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 MassHealth Universal healthcare (2006)
96% insured/4% uninsured; however pockets (immigrants, minorities) of Cultural/linguistic gap:
Challenges with coordination of care
Incidence: 1 in 178 (2001); 1 in 108 (2005); 1 in 85 (2013);
Habilitative
MassHealth 2005: racial differences substantially lessened.
Home & Community
May reflect groups with greater barriers to early screening
Suggests screening improved among racial minorities
Shrinking racial gap:
Infants of mothers whose primary language was not English or were ARICA law (2011) applies to private, state
Average age of diagnosis for children in EI:

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

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, maternal & child 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

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

Wait Time Survey

<table>
<thead>
<tr>
<th>DBP Clinics (n=26)</th>
<th>Pediatricians (n=106)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Top reasons late referral:</td>
<td>Parents unaware of milestones/developmental delays (77%) Primary language not English (59%) Limited caregiver ability (55%) Non-English speaking patients: 25% = 81% 51-75% = 4% I have access to: Interpreters Cultural liaisons Bilingual providers I do not have access to language services: 35%</td>
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<td>&gt;1 to 6 mos. (median 3 mos.) Lower SES (44%) &gt;1 to over 12 mos. (median 5 mos.) Lower SES (60%) &gt;1 to 9 mos. (median 3 mos.)</td>
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</tbody>
</table>
| Insurance Utilization: | Universal healthcare (2006) 96% insured/4% uninsured; however pockets (immigrants, minorities) of Cultural/linguistic gap:
Challenges with coordination of care
Incidence: 1 in 178 (2001); 1 in 108 (2005); 1 in 85 (2013);
Habilitative
MassHealth 2005: racial differences substantially lessened.
Home & Community
May reflect groups with greater barriers to early screening
Suggests screening improved among racial minorities
Shrinking racial gap:
Infants of mothers whose primary language was not English or were ARICA law (2011) applies to private, state
Average age of diagnosis for children in EI:

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-CSCN, 2010)
<table>
<thead>
<tr>
<th>MA % or #</th>
<th>U.S. % or #</th>
</tr>
</thead>
<tbody>
<tr>
<td>YSHCN who received services to transition</td>
<td>47%</td>
</tr>
<tr>
<td>Hispanic</td>
<td>35%</td>
</tr>
<tr>
<td>Black, non-Hispanic</td>
<td>20%</td>
</tr>
<tr>
<td>Other, non-Hispanic</td>
<td>35%</td>
</tr>
<tr>
<td>White, non-Hispanic</td>
<td>51%</td>
</tr>
</tbody>
</table>

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

“60% of the IEP’s I need appear to have been translated by Google Translate. The translation is not good or very clear.”

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

“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.”

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

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%.”

In Their Own Words

“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%.”

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