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

Elaine Gabovitch
University of Massachusetts Medical School

Et al.

Let us know how access to this document benefits you. Follow this and additional works at: https://escholarship.umassmed.edu/commed_pubs

Part of the Health Law and Policy Commons, Health Policy Commons, Health Services Administration Commons, Health Services Research Commons, Mental and Social Health Commons, and the Psychiatry and Psychology Commons

Repository Citation

This material is brought to you by eScholarship@UMassChan. It has been accepted for inclusion in Commonwealth Medicine Publications by an authorized administrator of eScholarship@UMassChan. For more information, please contact Lisa.Palmer@umassmed.edu.
The Healthy People 2020 Roadmap for Massachusetts Children & Youth with ASD/DD
Understanding Needs and Measuring Outcomes
Elaine Gabovitch, MPA, Courtney Dutra, MPA & Emily Lauer, MPH
University of Massachusetts-Eunice Kennedy Shriver Center

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 UMMMS-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
Psychotropic Medication use
Infants of mothers whose primary language was not English or were
Diagnosis and treatment of ASD (ABA, speech, etc.); no $ limit, no age limit
UMMS
Suggests screening improved among racial minorities
Cultural/linguistic gap:
Universal healthcare (2006)
Habilitative, rehabilitative, pharmacy, psychiatric, psychological, therapeutic
MassHealth in the process of expanding coverage (>21)
ERISA plans federally regulated and exempt from state law
At least 1/3 children with flagged prescription profiles had utilization claims

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 MA: 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

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
- UMMMS-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

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