

Understanding the Present to Leverage the Future for Children and Youth with ASD/DD

Highlights from Three State Autism Planning Projects



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Background

From 2013 to 2016, HRSA-MCHB awarded state autism planning grants “for improving services for children and youth with autism spectrum disorder (ASD) and other developmental disorders (DDs)” as an extension of Healthy People 2020 for children and youth with special health care needs (CYSHCN) for those with autism spectrum and other developmental disorders (ASD/DD).

The states of Massachusetts, New Hampshire and Texas performed various activities to establish state autism plans to measure and monitor the following six core indicators for quality improvement purposes:

- Early identification
- Medical home
- Access to community-based systems of care
- Family involvement
- Transition from pediatric to adult health care and
- Insurance/financing

This poster shares their methods for conducting their investigations and the lessons learned by doing so.

Methods

Massachusetts:

The Grant Team conducted key informant interviews and focus groups as well as gathered data from a combination of national and state surveys and state data. A 25-member project advisory board provided quarterly guidance and a final review of the needs assessment report to be used by the Massachusetts Autism Commission to recommend legislative and other actions.

New Hampshire:

The Grant Team worked with the NH Council on Autism to complete a comprehensive Needs Assessment in Year 1. This process incorporated family forums, key informant discussions and World Cafes. The State Plan finalized in Year 2 utilized additional stakeholder groups and key informant surveys.

Texas:

The Grant Team created a subcommittee of the *Act Early Texas!* Autism Commission to complete a comprehensive Needs Assessment, using the *Pennsylvania Autism Needs Assessment*⁵ survey [with permission from Lindsay Shea DRPH, MS from ASERT] divided into Pre-Elementary, Elementary, Middle & HS, and Adult age ranges. A fifth Self-Advocate adult survey varies considerably in format and will be reported separately in the *Texas Autism State Plan*. Surveys were accessible via Survey Monkey on smartphones, tablets, and PCs. Paper formats were also available.

Conclusions:

The lessons learned by the three states effectively demonstrate that the route for navigating change and building sound futures for children and youth with ASD/DD must first start with a comprehensive statewide assessment of needs supported by a collective impact approach to measure and monitor progress across all core indicators.

Doing so will result in successful outcomes for diverse and complex populations with ASD well into their adult years.

State Planning Grants for Improving Services for Children and Youth with Autism Spectrum Disorder and other Developmental Disabilities, U.S. Department of Health and Human Services/Health Resources and Services Administration (HRSA) grant New Hampshire # H6MMMC26245; Massachusetts # H6MMMC26244; Texas # H6MMMC26246.

Massachusetts

- Focus on underserved children and youth with ASD/DD
- State priority to “determine the number of people with autism in Massachusetts and their support needs by implementing a plan for consistent statewide data collection.”
- Report addressed six core indicators plus education and housing AND race, culture, language, region, level of function, and mental health within each domain.

Approaches Used:

- **Qualitative:** 50 Key informant interviews, 11 focus groups across 5 state regions state, 5 self-advocate interviews
 - **Professional groups included:** early childhood professionals, community health center medical providers, transition specialists, community service providers, and others
 - **Parent groups included:** parent leaders who are also autism-related professionals, diverse cultural and racial groups
- **Quantitative:** CAHMI survey data for the state & U.S., research study findings, state agency data sets and aggregated reports.

Rural/ Regional

- Project advisory board meetings were conducted quarterly in person and remote participation.
- Parent and professional focus groups (11) conducted in all five state regions.
- Self-advocates were paid a stipend for their interviews.
- Parents were paid a stipend for participation on focus groups.

Culture/Language

- Culture and language were critical concerns for focus groups.
- Semi-structured interviews were conducted with the use of interpreters for the following parent focus groups: African-American (4 parents), Chinese (5), Haitian-Creole (3), Hispanic (2 groups with 6 and 5 parents each) and Vietnamese (11).
- Parents were all paid for their participation, as well as babysitting was provided. Focus groups were held in local facilities used by the families.
- Meals were served in the native foods of the cultural group.

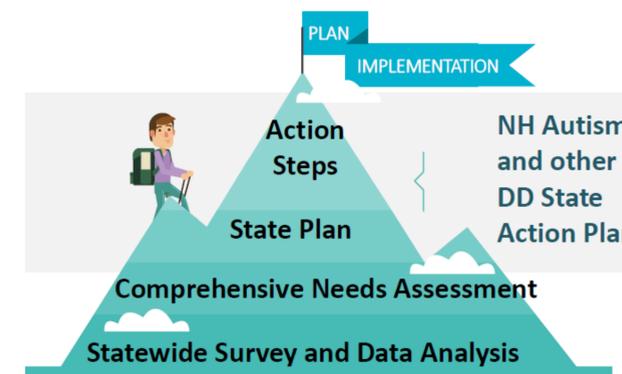
Data Collection

- States that participate in the CDC’s Autism & Developmental Disabilities Monitoring network may have more readily available data.
- The National Survey of Children’s Health and the National Survey of CSHCN yielded important trends for each of the six core outcome indicators though the state sample size was too small to produce consistently meaningful findings. More participants would be useful in the future.
- Two surveys conducted by the project team provided insights into early identification practices and needs for pediatric providers and diagnostic specialty clinics.
- State data is currently collected separately between departments, but shared databases are in planning which would reduce information silos and allow for better coordination and sharing.
- The presence of university centers conducting autism research is an important source of data.
- Best data collection and reporting practices from other states could have implications for Massachusetts such as value streaming, state indicator online dashboards, telehealth and telepractice, benchmarking and other useful monitoring and reporting methods.
- Outcome and process measures are important for future monitoring.

Recommendations:

- Include self-advocates and families in reviewing and interpreting data.
- Consider the use of person-first and identity-first language in meetings, communications and reports; review the use of the term ASD which may feel pathologizing to adults with autism .
- Recommend regional and systems gap filling actions for future monitoring.
- Use data findings to participate on the Commission’s data subcommittee.

New Hampshire



Rural/Regional

- State Plan committees were conducted with both in person and remote options
- Focus groups in English (6) and Spanish (2) conducted locally.
- Stakeholder forums (3) hosted locally
- Focus and stakeholder groups were specifically prompted to discuss how location/distance impacts access to services.

Income/Poverty

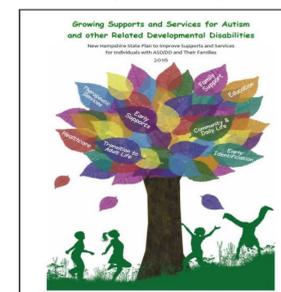
- Stipends for family participation in focus groups and for Grant Workgroups in order to address financial constraints for participation.
- Focus/stakeholder groups were prompted to discuss how cost and adequacy of insurance impacts access to services.

Culture/Language

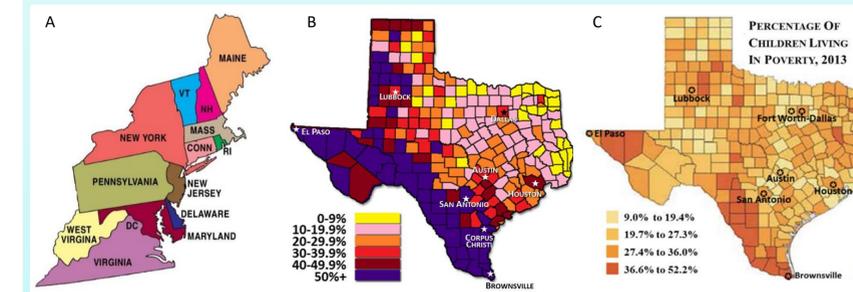
- Spanish focus groups were conducted by community broker.
- Culture/language incorporated into every topic area vs. being separate topic. This approach is in State Plan as well.

Recommendations:

- Recognize the value of family leaders by including them in the design and implementation
- Recruit diverse family representation for workgroups
- Design groups that allow for local involvement with in person or through remote access
- Reflect value of family involvement with stipends, child care, and transportation (as available)
- Identify community locations were ‘locals’ are comfortable
- Ask all families to reflect on the needs of underserved groups- this can help to raise awareness, identified groups in need of support and suggest family friendly approaches
- Emphasize that language/culture are not separate and apart.



Texas¹



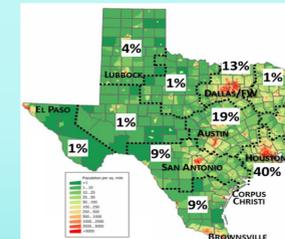
Texas’ size

- is equal to 13 northeast states combined [A],
- includes 9.7% of the total US child population [7.15M],²
- 49.7% of whom are Hispanic [B],³ and
- 26% of whom live in poverty [C, range of 9.1% - 49% for 254 counties].⁴

The *Act Early Texas!* Autism Commission used the PANA document for the Pre-Elementary, Elementary, Middle & High School, and Adult ages. Combined data from the four age groups are presented in this poster.

Rural/ Regional

- Texas’ child population is 13% rural and 87% urban located.
- We specifically marketed to rural HHSC Regions through the *Act Early Texas!* Autism Commission.
- 11% of total respondents from rural HHSC regions.



Culture/ Language/ Income/ Poverty

- Culturally appropriate versions of the *PA Autism Needs Assessment* survey were created in Spanish and Vietnamese.
- Marketing focused on Spanish and Vietnamese speakers across the entire State.

| Total N | Male | Female | Hispanic | Black | Asian/ Pacific Islander | Alaskan/ Native American | Caucasian | Other |
|---------|------|--------|----------|-------|-------------------------|--------------------------|-----------|-------|
| 1,083 | 81% | 19% | 26% | 10% | 6% | 1.8% | 75.5% | 3.5% |

Recommendations

- Meaningful focus groups across such a large geography were deemed impractical given available resources but in retrospect would most likely have vastly improved input from Latino and Vietnamese families.
- *Promotoras* and other community healthcare workers should definitely be utilized, especially in large states, to reach the those without digital access and those with lower SES levels.
- Successful marketing efforts require state-wide buy-in and resources.



¹ Pauline A Filipek MD, Stephanie Sokolosky Edd BCBA-D, Prisca Franklin BA, Alayna Townsend PhD CCC-SLP
² Center for Public Policy Priorities. KIDS COUNT Annual Data Book. Austin, TX: Center for Public Policy Priorities; 2015.
³ hardhatters.com/2014/03/texas-sized-transformation-population-changes-lone-star-state/
⁴ CPPP. The State of Texas’ Children 2016 Race and Equity - Texas’ Kids Count Project - Children living in poverty data. Austin, TX: CPPP; 2016.
⁵ http://www.paautism.org/resources/Caregivers-or-Parents/Resource-Details/Itemid/280