Solving the Autism Puzzle for Your State:
A Review of ASD/DD Planning & Implementation
Activities from Four States

Reports from: Massachusetts, New Hampshire, Texas and Tennessee
May 7, 2017

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Massachusetts Healthy People 2020 Autism Roadmap Project

Elaine Gabovitch, MPA
UMass Medical School-Shriver Center
Massachusetts Department of Public Health
March 7, 2017

Thanks to our Project Team!

Project Team
• Elaine M. Gabovitch, MPA
  • Shriver Center LEND Program
  • Massachusetts Act Early Program
• Emily Lauer, MPH
• Courtney Dutra, MPA
• Center for Developmental Disability Evaluation & Research (CDDER)

Project Advisory Board
• Family members & self advocates
• 2 LEND programs (UMMS & UMB)
• State agencies: BTP, EEC, EDHHS, DOL, DESE, DPH, MassHealth
• BUSPH MCH Program
• Boston Public Health Commission
• Federation for Children with Special Needs
• MA Developmental Disabilities Council
Project Overview

Four project goals:
1. Conduct needs assessment;
2. Refine state plan in comprehensive report;
3. Outline future surveillance;
4. Disseminate findings.

Six MCHB core outcome indicators:
- Early Identification
- Medical Home
- Access to Care
- Family Involvement
- Healthcare Transition
- Insurance PLUS Population Data
- Transition to Adult Life
- Education
- Housing & Cultural Considerations

Focus on underserved children & youth:
- Race, culture, language, immigrant status, region, function, mental health.

Methods

Quantitative:
- 50 key informant interviews
- National surveys, local surveys, & aggregated state reports
- Our own surveys
  - Pediatric Provider Survey (2013)
- Assessed via descriptive statistics

Qualitative:
- Twelve, 90-minute focus groups (3/15 – 12/15)
- 78 participants
- 5 regions
- Professionals (EI, CHCs, community services, transition)
- Parent leaders in related professions
- Diverse communities (African-American, Chinese, Latino, Haitian, Vietnamese)
- Five interviews with autistic adult self-advocates

Report sections:
- Core outcome indicator (6 MCHB core + 5 additional)
- Background
- Summary of state environment
- Identified needs: quantitative & qualitative findings
- Future possibilities
- Resources
- Recommendations
- Appendices
Overarching lessons learned

- The importance of the Project Advisory Board
- The importance of the Autism Commission
- Need for centralized entity to monitor processes
- Legislation may be needed
- Qualitative data
  - Fills gaps & points out emerging trends
  - Focus groups and key informant interviews provide rich insights
  - Self-advocates are essential to give meaning to transition
  - Professional groups need to be topic-focused
  - Multi-cultural parent groups gave insights that allowed us to add & change topics
  - Need to provide stipends, childcare, transportation, culturally appropriate interpreters
- Population data: Incidence of one in 70 children in MA with ASD (MDPH EI)
- Early identification: Gaps re: average age & type of screening, wait times, regional & racial/cultural disparities
- Medical Home: Most families have usual source of care, but need care-coordination & family centered care.
- Access to care: Few quantitative measures exist. Great needs: Medicaid acceptance, workforce capacity, trained ABA therapists, regional/transportation needs, poverty, etc.
- Family & self-advocate involvement: Family engagement opportunities exist; self-advocates need more.
- Healthcare transition: Great need for access, navigating adult healthcare & more providers.
- Transition to adult life: State progress being made due to legislation, measures needed.
- Insurance: Need to understand the % of children NOT covered.
- Education: Needs around language & translation.
- Housing: Need for executive function support to avoid homelessness. More data needed.
- Cultural considerations: Need for services, trusted providers, community education.

Highlighted findings

- Few quantitative measures exist. Great needs: Medicaid acceptance, workforce capacity, trained ABA therapists, regional/transportation needs, poverty, etc.
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Overarching recommendations (also by indicator)

1. Set state relevant targets & monitor progress
2. Obtain large data sets to better understand needs & inform planning
   - a) Consider conducting Massachusetts survey similar to national surveys to increase # &
   - b) Investigate linking state databases, particularly emerging ones
   - a) Monitor # pediatric & specialty physicians for capacity building
   - b) Invest in workforce development to increase # trained professionals across indicators
4. Prioritize understanding racial, cultural & regional disparities.
5. Share Massachusetts MCHB Core Outcome Indicator Data online with the public.
6. Employ innovative practices to approaching data collection and analysis.
   - a) Fully engage community organizations, families and self-advocates
   - b) Review the intersection of government and university research
   - c) Invite other states to share promising practices
7. Conduct focus groups to monitor public response.
Final outcomes

• Shared findings with MA Autism Commission Data Subcommittee on January 2017
• Joined Data Subcommittee to work on future actions based on report recommendations
• Currently fielding calls from advocates who wish to use findings
• Ongoing public engagements and dissemination opportunities

Thank you!
Report available at www.maactearly.org

For more information, please contact:
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March 4-7, 2017 | Kansas City, MO

Growing Supports and Services for Autism and other Related Developmental Disabilities

the
New Hampshire State Plan to Improve Supports and Services for Individuals with ASD/DD and Their Families

New Hampshire: Elizabeth Collins, RN-BC, MSN
CVSHCN Director/NH DHHS
Project Overview

1. Conduct a thorough Needs Assessment
2. Create a comprehensive and measurable State Plan informed by the Needs Assessment
3. Develop a State Action Plan Workbook

NH Autism State Plan Team

- Special Medical Services/Title V CYSHCN
  - CYSHCN Director is the grantee and provides oversight to grant implementation.

- NH Family Voices
  - The project coordinator, employed by NH Family Voices, is responsible for coordination and implementation of the work plan and serves as the liaison to the NH Council on ASD.

- NH LEND
  - NH LEND faculty and trainees involved in conducting and analyzing input from focus groups with families of individuals on the autism spectrum being held around the state and Stakeholder forums.

- NH Council on Autism Spectrum Disorders
  - Serves as the Advisory Board for the project and has established member workgroups to provide input and guidance.

Each partner had representation on the core planning group for the grant. Additional stakeholders were participants in the Needs Assessment and State Plan Workgroups.
Needs and Gaps

Needs Assessment Activities

- DATA SETS REVIEWED
  - Department of Education Census by Disability (Federal and State)
  - NH State Registry for ASD
  - National Survey of Children with Special Health Care Needs
  - NH Needs Assessment Survey 2012

- DATA COLLECTION
  - 8 Focus Groups including 2 for Spanish Speaking Families
  - Self Advocate/Young Adult Focus Group
  - 3 Stake Holder Forums

- AREAS OF FOCUS
  - Information about Services
  - Transition
  - Resiliency

FINDINGS

SERVICES
- Early intervention services
- Parental involvement
- School transition services
- Resiliency

INFORMATION ABOUT SERVICES
- Service coordination
- Parent involvement
- Community involvement

COORDINATION OF CARE
- Transition services
- Resiliency services

TRANSITION
- Transition planning
- Supports for school transition
- Supports for work transition

RESILIENCY
- Mental health services
- Social support services
- Financial assistance information
NH State Plan to Improve Supports and Services for Individuals with ASD/DD and Their Families

Design of the State Plan

In Each of the 9 Focus Areas:

• Each begins with a definition of the Focus Area specific to the NH State Plan for ASD/DD.
• Priorities are identified as recognized by stakeholders.
• Goals clarify the movement needed to address the Focus Area.
• Recommendations identify the steps, partnerships and awareness activities that will be addressed in the Action Plan Workbook.
• Barriers are recognized. If there are infrastructure components they may have an impact on other sections of the plan and those linkages are identified in the Roots section.

Action Plan Workbook

All 9 Focus Areas were detailed with:

• Breakdown by Recommendations
  • Key/Needed Partners
  • Needed Resources
  • Realistic Action Steps
  • Success Criteria
  • Timescale
  • Open entry box for Status updates and Comments

Pauline A. Filipek MD FAAP, Prisca Franklin, Alayna Townsend PhD CCC-SLP, UT Health Science Center at Houston, Stephanie Sokolosky EdD BCBA-D, and the Act Early Texas! Autism Commission

Funded by State Planning Grants for Improving Services for Children and Youth with Autism Spectrum Disorders and other Developmental Disabilities, US DHHS/HRSA grant #H6MMC26246

Texas is • larger than the 13 northeast states combined;
Texas is

- larger than the 13 northeast states combined;
- mainly a rural state; and is
- home to 9.7% [7.15M] of the entire US child population;
- home to 9.7% [7.15M] of the entire US child population;
  - 49.7% of whom are Hispanic;
- 26.7% of whom live in poverty [range 9.1-49% across 254 counties].

Percentage Hispanic Population

Percentage of Children Living in Poverty, 2013
Texas has never before performed a statewide Needs Assessment for Autism Spectrum or other Developmental Disorders [ASD/DDs]... although Texas parents have participated in the National Surveys for CYSHCN or NSCH.

When the State Planning Grant was funded, the Act Early Texas! Autism Commission was formed on the foundation of the academic autism centers in Texas, to direct the activities leading to a State Autism Plan.

The Act Early Texas! Autism Commission

The Needs Assessment Workgroup determined that the Pennsylvania Autism Needs Assessment would be the best model for Texas [with permission].

Four age-specific surveys filled out by primary caregiver:
- Pre-Elementary,
- Elementary,
- Middle & High School, and
- Adult.

Culturally-appropriate versions were also created in Spanish and Vietnamese.

The Act Early Texas! Autism Commission

A fifth PANA survey titled “Individuals over 18 who Answered for Themselves” was designed to be filled out by adult individuals with ASD/DDs.

We changed the name of the latter survey to “Self-Advocates” which unfortunately lead to considerable confusion with professional advocates (who were not self-advocates or individuals with ASD) and other professionals incompletely filling out this survey.
1,128 Needs Assessment Responses [Goal 1,150]

Demographics

<table>
<thead>
<tr>
<th>% AE/7 NA</th>
<th>Male</th>
<th>Female</th>
<th>Hispanic</th>
<th>Black</th>
<th>Asian/PI</th>
<th>AK/NA**</th>
<th>White</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>80%</td>
<td>20%</td>
<td>26%</td>
<td>10%</td>
<td>7%</td>
<td>2%</td>
<td>77%</td>
<td>4%</td>
<td></td>
</tr>
</tbody>
</table>

Highest Education Level Attained

<table>
<thead>
<tr>
<th>% AE/7 NA</th>
<th>No/Some High School</th>
<th>High School</th>
<th>Some College</th>
<th>College Degree</th>
<th>Advanced Degree</th>
</tr>
</thead>
<tbody>
<tr>
<td>2%</td>
<td>9%</td>
<td>18%</td>
<td>36%</td>
<td>30%</td>
<td></td>
</tr>
</tbody>
</table>

Location of Responders

<table>
<thead>
<tr>
<th>% AE/7 NA</th>
<th>Urban</th>
<th>Rural</th>
</tr>
</thead>
<tbody>
<tr>
<td>89%</td>
<td>11%</td>
<td></td>
</tr>
</tbody>
</table>

No significant differences in demographics across the specific surveys.

First Concerns, Diagnosis & Finding Professionals

<table>
<thead>
<tr>
<th>Mean ± SD</th>
<th>Pre-Elementary</th>
<th>Elementary</th>
<th>Middle/ High School</th>
<th>Adult</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age at Initial Concern</td>
<td>1.7 ± 0.8</td>
<td>2.0 ± 1.5</td>
<td>2.4 ± 1.9</td>
<td>2.0 ± 1.5</td>
</tr>
<tr>
<td>Age at Diagnosis [p&lt; 0.0001]</td>
<td>2.9 ± 1.1</td>
<td>4.1 ± 2.0</td>
<td>5.4 ± 3.6</td>
<td>6.0 ± 6.2</td>
</tr>
<tr>
<td># Professionals Seen before a Diagnosis [p&lt; 0.001]</td>
<td>2.3 ± 1.5</td>
<td>2.8 ± 5.7</td>
<td>3.0 ± 3.2</td>
<td>4.1 ± 4.0</td>
</tr>
</tbody>
</table>
Referrals Received at Diagnosis

<table>
<thead>
<tr>
<th>Given a follow-up appointment</th>
<th>Pre-Elementary</th>
<th>Elementary</th>
<th>Middle/High School</th>
<th>Adult</th>
</tr>
</thead>
<tbody>
<tr>
<td>Referrals to:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• specialist for further assessment</td>
<td>29%</td>
<td>26%</td>
<td>23%</td>
<td>21%</td>
</tr>
<tr>
<td>• specialist for treatment (p &lt; 0.002)</td>
<td>33%</td>
<td>33%</td>
<td>24%</td>
<td>17%</td>
</tr>
<tr>
<td>• Early Intervention</td>
<td>43%</td>
<td>37%</td>
<td>35%</td>
<td>33%</td>
</tr>
<tr>
<td>• support groups</td>
<td>24%</td>
<td>26%</td>
<td>23%</td>
<td>19%</td>
</tr>
<tr>
<td>• websites or literature (p &lt; 0.0005)</td>
<td>44%</td>
<td>37%</td>
<td>32%</td>
<td>19%</td>
</tr>
<tr>
<td>Received no referrals, support group information, literature or follow-up appointment whatsoever (p &lt; 0.02)</td>
<td>13%</td>
<td>12%</td>
<td>19%</td>
<td>20%</td>
</tr>
</tbody>
</table>

Educational Services for Pre-Elementary, Elementary, Middle/High School Surveys

- Only 75% had an active IEP
  - Only 55% qualified under TEA “Autism” criteria
- 19% never had an IEP
- Independent ADLs increased with age BUT
  - ONLY 20% of the Middle/HS and Adults could:
    - request their wants or needs independently, or
    - indicate if they were sick or hurt.

Medical Services Payments

- 46% Private
- 35% Medicaid/Waivers
- 14% Out of pocket
- 5% Don’t know
- 2% Other
IDEA Part B Transition Planning Services for Middle/High School, Adult and Self-Advocate Surveys

Over 40% Middle/HS/Adults & over 70% Self-Advocates denied ever receiving:
- Transition planning;
- Transition assessment;
- Individual transition plan (ITP);
- School meeting where transition was discussed; or
- Student participation in transition planning.

IDEA Part B Transition Planning Services for Middle/High School, Adult and Self-Advocate Surveys

Over 50% denied ever receiving:
- Assisted technology and instruction;
- Vocational rehabilitation services;
- Career counseling;
- Transportation training/instruction;
- Post-HS training (eg, college/certificate/technical/trade);
- Independent living training (eg, self-help, safety);
- Behavior intervention plan for challenging behavior;
- Positive behavior supports;
- Case worker responsible for transition;
- Job-related social communication skills;
- Community living/housing training;
- Functional life-skill training/instruction, self-care instruction.

Autism Needs Assessment Summary

- significant weaknesses exist in serving children and youth with ASD/DDs in Texas.
  - Independent of rural service-shortage areas;
  - Strongly related to ethnicity, with Hispanic individuals receiving the least services.
- 2016-2017 Houston Chronicle investigative report: predetermined statewide 8.5% SpEd cap since 2004 for all 1,054 ISDs under threat of retribution.
- Texas still rated 50th by United Cerebral Palsy
Autism Needs Assessment Summary

On the positive side:

• Age-at-Diagnosis has dropped from age 6 to 3 years, but is still well above average relative to other states.
• # professionals to obtain the diagnosis has also dropped but, again, there is still considerable room for improvement.
• Initiatives continue without State Implementation funding for Project ECHO and telemedicine models to better reach those most need statewide.

Solving the Autism Puzzle for your State

Steps to Universal Autism Screening in Tennessee

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Medical Director and Past President, Tennessee Chapter, American Academy of Pediatrics

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Susan H. Rollyson, M.Ed, Training Coordinator, Tennessee Chapter of the American Academy of Pediatrics (TNAAP)
Jenny Duramiks, RN, BSN, Asst. State Public Health Nursing Director

Thanks to our team

• Toni M. Whitaker MD, MD, FAAP, Associate Professor Pediatrics, Developmental Pediatrics, University of TN<br>Boling Center for Developmental Disabilities
• Zachary Warren, Ph.D, Associate Professor of Pediatrics, Vanderbilt University Medical Center
• Susan H. Rollyson, M.Ed, Training Coordinator, Tennessee Chapter of the American Academy of Pediatrics (TNAAP)
• Jenny Duramiks, RN, BSN, Asst. State Public Health Nursing Director
Our Journey

- 2002 TN Autism Services Plan (Senate Joint Resolution 567)
- Defining Stakeholders 2002-2012
- 2009 Summit on Autism Southeast Region developed the TN Autism Team
- 2012 HRSA planning grant developed TN Autism Summit Team
- 2014 TN Autism Plan released

TN Autism Summit Team: Defining Needs

- Early Identification
- Service Coordination
- Information for Families
- Education
- Healthcare
- Adulthood

Work addressed best practices, existing and emerging models, and recommendations for addressing gaps and needs

Working Our Plan: Screen All Children for ASDs

- Identify existing and potential partnerships before proposing new programs
  - Centers for Disease Control (CDC) Act Early Ambassador
  - Leadership Education in Neurodevelopmental and Related Disabilities (LEND) programs
  - Treatment and Research Institute for Autism Spectrum Disorders (TRIAD), Vanderbilt Kennedy Center
  - Tennessee Chapter of the American Academy of Pediatrics (TNAAP)
- Survey existing screening procedures and processes
  - TN Department of Health locations
  - Tennessee Early Intervention Program
  - TennCare EPSDT Program
  - TNAAP Screening Tools and Referral Training (START) Program for community providers
- Pilot a training tool and methodology
  - Modified Checklist for Autism in Toddlers, Revised with Follow-up (MCHAT-R/RF)
Challenges and Solutions

- Tennessee is large and long (95 counties; 440 miles long)
- Limited trainers in few locations
- Department of Health locations driven by nursing protocols; RNs provide most of the care
- Delivering training materials and tools to locations
- Adjusting workflow to implement ASD screening
- Face to face meetings with regions to start; followed with webinar training
- Utilized existing START network and infrastructure
- Content designed to train regional nursing supervisors to train front line staff
- Developed a 14 min MCHAT R/F Training Video to allow reliable screening tool implementation
  
  http://tnaap.org/training_videos

- Department of Health Physician and Nursing Leaders championed the trainings
- Content development was a shared responsibility and outgrowth of the partnerships developed by the Autism Summit Team
- Regional Department of Health nursing supervisor preparatory trainings were done face to face and resulted in better “buy in”
- A 2 Hour Training Webinar allowing nursing supervisors to train staff provided specific information on each step of screening implementation was completed in Sept 2015
- Follow up technical support and training packets were provided for all locations
- Trainings and implementation of screening moved rapidly; by Jan 2016 327 public health nurses were trained and screening had begun

Thank You!

Questions