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

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

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Keywords
diverse cultures, autism spectrum disorder, developmental disabilities, minority cultures, youth, children
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.

**Background**

**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 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.
- 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: 6.5 million; 367,087 children under 5
- Child population by race: Non-Hispanic White, 66%; Non-Hispanic Black 8%, Hispanic, 16%; Asian, 8%
- 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.

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.

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

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.

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?”

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.

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

**Across Culture Results**

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<thead>
<tr>
<th>Need for services</th>
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<tbody>
<tr>
<td>At home services (i.e. ABA)</td>
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<tr>
<td>Respite</td>
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<tr>
<td>Community and family support</td>
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<td>Transportation</td>
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<tr>
<th>Blame and Stigma</th>
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<tbody>
<tr>
<td>Parents “at fault” for child having autism</td>
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<tr>
<td>No translation for word “autism”</td>
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<tr>
<td>Community isolation</td>
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</tbody>
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<tr>
<th>Lack of knowledge</th>
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<tbody>
<tr>
<td>Right to translation and interpretation</td>
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<tr>
<td>Educational rights</td>
</tr>
<tr>
<td>Available services</td>
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<tr>
<td>How to navigate the system</td>
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<th>Importance of trusted provider</th>
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<td>PEP</td>
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<tr>
<td>Education: Daycare, Pre-K, Kindergarten, Early Head Start</td>
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**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.
- Developmental milestones information in multiple languages.
- IEPs and related communications must adhere to federal law.
- 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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