Agenda

• Project Background
• Key Activity Areas
  – Early Identification
  – Insurance and Utilization
  – Access to Care
  – Education and Transition
• Summary & Next Steps
**Project Overview**

In response to a call for proposals from HRSA-MCHB for state autism planning projects and from the recent recommendations of the Massachusetts Autism Commission for implementing a plan for consistent statewide data collection related to services and supports for people with ASD in MA, **we will develop a comprehensive statewide approach to address the needs of MA children and youth with autism and developmental disorders by implementing consistent statewide data collection practices.**

**Goal 1:** Conduct a state needs assessment for MA children & youth with ASD & DD that aligns with the six MCHB Healthy People 2020 indicators
Goal 2: Refine the state autism plan to address identified needs

The needs assessment will result in a proposed state plan report that will be compared with the pre-existing MA Autism Commission state plan and refined with advisory board input.

Goal 3: Outline an evaluation plan and program surveillance strategy to monitor and report on state ASD/DD activities and outcomes in the future.

The evaluation plan and surveillance strategy will be comprehensive, produced in collaboration with advisory board input. It will be added with the state plan into the final report.
Background: Evaluation

**Goal 4: Measure the project goals, objectives, and deliverables throughout the two-year period.**

Progress reports to HRSA-MCHB and the project advisory board have been disseminated over the grant period. Quarterly advisory board meeting summaries & evaluations have been shared. The final project report will be available to Massachusetts Autism Commission, advisory board & public.

---

Progress to Date

**To date:**

- Sourced **numerous data sets** and identified those available for secondary analysis
- Designed and conducted a *diagnostic clinic wait time survey* and a *pediatric provider survey*
- Held over **40 key informant interviews** including self advocates
- Held **seven focus groups** that targeted parents of children with ASD/DD or professionals working in the field
  - 2 cultural groups
  - 2 “parent leader” focus groups of parent-professionals
  - 2 professional groups (EI and Transition)
  - 1 medical provider group
Healthy People 2020  Six Core Indicators

1. Early Identification and Screening
2. Medical Home
3. Accessible Community-based Service System
4. Family Involvement
5. Transition to Adult Health Care, Work & Independence
6. Adequate Private &/or Public Insurance to Pay for Services

Early Identification

“Some pediatricians advise a ‘wait and see’ approach to families’ concerns. This doesn’t give parents the sense that time is of the essence. Parents are left with the impression it’s not a big deal, but time is being lost.”
Massachusetts Population Stats

- 6.6 million residents; 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, and Vietnamese, many more

- Poverty & diversity are closely linked**:
  - Federal poverty line: 14.4% overall; 25-30%, diverse families
  - Est. birth through 5 from underserved families: 91,772 (25%)

- CYSHCN***: 238,810 total; DD: 41,314 (17.5%); ASD: 21,183 (8.9%)
  - Early intervention (Part C) & special education (Part B) (2010) Birth through age 5 = 31,824 (8.6%)

- Est. 1,600 pediatricians

Early Identification

**What we found:**

- **Conflicting developmental screening reports** for MA on national surveys
  - Early & continuous screening: NS-CSHCN (2010): 89%

- CBHI requires routine *behavioral health screening at well child visits* using standardized MassHealth approved behavioral health assessment tools (including developmental & ASD screening); and when indicated, diagnosis and treatment
  - Developmental tools: ASQ:SE; PEDS; BITSEA; SWYC; Autism tool: M-CHAT

- ASQ *developmental screenings & parent education* with Coordinated Family & Community Engagement (CFCE) programs early education programs through Race to Top program (in English & Spanish)

- **No known data about MA screening except billing codes** for MassHealth that shows screening was done

- **All Payer Claims Data** may have info on screening and diagnosis, but not tied together – for future review
Screening: NSCH 2011-2012

National Survey of Children’s Health 2011-2012 for MA

- Parent report survey
- Estimated that between 1.16% - 3.24% of children aged 2-17 in non-institutionalized settings currently have autism. Compares to 1.6% - 2.0% nationally
- Reported that doctors asked parents about developmental concerns in age 0-5 patients 62.8% of time; did not ask 37.2%
- Reported that children ages 10-71 months received 2 types of screening content (development; communication or social behaviors) 55.1% of time; did not 44.9%

Diagnosis: NSCH 2011-2012

Age at diagnosis of ASD

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Percent of children with ASD</th>
<th>US</th>
<th>MA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Birth to 2 years</td>
<td>26.2</td>
<td>20.3</td>
<td></td>
</tr>
<tr>
<td>3-5 years</td>
<td>39.4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6-10 years</td>
<td>26.8</td>
<td>20.0</td>
<td></td>
</tr>
<tr>
<td>11-17 years</td>
<td></td>
<td>7.5</td>
<td>6.9</td>
</tr>
</tbody>
</table>
Diagnosis NS-CSHCN

<table>
<thead>
<tr>
<th>Reported Dx (NS-CSHCN, 2010)</th>
<th>MA % or #</th>
<th>U.S. % or #</th>
</tr>
</thead>
<tbody>
<tr>
<td>Birth to 2 years</td>
<td>5,340</td>
<td>(25%) 224,010</td>
</tr>
<tr>
<td>3 to 5 years</td>
<td>9,203</td>
<td>(43%) 372,355</td>
</tr>
<tr>
<td>6 to 10 years</td>
<td>4,209</td>
<td>(20%) 183,371</td>
</tr>
<tr>
<td>11 to 17 years</td>
<td>2,431</td>
<td>(12%) 53,170</td>
</tr>
</tbody>
</table>

*Appears overestimated @ 75% over age 2

<table>
<thead>
<tr>
<th>Reported Dx (DESE 2011)</th>
<th>MA % or #</th>
</tr>
</thead>
<tbody>
<tr>
<td>6 to 21 years on IEP w/ ASD</td>
<td>9,886</td>
</tr>
<tr>
<td>Full inclusion</td>
<td>35.9%</td>
</tr>
<tr>
<td>Partial inclusion</td>
<td>15.6%</td>
</tr>
<tr>
<td>Sub separate program</td>
<td>31.3%</td>
</tr>
<tr>
<td>Out of district program</td>
<td>17.2%</td>
</tr>
</tbody>
</table>

*Hard to distinguish actual # with ASD due to 13 categories on IEP

Possible barriers:
- Shortage of diagnosticians by region
- Lack of training
- Language barriers
- Cultural disparities
- 25% immigrants or poverty-level households

Intervention: NSCH 2011-2012

- Does [child name] have any developmental problems for which he/she has a written intervention plan called an IFSP or IEP? Age 1-5
  - 100% of children with autism have IFSP/ISP (very small sample)

- Does the child have a health problem, condition, or disability for which he/she has a written intervention plan called an Individualized Education Program or IEP? (age 6-17)
  - 96% of children with autism have IEP
Early ASD Identification Study in MA

• 2011 study (Manning et al.) examined trends in ASD by age 36 months and identified characteristics associated with early diagnoses in MA.

• METHOD: MA birth certificate & EI program data linked to identify infants born 2001 – 2005 enrolled in EI who received ASD-related services before age 36 months
  – Rate of early ASD diagnoses increased 66% between 2001 and 2005 reflective of national trend
  – Incidence of ASD: 1 in 178 (2001); 1 in 108 (2005); 1 in 85 (2013)
  • Latest update: 1 in 78 (2015)
  – Average age of diagnosis for children in EI: 2.56 years old


Early ASD Identification Study in MA

• Cultural/linguistic gap:
  – Infants of mothers whose primary language was not English or were foreign-born had lower odds of an early ASD diagnosis
  • May reflect groups with greater barriers to early screening

• Shrinking racial gap:
  – 2001: lower rates of early ASD diagnoses in racial minorities
  – 2005: racial differences substantially lessened.
  • Suggests screening improved among racial minorities

• Maternal education/racial differences:
  – Non-Hispanic whites mothers with 4+ years of college: early ASD diagnosis less frequent among children compared with high school graduation
  – All other race/ethnic groups with more education than those with less education, more early ASD diagnoses
  • Suggests screening gaps in minorities with lower educational levels, particularly non-Hispanic ‘other’ races
Pediatric Provider Survey 2013-14

Response

• Emails disseminated in 3 waves to 1,600 MA pediatricians (8/13, 11/13, 1/14)
• 106 respondents (6.6% response rate)
• Regions: Metro Boston (50%), Northeast (17%), Western (14%), Central, (12%), Southeast (10%)
• Settings: Urban (50%), Suburban (49%), Rural (2%)

Highlights: Areas of Reported Positives

• 34% with more than 51% of patients on MassHealth
• Screening tool use: M-CHAT (91%); PEDS (74%) ASQ-3 or ASQ:SE (6%)
• Routine autism screening ages: 12 mos. (35%); 18 (93%); 24 (88%)

Wait Time Survey 2015

Response

• Emails disseminated to 40 contacts on 3/4/15
• 26 respondents through 3/31 (65% response rate)
• 18 identified selves if follow-up needed
• Most major medical centers represented:
  BayState Medical, Boston Medical Center, Children’s Hospital, MGH Lurie Center, Tufts Medical Center, UMass CANDO, UMass Memorial Medical Center
• Many small clinics or individuals represented but not all identified
• Smaller or less known centers may not have responded (16)
### Comparison of DBPs vs. Pediatricians

<table>
<thead>
<tr>
<th></th>
<th>DBP Clinics</th>
<th>Pediatricians</th>
</tr>
</thead>
<tbody>
<tr>
<td># locations</td>
<td>45</td>
<td>103</td>
</tr>
<tr>
<td><strong>Wait times</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2 months = 22%</td>
<td></td>
<td>2 months = 26%</td>
</tr>
<tr>
<td>3 months = 24%</td>
<td></td>
<td>3 months = 23%</td>
</tr>
<tr>
<td>6 months = 18%</td>
<td></td>
<td>6 months = 33%</td>
</tr>
<tr>
<td><strong>Timely referral</strong></td>
<td><strong>Re: PCPs referrals</strong></td>
<td><strong>Re: Timely Dx feedback</strong></td>
</tr>
<tr>
<td>Most PCP are NOT timely = 8%</td>
<td></td>
<td>Strongly disagree = 0%</td>
</tr>
<tr>
<td>Some NOT timely = 46%</td>
<td></td>
<td>Disagree = 12.5%</td>
</tr>
<tr>
<td>Usually timely = 42%</td>
<td></td>
<td>Neutral = 23%</td>
</tr>
<tr>
<td>Always timely = 4%</td>
<td>*defined as within one month</td>
<td>Agree = 44%</td>
</tr>
</tbody>
</table>

### Top reasons late referral:

- Parents unaware of milestones/red flags (77%)
- Primary language not English (59%)
- **PCP did not screen** (55%)
- Limited caregiver ability (55%)
- Lower SES (55%)

### Top 3 detection needs:

- Train PCPs screen/refer (44%)
- Outreach to early childhood programs (44%)
- Regional networks re: Early ID between EC, EI, PCP & Dx (52%)

- Train PCPs screen/refer (40%)
- Better availability of ASD Dx specialists (80%)
- Better communication w/ ASD Dx specialists (43%)
### Comparison of DBPs vs. Pediatricians

<table>
<thead>
<tr>
<th>% non-English speaking patients</th>
<th>DBP Clinics</th>
<th>Pediatricians</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>&lt;25% = 81%</td>
<td>&lt;20% = 61%</td>
</tr>
<tr>
<td>25-50% = 12%</td>
<td>21-50% = 24%</td>
<td></td>
</tr>
<tr>
<td>51-75% = 4%</td>
<td>51-80% = 13%</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>I have access to...</th>
<th>DBP Clinics</th>
<th>Pediatricians</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interpreters = 58%</td>
<td></td>
<td>Interpreters = 93%</td>
</tr>
<tr>
<td>Translators = 23%</td>
<td></td>
<td>Translators = n/a</td>
</tr>
<tr>
<td>Cultural liaisons = 15%</td>
<td></td>
<td>Cultural liaisons = 9%</td>
</tr>
<tr>
<td>Bilingual providers = 15%</td>
<td></td>
<td>Bilingual providers = 40%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>I do not have access to language services</th>
<th>DBP Clinics</th>
<th>Pediatricians</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>35%</td>
<td>N/A</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>What do you do when patient's family does not speak English?</th>
<th>DBP Clinics</th>
<th>Pediatricians</th>
</tr>
</thead>
<tbody>
<tr>
<td>Re: Evaluation: Use translated measure (23%)</td>
<td></td>
<td>Re: Screening: Use translated measure (45%)</td>
</tr>
<tr>
<td>Perform w/ interpretation (62%)</td>
<td></td>
<td>Perform w/ interpretation (70%)</td>
</tr>
<tr>
<td>Do not evaluate (35%)</td>
<td></td>
<td>Do not screen (20%)</td>
</tr>
</tbody>
</table>

### Regional Wait Times – Early ID

- **Western Region**: >1 or 6 mos. (median 6 mos.)
- **Central Region**: >1 to 6 mos. (median 3 mos.)
- **Metro-Boston**: >1 to 9 mos. (median 3 mos.)
- **Southeast Region**: >1 to over 12 mos. (median 2 mos.)
- **Northeast Region**: 2 to 12 mos. (median 5 mos.)
Early Identification

What we’re still seeking:

- **Screening** (Dev & ASD)
  - #/% of children screened
  - Average age
- **Diagnosis**
  - #/% of children diagnosed by subspecialist
  - Average age
- **All Payer Claims one key source of data**

• Intervention
  - #/% children receiving intervention from referrals
  - Wait times from Dx referral to intervention

• **Further understanding about:**
  race, ethnicity, primary language, immigrant status, region, income level, level of function, mental health

In Their Words....

Themes from the Focus Groups:

- Diagnosis depends heavily on the doctor (over/under diagnoses).
- Diagnosis heavily influenced by language, culture and literacy.
- Lack of diagnostic specialists in furthest regions of state.
- For some families, transitioning out of EI is like falling off a cliff. They go from a family centered EI program into the child-centered schools.
- Cognitively bright kids diagnosed very late in some areas.
- Parents are overwhelmed. They are given a list of resources and don't know where to start. ASD may not be their main priority in competition with more immediate & elementary family needs.
- Training sessions with daycare providers have been successful in educating parents and identifying early warning signs.
“My biggest concern is the vast difference money makes. For low income families, so few providers take MassHealth.”

Adequate Private &/or Public Insurance to Pay for Services

**Indicator:**
- This core indicator addresses adequate private and/or public insurance to pay for the services that children and youth with ASD and DD need

**Context in Massachusetts:**
- Universal healthcare (2006), including expanded Medicaid post-ACA
  - 96% insured; however pockets (immigrants, minorities) of uninsured
- Autism-specific coverage:
  - ARICA law (2011) - applies to state-regulated plans; ERISA plans are federally regulated and exempt from state law.
    - Diagnosis and treatment of ASD; no $ limit, no age limit
    - Habilitative, rehabilitative, pharmacy, psychiatric, psychological, therapeutic
  - MassHealth in the process of expanding coverage (<21)
- UMMS-Shriver Autism Insurance Resource Center assists families and providers with information on insurance coverage in MA (3,000+ contacts)
- Home and Community-based waiver expansion for children with autism & ID
 Adequate Private &/or Public Insurance to Pay for Services

**What we found:**

- NS-CSHCN data predate universal healthcare in MA, the ARICA law, and passage of the ACA.
- MassHealth covers 38% of state families including CSHCN and low-income families
- DDS Autism Waiver: (Age cap of 9 years)
  - Subset of families below 300% of FPL eligible for DDS Autism Waiver
  - 157 covered; 6,000 low-income children enrolled in MassHealth
  - 205 can be served/year; 800 applications received last year

 Adequate Private &/or Public Insurance to Pay for Services

**What we found – Gaps & Barriers:**

- Concerns about Network Adequacy for autism diagnosis and treatment
  - Relatively high # of BCBA programs here
  - Working toward licensing of BCBAs for consumer protection
- Gaps in services –
  - ERISA plans – some select coverage, but only 3-6 yrs
  - Some insurers argue autism treatments are not medically necessary
  - Co-pay burden for some therapies
  - No coverage for **care coordination**
  - Housing – esp. for young adults
“In our programs, 50% of people referred to local medical centers for an Autism evaluation don’t show up. With the use of family navigators, that number increases to 90%.”

### Accessible community-based service system

**What we found:**

<table>
<thead>
<tr>
<th>Demographics (NS-CSHCN, 2010)</th>
<th>MA % or #</th>
<th>U.S. % or #</th>
</tr>
</thead>
<tbody>
<tr>
<td>CSHCN with easy access to community services</td>
<td>68%</td>
<td>65%</td>
</tr>
<tr>
<td>Hispanic or Latino</td>
<td>59%</td>
<td>59%</td>
</tr>
<tr>
<td>Non-Hispanic Black</td>
<td>67%</td>
<td>64%</td>
</tr>
<tr>
<td>Non-Hispanic Other</td>
<td>65%</td>
<td>61%</td>
</tr>
<tr>
<td>Non-Hispanic White</td>
<td>71%</td>
<td>68%</td>
</tr>
<tr>
<td>Care coordination rec’d &amp; satisfied</td>
<td>66%</td>
<td>69%</td>
</tr>
<tr>
<td>Help with care coordination</td>
<td>28%</td>
<td>21%</td>
</tr>
<tr>
<td>MH services accessed last 12 mos.</td>
<td>68%</td>
<td>40%</td>
</tr>
<tr>
<td>Problems getting specialist care</td>
<td>20%</td>
<td>24%</td>
</tr>
<tr>
<td>*Minimal Quality of Care Index met</td>
<td>45%</td>
<td>41%</td>
</tr>
</tbody>
</table>

*Current status of accessible systems of care unknown for children with ASD in MA.*
Accessible community-based service system

- Psychotropic Medication use
  - MassHealth recently instituted prior authorization rules for children, based on recent GAO report
    - E.g. inter- and intra-class polypharmacy
  - At least a third of children with flagged prescription profiles had utilization claims with ASD diagnoses
  - Challenges with coordination of care – talks with MA Children’s Behavioral Health Initiative on strategies

- A top priority recommendation of MA Autism Commission; includes single point of entry; should include region, race, culture, age, etc.

In Their Words....Medical Providers

- It’s challenging to know when to advise parents to wait and see and when to be concerned about development.
- Challenging to get parents to follow-up with a developmental specialist - they are already so overwhelmed.
- It’s difficult to conduct M-CHAT given so many different languages and dialects – it takes a very long time.
- Significant barriers in contacting and working with schools and adult services: “We just don’t know what’s happening outside of here.”
- Issues with guardianship and transition – who does what? What is the role of the PCP?
- There is not necessarily the expertise and training to work with ASD in the medical community. “There is not much we can do...these kids don’t have a lot of medical issues. They just need services”
- Time to see patients with ASD takes double the time and is not reimbursed: “Shoots my whole day seeing other patients.”
Education and Transition

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

Transition to Adult Health Care, Work & Independence

Indicator:

*Youth with special health care needs receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.*
Indicator #5: Transition to Adult Health Care, Work & Independence

What we found:

<table>
<thead>
<tr>
<th>Transition to Adult Health Care (NS-CSHCN, 2010)</th>
<th>MA % or #</th>
<th>U.S. % or #</th>
</tr>
</thead>
<tbody>
<tr>
<td>YSHCN who receive services to transition</td>
<td>47%</td>
<td>40%</td>
</tr>
<tr>
<td>Hispanic</td>
<td>35%</td>
<td>25%</td>
</tr>
<tr>
<td>Black, non-Hispanic</td>
<td>29%</td>
<td>28%</td>
</tr>
<tr>
<td>Other, non-Hispanic</td>
<td>35%</td>
<td>40%</td>
</tr>
<tr>
<td>White, non-Hispanic</td>
<td>51%</td>
<td>46%</td>
</tr>
</tbody>
</table>

What we found:

• MRC Vocational Rehabilitation Services:
  – 1,100 people with ASD receiving services (4% of VR client base)
  – Over 65% are under age 20 – due to collaboration with school systems

• Department of Developmental Services:
  – 32% of eligible people had both ID & ASD diagnosis
  – 76% of applicants eligible; 24% ineligible
  – If ineligible, 33% had ASD

• Department of Mental Health:
  – 22,000 individuals served
  – DMH services not designed to address behavioral support for ASD

• Higher Education:
  – 10,240 students with disabilities in public higher ed; 70% community colleges
  – 582 with ASD; 450 enrolled at community colleges
Indicator #5: Transition to Adult Health Care, Work & Independence

**What we’re looking for:**

- **Adult Health Care Transition**
  - % written transition plan for health & medical history
  - % appropriate adult provider identified at age 22
  - % youth educated to understand health
  - % planning for future education
  - % planning for future employment

- **Quality of Life**
  - % age-appropriate independent living
  - % satisfied with lives

- **Other:**
  - # Transition assessments for IEP
  - # Transition Planning Forms in IEP
  - # ISP for graduates
  - # in need of Mental health services not getting them
  - # in need of Housing
  - # who are not able to obtain transportation

**Quality of Life**

- % employed
- % postsecondary education
- % limited daily activities

**In Their Words....Education**

- Educational advocacy is essential.
- Disparities in how African-American boys are diagnosed in the school system (Learning Disabilities or Attention Deficits).
- Skill building in school ceases to exist in home environment for some families or vice versa: school is a black hole for families. What's happening there in terms of skill development?
- Poor translation and interpretation (not culturally competent) in the IEP.
- Non-English speaking families feel ignored.
- Some non-English speaking families told to sign the IEP on the spot.
- Inconsistencies across schools in transitioning planning.
- Transition age crisis – falling into the cracks, limited clinicians & long wait times
In Their Words....Transition Needs

- Clear guidance is needed about what families are responsible for and what schools are responsible for in the transition process
- Transition conversation needs to start earlier than age 14
- Parent training in elementary school
- Training for teachers, parents, and kids simultaneously (all day conference)
- Schools should be informed about great initiative like Inclusive Concurrent Enrollment (ICE) done in partnership with community colleges that they may not be aware of

In Summary....
It’s all about culture

Culture cuts across all core indicator domains and subgroups.

*Some examples shared during the focus groups:*

- Some cultures are not accustomed to well-visit checks
- For some cultures, not speaking before age 2 is not seen as a negative
- Asian cultures do not traditionally ask questions of the doctor or bring up concerns; not taught to “stand up to anyone”
- Autism in African-American and Hispanic boys may be misunderstood as ADHD or mental health issues, or discipline issues

Next steps!

Continue focus groups & key informant interviews through early July.
Start data analysis and report writing through summer.
Review findings with data sources & project advisory board.
Complete report and share with Commission and online
Questions?

Thank you!
Please contact us if you have anything to share.
Elaine.Gabovitch@umassmed.edu

For more information about MA Act Early, visit:
www.MAActEarly.org