When Autism Has No Name

Considering Culture & Language in Early Identification

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UMass Medical School – E.K. Shriver Center
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UMASS MEDICAL SCHOOL

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Learning Objectives

- Explain cultural & linguistic disparities in early identification of developmental concerns
- Identify steps for eliciting concerns and conducting developmental surveillance & screening with families from culturally & linguistically diverse backgrounds
- Navigate cultural & linguistic barriers to diagnosis and treatment
- Obtain resources to help!

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2010: 1 in 110

2012: 1 in 88

What can we do to address the needs of the 1 in 68?

Early identification and intervention are the answers.

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U.S. ASD prevalence

- Stable since 2014
  - Up 30%, 2008-2010
- 1% prevalence birth to 22
  - 1:68 overall
  - 1:42 boys
  - 1:189 girls

U.S. average Dx age

- Autistic Disorder: 4 years
- ASD/PDD: 4 years, 5 months
- Asperger syndrome: 6 years, 3 months

CDC, 2013 (based on DSM-IV-TR)

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Identification of ASD in Massachusetts

- Average age of diagnosis is **25.6 months** for MA children served by EI
- Incidence rate is **one in 70** (MA DPH, 2016)

However, certain populations of children still do not receive timely screening & evaluation. These include:

- Children from families with **English as a secondary language**
- Children from families who are **foreign born**
- Children whose mothers are under the age of 24

•Manning et al., 2011

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What we did about it…

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Massachusetts Act Early Program

Screen early | Screen often | Screen all

Vision

The Massachusetts Act Early Coalition works to strengthen state and community systems for the early identification and intervention for children with signs of developmental disabilities, such as autism spectrum disorders.

The coalition envisions a future that uses a **family-centered model that overcomes geographic, socio-economic, cultural, and linguistic barriers to assure equal access to developmental screening for all children in the Commonwealth.**

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Mission

Massachusetts Act Early aims to educate parents and professionals about **healthy childhood development**, **early warning signs** of developmental disorders including autism spectrum disorder, the importance of **routine developmental screening**, and **timely early intervention** whenever there is a concern.

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Our coalition

MA Act Early has 120+ state team members, with an executive steering committee.

State team members represent families, university centers of excellence, health care organizations, public health, early education, day care, elementary & secondary education, disability agencies, family support agencies, advocacy groups, and research centers.

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Our goals

1. Increase public awareness of Autism Spectrum Disorder
2. Increase training for health care, early childhood, & educational professionals
3. Shorten wait times between screening & diagnosis and diagnosis & intervention
4. **Develop culturally competent autism screening materials and training curricula for early childhood educators, community health centers and pediatric practices across Massachusetts**

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So, what about culture?

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Culture?
Let's start with a definition

"A group of people's way of life, consisting of predictable patterns of values, beliefs, attitudes & behaviors. These patterns are learned and passed from generation to generation."

Mandell, D. & Novak, M. (2005). The role of culture in families' treatment decisions for children with autism spectrum disorders. *MRDDRR, 11*: 110-115.

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What shapes culture?

- Race
- Ethnicity
- Language
- Gender
- Sexual orientation
- Spirituality/religion
- Literacy
- Status/caste

Filipek, P. (n.d.). So what does “chulcha” have to do with disabilities? Reflections by a Gringa from Baa-stin. Act Early Texas.

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Latino culture

- Cuba
- Mexico
- Dominican Republic
- San Salvador
- Costa Rica
- Colombia
- Venezuela

Filipek, P. (n.d.). So what does “chulcha” have to do with disabilities? Reflections by a Gringa from Baa-stin. Act Early Texas.

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Cultural Influences

Varying perception of the cause of illness

Cultural influence on help-seeking and attitudes toward health, school and government

We have a set language & belief system

Diverse belief systems regarding health, mental health, healing, wellness

Previous experiences of biases

Schonwald, A. (2015). Boston Children's Hospital.

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Cultural competence is important, so…

- Start by understanding your own culture
- Acknowledge cultural differences
- Incorporate values & principles enabling cross-cultural work
- Conduct personal & organizational self-assessment
- Manage the dynamics of difference
- Acquire cultural knowledge & skills
- View behavior in a cultural context
- Adapt to the community

Cross TL, Bazron BJ, Dennis KW, Isaacs MR. Towards a Culturally Competent System of Care: A Monograph on Effective Services for Minority Children Who Are Severely Emotionally Disturbed: Volume I. Washington DC: Georgetown University Center for Child & Human Development, 1989.

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And, what about language?

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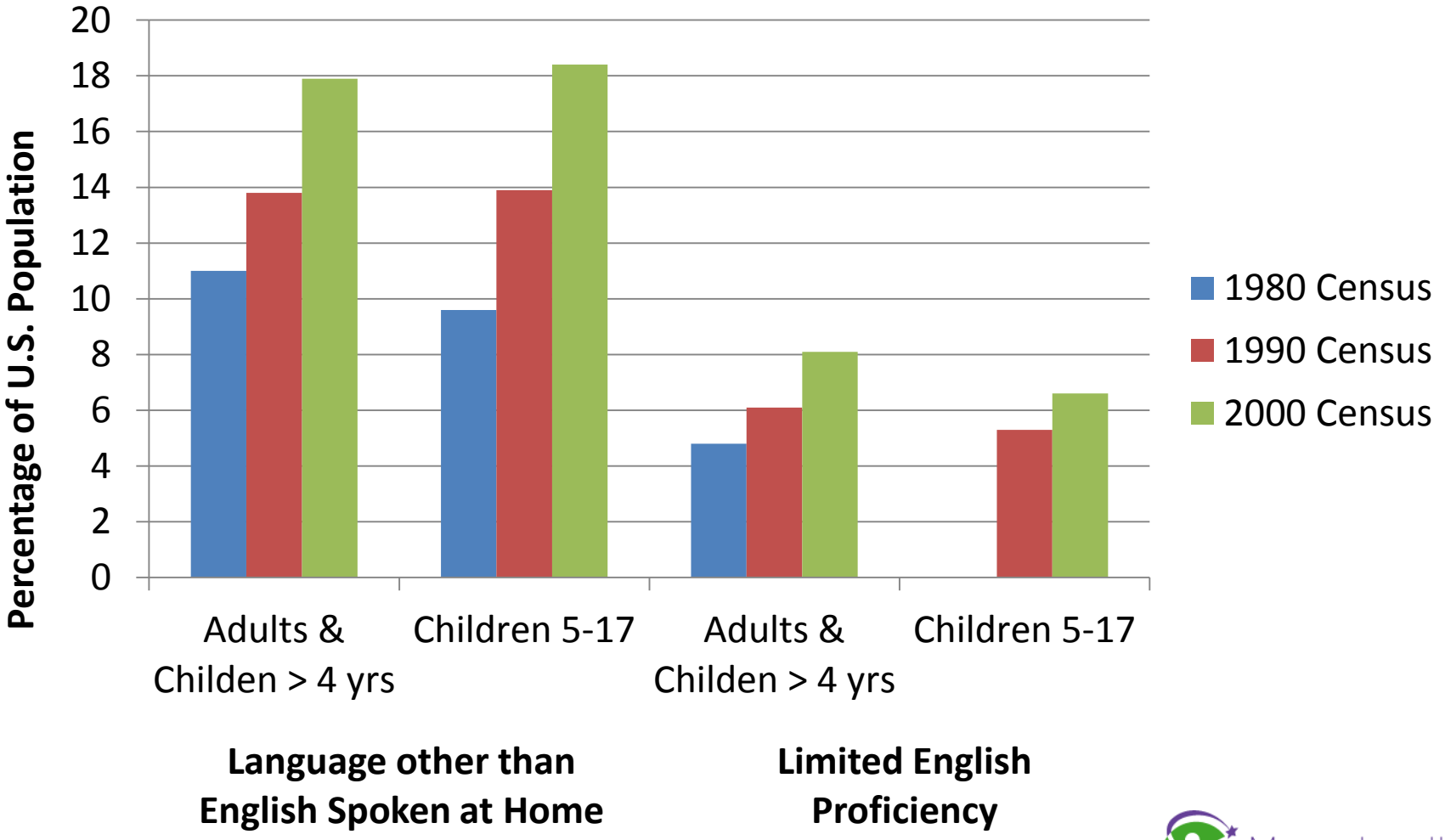
U.S. becoming increasingly diverse & bilingual



Alsheikh, O. (2017). Language Barriers to Healthcare in the U.S.

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Risk of suboptimal health care

- For patients who cannot speak English well
  - Greater risk of not receiving preventative services
  - Less likely to have regular PCP
  - Fewer visits and return for follow up
  - Less likely compliance with medical advice due to confusion
  - Less satisfied with healthcare & communication
- Apply this to families of children & youth

Jacobs et al., (2001). Impact of interpreter services on delivery of healthcare to LEP patients.

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The problem with assessment

- Few standardized assessments that are valid and reliable measures of linguistic structure for children outside of white Western populations[1]
  - Includes dialects as well as languages
- More challenges with measures of pragmatic language and social communication skills[2]
- Different cultures respond differently to delays based on cultural values & awareness around hard signs such as language versus social milestones[3]

([1]Hirsch-Pasek et al., 2005; [2]Norbury & Sparks, 2012; [3]Coonrod & Stone, 2004)

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What we did next…

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Early Diagnoses of Autism Spectrum Disorders in Massachusetts Birth Cohorts, 2001–2005

Susan E. Manning, Carol A. Davin, Wanda D. Barfield, Milton Kotelchuck, Karen Clements, Hafsatou Diop, Tracy Osbahr, Lauren A. Smith

Certain populations of children still do not receive timely screening & evaluation. These include:

- Children from families with **English as a secondary language**
- Children from families who are **foreign born**
- Children whose mothers are under the age of 24

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Health Disparities in Autism (US)

Rates of ASD Diagnosis

- 57% less for AA than non-Hispanic white children

Age of Diagnosis

- White children diagnosed
  - ~1.5 years earlier than AA
  - ~2.5 years earlier than Latino

Misdiagnosis

- AA children 3X more likely to receive another diagnosis first (e.g., ADHD, ODD, learning disability)

Schonwald, A. (2015). ASD Presentation. Boston Children's Hospital.

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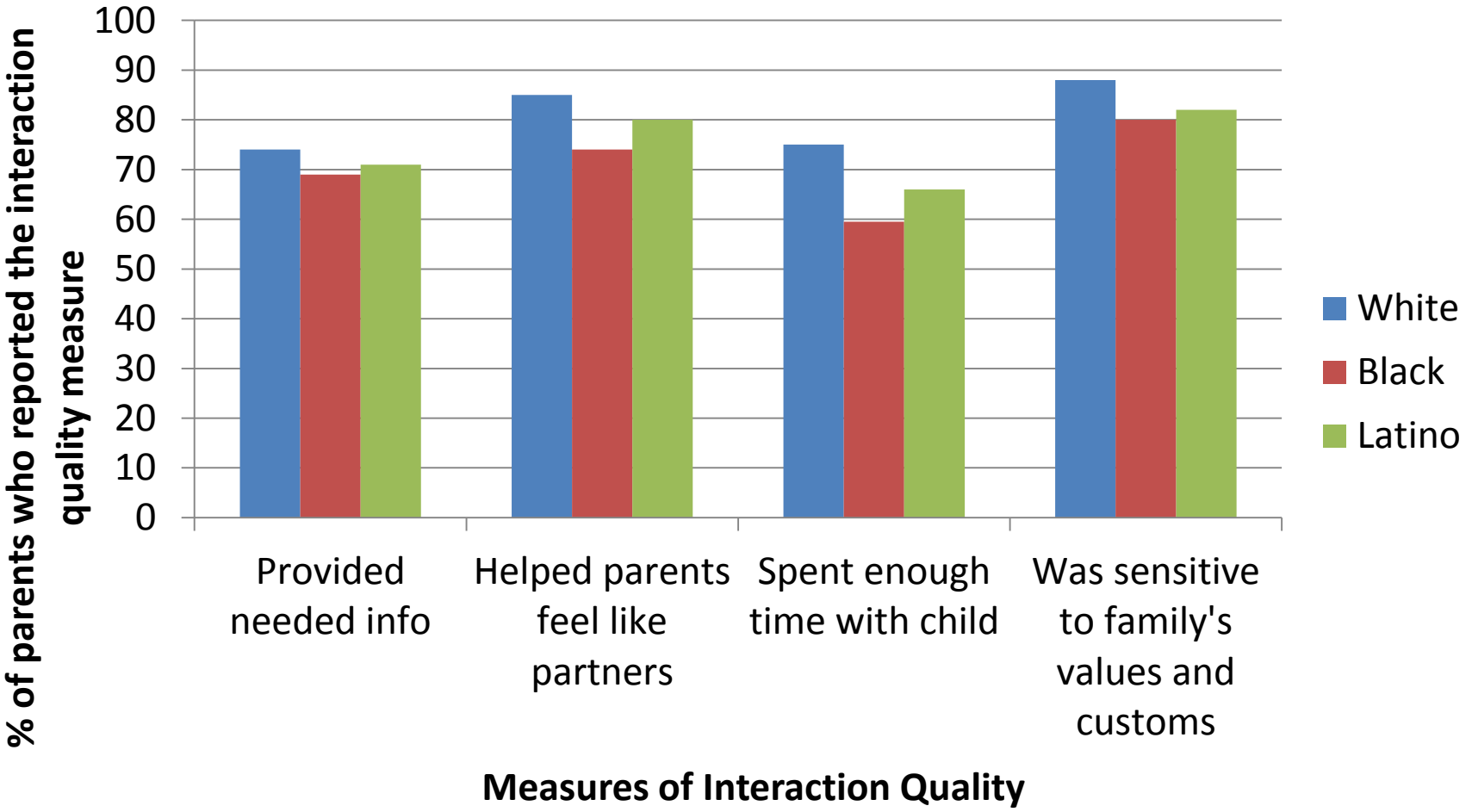
Quality of Health Care Provider Interactions, 2009-10



Mangana, S., Parish, S., Son, E., & Igdalsky, I. (2014). Racial Disparities in the Quality of Health Care Provider Interactions for Children with Autism & other DDs.

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MA Act Early Provider Surveys

	DBP Clinics (n=26)	Pediatricians (n=106)
Top reasons late referral:	Parents unaware of milestones/red flags (77%)	Parents unaware of milestones/red flags (88%)
	Primary language not English (59%)	Primary language not English (61%)
	Limited caregiver ability (55%)	Limited caregiver ability (62%)
	Lower SES (44%)	Lower SES (60%)
% non-English speaking patients:	<25% = 81% 25-50% = 12% 51-75% = 4%	<20% = 61% 21-50% = 24% 51-80% = 13%
I have access to:	Interpreters = 58% Translators = 23% Cultural liaisons = 15% Bilingual providers = 15%	Interpreters = 93% Translators = n/a Cultural liaisons = 9% Bilingual providers = 40%
I do not have access to language services:	35%	N/A
What do you do when patient's family does not speak English?	Re: Evaluation: Use translated measure (23%) Perform w/ interpretation (62%) Do not evaluate (35%)	Re: Screening: Use translated measure (45%) Perform w/ interpretation (70%) Do not screen (20%)

Gabovitch et al., (2013) MA Pediatric Provider Survey.
Gabovitch et al., (2015). MA Dx Specialist Wait Time Survey.

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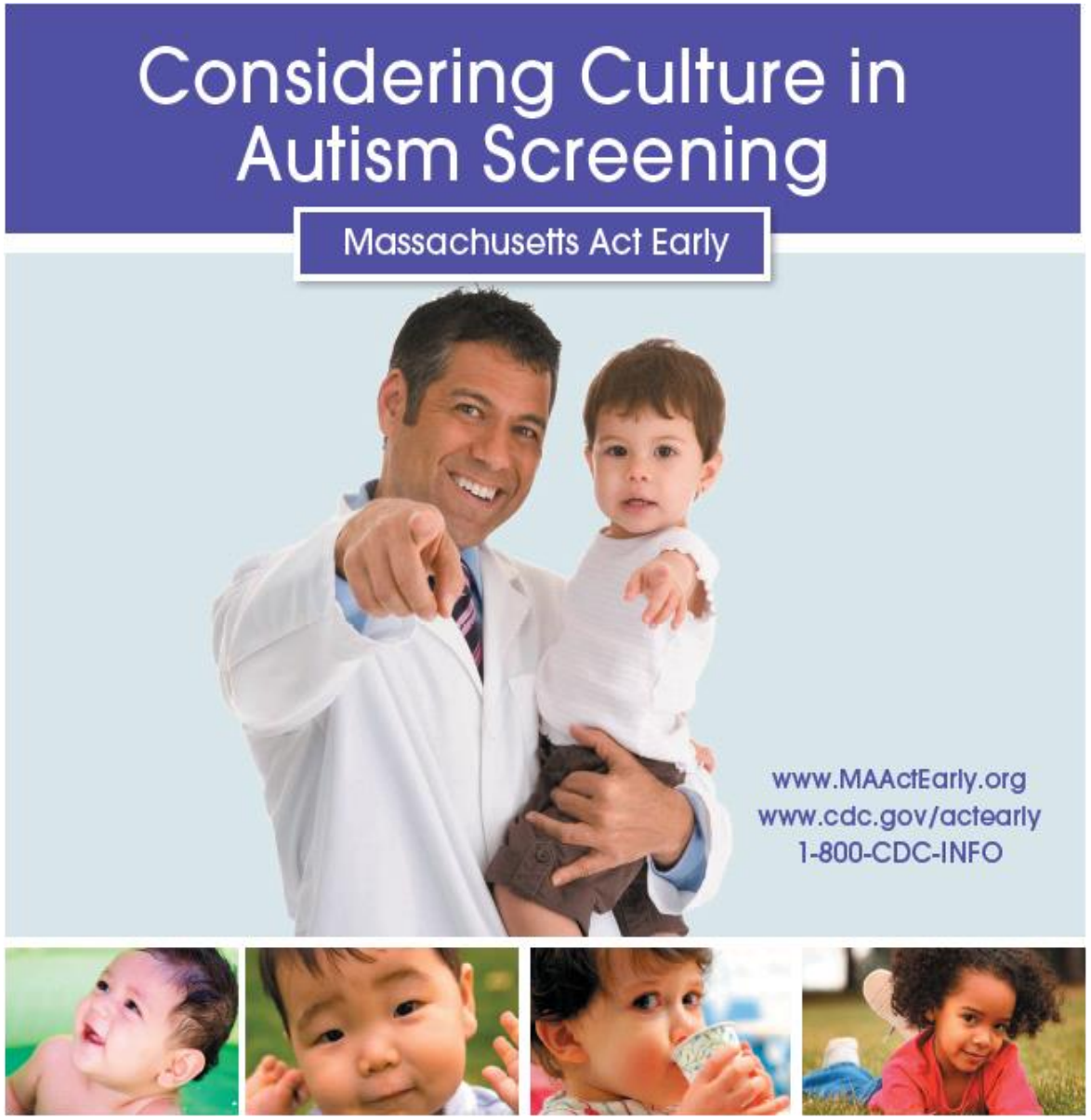
What's included?

- Guide components:
  - Considering Culture guide for physicians
  - Referral at a Glance
  - Pediatric Staff Roles
  - Fact sheets
- M-CHAT components:
  - Screening tool in English, Spanish, Chinese, Haitian, Vietnamese
  - Instructions
  - Scoring guide
  - Follow up interview



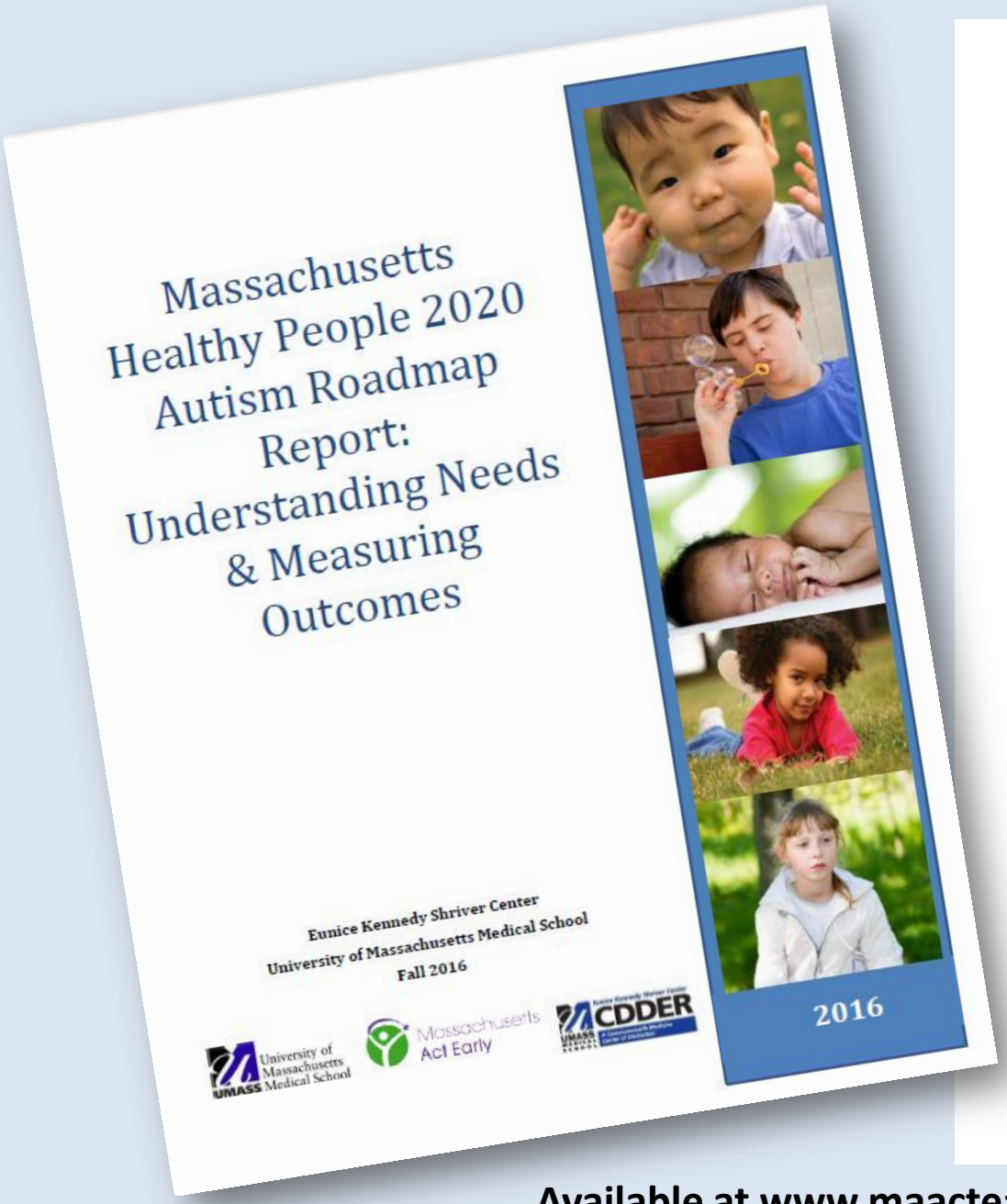
Available at www.maactearly.org

Considering Culture in Autism Screening: Training Curriculum for Pediatric Providers

Purpose: *A flexible training for pediatric providers on culturally & linguistically competent screening, evaluation, and referral-to-intervention services for children with autism and other developmental disorders*

Goals:

- Live training modules include didactic information, case studies, and supplementary materials
- Features case study videos with retrospective interviews from 4 culturally diverse families; addresses the role of cultural liaisons & brokers
- Pilot tested training on pediatric and family medicine residents from 2 Greater Boston teaching hospitals
- Evaluated efficacy and feasibility via pre-tests and post-test measures of knowledge, applied knowledge, and attitude, as well as post-tests of satisfaction



Roadmap Report:

1. assesses ***state needs of children with ASD and DD*** that align with six MCHB core indicators
2. refines the existing state plan to ***address identified needs***; and
3. outlines a comprehensive evaluation plan and program surveillance strategy to ***monitor and report on future state ASD/DD outcomes***.

*Focuses on underserved children & youth by **race, culture, language, immigrant status**, region, transition age, insurance coverage, level of function, and mental health status.*

Available at www.maactearly.org

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Coming this spring to Cable TV & YouTube

1, 2, 3, Grow!

- Cable TV series broadcast across state in 8 cultures/languages:
  - English
  - Spanish
  - Arabic
  - Brazilian Portuguese
  - Chinese
  - Haitian Creole
  - Vietnamese
  - African-American (English)
- How to monitor a child's development
  - At ages 1, 2 & 3
  - 4 domains: Movement, social, communication, thinking
- What to do when concerned
- Where to find MA resources to help

Available at www.maactearly.org

Included in 1, 2, 3, Grow!

- Program hosts & pediatric specialists sharing info in languages and cultures
- Short videos showing milestones
- Taped parent interviews of concerns & advice
- Places to contact for help
- Materials in 7 languages:
  - *Tracking Milestones Brochure*
  - *Milestones Checklists*
- To be archived on YouTube, UMMS & MA Act Early partner web sites

Resources, Info & Tools

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Online Resources

- Tawara Goode, MA
  Director, National Center for Cultural Competence
  - *NCCC Self-Assessment for CSHCN*
  - http://nccc.georgetown.edu
- Pauline Filipek, MD, Professor Pediatrics, U Texas Houston
  CDC Ambassador, Act Early Texas!
  - *So What Does 'Chulcha' Have To Do With Disabilities??? Reflections by a Gringa from Baa-stin*
  - https://elpaso.ttuhsc.edu/cme/_documents/FILIPEK%20El%20Paso%20Culture%202016.pdf
- U.S. Health & Human Services, Think Cultural Health
  - National CLAS Standards
    https://www.thinkculturalhealth.hhs.gov/clas/standards

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Translated Materials for Families

- Act Early translated materials
  - https://www.maactearly.org/translated-materials.html
- Medical Home Parent Tips
  - www.medicalhome.org/leadership/brochures.cfm
- Autism Speaks
  - Resources for non-English speaking families
  - http://www.autismspeaks.org/family-services/non-english-resources
- Autism Around the Globe
  - http://www.autismaroundtheglobe.org/about_aatg.asp

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Home | About Us | How Can We Help? | Materials & Resources | Webinars & Trainings | FAQ | News | Blog | Contact Us

Welcome to Massachusetts Act Early

Massachusetts Act Early aims to educate parents and professionals about healthy childhood development, early warning signs of autism and other developmental disorders, the importance of routine developmental screening, and timely early intervention whenever there is a concern.

Whether you are a parent or a professional who works with young children and their families, our hope is that you will find helpful information at the MA Act Early website to promote healthy development in all children.

Please visit us often as we add new information to reflect our growing state campaign. We hope to see you again soon!

Massachusetts Act Early is the state campaign for the national "Learn the Signs. Act Early." program run by the Centers for Disease Control and Prevention's (CDC) National Center on Birth Defects and Developmental Disabilities (NCBDDD), in collaboration with the Health Resources & Services

Download free Massachusetts "Learn the Signs. Act Early." materials

"Learn the Signs. Act Early." materials The Massachusetts Act Early campaign is happy to announce that we now have Massachusetts versions of key CDC "Learn the Signs. Act Early." brochures and booklets. The materials are customized with contact information for families in need of assistance from either:

- Family TIES of Massachusetts,
- MA Department of Early Education and Care, or
- MA Department of Elementary and Secondary Education.

Please click here to access these

www.maactearly.org

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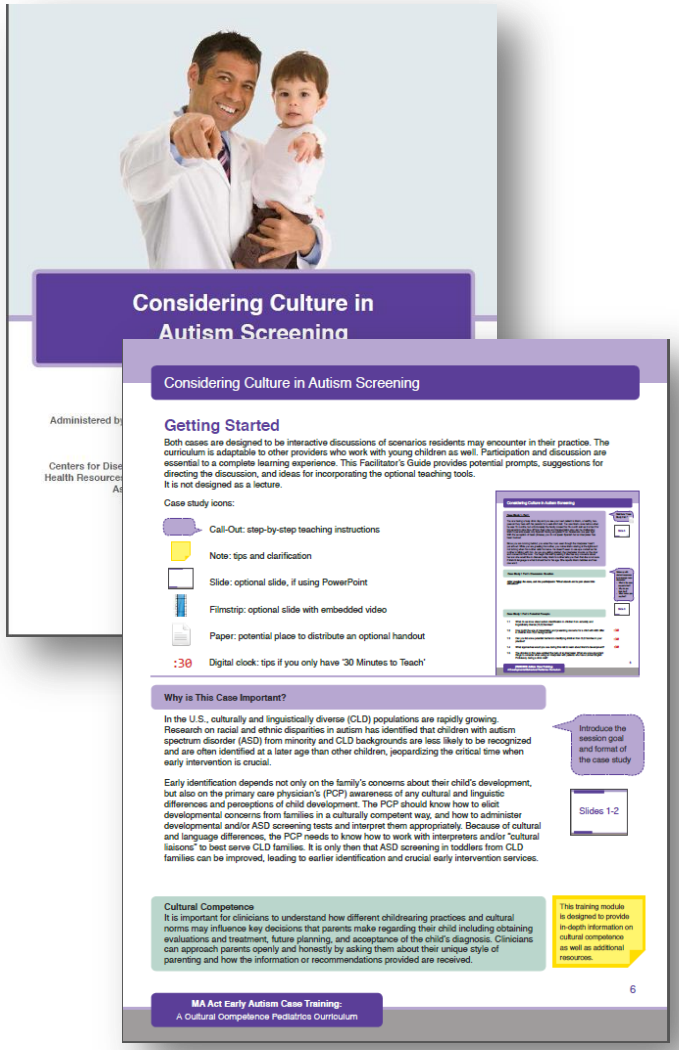
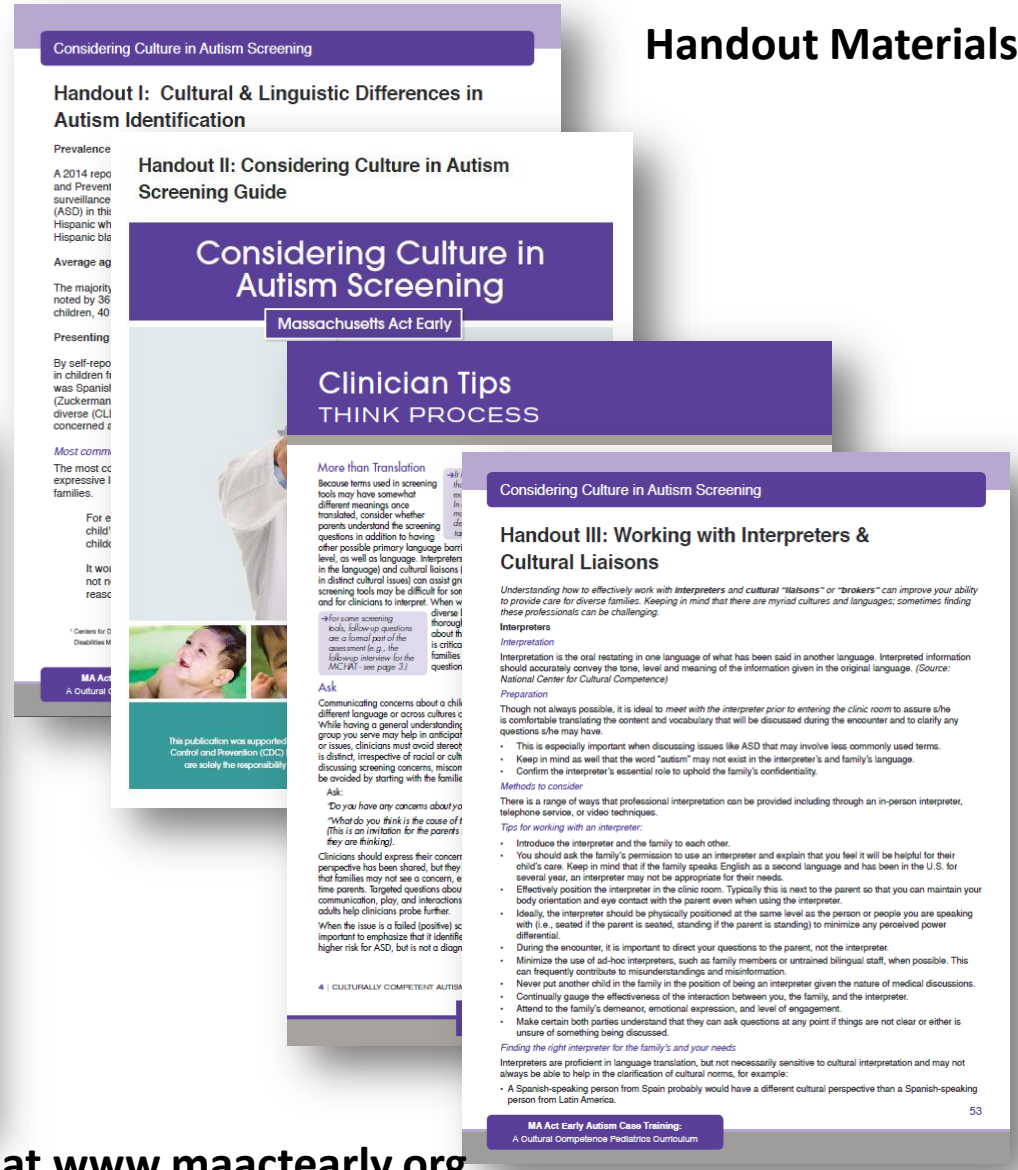
Considering Culture in Autism Screening

Facilitator Guide



Handout Materials



Available at www.maactearly.org

Autism Case Training:
A Developmental-Behavioral Pediatrics Curriculum

Considering Culture in Autism Screening

Autism Case Training:
A Developmental-Behavioral Pediatrics Program
Case # 1: Mario

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The Massachusetts Act Early Campaign is the state chapter of the national CDC's "Learn the Signs. Act Early." Program.

Learning Objectives

1. *Identify the steps for eliciting concerns and conducting developmental surveillance and screening with families from culturally and linguistically diverse (CLD) backgrounds.*
2. *Know how to discuss the outcomes of developmental and/or autism screening with CLD families.*
3. *Understand cultural & linguistic considerations when discussing developmental delays and autism with CLD families.*

Cultural lessons learned

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Cultural considerations

- Unfamiliar, culturally bound concepts of screening, early identification, intervention
- Fear of stigma in the community
- Anxiety provoking, confusing, especially with language & cultural barriers
- Children's behavior may reflect cultural norms
- Some behaviors seen as culturally appropriate
- More involved than just translation – more than interpreting language – culture too

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Lessons learned

- It's more than translation
- Start with the family's perspective
- The term "autism" may present linguistic challenges
- Eye contact & pointing may be considered rude in certain cultures
- Follow up – help families do the legwork with resources
- Finding common ground may take time based on your concerns
- Cultural liaisons & brokers may provide insights to increase sensitivity

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Lessons learned

- The importance of cultural liaisons
- Early childhood educators may serve as key partners
- Second generation Americans may face considerable family issues
- Eye contact & pointing concerns may affect M-CHAT usage
- Immigrant families bring unique concerns
- Disability stigma may vary by culture

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Lessons learned

- Families may attribute symptoms to something other than a health condition
- Failure to respond may be interpreted as “willfullness” and other behaviors falling within bounds of normalcy
- How parents interpret symptoms may have critical impact on type of treatments they use or if they engage at all

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Moving Beyond Google Translate: What Massachusetts Families from Diverse Cultures Need for Effective Autism Services and Supports

Courtney Dutra, MPA, Elaine Gabovitch, MPA, Emily Lauer, MPH, Rosalie Jiang, BA & Julie Whyte, BA
University of Massachusetts-Eunice Kennedy Shriver Center

Background

The demographics of the United States are shifting, causing service systems to face an ever-increasing need to accommodate a broader array of cultural and linguistic backgrounds. Progress is needed to ensure systems are prepared to competently serve current and future populations.

The project team conducted a state needs assessment of children and youth with Autism Spectrum Disorder (ASD) and Developmental Disabilities (DD) that aligns with the six MCHB Healthy People 2020 core indicators (i.e., early identification, medical home, access to community-based systems of care, family involvement, transition to adulthood, and insurance). The results will inform state efforts to establish a state-level data collection and surveillance plan for systems of services for children and youth with ASD and DD.

Preliminary data from the needs assessment across multiple sources indicate that screening and evaluation for ASD and other DD's in Massachusetts occur less frequently in non-native English-speaking populations and other minority cultures, demonstrating a need for systemic improvement.

Methods

- Six, 90-minute focus groups with culturally and linguistically diverse participants held across the state to better understand the effects race, culture & language have on the six core indicators.
- Parents of children or youth with ASD and/or DD were recruited through existing, community networks and paid a small stipend for their time.
- Focus groups were led by an experienced facilitator, an assistant facilitator and a note-taker.
- Questions were translated & shared in advance.
- Culturally competent interpreters were used in each group.
- Focus group notes were transcribed verbatim & analyzed using Atlas TI qualitative software.
- Notes were coded according to primary questions and then sub-divided into secondary and tertiary categories.

Participant Groups

Massachusetts Demographics:

- Number of residents: 6.6 million; 367,087 children under 5
- Child population by race: Non-Hispanic White, 66%; Non-Hispanic Black 8%, Hispanic, 16%; Asian, 6%
- Children in immigrant families: 27%
- Predominant languages: Cambodian, Chinese, Haitian-Creole, Portuguese, Somali, Spanish, Vietnamese and many more

Focus Groups: Vietnamese, African-American, Haitian, Hispanic, Chinese

What Do Parents Say They Need?

I wish there could be someone, a professional, who spoke my language and was able to comprehensively walk me through each step and let me know about my rights…someone who managed this whole process.

Sometimes we have to reread documents 5-6 times and we still don't know what they say.

80% of the IEP's I read appear to have been translated by Google Translate. The translation is not very good or very clear.

There was a year wait at the Boston hospital to be diagnosed. Instead, I made an appointment at a hospital up north. I had to rent a car on our own out of our own pocket because I wanted him to be seen and diagnosed as soon as possible.

Our ABA service providers are wonderful but we aren't able to communicate with them. We have no access to them because they're monolingual and they don't speak Chinese. We would benefit so much more and get so much more from ABA if we could communicate with them.

The school is supposed to send home the documents interpreted. They ignore us or they translate it with Google Translate and it's not understandable.

After my child was diagnosed, the doctor printed out some Google stuff for me and asked, "Can you access Google stuff at home? How much English do you understand?"

Not only do we need trained professionals in the community, we need all types of language access that are carried out with people who have proficiency in the culture as well as the language. Proficiency is the key.

Across Culture Results

Need for services
- At home services (i.e. ABA)
- Respite
- Community and family support
- Transportation

Blame and Stigma:
- Parents "at fault" for child having autism
- No translation for word "autism"
- Community isolation

Lack of knowledge
- Right to translation and interpretation
- Educational rights
- Available services
- How to navigate the system

Importance of trusted provider
- PCP
- Education: Daycare, Pre-K, Kindergarten, Early Head Start

Culture-Specific Perspectives Shared

Asian: Respect for authority gets in the way of raising concerns (i.e. teachers, doctors). Parents do not reach out to their community due to fear of stigma.

Vietnamese: Lack of community support leads to feelings of isolation. Respect for elders; older family members have significant influence.

Chinese: High value placed on education and in helping their child learn; however, significant frustration expressed not getting information or documents in language.

Hispanic: Community-orientated. Parents in lower-income communities may need to prioritize basic living needs. Concerns expressed about transition age skills and training.

Haitian: Isolation from their community. Maternal stress and depression related to navigating the service system and fighting for services. Feelings of inequity.

African-American: Concerns about racism, misdiagnoses of behavioral disorders vs. ASD. Pressure on mothers to meet all family needs; patriarchal concerns.

Discussion

Culturally and linguistically competent information, resources, and services are essential to help families of children with ASD move beyond common obstacles to meeting their needs. At present, state service and support systems may not be fully structured to accommodate diverse needs.

Among our preliminary recommendations:

- A one stop, multilingual online information & referral source for families and professionals that explains systems & processes, such as the state information & referral site INDEX.
- IEPs and related communications must adhere to federal law.
- Promotion of the CDC's Act Early campaign that provides developmental milestones information in multiple languages.
- Recruitment of trained bi-cultural and bi-lingual professionals from the fields of health care, education, advocacy, and clinical therapy.
- Training to promote cultural competence in the medical home.
- State-legislated reimbursable multilingual/cultural telepractice services.

The results will be used to call attention to cultural & linguistic disparities in our final report recommendations for refinements to the existing Massachusetts Autism Commission plan by end of Summer 2016.

This project was funded by HRSA-MCHB as part of a State Autism Planning Grant.

Recommendations

- Build, measure & monitor trained workforce capacity
- Understand the importance of the community; cultural brokers & liaisons are essential partners
- Train interpreters to speak language, know culture, and be proficient with medical terminology
- Offer all materials, resources & websites in English in the languages of local communities
- Bilingual, bicultural home-based services (ABA, SLT, etc.)
- Help families navigate system barriers that can prevent seeking help (transportation, public benefits, housing, employment)
- Partner with daycare and other community providers

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Bank of America, N.A.

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Health Resources & Services Administration-Maternal & Child Health Bureau (HRSA-MCHB)
Association for Maternal and Child Health Programs (AMCHP)
Association for University Centers on Disabilities (AUCD)
Porter Novelli

How about you?
How can **you** promote healthy development?

Thanks to our funders!

What?	Who?
Our Backbone Organization	UMass Medical School-Shriver Center
Learn the Signs. Act Early.	CDC, AUCD, AMCHP
CCiA Guide & Kit	AMCHP State Systems Grant 2011-12
CCiA Curriculum for Providers	Deborah Munroe Noonan Memorial Research Fund 2013-14
Healthy People 2020 State Autism Roadmap Report	HRSA-MCHB, State Autism Planning Grant, 2013-2016
1, 2, 3, Grow! Shows for families of young children	AMCHP Developmental Monitoring in State Systems Grant 2016-19

University of Massachusetts Medical School
Eunice Kennedy Shriver Center

AMCHP
Association of Maternal & Child Health Programs

CDC
Centers for Disease Control and Prevention

HRSA
Maternal & Child Health

AUCD
Association of University Centers on Disabilities
Research, Education, Service

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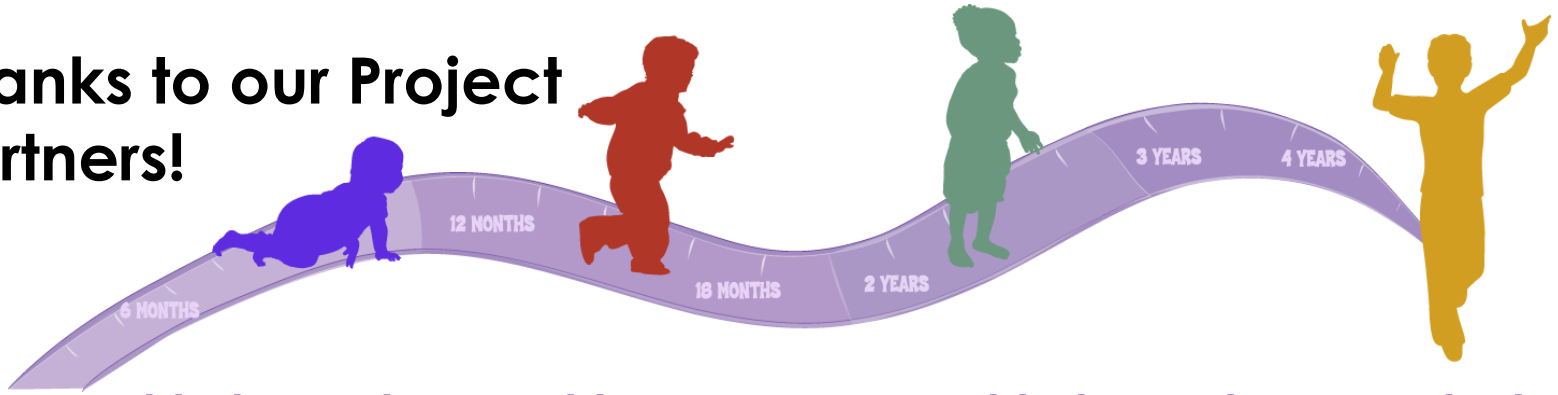
Thanks to our Project Partners!



Considering Culture Guide

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Considering Culture Curriculum

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•Intercultural Productions

Healthy People Autism Roadmap

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•Emily Lauer, MPH
•Courtney Noblett-Dutra, MPA
•Project Advisory Board (~30 members)

1, 2, 3, Grow!

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•Joan Rafferty, MA, CCC-SLP, Co-lead**
•Intercultural Productions
•BNN-TV
•Development Team, Multicultural Partners & Project Advisory Board, (40+ members)

And thanks to all of *you*!

Questions?

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