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

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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.

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