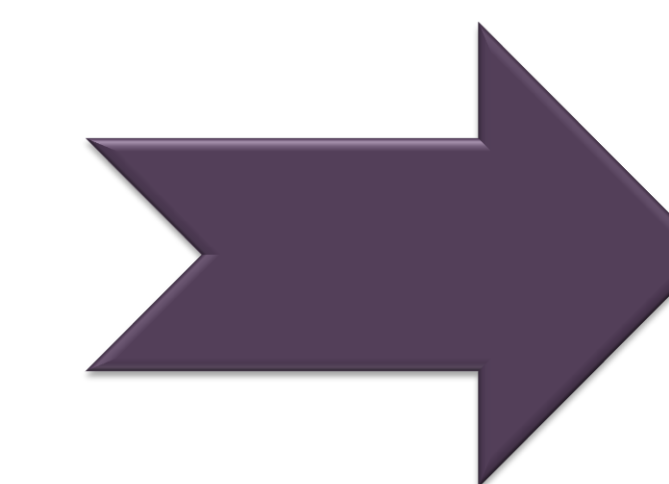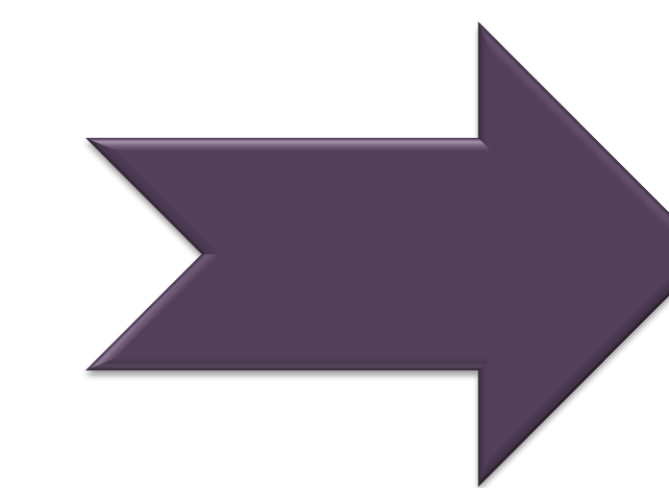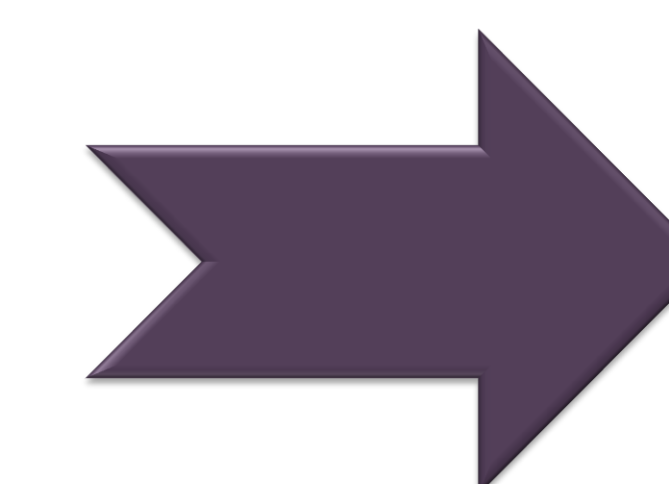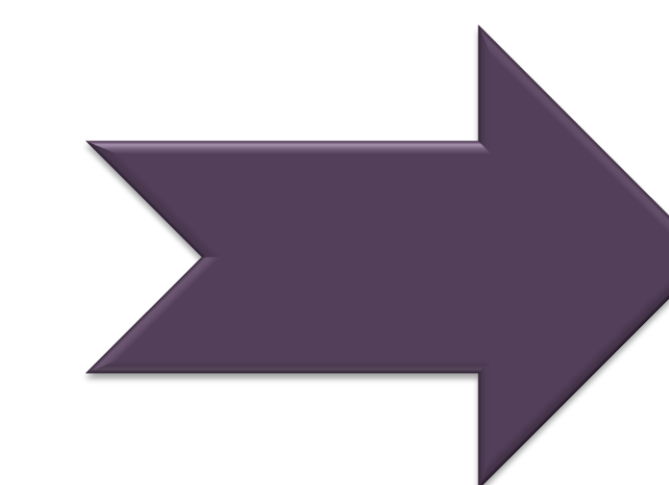| Category | Barriers | Solutions |
|---|---|---|
| Care Coordination & Case Management | • Coding and billing;<br>• Lack of billing for coordination | • Family TIES model<br>• Primary Care Behavioral Health model |
| Early Childhood Education Providers | • Lack of education and training about ASD<br>• Cross systems coordination challenges<br>• Questions around diagnosis (who diagnoses? Implications for eligibility?) | • Include training in licensing and core curriculum<br>• Family navigators<br>• State policies & laws around diagnosis |
| Training Materials, Services & Resources | • Lack of workforce development<br>• Lack of user-friendly language | • Incentives for workforce diversification<br>• Plain language methods<br>• Effective storytelling (video, infographics etc.) |
| Using Technology | • Lack of accessible resources<br>• Interpreting documents<br>• Confidentiality concerns | • Student interns to teach families<br>• More training on design<br>• Better use of "cloud platforms"<br>• Telehealth - e-consults and e-supervision |
| Evaluation & Monitoring | • Lack of data sharing<br>• Data fragmentation<br>• Establishing baseline measures<br>• Building champions in diverse communities | • Tie grant funding to data sharing agreements<br>• Work with skilled evaluators<br>• Empowerment, patient activation, and parent involvement as measures of success<br>• Community Champions, LEND Community Fellows |
| Interpreters & Cultural Liaisons | • Lack of funding<br>• Lack of numbers<br>• Lack of resources | • Use of language lines<br>• Engage college students<br>• FaceTime or Skype to increase access<br>• Formal partnerships to share resources |
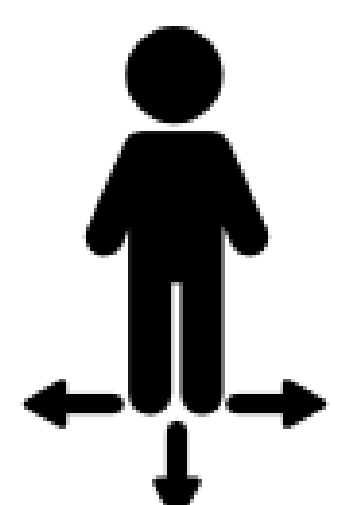
## State Examples

Priority diagnostic slots

Interpreters on Child Development Clinic Teams

Trainings on... Cultural Humility

Cultural Competency for providers

*It's all about culture...*

Translation of educational and awareness materials

Health equity in state health improvement plans

Coordinated QI to address regional & systems "culture"