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

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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 UMMSS-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 Healthy People 2020 core indicator areas of early identification, instituting universal insurance coverage, and offering resources and services that support children and youth with ASD/DD and their families.
(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 83 (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

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.

Funding: Health Resources & Services Administration-Maternal & Child Health Bureau