

Massachusetts Act Early State Team  
2015 Spring Summit Report:  
*Considering Culture in Autism Screening & Systems of Care*

Massachusetts Act Early



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**July 14<sup>th</sup>, 2015**



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## Introduction

### Summit Meeting and Peer-to-Peer Exchange

**Background:** Children with ASD/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. To address this concern, a number of SPHARC grantee states are conducting cultural competency projects to increase equitable early identification of children at risk for autism and developmental disorders (ASD/DD).

For its part, Massachusetts Act Early Program developed and launched the *Considering Culture in Autism Screening* training project in 2014-2015. For the second of its biannual state team summit meetings, the MA Act Early Steering Committee planned a day focused on the theme of cultural and linguistic competence in early identification of ASD/DD. The Association of Maternal & Child Health Programs (AMCHP) partnered with MA Act Early to expand its Spring 2015 Summit meeting into a two-day event about *Considering Culture in Autism Screening and Systems of Care* held at the Boston Children's Museum on June 16 and 17, 2015 in coordination with its own annual SPHARC grantee Peer-to-Peer Exchange meeting. The Association of University Centers on Disabilities (AUCD) also provided technical assistance for the event. The participating SPHARC grantee states included Connecticut, Iowa, Maine, Massachusetts, Minnesota, New Hampshire, and Virginia. The Peer-to-Peer Exchange was designed to develop skills and build the capacity of State Autism Grantees to be prepared to address emerging MCH issues as they apply to Children and Youth with Special Health Care Needs (CYSHCN). The two-day joint Peer-to-Peer Exchange focused on the sharing of programs, strategies and lessons learned to address cultural and linguistic gaps in screening, evaluation, and referral to intervention services.

The following report will focus on the initial details of the Summit portion of the two days and will provide the results of break-out group discussions that explored cultural and linguistic barriers and identified potential solutions for addressing them.

**Summit Meeting Agenda - June 16, 2015:** A total of fifty-six individuals from the seven participating states attended the Summit meeting. Thirty-five members of the Massachusetts Act Early state team and twenty-one visitors from grantee states attended the first day.

Morning: During the first part of the day, participants first received an overview of HRSA grant activities in Massachusetts through the *Healthy People 2020 State Autism Roadmap* project.

The main part of the day involved state team members and guests participating in a two-hour training session on *Considering Culture in Autism Screening*, which is modeled after the CDC's "Learn the Signs. Act Early" Autism Case Training curriculum to train pediatricians and other providers in culturally competent screening, evaluation, and

referral to intervention services for children with ASD/DD. *Considering Culture* is an interactive, case-based training session and focuses primarily on the screening and identification of young children with ASD/DD from immigrant backgrounds and the needs of their families. Through sharing two case studies, videotaped interviews with parents from four cultures, didactic information and supplementary handouts, the morning explored a number of relevant themes using discussion prompts to engage participants and to introduce novel information as needed. The training is designed to elicit group discussion and sharing of experiences.

Afternoon: The afternoon started with a 3-member speaker panel who represent and/or work with culturally diverse families through community outreach related to early childhood development and signs of concerns.

It was followed by facilitated break-out groups to brainstorm cultural and linguistic challenges and brainstorming solutions for early identification of autism and other developmental disorders. Topics for each table were pulled from the *Considering Culture* curriculum such as: training issues; immigration issues; community acceptance/stigma around ASD/DD; language issues; regional issues; etc. Leading ideas from each topic area are shared in this post-Summit summary report.

**Peer-to-Peer Exchange Meeting Agenda - June 17, 2015:** A total of thirty-one individuals from the seven participating states attended the Peer-to-Peer Exchange meeting on the second day. The attendees were comprised of members of the MA Act Early Steering Committee and grantees from visiting states.

The SPHARC Peer-to-Peer Exchange focused on presentations and sharing among participating state teams to address cultural competency in systems of care through their HRSA state grant and broader work in the state. Participants discussed challenges and successes/strategies on a variety of topics related to the issue of culture and language in ASD/DD detection. Participants identified action steps and resources/contacts that they will be able to apply to work in their states.

## **Facilitated Breakout Groups**

**Purpose:** The Summit included break-out groups to identify cultural and linguistic barriers surrounding autism screening and to brainstorm possible solutions towards improving cultural equity in early identification and systems of care for ASD/DD.

**Method:** Upon registration, each participant selected their top three choices of discussion topics. Six topics with the most votes were selected for break-out groups:

1. Care Coordination/Case Management among Agencies
2. Training Early Childhood Education Providers
3. Training Materials, Services, and Resources
4. Using Technology to Monitor Screening, Track Disparities, Provide Telehealth, Etc.
5. Evaluation and Monitoring of Outreach Efforts
6. Use of Culturally Competent Interpreters and Cultural Liaisons

A facilitator and recorder were assigned for each group based on the individual's expertise. The facilitators and recorders were MA Act Early Steering Committee members, AMCHP or AUCD representatives, or leaders from other states. Each break-out table had approximately 8-10 members, including the facilitator and recorder. Members of each group were assigned to break-out groups based on their top choices during registration. The facilitator received a session guide to assist in leading the discussion. The recorders received a note-taker template that included columns for barriers, strategies and solutions, lessons learned, what technical assistance was needed, as well as other notes. Each table had approximately one hour to discuss their topic. Afterwards, each break-out group reported a summary of their findings, highlighting two barriers and two corresponding solutions that arose during their discussion. Both the notes and summaries were used to create this final report.

## Results

### Care Coordination/Case Management among Agencies

**Facilitator:** Kass Braden, UMass Medical-E.K. Shriver Center

**Recorder:** Maria Murillo, AMCHP

The largest barrier raised was the ***lack of billing*** for care coordination and case management. Currently, there is a fractured system of billing in the medical model that is grant-based rather than embedded in systems. In Minnesota, family medicine clinics may use a medical home model, but many know little about children and families with developmental disabilities. Coding and billing is often a problem, and families often receive bills they should not. In Massachusetts, parents often have to play the role of the therapist and care coordinator, as most clinics do not have care coordinators of their own. In Maine, billing is a problem across all agencies including the health system, the social security system, and the education system.

Possible solutions include the ***Family TIES model*** and the ***Primary Care Behavioral Health model***.

Through the Family TIES model, regional coordinators reach out to diverse cultures to establish relationships with parents and adults who have social power within a particular minority community. By working with these people, Family TIES has been able to bring families together, reduce stigma and isolation, and connect families to resources. This model provides support to families and assists with coordination of care. Family Ties is through the Department of Public Health, and is now in 50 different communities.

Another solution is the Primary Care Behavioral Health Model. The care coordinator in this model is a psychologist working within the primary care clinic as a partner in the day-to-day evaluation and care of partners and families. This psychologist is already skilled in behavioral health, and would only need training for care coordination. The psychologist could then identify both behavioral issues related to quality of life and holistic needs of a family or adult. They could reach out to community resources for the family. Additionally, because psychologists have some medical knowledge, they could directly access medical care providers as well as provide therapy if needed. These psychologists would have a “prevention” approach. Most importantly, they will be able to bill for their services separately from the physician. Not only will they not be costly to a clinic, they can bring in money for the clinic.



## Training Early Childhood Education Providers

**Facilitator:** Chris Pond, Massachusetts Department of Early Education and Care

**Recorder:** Mary-Ellen Efferen, Department of Elementary and Secondary Education

Barriers for training early childhood educators include ***lack of education and training given to early educators about ASD***. Professional training needs to be assessed in terms of what training exists, what its rules are, and its impact. Then, gaps need to be filled so that it can be iterative, ongoing, comprehensive, and cross-sector. Training should be included in **licensing and core curriculum** of providers such as speech language pathologists.

Additionally, the **multiple systems** involved in early childhood education such as Part C, Part B, DDHS, CMS, EPSDT, and DPH makes coordination and training complicated. **Family navigator programs** are culturally competent and trusted and therefore should be brought into these systems as a solution.

Lastly, a barrier discussed was the question of **who can diagnose** in states. Can educators diagnose and if so what are the consequences for families and eligibility? Solutions to this barrier are **state policies and laws** that specify who can make diagnoses.

## Training Materials, Services, and Resources

**Facilitator:** Elaine Gabovitch, UMass Medical-E.K. Shriver Center LEND

**Recorder:** David Helm, ICI/Children's Hospital Boston LEND and UCEDD

Two barriers raised in training materials, services, and resources include ***lack of workforce development*** and ***user-friendly language***.

Diverse populations need to be recruited for development and training, and there needs to be **incentives** for diversifying the work force. Workforce development should be **interdisciplinary**, and educators should be taught about diversity. **More males** should be trained to reach out to fathers, and a pipeline of trained people should be established. Quality improvement projects can be used as a model in training.

Secondly, lack of user-friendly language is a current barrier in training materials. **Plain language methods** that aren't just on paper should be used to reach out to all communities and populations. Fewer words and more visuals should be used. **Effective storytelling** through videos or audio can prompt interest. For example, Haitian communities enjoy listening to radio shows. Methods such as videos, infographics, and smartphone apps can reach families. Tech applications that are affordable for families are needed. Lastly, Americans should be introduced to other languages early in life in order to facilitate cultural competence.

## Using Technology to Monitor Screening, Track Disparities, Provide Telehealth, Etc.

**Facilitator:** Mary Andrianopoulos, UMass Amherst

**Recorder:** Ann Gionet, Connecticut Department of Public Health

Barriers surrounding using technology included ***making resources accessible*** for families, ***interpreting documents, confidentiality concerns, and advocacy training***.

Families are often overwhelmed and may not have the technology needed to access ASD resources. Education is needed to show parents how to use the web, and a possible solution is to ***utilize student interns*** to teach families. Technology needs to be ***family-friendly, universally designed, culturally and linguistically appropriate, and at a 4-6<sup>th</sup> grade reading level***. Keeping up with technology needs to be balanced with the human component; we need to determine which applications and webinars are appropriate and if clinicians and others have the skills to access these technologies. Even technical staff may not know certain programs and applications.

Another issue raised was interpreting documents so that they are clearly translated and language-sensitive. An intern from a local university can be used to assist with this task. Additionally, in order to make technology universally designed, a developer can take a class at a university to ***learn more about design***, or a non-profit can “gift” web design. The Center for Applied Central Technology (CACT) may be able to help with web design and testing as well. Apps can also be customized. Technical assistance needed would be a dedicated person to technology.

In order to secure confidentially and follow HIPAA, information such as IEPs can be ***secured in a “cloud” platform***. Information can be brought down, edited, returned, and deleted from the computer in order to protect families. Facility HIPAA policy needs to be reviewed, and the platform needs to be secured. It is important to note that security measures are always evolving and changing, and the platform needs to reflect those changes.

Lastly, technology needs to be ***cross-collaborated to meet the needs of the community, clinic, hospital, and family***. ***Tele-health*** can be utilized through webinars and applications. To increase access, advocates and clinicians can e-consult and e-supervise. A ***secure platform*** would be needed; Skype is not secure, but Adobe Connect may be. Also, a hack-a-thon could be introduced where people would try to break into technology in order to test the securities of these sites. These technologies could allow creative ways to treat clients and train parents and educators.

## Evaluation and Monitoring of Outreach Efforts

**Facilitator:** Kate Taft, AMCHP

**Recorder:** Jennifer Hall-Lande, MN Act Early Team

Barriers discussed for evaluation and monitoring of outreach efforts included ***sharing data, the fragmentation of data collected, obtaining a baseline measure, and building champions within diverse cultural communities.***

The group acknowledged that effective evaluation and monitoring across states and projects is a significant challenge, especially in terms of sharing data. Data are valuable and crucial in order to tell a comprehensive story, but take a lot of time to collect and disseminate. Ideally, there would be a centralized data sharing system. Rhode Island's ***KIDSNET*** is a model of sharing data across agencies. A solution proposed to increase data sharing is to ***tie grant money to a data sharing agreement.***

A second barrier raised was the discrepancies in data collected across agencies, making it difficult to collect data and show long-term impact. Good quantitative data can sometimes feel invasive, especially among diverse communities, whereas ***qualitative data seems to be more accessible.*** Surveys can seem cold, but although qualitative data is sometimes better, it is more time-consuming to analyze. A ***skilled evaluator*** is needed to collect data in diverse communities. Massachusetts utilizes the skills of an epidemiologist to help design a way to collect meaningful information and pool data together. A solution is to use measures such as empowerment, patient activation, and parent involvement as ***measures of success.*** For example, measuring parent participation and attendance levels in IEP meetings is a way to measure parent involvement. Then, a way to measure long-term impact needs to be determined from the frequency and satisfaction data. Additionally, ***sustainability*** needs to be considered once grant funding ends.

For obtaining a baseline measure, solutions included clearly defining a goal, defining the measurement, and using a skilled evaluator for collecting data in diverse communities. For building champions within diverse communities, solutions included ***LEND Community Fellows, Community Champions, and proper timing.*** Resources would be needed to do outreach in the community, and resource cross-sharing would need to occur across partners.

## Use of Culturally Competent Interpreters and Cultural Liaisons

**Facilitator:** Ivys Fernandez-Pastrana, Boston Medical Center

**Recorder:** Peggy Swalis, Child Health Specialty Clinics at the University of Iowa

***Lack of funding, lack of numbers, and lack of resources*** were barriers raised in use of culturally competent interpreters and cultural liaisons.

Funding is often not available because legislators often do not fund small populations and geographical regions. Additionally, family navigators and cultural liaisons need to be “billable”, and interpreters are often very expensive. Creating partnerships with key stakeholders and agencies could increase funding.

Not having enough cultural liaisons and interpreters is another barrier. Currently, few EI staff members have bilingual skills and even fewer have cultural competency skills. Using a ***language line*** would be a first step in solving this issue, but it isn’t as ideal as having an interpreter. There is also a need for ***more culturally competent specialists***, especially those with a diverse background. Utilizing ***college students*** as interpreters and cultural liaisons in exchange for college credits or credentialing may be a cost-effective solution to increase numbers. Colleges could also translate documents. Additionally, using ***FaceTime or Skype*** could help increase access, as well as sharing cultural liaisons across states. Community members could be hired as staff, but funding would be needed.

Lastly, more resources are needed. Not all systems use interpreters all the time, which creates a system barrier. ***Formal partnerships among agencies in community regions*** are needed to share resources. Ensuring confidentiality and compliance is also needed. The Family TIES model uses hospital records to determine interpreter need.

*Gaston Institute – 2015 Boston Report:*

[http://www.umb.edu/editor\\_uploads/images/gaston/2015\\_Regional\\_Meeting\\_GI\\_Presentation.pdf](http://www.umb.edu/editor_uploads/images/gaston/2015_Regional_Meeting_GI_Presentation.pdf)

**Appendix 1: Break-out Groups Assignments**

|          | <b>Group</b>                          | <b>Facilitator &amp; Recorder</b>                                    | <b>Round 1</b>   | <b>Round 2</b>  |
|----------|---------------------------------------|--|--|---|
| <b>1</b> | Care coordination and case management | F: Kass Braden<br>R1: Maria Murillo<br>R2: Ann Gionet                | Laurel Wils<br>Nancy Cronin<br>Jennifer Pineo<br>Kristofer Earles<br>Barbara Dalbec<br>Kelley Devlin<br>Faith Behum<br>Suzanne Bloomer               | Darcy Rubino<br>Nicole Prudent<br>Maryann Kane<br>Suzanne Gottlieb<br>Louann Larson<br>Lauren Bartolotti<br>Meredith Martinez<br>Meg Manning<br>Alicia High |
| <b>2</b> | Training Early Educators              | F: Chris Pond<br>R: Mary-Ellen Efferen                               | Jennifer Epstein<br>Deanna Buck<br>Meredity Pizzi<br>Nancy Evans<br>Marette Power<br>Shirley Huang<br>Darcy Rubino<br>Alicia High                    | Wanda Castillo<br>Donna Gilles<br>Marie Duggan<br>Suzanne Bloomer<br>Tera Yoder<br>Sue McCarthy<br>Jeanine Mindrum<br>Claudia Catalano                      |
| <b>3</b> | Training materials                    | F: Elaine Gabovitch<br>R: David Helm                                 | Marie Duggan<br>Katy Schalla Lesiak<br>Jeanine Mindrum<br>Gina Mittal<br>Maryann Kane<br>Jen Doris<br>Rachell Swanson-Holm<br>Claudia Catalano       | Janet Clark<br>Meredith Pizzi<br>Mariam Egal<br>Mary Castro Summers<br>Kendra Kelley<br>Neal Goodman<br>Deanna Buck<br>Alyssa Kaplan                        |
| <b>4</b> | Using Technology                      | F: Mary Andrianopoulos<br>R1: Ann Gionet<br>R2: Shannon Haworth      | Sophia Faldonie<br>Suzanne Gottlieb<br>Neal Goodman<br>Kendra Kelley<br>Meredith Martinez<br>Nicole Prudent<br>Lauren Bartolotti<br>Margaret Mahoney | Laurel Wils<br>Peggy Swalis<br>Katy Schalla Lesiak<br>Jennifer Epstein<br>Shari King<br>Nancy Evans<br>Courtney Dutra                                       |
| <b>5</b> | Evaluation and Monitoring             | F: Kate Taft<br>R1: Jennifer Hall-Lande<br>R2: Rachelle Swanson-Holm | Mariam Egal<br>Shari King<br>Meg Manning<br>Tera Yoder<br>Louann Larson<br>Shannon Haworth<br>Oahn Bui   | Gina Mittal<br>Jennifer Pineo<br>Kimyatta Campbell<br>Sophia Faldonie<br>Barbara Dalbec<br>Jen Doris<br>Kristofer Earles                                    |
| <b>6</b> | Use of cultural liaisons              | F: Ivys Fernandez<br>R1: Peggy Swalis<br>R2: Maria Murillo           | Sue McCarthy<br>Janet Clark<br>Wanda Castillo<br>Mary Castro Summers<br>Donna Gilles<br>Kimyatta Campbell<br>Courtney Dutra<br>Alyssa Kaplan         | Faith Behum<br>Kelley Devlin<br>Jennifer Hall-Lande<br>Shirley Huang<br>Marette Power<br>Nancy Cronin<br>Oahn Bui<br>Margaret Mahoney                       |



**Appendix 2: Facilitator Guide**



**Break Out Groups: Session Guide**

This session will provide an opportunity for participants to meet in small groups on specific topics to discuss common barriers, strategies, successes, resources, and lessons learned.

| Roundtable Topic  | Expert/Facilitator      | Note Taker   |
|---|-------------------------|--|
| Care coordination/case mgmt. among agencies                                 | Kass Braden             | R1: Maria Murillo<br>R2: Ann Gionet                  |
| Training early childhood education providers                                | Chris Pond              | Mary-Ellen Efferen                                   |
| Training materials, services & resources                                    | Elaine Gabovitch        | David Helm   |
| Using tech to monitor screening, track disparities, provide telehealth, etc | Mary Andrianopoulos     | R1: Ann Gionet<br>R2: Shannon Haworth                |
| Evaluation & monitoring of outreach efforts                                 | Kate Taft               | R1: Jennifer Hall-Lande<br>R2: Rachelle Swanson-Holm |
| Use of culturally competent interpreters and cultural liaisons              | Ivys Fernandez-Pastrana | R1: Peggy Swalis<br>R2: Maria Murillo                |

**Goals: To identify 1) Common cultural barriers (related to the topic area); 2) strategies to address those barriers; 3) examples of successes and best practices, and 4) opportunities for technical assistance that would help states make progress and have an impact in this area.**

Your role as topic expert/facilitator is outlined below. You will also have a note taker at your table to captures common themes from the discussion in a breakout discussion template.

**Roundtable Discussion Guide (30 minutes per round):**

- Start each round by asking participants to identify themselves individually (i.e., name, state, sector). Please also ask participants to describe their biggest need/challenge relevant to <<topic>> during introductions.
- Facilitate the conversation to encourage individuals and states to share their challenges, and offer solutions/best practices to each other. This is also an opportunity for you to offer your expertise/experience in addressing challenges. Keep in mind the goals of the session (above).
- Work with the roundtable group to narrow the barriers and solutions to no more than 1

or 2 per group for reporting out. To do this, go over the range of ideas identified by the group (i.e., barriers, strategies, best practices & opportunities for technical assistance) and ask the group to vote on the most important 1 or 2.

- After the first 30 minute roundtable participants will rotate to their second topic. At their new rotation, have participants introduce themselves again. You can also provide an overview of common themes were addressed in the prior discussion, especially if something major came up. This is an opportunity to get feedback from a second group.
- Some example questions/discussion prompts to get the conversation going (optional and at the discretion of the facilitator):
  - **Getting Started:**
    - What is your biggest (cultural/linguistic) barrier related to this discussion?
    - What part of that can we tackle right now?
  - **Getting Into It:**
    - Has anyone had any related success that they want to share?
    - What opportunities are available?
    - What do we NEED to be able to realize the potential of these opportunities?
    - What are potential pitfalls we need to be wary of?
    - How can we work together on this either within the state or across states?

#### **Report Out Guide:**

- After the breakout rotations, everyone will come back together in the large group. AMCHP/Act Early staff will facilitate the report-outs.
- Each facilitator will briefly (2-3 min) report out on their topic discussions on the following areas:
  - **Top 2 common barriers**
  - **Top strategies to address those 2 barriers**
  - **Technical assistance opportunities/needs identified (if any)**
- State participants will also have an opportunity to comment and ask questions during the open discussion.
  - **Questions to include in a whole group discussion:**
    - What's the best way to continue this conversation?
    - How can federal and national organization partners help move us forward?

#### **Final follow-up:**

The facilitator and recorder will turn over notes to Julie Whyte, a project intern for MA Act Early to include in the final report summary of the break-out activities.



**Appendix 3: Notetaker Template**

**Breakout Discussion Notetaker Template**

**TOPIC:** \_\_\_\_\_

| <b>Barrier</b>  | <b>Strategies / Solutions</b>   | <b>Lessons Learned</b>   | <b>Technical Assistance Needs</b>                     | <b>Other Notes</b>                               |
|---|---|--|---|--|
| <i>What cultural/ linguistic barriers have you seen in regards to this topic?</i> | <i>How did you/others address the problem? What are promising strategies/ activities?</i> | <i>What did you learn? What were the outcomes? What would you recommend going forward?</i> | <i>What TA would be helpful to you going forward?</i> | <i>Other notes / resources of interest /etc.</i> |
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