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## The Healthy People 2020 Roadmap for Massachusetts Children & Youth with ASD/DD: Understanding Needs and Measuring Outcomes

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### Background:

The Massachusetts Autism Commission 2012 report identified “a critical need to develop a comprehensive statewide approach” to respond to the needs of the rapidly increasing population of people with autism spectrum disorder and developmental disabilities (ASD/DD). In response, the UMMS-Shriver Center has been conducting a needs assessment to inform efforts to establish a state-level data collection and surveillance plan for systems of services for children and youth with ASD/DD.

### Methods:

The project’s objectives are to:

- (1) Assess state needs of children with ASD and DD that align with six MCHB core indicators (i.e., early identification, medical home, access to community-based systems of care, family involvement, transition to adulthood, and insurance);
- (2) Make recommendations to refine the existing Massachusetts Autism Commission plan and address identified needs; and
- (3) Outline an ongoing surveillance strategy to monitor and report on future state ASD/DD outcomes.

This project has focused on understanding several factors including race, culture, language, region, level of function, and mental health.

### Preliminary Findings:

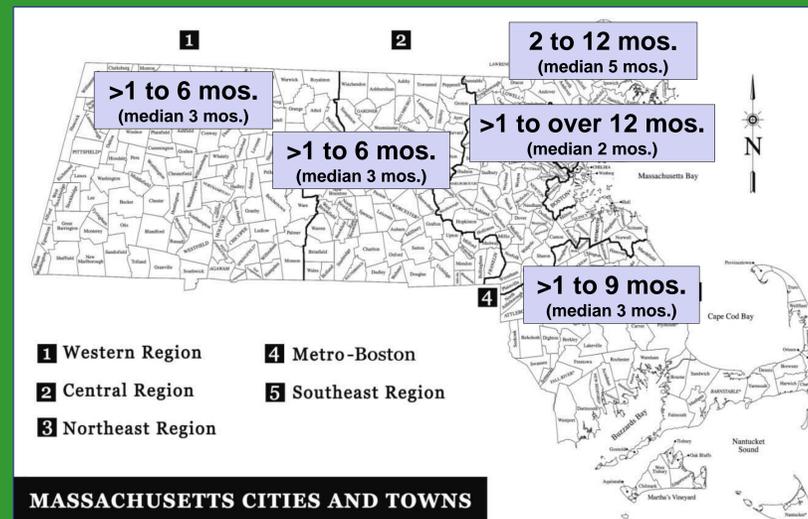
Although Massachusetts is a resource rich state, through a review of secondary data analysis, key informant interviews, focus groups, and surveys, the needs assessment has identified certain gaps in services and coverage. Selected findings are shared here, though much more exists.

## Results

### Early Identification

- **Trends in ASD by age 36 months** and identified characteristics associated with early diagnoses in MA (Manning et al, 2011):
  - Rate of early diagnoses: **Increased 66%** from 2001 - 2005
  - Incidence: 1 in 178 (2001); 1 in 108 (2005); 1 in 85 (2013); **1 in 78 (2015)**
  - Average age of diagnosis for children in EI: **2.56 years old**
- **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

### Wait Time Survey



	DBP Clinics (n=26)	Pediatricians (n=106)
Top reasons late referral:	Parents unaware of milestones/red flags (77%)	Parents unaware of milestones/red flags (88%)
	Primary language not English (59%)	Primary language not English (61%)
	Limited caregiver ability (55%)	Limited caregiver ability (62%)
	Lower SES (44%)	Lower SES (60%)
% non-English speaking patients:	<25% = 81%	<20% = 61%
	25-50% = 12%	21-50% = 24%
	51-75% = 4%	51-80% = 13%
I have access to:	Interpreters = 58%	Interpreters = 93%
	Translators = 23%	Translators = n/a
	Cultural liaisons = 15%	Cultural liaisons = 9%
	Bilingual providers = 15%	Bilingual providers = 40%
I do not have access to language services:	35%	N/A
What do you do when patient’s family does not speak English?	Re: Evaluation: Use translated measure (23%) Perform w/ interpretation (62%) Do not evaluate (35%)	Re: Screening: Use translated measure (45%) Perform w/ interpretation (70%) Do not screen (20%)

### In Their Own Words

“My biggest concern is the vast difference money makes. For low income families, so few providers take MassHealth.”

“The biggest problem is that the folks doing transition for your child have no idea what adult services look like...And so folks don't really know what they are going to get.”

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

“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%.”

“We see a lot of homeless families and they are just trying to get by. They need the diagnosis, but where they are living is horrendous. But they need that outreach to prioritize the services they need.”

### Insurance Utilization

- **Universal healthcare (2006)**
  - 96% insured/4% uninsured; however pockets (immigrants, minorities) of uninsured with sharp contrasts between socio-economic areas (e.g., East Boston: 23.7%; New Bedford: 22.1%; 10 affluent census tracts in MA: 0%)
- **Autism-specific coverage:**
  - ARICA law (2011) applies to private, state-regulated plans
    - Diagnosis and treatment of ASD (ABA, speech, etc.); no \$ limit, no age limit
    - Habilitative, rehabilitative, pharmacy, psychiatric, psychological, therapeutic
  - MassHealth in the process of expanding coverage (<21)
  - ERISA plans federally regulated and exempt from state law
- **UMMS-Shriver Autism Insurance Resource Center** assists families and providers with information on insurance coverage in MA (3,000+ contacts)
- **Home & Community-based Waiver** expansion for children with ASD & ID

### 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 1/3 children with flagged prescription profiles had utilization claims with ASD diagnoses
- **Challenges with coordination of care;** talks on strategies with MA Children’s Behavioral Health Initiative

### Transition to Adult Health Care

Transition to Adult Health Care (NS-CSHCN, 2010)	MA % or #	U.S. % or #
YSHCN who received services to transition	47%	40%
Hispanic	35%	25%
Black, non-Hispanic	20%	28%
Other, non-Hispanic	35%	40%
White, non-Hispanic	51%	46%

### Discussion

Through a triangulated data review to examine state strengths and needs in the six Healthy People 2020 core indicator areas of early identification, medical home, access to community-based systems, family involvement, insurance and transition, preliminary findings indicate that while Massachusetts has done well in such areas as lowering the average age of identification, instituting universal insurance coverage, and offering resources and services that support children and youth with ASD/DD and their families, its challenges now lie in addressing barriers by region, socio-economics, mental health, and culture, race and language. Old data systems need updating. Providers may not take Medicaid. Essential therapies like ABA need more therapists. Access to the All Payer Claims Database, which has just released its 3.0 version, is needed to better understand healthcare access and outcomes. The future will lie in sharing our findings with the Commission and diverse communities to work on the most meaningful solutions together.

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