



# Elaine Gabovitch Massachusetts



# Massachusetts overview

- 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
- 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%)
  - 38-50% of children on MassHealth (Medicaid)
- 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

\*U.S. Census (2010) [www.quickfacts.census.gov](http://www.quickfacts.census.gov)

\*\*Annie E. Casey Foundation Kids Count Data Center based on 2011 U.S. Census data

\*\*\*National Survey of Children's with Special Health Care Needs (NSCSHCN) 2009-10



# Massachusetts Act Early state team

- Est. April 2010
- 40 - 60+ state team members represent parents, health care organizations, public health, early education, elementary and secondary education, disability agencies, family support agencies, advocacy groups, UCEDDs & LENDs, and research centers
- Made up of executive steering committee, 3 task forces, and 3 grant project teams to date
- Steering committee meets quarterly
- State team meets twice per year at bi-annual summit meetings



# Massachusetts vision & mission

**\* Screening early \* Screen often \* Screen all \***

- **Vision**

*The Massachusetts Act Early Coalition works to strengthen state and community systems for the early identification and intervention for children with signs of developmental disabilities, such as autism spectrum disorders. The coalition envisions a future that uses a family-centered model that overcomes geographic, socioeconomic, cultural, and linguistic barriers to assure equal access to developmental screening for all children in the Commonwealth.*

- **Mission**

*Massachusetts Act Early aims to educate parents and professionals about healthy childhood development, early warning signs of developmental disorders including autism spectrum disorder, the importance of routine developmental screening, and timely early intervention whenever there is a concern.*



# Massachusetts goals

1. Conduct outreach to parents and providers to increase public awareness of healthy developmental milestones, as well as signs of developmental disorders including autism spectrum disorder
2. Increase training for health care, early childhood, and elementary educational professionals
3. Shorten the wait times between screening and diagnosis as well as diagnosis and intervention
4. Develop culturally competent autism screening materials and training curricula for early childhood and elementary educators, clinicians, community health centers and pediatric practices



# System Components

- Developmental & autism screening in MA
  - Children’s Behavioral Health Initiative (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
  - Manning et al. study (2011)
    - Incidence of ASD: 1 in 178 (2001) ; 1 in 108 (2005); 1 in 85 (2013)
    - Average age of diagnosis for children in EI: 2.56 years old
    - Primary language not English or foreign-born: Lower odds of early ASD diagnosis; may reflect groups with greater barriers to screening
  - Children under age 6 ever received developmental screen = 199,848 (53%) (NSCH 2011-2012)
- Referral and response to referral
  - Pediatric Provider Survey (2014)
  - Diagnostic Wait Time Survey (2015)
  - EI eligibility – medical diagnosis, team evaluation, or “at risk”



# Learning opportunities

- Hoping to learn from other states regarding:
  - Cultural/linguistic best practices
  - Outreach efforts
    - By region, culture, language, profession, etc.
  - Measurement
    - Data collection/monitoring
    - Screening, diagnosis, referral, wait times
  - Creating statewide infrastructure for referral networks

