Massachusetts Healthy People 2020 Autism Roadmap Report: Understanding Needs & Measuring Outcomes

Eunice Kennedy Shriver Center

University of Massachusetts Medical School

Fall 2016

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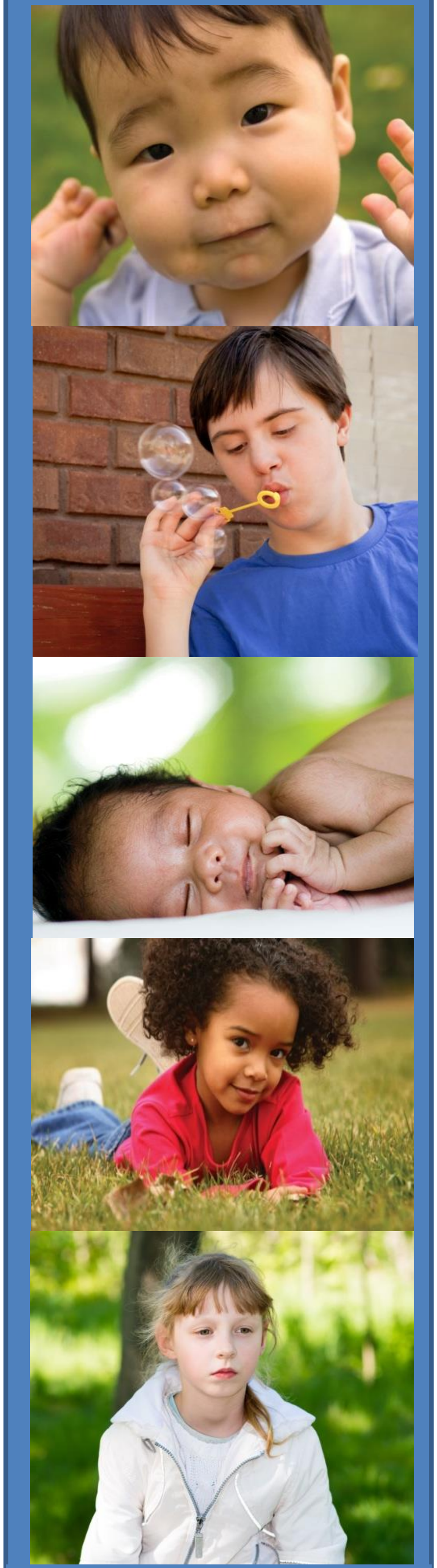

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Healthy People 2020 Roadmap Report for Massachusetts Children and Youth with ASD/DD

Understanding Needs and Measuring Outcomes

Fall 2016

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EXECUTIVE SUMMARY

BACKGROUND. In 2013, the Massachusetts Governor's Special Commission Relative to Autism ("Autism Commission") issued a landmark report that determined in spite of Massachusetts' national leadership on a host of autism issues, gaps in services and supports still persist in the state and that "there is a critical need to develop a comprehensive statewide approach that will respond to the needs of this rapidly increasing population." One major priority called to "determine the number of people with autism in Massachusetts and their support needs by implementing a plan for consistent statewide data collection."[1]

In response, the University of Massachusetts Medical School-Eunice Kennedy Shriver Center (UMMS-EKS) obtained grant funding from the Health Resources & Services Administration-Maternal & Child Health Bureau (HRSA-MCHB) to conduct a state autism needs assessment from September 2013 through October 2016. Members of the project team represent the Shriver Center Leadership Education in Neurodevelopmental and Related Disabilities (LEND) program, the Massachusetts Act Early program, and the Center for Developmental Disabilities Evaluation and Research (CDDER). To conduct the needs assessment, the project team used the framework of the six "Healthy People 2020" MCHB core outcome indicators for children and youth with special health care needs (CYSHCN) as well as additional supplemental indicators with a special focus on Massachusetts children and youth with autism spectrum disorder and other developmental disorders (ASD/DD).

PURPOSE. This report shares our needs assessment findings to assist the Massachusetts Autism Commission in developing a blueprint for better data collection across the system of care that serves children and youth with ASD/DD and their families in Massachusetts. We provide potential sources of and recommendations for both public and private data collection within the state that can be considered by the Commission and its subcommittees and built upon and monitored by appropriate stakeholder entities. We also offer future possibilities that may need more development and surveillance and resources that may help.

Our three project goals included:

1.) Assess and quantify baseline data for the state needs of children and youth with autism and developmental disabilities aligned with six MCHB core outcome indicators;
2.) Make recommendations to address needs identified from the needs assessment; and
3.) Offer comprehensive and strategic surveillance recommendations to monitor and report on future state autism/DD activities and outcomes.

The six MCHB core outcome indicators are: Early Identification, the Medical Home, Access to Care, Family Involvement, Transition to Adulthood, and Insurance. In addition, we have added three related topic sections to the report: Education, Housing and Cultural Considerations. Within each of the six MCHB core outcome indicator topics, this report will focus on several factors for underserved children and youth: race, culture, language, immigrant status, region, level of function, and mental health.

METHODS. The needs assessment sought to identify, understand and gather existing quantitative and qualitative data from a variety of sources across the state. To assist with these activities, the project team convened the broad leadership of a coalition of Massachusetts autism and

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[1] Massachusetts Autism Commission (March 2013). *Report of the Massachusetts Special Commission Relative to Autism*, page 8. http://www.mass.gov/anf/docs/mddc/autism-commission-report-full.pdf

developmental disabilities stakeholders to meet quarterly as our project advisory board through all aspects of the planning, review and report writing process.

> **QUANTITATIVE INFORMATION.** Over the 3-year period, we conducted over 50 key informant interviews with agency representatives from the project advisory board, state agency data managers, community organization directors, and other content experts to determine which organizations collect specified quantitative data by indicator and the availability of their data sets. We gathered and analyzed quantitative data from national surveys, local surveys, and aggregated state reports. We conducted our own online *Wait Time Survey* (January 2015) to better understand the length of diagnostic clinic waiting lists for full evaluation. Quantitative data were assessed via descriptive statistics.
>
> **QUALITATIVE INFORMATION.** Twelve, 90-minute focus groups totaling 78 participants were conducted across the five regions of the state. Some focus groups were targeted to providers and/or parent leaders representing health care, early intervention, early education, school systems, and transitional services. Others were targeted to family members from a variety of backgrounds and ethnicities. We conducted five interviews with autistic adult self-advocates to complete the lived perspectives shared. The qualitative perspectives were purposefully gathered through a variety of methods, from a variety of stakeholders including both self-advocates and key informants varying across role, geography and culture.
>
> **DISSEMINATION.** We have disseminated our work-in-progress through local presentations at our quarterly project advisory board meetings; through presentations and posters at national conferences, meetings and symposia. Final dissemination of our work includes distributing this report to our Project Advisory Board, the Data Subcommittee of the Massachusetts Autism Commission, and ultimately to the entire Massachusetts Autism Commission for their use. We will post the final report online for public information as well.

LIMITATIONS. Although this report provides a comprehensive array of available data found in national surveys, research studies, state and local records, reports and surveys that address our six core outcome indicators and supplemental categories, it is restricted by the paucity of national and state information on certain topics. The data sources we used to produce the report could hold promise for future monitoring, however much of the data available through national surveys did not have sample sizes large enough to provide reliable results and would require larger data sets and more funding to provide statistically significant data findings in the future. We still don't have answers to many essential questions – particularly about access to community-based systems of care; workforce capacity and state infrastructure; racial, cultural, linguistic and regional disparities; and transition to adult life, including health care transition. Based on this, this report is a first step, but not a final destination.

This report offers baseline information in a structured, accessible format. Our compilation of available Healthy People 2020 indicators for children and youth with ASD/DD in Massachusetts represents a critical step forward in establishing what we know, and what we need to know, to improve the quality of life for children and youth with ASD/DD in Massachusetts. Our hope is that our report's recommendations will be useful to the Massachusetts Autism Commission when moving forward with future policies, practices or legislation that might address and monitor the needs of children and youth with autism and developmental disabilities and their families in the state.

Selected Findings and Recommendations

Several consistent themes emerged as major gaps in our state ASD infrastructure and identifying the data sources most needed to assist in filling these gaps. The main findings and gaps are presented here first, followed by recommendations for each core outcome indicator. More information is available in each of the related report sections. Major overarching report recommendations appear at the end of the Executive Summary.

Key Findings and Recommendations by Core Outcome Indicator

POPULATION & PREVALENCE DATA

The American Academy of Pediatrics (AAP) estimates that about one in six children in the U.S. (about 15%) has a developmental disability, ranging from mild disabilities such as speech and language impairments to serious developmental disabilities, such as intellectual disabilities, cerebral palsy, and autism. Similarly, national surveys estimate 17.3% of Massachusetts CSHCN between the ages of 2-17 have developmental delays. According to the most recent state data analyzed in 2016 by the Massachusetts Department of Public Health, the incidence rate for early ASD diagnoses (before the age of 36 months) is estimated at one in 70 children.

Population and prevalence data recommendations include:

1.) Propose Massachusetts to be a CDC ADDM network surveillance monitoring site, or consider similar methodology leveraging the state's advanced healthcare-related information sources.
2.) Monitor state data trends using future versions of the NSCH or develop a similar survey for Massachusetts.
3.) Share Massachusetts MCHB Core Outcome Indicator Data online.

EARLY IDENTIFICATION

The state of Massachusetts is ahead of most other states in the early identification of young children at risk for autism spectrum disorder (ASD) and other developmental disabilities. Recent historical events and changes in policy that may have influenced this outcome include the advent of the Children's Behavioral Health Initiative (CBHI), the MassHealth requirement for behavioral screening at all pediatric well-visits, and public awareness campaigns such as the CDC's "Learn the Signs. Act Early." campaign and the work of the Massachusetts Act Early state team, among other possibilities.

In spite of these encouraging local successes, both state and national data sources reveal remaining areas of need for developmental and autism screening, diagnosis and referral to interventions in Massachusetts. For example, an important knowledge gap still left to be determined is the average age at which developmental and autism screenings occur, the types of screenings conducted, and the average elapsed time from screening to diagnosis and from diagnosis to intervention. Massachusetts Department of Public Health (MDPH) study findings suggest that children from non-English-speaking families, foreign-born parents, or mothers under the age of 24 may have lower odds of early identification before the age of three. EI referral data indicate that there may be pockets of regional identification disparities in Western Massachusetts and the Southeast region including Cape Cod and the Islands, which is supported by focus group input.

Early identification data recommendations include:

1.) Set early identification targets and monitor progress on an annual basis.

2.) Examine methods used by MassHealth review studies for feasibility and possible replication.
3.) Use both Early Intervention data (Part C) and school data (Part B) to monitor early identification.
4.) Build and monitor early identification workforce capacity and development.
5.) Prioritize monitoring and addressing identified racial/ethnic disparities in early identification.

MEDICAL HOME

Considering the high level of medical needs for the population of Massachusetts children with ASD based on the prevalence of co-morbid health conditions affecting one's functional abilities, there is considerable need for medical homes to serve this population's needs. Most parents report having a usual source of care and a personal health care provider for their child, but few report receiving effective care coordination and family-centered care. With the large number of providers in the state, greater capacity is needed to serve this population well in dedicated, coordinated, ongoing, family-centered, culturally competent and comprehensive medical homes. Collecting medical home related data to understand and support workforce development and training, outreach and promotion of this important concept to practices in the state as part of medical home transformations, and monitoring progress appears to be a critical need.

In spite of the presence of patient-centered medical home demonstration projects across the country in recent years, such as the Children's Health Insurance Program Reauthorization Act (CHIPRA) initiative in Massachusetts, little is known about how medical homes fare when serving the state's CYSHCN with autism. National surveys provide only limited information based on small sample sizes. Innovative practices such as the use of family navigation projects and telehealth/telepractice to train and increase workforce capacity hold promise for providing greater access to family-centered, culturally-competent care coordination services for these children and youth, however they are limited as well.

Medical Home data recommendations include:

1.) Set medical home targets and monitor progress on an annual basis.
2.) Obtain a larger data sample related to the medical home needs of CYSHCN with ASD.
3.) Obtain data to measure and monitor in-hospital utilization trends.
4.) Build and monitor medical home workforce capacity and development.

ACCESS TO CARE

The core outcome indicator, Access to Community-Based Systems of Care, is one of the six indicators with the greatest level of need for CYSHCN with autism in Massachusetts.

Within the state, there are few quantitative measures that exist to substantiate the current status of criteria for an accessible community-based system of care. National surveys, while limited, indicate that when considering how accessible systems of care are for families who care for CYSHCN with autism compared to other CYSHCN, families of children with autism access fewer of the six core outcomes indicator domains within the health care system than other CYSHCN. Thus, the state's health care system is not achieving enough of the age-relevant core indicators needed for a high standard of care. Moreover, families also report experiencing some difficulty accessing specialty care, having a high need for mental health services, and experiencing personal hardships supporting their family members. Assessment within demographic or other subgroups of CSHCN with autism is critical to develop appropriate interventions and policy responses.

Discrete areas of need for access include diagnostic wait times for evaluation and referral to intervention, which fluctuate across the state. Special attention should be paid to building regional workforce capacity both for having enough specialists, as well as opening up better access for providers to accept MassHealth for those families who rely on it. Education and training as well as resource materials are needed to build parent awareness of the importance of monitoring developmental milestones and red flags, as well as PCP confidence in screening and referral practice. There is also a great need for strengthening cultural and linguistic competence among providers through workforce development. Massachusetts still does not have enough ABA therapists to meet the demand of families, limiting access to ABA services and raising concerns about network adequacy for autism treatment. Southern Massachusetts/Cape Cod and Western Massachusetts experience regional disparities because often families cannot access services locally and must take the time to travel to Boston. Many providers in these regions may not accept MassHealth locally, so families experience additional health care access-related disparities. Restrictions to access for families living in poverty are significant.

Access to Care data recommendations include:

1.) Obtain data to measure and monitor access to care.
2.) Obtain a larger data sample for national survey questions related to access to care for CYSHCN with autism.
3.) Set access to care targets and monitor progress on an annual basis.
4.) Build and monitor workforce capacity and development for access to community-based systems.
5.) Educate parents about navigating and accessing support systems.

FAMILY & SELF-ADVOCATE INVOLVEMENT

The principle "Nothing about us without us" should be rigorously applied without exception in including all those who have or care for someone with autism, be they self-advocates or family members. Massachusetts rates highly in this area when considering the many opportunities available for families to participate as advisors and experts on committees and task forces as well as family professional employees in human service organizations. Opportunities for autistic self-advocates are not as prevalent.

The national NS-CSHCN survey shows that the four components indicating whether providers meet the family involvement standard were likely to be met for all CSHCN with autism in Massachusetts (between 70-90% satisfaction) aligning closely with U.S. children with autism, as well as all CSHCN in Massachusetts and nationally. Nonetheless, family partnership for Massachusetts CSHCN with autism was still reported less often than CSHCN in general by about 10-20%, indicating improvement may be needed. More is needed to be known about this indicator in general.

Family & Self-Advocate Involvement data recommendations include:

1.) Set family involvement targets and monitor progress on an annual basis.
2.) Obtain a larger data sample related to national survey questions related to family involvement.
3.) Build and monitor family & self-advocate workforce capacity and development.

TRANSITION TO ADULT HEALTH CARE

While the 2013 Massachusetts Autism Commission Report prioritized transition age issues prominently in its examination and recommendations, health care transition was not included among the other categories of education, employment, independent living and self-determination. The health care transition core outcome indicator is an area of great need compared to other Healthy People 2020 goals for autistic youth with special health care needs (YSHCN) in Massachusetts. Targets for providing parents with guidance on what to anticipate in the transition to adult health care providers are not being met for autistic YSHCN in Massachusetts. It is an area of much needed change in health care for autistic YSHCN, just only in Massachusetts but across the country and provides an opportunity to gather data and monitor progress in the future.

Among focus group participants, medical providers expressed great hesitance when working with transition age patients with autism. When asked about their greatest health care needs, self-advocates identified navigating the adult health care system as a top concern. Issues of sexuality, gender and sexual identity also arose as areas of particular importance. Communication and independence in working with providers were also raised as needs.

Thus, this report attempts to fill in some of the unknowns on this important topic for autistic youth and yet, there is still much to be understood about this particular area for youth.

Transition to Adult Health Care data recommendations include:

1.) Set health care transition targets and monitor progress on an annual basis.
2.) Obtain a larger data sample for national survey questions related to health care transition for autistic YSHCN.
3.) Build and monitor workforce capacity and development for health care transition.
4.) Educate transition age youth and families about health care transition.
5.) Increase efforts to support and incentivize adult health care providers to accept young adults as patients. Consider efforts to track provider network capacity for adults with developmental and intellectual disabilities.
6.) Improve long-term planning for health care transition and the use of evidence-based guides and models.

TRANSITION TO ADULT LIFE

While there are no MCHB core outcome indicators transitioning to adult life separate from health care, it is an equally important area for which to set goals, establish baseline data, and conduct ongoing monitoring to measure progress. Little is known about this particular indicator in the state, leaving much room for future investigation and monitoring. Similar to the Access to Care indicator, Transition to Adult Life is one of the areas in this report showing the greatest level of need for YSHCN with autism in Massachusetts.

Due to new collaborative efforts between state agencies that serve autistic young adults based on the legislative change prompted by the Autism Omnibus Bill of 2014, there is hopeful progress being made that is still in need of published target goals and outcomes. More evidence-based practices are needed in supporting autistic people, and additional service model options. Workforce development and capacity building are needed to help more professionals understand how to support and include this community in transitioning from secondary to post-secondary life accessing the full complement of educational supports, accessing adult services, gaining job experience and employment, staying safe when interacting with law enforcement, and living high quality adult lives in general. For those systems that fall outside of state government or that present challenges with tracking adult activities such as higher education, there is no consistent way to measure and monitor outcomes for this population. Autistic adult self-advocates describe needs with employment, executive function, learning to self-advocate, and navigating the adult service system as high priorities.

Transition to Adult Life data recommendations include:

1.) Set transition to adulthood targets and monitor progress on an annual basis.
2.) Use emerging state electronic data resources and other models to gather more information about transition to adulthood for autistic youth.
3.) Build and monitor workforce capacity and development for transition to adult life.
4.) Educate youth and parents about transition to adult life.
5.) Form a statewide transition coalition to minimize silos between services and to foster a learning community to improve services.

INSURANCE

The most recently-available national survey findings preceded changes to insurance coverage for autism in Massachusetts including Act Relative to Insurance Covering Autism (ARICA) and expansion of coverage of autism treatment services under MassHealth. Questions about the ability to see needed providers compared to other CSHCN and to estimate out-of-pocket costs for families of children with autism are important to monitor and understand subsequent to local policy changes. Importantly, there is a need to understand the percentage of children with autism not covered under ARICA or by MassHealth, but by self-funded health insurance plans which are not mandated to cover autism treatment services. This subset could experience significant insurance disparities that are worth further investigation. Although the small sample sizes preclude using national survey data for meaningful conclusions, these surveys could be the source of helpful information if sample sizes were larger.

More information is needed regarding network adequacy for various specialties within various types of insurance coverage, particularly with the expanded efforts for purchase of health insurance through the health exchanges, and as some insurers transition to managed care and other new models. Particularly, some of the network adequacy measures required of insurers, for example those specified by federal guidance for Medicaid managed care models[2], may be insufficient if they do not specifically consider the needs of children with special health care needs like autism. Specifically, more information is needed regarding network adequacy for children on Medicaid in remote areas or in areas with a high proportion, and particularly for specialists.

There have been numerous recent policy changes in the state related to insurance coverage in general, and specifically for children with autism. These represent important opportunities for the state to measure their impact for children with autism in the state to ensure they are functioning as intended, are adequately addressing identified or known gaps, and do not have other unintended consequences. The measures discussed in this section are only able to inform a portion of the insurance-related experiences necessary to inform these questions.

Insurance data recommendations include:

1.) Set insurance targets and monitor progress on an annual basis.
2.) Leverage existing electronic resources and/or obtain a data sample related to insurance coverage and network adequacy.
3.) Build and monitor workforce capacity and development for insurance.

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[2] Centers for Medicare & Medicaid Services (CMS), Medicaid and CHIP Managed Care Final Rule, April 25, 2016, https://www.medicaid.gov/medicaid/managed-care/guidance/index.html#

EDUCATION

In almost every focus group, education was one of the first topics that participants brought up and spoke passionately about – sometimes as soon as in the opening introductions. Most of the concerns came from the multicultural focus groups.

One of the most common educational themes was around language and translation. Many participants expressed a need for appropriate translation of educational documents, such as Individualized Education Programs (IEPs) and progress reports by skilled professional bicultural, bilingual translators as well as language interpretation also needed by interpreters with the same skills and backgrounds. Families requested that they receive many more materials in their languages than just the IEP and progress reports, but also daily communication notes.

The education and transition planning that youth receive in preparation for adult life begins in high school, but needs to continue through the 18-22 year old period. Adequate and high quality job training and skill building are needed. Unfortunately, these needs are highly variable and individual. Service availability and quality appear to vary across school districts, presenting an opportunity for promising models to be shared across districts.

At the systems level, sharing data systems with the education system was also an area of need between state agencies.

Education data recommendations include:

1.) Set education targets and monitor progress on an annual basis.
2.) Measure, monitor and address cultural equity for translated special education documents and communications with families.

HOUSING & HOMELESSNESS

For autistic youth, transition age is a critical developmental stage for executive function, which governs one's ability to "plan, organize, strategize, pay attention to and remember details, and manage time and space". Many experience executive functioning challenges for their entire lives. When applied to seeking housing, it can compound their ability to overcome homelessness. The implications include such risks as dropping out of high school or college, mental illness, sexual exploitation, chronic adult homelessness, and death. More state data is needed to be measured and monitored for the status of housing and homelessness for transition age youth and young adults with autism.

Housing & homelessness data recommendations include:

1.) Set housing and homelessness targets and monitor progress on an annual basis.
2.) Build and monitor workforce capacity and development.
3.) Consider researching and investing in promising new housing models for families of children of youth with autism, as well as adults with autism.

CULTURAL CONSIDERATIONS

There were a number of common themes that emerged in cultural focus groups. Four predominant themes included: the need for services, community blame and stigma, families' lack of knowledge, and the importance of trusted providers. Family members from the same culture also expressed a number of culture-specific needs. The most common categories of disparities included: early identification, access to community-based services, language and cultural barriers in communicating with schools, as well as high quality interpreters, home-based services and bi-lingual, bi-cultural professionals.

Predominant expressed needs included: information given to parents in their language at the time of diagnosis; services for high-functioning children with autism, especially in non-white cultures; social skills training for parents on how to help their children with autism; school advocates who speak their language/know their culture; and basic training on autism for parents new to the system but also more advanced training on subjects such as educational rights for more experienced parents.

Cultural considerations for data recommendations include:

1.) Set targets for reduction of cultural disparities and monitor progress on an annual basis.
2.) Build and monitor workforce capacity and development.
3.) Address related issues for cultural and linguistic access.

Overarching Recommendations

Certain recommendations cut across several of the core outcome indicators. The following represent the main recommendations of this report based on the needs shared in each of the report sections:

1.) Set targets and monitor progress for Healthy People 2020 indicators and other topics that do not have indicators.

2.) Obtain large data samples to better understand needs and inform policy and resource planning needs.
    a. Consider either supporting oversampling within national surveys for Massachusetts or conducting a similar survey in the state
    b. Leverage existing and emerging electronic data resources in the state
    c. Investigate linking state databases, particularly emerging ones

3.) Build and monitor workforce capacity, training and development.
    a. Monitor the number of pediatric and specialty physicians in the state for capacity building
    b. Invest in workforce development to increase the number of trained professionals across indicators

4.) Prioritize understanding racial, cultural and regional disparities.

5.) Share Massachusetts MCHB Core Outcome Indicator Data online with the public.

6.) Employ innovative practices to approaching data collection and analysis.
    a. Fully engage community organizations, families and self-advocates
    b. Review the intersection of government and university research
    c. Invite other states to share promising practices
    d. Conduct focus groups to monitor public response

OVERVIEW

Background

National survey data on the six "Healthy People 2020" Maternal and Child Health Bureau (MCHB) core outcome indicators for children and youth with special health care needs (CYSHCN) indicate that Massachusetts is meeting many of its objectives. Yet for Massachusetts' children and youth with autism and other developmental disabilities, there are still many perceived disparities by race, ethnicity, language, income level and region.

In 2013, the Massachusetts Governor's Special Commission Relative to Autism ("Autism Commission") issued a landmark report that determined in spite of Massachusetts' national leadership on a host of autism issues, gaps in services and supports still persist in the state and that "there is a critical need to develop a comprehensive statewide approach that will respond to the needs of this rapidly increasing population."[3] One major priority called to "determine the number of people with autism in Massachusetts and their support needs by implementing a plan for consistent statewide data collection."[3]

In response, the University of Massachusetts Medical School-Eunice Kennedy Shriver Center (UMMS-EKS) proposed a project to the Health Resources & Services Administration-Maternal & Child Heath Bureau (HRSA-MCHB) entitled *The Healthy People 2020 Roadmap for Massachusetts Children and Youth with ASD/DD: Understanding Needs and Measuring Outcomes.* As a result, Massachusetts was one of four other states awarded "state autism planning grants" by HRSA-MCHB including Kansas, New Hampshire and Texas.

From September 2013 through October 2016, the UMMS-EKS project team conducted a state autism needs assessment in line with HRSA-MCHB's funding priorities, in an attempt to contribute to the Massachusetts Autism Commission's data collection objectives. The UMMS-EKS project team includes members from the Eunice Kennedy Shriver Center Leadership Education in Neurodevelopmental and Related Disabilities (LEND) program, the Massachusetts Act Early program and the Center for Developmental Disabilities Evaluation and Research (CDDER),

The purpose of this report is to create a blueprint for better data collection of existing services and supports for children and youth with autism spectrum disorder and other developmental disabilities (ASD/DD) for systems of care in Massachusetts. We provide potential sources of and recommendations for data collection within the state both public and private that can be built upon and monitored, as well as future possibilities that may need more development and surveillance.

Our three project goals include the following:

1.) Assess and quantify baseline data for the state needs of children and youth with autism and developmental disabilities aligned with six MCHB core outcome indicators;
2.) Make recommendations to address needs identified from the needs assessment; and
3.) Offer comprehensive and strategic surveillance recommendations to monitor and report on future state autism/DD activities and outcomes.

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[3] Massachusetts Autism Commission (March 2013). *Report of the Massachusetts Special Commission Relative to Autism*, page 8. http://www.mass.gov/anf/docs/mddc/autism-commission-report-full.pdf

The following six MCHB core outcome indicators served as the framework to define the project's needs assessment, determine the plan, and measure the known outcomes in the following domains for children and youth with ASD and DD. We have dedicated separate sections to each topic. In addition, we have added three related topic sections to the report: Education, Housing and Cultural Considerations. Within each of the six MCHB core outcome indicator topics, this report will focus on several factors for underserved children and youth: race, culture, language, immigrant status, region, level of function, and mental health.

Healthy People 2020 Six Core Outcome Indicators

1.) Screening leading to early identification and intervention
2.) Culturally competent, family-centered medical homes
3.) Accessible community-based service systems
4.) Family involvement
5.) Transition to adult services including health care
6.) Insurance/financing of needed services

Many of the MCHB core indicators intersect with the priorities set in the *2013 Massachusetts Autism Commission Report*. We have attempted to address these core indicators in tandem with the Commission's priorities, wherever possible. Thus, within several of the report's sections, reference will be made to Commission findings, activities and plans that have occurred since the 2013 report.

Our hope is that this report will serve as a launch pad to identify areas of gaps and needs across the state for further investigation and action. As such, the report is comprehensive but not complete. It is meant to be used as a tool by the Massachusetts Autism Commission, its Data Subcommittee and the public for further investigation and integration of state-based data sources presented herein and to help set future policy for monitoring of state autism services and supports. Lastly, it should be mentioned that charting known baselines will set the foundation for setting informed goals and monitoring and evaluating real outcomes in a systematic approach.

The Critical Use of Language

Approximately one out of five adults in the U.S. lives with some type of disability. At minimum, there are 53 million individuals each with their separate perspectives and preferences about how disability impacts their lives. Perhaps nowhere is this more immediately recognizable than in the use of language. Language not only is important – it is critical – because it reveals and shapes our values and beliefs.

Our readers represent countless diverse perspectives when it comes to the topics of language, disability and identity. Some are "autistic" adults, some are family members of children and youth "with autism", some work in human services, education and other fields that deliver services and supports to the "autism community," and some are health care and public health professionals where the term "autism spectrum disorder" or "ASD" signifies specific diagnostic criteria that charts the path to identification and treatment. We respect and uphold these diverse perspectives to the best of our abilities in this report. To this end wherever possible, the report will alternate between the use of "identity-first" and "person-first" language, as well as alternate where appropriate between the use of the diagnostic term "autism spectrum disorder" (ASD) and the simple and descriptive term "autism."

The Language of Identity

"Identity-first" language is based around the idea that an individual's disability is intrinsic to their self-concept and should be used out of respect to the person. Examples would be the phrases "disabled people," "deaf or blind people," or "autistics."

"Person-first" language aims to ensure that individuals are not solely or immediately identified by their functional limitations but rather seen as a person first who happens to have a disability or neurological difference. Examples would be the phrases "children with autism" or being "on the autism spectrum."

The Language of Neurodiversity

There is a growing controversy related to the popular use of diagnostic labels that describe autism. The fifth edition of the *Diagnostic & Statistical Manual of Mental Disorders* (DSM-5) published by the American Psychological Association (APA) sets the diagnostic criteria for "autism spectrum disorder" (ASD) used mostly by clinical, health care and public health professionals. The DSM has been updated several times over the last few decades to reflect new research and ongoing practice. The criteria were changed to improve the accuracy of the diagnoses and to allow clinicians the ability to describe specific symptoms seen in individuals. It also provides insurers with the technical terminology to approve coverage for diagnosis and treatment. It may also be used for population data to assist with the measurement of planning, implementation or progress monitoring efforts.

For many autistic adults, however, the term "ASD" holds a pathologizing meaning. An autistic key informant stated, "Most autistic adults see autism as a difference, not as a disorder or a deficiency of any kind. Language such as that which appears in the DSM is completely rejected. In fact, many would go so far as to say that autism has no place in the DSM; that it is not a mental disorder, any more than is homosexuality (a condition that, not too many years ago, was also in the DSM)."

Journalist Steve Silberman, the author of the book *NeuroTribes: The Legacy of Autism and the Future of Neurodiversity* states, "Autism is a natural form of human neurodiversity. Labeling it as a "mental disorder" or a "disease" has no scientific basis, has no benefit for Autistic people or their families, and leads inevitably to stigmatization, shame, and marginalization. Blind people, Deaf people, and many other disabled people get the services and accommodations they need without being labeled as having mental disorders. We don't have to call autism a disorder or a disease to acknowledge that Autistic people are disabled and can require accommodations. Stop worrying about the latest changes to the DSM's diagnostic criteria, and just remove autism from the DSM entirely, just like homosexuality was rightly removed years ago."

For the purposes of this report, we will use identity-first language in sections related to transition age and adult topics. We will use person-first language in sections related to children and youth. We will use the term "autism spectrum disorder" or ASD whenever related to medical, public health, or insurance-related topics in the sections for which the technical or diagnostic term has a specific meaning or when quoting other sources who have used the term. We will simply use "autism" or "autistic" in the sections related to non-technical topics such as community and adult life.

The bottom line is that this report supports the principle that people are entitled to choose their own labels. Such diversity is a vital reminder of how important it is for everyone, regardless of ability or disability, to make sure their preference is understood and respected. It is our attempt and desire in this report to honor these preferences.

Understanding Healthy People 2020 and Outcome Indicators for CYSHCN

Children and youth with special health care needs (CSHCN or CYSHCN) are defined by the U.S. Department of Health and Human Services (HHS), Health Resources & Services Administration (HRSA), Maternal and Child Health Bureau (MCHB) as:

> *"...those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally."*[4]

This definition is broad and inclusive, and it emphasizes the characteristics held in common by children with a wide range of conditions. Since 1989, the goal of the State Title V programs for CSHCN has been to provide and promote family-centered, community-based, coordinated care for CSHCN and to facilitate the development of community-based systems of services for such children and their families.[4] The long-term outcome of such systems development is that all families are able to access health and related services along the continuum of care in a manner that is both affordable and meets their needs; policies and programs are in place to guarantee that children have access to quality health care; providers are adequately trained; financing issues are equitably addressed; and families play a pivotal role in how services are provided to their children.

A long-term national goal was first articulated in *Healthy People 2000: National Health Promotion and Disease Prevention Objectives*:

> *"Increase the proportion of states and territories that have service systems for children with or at risk for chronic and disabling conditions as required by Public Law 101-239."*

The MCHB, together with its partners, has identified core outcomes for the community-based system of services required for all CSHCN under Title V, under Healthy People 2000, and reiterated under Healthy People 2010 and Healthy People 2020. These outcomes provide a concrete way to measure progress in making family-centered care a reality and in putting in place the kind of systems all CSHCN deserve. According to MCHB, progress toward the overall goal can be measured using these six critical indicators:

1.) *Children are screened early and continuously for special health care needs;*
2.) *CSHCN receive coordinated, ongoing, comprehensive care within a medical home;*
3.) *Community-based services are organized so families can use them easily;*
4.) *Families of CSHCN partner in decision-making regarding their child's health;*
5.) *Youth with special health care needs receive the services necessary to make transitions to adult health care.*
6.) *Families of CSHCN have adequate private and/or public insurance to pay for needed services.*

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[4] http://mchb.hrsa.gov/cshcn0910/core/co.html

Thus, each report section herein will provide Maternal, Infant & Child Health (MICH) goals and targets based on the above six indicators for the United States. Providing these tables will show opportunities for goal-setting, data capture and surveillance in Massachusetts in the future.

Throughout this report among other national reports presented, we will share key national data outcome measures published by the national *Child and Adolescent Health Measurement Initiative (CAHMI)*. [5] Established in 1998, CAHMI's primary focus is to advance patient-centered child health and health care quality measurement and improvement. The two main CAHMI surveys featured in this report are the *National Survey of Children's Health* (NSCH) and *the National Survey of Children with Special Health Care Needs* (NS-CSHCN). National, state, and regional data findings from the NSCH and the NS-CSHCN can be found at the Data Resource Center for Child & Adolescent Health (DRC), an online resource that provides access to data findings from large population-based surveys of parents reporting on the health care needs of their children. Both studies were led by the National Center for Health Statistics at the Centers for Disease Control under the direction and sponsorship of the federal Maternal and Child Health Bureau (MCHB).[6]

The sampling and data collection for the National Survey of Children's Health and the National Survey of Children with Special Health Care Needs are conducted by the State and Local Area Integrated Telephone Survey (SLAITS). The National Center for Health Statistics developed this approach to quickly and consistently collect information on a variety of health topics at the state and local levels. Other national surveys that collect through the SLAITS program include the *2011 Survey of Pathways to Diagnosis and Services*, a regional survey for children and youth with autism, the *National Immunization Survey*, and the *National Survey of Early Childhood Health*.

The NSCH provides nationally representative data on various aspects of children's lives including the medical home, access to quality health care, and the child's family, neighborhood, school, and social context. It was conducted three times: 2003, 2007, and 2011-12. The population sampled included non-institutionalized children in the US ages 0-17 years which are weighted to represent U.S. children overall.

The NS-CSHCN provides a consistent source of both national- and state-level data on the size and characteristics of the population of CSHCN. This survey provides information on the prevalence of CSHCN in the nation and in each state, the demographic characteristics of these children, the overall health and health status of CSHCN, including medical home, adequate health insurance, access to needed services, and adequate care coordination. Other topics include functional difficulties, transition services, and shared decision-making. It was conducted three times between 2001, 2005-2006 and 2009-2010. The population sampled represented non-institutionalized CSHCN in the U.S. ages 0-17 years which were also weighted to represent U.S. CSHCN overall.

Going forward, CAMHI will integrate the NS-CSHCN survey into the NSCH. The combined survey is currently being conducted again by the Census Bureau in 2016, with initial data expected in 2017 and then will be conducted annually in the future. The NSCH will update and publish U.S. outcomes annually and state outcomes every two years.

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[5] http://www.cahmi.org/resources/researchers-and-educators/

[6] U.S. Health & Human Services, Health Resources & Services Administration, Maternal & Child Health Bureau (HRSA-MCHB) (n.d.). http://mchb.hrsa.gov/

For the purposes of this report, we have focused on those CYSHCN with autism and other developmental disorders living in Massachusetts as a subset of the larger categories of children represented within these two reports.

CAHMI SURVEY DATA LIMITATIONS. The NSCH reports its national and state-based results based on all children 2-17 years while the NS-CSHCN report is based on a subpopulation of CYSHCN in the same age group. It is important to note that both surveys represent small sample sizes of children with autism in Massachusetts: 31 and 74 respectively in the latest surveys available. Due to these low numbers, the surveys do not have much statistical power to estimate differences in outcomes for children with autism compared to other children. Small sample sizes for subgroups like children with autism generally only permit these surveys to estimate outcomes within a broad range. Therefore, it is important for the reader to consider the 95% confidence interval ranges when interpreting the results. The 95% confidence interval is a range within which the "true" level of a particular outcome is likely to lie. We will present these ranges through the report, as well as weighted population estimates. Comparing these state findings to national trends may assist in seeing patterns worth consideration.

In addition, these surveys are based on parent report and, as such, do not represent findings based on objective diagnostic information. Please consider these limitations when reading the national survey data in each section.

METHODS

As previously described, the *Massachusetts Healthy People 2020 Autism Roadmap* needs assessment project included the following:

1.) Assess and quantify baseline data for the state needs of children and youth with autism and developmental disabilities aligned with six MCHB core outcome indicators;
2.) Make recommendations to address needs identified from the needs assessment; and
3.) Offer comprehensive and strategic surveillance recommendations to monitor and report on future state autism/DD activities and outcomes.

Our data collection goals and analysis methods are described below.

Goal 1. Conduct the needs assessment using the six MCHB core indicators.

The needs assessment was conducted in two phases: an exploration phase and an analysis phase.

Exploration phase

The project's exploration phase sought to identify, understand and gather existing quantitative and qualitative data from a variety of sources across the state. To assist with these activities, the project team convened the leadership of a broad coalition of Massachusetts autism and developmental disabilities stakeholders to meet quarterly as our project advisory board through all aspects of the planning and review process from September 2013 through October 2016. The advisory board included state agency representatives, members of the Massachusetts Act Early state team, family and community-based organizations, autistic self-advocates, multidisciplinary providers, university research faculty and many others from all regions across the state.

With the advisory board's input, we presented the six indicators and relevant Commission recommendations, determined project feasibility, prioritized identified needs and sources, allocated resources, and approved and operationalized our process. We asked the board to assess the team's approach at the end of each meeting using an evaluation questionnaire to provide ongoing anonymous feedback so that we could make adjustments to the project over the course of the three-year period.

Quantitative Approach

IDENTIFYING DATA SOURCES. Over the 3-year period, we conducted over 50 key informant interviews with agency representatives from the project advisory board, state agency data managers, community organization directors, and other content experts to determine which organizations collect specified data by indicator and the availability of their data sets. Based on this information, we distributed a project "fact sheet" for key informants (see Appendix) to explain the project and the intent of our data requests as well as to seek their agreement to share their data sets with us for abstraction. We were able to obtain participation only from select state agencies whose data are shared in the report. Additionally, some state agencies that did not have data to contribute did inform state context and planned activities included in the report.

QUANTITATIVE DATA. Most of the quantitative data in the following report come from national surveys, local surveys, and aggregated reports.

QUANTITATIVE SURVEY. We conducted our own *Wait Time Survey* (January 2015) to better understand the length of diagnostic clinic waiting lists for full evaluation. We reviewed the draft with the project advisory board and with members of the Massachusetts Chapter of the American Academy of Pediatrics (MCAAP) for their feedback. We conducted the survey online. To poll diagnostic clinics, we compiled a list of medical centers and contact information from the Massachusetts Act Early state team files as well as with the help of our project advisory board. Via direct email contact, we invited administrators and division chiefs from medical centers and clinics across Massachusetts to complete the survey by providing them with a link to the online survey tool. Highlights are shared in the section on an "Accessible Community-Based Service System" (Access section).

Qualitative Approach

QUALITATIVE KEY INFORMANT INTERVIEWS. We conducted semi-structured key informant interviews by telephone and in person with organizational, family and self-advocacy leaders from across the state throughout the exploratory phase. In addition to providing leads to data sources, these key informants helped us better understand the work being done in the field, learn about plans on the horizon for new and better data management (e.g., new shared databases between agencies and pending memoranda of understanding for data sharing across agencies), and obtain key reports, community agency survey data and other useful information shared in this report. They provided insights into the "state of the state" for the six core outcome indicator topics under review, as well as the three supplemental topics. They also facilitated our connection to other potential informants.

QUALITATIVE FOCUS GROUPS. A major source of information and insights for this report came from qualitative focus groups. Twelve, 90-minute focus groups with 78 participants in total were conducted across the five regions of the state (see Access section for Massachusetts state map broken into five corresponding regions) between March 20, 2015 and December 5, 2015. Some focus groups were targeted to providers and/or parent leaders representing health care, early intervention, early education, school systems, and transitional services. Others were targeted to family members from a variety of backgrounds and ethnicities. Parents of children or youth with autism and/or developmental disabilities were recruited through existing community networks and paid a stipend for their time. Focus groups were led by an experienced facilitator, an assistant facilitator and a note-taker. Questions were translated and shared in advance with culturally diverse groups and culturally/linguistically competent interpreters were used in each group. Focus group notes were transcribed verbatim and themes were analyzed using Atlas TI qualitative software. Notes were coded according to primary questions and then sub-divided into secondary and tertiary thematic categories.

Table M-1. List of Focus Groups by Type by Date

Participant Group	Number of Participants	Location	Date
Hispanic Parents	6	Lawrence/Northeast Region	March 20, 2015
African-American Parents	4	Springfield/Western Region	April 8, 2015
Early Identification Professionals	8	Western Region	April 9, 2015
Community Health Center Medical Professionals	11	Metro Boston Region	April 23, 2015
Parent Leaders	3	Metro Boston Region	May 10, 2015
Transition Professionals	9	Metro Boston Region	May 11, 2015
Parent Leaders	3	Metro Boston Region	May 27, 2015
Vietnamese Parents	10	Metro Boston Region	July 1, 2015
Community Services Professionals	11	Southeast/Cape Cod Region	July 28, 2015
Hispanic Parents	5	East Boston/ Metro Boston Region	November 13, 2015
Chinese Parents	5	Metro Boston Region	November 21, 2015
Haitian Parents	3	Metro Boston Region	December 5, 2015
Total focus group participants	**78**	**5 regions**	

The following table describes the types of participants in each of the parent leader or professional focus groups and the topics explored with each.

Table M-2. Parent leader/professional focus group participants and topics explored

<table>
<tr><th>Type of focus group</th><th>Type of focus group participants</th><th colspan="2">Topics explored</th></tr>
<tr><td><i>Early Identification Professionals</i></td><td>DDS area office supervisors, educational consultants, inclusion specialists, clinical social worker, EI consultants, provider agency service directors, EI specialists, parent advocates, Autism Support Brokers, public health specialists, Autism awareness advocate and founder of community inclusion programs.</td><td colspan="2">Early identification
Access to community-based systems
Cultural needs</td></tr>
<tr><td><i>Parent Leaders</i></td><td>Autism resource specialists, family specialists/advocates, researchers, attorneys, and educational specialists from Autism support centers, clinical programs, and nonprofit agencies. Parents of teenagers and young adults on the spectrum. One participant was the parent of an adult. Another participant was a sister-in-law to an adult with autism.</td><td>Group #1:
Education (IEPs)
Medical Home
Transition to Adult Living
Transition to Adult Health care
Mental Health</td><td>Group #2:
Education (IEPs)
Transition to Adult Living
Transition to Adult Health care
Mental Health</td></tr>
<tr><td><i>Community Services Professionals</i></td><td>Clinical nurses, program directors, parent coordinators, EI Directors, and resource specialists from provider agencies, family support centers, and DDS</td><td colspan="2">Early identification
Access to community-based systems
Transition</td></tr>
</table>

Type of focus group	Type of focus group participants	Topics explored
Community Health Center Medical Professionals	Family, pediatric and adult Nurse Practitioners, general pediatricians, family medicine physicians, and case managers from a Boston community health center	Early identification Transition
Transition Professionals	Project coordinators, attorney and advocate, director of transition services, transition advocate, clinical program directors, transition specialists, and parent activists from state and private agencies	Transition Insurance Access to community-based systems

The following table describes the types of participants in each of the cultural/linguistic parent focus groups. The topics explored with these groups were primarily early identification, access to community-based systems, transition to adult living and transition to adult health care.

Table M-3. Parent cultural/linguistic focus group participants and topics explored

Type of focus group	Type of focus group participants
Hispanic, Lawrence group	Parents of a school and transition age children and one young adult with autism
Hispanic, Boston group	Parents of school age children with autism
Vietnamese group	Parents of a pre-school age, elementary age, middle school age, and transition age children with autism
Chinese group	Parents of school age children with autism; one family advocate
Haitian group	Parents of teenagers and young adults with autism
African-American group	Parents of young children and teenagers with autism/PDD-NOS

Parents had a lot to share and often, during introductions, they would state their name and immediately describe the most burning issue for their child. Typically, they would highlight educational needs and disparities, though education was not a topic originally included in the project team's list of semi-structured interview questions. As a result, we have included a section on education to acknowledge it as a prominent system serving children and youth with autism in addition to other health care and community systems.

In certain focus groups, the final question "What do you need?" was added to prompt participants to prioritize and share their greatest perceived needs for their child.

Analysis Phase

The project team mined and reviewed the data collected, comparing datasets when possible to review them for duplication and existing gaps. The team also analyzed the collection procedures used for the data, and where possible gathered information about perceived quality and generalizability of the data collected. Feasibility for collecting data going forward, as well as ways to improve or enhance data collection in the future will be shared in the report recommendations.

DATA ANALYTIC PLAN. For quantitative data collected from agencies, we frequently described findings with descriptive statistics. Where possible, quantitative data was triangulated with other data sources and/or Focus group and key informant input to confirm and enhanced quantitative findings. The project team considered the following themes in our analysis: race, culture, language, income, immigrant status, level of function, and mental health needs.

Goal 2. Refine the existing state plan to address needs identified from the needs assessment.

The project team presented the needs assessment report draft to the project advisory board and other topic experts in October 2016 for their feedback on its accuracy, as well as incorporated report findings from the preexisting 2013 Massachusetts Autism Commission Report and recent agency presentations to the new permanent Commission. Based on project advisory board feedback, the project team produced the final report to advise the Massachusetts Autism Commission's state plan in the categories studied for the state and five regions with insights on data to gather, analyze and monitor in the future.

Goal 3. Propose recommendations for future monitoring.

Recommendations to collect data and monitor future outcomes and impacts for the six core outcome indicators are summarized at the conclusion of this report for future monitoring and surveillance practices. Our hope is that the recommendations will be useful to the Massachusetts Autism Commission when moving forward with future policies, practices or legislation that might address and monitor the needs of children and youth with autism and developmental disabilities and their families in the state.

Goal 4. Disseminate our findings.

Throughout the project, we have disseminated our work through local presentations at our quarterly project advisory board meetings; through presentations and posters at national conferences, meetings and symposia, such as the Association of University Centers on Disability (AUCD), Association of Maternal and Child Health Programs (AMCHP), the HRSA-MCHB State Public Health Autism Resources Center (SPHARC), and Autism CARES; through the Massachusetts Chapter of the AAP's (MCAAP) Children's Mental Health Task Force (CMHTF), and the Massachusetts Act Early State Team Summit Meetings. Final dissemination of our work includes distributing this report to the project advisory board, the Data Subcommittee of the Massachusetts Autism Commission, and ultimately to the entire Massachusetts Autism Commission for their use as well as online for public information and use.

POPULATION DEMOGRAPHICS & PREVALENCE

To understand the estimated prevalence of ASD in Massachusetts, total population statistics provide the larger context. This report presents data across the six Healthy People 2020 core outcome indicators for state CYSHCN ranging in age from birth through age 18, and wherever possible for young adults through age 22, or as high as age 26 as appropriate. To identify regional patterns and trends, the state was broken into five regions to map services and supports for Massachusetts children. We will first discuss the state population demographics overall and then will narrow our focus to CYSHCN with autism and other developmental disabilities.

Background

General Population Data[7]

There are over 6.7 million Massachusetts residents with an estimated 1.4 million children and youth under the age of 18 (20%) of which 367,000 are under 5 years old (26%).[8] The table below shares information about the entire Massachusetts population, primarily from the U.S. Census. The child population represents the ages of birth through age 17. The adult population starts at the age of 18.

Table P-1. Demographic Population Statistics (2015): Massachusetts vs. U.S.[9]

Category	Massachusetts			U.S.		
	N	% of population	% of children	N	% of population	% of children
Total births (June, 2016) [10]	71,908	1.1%		3,988,076	1.2%	
Child population age 0-4[8]	366,562	5.4%	26%	19,907,281	6.2%	27%
Child population age 5-11 [8]	530,187	7.8%	38%	28,738,793	8.9%	39%
Child population age 12-14 [8]	239,790	3.5%	17%	12,370,713	3.8%	17%
Child population age 15-17 [8]	250,548	3.7%	18%	12,628,324	3.9%	17%
Total population under age 18 [8]	1,386,062	20.4%		73,645,111	22.9%	
Adult population age 18-24 [8]	701,025	13%		31,219,892	13%	
Total population (est.)[8]	6,794,422	100%		321,418,820	100%	

The state's population of children and youth from minority populations ages birth through 17 is estimated to be 504,177 (36%).[11] The table below breaks down various racial and ethnic populations, as well as includes data on immigrant families.

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[8] U.S. Census Bureau, 2015. https://www.census.gov/quickfacts/table/PST045215/25/accessible

[9] Annie E. Casey Foundation Kids Count Data Center, American Community Survey based on 2009-2013 U.S. Census Bureau data, http://datacenter.kidscount.org/; Please note that most of the data in the population statistics tables are centralized at the KIDSCOUNT Data Center with links to the primary sources. This site can serve as a tool for future monitoring purposes.

[10] National Center for Health Statistics, June 2016

[11] U.S. Census Bureau, 2015.

Table P-2. Child Population by Race/Ethnicity (2015): Massachusetts vs. U.S.[9]

Category	*Massachusetts N (%)*	*U.S. N (%)*
Non-Hispanic White	882,910 (64%)	37,927,474 (52%)
Hispanic or Latino	240,644 (17%)	18,150,181 (25%)
Non-Hispanic Black	115,262 (8%)	10,166,122 (14%)
Non-Hispanic Other (Asian or other)	92,202 (7%)	3,579,248 (5%)
Non-Hispanic Two or More Race Groups	52,846 (4%)	3,046,202 (4%)

There are approximately 385,000 immigrant families in Massachusetts, representing about 28% of all families in the Commonwealth. This is slightly higher than the national level of 24% of families. Within Boston, there are 56,000 immigrant families accounting for over half (52%) of all families in the city. Approximately 14.5% of Massachusetts families, and about half (52%) of immigrant families within the state have recently arrived in the U.S. as refugees or immigrants and do not speak English as their primary language. Their regions of origin include: Latin America (40%), Asia (28%), Europe (18%) and Africa (12%).[12] Other than English, a variety of languages are spoken in Massachusetts with the predominant languages including Cambodian, Chinese, Haitian-Creole, Portuguese, Somali, Spanish, and Vietnamese.[13] The percentage of immigrant families in the state where the parents have difficulty speaking English is similar to the national levels (56%).

Table P-3. Children and Young Adults in Poverty: Massachusetts vs. U.S. (2014)[9]

Category	*Massachusetts N (%)*	*U.S. N (%)*
Children in Poverty under age 18	208,000 (15%)	15,686,000 (22%)
Children in Poverty 0-5	74,000 (17%)	5,593,000 (24%)
Children in Poverty 6-17 (2014)	133,000 (14%)	10,093,000 (21%)
Persons in Poverty 18-24 (2014)	106,000 (19%)	7,033,000 (25%)

It is also important to consider poverty and income levels when understanding the needs of children and youth. The table below provides a snapshot of the state. Fifteen percent of children live below the federal poverty line (FPL).[10] The three counties with the greatest number of families living below the FPL are Berkshire County (20.4%), Hampden County (26.2%), and Suffolk County (31.5%).[14] There is a strong link between ethnic and racial diversity and poverty in the state. Racially and ethnically diverse areas have approximately 25-30% of the population living at the FPL with 29% of that group living at 200% FPL. Of these groups, families from the following backgrounds experience the greatest amount of poverty: Hispanic or Latino (38%), Black or African American (31%), and two or more races (22%) compared to Asian (10%) and White (8%).

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[12] American Community Survey 2014.

[13] Massachusetts Department of Public Health (October 2010). *Foreign Language Guide*. Office of Public Health Strategy and Communications Revised.

[14] Massachusetts Budget & Policy Center, 2014.

The vast majority of children and youth birth to age 18 are covered by health insurance. Each year since universal health care was introduced in Massachusetts, the number of uninsured children continues to decrease. In 2011, 24,000 were uninsured at 0.2% of the total population. Today, that number has been reduced even further to 16,000 at 0.1%.

Table P-4. Children without Health Insurance: Massachusetts vs. U.S. (2015)[15]

Category	*Massachusetts N (%)*	*U.S. N (%)*
Children without Health Insurance (2015)	16,000 (0.1%)	4,397,000 (6%)

Children with Disabilities

The American Academy of Pediatrics (AAP) estimates that about one in six children in the U.S. (about 15%) has a developmental disability, ranging from mild disabilities such as speech and language impairments to serious developmental disabilities, such as intellectual disabilities, cerebral palsy, and autism.[16] Similarly, the findings from the National Survey of Children with Special Health Care Needs (NS-CSHCN) estimates 17.3% of Massachusetts CSHCN between the ages of 2-17 have developmental delays.[17]

The tables below share state and national demographic information about the population of children with special health care needs (CSHCN) as well as state data about children with disabilities. It is estimated that about 65% (n=238,810) children in the state have one or more special health care need.[18] When examining program participation, including Early Intervention Part C and Special Education Part B in 2010, almost 9% (n= 31,824) of children aged birth through five years participated.[19] Within CSHCN, about 17% (n=41,000) are estimated to have developmental disabilities and 9% (n=21,000) have ASD.[15]

Table P-5. Massachusetts Children with Disabilities

Category	*Massachusetts N (%)*	*U.S. N (%)*
Children with Special Health Care Needs (CSHCN) (2009-10)[15]	312,000 (22%)	14,598,000 (20%)
Birth through age 3 receiving early intervention services (Part C) (2014)[20]	33,533 (8.6%)	350,581 (2.95%)

In 2012, approximately 38% of all children in Massachusetts (n=547,232) were reported to have received MassHealth coverage.[21]

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[15] Population Reference Bureau, analysis of data from the U.S. Census Bureau, 2008-2015 American Community Survey.

[16] Pediatrics, 2011.

[17] National Survey-Children's with Special Health Care Needs (NS-CSHCN 2009-10). (For more information about the survey, please see the section on "Understanding Healthy People 2020 and the Core Outcome Indicators for CYSHCN").

[18] National Survey of Children's Health (NSCH, 2011-12). (For more information about the survey, please see the section on "Understanding Healthy People 2020 and the Core Outcome Indicators for CYSHCN").

[19] OSEP, U.S.DOE, IDEA Data Accountability Center

[20] The Early Childhood Technical Assistance (ECTA) Center, http://ectacenter.org/partc/partcdata.asp.

Table P-6. MassHealth Enrollment 2012[22]

Category	*Massachusetts N (%)*
Children without Disabilities Enrolled in MassHealth	516,460 (94%)
Children with Disabilities Enrolled in MassHealth	30,772 (6%)
All Children Enrolled in MassHealth	547,232

Autism Prevalence and Incidence Data

Prevalence refers to the "proportion of persons who have a condition at or during a particular time period, whereas incidence refers to the proportion or rate of persons who develop a condition during a particular time period."[23] While prevalence and incidence are similar, prevalence includes all cases both new and pre-existing present during a given time period whereas incidence includes only new cases.

National Autism Prevalence Data

The Centers for Disease Control and Prevention (CDC) Autism and Developmental Disabilities Monitoring (ADDM) Network is an active surveillance system that provides estimates of the prevalence and characteristics of ASD among children aged 8 years whose parents or guardians reside in 11 ADDM Network sites in the United States[24].

Their 2016 prevalence update report estimates that about one in 68 eight-year-olds in the U.S. (14.6 per 1,000) have been identified with ASD (CDC, 2016).[25] The report breaks down prevalence by participating states and metropolitan areas. The report estimates the average age of diagnosis for children with autistic disorder at 3.1 years and Asperger syndrome at 6.2 years.[26] Estimated prevalence was significantly higher among boys aged 8 years (one in 42, or 23.6 per 1,000) than among girls aged 8 years (one in 189, or 5.3 per 1,000). Of note, the report estimates that black and Hispanic children receive developmental evaluations later than white children nationally.

Massachusetts Autism Population Statistics

The 2013 Massachusetts Autism Commission report applied the national prevalence statistic to Massachusetts population data, which suggested that approximately 75,000 people in Massachusetts have autism. Autism prevalence has been documented to be on the rise in the state and has impacted a number of service systems as children and youth age into their adult years.

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[21] Office of Medicaid, MA EOHHS, 2012.

[22] Massachusetts Budget & Policy Center, http://www.massbudget.org

[23] Centers for Disease Control & Prevention (CDC, 2012). Principles of Epidemiology in Public Health Practice, Third Edition. An Introduction to Applied Epidemiology and Biostatistics. https://www.cdc.gov/ophss/csels/dsepd/ss1978/lesson3/section2.html

[24] http://www.cdc.gov/mmwr/volumes/65/ss/ss6503a1.htm#T1_down

[25] Christensen, DL, Baio J, Van Naarden Braun K, Bilder D, Charles J, Yeargin-Allsopp M, et al. (April 1, 2016). *Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites*, United States, 2012; CDC Surveillance Summaries, 65(3);1–23

[26] Although Asperger syndrome is no longer included in the DSM-5, the CDC prevalence data continues to track it based on the historical nature of the timeframes presented in the report.

Estimating the number of Massachusetts children and youth with ASD under the age of 18 with the CDC's prevalence statistics for 2005, 2010 and 2015 applied to U.S. Census data for those years would yield the following possible increases:

Table P-7. Estimated number of MA children with ASD under the age of 18*[27]

	2005	2010	2015
# of children under age 18 with ASD	10,000	13,065	20,383
CDC prevalence rates	1 in 250	1 in 110	1 in 68

Note: Interpret these figures with caution as they are only estimates for MA based on rates measured in other metropolitan areas.

STATE AUTISM PREVALENCE ESTIMATES FOR MASSACHUSETTS. According, to the most recent state data analyzed in 2016 by the Massachusetts Department of Public Health, the incidence rate for early ASD diagnoses (before the age of 36 months) is estimated at one in 70 children.[28] (More information is available in the Early Identification section).

Recommendations: Population & Prevalence Data

To track and report annual estimates of the prevalence of ASD among children in Massachusetts, we offer the following recommendations:

1.) PROPOSE MASSACHUSETTS TO BE A CDC ADDM NETWORK SURVEILLANCE MONITORING SITE, OR CONSIDER SIMILAR METHODOLOGY LEVERAGING THE STATE'S ADVANCED HEALTHCARE-RELATED INFORMATION SOURCES.

The CDC holds a competitive grant process every few years for states to become part of the ADDM network.[29] Massachusetts may wish to submit a proposal in the future. This would be a way to bring funding to the state toward contribution to national and local prevalence surveillance as part of state data collection. The grants cover four year periods and are highly competitive. There were two components for the last round: Component A funded surveillance of autism spectrum disorder (ASD) and developmental disabilities (DDs) (i.e. cerebral palsy (CP) and intellectual disability (ID) among 8-year-olds. Component B funded surveillance of ASD among 4-year-olds. Component A was required for all applicants, while applying for Component B funding was optional. Matching school, medical and birth records is involved to confirm a fixed diagnosis at 8 years, and a major metropolitan area must be the focus of the grant.

ADDM Network goals that could benefit Massachusetts are to:

- Describe the population of children with ASD,
- Compare how common ASD is in different areas of the country,

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[27] Based on American Community Survey 2006-2008 & U.S. Census 2015 estimates

[28] Massachusetts Department of Public Health, 2016. (More information is available in the Early Identification section).

[29] Centers for Disease Control & Prevention (CDC) Autism and Developmental Disabilities Monitoring (ADDM) Network web site. http://www.cdc.gov/ncbddd/autism/addm.html.

- Identify changes in ASD occurrence over time, and
- Understand the impact of ASD and related conditions in U.S. communities.

We recommend that Massachusetts state agencies on the Autism Commission consider applying to become a CDC ADDM network state in the next round of applications.

Alternatively, the state could choose to adopt the methodology of the CDC ADDM network to conduct its own estimates. Numerous state-specific resources exist within the state of MA that may allow enhancement and/or greater resource efficiency of the CDC ADDM methodology, including electronic health records of major medical centers and the All Payer Claims Database[30] which is the most comprehensive source of health claims data in the state from both public and private payers.

2.) MONITOR STATE DATA TRENDS USING FUTURE VERSIONS OF THE NSCH, POTENTIALLY WITH SUPPORT TO ENHANCE THE STATE-SPECIFIC SAMPLE SIZE, OR DEVELOP A SIMILAR SURVEY FOR MASSACHUSETTS.

The National Survey of Children's Health (NSCH) survey is currently being conducted by the Census Bureau in 2016, with initial data expected in 2017. Among other changes, the 2016 NSCH will integrate the National Survey of Children with Special Health Care Needs (NS-CSHCN) into its survey questions. We recommend reviewing the 2017 version of the survey to monitor changes in data trends for children with ASD in Massachusetts. The frequency of NSCH updates may be annual, though this needs to be confirmed.

While the national surveys ask important and relevant questions across all six Healthy People 2020 core outcome indicators as well as basic demographic information about the population with special health care needs (SHCN) and ASD, the state sample sizes are quite limited such that any estimates for CYSHCN with autism are based on very little information and therefore subject to error. However, the questions and survey structure are useful, and a state supplement or coordinated efforts with the funder of the survey, Health Resources & Services Administration (HRSA), may be beneficial to oversample children in Massachusetts for the purpose of improving the precision of these estimates.

Alternatively, there may be some insights to be gained by piloting a state-specific version for Massachusetts with the proper funding to increase the results, given the quality of information it could potentially yield. The state would need to consider the feasibility and benefit of this type of surveillance.

3.) SHARE MASSACHUSETTS CORE OUTCOME INDICATOR DATA ONLINE.

With proper funding and support, a data portal web site (i.e., dashboard) that shares a variety of relevant state information with the public about Massachusetts children and youth with ASD (as well as other CSHCN as appropriate) could serve to communicate benchmark targets and progress updates as part of a collective impact/community collaborative movement. The data would include population and prevalence data broken down by subcategories using the new NSCH survey results and U.S. census data. It would also include the six Healthy People 2020 MCHB core outcome indicators in this report along with any new data that the Massachusetts Autism Commission decides to track in the future. Within each core domain, outcome and

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[30] www.chiamass.gov/**ma**-apcd/

process results would be shared (e.g., the number of children and families served by region, the status of workforce capacity and development, the length of wait times for services, and other relevant metrics).

As an example, one promising practice is the *Healthy Vermonters 2020*[31] data portal. The Vermont Department of Health has published their state health assessment plan via an online dashboard that documents the health status of Vermonters and will guide the work of public health through 2020. Their report presents more than 100 public health indicators and goals carefully chosen by state government, health and human services professionals, and the public from the many hundreds set out by the Healthy People 2020 initiative to improve the health of the nation. Among these are their *Early Childhood Screening Indicators,* some of which have goals still in development. These include increasing the percentage of children who are screened for autism and other developmental delays by 24 months of age and have first evaluation with an autism diagnosis by 36 months of age, among other relevant and related indicators.

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[31] http://healthvermont.gov/hv2020/report.aspx

Healthy People 2020 Core Outcome Indicators

Baseline Findings

EARLY IDENTIFICATION

Healthy People 2020 Core Outcome Indicator #1

Children Are Screened Early and Continuously for Special Health Care Needs

The following section shares information about early identification of autism and other developmental disorders by looking at national and state data related to developmental and autism screening, diagnosis, and intervention in Massachusetts. We present quantitative data looking at the state environment, needs, and future possibilities. We also share some promising and supportive local initiatives that promote developmental and autism screening through the work of early childhood professionals outside of the health care environment. In addition, we profile the CDC's "Learn the Signs. Act Early." autism awareness program and the work of its local chapter, Massachusetts Act Early. We also provide qualitative insights from focus groups. Lastly, we will offer resources and recommendations that arise from this assessment.

Background

Early and continuous screening for special health care needs is a core indicator that is being achieved in Massachusetts according to national child health surveys and state-specific review studies. Numerous studies have documented that the early diagnosis of ASD is essential to ensure that children receive early and intensive intervention services, which positively impact developmental progress and long-term outcomes.

The Health Resources & Services Administration-Maternal and Child Health Bureau (HRSA-MCHB) defines screening as "a population-based intervention to detect a particular condition or disease" that is a comprehensive, ongoing practice of monitoring and assessment of children and youth.

Screening has two major goals:

> *"First, it is critical to identify, as early as possible, children in the general population who have special health care needs so that they and their families can receive appropriate services to reduce long term consequences and complications. Some needs may be identified in infancy, or during the perinatal period, while others may emerge later in childhood and adolescence.*
>
> *Second, and equally important, children and youth with special health care needs require ongoing assessments to identify newly emerging issues including developmental/behavioral issues, oral health, and psychosocial issues, and to prevent secondary conditions that may interfere with development and well-being. Ongoing assessment should also focus on identifying the unique strengths of each child and family."*[32]

The Bright Futures Guidelines for Health Supervision of Infants, Children, and Adolescents, supported by the American Academy of Pediatrics (AAP) and the MCHB recommends that pediatric health care providers conduct routine developmental screening at the 9, 18 and 30 month well-child visits and autism screening at the 18 and 24 or 30 month well-child visits. In tandem, developmental surveillance is recommended at each well-child visit from infancy through adolescence.[33]

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[32] http://mchb.hrsa.gov/cshcn0910/core/pages/co4/co4cas.html

[33] Bright Futures/AAP, 2014.

Van Cleave et al.[34] conducted a systematic review of the evidence for practice-based interventions to increase the proportion of patients receiving recommended screening and follow-up services in pediatric primary care. The authors noted that monitoring screening alone may overestimate changes in identification and treatment of conditions. Adequate physician follow-up with ongoing outcome assessment seems to be effective. Pairing the outcome with practice screening interventions will help refine interventions to move toward effective, efficient screening in primary care pediatrics.

MCHB has set the targets presented in the table below as key Maternal, Infant and Child Health (MICH) outcomes of Healthy People 2020 for the early identification of children and youth with special health care needs. The MCHB national target-setting method is a goal of 10% improvement over baseline. For the purposes of this report, we will consider this goal for children with autism and developmental disabilities specifically.

Maternal & Infant Child Health Indicator (MICH) 29: Increase the proportion of young children with ASD and other developmental delays who are screened, evaluated, and enrolled in special services in a timely manner.

MICH Indicator	Baseline	National Target
MICH 29.1[35]: Increase the proportion of children (aged 10-35 months) who have been screened for an Autism Spectrum Disorder (ASD) and other developmental delays.	22.6 percent of children aged 10 to 35 months were screened for an Autism Spectrum Disorder (ASD) and other developmental delays in the past year as reported in 2007.	24.9 %
MICH-29.2[36]: Increase the proportion of children with ASD having a first evaluation by 36 months of age.	42.7 percent of children aged 8 years with ASD had a first evaluation by 36 months of age, as reported in 2006	47.0 %
MICH-29.3[37]: Increase the proportion of children with ASD enrolled in special services by 48 months of age.	52.4 percent of children aged 8 years with ASD were enrolled in special services by 48 months of age, as reported in 2006	57.6%
MICH-29.4[38]: (Developmental) Increase the proportion of children with a developmental delay with a first evaluation by 36 months of age.	No baseline specified	NA
MICH-29.5[39]: (Developmental) Increase the proportion of children with a developmental delay enrolled in special services by 48 months of age.	No baseline specified	NA

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[34] Van Cleave, J., Kuhlthau, K., Bloom, S., Newacheck, P.W., Nozzolillo, A.A., Homer, C.J., & Perrin, J. (2012). Interventions to improve screening and follow-up in primary care: A systematic review of the evidence. *Academic Pediatrics, 12*(4): 269-82. PMID: 22575809.

[35] National Survey of Children's Health (NSCH) 2011-12, HRSA/MCHB and CDC/NCHS

[36] Autism and Developmental Disabilities Monitoring Network (ADDM), CDC/NCBDDD

[37] Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP), CDC/NCBDDD

[38] NSCH, HRSA/MCHB and CDC/NCHS

According to the MCHB, nationally the likelihood of receiving a standard developmental screen varies slightly by race and ethnicity, from 47.3% of non-Hispanic Black children to 50.5% of non-Hispanic White children.[39]

Massachusetts should consider whether these national targets are appropriate for the state and determine how state data could be used to set these or similar state-appropriate baselines for Massachusetts children.

Summary of State Environment: Early Identification

Both state and national data sources indicate successes and remaining areas of need for developmental and autism screening, diagnosis and referral to intervention in Massachusetts. These data sources can be used to track, project and monitor the critical points along the path to early identification.

According to a 2013 Kids Count report entitled "Massachusetts Leads in Child Behavioral Health Screening; Reaches Out to Mothers As Well" based on findings from the 2011-12 National Survey of Children's Health (NSCH), Massachusetts is well ahead of all other states in administering developmental screens to low-income children before the age of six. The report estimated that two-thirds of Massachusetts children <200% FPL (69%) received a developmental screening compared to less than one-third of children nationwide (30%).[40]

This success is due in large part to the state mandate resulting from the 2001 court decision for the *Rosie D. v. Patrick* class action lawsuit which found that the state was in violation of the federal Medicaid Act because it was failing to provide home-based mental health services to children with "serious emotional disturbance." The outcome resulted in the Massachusetts Medicaid program MassHealth requiring that all children under the age of 21 years receive a behavioral health screening at pediatric well-child visits, effective December 31, 2007. Under the resulting Children's Behavioral Health Initiative (CBHI), providers accepting MassHealth coverage must provide early, periodic and standardized screening at well child visits using standardized MassHealth approved behavioral health assessment tools (including developmental & ASD screening), and when indicated, diagnostic assessment and treatment.

MassHealth-approved tools for developmental screening include[41]:

- Ages & Stages Questionnaires: Social Emotional (ASQ:SE, Bricker & Squires)
- Parents Evaluation of Developmental Status (PEDS, Glascoe)
- Brief Infant-Toddler Social Emotional Assessment (BITSEA, Carter)
- Survey of Well-Being in Young Children (SWYC, Perrin et al.)

The Modified Checklist for Autism in Toddlers (Revised Version with Follow-Up) (M-CHAT-R/F, Robins, Fein et al.) is also approved by MassHealth for autism screening.[50]

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[39] http://mchb.hrsa.gov/cshcn0910/core/pages/co4/ds.html

[40] Wagman, N. (November 3, 2013). *Massachusetts Leads in Child Behavioral Health Screening; Reaches Out to Mothers As Well*. Massachusetts Budget and Policy Center.

[41] Chart of MassHealth approved screening tools (2016). http://www.mass.gov/eohhs/gov/commissions-and-initiatives/cbhi/screening-for-behavioral-health-conditions/behavioral-health-screening-tools/chart-of-masshealth-approved-screening-tools.html

Identified Needs: Early Identification

Quantitative Findings

Developmental and Autism Screening

Screening for Behavioral Health Using Massachusetts Medicaid Claims

MassHealth records and the state's All Payer Claims Database (APCD) are the two sources that log whether developmental and autism screenings have been conducted for children through the use of medical billing codes. However, because the main purpose of these data sources is to facilitate payment for medical services, they do not indicate which tool was used, or what the follow-up may have been for either a diagnostic referral or to conduct another screening as part of developmental surveillance.[42] Starting in 2008, medical providers were required to use a modifier in their billing to indicate the outcome of the behavioral health screening, and in 2011 this modifier was required for reimbursement.

KUHLTHAU ET AL. 2011 STUDY. A 2011 study by Kuhlthau et al.[43] explored rates of screening and identification and treatment for behavioral concerns using billing data from MassHealth data immediately following the start of the CBHI screening and intervention program. They conducted a retrospective review of the number of pediatric well-child visits, number of screens, and number of screens that identify risk for psychosocial problems from January 2008 (the month pediatric screening started) to March 2009. During the surrounding one-year period, they also examined the number of claims with a behavioral health evaluation code. To measure outcomes, they used percentage of visits with a screen, percentage of screens identified at risk, and number of children seen for behavioral health evaluations. The results revealed a major increase from 16.6% of all Medicaid well-child visits coded for behavioral screens in the first quarter of 2008 to 53.6% in the first quarter of 2009. Additionally, the children identified as at risk increased substantially from about 1,600 in the first quarter of 2008 to nearly 5,000 in Quarter One of 2009. The children with mental health evaluations increased from an average of 4,543 to 5,715 per month over a one-year period. The data suggest payment and a supported mandate for use of a formal screening tool substantially increased the identification of children at behavioral health risk. Findings suggest that increased screening may have the desired effect of increasing referrals for mental health services.

HACKER ET AL. 2014 STUDY. In another study published in 2014, Hacker et al.[44],[45] analyzed MassHealth claims data of children continuously enrolled between July 2007 and June 2010 found that 45% of children had been screened for behavioral health conditions. It is important to note that the CBHI was implemented in 2008, which requires providers to conduct behavioral health screenings at well-child visits for all children under 22 years old who were covered by Medicaid. Children who were not screened fell into two categories: those who received a well-child visit but did

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[42] It may be possible to link screening and eventual diagnosis in other payer medical claims longitudinally, however, this method has not been tested in this state.

[43] Kuhlthau K, Jellinek M, White G, Vancleave J, Simons J, & Murphy M.(2011). Increases in behavioral health screening in pediatric care for Massachusetts Medicaid patients. *Archives of Pediatric & Adolescent Medicine. 165* (7):660-4. PMID: 21383254.

[44] Hacker KA, Penfold RB, Arsenault LN, Zhang F, Murphy M, & Wissow LS. (October, 2014). Behavioral Health Services Following Implementation of Screening in Massachusetts Medicaid Children. *Pediatrics, 134* (4): 737–746.

[45] Hacker KA, Penfold RB, Arsenault LN, Zhang F, Murphy M, & Wissow LS. (January, 2014). Screening for Behavioral Health Issues in Children Enrolled in Massachusetts Medicaid. *Pediatrics, 133* (1).

not receive a screening (29% of children) or those who did not receive a well-child visit or screens during the year (another 29% of children). Of the children who were screened, 14.7% had a positive screening for a behavioral health condition. About 27% of children received behavioral health services after screening including psychiatric evaluations or therapy, and 98% received the services within 90 days of this screening. However, only one-third of newly identified children received services. Children who received well-child visits and later obtained behavioral health services were more likely to receive psychotherapy treatment, while children in behavioral health services who did not receive well-child visits were more likely to receive psychopharmacology. Minority children, especially children of Asian descent were less likely to receive behavioral health services and less likely to be screened.[44] However, Hispanic children were more likely to have a positive behavioral health screening.[45] This methodology could be replicated because medical providers in the state were required to use a modifier in their billing to indicate the outcome of the behavioral health screening starting in 2008, and starting in 2011 this modifier was required for reimbursement adding a greater likelihood it would be used.[46]

SAVAGEAU ET AL. 2016 STUDY. A third source that charted the progress of the required CBHI implementation of screenings during the two years of state fiscal year (SFY) 2010 and 2012 is a study by Savageau et al[47]. The results suggest that the implementation of CBHI has had a large impact on behavioral health screening and treatment utilization among children and youth receiving MassHealth.

The study assessed the uptake of the required screening following the implementation of the CBHI using a repeated cross-sectional design to examine change in behavioral health screening, referrals, and treatment utilization. The study population included children and adolescents under the age of 21 years who were enrolled in a MassHealth managed care organization or the Primary Care Clinician case management plan during the study period. Medical records and MassHealth claims data from a total of 2,000 MassHealth children and adolescents for each year were reviewed for change in behavioral health screening, referrals, and treatment utilization. Of the 4,000 total medical records, 3,801 were abstracted (95% retrieval rate).

Table EI-1 shows highlights from an earlier 2014 report[48] by the research group indicate that the implementation of the CBHI regulations and payment has resulted in widespread behavioral health screening in primary care practices in Massachusetts that care for children and youth on MassHealth.

According to the authors, pediatricians seem aware of the need to screen children as recommended by the AAP. While studies have noted that such screenings may not be routine or standardized, the CBHI seems to have demonstrated high levels of screening statewide. Still, given the observed significant increases in formal screening documented in this report, the prevalence of positive findings is potentially underestimated since over two-thirds (67%) of visits where a formal screening occurred had no documentation in the medical records on the results of those screens. The report also cannot estimate the full extent of referrals from screening since the medical record may not be a good source of information regarding referral for behavioral health services within MassHealth

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[46] Hacker KA, Penfold RB, Arsenault LN, Zhang F, Murphy M, & Wissow LS. (October, 2014). Behavioral Health Services Following Implementation of Screening in Massachusetts Medicaid Children. *Pediatrics, 134* (4): 737–746.

[47] Savageau, J., Keller, D., Willis, G., Muhr, K., Aweh, G., Simons, J. & Sherwood, E. (2016). Behavioral health screening among Massachusetts children receiving Medicaid. *The Journal of Pediatrics, 178*: 261-7.

[48] Savageau, J., Willis, G., Keller, D., Muhr, K., Aweh, G., & O'Connell, E. (2014). *Clinical Topic Review 2013 - Behavioral Health Screenin Among MassHealth Children and Adolescents.* UMASS Medical School-Center for Health Policy & Research (CHPR).

because a PCP is not required in order for a family to access a specialty provider directly. The report only captured screenings and referrals directly related to well-child visits and thus may underestimate the true number of referrals following screenings. In addition, the study also uncovered the need for quality improvement related to access to behavioral health screening for families whose primary language is not English.

Table EI-1: Behavioral Health Screening Among MassHealth Children & Adolescents (Savageau et al., 2014).

Selected Findings	**Supporting data (n = 3,801)**	
	2010	***2012***
Behavioral health screening at Well Child Visits is widespread, with the majority of screenings using MassHealth approved tools.	*86%*	*89%*
Reported % of MassHealth children and adolescents screened positive for BH conditions consistent with reported prevalence of BH conditions among US children (estimated between 13% and 24%).	*Formal screen 21%*	*Formal screen 19%*
	Informal screen 13%	*Informal screen 15%*
Use of BH screening tools in language other than English is very low (20% reported primary language not English).	*8% used*	*7.9% used*
Most frequently used screening tool – PEDS	*46.3% used* *16% positive results*	*44.6% used* *12% positive results*
Most frequently used screening tool – M-CHAT	*12.2% used* *3% positive results*	*12.9% used* *6% positive results*
Referral rates to BH services after screening were significantly higher in 2010 & 2012 than in 2008. *(Compared to 2% baseline in 2008)*	*15%*	*11%*

BH = behavioral health

Universal screening because of the CBHI for behavioral health conditions including autism and other developmental disabilities provides a unique opportunity to examine the impact of universal screening on service utilization statewide and to determine whether these activities result in earlier intervention and improved health outcomes for children and youth at risk for these conditions. Finally with regards to the above findings and noting the high frequency usage of the M-CHAT autism screening tool, the authors credit the increased nationwide attention given to early identification through public awareness programs that are designed to inform physicians, parents and others who work with young children about how to recognize the signs of developmental disabilities early and across cultures and socioeconomic backgrounds. To learn more about such initiatives, the CDC's "Learn the Signs. Act Early" campaign and the local Massachusetts Act Early chapter are discussed later in this section under "Resources."

CBHI implementation has been a powerful systems-level change agent and a possible model for other areas needing positive change. In addition to pointing out the opportunities for methodology replication, examination of universal screening on service utilization, and the potential results on positive outcomes, these studies also highlight the great need for quality improvement to reduce linguistic and cultural disparities in the behavioral health screening process. The extent to which

CBHI implementation can provide measurable outcomes is limited, but should be explored further for opportunities.

Developmental Screening in Massachusetts

National Survey Information about Developmental Screening

The two national surveys that corroborate and may provide further insights into how well Massachusetts is faring in delivering timely developmental screening to children are the 2011-2012 National Survey of Children's Health (NSCH) which provides results *for all children* and the 2009-10 National Survey-Children's with Special Health Care Needs (NS-CSHCN) which provides results for *children with special health care needs.* Wherever there are apt comparisons with national results, we note it below. (For more information about the reliability of these surveys based on low sample sizes in Massachusetts, please refer to the Overview section).

These surveys ask Massachusetts parents to report whether they had "any concerns about learning, development, or behavior" and whether they filled out a questionnaire "about specific concerns or observations about development, communication or social behaviors" for their children. They do not provide insights into autism screening.

DOCTOR ASKED ABOUT DEVELOPMENTAL CONCERNS (BIRTH-5). The NSCH estimates that 62.8% (C.I. 57.2-68.4%)[49] of parents of all Massachusetts children aged 0-5 were asked about developmental concerns at a well-child visit, significantly exceeding the survey's national estimate of parents of 51.8% (C.I. 50.5-53.1%) of children being asked about any concerns by over 10%. However, 37.2% of Massachusetts parents were not asked about concerns.

Table EI-2. During past 12 mos., doctor asked about developmental concerns (parents of children aged 0-5 years), NSCH 2011-12

		Had visit, did NOT ask	Had visit, YES asked	Total
U.S.	*%*	48.2%	51.8%	
	C.I.	(47.0 - 49.5%)	(50.5 - 53.1%)	
	n	13,024	15,502	28,526
	Pop. Est	10,942,401	11,739,556	22,681,957
Massachusetts	*%*	37.2%	62.8%	
	C.I.	(31.7-42.8%)	(57.2-68.4%)	
	n	195	360	555
	Pop. Est	154,020	259,833	413,853

C.I. = 95% Confidence Interval. Percentages are weighted to population characteristics.

n = cell size. Use caution in interpreting cell sizes less than 50.

Note: Per AAP guidelines, all young children should be offered a developmental screening at 9 mos., 18 mos. and 30 mos. well child visits.

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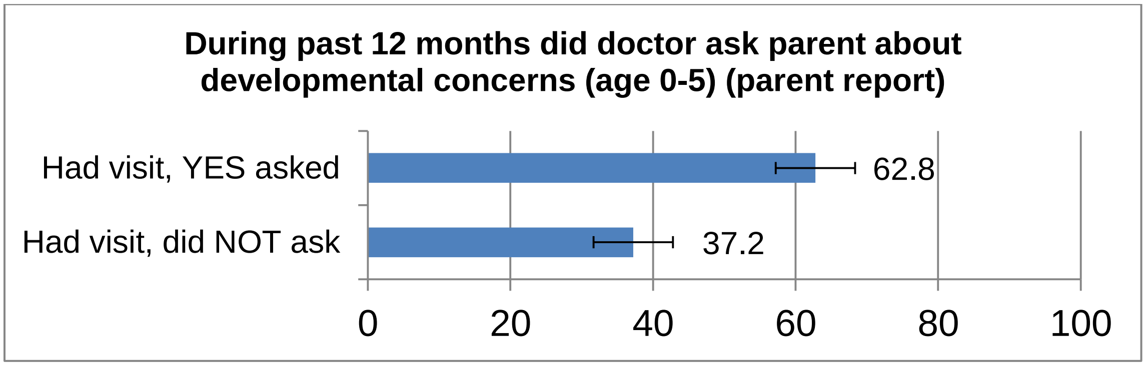
[49] National surveys are based on a sample of people and therefore provide estimates of different outcomes. We will present both the point estimates, in this case 62.8% of parents of MA children, and confidence intervals: (C.I. 57.2-68.4%). The confidence interval can be interpreted as: We are 95% confident that the true rate of parents of MA children asked about developmental concerns in MA is somewhere between 57.2% and 68.4%.

**Graph EI-3. During past 12 mos., doctor asked about developmental screening (0-5)
NSCH 2011-12**



The NS-CSHCN estimates that parents of 67.1% (C.I. 56.5-77.7%) of Massachusetts' CSHCN aged 0-5 were asked to complete a formal developmental screening questionnaire at a well-child visit. However, almost 30% (18.4-38-5%) were not asked. Rates of screening in MA significantly exceed the estimates of national screening rates considerably (by almost 20%), where 49.9% (C.I. 47.8-52.1%) of parents of CSHCN were asked to fill out a questionnaire and almost 50% were not asked.

Table EI-4. During past 12 mos., did a doctor or other health care provider have you fill out a questionnaire about specific concerns or observations you (parent) may have about your child's development, communication, or social behaviors? (CSHCN 1-5 years), NS-CSHCN 2009-10

		No, did not fill out questionnaire	**Yes, filled out questionnaire**
U.S.	*%*	49.0%	49.9%
	C.I.	(46.9-51.1%)	(47.8-52.1%)
	n	1,054,066	1,074,360
	Pop. Est	9,487,574	839,275
Massachusetts	*%*	28.5%	67.1%
	C.I.	(18.4-38.5%)	(56.5-77.7%)
	n	34	78
	Pop. Est	11,225	26,474

C.I. = 95% Confidence Interval. Percentages are weighted to population characteristics.

n = cell size. Use caution in interpreting cell sizes less than 50.

Compared to the NSCH results, it is clear that pediatric health care providers in Massachusetts are conducting both formal and informal screening for developmental concerns. In comparison with national results, Massachusetts appears to be well ahead of the rest of the country in developmental screening.

CHILD RECEIVED BOTH TYPES OF SCREENING CONTENT (10-71 MOS.). The 2011-12 NSCH estimates that 55.1% (C.I. 48.9-61.3%) of all Massachusetts children aged 10-71 months received two *types of screening content (development; communication or social behaviors) at a well-child visit.* Forty-four percent (44.9%, CI: 38.7-51.1%) of parents reported that their child was not screened for both development and communication or social behaviors. Compared to only 30.8% (C.I. 29.5-32.1%) of

U.S. children reported to have received both types of screenings, Massachusetts results significantly exceed the national estimate by almost 25%.

Moreover in the previous 2007 NSCH, only 16.4% of Massachusetts parents reported that their child "received a standardized screening for developmental or behavioral problems" compared to only 19.5% in the rest of the U.S. By the 2011 NSCH, the Massachusetts number had improved by almost 40 percentage points. Even so, there is still room for improvement according to these findings.

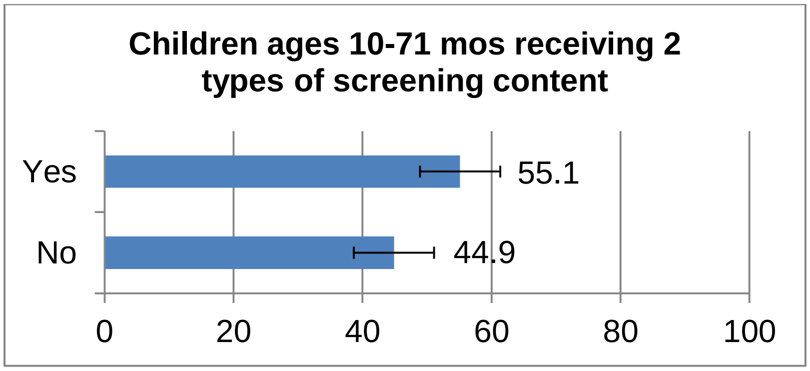
Table EI-5. Children ages 10-71 mos., receiving both types of screening content, NSCH 2011-12

		No, did not receive both types of content	**Yes, filled out questionnaire and received both types of screening content**	**Total**
U.S.	*%*	69.2%	30.8%	
	C.I.	(67.9-70.5%)	(29.5 - 32.1%)	
	n	17,086	7,192	24,278
	Pop. Est	13,243,726	5,896,657	19,140,383
Massachusetts	*%*	44.9%	55.1%	
	C.I.	(38.7-51.1%)	(48.9-61.3%)	
	n	220	226	446
	Pop. Est	152,687	187,580	340,267

C.I. = 95% Confidence Interval. Percentages are weighted to population characteristics.

n = cell size. Use caution in interpreting cell sizes less than 50.

Graph EI-6. MA children ages 10-71 mos., receiving both types of screening content, NSCH 2011-12



Early Childhood Developmental Screening Programs

In addition to screening conducted by primary health care providers, developmental screening can be conducted by a number of professionals in health care, community, and school settings serving as strategic community partners in promoting healthy early childhood development. Two Massachusetts programs that have stood out in particular have been offered by the Massachusetts Department of Early Education and Care (EEC) and Thrive in 5 Boston. Both have implemented developmental screening programs in recent years targeted to early childhood educators and parents of young children.

EARLY EDUCATION & CARE RACE TO THE TOP LEARNING CHALLENGE: HELP ME GROW. From 2010 to 2015 the Massachusetts Department of Early Education and Care (EEC) leveraged resources from the National Help Me Grow Center (HMG) and their Race to the Top-Early Learning Challenge (RTTT-ELC) grant in partnership with United Way of Massachusetts Bay and Merrimack Valley. The underlying purpose of RTTT was to implement innovative and aggressive strategies to increase college and career readiness for all students and close persistent achievement gaps. For the RTTT-ELC initiative, the underpinning of this work was the notion that "brain building is in progress for young children in enriching environments with caring adults and meaningful and engaging interactions."

The Help Me Grow model aimed to connect pediatricians, centralized call centers, early education and care educators and programs, and families to ensure that young children receive the developmental screenings, assessments and supports that they need to grow and thrive. The Massachusetts program used its Coordinated Family and Community Engagement programs (CFCEs) to provide support and education to families and caregivers around child development using both the Ages and Stages Questionnaire (ASQ-3) and the ASQ:Social-Emotional (ASQ:SE) developmental screening tools. CFCEs connected families to appropriate services and resources in their communities. Parents could bring their completed ASQ to their child's pediatrician who could use it to complement their own scheduled screening. For those who accept MassHealth, they would need to use a MassHealth approved screening tool since MassHealth does not reimburse for the ASQ-3.

The table below reflects screenings done under the Help Me Grow program in Massachusetts between July 1, 2011 and May 15, 2013. This is not indicative of all Help Me Grow ASQ screenings; it represents only the data that had been entered online. It does indicate the utility of such a program in assisting in the identification of children with developmental concerns. As the average screening age range of 30-60 months suggests, the ASQ screenings have application for both children under the age of three as well as preschool age and above.

Table EI-7. Help Me Grow ASQ screenings between July 1, 2011 and May 15, 2013

Language	Number of ASQ-3 Screenings	Number of ASQ-SE Screenings	Most Common Age Interval, ASQ-3	Average Age Interval, ASQ-3	Most Common Age Interval, ASQ-SE	Average Age Interval, ASQ-SE
English	656	280	36mos	30.2	36mos	34.4
Spanish	69	31	36mos & 60mos	34.8	36mos	36.6

Source: EEC Help Me Grow program, 2013.

In addition, EEC's Help Me Grow program worked with the Mass 2-1-1 call center to add search terms related to screening and referral for autism and other developmental concerns. It is not certain if Mass 2-1-1 call center is still actively using these terms and collecting data on their usage, but it is another place to possibly measure the frequency of calls and referrals for developmental concerns.

Although the Help Me Grow program ended at the end of the Race to the Top grant, the CFCEs continue to work with families using the ASQ screens.

THRIVE IN 5: SCREEN TO SUCCEED PROGRAM. From 2008 through 2016, Thrive in 5 was Boston's citywide movement to ensure all Boston children have the opportunities and support they need for success in school and beyond. It was created under former Boston Mayor Thomas Menino as a partnership between the United Way of Massachusetts Bay and Merrimack Valley and the City of Boston, as well as many other funders and community partners. Thrive in 5 set family and community engagement, quality early education and care and healthy child development as their overarching goals. Built upon the EEC's former Help Me Grow CFCE screening model for use in Boston, Thrive in 5 integrated and boosted their efforts.

Under Thrive in 5's healthy child development goal, the *Screen to Succeed* program uses a citywide, universal screening system to measure children's development in their early years. *Screen to Succeed* is still going strong under the United Way and hinges upon the idea of the "brain building" phase of a child's life. The program has two goals:

1.) Support children and families: Build community capacity to screen children early for potential developmental delays, and use the ASQ as a tool for family engagement, education and referral to services.
2.) Drive policy and systems change: Create a universal screening system to gain a better understanding of the developmental progress of young children in Boston to inform funding and policy decisions.

The *Screen to Succeed* program collects ASQ data through multiple sources:

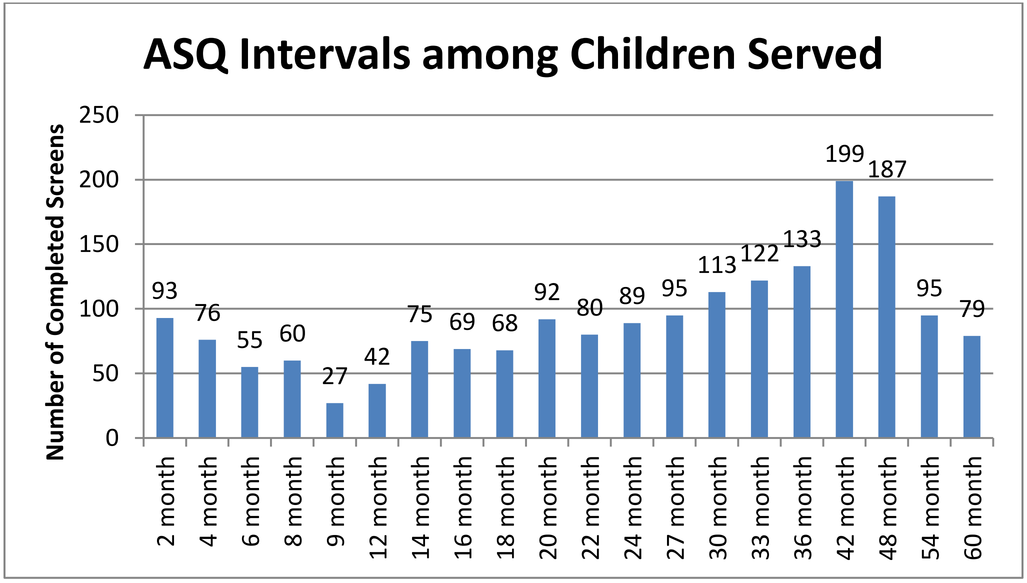
- Peer-to-peer parent screener who could connect with families in their communities in their own languages and cultures and offer the screening as well as resources and information based on the results.
- Parents screening their own children in their own homes with the support of trained staff as part of learning about early child development.
- Early education and care providers to gather data from the ASQ screenings conducted in their programs.

A data report on the *Screen to Succeed* program from May 2013 through June 2015 (Thrive in 5, September 24, 2015) found that in Boston, 2,279 screens had been completed of which 2,071 children were unique, first time screens and 193 children received two or more screens (210 re-screens completed).

As shown in Table EI-8, starting at 20 months through 54 months, the ASQ screenings were increasingly used. The ages of 42 and 48 months appear to be the highest period of use. Ideally, developmental screening should occur routinely within the range of 9, 18 and 30 months of age.

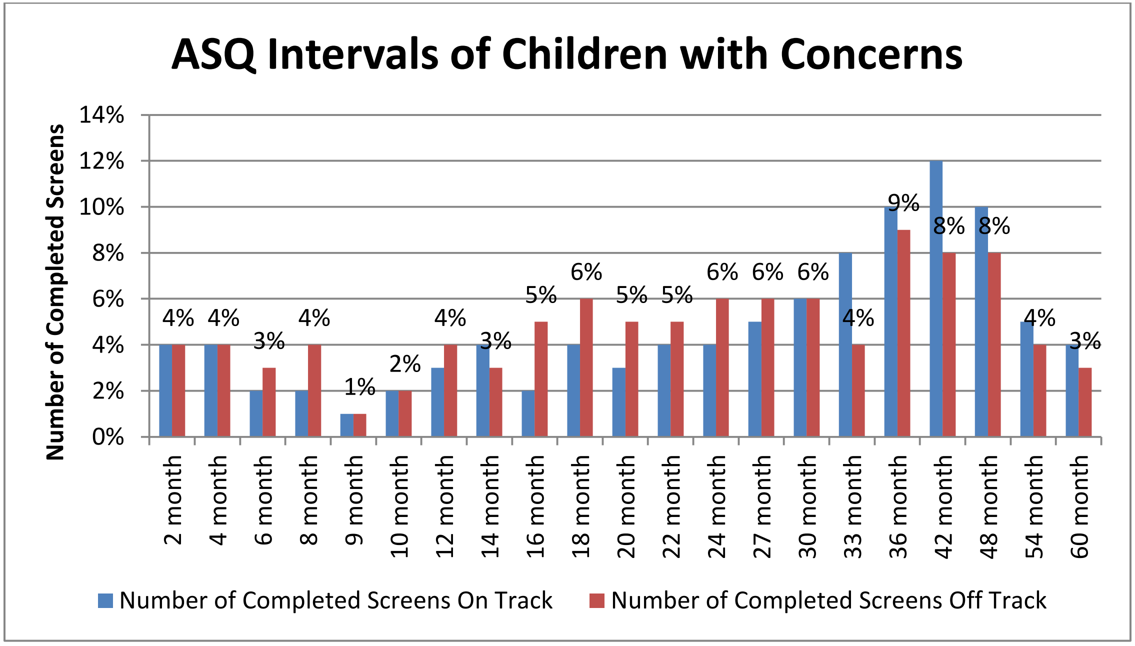
Of the 16 Boston neighborhoods participating in the *Screen to Succeed* program, Dorchester was well ahead of the other parts of the city totaling 841 screens compared to the next highest screens: Brighton at 193, Jamaica Plain at 143, Roxbury at 135. The fewest number of screens were recorded in Downtown Boston at 12 and Charlestown at 15.

Table EI-8. ASQ intervals among children served in Boston (n = 737) (May 2013-June 2015)



Of the children screened, 51% were male and 49% were female (n=1,990). Regarding race and ethnicity, 37% were Latino/Hispanic children, 9% were Haitian/Caribbean and 6% were Cape Verdean (n=966). Of the races among children screened (n=1,219) 23% were white, 18% were Asian, 26% were black or African American, 25% were "other" and 8% were bi- or multi-racial. Of the languages spoken for children screened (n=1,040) 47% spoke English, 20% spoke two or more languages, 17% spoke Spanish, 9% spoke Vietnamese, 2% spoke Cape Verdean, 1% spoke Portuguese, 1% spoke Chinese, 1% spoke Haitian-Creole and 2% spoke an "other" language.

Table EI-9. ASQ intervals among children served with concerns (n = 737) (May 2013-June 2015)



The overall ASQ results in Table EI- 9 show that 59% of the children screened were "on track" with the acquisition of developmental milestones (meaning that no further follow-up was needed), 22% showed a "potential concern," and 19% showed a "strong concern."

Of the 846 children with concerns, slightly more boys showed a potential concern (24% boys to 20% girls) (n=456) or a strong concern (21% boys to 20% girls) (n=390) (data not shown). Those children who were "off track" were slightly higher than those who were "on track" from 10 months through 27 months though the percentage of off track between 36 and 48 months trailed behind the majority of on track children starting from 30 months on and yet they still exceeded the percentage of younger children indicating that they were flagged for concerns later than desired. Those with concerns largely fell into racial minority groups (28% Black, 27% Other, 21% Asian, 21% white and 3% multi-racial (data not shown).

The data findings yielded interesting questions for future programming such as asking caregivers to share their age in order to identify teen parents who might benefit from enhanced parenting education, reviewing if a positive outcome is influenced by two or more children in the home, and other research questions.

Lastly from 2012-2015, *Screen to Succeed* had achieved the following:

- Trained and supported over 20 parent screeners in 3 neighborhoods
- Partnered with 13 family organizations to offer ASQ screening during playgroups and other family activities totaling 550 screens
- Partnered with 12 early education and care providers to gather data for approximately 850 children
- Formed a learning community with parent screeners and partners
- Influenced activities and opportunities that community-based organizations are providing for families with young children

Since the route to identifying autism is through developmental screening before an autism screen is conducted, programs such as the two above hold promise for reducing disparities in screening and engaging families in developmental monitoring while tracking data to monitor outcomes and plan for the future. Workforce development should also be measured to identify baselines from which to build capacity, to set goals and measure outcomes.

Autism Diagnosis

The importance of understanding and monitoring the average age of an autism diagnosis cannot be underestimated. These days, it is widely accepted and evidence shows that the earlier that autism is identified and evidence-based intervention is delivered, the better for the functioning and long term outcomes for both the child and family. Emerging research is confirming a critical window of time for certain children, dubbed the "optimal outcome" window[50], meaning that when identified early enough, a subset of children with autism outgrow their diagnoses. Research suggests that those people who lost their autism diagnoses were diagnosed younger, before 31 months of age,[51,52] and

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[50] Fein D, Barton M, Eigsti IM, Kelley E, Naigles L, Schultz RT, et al. (2013). Optimal outcome in individuals with a history of autism. *Journal of Child Psychology and Psychiatry, and Allied Disciplines, 54*(2), 195-205. doi:10.1111/jcpp.12037 [doi]

[51] Wiggins LD, Baio J, Schieve L, Lee LC, Nicholas J, & Rice CE. (2012). Retention of autism spectrum diagnoses by community professionals: Findings from the autism and developmental disabilities monitoring network, 2000 and 2006. *Journal of Developmental and Behavioral Pediatrics, 33*(5), 387-395. doi:10.1097/DBP.0b013e3182560b2f [doi]

[52] Turner LM, & Stone WL. (2007). Variability in outcome for children with an ASD diagnosis at age 2. *Journal of Child Psychology and Psychiatry, and Allied Disciplines, 48*(8), 793-802. doi:JCPP1744 [pii]

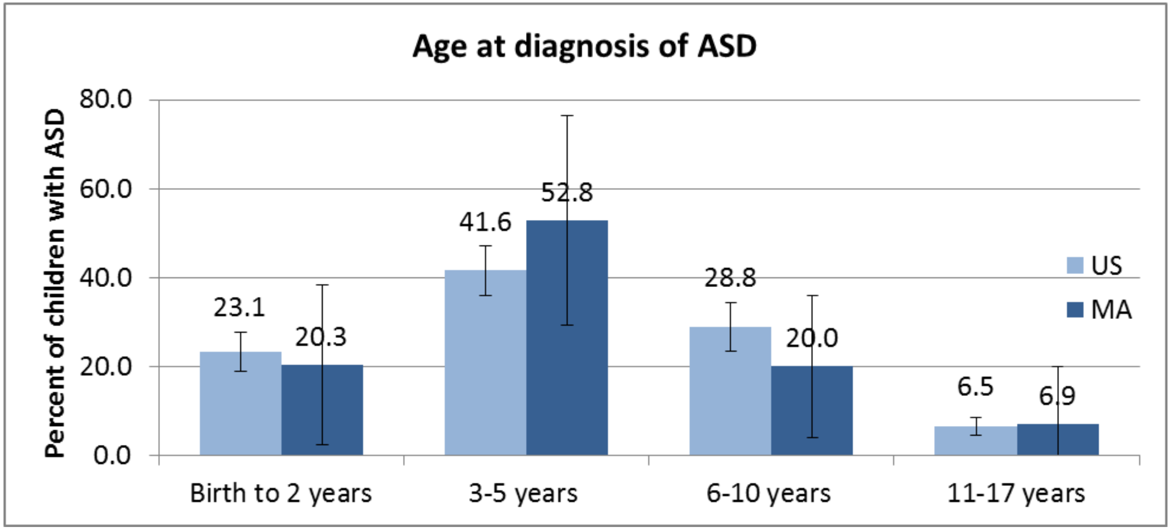
underwent earlier and more intensive autism intervention[53]. Outcomes like these make it more important than ever to establish and track the baseline of diagnostic data to chart and influence the progress of early diagnoses leading to earliest possible interventions for all children with autism.

National Survey Information about Autism Diagnosis

National data from the NSCH and NS-CSHCN provide limited insights into the average age of diagnosis in Massachusetts, though ask important questions and provide some helpful national outcomes. Due to the small state sample sizes for all results in this section, these data are not reliable enough for the purposes of this report, making further investigation in Massachusetts necessary. State data findings to follow yield more salient estimates for autism diagnosis. (For all data tables, see the Appendix section under "Early Identification Data". For more information about reliability of the NSCH and NS-CSHCN for Massachusetts results, please see the Overview section).

AGE AT DIAGNOSIS. The 2011-12 NSCH estimates the following distribution of age ranges for when Massachusetts children were first diagnosed with ASD: 20.3% (C.I. 2.3-38.4%) from birth to 2, 52.8% (C.I. 29.2-76.4%) from 3-5 years old, 20.0% (C.I. 3.9-36.0%) from 6-10 years old, and 6.9% (C.I. 0.0-20.0%) from 11-17 years. The percentages are not significantly different from national estimates at 23.1% (C.I. 18.7-27.5%) from birth to 2, 41.6% (C.I. 36.0-47.1%) from 3-5 years old, 28.8% (23.5-34.2%) from 6-10 years old, and 6.5% (C.I. 4.5-8.5%) from 11-17 years old.

Chart EI-10. Age at diagnosis of ASD, NSCH, 2011-12



The 2009-10 parent-reported NS-CSHCN estimates that Massachusetts CYSHCN with ASD were diagnosed in the following age ranges: 25.2% (CI. 14.2-36.3%) from birth to 2, 43.4% (CI. 28.4-58.5%) from 3-5 years old, 19.9% (CI. 10.2-29.6%) from 6-10 years old and 11.5% (CI. 0.0-23.2%) from 11-17 years. This lines up closely with the survey's national estimates of 26.9% (C.I. 23.9-29.9%) from birth to two, 44.7% (C.I. 41.5-47.9%) from 3-5 years, 22.0% (C.I. 19.6-24.4%) from 6-10 years and 6.4% (C.I. 5.1-7.7%) from 12-17 years old.

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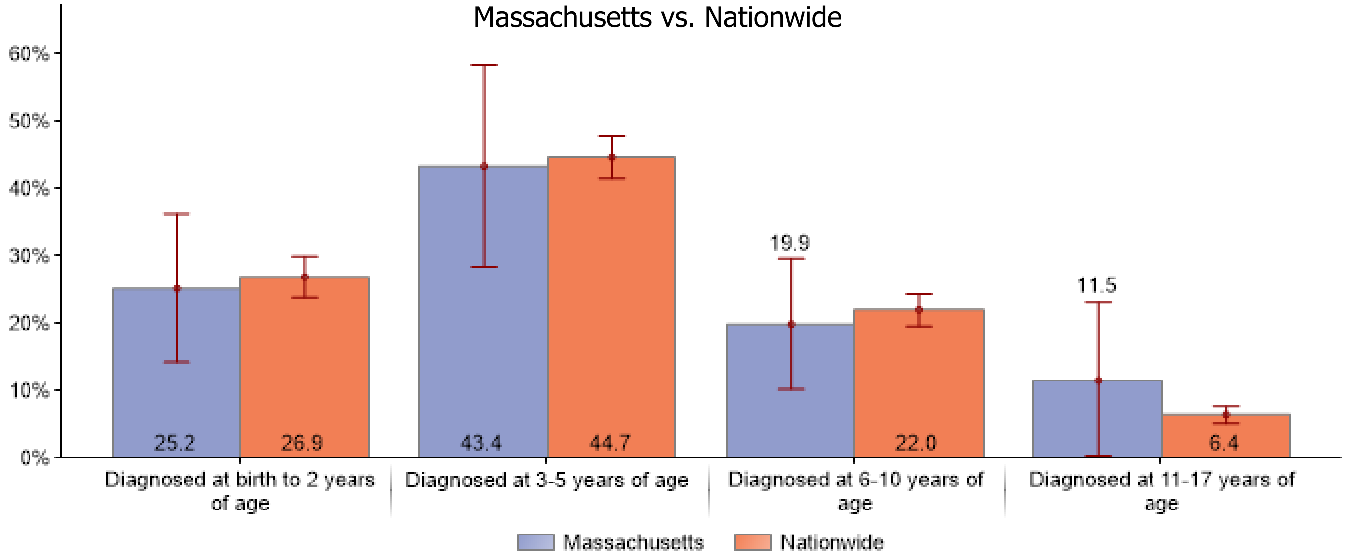
[53] Anderson DK, Liang JW, & Lord C. (2014). Predicting young adult outcome among more and less cognitively able individuals with autism spectrum disorders. *Journal of Child Psychology and Psychiatry, and Allied Disciplines, 55*(5), 485-494. doi:10.1111/jcpp.12178 [doi]

Chart EI-11. Age at diagnosis of ASD, NS-CSHCN, 2011-12



TYPE OF DIAGNOSING HEALTH CARE PROVIDER. The NSCH 2011-2012 looked at the types of health care providers who "first told you your child had autism or ASD". Although the results are not large enough to be meaningful, understanding the source of diagnosis is an important question to plan for building workforce capacity and investing in development, especially for those regions of Massachusetts such as the Southeast and Western Massachusetts that may be in need of more diagnostic specialists. Therefore further investigation is warranted to fully understand the type, number and locations of specialists providing diagnoses in Massachusetts.

Compared to the rest of the country, Massachusetts is fortunate to have a high number of diagnostic specialists, however they may be concentrated in regions such as Metro Boston. Without enough specialty providers, with long wait times, and with only certain providers accepting MassHealth, there is a need to understand and build capacity in regions that continue to experience disparities, making this an important baseline to set and monitor for progress over time. (See "Wait Time Survey" in Early Identification section for more information).

The top physicians reported by parents to have shared their child's ASD diagnosis were psychiatrists, specialist doctors (other than DBPs, psychiatrists, or neurologists), specialist pediatricians such as DBPs, pediatricians or other general pediatric health care provider, other non-school psychologists and neurologists. It is not possible to identify which types of physicians are diagnosing most frequently in MA due to extremely low sample sizes. National estimates showed the top diagnosing physicians as general pediatricians at 21.6% (C.I. 12.8-25.4%), specialist pediatricians such as DBPs at 15.8% (12.2-19.4%), other non-school psychologists at 13.3% (10.29-16.29%), psychiatrists at 12.1% (C.I.9.6-14.7%), however the relative contribution to diagnoses was not significantly different between these specialties and they cannot therefore be ranked.

State Information about Autism Diagnosis

EARLY DIAGNOSIS OF ASD. In an effort to monitor trends in early diagnoses of ASD in Massachusetts prior to age 36 months, a Massachusetts Department of Public Health (MDPH) study[54] reviewed in-state births to resident mothers over the period of 2001 through 2005 to

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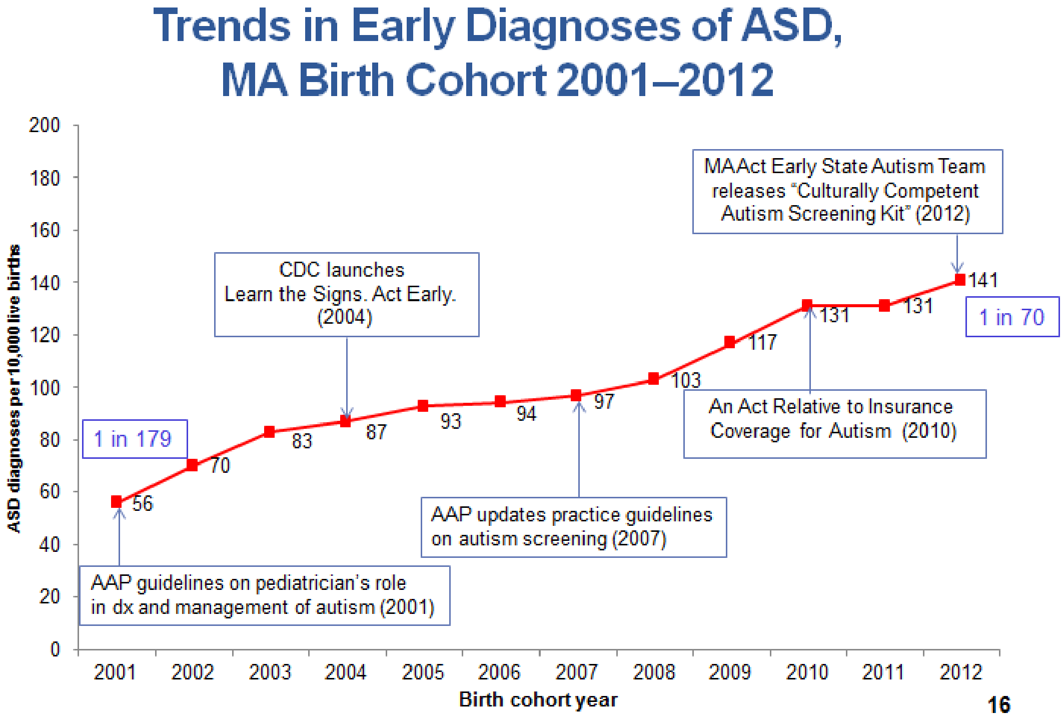
[54] Manning S, Davin CA, Barfield WD, Kotelchuck M, Clements K, Diop H, Osbahr T, & Smith L. (2011). Early diagnoses of autism spectrum disorders in Massachusetts birth cohorts, 2001-2005. *Pediatrics, 127*, 1043.

examine trends in ASD by age 36 months (early diagnoses) and identify characteristics associated with such early diagnoses in Massachusetts. State birth certificate data in the Pregnancy to Early Life Longitudinal (PELL) data system and Massachusetts Early Intervention program data were linked to identify infants who were born 2001 – 2005, stayed in Massachusetts after birth, enrolled in early intervention, and received autism-related services before age 36 months.

A total of 3,013 children (77 per 10,000 live births) were enrolled in Early Intervention for ASD before the age of 36 months. The study found that the estimated incidence of ASD in children under 3 years in Massachusetts increased 66% from 1 in 179 (56/10,000) among the 2001 birth cohort to 1 in 108 (93/10,000) among the 2005 birth cohort, reflective of the increasing national trend seen in other studies. The study also found that infants of mothers whose primary language was not English or who were foreign-born, or mothers younger than 24 years of age had lower odds of an early autism spectrum disorder diagnosis. The adjusted odds male to female ratio of early ASD was 4.5:1 (controlling for several maternal and infant characteristics). Non-singleton, low birth weight, and preterm infants had higher odds of early ASD diagnoses. These findings may reflect groups whose children are less likely to be identified due to language, culture and parental age barriers.

Table EI-12. Trends in Early Diagnosis of ASD, MA Birth Cohort 2001-2012, Manning et al.



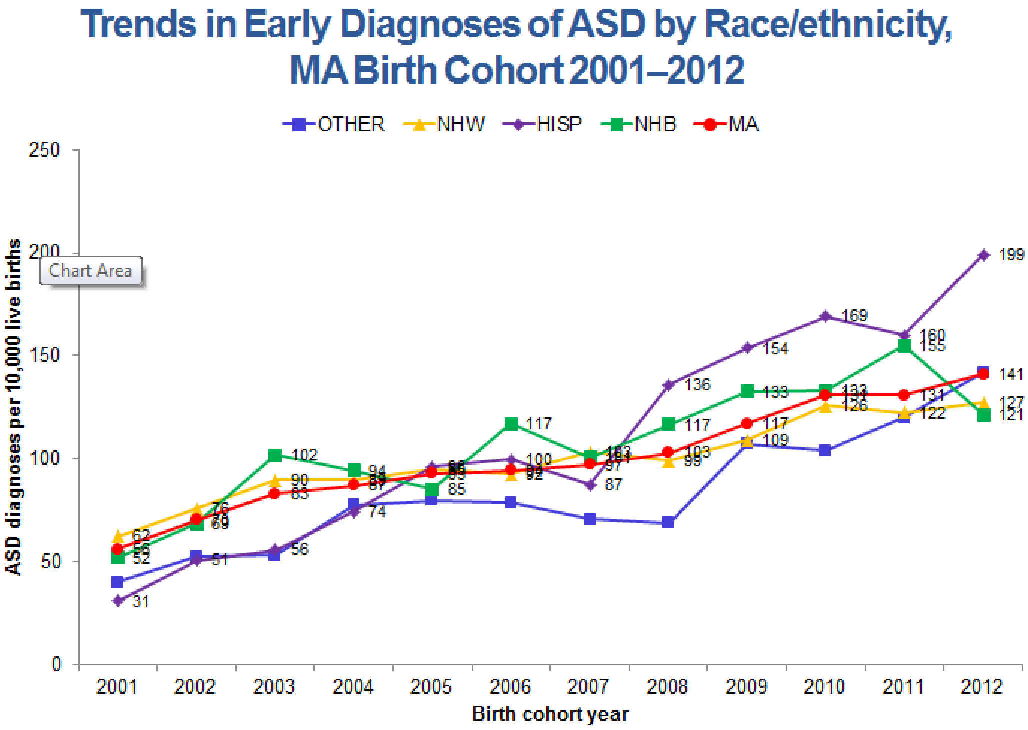
Source: MA Pregnancy to Early Life Longitudinal Data System – Preliminary data.

In 2001, there were much lower rates of early ASD diagnosis in racial minorities; however, in 2005 racial differences substantially lessened. This suggests that screening improved among racial minorities during this time frame in the state and could be reflective of similarly timed screening efforts in Massachusetts. In non-Hispanic whites, early ASD diagnosis was less frequent among children of mothers with 4+ years of college compared with high school graduation. In contrast, more early ASD diagnoses occurred among children of all other racial/ethnic groups with more education than those with less education which is suggestive of screening gaps in minorities with lower educational levels, particularly non-Hispanic "other" races. Although Early Intervention has been successful in capturing reliable data for those children served, there is a need to understand the outcomes for children who are not picked up in time to receive EI services such as those who come from non-English speaking families.

In an unpublished 2016 follow-up study, the MDPH team[55] found that early diagnoses of ASD increased to 1 in 70 births in 2012 (141/10,000) indicating that early diagnoses of ASD before 36 months of age continue to increase in Massachusetts. The following table overlays the series of historical events and changes in policy (e.g., public awareness campaigns) along a timeline to see possible influences on prevalence findings for the Massachusetts birth cohort from 2001 through 2012. Given that under the CBHI in 2008, MassHealth commenced the requirement of behavioral screening at all pediatric well-visits, its strong influence should also be considered as a factor in the continuing encouraging outcomes in increased autism diagnoses.

Socio-demographic disparities in early ASD diagnoses exist, but are changing. Hispanics have experienced a disproportionately high increase, irrespective of language. ASD diagnoses among Massachusetts children by age 36 months appear higher than expected based on national estimate of one in 68 among 8 year-olds.

Table EI-13. Trends in Early Diagnosis of ASD by Race/Ethnicity, MA Birth Cohort 2001-2012, Manning et al.



Source: MA Pregnancy to Early Life Longitudinal Data System – Preliminary Data [56]

According to the authors, potential explanations for the increasing trend in early ASD diagnoses could indicate a true increase in prevalence, more widespread and effective screening and diagnosis,

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[55] Manning & Diop (May, 2016). Presentation at 2016 MEIC Conference, Marlborough MA.

[56] The abbreviations in the legend for the *Trends on Early Diagnoses of ASD by race/ethnicity* table above represent the following: NHW, non-Hispanic White; HISP, Hispanic; NHB, non-Hispanic Black; MA, multiple races/ethnicities.

increased efforts to identify ASD early, increased use of the diagnoses to qualify a child for intensive services, and/or increased parental awareness/advocacy.

Limitations of this study include the fact that diagnosis of ASD in EI has not been validated. It is also possible that these results underestimate early ASD diagnoses since records were missing information on key linkage variables. In addition, out of state births, adoptions, and children with ASD who are not enrolled in EI are not included. Finally, EI data include information on children from birth to age 36 months only and no data were available on ASD diagnoses in older children.

The MDPH ASD incidence estimates are currently the best available for Massachusetts for those children who were diagnosed and receiving early intervention before their third birthday. This leaves open the question about those children who may not have been identified in time to be reported in DPH numbers. School data may introduce confounding diagnostic categories due to inconsistencies with classification categories, multiple coders from a variety of school systems, inaccurate and over-diagnosis of children in an attempt to get services. Yet, it is possible that there are pockets in the state where early diagnosis is less successful due to regional, cultural, linguistic and other issues. It will be important to understand where these barriers may exist and to determine the best way to capture these data in the future to reduce possible inequities.

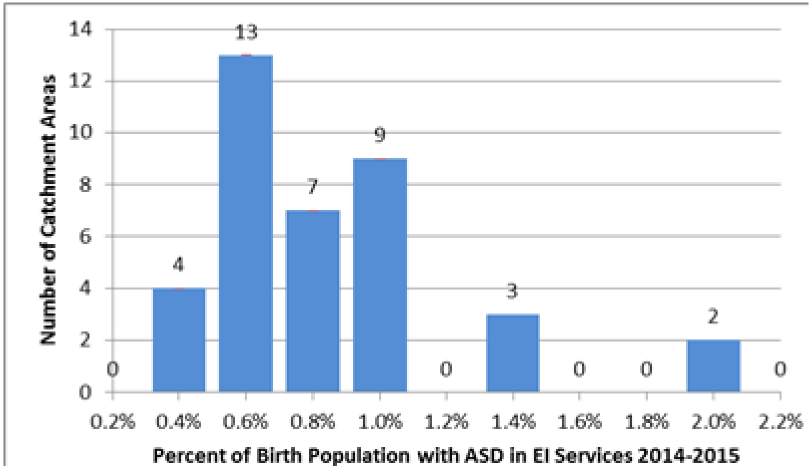
EARLY INTERVENTION AND REFERRAL. The numbers of Massachusetts children with ASD served by the MDPH Early Intervention Office of Specialty Services have grown significantly since 1999 to present. The table below shares information about annual EI enrollments:

Table EI-14. Estimated # of MA children with ASD under the age of 36 months enrolled in EI

	1999	2004	2009	2015
EI Specialty Services Enrollment	340	775	1,321	2,008

An analysis of MDPH Early Intervention Referrals was conducted by our project team to explore whether there are differences in catchment area in identification and service provision for young children (age birth to 3 years) in Massachusetts who might not be identified and served as early as other children living in other catchment areas. To understand this better, we compared birth population by catchment area to children enrolled in Early Intervention in general as well as by ASD diagnosis and compared it to the number of EI offices and known physicians in the catchment areas, as well as to other factors: age of diagnosis, race/ethnicity and language spoken at home.

Figure 15. Array of % of birth population with ASD in EI services by Catchment area



In Fiscal Years 2015 and 2016 (July 1, 2014 to June 30, 2016), the MDPH's Early Intervention program served a total of 38,478 children with special health care needs (CSHCN) aged birth to 3 years. Of these CSHCN receiving EI services, 5.29% or 2,036 were known to have ASD. The percent of CSHCN in EI with ASD ranges across the state's 38 catchment areas from a low of 2.2% to a high of 10.7% with a median of 4.9% and an average of 5.3% having a diagnosis of ASD.

When compared with the birth population in 2012, 2013 and 2014 representing those children eligible for EI services during this period, about 17.8% of all children in Massachusetts received EI services, and 0.94% of all children were served in EI with an ASD diagnosis. When examining the data by catchment area, the percentage of the birth population served in EI services with ASD ranged from 0.42% to 2.16%, with a median of 0.83% and a mean of 0.94%. The distribution of catchment areas by the percent of the birth population served with ASD is shown in the figure to the right. More information about children served by catchment area is available in the Appendices under "Early Identification Data."

The table below presents the five catchment areas in the state with the lowest percentage of the birth population served by EI with ASD, as well as the five catchment areas with the highest percentages. While the number of EI centers per catchment area was significantly correlated with the size of the birth population[57], it was not correlated with either the proportion of the population enrolled in EI services[58], or the proportion of the population enrolled in EI services with ASD.[59]

Table EI-16. MA catchment areas with lowest vs. highest % of birth population served by EI with ASD

EI Catchment Areas[60]		**Birth Pop. (2012+2013 + 2014)**	**Early Intervention**		**% of Population Served by EI**		**# of EI Ctr's**
Ctr #	**Cities and Towns**		**Total Served**	**ASD Served**	**Total Served**	**ASD Served**	
Lowest 5 Catchment Areas, Based on % of Birth Population Served in EI with ASD							
9	Becket, Cheshire, Dalton, Hancock, Hinsdale, Lanesborough, Lee, Lenox, Peru, Pittsfield, Richmond, Tyringham, Washington, Windsor	2,132	373	9	17.50%	**0.42%**	1
7	Barnstable, Bourne, Brewster, Chatham, Chilmark, Dennis, Eastham, Edgartown, Falmouth, Gay Head, Harwich, Mashpee, Nantucket, Oak Bluffs, Orleans, Provincetown, Sandwich, Tisbury, Truro, Wellfleet, West Tisbury, Yarmouth	5,519	765	24	13.86%	**0.43%**	1
22	Cambridge, Somerville	6,727	797	34	11.85%	**0.51%**	2
19	Braintree, Cohasset, Hingham, Hull, Norwell, Scituate. Weymouth	4,900	685	29	13.98%	**0.59%**	1
13	Belmont, Waltham, Watertown	4,776	673	30	14.09%	**0.63%**	1
Highest 5 Catchment Areas, Based on % of Birth Population Served in EI with ASD							
27	East Longmeadow, Hampden, Longmeadow, Springfield, Wilbraham	7,767	2,161	168	27.82%	**2.16%**	3
10	Belchertown, Chicopee, Granby, Holyoke, Ludlow, Monson, Palmer, South Hadley, Southampton, Ware	5,969	1,208	123	20.24%	**2.06%**	2

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[57] Linear regression, R^2= 0.67, p=<0.01

[58] Linear regression, R^2=0.005, P=0.67

[59] Linear regression, R^2=0.06, p=0.14

[60] Data provided by MDPH Early Intervention program; Analysis by E. Lauer, UMMS-Shriver CDDER

EI Catchment Areas[60]		Birth Pop. (2012+2013 + 2014)	Early Intervention		% of Population Served by EI		# of EI Ctr's
Ctr #	Cities and Towns		Total Served	ASD Served	Total Served	ASD Served	
35	Alford, Egremont, Great Barrington, Monterey, Mount Washington, New Marlborough, Otis, Sandisfield, Sheffield, Stockbridge, West Stockbridge	388	71	6	18.30%	**1.55%**	1
2	Ashburnham, Barre, Gardner, Hardwick, Hubbardston, New Braintree, Oakham, Princeton, Rutland, Templeton, Westminster, Winchendon	2,159	300	32	13.90%	**1.48%**	1
11	Bellingham, Blackstone, Douglas, Franklin, Grafton, Hopedale, Medway, Mendon, Milford, Millbury, Millville, Northbridge, Sutton, Upton, Uxbridge	5,918	922	83	15.58%	**1.40%**	1

Throughout the state of Massachusetts, the EI program has identified 394 diagnosticians spread across the 38 catchment areas. Statewide, in the FY15/16 service year, there were 12.1 diagnosticians per 100 children served in EI with ASD, ranging from 11 diagnosticians per 100 children with ASD in EI to 78 diagnosticians per 100 children with ASD in EI, a median rate of 48 per 100 and average of 47 per 100. There was not a significant association between the rate of diagnosticians per 1,000 children born in the catchment areas and the percent of children with ASD enrolled in Early Intervention services.[61]

In terms of Age at Diagnosis, the majority of children with ASD in EI services were diagnosed at 25-30 months (43%), followed by 19-24 months (33%) and 31-35 months (13%). Most catchment areas had similar distributions in age at diagnosis as statewide patterns. However, some variation occurred across catchment areas. For example, Catchment Area 29 (Fall River, Freetown, Somerset, Swansea, Westport), had almost a third of their EI enrollees with ASD diagnosed between 31-35 months, and 40% were diagnosed between 25-30 months. In Catchment Area 13 (Belmont, Waltham, Watertown), 28% of children with ASD in these services were diagnosed between 31-35 months, and 38% were diagnosed between 25-30 months. Distributions of age at diagnosis for children with ASD enrolled in EI are presented for each catchment area in the Appendix.

Statewide, approximately half of the children with ASD served in EI were white (54%), about a quarter were Hispanic (26%), 9% were African American, 7% were Asian and 3% were of multiple races. Racial distributions ranged greatly per catchment area; for example between 22% and 100% were Caucasian, however this distribution would need to be compared to birth populations in each catchment area to identify any differential representation. Of children enrolled in EI with ASD, the primary language spoken at home for the children is English (81% statewide), ranging from 47% of children to 100% across catchment areas with a mean and median of 83% of children. Other major languages included Spanish (9% statewide, 0-37% of children and mean of 11% within catchment areas), Portuguese (2% statewide, 0-11% of children and mean of 3% within catchment areas) and Chinese (1% statewide, 0-9% of children and mean of 1% within catchment areas). Additionally a subset reported another language spoken at home (7% statewide, 0-24% of children and mean of 10% within catchment areas). Catchment areas with the highest rate of other language spoken at home included Area 22 (Cambridge, Somerville) at 24%, Area 4 (Ashland, Dover, Framingham,

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[61] Correlation r=0.0921, p=0.5877

Holliston, Hopkinton, Natick, Sherborn, Sudbury, Wayland) at 23%, and Area 28 (Everett, Malden, Medford) at 19%.

With the help of data from the MDPH's EI Program, our project team was able to review the above to answer the questions of whether there might be pockets in the state where fewer children with ASD receive timely EI services before the age of three and if so, the differences that might characterize these small subsets of the larger population of children in EI with ASD. There may be some possible areas that could benefit from further investigation on the South Shore and Cape Cod, in Western Massachusetts, and in communities just outside of Boston. The question is whether there is something different about these areas that make these data ring true or rule out this possibility. Although there appears to be no association with a shortage of diagnostic specialists in these areas according to these data, our project team has heard anecdotally through focus groups and key informant interviews that shortages do exist, particularly in the Southeast and Western regions of the state and present important gaps for early identification. Thus, more investigation is needed.

Qualitative Findings

Focus Groups: Early Identification

The research team conducted one focus group specifically on the topic of Early Identification in order to better understand how children are typically screened, barriers to timely diagnoses, and available resources and services. Questions about screening and diagnoses were also asked across all of the cultural focus groups, the parent leader groups, and the professional groups. Additional information about these groups is in the Methods section.

SCREENING. The Western Massachusetts Early Identification focus group responded that children in that area typically receive screening through their pediatricians. One participant involved with day care providers felt there was a need to provide education to these early childhood professionals on the "red flags'" for autism as well as some training about how to communicate these concerns to parents.

> "*Daycare providers sometime feel that their hands are tied [in being able to communicate concerns to parents] and sometimes there are policies against it. Perhaps there can be a checklist of early ASD signs included at daycare enrollment."* - Autism Awareness Advocate and parent of a child with ASD.

Participants in other focus groups responded that the pediatrician typically performs the screening, either by using a standardized tool, or by asking the parents questions. Some of the non-English speaking parents in the focus groups reported that the pediatrician observed the child and recognized they had autism without doing a formal screening. One Vietnamese parent of a young child reported that her first child also had Down syndrome and that the pediatrician "passed them along" without conducting a screening, presumably because the child already had Down syndrome. **Non-English speaking parents reported that the screening forms were primarily available in English only, suggesting a potential barrier to accurate screening.** One Hispanic parent of a 6-year-old explained, "The doctor wasn't concerned about my child's development. It wasn't until she went to a regular school in kindergarten, and that's when the teacher expressed concern."

DIAGNOSIS. Focus group participants consistently expressed a need for skilled diagnosticians, especially in the Western and Southeastern regions of the state. In both regions, participants in the professional focus groups expressed concern about what they perceived to be either over-, or under-diagnoses of autism.

> *"I'm concerned about over-diagnosis. Some kids receive a diagnosis and no one who sees them later sees the [autism symptoms]. This waters down the services. And the schools are starting to disregard the diagnosis. It's like the child that cries wolf. Some schools will now only accept the neurologist form for the diagnosis."* – Inclusion Consultant, Western region*.*
>
> *"We still see people who see kids with significant needs who say 'I don't think this person has a diagnosis, but I'm going to put autism down so they can get the services and we'll take it off later'. But this is a lifelong diagnosis. Kids who should not have the diagnosis are getting diagnoses, and kids who should get the diagnosis are not getting it. It's about the quality of the diagnosis."* – Director of EI, Southeast region.

In comparison, other participants explained that some doctors are overly-hesitant to give the diagnosis out of concern of labeling or stigmatizing the child. The shortage of diagnostic specialists was another prevalent regional concern. As one public health expert explained further, "So we need not just more diagnosticians, but *skilled* specialists making appropriate diagnoses. Legally, a dermatologist can give a diagnosis. So some pediatricians know what they're doing, others are saying they got a positive score on the M-CHAT, so they can give a diagnosis."

Another concern had to do with incorrect diagnoses contributing to potential racial stigmatization. The African American focus group stated that children in their community are consistently mis- and under-diagnosed as having behavioral problems, learning disabilities, ODD or ADHD, instead of autism, particularly for young boys. This, in turn, can lead to inappropriate and ineffective interventions for these children.

"I've heard from families they go in with a concern but the pediatrician says maybe there is a delay but let's check in another 3 or 6 months. The pediatricians don't give the parents an idea that time is of the essence. So parents are left with the impression it's not a big deal, but time is being lost."

– Autism Awareness Advocate and parent of a child with ASD

Participants in the Western EI focus group also explained that some high functioning children are diagnosed very late.

> *"It surprised me greatly when I got into the school system to see how many kids are diagnosed at a late age. These tend to be kids who are cognitively very bright so people tend to attribute it to being bright and having xyz [anxiety, social problems, etc.]." –Educational Consultant.*

EI specialists in both the West and the Southeast regions expressed concern that they were receiving referrals late. As one EI Director stated, "We are getting the referrals in EI, but we are getting them too late. And we are still getting referrals from physicians saying it's just a speech and language issue but you get out to the family and you can immediately tell it's much more."

"We are still getting 3 and 4 year olds with glaring symptoms, classic autism. But in those cases the parents wanted to wait and see."

– Educational Consultant in the West.

BARRIERS TO TIMELY SCREENING AND DIAGNOSES.

Participants identified the following barriers to timely diagnoses:

- ***Lack of awareness*** by parents, primary care doctors or other professionals (i.e. day care teachers) about the early signs of autism. As one participant in the southeast with decades of clinical experience explained, "Physicians are not always responsive to parents' concerns. If it's a boy, or if they are the second child, we are still hearing this as reasons why those symptoms may not be autism."

- ***Difficulties in completing screening tools.*** Several participants commented that certain screening tools are "long and difficult for some parents", especially those with low literacy or if the forms are not offered in the parent's native language. Said one autism consultant, "I had a physician that didn't know the mom couldn't read. And so she [the mom] just checked anything. In that case, the M-CHAT doesn't mean anything." In the focus group conducted with medical providers at a community health center, pediatricians and family medicine physicians agreed that "it's difficult to conduct the M-CHAT given so many different languages and dialects – it takes a very long time."

- ***Difficulties in scheduling or attending diagnostic appointments.*** There are very long wait times for appointments in some areas of the state, as well as long distances for families to travel. Communication challenges with diagnostic providers also exist and this further prohibits scheduling of appointments. Some participants expressed concern that the majority of scheduling happens during daytime hours when most parents are working and cannot answer phones. Securing childcare to attend appointments and arranging transportation are also barriers.

- ***Language or cultural barriers*** between parents and primary care doctors or between parents and developmental specialists. These language or cultural differences may contribute to the provider misinterpreting a child's autism symptoms or may affect the level of comfort and trust the parent feels in sharing developmental details with the provider. Many practices use a language line to gain access to languages not supported in their clinics.

  "…Translating is not seamless. The family will say they have no concerns…And the M-CHAT is long and difficult to translate. The Spanish version is given to Portuguese-speaking patients because it's the closest we have. We have to rephrase some of the questions that they have answered 'yes' or 'no' to and then the parent says, 'Oh yes or no.'" – Health care provider

  "The language line doesn't always account for dialects. For example, I have a Cape Verdean family who says they can't understand the language line. A Cape Verdean staff member told me that there are five different dialects spoken in Cape Verde." – Nurse practitioner

  "I would include parents who cannot read. We get blank forms back if they can't read, or all the boxes are checked…" – Health care provider

- ***A preference to "wait and see"*** by either the primary care physician or the family to wait and see if autism symptoms improve. Parents and professionals may not prioritize diagnostic visits or adequately understand the importance of early diagnosis. When asked how easy it is to recognize early signs of autism, medical providers in the focus group stated that it is "challenging to know when to advise parents to wait and see and when to be concerned about development", especially given the limited time allocated for well visits or when working with new or transient families; providers indicated it takes time to get to know a child and recognize the symptoms. Parents, especially low-income or transient families, face similar challenges.

As one pediatric nurse states, "It's challenging to get parents to follow-up with a developmental specialist – they are already so overwhelmed. Parents think 'he's still young; we'll give him more time'. They keep putting the appointments off."

- ***Cultural norms.*** Disparities exist due to certain cultural norms that exist in various racial and ethnic communities. According to providers, children from certain regional ethnic communities are less likely to receive diagnoses. A Southeast state agency representative shared, "There is a large Brazilian community that is very 'closed door.' We've got such a large Brazilian community but we have only a handful of clients who are Brazilian. The situation is similar for the Jamaican community." A Boston nurse stated, "For some families, it's not an issue if the child is not talking. In Vietnam, families don't even get routine check-ups. Families only go to the doctor if they are sick. We can't get Vietnamese families to bring in their kids for checks."

> "In multigenerational households, the parents might not be the decision makers. Grandparents might want to wait, not knowing about Autism, and they might be blaming the mother for not teaching their child. There might also be blame about the parent not spending enough time with their child."
>
> – Culturally diverse parent and autism advocate

Cultural differences may also affect a parent's decision to follow-up with diagnostic appointments, especially in multi-generational or patriarchal households. As one parent professional explained, "You see this [parents not following up with a developmental specialist] a lot with young couples where one of the parents might not be living in the home. It becomes a way that the absent parent can assert control by refusing to allow the child to be seen." In cultures where the father is very influential, culturally diverse participants explained that the father may be adamant that "nothing is wrong with my son" and refuse to see a specialist.

Intervention. Throughout the focus groups, participants identified what they felt were the greatest needs in Early Intervention.

Post-diagnosis, parents may not always follow up with Early Intervention. "I have a few parents I am working with who have received a diagnosis and have had the diagnosis for a few years but they still really don't know what autism is, they haven't gotten any service." - Culturally diverse parent leader.

Some participants described large caseloads for autism specialists, especially in the farthest reaches of the state. In these parts of the state, participants indicated that it was not uncommon to see children aged 3-5 years who had never seen EI, even though they were diagnosed before age three. As one professional stated, "Parents are overwhelmed. They are given a list of Early Intervention resources post-diagnosis and don't know where to start. ASD may not be their main priority in competition with more immediate & elementary family needs."

The transition from Early Intervention and into the public schools can also be challenging for families. As one EI Specialist stated, "For some families, transitioning out of EI is like falling off a cliff. They go from a family centered EI program into the child-centered schools."

Focus Group Recommendations

Focus group participants identified the following recommendations regarding early identification:

- Educate parents on the importance of receiving Early Intervention before age 3.
- Support parents with coordinating and attending diagnostic appointments.

- Provide targeted education and outreach to the cultural community on recognizing symptoms.
- Training sessions with daycare providers have been successful in educating parents and identifying early warning signs; however, some EI providers may feel ill-equipped to converse with parents about autism. Training in this area may be helpful.
- Provide a financial incentive to primary care physicians to conduct screenings.
- Revise M-CHAT-R/F to identify which items correlate with which outcomes. This would allow PCPs to better interpret the results.
- Provide support, education, and training to primary care physicians on screening.

Future Possibilities: Early Identification

Some of our findings for the Early Identification core outcome hold promise for the future as sources for data collection purposes or ways to display and share data with the public and between state agencies. This section points out some measurable ideas worth considering.

MASSACHUSETTS EARLY IDENTIFICATION RESOURCES. Prior research suggests that changing trends in early ASD diagnosis by race/ethnicity might be due in part to the success of national and local initiatives to improve early identification. However, such initiatives may not be well known and thus are underutilized. There are pockets of excellence across the state that provide preexisting educational and outreach materials for parents and professionals, training curricula for early childhood and pediatric health care professionals, and other free resources that can be used to directly address early identification disparities and workforce development needs. Massachusetts Act Early at www.maactearly.org is an example of such a collaborative effort spanning multidisciplinary organizations and agencies across the state. To be sustainable, the activities behind such resources need fiscal support. The 2013 Massachusetts Autism Commission report supported this campaign as part of its Priority #7:

"Improve access to autism screening, diagnosis, and Autism Specialty Services through Early Intervention for children diagnosed with autism and those considered at high risk for autism."

Three recommendations specifically mention state agencies supporting and partnering with Massachusetts Act Early to develop a coordinated plan aimed at increasing the availability of clinicians trained to provide comprehensive evaluations of young children at risk for autism, while increasing the pool of trained clinicians and to administering culturally competent screening protocols in languages other than English. Process measures for clinical workforce development, state infrastructure to deliver evaluation services and culturally competent practice improvement are activities that can be monitored to show progress and to address core outcomes.

SOCIAL EMOTIONAL WELLNESS MONITORING AND DETECTION. Social-emotional wellness is another critical part of developmental monitoring in children of all ages. To that end, the Massachusetts Maternal Child Health Transformation Coalition is preparing to issue a position statement entitled *Integrating Social Emotional Wellness in Primary Care for Children Birth to Five in Massachusetts*. The statement presents the need, the importance and strategies that pediatricians and other primary care providers can employ in their work with young children and families and is endorsed by numerous leading state organizations and groups.[62]

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[62] Department of Public Health (DPH), DPH Interagency Coordinating Council, Department of Mental Health (DMH), Department of Early Education and Care (EEC), Boston Public Health Commission (BPHC), Massachusetts Chapter of the American Academy of Pediatrics (MCAAP), Massachusetts Child Psychiatry

Although early identification is a key part of this effort, social emotional wellness extends beyond detection as a critical ongoing practice within the medical home. With Massachusetts leading the way in providing an important focus on children's social and emotional health, the future holds promise for monitoring this aspect of children's development along the autism spectrum as well. As reported earlier in the NSCH results, Massachusetts was ahead of the country in developmental screening, but there is still room for much improvement in screening for both development *and* communication or social behaviors. This initiative may hold the key.

MASSACHUSETTS ALL-PAYER CLAIMS DATABASE (APCD) AND MASSHEALTH DATABASE. The clear success of the CBHI's influence on increases in screening for practices that accept MassHealth payments is encouraging. There is still however the need to know which screenings have been conducted, how often, and which follow up measures were employed, among other key questions. These billing data could be used to track, project and monitor screening to diagnosis to intervention. We have learned through key informant interviews that a number of state groups and agencies may be planning to use the APCD in the future to understand the needs of children with ASD or larger but highly relevant groups. (See the Insurance section on "Medical Billing (Claims) Data" for more information on this topic).

The research protocol used by Savageau et al.[63] that reviewed medical records and MassHealth claims data for change in behavioral health screening, referrals, and treatment utilization may also provide direction for future monitoring purposes. Table EI-18 provides the sources used by the research team to measure change.

Table EI-17. Outcome measures and affiliated data sources (Savageau et al., 2014)

Measure	Description	Source
Formal screening rate	The percent of well child visits for children and adolescents with a standardized behavioral health screening. Standardized behavioral health tools are those approved by MassHealth.	Medical record data
Positive screening rate	The percent of well child visits for which a positive screen for behavioral health conditions resulted from a formal screening.	Medical record data
Referral rate	The percent of well child visits where a positive screen from a formal screening resulted in a referral for behavioral health services.	Medical record data

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Access Project (MCPAP), Thom Child & Family Services, Jewish Family & Community Services (JF & CS), Judge Baker Children's Center, Massachusetts Association for Infant's Mental Health (MAIMH), and Massachusetts Act Early.

[63] Savageau J, Willis G, Muhr K, Keller D, Aweh G & O'Connell E. (September, 2014). *Clinical Topical Review 2013 – Behavioral Health Screening Among MassHealth Children and Adolescents*. UMASS Medical School Center for Health Policy & Research (CHPR).

Measure	Description	Source
Behavioral Health Utilization		
Formal screening	The percent of well child visits with a screen (positive or negative) from formal screening where the child subsequently received treatment within six months of the screen.	Medical record and MassHealth data
Informal screening/surveillance	The percent of well child visits with a screen (positive or negative) from an informal screening where the child subsequently received treatment within six months of the screen.	Medical record and MassHealth data

CBHI implementation has been a powerful systems-level change agent and a possible model for other areas needing positive change. The extent to which it can provide measurable outcomes is limited but should be explored further for opportunities.

STATE ASSIGNED STUDENT IDENTIFIER (SASID) TRACKING. According to the Massachusetts Department of Elementary and Secondary Education's web site,[64] a State Assigned Student Identifiers (SASID) is:

> *"a unique identifier given to each student receiving a publicly funded education in Massachusetts. The SASID number remains with the student throughout his or her educational life in grades pre-K through 12, even as the student transfers from one district or school to another. If the student leaves the state and returns, the student will receive his/her original SASID. Districts can apply for a SASID using the Single Student Registration (SSR) or the Multiple Student Registration (MSR) applications. Once the SASID is assigned, districts can retrieve the unique identifier using the Publish Manager application."*

A memorandum of understanding has been in process between the Department of Public Health and the Department of Elementary and Secondary Education to assign SASID IDs to children when they enter E.I. services instead of when they first enter the school system, allowing better tracking across systems.

This is a promising practice that could assist in data collection by producing accurate coding for ASD at an earlier age, traveling with the child over the course of early childhood and school years, reflecting adjustments in diagnostic classifications and related public services, and more accurately monitoring outcomes and forecasting needs.

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[64] http://www.doe.mass.edu/infoservices/data/sims/sasid/

Resources: Early Identification

CDC's "Learn the Signs. Act Early" Campaign & Massachusetts Act Early

Two robust national and state resources for the promotion of early identification of autism and developmental disabilities are the Center for Disease Control and Prevention's (CDC) national public awareness campaign "Learn the Signs. Act Early."[65] and its local state chapter, the Massachusetts Act Early[66] program. This report measures the activities of both in Massachusetts to show the influence of this program on the larger goals and results of the Early Identification core outcome indicator (see Access section for more information about the Autism CARES Act as a national resource responsible for this and other national and state initiatives).

National CDC's "Learn the Signs. Act Early" Campaign

The national CDC's "Learn the Signs. Act Early." (LTSAE) campaign was launched in October 2004 after extensive research and with help and support from national partners. It aims to change perceptions about the importance of identifying developmental concerns early and gives parents and professionals the tools to help accomplish this goal. The campaign promotes awareness of healthy developmental milestones during early childhood, the importance of tracking each child's development, and the importance of acting early whenever there is a concern.

Working with state, U.S. territory, and national partners, the national LTSAE campaign aims to:

- Help improve early childhood systems by enhancing collaborative efforts within each state and territory to improve screening and referral to early intervention services through Act Early summits;
- Support Act Early Ambassadors to expand the program's reach; and
- Support Act Early state teams with State Systems Grants to improve early identification of autism and other developmental disabilities.

Through the LTSAE campaign, the CDC has partnered with HRSA, Association of University Centers on Disabilities (AUCD), Association of Maternal and Child Health Programs (AMCHP), and state-level systems focused on advocacy, early intervention, public health, education, and health care to improve early identification of developmental delay. The coalition rolled out 11 regional summits across the country from 2008 through 2010 to achieve the above aims. Including the states and territories, there are currently 25 or more state teams of which Massachusetts represents one of the most active state teams (see below). In 2011, the coalition introduced the Act Early Ambassador program. Over four cohorts to date, the number of state ambassadors have been: 11 from 2011-2012, 25 from 2012-2014, 30 from 2014-2016, and now 45 from 2016-2018 representing 41 states and three territories. The CDC Ambassador to Massachusetts has served as on all four cohorts from 2011 to present.

At the heart of the campaign's efforts are the CDC's free research-based, parent-friendly resources to assist pediatric physicians, early childhood educators and parents with child developmental monitoring from age 2 months to 5 years. These include a myriad of written materials and online apps, as well as a full complement of in-classroom and online training modules for professional credits at no cost. Most Act Early state teams participate in dissemination of LTSAE campaign materials and trainings, along with other supporting activities through their state plans. To see the full range of free LTSAE resources, visit: www.cdc.gov/actearly.

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[65] www.cdc.gov/actearly
[66] www.maactearly.org

The national collaborative of partner organizations has supported a number of research and evaluation projects conducted by Act Early teams across the country to advance understanding of how to improve early identification of children with autism and other developmental disabilities, especially among population groups with health disparities. In one national study, pediatricians aware of the campaign were significantly more confident discussing cognitive development (84% vs. 74%) with parents of their patients. In addition, pediatricians familiar with the campaign were more likely to be aware of resources available for referral and treatment (87% vs. 70%) and to have resources to educate parents than physicians who had not heard of the campaign (59% vs. 44%)[67].

Massachusetts Act Early campaign

In April 2010, Massachusetts participated in the last regional summit along with the other New England states. The meeting resulted in the formation of the Massachusetts Act Early state team, which later launched its own first state summit meeting in November 2010 and created its state autism plan for early identification efforts. The state summit meetings have continued since 2010, averaging two per year.

Massachusetts Act Early (MA Act Early) is composed of a state team with 60+ active members (170 members total), a 17-member executive steering committee, and a state team leader who coordinates the local campaign and also serves as the CDC's Act Early Ambassador to Massachusetts. State team members are located in every region of the state and represent families and caregivers, university centers of excellence, health care organizations, public health, early education, day care, elementary and secondary education, disability agencies, family support agencies, advocacy groups, and research centers.

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. Its mission 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. The MA Act Early state team's goals are:

1.) Conduct public outreach to increase developmental monitoring in all young children as well as awareness of autism spectrum disorder (ASD) and other developmental disorders (DDs);
2.) Increase training for health care, early childhood and educational professionals;
3.) Shorten the wait times between screening and diagnosis as well as diagnosis and intervention; and
4.) Reach out to diverse communities using culturally and linguistically competent resources, such as materials, training and media for families of young children, early childhood educators, early intervention providers, community health centers and pediatric practices across the state.

To this end, the state team has developed a number of products through task forces and project teams with grant funding since its inception in 2010, including the following:

- Massachusetts Act Early web site at www.maactearly.org (AUCD mini-grant and in-kind efforts)

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[67] Daniels, A.M., Halladay, A.K., Shih, A. Elder, L.M. & Dawson, G. (2014). Approaches to enhancing the early detection of autism spectrum disorders: a systematic review of the literature. *Journal of the American Academy of Child & Adolescent Psychiatry*, 53(2):141-52. doi: 10.1016/j.jaac.2013.11.002. Epub 2013 Nov 19.

- Customized Tracking Milestones brochure and Milestones Moments booklets (AUCD mini-grant)
- Autism and Developmental Disorders Diagnostic Services in Massachusetts (in-kind efforts)
- Referral Information-at-a-Glance (AMCHP State Systems grant and in-kind efforts)
- *Considering Culture in Autism Screening* Guide and Kit (AMCHP State Systems grant)
- *Considering Culture in Autism Screening* Curriculum (Deborah Munroe Noonan Memorial Research Fund)
- *Developmental Screening in Massachusetts Webinar: An Alliance between Early Childhood Educators and Pediatricians* (Massachusetts Department of Early Education & Care, Race to the Top-Early Learning Challenge Grant ISA)
- *Developmental Monitoring* Cable TV and Radio Series (AMCHP State Systems grant)

This information has been disseminated widely at national and state conferences. Additionally, the state team has developed over time from a task-force-based model to learning community and collective impact approaches. State team members share their work and educate each other at state summit meetings. Many of them have authored publications that are also posted on the MA Act Early web site.

In concert with the state team's goal to reduce cultural disparities in screening and detection, state team members have also assisted in the translation of the M-CHAT autism screening tool into Haitian-Creole and the *Tracking Milestones* brochure and *Milestones Moments* booklet into Vietnamese. The Massachusetts Act Early web site shares translated materials in 21 languages pooled by our own and other Act Early states' efforts. We are known for our contributions to cultural competence efforts by Act Early states across the country.

MA Act Early Campaign Activities, Trainings and Materials

There is a direct link between the public awareness activities of the LTSAE national campaign and the MA Act Early campaign on the public health and early identification of young children at risk for autism and other developmental disabilities. The MA Act Early campaign is an in-kind, collaborative effort between a number of state team partners who are working together in a collective impact approach to disseminate materials, promote training, and create local resources. These activities are largely unknown but serve to increase workforce capacity across the state and promote healthy development of young children through educating families. The MA Act Early program can serve as a model for other efforts to improve the quality of life for the state's children and youth with autism and other developmental disorders. These activities should be monitored as contributing factors to increases in detection and referral across the state, needing a standard way to measure and report them.

TRAINING CURRICULA.

CONSIDERING CULTURE IN AUTISM SCREENING. The MA Act Early state team has created a number of products and resources, but one of its most important efforts was influenced by the 2011 study in *Pediatrics* by Manning et al.[68] that found non-English speaking families in Massachusetts were less likely to participate in screening, diagnosis and intervention.

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[68] Manning S, Davin CA, Barfield WD, Kotelchuck M, Clements K, Diop H, Osbahr T, & Smith L. (2011). Early diagnoses of autism spectrum disorders in Massachusetts birth cohorts, 2001-2005. *Pediatrics, 127*, 1043.

As a result, Gabovitch et al. developed free downloadable materials for pediatric providers to use when conducting autism screening with children from diverse families. The *Considering Culture in Autism Screening Kit* was funded by a 2012 grant from the Association of Maternal and Child Health Programs (AMCHP) and is composed of a cultural competency clinician tips guide, a referral resource listing, several translations of the M-CHAT-R/F autism screening tool into an online and printed screening kit.

Building on the success of this product, Gabovitch et al. developed a two-module training curriculum that includes videotaped interviews from parents of children with autism from four cultures, didactic information, case studies, and supplementary materials under grant funding through the Deborah Monroe Noonan Memorial Research Fund in 2014. The CDC and AMCHP provided in-kind support to the project, which was modeled after the CDC's Autism Case Training (ACT) curriculum modules. Members of the MA Act Early state team (Gabovitch et al, 2012) created two products. The *Considering Culture in Autism Screening* curriculum (facilitator guide, curriculum handouts, PowerPoint slides and video grid) is freely available for public use[69] and will require pre- and post-testing results to be submitted MA Act Early in exchange for its use.

DEVELOPMENTAL SCREENING IN MASSACHUSETTS: AN ALLIANCE BETWEEN EARLY CHILDHOOD PROGRAMS AND PEDIATRICIANS. This webinar was jointly sponsored under an ISA between the Massachusetts Act Early Program at the UMASS Medical School-Eunice Kennedy Shriver Center, Massachusetts Department of Early Education & Care and the United Way of Mass Bay and Merrimack Valley. The 40-minute archived training webinar[70] informed Massachusetts pediatric providers about the importance of developmental screening for all young children and the need for referral to developmental specialists for further evaluation and intervention of those young children at risk for developmental delays and disorders. The training webinar described the central role that Coordinated Family and Community Engagement programs (CFCEs) play for parents and families in Massachusetts as a hub for referral resources and services and as community/screening partners for health care providers. It described how they are using the MassHealth-approved Ages & Stages Questionnaires (ASQ-3 and ASQ:SE) screening tools to monitor development in young children and about other Massachusetts CBHI-approved screening tools that they can use as complementary measures in their practices.

DEVELOPMENTAL MONITORING CABLE TV AND RADIO SERIES. Additionally, parents of young children will be the target audience for the upcoming MA Act Early *Developmental Monitoring* Cable TV and Radio Series funded by a two-year AMCHP State Systems grant from April 2016-March 2018. The project goal is to educate families from across the state about healthy developmental milestones in young children and what to when concerned, with a particular focus on families from racially, culturally, economically, and regionally diverse communities. The project will air TV and radio broadcasts about how to monitor development in young children ages 2 months through 5 years in the 7 most predominant languages and cultures in the state: English, Spanish, Chinese, Vietnamese, Haitian-Creole, Portuguese and Khmer. In addition, one of the radio broadcasts will specialize in issues concerning African American children in the screening process. Information will be shared about what to do when concerned about a child and LTSAE resources and contact information will lead parents to supports during this process. The programs will be promoted, aired, and archived in 2018 on multiple online platforms The MA Act Early state team will reach out to local cable TV stations across the state to air these broadcasts which will also be archived on YouTube and shared across the country.

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[69] Materials can be found at: www.maactearly.org

[70] http://www.maactearly.org/developmental-screening-in-ma-archived-webinar1.html

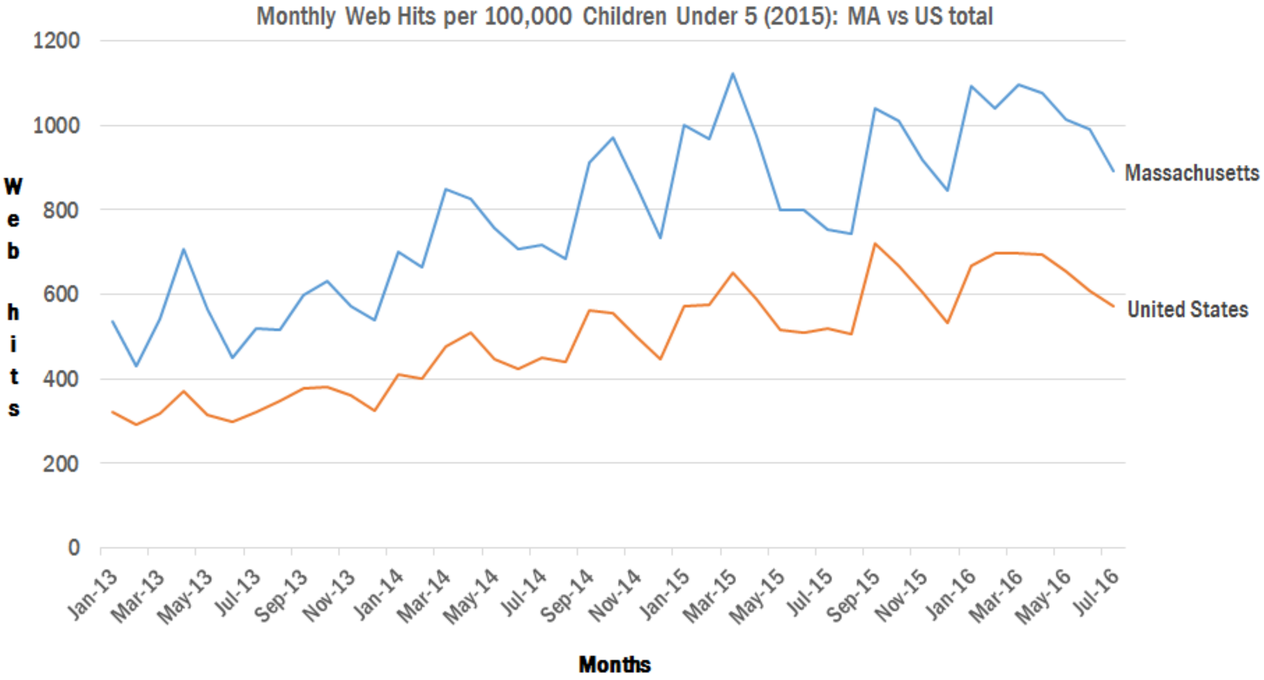
CUSTOMIZED MATERIALS.

MILESTONES MOMENTS BOOKLETS FOR MASSACHUSETTS. Within the MA Act Early state campaign, the largest bulk order of customized booklets placed to date was by the Massachusetts Home Visiting Initiative (MHVI) of MDPH. They packed 4,000 Milestones Moments booklets into Welcome Family bags to be distributed to families in 2016. The program ordered 12,000 copies to be printed (10,000 in English and 2,000 in Spanish) and held the balance for future bags as well as distributed them to Family TIES of MA, MA Act Early and 6 other Early Intervention programs and nonprofits.

National CDC LTSAE Campaign Statistics for Massachusetts

CDC LTSAE WEB SITE VISITS. The graph and the table below show the number of web hits from Massachusetts visitors to the national CDC's LTSAE web site at www.cdc.gov/actearly compared to visitors from the rest of the country. Both Massachusetts and US activity overall are trending in a positive direction. Due to state engagement and interest, Massachusetts activity has exceeded other states by between 58% to 67% per month on average. MA Act Early state team communications via its email distribution list and Facebook fan page promoting the national LTSAE campaign resource materials and trainings, as well as community outreach and state team meetings are contributing to this level of engagement.

Table EI-18. Monthly Web Hits from Massachusetts for www.cdc.gov/actearly [71]



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[71] CDC LTSAE Program, 2016

Table EI-19. Average Monthly LTSAE Web Hits per 100,000 Children Under 5 from 2013 – 2016 (CDC, 2016)

Year	MA	US	% Difference
2013	553.28	336.43	64%
2014	783.23	469.19	67%
2015	914.33	580.48	58%
2016	1028.51	655.78	57%

Source: CDC LTSAE Program, 2016

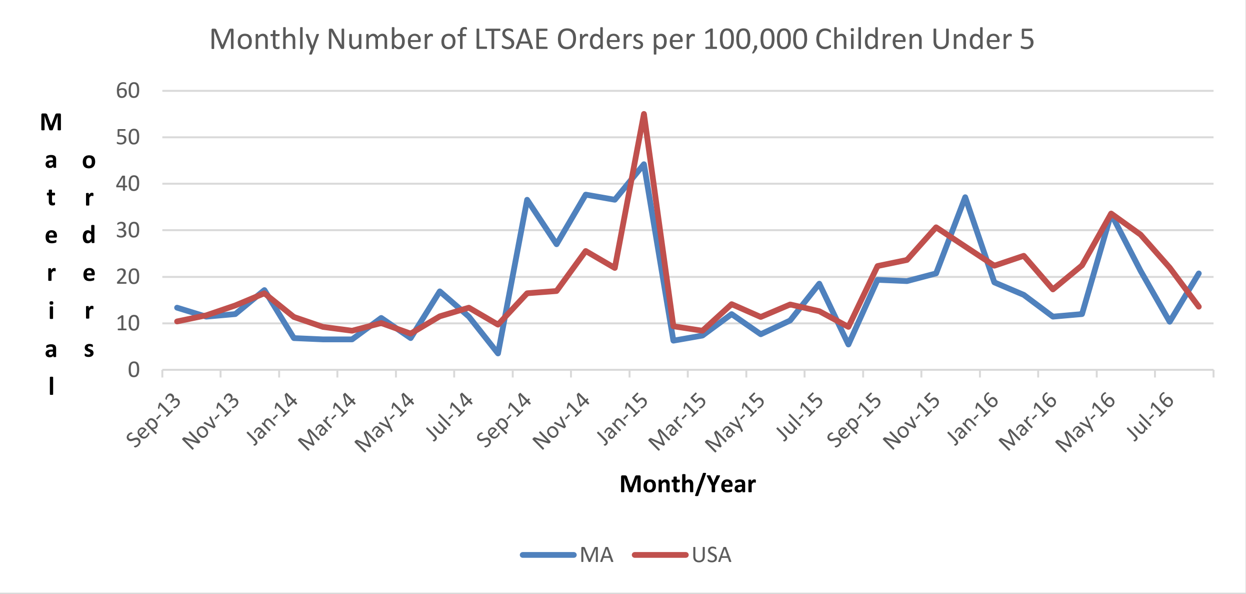
MA ACT EARLY SOCIAL MEDIA. The MA Act Early also has its own website at www.maactearly.org and a MA Act Early Facebook fanpage at www.facebook.com/maactearly that provide a home for national and local campaign information and resources as well as data sources to monitor interest in the topic of early identification. Data enumerating MA Act Early web hits and Facebook page posts are not available.

CDC LTSAE FREE TRAININGS FOR HEALTH CARE PROVIDERS AND EARLY CHILDHOOD EDUCATORS. Massachusetts health care provider activity on the CDC LTSAE web site at www.cdc.gov/actearly continues to grow for those participated in and completed their free online Autism Case Training (ACT) modules and earned free continuing medical education credit since September 2013 through September 2016. There have been 300 ACT modules completed for credit to date with growth in participation each year. (See graph and table charting activity in Appendices under "Early Identification Data").

Massachusetts early educator activity on the CDC LTSAE web site at www.cdc.gov/actearly is stable for those who participated in and completed their free online Watch Me! modules and earned free continuing education credit since December 2014. The Watch Me! Program launched in late 2014, had its peak of activity in the spring of 2015 and have tapered off in 2016 totaling 203 participants through September 2016. (See graph and table charting activity in Appendices under "Early Identification Data").

CDC LTSAE FREE RESOURCE MATERIALS. In terms of getting the many *Learn the Signs. Act Early.* free resource materials into the hands of families, the CDC's reported LTSAE orders and bulk orders show how Massachusetts has participated in the national program compared to other U.S. states on average. The graph and chart below show that the period of September 2014 through January 2014 was the busiest for individual orders from Massachusetts.

Table EI-20. Monthly orders of free CDC LTSAE resource materials for families by MA web visitors[72]



Over the period of 2013 through 2016, the orders of materials increased steadily. By far, the most popular materials were for the *Amazing Me! It's Busy Being Three* children's book, primarily for the English version but also in Spanish, as well as the *Milestones Moments* booklets in English. In addition, orders for Growth Charts*, Tracking Milestones* brochures, LTSAE materials discs, and Parent Kits (with growth charts and *Milestones Moments* booklets) were popular. Orders spanned all regions of the state with the exception of Cape Cod and parts of the South Shore.

Table EI-21. Monthly orders of free CDC LTSAE resource materials for families by MA web visitors[73]

	MA		USA	
	Total Number	**Items per 100,000 children <5**	**Total Number**	**Items per 100,000 children <5**
Total Orders	2252	614.4	126,799	636.9
Total Materials	91721	25,022.0	5,233,692	26,290.3

From September 1, 2013 to August 31, 2016

The periods from January 2015 through May 2015, August through September 2015 and in the month of April 2016 appear to be the busiest for bulk orders from Massachusetts to the CDC. The most popular bulk materials were overwhelmingly the LTSAE promotional flyer and the *Tracking Milestones* brochures in Spanish.

The largest bulk orders were from Mattapan for Spanish versions of the *Milestones Moments* booklets and *Tracking Milestones* brochures. In addition, other predominant regions of the state ordering materials included Boston, Fitchburg, Holyoke, Lawrence, Peabody and Worcester. Clearly, there has been a push for these materials in Spanish-speaking communities.

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[72] CDC LTSAE, 2016

[73] CDC LTSAE, 2016

Recommendations: Early Identification

The state of Massachusetts is ahead of most other states in the early identification of young children at risk for autism spectrum disorder (ASD) and other developmental disabilities. Recent historical events and changes in policy that may have influenced this outcome include the advent of the Children's Behavioral Health Initiative (CBHI), the MassHealth requirement for behavioral screening at all pediatric well-visits, and public awareness campaigns such as the CDC's "Learn the Signs. Act Early." campaign and the work of the Massachusetts Act Early state team, among other possibilities.

In spite of these encouraging local successes, both state and national data sources reveal remaining areas of need for developmental and autism screening, diagnosis and referral to intervention in Massachusetts. For example, an important knowledge gap still left to be determined is the average age of developmental and autism screenings, the type of screening, and the average elapsed time from screening to diagnosis and from diagnosis to intervention. MDPH study findings suggest that children from non-English-speaking families, foreign-born parents, or mothers under the age of 24 years may have lower odds of early identification before the age of three. EI referral data indicate that there may be pockets of regional identification disparities in Western Massachusetts and the Southeast region including Cape Cod and the Islands, which is supported by focus group input.

To better understand and address these gaps, we offer the recommendations below:

1.) SET EARLY IDENTIFICATION TARGETS AND MONITOR PROGRESS ON AN ANNUAL BASIS.

The national Maternal, Infant & Child Health (MICH) Outcome Indicators for Early Identification may be useful to Massachusetts in setting targets and monitoring progress by related indicator criteria. To review, those indicators are:

- **MICH 29.1**: Increase the proportion of children (aged 10-35 months) who have been screened for an Autism Spectrum Disorder (ASD) and other developmental delays.
    - National Baseline: 22.6% of U.S. CSHCN with autism (National target = 24.9%)
- **MICH-29.2**: Increase the proportion of children with ASD having a first evaluation by 36 months of age.
    - National Baseline: 42.7% of U.S. CSHCN with autism (National target = 47.0%)
- **MICH-29.3**: Increase the proportion of children with ASD enrolled in special services by 48 months of age.
    - National Baseline: 52.4% of U.S. CSHCN with autism (National target = 57.6%)
- **MICH-29.4**: (Developmental) Increase the proportion of children with a developmental delay with a first evaluation by 36 months of age.
    - No national baseline specified.
- **MICH-29.5**: (Developmental) Increase the proportion of children with a developmental delay enrolled in special services by 48 months of age.
    - No national baseline specified.

The Massachusetts Autism Commission could consider whether these national targets are appropriate for the state and determine how and which data sources can be used to measure and monitor these core outcomes. Since Massachusetts leads the country in the early identification of and intervention for children with ASD and/or with developmental delays, the national targets above would most likely not be appropriate and if used would need to be adjusted or tailored to regions of the state that continue to experience gaps.

2.) EXAMINE METHODS USED BY MASSHEALTH REVIEW STUDIES FOR FEASIBILITY AND POSSIBLE REPLICATION.

Using state data to identify the average age of developmental and autism screenings, the type of screening, and the average elapsed time from screening to diagnosis and from diagnosis to intervention is an important gap to be filled in early identification. Tapping into a claims data system such as MassHealth or All Payer Claims Data (APCD) could assist data analysts in tracking, projecting and monitoring the critical points along the path to early identification and provide an accurate estimate of ASD diagnoses and intervention as well as reduce possible suspected disparities by culture, language, maternal age and region. Using these outcomes could help refine interventions to move toward effective, efficient screening in primary care pediatrics.

The lessons learned from the various MassHealth review studies presented herein that examined the impact of the Children's Behavioral Health Initiative (CBHI) on increasing behavioral health referrals may hold insights into possible methods to monitor meaningful future outcomes. The methods used in these studies offer unique opportunities to develop true referral estimates and to understand the impact of universal screening on service utilization. If feasible, medical records reviewed in combination with state data could provide a deeper understanding of early identification than the use of data systems such as MassHealth or All Payer Claims (APCD) alone.

Other considerations within this category include:

- Studying medical charts against billing claim encounter forms to review consistency in coding for screening and whether screens are positive or negative.
- Studying pharmacy data to help determine whether screening and the early identification of CYSHCN with behavioral health conditions leads to more appropriate use of medications and to address concerns about the overuse of atypical anti-psychotic medications.
- Conducting a longitudinal analysis to explore the data's ability to predict utilization of future services, including pharmacy, as well as provider and specialty services.

3.) USE BOTH EARLY INTERVENTION DATA (PART C) AND SCHOOL DATA (PART B) TO MONITOR EARLY IDENTIFICATION.

PART C. The Massachusetts Department of Public Health's (DPH) Early Intervention (EI) Program has provided some of the best data available to set the baseline for the autism incidence rate and the average age of diagnosis for those children under the age of three years receiving EI services. In particular, DPH EI studies have been able to identify subpopulations with lower odds of receiving a timely diagnosis, such as children from non-English-speaking or foreign-born families or from mothers under the age of 24.

Other EI data review considerations include:

- Continuing to monitor EI data, which documents progress in changing population outcomes and aids in understanding underlying reasons for these promising results.

- Linking EI data to population-based vitals data, which may be useful identifying disparities by catchment area and region. Results can be used to inform the MDPH Early Intervention program and anticipate future service demand and resource needs.[74]

PART B. Prioritization of finalizing an agreement between DPH and DESE to use the State Assigned Student Identifier (SASID) code starting when a child is first enrolled in EI could go far in understanding the prevalence of autism and developmental disabilities in the state. Doing so would assist in data collection by producing accurate coding at an earlier age, traveling with the child longitudinally over the course of early childhood and school years, reflecting adjustments in diagnostic classifications and related public services, and more accurately monitoring outcomes and forecasting needs. This action would enter EI data into the ESE system, which would later impact the accuracy and consistency of other state data systems as well.

Other school data review considerations include:

- Training school administrators responsible for coding disability classification to apply consistent and appropriate coding for students with ASD/DD using similar criteria as EI might apply to the SASID.
- Conducting school record reviews to monitor for quality.

4.) BUILD AND MONITOR EARLY IDENTIFICATION WORKFORCE CAPACITY AND DEVELOPMENT.

It is important to measure workforce capacity and to monitor workforce development through training to meet the outcome indicators listed above. Doing so will influence the creation of a state infrastructure of trained and networked early childhood, educational, clinical, and pediatric providers who are equipped to reach out and educate parents about the importance of developmental monitoring in young children, to practice timely screening, diagnosis and referral to intervention, and to exercise cultural competence in their efforts.

The EEC's CFCE program and Thrive in 5's *Screen to Succeed* program presented herein could serve as helpful models for early childhood educator workforce development and may have relevant data to share for this purpose. The CDC's LTSAE program's online and didactic "Watch Me!" training for early childhood educators and "Autism Case Training (ACT)" curricula for health care providers may also be a resource to support capacity building. Massachusetts Act Early's "Considering Culture in Autism Screening" curriculum may be a resource for building cultural competence in practices. The Massachusetts Act Early state team is a networked, collaborative learning community of state agencies and organizations whose efforts are positioned for collective impact.

The Massachusetts Autism Commission could consider leveraging these resources and others to measure and monitor the state's workforce capacity to screen, diagnose and treat ASD and other DDs; particularly for children from diverse cultural and linguistic populations and in remote regions such as Western Massachusetts and the Southeast/Cape Cod.

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[74] Manning SE, Davin CA, Barfield WA, Kotelchuck M, Clements K, Diop H, Osbahr T & Smith LA. (2011). Early Diagnoses of Autism Spectrum Disorders in Massachusetts Birth Cohorts, 2001 - 2005. *Pediatrics.* DOI: 10.1542/peds.2010-2943.

Other workforce development considerations include:

- Tracking state workforce capacity.
- Considering legislative efforts to support building and sustaining capacity.
- Targeting regions experiencing the greatest disparities, such as the Southeast/Cape Cod and the Islands and the Western region.
- Tracking the type, number and locations of diagnostic specialists.
- Tracking those diagnostic specialists and treatment providers who accept MassHealth.
- Working with medical schools, medical centers, and the MCAAP to recruit and train diagnostic specialists due to the reported shortage of diagnosticians in the state, particularly in the Western region and on Cape Cod and Islands, that adds to delays to follow-up care for children who have a positive screen for autism.
- Brainstorming creative recruitment and retention efforts with the MCAAP and regional medical centers to attract providers to regions that have shortages.
- Reaching out to the state pediatric community through the MCAAP and the Massachusetts League of Community Health Centers (MLCHC) to brainstorm solutions to barriers impeding practitioners from implementing the AAP's standardized autism screening at the recommended well visit ages, such as time limitations and reimbursement rates that fail to cover the cost of the screening.
- Training early childhood and elementary/secondary educators in early identification, particularly for diverse populations of children considering cultural, linguistic and racial barriers, to influence timely and accurate diagnoses.
- Expanding and supporting CFCE, Thrive in 5 and other home visiting/family support models across all regions to support children and families and drive policy and systems change through creating a universal screening system and educating parents on child development.
- Providing fiscal support for public awareness campaigns such as Massachusetts Act Early's collaborative collective impact efforts.

5.) PRIORITIZE MONITORING AND ADDRESSING IDENTIFIED RACIAL/ETHNIC DISPARITIES IN EARLY IDENTIFICATION.

The CDC ADDM Network supports the above MICH Outcome Indicators and stresses that these goals should "reduce disparities by race/ethnicity in identified ASD prevalence, the age of first comprehensive evaluation, and presence of a previous ASD diagnosis or classification." Research indicates that children with ASD from culturally and linguistically diverse backgrounds are less likely to be identified for evaluation and services or are diagnosed at later ages than English-speaking children[75,76,77].

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[75] Mandell DS, Listerud J, Levy SE & Pinto-Martin JA. (2002). Race differences in the age at diagnosis among Medicaid-eligible children with autism. *Journal American Academy Child Adolescent Psychiatry, 41* (12), 1447-1453.

[76] Mandell DS, Wiggins LD, Carpenter LA., Danieis J, DiGuiseppi C, Durkin MS, et al. (2009). Racial/ethnic disparities in the identification of children with autism spectrum disorders. *American Joumal of Public Health, 99*,493-498.

[77] Travers JC, Tincani M & Krezmien MP. (2011). A Multi-year National Profile of Racial Disparity in Autism Identification. *Journal of Special Education*. DOI: 10.1177/0022466911416247.

Although Massachusetts data indicates that we are meeting many of the MICH indicators for Early Identification, most previously shared studies found that more is needed to be known about the average age of screening, diagnosis, and referral to intervention for minority children, in particular, those from non-English-speaking or foreign-born backgrounds. If there is a delay, these children may not receive Autism Specialty Services, which terminate at age three. With 25% of the Massachusetts population coming from immigrant or poverty-level households associated across regions of the state who may not have the services available for timely, accurate screening, this is a variable that needs closer examination and measurement.

Other disparities considerations include:

- Meeting with diverse communities to address their needs in reducing early identification disparities.
- Translating all developmental and autism parent education materials on developmental milestones monitoring into the predominant languages and cultures in the state.
- Encouraging the use of translated screening tools in pediatric practices.
- Encouraging the use of cultural liaisons and family navigators in pediatric practices.
- Training and recruiting bi-lingual and bi-cultural health care providers in areas serving diverse populations.
- Providing training health care providers that serve diverse populations on how to accurately recognize the signs of developmental concerns in children from non-English speaking families using cultural competency curricula such as Massachusetts Act Early's "Considering Culture in Autism Screening."

MEDICAL HOME

Healthy People 2020 Core Outcome Indicator #2

CSHCN will receive coordinated, ongoing, comprehensive care within a medical home

The Medical Home is "an approach to primary care where primary care providers, families and patients work in partnership to improve quality and value in the health care system, and improve health outcomes for individuals with chronic health conditions and disabilities."[78]

The following section shares information about the Medical Home by looking at the elements of a medical home for CSHCN as they relate to ASD. For the purposes of assessing how the medical home serves children and youth with ASD in Massachusetts, this section examines the status of care coordination and family-centered care. We describe the state environment of pediatric practices, medical homes, and family navigation. We present national and state quantitative data findings looking at the complex medical needs of children and youth with ASD and then in-patient and emergency department care and utilization. We then provide qualitative insights from focus groups. Lastly, we offer future possibilities and recommendations.

Background

The American Academy of Pediatrics (AAP) promotes the concept of the Medical Home in primary care. In a medical home, the provider works collaboratively with the family to ensure that the child's medical and non-medical needs are met and the provider is responsible for assisting the family to access services (e.g., specialty care, educational services, support services) and for coordinating that care. A medical home is one that provides care that is "accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective."[79]

McAllister, Cooley, Van Cleave, Boudreau, and Kulthau (2013)[80] studied the essential factors to the medical home transformation of high-performing primary care practices. Four critical elements emerged as drivers of a practice's transformation to becoming a medical home over time:

1.) A culture of quality improvement,
2.) Family centered care with parents as improvement partners,
3.) Team-based care, and
4.) Care coordinators.[81,82]

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[78] MN Department of Human Services & MN Department of Health (2013). Measures that matter data brief: *Autism Spectrum Disorders: Findings from the National Survey of Children with Special Health Care Needs 2009/10*.

[79] Medical Home Initiatives for Children With Special Needs Project Advisory Committee, (July, 2002). The Medical Home. *Pediatrics, 110* (1).

[80] McAllister J, Cooley WC, Van Cleave J, Boudreau AA, & Kuhlthau K. (2013). Medical home transformation in pediatric primary care – What drives change? *Annals of Family Medicine, 11*, S 1.

[81] American Academy of Pediatrics, Medical Home Initiatives for Children With Special Needs Project Advisory Committee. The medical home. *Pediatrics. 2002*;110(1 pt 1): 184–186.

[82] American Academy of Pediatrics Committee on Children with Disabilities. 1999. Care coordination: Integrating health and related systems of care for children with special health care needs. *Pediatrics*; *104*(4):978-981.

To be able to measure the critical elements of a medical home for children and youth with ASD, it is important to first define care coordination and family-centered care that contribute to the "medical homeness" of a practice. It is also important to be aware of the concept of "family navigation" as an emerging best practice in care coordination.

CARE COORDINATION. According to a 2005 article in *Pediatrics*,[83] care coordination is described as:

> *"…a process that facilitates the linkage of children and their families with appropriate services and resources in a coordinated effort to achieve good health. Care coordination for children with special health care needs often is complicated because there is no single point of entry into the multiple systems of care, and complex criteria frequently determine the availability of funding and services among public and private payers. Economic and sociocultural barriers to coordination of care exist and affect families and health care professionals. In their important role of providing a medical home for all children, primary care physicians have a vital role in the process of care coordination, in concert with the family."*

FAMILY-CENTERED CARE. The MCHB defines family-centered care as an approach to care that "assures the health and well-being of children and their families through a respectful family-professional partnership. It honors the strengths, cultures, traditions, and expertise that everyone brings to this relationship [and is] the standard of practice which results in high quality services".

Implicit in this definition are the core tenets of family-centered care which include regarding the family unit as a constant in the child's life, building on family strengths, empowering families to advocate for their child's and their own needs, involving families in decision making about care, providing continuity of care, promoting parent-professional partnership and collaboration, developing cultural competence, ensuring equity, understanding the importance of community-based services, and generally improving services to CSHCN and their families.[84]

FAMILY NAVIGATION, AN EMERGING BEST PRACTICE IN PROVIDING MEDICAL HOMES. Family navigation is an emerging best practice for family-centered care coordination in autism services, both locally and across the country. It aims to reduce health disparities for underserved populations and address barriers to patient care. These barriers include complex care systems, financial and economic concerns, language and cultural issues, patient-provider communication, transportation, bias, and fear or stigma. Family navigators meet with families at a time and location that is convenient to the family. They help ensure timely and appropriate treatment by guiding and supporting the family as they navigate the many services needed to support a newly diagnosed child with ASD. This may include accompanying families to meetings in the community, such as IEP meetings, joining families at outpatient medical visits, helping to arrange transportation, or helping families advocate for themselves. A local example of family navigation is the work of Dr. Marilyn Augustyn and her colleagues at Boston University School of Medicine who have been studying the application of family navigation in the Greater Boston area over many years to "determine whether the use of patient navigation, for families of young children newly diagnosed with ASD, improves the services the children receive, decreases the burden of parenting stress, and improves family

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[83] AAP Council on Children With Disabilities Executive Committee (2005). Care Coordination in the Medical Home: Integrating Health and Related Systems of Care for Children With Special Health Care Needs, *Pediatrics, 116* (5).

[84] McPherson M. (2005). U.S. Department of Health and Human Services, Maternal and Child Health Bureau. *MCHB definition of family-centered care*. Retrieved June 15, 2007, from http://mchb.hrsa.gov/

functioning." Their team described family navigation in a 2014 article in *Zero to Three* that is helpful in understanding how it reduces disparities.[85]

MCHB has set the targets presented in the table below as key Maternal, Infant and Child Health (MICH) outcomes of Healthy People 2020 for the medical home for children and youth with special health care needs. The MCHB national target-setting method is a goal of 10% improvement over baseline. For the purposes of this report, we will consider this goal for children with autism specifically.

Table MH-1: MICH-30 Baseline & Targets for Medical Home Indicator

Maternal & Infant Child Health Indicator [86]	Baseline	Nat'l Target
MICH-30.2: Increase the proportion of children with special health care needs who have access to a medical home	47.1 percent of children under age 18 years with special health care needs had access to a medical home in 2005–06	51.8%

Massachusetts will need to determine if/how data collection can be accomplished to provide a baseline measure of how the state's children and youth with autism are accessing medical homes and to be able to monitor this goal over time.

Summary of State Environment: Medical Home

There is an important distinction between a medical practice and the type of medical home previously described. Massachusetts is a state with many medical practices, but the current status of the Medical Home in Massachusetts for children and youth with ASD is difficult to measure. Current national surveys indicate that as many as 63% of U.S. parents of children and youth with special health care needs (CYSHCN) report having received the basic criteria of a medical home. For CYSHCN with ASD however, national surveys report that they are less likely to receive these services, and it is likely that this trend applies to children and youth with ASD in Massachusetts as well.

PEDIATRIC PROVIDERS IN MASSACHUSETTS. To care for the state's children and youth, it was estimated in 2013 that there were approximately 1,676 pediatricians, 1,270 family practice physicians, and 361 pediatric nurse practitioners in Massachusetts at the time.[87] That same year, the Massachusetts Chapter of the American Chapter of Pediatrics (MCAAP) reported having 1,823 members, an increase from 1,769 in 2012. Approximately 300 pediatricians serve on various MCAAP committees that include the Children's Mental Health Task Force, the Committee on Disabilities, and the Pediatric Council which are actively involved in influencing and setting health care policy and practice in the state, particularly for vulnerable child populations. In addition, there are 55 community health center organizations in Massachusetts with more than 300 total access sites that belong to the Massachusetts League of Community Health Centers. Many pediatric practices are centralized in the Greater Boston area, though more practices are emerging across the state with a continued need to expand in the furthest regions such as Southeastern Massachusetts/Cape Cod and the islands and Western Massachusetts. It is important to establish a baseline and track the current number of pediatric practices, but more than that, it is important to understand the actual number that are operating as true medical homes. An opportunity exists to work with these

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[85] Blenner S, Fernandez I, Giron A, Grossman X & Augustyn M. (2014). Where do we start? Using family navigation to help underserved families. *Zero to Three, 34*(6): 4-8.

[86] Data Sources: 2009-10 National Survey of Children with Special Health Care Needs (NS-CSHCN), HRSA/MCHB and CDC/NCHS

[87] Health Data Solutions interview, 2013.

practices to provide workforce training and development around serving children and youth with ASD in the medical home as well.

MEDICAL HOME PRACTICES IN MASSACHUSETTS. The number of practices having medical homes in Massachusetts is unknown. The National Committee for Quality Assurance (NCQA) listed 719 Massachusetts practitioners in 2011 as having achieved a "patient-centered medical home".[88] Similarly, under the Massachusetts Executive Office of Health and Human Services (EOHHS), the Massachusetts Patient Centered Medical Home Initiative (PCMHI) had 46 current participating practices around the same time, all of which were aiming for NCQA recognition. The initiative had set the goal for all primary care practices in Massachusetts to become patient-centered medical homes by the year 2015. Other systems (Partners, UMass, Baystate, Cambridge Health Alliance) have had "in-house" medical home transformation projects, but no information is readily available on their outcomes to our knowledge.

One particular medical home project was the Children's Health Insurance Program Reauthorization Act of 2009 (CHIPRA) Medical Home Initiative of 13 Massachusetts practices working to create practice transformation to medical home principles. The practices were selected to participate in a Medical Home project as part of a grant from the Centers for Medicare and Medicaid. The Massachusetts CHIPRA Medical Home Initiative administered and tested the set of 24 core measures of pediatric health care endorsed by the Agency for Health Care Quality; convening a Statewide Child Health Coalition to provide advice and guidance to the State (number of participants unknown); supporting the implementation of a "medical home" model of care at pediatric practices across Massachusetts (number of pediatric practices unknown). The CHIPRA Initiative was a pilot and is no longer active.

The Massachusetts CHIPRA Medical Home Initiative could be a potential model from which there may be some lessons that could apply to medical homes for children with ASD in the future, though the pilot did not address or study the medical home for children with ASD specifically. As an update on November 2016, NCQA listed 3,163 Massachusetts clinicians in their PCMH Recognition Directory but does not share the number of pediatric practices.

RESEARCH ON MEDICAL HOME ACCESS. In 2009, Singh, Strickland, Ghandour and Van Dyck[89] examined geographic disparities nationally in medical home access for CSHCN aged birth to 17 years, since reducing social and geographic inequalities in health and health care is a national priority. When reviewing the prevalence of not having a medical home, Massachusetts emerged as having a 50% higher odds of not having access to a medical home (53%) than Iowa at 46%. Other notable results reflecting the status of not having a medical home included: race (68%Hispanic, 63% non-Hispanic Black, 57% Other non-Hispanic, 47.2% White, non-Hispanic); primary language spoken at home (78% non-English speakers); and 67% low poverty level threshold. Other national studies related to race and household language further support that disparities exist for CSHCN.[90,91]

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[88] http://recognition.ncqa.org

[89] Singh G, Strickland B, Ghandour R & van Dyck P. (2009). Geographic disparities in access to the medical home among US CSHCN. *Pediatrics, 124*, S352.

[90] Bennett A, Rankin K & Rosenberg D. (2012). Does a medical home mediate racial disparities in unmet health care needs among children with special health care needs? *Maternal & Child Health Journal, 16*, 330-338.

[91] Yu S & Singh G. (2009). Household language use and health care access, unmet need, and family impact among CSHCN. *Pediatrics, 124*, S414.

A 2012 study[92] by Lin, Yu and Harwood confirms immigrant disparities accessing a medical home for children with ASD and DD as well. Components of a medical home were inversely related to the state's immigrant and non-English speaking population, further supporting the hypothesis from the Massachusetts EI study by Manning et al. (2011)[93] that state CSHCN are at risk of not being identified for ASD by age 3 due to a parent's status as non-English speaking.

FAMILY NAVIGATION IN MASSACHUSETTS. As described earlier, Dr. Emily Feinberg, Ivys Fernandez-Pastrana, Yaminette Linhart and others on their research team from the Boston University School of Public Health (BUSPH) and Boston University School of Medicine are currently studying the effectiveness of the family navigator model through *Project EARLY: Engagement, Assessment, Referral, & Linkage for Young Children*, a randomized, comparative effectiveness trial with conventional care management services. The study is taking place in three integrated primary care networks and their affiliated Developmental and Behavioral Pediatrics (DBP) clinics at Boston Medical Center, Children's Hospital of Philadelphia, and Yale University Medical School. Children at risk for autism are enrolled. Families will work one-on-one with the navigator. The navigator provides off-site support such as home visits or accompanying families to appointments.

According to the Project EARLY research team, "The goal of the family navigator during the diagnostic evaluation period is to ensure timely completion of the evaluation. The focus of these interactions is to understand the structure and purpose of the evaluation, gather and complete required materials, and address logistic barriers related to the diagnostic visit. The navigator will continue to work with the family after the diagnostic evaluation to access recommended services and support the family's engagement in treatment."[94]

Previous to Project EARLY, the BUSPH research team piloted and closely studied various aspects of the family navigator model in providing care and access for families of children with special needs, in particular autism as well as maternal depression. Their research has included diverse families from a variety of cultures. Reviewing their previous studies can provide the efficacy behind the model as a way to help others with the concept.[95]

HRSA also promotes the use of family navigators in their implementation grants. Family navigation was a key piece of HRSA's vision in the 2016 award cycle for state implementation grants. They are an expected piece of best practices in the future in addition to community health workers and other forms of outreach and support.

> "[By my estimates], 50% of people in our programs who are referred to local medical centers for an autism evaluation don't show up. With the use of family navigators, that number increases to 90%."
>
> –Parent Coordinator at a community health center

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[92] Lin S, Yu S & Harwood R. (2012). Autism spectrum disorders and developmental disabilities in children from immigrant families in the United States. *Pediatrics, 130*, 191.

[93] Manning SE, Davin CA, Barfield WA, Kotelchuck M, Clements K, Diop H, Osbahr T & Smith LA. (2011). Early Diagnoses of Autism Spectrum Disorders in Massachusetts Birth Cohorts, 2001 - 2005. *Pediatrics*. DOI: 10.1542/peds.2010-2943

[94] Feinberg E, Abufhele M, Sandler J, Augustyn M, Cabral H, Chen N, Linhart YD, Levesque ZC, Aebi M, Silverstein M. (2016, May 2). Reducing Disparities in Timely Autism Diagnosis Through Family Navigation: Results From a Randomized Pilot Trial. *Psychiatric Services*.

[95] Feinberg E, Augustyn M, Sandler J, Ferreira-Cesar Z, Chen N, Cabral H, Beardslee B, Silverstein M. (2014). Improving maternal mental health after a diagnosis of autism spectrum disorder: Results from a randomized controlled trial. *JAMA Pediatrics. 168* (1) 40-46.

Identified needs: Medical Home

Quantitative Findings

National Surveys

Understanding the Medical Profile and Needs of CYSHCN with ASD

According to the CDC, "Autism Spectrum Disorder (ASD) is a group of developmental disabilities that can cause significant social, communication and behavioral challenges….ASD affects each person in different ways, and can range from mild to severe." Consequently, nearly all children with ASD qualify as having special health care needs (SHCN), because they experience at least one type of ongoing condition that results in a greater than routine need for health and related services, and therefore would likely benefit from receiving care in a medical home model.

Understanding the proportion of children and youth with one or more chronic health care conditions can speak to the need for effective care coordination and a dedicated medical home. Many CYSHCN with ASD experience more complex medical issues than other CYSHCN generally and may have increased rates of medical and psychiatric co-morbidities including epilepsy, gastrointestinal disturbances, sleep issues, anxiety, depression, and respiratory, food and skin allergies.[96,97 ,98]

The 2011-12 National Survey of Children's Health (NSCH) and 2009-10 National Survey of Children's Health Care Needs (NS-CSHCN) both ask parents questions to identify the existence of one or more chronic, co-morbid health conditions and the level of functional limitations experienced as a result. Although the Massachusetts sample size is limited due to size and the 95% confidence intervals are too wide to be reliable or precise, this source represents some of the only data currently available for children with autism in the state. We present the results and compare them to national trends to provide insights where possible (more information about the NSCH and NS-CSHCN in the Overview section).

CHRONIC HEALTH CARE CONDITIONS IN MASSACHUSETTS. According to NSCH data, 91.7% (C.I. 80.8 - 100.0%) of children with ASD in Massachusetts currently have two or more chronic health care conditions[99] from a list of 18 conditions compared to 12.5% (C.I. 10.4-14.5%) of all children in the state. These data align with national findings with 95.3% (C.I. 93.7 - 97.0%) of children with ASD and only 9.6% (C.I. 9.2 - 10.0%) of all U.S. children having 2 or more health conditions.

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[96] Buie T, Campbell D, Fuchs G, Furuta G, Levy J, Van de Water J, et al. (2010). Evaluation, diagnosis and treatment of gastrointestinal disorders in individuals with ASDs: A consensus report. *Pediatrics, 125*: S1-S18.

[97] Iannuzzi D, Kopecky K, Broder-Fingert SB, Connors S. (2015). Addressing the needs of individuals with autism: Role of the hospital-based social worker in implementation of a patient-centered care plan. *Health and Social Work*. doi: 10.1177/0009922813485974

[98] Osterkamp EM, Costanzo AJ, Ehrhardt BS & Gormley DK. (2013). Transition of care for adolescent patients with chronic illness: Education for nurses. *Journal of Continuing Care in Nursing, 44*: 1-5.

[99] The list includes the following conditions to bodily functions, activities or participation, and emotional or behavioral factors: Attention Deficit Disorder or Attention Deficit Hyperactivity Disorder (ADD or ADHD); depression; anxiety problems; behavioral or conduct problems, such as opposition defiant disorder or conduct disorder; ASD, Asperger disorder, pervasive developmental disorder, or other autism spectrum; any developmental delay; intellectual disability; cerebral palsy; speech or other language problem; Tourette syndrome; asthma; diabetes; epilepsy or seizure disorder; hearing problems; vision problems that cannot be corrected with standard glasses or contact lenses; bone, joint or muscle problems; or a brain injury or concussion.

Table MH-2. Children with one or more current chronic health conditions (out of 18), NSCH 2011-12

		Does not have current chronic health condition	Currently has 1 chronic health condition	Currently has 2 or more chronic health conditions	Total
All U.S. children	*%*	76.4%	14.0%	9.6%	
	C.I.	(75.8 - 77.0%)	(13.5 - 14.5%)	(9.2 - 10.0%)	
	n	73,343	12,860	9,468	95,671
	Pop. Est	56,330,970	10,283,381	7,099,219	73,713,570
All U.S. children with ASD	*%*		4.70%	95.30%	
	C.I.		(3.0 - 6.4%)	(93.7 - 97.0%)	
	n	0	93	522	615
	Pop. Est	0	45,783	1,115,261	1,161,044
All MA children	*%*	73.9%	13.7%	12.5%	
	C.I.	(71.2 - 76.6%)	(11.6-15.7%)	(10.4-14.5%)	
	n	1,379	263	219	1,861
	Pop. Est	1,034,113	191,391	174,365	1,399,869
*All MA children with ASD**	*%*		8.3%	91.7%	
	C.I.		(0.0 - 19.2%)	(80.8 - 100.0%)	
	n	0	3	28	31
	Pop. Est	0	2,306	25,312	27,618

C.I. = 95% Confidence Interval. Percentages are weighted to population characteristics.
n = cell size. Use caution in interpreting cell sizes less than 50

According to NS-CSHCN data, more than half of all CSHCN with ASD in Massachusetts (55.4%, C.I. 41.3 - 69.6%) currently have 4 or more chronic health care conditions from a list of 20 conditions[100] compared to 16.9% (C.I. 13.3 - 20.4%) of the state's entire CSHCN population (almost 40% more). These data closely align with the national findings of 55.3% (C.I. 52.1 - 58.4%) of U.S. CSHCN with ASD and 16.6% (C.I. 15.8 - 17.3%) of all U.S. CSHCN having 4 or more health conditions.

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[100] The list includes: Attention Deficit Disorder or Attention Deficit Hyperactivity Disorder (ADD or ADHD); depression; anxiety problems; behavioral or conduct problems, such as opposition defiant disorder or conduct disorder; ASD, Asperger disorder, pervasive developmental disorder, or other autism spectrum; any developmental delay affecting the child's or youth's ability to learn; intellectual disability; asthma; diabetes; epilepsy or seizure disorder; migraine or frequent headaches; a head injury, concussion, or traumatic brain injury; heart problem including congenial heat disease; blood problems such as anemia or sickle cell disease; cystic fibrosis; cerebral palsy; muscular dystrophy; Down syndrome; arthritis or other joint problems; and allergies.

Table MH-3. Has a doctor or other health care provider told you that your child currently has (one or more current chronic health conditions from list of 20), NS-CSHCN 2009-10

		Does not have current chronic health condition	Currently has 1 chronic health condition	Currently has 2 chronic health conditions	Currently has 3 chronic health conditions	Currently has 4 or more chronic health conditions	Total
All U.S. CSHCN	*%*	12.3%	30.6%	28.0%	12.5%	16.6%	
	C.I.	(11.7 - 12.9%)	(29.8 - 31.5%)	(27.2 - 28.9%)	(11.98 - 13.1%)	(15.8 - 17.3%)	
	n	4,988	12,883	11,561	4,907	5,900	40,239
	Pop. Est	1,363,084	3,401,916	3,109,297	1,385,076	1,842,009	11,101,382
All U.S. CSHCN with ASD	*%*	0.0%	6.8%	18.7%	19.2%	55.3%	
	C.I.	-	(5.4 - 8.2%)	(16.5 - 20.9%)	(16.9 - 21.5%)	(52.1 - 58.4%)	
	n	-	229	611	653	1,562	3,055
	Pop. Est	-	57,167	156,971	161,382	463,755	839,275
All MA CSHCN	*%*	11.7%	29.2%	28.4%	13.8%	16.9%	
	C.I.	(9.1 - 14.4%)	(25.2 - 33.2%)	(24.6 - 32.2%)	(10.1 - 17.6%)	(13.3 - 20.4%)	
	n	96	236	237	95	124	569
	Pop. Est	30,281	75,519	73,480	35,737	43,669	258,686
*All MA CSHCN with ASD**	*%*	0.0%	8.0%	17.2%	19.3%	55.4%	
	C.I.	-	(0.8 - 15.2%)	(7.9 - 26.6%)	(9.6 - 28.9%)	(41.3 - 69.6%)	
	n	-	6	14	27	37	84
	Pop. Est	-	1,701	3,651	4,085	11,746	21,183

C.I. = 95% Confidence Interval. Percentages are weighted to population characteristics.

n = cell size. Use caution in interpreting cell sizes less than 50

Note: Given the range of the estimates, it appears that the sample size may be too small to meaningfully estimate the percentage of children with ASD with 1 or more chronic health condition within Massachusetts.

Frequency missing = 31

Comparing the Massachusetts NS-CSHCN to the NSCH confirms the need, since the results are that vast majority of CSHCN with ASD and of all children with ASD have two or more chronic health care conditions. Comparing Massachusetts CSHCN with ASD are similar to findings for all U.S. CSHCN with ASD with two or more chronic health care conditions, confirming the medically complex nature of this population.

FUNCTIONAL LIMITATIONS. CSHCN with ASD experience complex health care needs that may influence their overall health status and daily activities. According to the 2009-10 NS-CSHCN, approximately half of Massachusetts CSHCN with ASD (50.6%, C.I. 35.6 - 65.5%) report that their condition affects their ability to do things "a great deal" which is significantly higher than 21.6% (C.I. 16.7 - 26.5%) reporting these limitations in the state's entire CSHCN population (almost 30% more). These data closely align with the national trends as illustrated in the table below.

Table MH-4. Does your child's medical, behavioral, or other health conditions / emotional, developmental, or behavioral problems, affect his/her ability to do things a great deal, some or very little?, NS-CSHCN 2009-10

		A great deal	Some	Very little	Total
All U.S. CSHCN	*%*	20.56%	44.85%	34.43%	
	C.I.	(19.6 - 21.5%)	(43.7 - 45.9%)	(33.3 - 35.5%)	
	n	4,832	11,631	8,878	25,341
	Pop. Est	1,495,556	3,262,043	2,504,103	7,261,702
All U.S. CSHCN with ASD	*%*	45.3%	44.3%	10.2%	
	C.I.	(41.9 - 48.7%)	(41.1 - 47.5%)	(8.5 - 12.1%)	
	n	1,215	1,342	294	2,851
	Pop. Est	356,415	348,672	80,651	785,738
All MA CSHCN	*%*	21.6%	42.1%	36.3%	
	C.I.	(16.7 - 26.5%)	(36.5 - 47.7%)	(30.4 - 42.2%)	
	n	92	218	170	480
	Pop. Est	35,158	68,433	59,068	162,659
*All MA CSHCN with ASD**	*%*	50.6%	42.2%	8.2%	
	C.I.	(35.6 - 65.5%)	(27.5 - 54.9%)	(1.5 - 14.9%)	
	n	28	37	7	72
	Pop. Est	10538	8592	1710	20840

C.I. = 95% Confidence Interval. Percentages are weighted to population characteristics.

n = cell size. Use caution in interpreting cell sizes less than 50

Frequency missing = 327

As for how often Massachusetts CSHCN with ASD reported being affected by their health condition(s), significantly more almost half (48.7%, C.I. 33.4 - 63.6%) children with ASD reported "always" being affected compared to 14.7% (C.I. 10.8 - 18.5%) of Massachusetts CSHCN in general. These data closely align with the national trends as illustrated in the table below.

Table MH-5. During the past 12 months/since birth, how often have your child's medical, behavioral, or other health conditions / emotional, developmental, or behavioral problems affected his/her ability to do things other children his/her age do?, NS-CSHCN 2009-10

		Never	Sometimes	Usually	Always	Don't Know	Total
All U.S. CSHCN	*%*	34.3%	40.5%	9.8%	15.2%	0.2%	
	C.I.	(33.4 - 35.1%)	(39.6 - 41.4%)	(9.2 - 10.3%)	(14.5 - 15.9%)	(0.1 - 0.2%)	
	n	14,795	16,318	3,652	5,408	63	40,236
	Pop. Est	3,806,433	4,498,168	1,084,066	1,690,780	19,239	11,098,686
All U.S. CSHCN with ASD	*%*	6.0%	26.8%	19.1%	47.9%	0.2%	
	C.I.	(4.6 - 7.5%)	(24.2 - 29.4%)	(16.8 - 21.5%)	(44.6 - 51.1%)	(0.0 - 0.4%)	
	n	192	869	610	1,376	6	3,053

		Never	Sometimes	Usually	Always	Don't Know	Total
	Pop. Est	50,730	224,580	160,615	401,725	1,367	839,017
All MA CSHCN	*%*	36.4%	38.8%	9.4%	14.7%	0.7%	
	C.I.	(32.2 - 40.7%)	(34.5 - 43.1%)	(6.9 - 11.9%)	(10.8 - 18.5%)	(0.0 - 1.8%)	
	n	306	313	71	96	2	788
	Pop. Est	94,250	100,385	24,369	37,904	1,777	258,685
*All MA CSHCN with ASD**	*%*	1.6%	35.4%	14.3%	48.7%	0.0%	
	C.I.	(0.0 - 3.9%)	(22.6 - 48.2%)	(5.8 - 22.7%)	(33.4 - 63.6%)	-	
	n	2	30	12	30	-	74
	Pop. Est	343	7,500	3,026	10,312	-	21,181

C.I. = 95% Confidence Interval. Percentages are weighted to population characteristics.

n = cell size. Use caution in interpreting cell sizes less than 50

Note: Given the range of the estimates, it appears that the sample size may be too small to meaningfully estimate the extent of how much the conditions affect children in MA within some of the rating categories.

Frequency missing = 31

By understanding co-morbidities and the effect of functional limitation based on any of co-occurring disorders with ASD above, these data could assist with planning, outreach, service provision and progress monitoring for any of these sub-populations within the autism spectrum. For example, a percentage of CYSHCN with Down syndrome have co-morbid ASD. Understanding their unique needs as a function of this dual diagnosis could determine future assistance for this group and their families. Likewise, measuring the baseline and monitoring the percentage of CYSHCN with ASD who experience mental health concerns such as depression and anxiety could be of great benefit to the state's autism community by using this national report or a similar one with enough power to assist with future planning.

Understanding the Status of the Medical Home in Massachusetts

The NSCH and the NS-CSHCN used the following indicators to assess the Medical Home: usual source of care, personal doctor or nurse, care coordination, and family-centered care.[101] A composite of these outcome elements is shared at the end of this section. (Tables for all indicators are available in the Appendix under Medical Home Data).

USUAL SOURCE OF CARE. One, basic element of a medical home is a regular place that children can go when they are sick. This may include a doctor's office, clinic, or community health center. Both the NSCH and the NS-CSHCN findings report that the vast majority of Massachusetts children with ASD have a usual place to go for sick care. The NSCH reported this finding for 89.9%(C.I. 73.2-100%) of children with ASD which aligns closely with 93% (C.I. 89.9-96.1%) of all US children with ASD, as well as all Massachusetts and U.S. children in general. Similarly, the NS-CSHCN reported 98.7% (C.I. 96.3-100%) of Massachusetts CSHCN with ASD have a usual place to go for sick care which aligns closely with 95.2% (C.I. 93.7-96.6%) of all U.S. CSHCN with ASD, as well as all Massachusetts CSHCN and U.S. CSHCN in general.

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[101] http://mchb.hrsa.gov/cshcn0910/core/pages/co2/co2mh.html

Personal Doctor or Nurse. The NS-CSHCN asked parents whether their child with ASD has a "doctor or nurse" (this could include general doctor, pediatrician, a specialist doctor, a nurse practitioner, or a physician's assistant). Based on the increased level of need of this population and the presence of specialty providers in the state, only 3.3% (C.I. 1.5-5.1%) of Massachusetts CSHCN with ASD do not have a doctor or nurse which is significantly less than U.S. CSHCN with ASD at 6.9% (C.I. 6.4-7.5%) of. More notable is that 40.0% (35.4-44.7%) of Massachusetts CSHCN with ASD have more than one provider which is similar to U.S. CSHCN with ASD (39.5%, C.I. 38.6-40.4%) and Massachusetts and U.S. CSHCN in general.

Effective Care Coordination. Neither the NSCH nor the NS-CSHCN reported positive results for Massachusetts children with ASD receiving effective care coordination as part of a medical home. Care coordination was measured by considering the proportion of CSHCN who receive care coordination services and how well that care was coordinated. The survey asked parents whether they received help coordinating their children's care, whether they needed additional help, and whether they got all the help they needed. Parents were also asked how satisfied they were with the communication among the child's doctors and other providers, as well as how satisfied they were with the communication between health care providers and schools and other systems that serve their children.

According to the NSCH, over half (56.6%, C.I. 32.7-80.5%) of children in Massachusetts with ASD reported needing, but not receiving, effective coordination, compared to a similar 56.2% of all U.S. children with ASD. This broad estimate suggests between that only between 5-36% of Massachusetts children with ASD did receive effective care coordination compared to 32.2% of all US children with ASD.

According to the NS-CSHCN, CSHCN with ASD report received far less care coordination than CSHCN in general. Overall, only 29.8% (C.I. 17.3%-42.3%) of Massachusetts CSHCN with ASD reported receiving coordinated care[102], showing no significant difference from national rates of 23.9% (C.I. 21.3-26.4%) of all U.S. CSHCN with ASD. Thus, approximately 70.2% (C.I. 57.7-82.7%) of Massachusetts CSHCN with ASD did not receive coordinated care. Compared with all CSHCN, significantly more CSHCN receive coordinated care 47.1% (C.I. 42.5-51.7%) in Massachusetts and 43% (C.I. 42.1-43.8%) in the U.S. As shown above, these results align closely with NSCH findings as well.

Family-Centered Care. Reports for family-centered care fared better than care coordination for Massachusetts CSHCN with ASD in the NS-CSHCN survey. The NS-CSHCN measured family-centered care by asking parents whether their child's providers spent enough time with the family, listened carefully to the parents, made the parents feel like a partner in their child's care, were sensitive to the family's customs and values, and provided the specific information that the parent needed.

Overall, 58.6% (C.I. 43.7-73.6%) of Massachusetts CSHCN with ASD reported receiving care that met all of the components of family-centered care[103], compared to 48.9% (C.I. 45.7-52.1%) of U.S. CSHCN with ASD showing no significant difference. Still, CSHCN in general received significantly more family-centered care in Massachusetts (71.5%, C.I. 67.4-75.6%) compared to CSHCN nationally (64.5%, C.I. 63.6-65.3%). However, between 26.4-56.3% of Massachusetts CSHCN with

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[102] For a child to qualify as receiving coordinated care, the parent had to report that they usually received help when needed, and that they were "very satisfied" with communication among providers (when needed) and communication between providers and other programs (when needed).

[103] For a child's care to qualify as family-centered, the parent needed to answer "usually or always" to each of the above elements.

ASD were estimated to not receive family-centered care, indicating improvement is needed for this medical home indicator.

RECEIPT OF ALL ELEMENTS OF COORDINATED, ONGOING COMPREHENSIVE CARE WITHIN A MEDICAL HOME. For Massachusetts children with ASD, neither the NSCH nor the NS-CSHCN reported positive results receiving all elements of "coordinated, ongoing, comprehensive care within a medical home", and in fact, both reported significant disparities.

For the NSCH, while 62.7% (C.I. 59.7-65.6%) of all Massachusetts children without disabilities or special health care needs received care that met the medical home criteria, significantly fewer Massachusetts children (30.1%, C.I. 7-53.3%) with ASD could report having a medical home, meaning that it is estimated that 46.7-93% were estimated to not have a medical home. While Massachusetts may do better than the rest of the U.S. in providing medical homes for children in general (54.4% in MA vs. 29% in the U.S.), these estimates show it is not any better for children with autism.

Similarly for the NS-CSHCN, only 29.8% (C.I. 17.3-42.3%) of Massachusetts CSHCN with ASD reported having a medical home, similar to 23.9% (C.I. 21.3-26.4%) of all U.S. CSHCN with ASD. For CSHCN in general, 47.1% (C.I. 42.5-51.7%) of Massachusetts CSHCN and 43% (C.I. 42.1-43.8%) of U.S. CSHCN reported having a medical home. The findings of estimates between 57.7-82.7% of Massachusetts CSHCN with ASD not having a medical home align with the NSCH results as well.

CONCLUSIONS BASED ON NATIONAL FINDINGS. Considering the high level of medical needs for the population of Massachusetts children with ASD based on the prevalence of co-morbid health conditions affecting one's functional abilities, there is considerable need for medical homes to serve this population's needs. Most report having a usual source of care and a personal health care provider, but few report receiving effective care coordination and family-centered care. With the number of providers in the state, greater capacity is needed to serve this population well in dedicated, coordinated, ongoing, family-centered, culturally competent and comprehensive medical homes. Collecting medical home related data to understand and support workforce development and training, outreach and promotion of this important concept to practices in the state as part of medical home transformations, and monitoring progress appears to be a critical need.

Regional Data on Medical Home

Consumer Assessment of Health Care Providers and Systems (CAHPS), 2014

Consumer Assessment of Health Care Providers and Systems (CAHPS) surveys ask consumers and patients to report on and evaluate their experiences with health care. These surveys cover topics that are important to consumers and focus on aspects of quality that consumers are best qualified to assess, such as the communication skills of providers and ease of access to health care services.

The CAHPS Survey table Mh-6 is useful in understanding some of the elements in a Medical Home which consumers rate as typical for the Northeast region[104] of the country. In this survey, parents rate providers highly, but there is still work to be done in supporting families in the Northeast in caring for their child's health. These findings could be applied to Massachusetts as part of improving medical home practice for children in general. While most families rate providers highly (82%), only 37% report that they support them in taking care of their child's health.

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[104] Data is not available specifically for the state of Massachusetts

Table MH-6: Consumer Assessment of Health Care Providers and Systems (CAHPS), 2014

CAHPS 2014 Indicators	Northeast	National
Provider's Attention to Your Child's Growth and Development	61%	57%
Provider's Advice on Keeping Your Child Safe and Healthy	59%	54%
Patients' Rating of the Provider	82%	82%
Providers Support You in Taking Care of Your Child's Health	37%	37%

State Data on Medical Home

Hospital In-Patient and Emergency Care for Patients with ASD

Due to the medically complex nature of this population, many CYSHCN with ASD are frequent visitors to hospital emergency departments and in-patient settings, making it imperative that health care providers are familiar with and trained in the needs of this population.

IN-PATIENT HOSPITALIZATION CARE. A study was conducted by Kopecky et al. at Massachusetts General Hospital to assess the in-hospital needs of 80 patients diagnosed with ASD.[105] Parents were recruited to complete a 21-item survey about the needs of their child with an ASD while in the hospital. Common concerns included child safety and the importance of acknowledging individual communication methods. Parents reported a diverse range of needs while in the hospital. These data support the concept that a pragmatic assessment of individual communication and sensory differences is likely to be essential in the development of an appropriate inpatient care plan.

The result of this work was the creation of an Autism Care Plan that is now being administered on all new patients with ASD at MGH. In fact, one of the study's authors, Dorothea Iannuzzi, is the parent of a young adult with autism whose in-patient hospital experience was the inspiration for the study. During a recent 2016 hospitalization, the care plan was administered for him without knowledge of her role in the original research. Such care plans may be another important source of data and could be used in other pediatric medical centers in the state.

EMERGENCY DEPARTMENT CARE. Iannuzzi et al. from the previous MGH research team conducted another study to identify medical problems most commonly presented to emergency departments among individuals with ASD as compared to non-autistic persons across age groups.[106] Data were obtained from the 2010 National Emergency Department database and was analyzed by age categories: 3–5, 6–11, 12–15, 16–18 and 19 years and older.

Epilepsy emerged as the leading presenting progress among autistic youth, ages 16 and above. Psychiatric conditions were primary among autistic youth aged 12–15 years, accounting for more than 11% of all visits. In this sample, age-related differences were noted in medical diagnoses among autistic versus non-autistic persons. This data source[107] is one that should be considered further to better understand presenting symptoms in EDs in Massachusetts.

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[105] Kopecky K, Broder-Fingert S, Iannuzzi D, & Connors S. (2013). The Needs of Hospitalized Patients With Autism Spectrum Disorders: A Parent Survey. *Clinical Pediatrics, 52* (7), 652-660.

[106] Iannuzzi DA, Cheng E, Broder-Fingert S & Bauman ML. (2014). Brief Report: Emergency Department Utilization by Individuals with Autism. *Journal of Autism and Developmental Disorders*
DOI 10.1007/s10803-014-2251-2

[107] Healthcare Cost and Utilization Project, www.ahrq.gov/research/data/hcup/

As this patient demographic of autistic youth ages into adulthood, it will become an imperative that ED physicians as well as primary care adult physicians become more aware of the more common emergent medical conditions for this patient group. Further, physicians and other health care providers must become aware of the fact that some of the symptoms presented by autistic patients, most especially among those who are non-verbal, may differ substantially from symptoms exhibited by neuro-typical patients. Given that care provided in the ED setting is extremely costly and inefficient, preventative health care education for this patient demographic is an important public health issue.

An issue that merits further evaluation is how many of the individuals presenting with self-injurious or aggressive behavior have been evaluated for underlying medical conditions. In many autistic people, maladaptive behavior can be an expression of physical pain or discomfort. Making the assumption that maladaptive behavior is purely psychiatric or "behavioral" in nature can result in inappropriate treatment intervention, which could then compromise the quality of care. The assumption that aberrant behavior is simply due to the autism can result in medical errors and or exacerbation of the presenting disorders. A complete medical work up is essential for individuals in order to rule out an underlying medical condition that could be the cause of the self- injury or aggression. This situation needs to be better understood through measurement and monitoring.

MassHealth Utilization Data[108]

Understanding MassHealth utilization provides insights into the pharmacy, emergency department and in-patient utilization of CYSHCN with ASD as a baseline for future monitoring of needs.

PHARMACY UTILIZATION: Over two-thirds of MassHealth members with an ASD diagnosis (68.3%) had at least one filled prescription during SFY 2012. The mean number of prescriptions per member for the year was 45.4, but with substantial variation (standard deviation of 56.7). Half of the 10,081 members with any prescriptions filled more than 25 prescriptions in the course of the year.
Table MH-7 shows the distribution of the number of prescriptions filled by member age group:

Table MH-7. Pharmacy Utilization in MassHealth Members

Age Group	# Members	% of Children	# RX	% of Total RX
0-2	533	3.6%	2,953	0.6%
3-8	4,057	27.5%	43,888	9.6%
9-13	3,117	21.1%	77,722	17.0%
14-21	3,140	21.3%	127,635	27.9%
22+	3,908	26.5%	205,970	45.0%
Total	14,755	100%	458,168	100%

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[108] Kirby P, UMMS Center for Health Policy & Research (CHPR), Office of Clinical Affairs, 2015.

EMERGENCY DEPARTMENT UTILIZATION. Over one-third (37.3%) of the ASD population had one or more ED visits during SFY 2012. The following table shows the proportion of members in each age group having one or more ED visits:

Table MH-8. Emergency Department Utilization

Age Group	# Members	% of Children	# Having ED Visit	% of Group
0-2	533	3.6%	253	47.5%
3-8	4,057	27.5%	1,533	37.8%
9-13	3,117	21.1%	960	30.8%
14-21	3,140	21.3%	1,075	34.2%
22+	3,908	26.5%	1,687	43.2%
Total	14,755	100%	5,508	37.3%

INPATIENT HOSPITALIZATIONS. About one-eighth (12.3%) of the ASD population had one or more inpatient hospital stays during SFY 2012. Table MH-9 shows the proportion of members in each age group having one or more inpatient stays:

Table MH-9. In-Patient Hospitalization

Age Group	# Members	% of Children	# Having IP Stay	% of Group
0-2	533	3.6%	38	7.1%
3-8	4,057	27.5%	249	6.1%
9-13	3,117	21.1%	302	9.7%
14-21	3,140	21.3%	475	15.1%
22+	3,908	26.5%	758	19.4%
Total	14,755	100%	1,822	12.3%

AUTISM IN-HOUSE UTILIZATION. Restricting to only MassHealth members (PCC Plan, fee-for-service, and MCO, and excluding dual eligibles), there were 12,841 unique members who received an ASD diagnosis according to FY 2012 inpatient claims. (Previously reported figures had included dual eligibles or people eligible for both Medicare and Medicaid/MassHealth) Of this group, 1,209 had at least one inpatient hospital claim, or 9.4% of the ASD group. The total number of hospital claims for the group was 4,398. The mean number of hospitalizations during FY 2012 for this group was 3.64, and the median number of hospitalizations was 2. (Note: these figures may significantly overstate the number of distinct episodes of inpatient care, because of the way inpatient hospitals bill MassHealth. A single episode can be broken up into multiple separate claims, each covering a subset of the number of days contained in the entire hospitalization.)

Table MH-10 presents the top 10 principal and secondary diagnoses associated with these hospital claims. Many of the primary and secondary diagnoses listed below are mental health-related, raising the question of coding accuracy since health conditions such as gastro-intestinal and seizure concerns often reported anecdotally by caregivers may be under-represented. (The Top 30 for each table in Appendix under Medical Home Data).

Table MH-10. Top 10 Principal Diagnoses Associated with Hospital Claims by ASD Members

Diagnosis	Description	Frequency	Percent	Cumulative Frequency	Percent
29690	Episodic mood disord NOS	777	17.74	777	17.74
29980	Pervasv Dev Dis - Cur NEC	298	6.8	1075	24.54
29900	Autistic disord - current	256	5.84	1331	30.39
30981	Posttraumatic stress dis	246	5.62	1577	36.00
29680	Bipolar disorder NOS	188	4.29	1765	40.30
29990	Pervasv dev dis-cur NOS	164	3.74	1929	44.04
31401	Attn deficit w hyperact	95	2.17	2024	46.21
311	Depressive disorder NEC	92	2.1	2116	48.31
29570	Schizoaffective dis NOS	90	2.05	2206	50.37
30000	Anxiety state NOS	79	1.8	2285	52.17

Table MH-11. Top 10 Secondary Diagnoses Associated with Hospital Claims by ASD Members

Diagnosis	Description	Frequency	Percent	Cumulative Frequency	Percent
31401	Attn deficit w hyperact	204	7.31	204	7.31
29980	Pervasv Dev Dis - Cur NEC	160	5.73	364	13.04
29900	Autistic disord - current	146	5.23	510	18.27
30981	Posttraumatic stress dis	130	4.66	640	22.93
29900	Autistic disord - current	108	3.87	748	26.8
29690	Episodic mood disord NOS	90	3.22	838	30.03
+	Missing	89	3.19	927	33.21
31381	Opposition defiant disor	74	2.65	1001	35.87
29980	Pervasv Dev Dis - Cur NEC	58	2.08	1059	37.94
V6284	Suicidal ideation	58	2.08	1117	40.02
31400	Attn defic nonhyperact	56	2.01	1173	42.03
78039	Convulsions NEC	55	1.97	1228	44

Understanding the utilization patterns of this patient demographic can assist greatly with planning for their future needs. Since many of these concerns can escalate for transition age youth and young adults, physicians and other health care providers must become aware the nuance in some of the symptoms presented by autistic patients, most especially among those who are non-verbal, that may differ substantially from symptoms exhibited by neuro-typical patients. Given that care provided in the ED setting is extremely costly and inefficient, preventative health care education for this patient demographic is an important public health issue as part of workforce development.

Qualitative Data

Focus Groups

Specific questions about the medical home were asked in the parent leader and medical provider focus groups. (Please refer to the Methods section for more information about these groups). Other focus groups were not asked directly about medical homes, but themes related to its elements, such as care coordination and family navigation, emerged from the groups. The following themes cut across all focus groups.

The medical home model was not commonly experienced among the participants in our focus groups, but almost all agreed that there is a strong need within the autism community for medical homes that offer care coordination and family navigators. Participants felt this would improve traditionally poor health outcomes in children with autism and developmental disabilities that they attributed to a lack of good medical care coordination through a dedicated medical home. This included medical tests that were ordered but not completed, as well as parents missing appointments with specialists.

The unique care required by children with autism may also be challenging in a medical home setting, as described by one clinical nurse with over 20 years of experience working with the autism population.

> *"Providers are pressured to see x visits per day. And the providers who are seeing kids with autism, it's a long, long day if you see 10 patients a day. Not only do you have parents who are advocating, you need to spend 10 minutes getting them to the scale."*

Parent leaders described the biggest barrier to effective medical homes as the inability of providers to bill medical insurance for care coordination services. They also described a strong need for providers who can deliver medical care and also provide care coordination/case management.

Care coordination was described as a necessary, but potentially burdensome, activity for families, especially those with few resources. Multiple parents commented that coordinating care for their children is both time-consuming and stressful.

> *"There is enormous stress on families to coordinate care for their children. It's not uncommon to spend 20 hours a week on this."* – Parent of an adult with ASD with over two decades of experience working with families.

"And while she had leukemia they put her in a medical home and it was the greatest experience they ever had. Parents are desperate for this [medical homes]."

–Parent Outreach Coordinator

It was generally felt that care coordination is more difficult for families with fewer resources.

> *"Our service system is really difficult for families to navigate. It is very confusing for families. The families that we talk to, they may not even have a computer, so they have to go to the library [to research services]. And then the computer shuts down because it's overloaded."*
> – Early Intervention Program Director with statewide perspective.

WHO COORDINATES CARE? Parents knew of nurse practitioners or other staff from local pediatric offices who were providing care coordination. Overall, participants felt more and more pediatric offices were providing care coordination.

Private care coordination was mentioned as an option for families who can afford to pay privately. One private care coordinator in the Boston area described her services as:

> *"It's my job to educate parents about the diagnosis or connect them to someone who's appropriate outside of the school system. I function as a case manager so get very involved in setting up with a psychiatrist or psychologist… I call myself a coach because then I get releases from parents to talk to everyone. I talk to parents, grandparents, educators, doctors, everybody. So from my perspective, it's really great because I get the whole picture. Then I can set up parent support groups that I organize based on age of children. My experience is over the long haul. I've worked with kids from elementary school and now in high school and out."*

The opportunity to visit multiple specialists in one location was mentioned frequently as a need for families.

> *"I consistently hear from families that they'd like a type of medical home where all the care is in one place. The strongest need is for DBP's in a community setting."* - Parent Leader, Director of an Autism Support Center.

Future possibilities: Medical Home

Some of our findings for the Medical Home core outcome are considered to be promising practices as well as possible data sources for the future. This section points out some measurable ideas worth considering.

Local Training for Pediatric Providers

OPERATION HOUSE CALL. The 2013 Massachusetts Autism Commission report supported the Operation House Call (OHC) program as part of its Priority #12: *"Improve the delivery of health care services for individuals with autism."* The Commission has endorsed the work of OHC to train providers in "medical, nursing, dentistry, physical therapy, occupational therapy, speech therapy, and other specialty degree programs."[109]

A program of the Arc of Massachusetts, OHC teaches young medical professionals essential skills to enhance the health care of persons with intellectual/developmental disability. OHC turns to families, parents and individual self-advocates as educators in a health care field that seldom focuses on more than making a diagnosis. It is a rare and important training opportunity. Through OHC, students begin to build confidence and interest in working with individuals with intellectual and developmental disabilities and their families.

This program has recently expanded workforce development and training at the following medical schools and universities: Boston University School of Medicine, Tufts Medical School, Simmons School of Health Sciences, UMass Medical School and Graduate School of Nursing, and Yale School of Nursing.

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[109] Massachusetts Autism Commission (March 2013). *Report of the Massachusetts Special Commission Relative to Autism*. http://www.mass.gov/anf/docs/mddc/autism-commission-report-full.pdf

SPECIAL HOPE FOUNDATION PROJECT. Nurses do not often play a significant role in transitional medical homes, even though they are ideally suited to coordinate such care. As a result, they may lack the knowledge about both ASD and the concept of transition from adolescent to adult health care services.

To address these gaps, the UMASS Medical School-Shriver Center in collaboration with the UMASS Medical School Graduate School of Nursing and OHC is developing an innovative training curriculum to prepare graduate-level family nurse practitioner students to provide patient-centered health care for transition age youth with ASD under a grant from the Special Hope Foundation. (More information is available in the section on Transition to Adult Health Care under "Future Possibilities").

Telehealth and Telepractice Models

Several innovative telehealth and telepractice models could help expand workforce capacity for the medical home. While insurance companies in Massachusetts do not reimburse for services delivered via Telehealth, there are models that are being studied in Massachusetts and used in other states.

- **TELEHEALTH TRAINING AND CONSULTATION.** Project ECHO[110] is a model that could prove helpful to medical homes with peer training around complex patient cases such as children with autism. Telehealth coaching models have helped pediatricians and other providers become a remote community of practice, not only helping the child but coaching each other to increase capacity and strengthen practice. There are webinars available online that explain this model in greater detail. It is getting much notice nationally as an emerging best practice.

- **TELEPRACTICE FOR SPEECH THERAPY.** Under a U.S. DOE grant, Dr. Mary Andrianopoulos and her colleagues at UMass Amherst in the Departments of Communication Disorders and Special Education are studying telepractice to supervise speech pathology graduate and doctoral students who are learning from working with children and families on the Massachusetts/New York border where there are no services close by. Telepractice in Dr. Andrianopoulos's studies has been shown to work effectively without compromising results. This could be particularly useful for serving those children who are regionally far removed but need care.

- **TELEPRACTICE ABA.** The state of Iowa uses a telepractice model to train ABA providers as well as to coach parents remotely to strengthen their skills at home.[111]

Recommendations: Medical Home

Considering the high level of medical needs for the population of Massachusetts children with ASD based on the prevalence of co-morbid health conditions affecting one's functional abilities, there is considerable need for medical homes to serve this population's needs. Most parents report having a usual source of care and a personal health care provider for their child, but few report receiving effective care coordination and family-centered care. With the large number of providers in the state, greater capacity is needed to serve this population well in dedicated, coordinated, ongoing, family-centered, culturally competent and comprehensive medical homes. Collecting medical home

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[110] https://www.autismspeaks.org/wordpress-tags/echo-autism

[111] For more information, please contact Elaine.Gabovitch@umassmed.edu.

related data to understand and support workforce development and training, outreach and promotion of this important concept to practices in the state as part of medical home transformations, and monitoring progress appears to be a critical need.

In spite of the presence of patient-centered medical home demonstration projects across the country in recent years, such as the CHIPRA initiative in Massachusetts, little is known about how medical homes fare when serving the state's CYSHCN with autism. National surveys provide only limited information based on small sample sizes. Innovative practices such as the use of family navigation projects and telehealth/telepractice to train and increase workforce capacity hold promise for providing greater access to family-centered, culturally-competent care coordination services for these children and youth, however they are limited as well.

1.) SET MEDICAL HOME TARGETS AND MONITOR PROGRESS ON AN ANNUAL BASIS.

The national Maternal, Infant & Child Health (MICH) Outcome Indicators for Medical Home may be useful to Massachusetts in setting targets and monitoring progress by related indicator criteria. To review, the indicator is:

- **MICH-30.2**: Increase the proportion of children with special health care needs who have access to a medical home
    - National Baseline: 47.1% of U.S. CSHCN with autism (National target = 51.8%)

The Massachusetts Autism Commission could consider whether this national target is appropriate for the state and determine how and which data sources can be used to measure and monitor this core outcome indicator.

2.) OBTAIN A LARGER DATA SAMPLE FOR NATIONAL SURVEY QUESTIONS RELATED TO THE MEDICAL HOME NEEDS OF CYSHCN WITH ASD.

Initial results of the NSCH and NS-CSHCN national surveys indicate over 70% of CYSHCN with ASD in Massachusetts do not receive all of the elements of a coordinated, ongoing, comprehensive medical home compared with other CYSHCN generally, though more data is needed to establish a reliable baseline from which monitor future progress. CYSHCN who have ASD and two or more chronic co-morbid conditions (over 90%) and affected a "great deal" by functional limitations (over 50%) are estimated to have greater needs than CYSHCN in general. The proportion not receiving care coordination is estimated at over half and those not receiving family centered care is estimated at almost 60%.

There are not enough data in the NSCH and NS-CSHCN to be reliable or precise enough to draw firm conclusions on issues related to the medical home needs of CYSHCN with ASD, but when compared to national trends there are important insights. Therefore, collecting medical home related data is needed to understand its status in order to support workforce development and training, as well as provide outreach and promotion of this important concept to practices in the state as part of medical home transformations. Establishing a baseline and monitoring progress appear to be critical needs.

3.) OBTAIN DATA TO MEASURE AND MONITOR IN-HOSPITAL UTILIZATION TRENDS.

It is important to record and monitor the level of need for and management of CYSHCN with ASD by reviewing in-patient hospital, emergency department and pharmacy utilization data, especially for those who are non-verbal, self-injurious, and/or aggressive. This becomes increasingly necessary as youth approach transition age. Understanding the utilization patterns of this group can assist with planning for their future needs and prepare the workforce for competently serving this population.

Other in-hospital/ED utilization considerations include:

- Using national or MassHealth emergency department data sets to monitor utilization.
- Training ED physicians as well as primary care adult providers about common emergent medical conditions with an emphasis on differing symptoms presenting for autistic patients compared to neurotypical patients (e.g., non-verbal communication, sensory needs, seizure disorders, maladaptive behaviors to communicate pain, etc.).

4.) Build and monitor Medical Home workforce capacity and development.

It is important to measure workforce capacity and to monitor workforce development through training to meet the outcome indicator listed above. Doing so will influence creating a state infrastructure of trained and networked medical home providers as well as in-hospital and ED settings that are equipped to coordinate care and treat CYSHCN with ASD.

The OHC program and the upcoming Special Hope project presented herein could serve as helpful models and may produce relevant data to share for this purpose.

The Massachusetts Autism Commission could consider leveraging these resources and others to measure and monitor the state's workforce capacity to provide coordinated, ongoing, comprehensive medical homes to CYSHCN with ASD.

Other workforce development considerations include:

- Tracking the type, number and locations of pediatric medical homes with help from the MCAAP, NICHQ, and others to count all NCQA certified medical homes.
- Monitoring state workforce capacity.
- Training and workforce development, including to address hospital in-patient and ED needs.
- Using telehealth to train providers and review difficult cases, particularly for those who are regionally remote, such as the Southeast/Cape Cod region and the Western region.
- Working with OHC, medical schools, medical centers, community health centers and the MCAAP and MLCHCs to train pediatric providers and practices on the medical needs of individuals with ASD, how to set up a medical home practice, and/or how to serve them better in a pre-existing medical home practice.
- Reaching out to the state pediatric community through the MCAAP and the Massachusetts League of Community Health Centers to brainstorm solutions to barriers impeding practitioners from implementing the medical home, such as time limitations and reimbursement rates that fail to cover care coordination and the extra time that this population often needs.
- Training and embedding family navigators in pediatric practices to provide care coordination.

ACCESSIBLE COMMUNITY-BASED SERVICE SYSTEM

Healthy People 2020 Core Outcome Indicator #3

Community-Based Services Are Organized So Families Can Use Them Easily

The following section reviews what is known about the accessibility of the various support systems for Massachusetts children and youth with autism and their families. We present identified needs through national survey data, state survey findings, and agency information first and then provide qualitative insights from focus groups. We discuss future possibilities and best practices, a number of local and federal resources, and recommendations at the conclusion.

Background

Effective promotion of health and health services for children and youth with special health care needs (CYSHCN) requires a system of care that is integrated, comprehensive, coordinated, family centered and consistent across the life course (or lifespan). Ideally, these systems are easy to navigate and foster positive experiences between families and health service providers.

The Health Resources & Services Administration-Maternal and Child Health Bureau (HRSA-MCHB) calls for "community-based services for children and youth with special health care needs to be organized so families can use them easily."

A community-based system of services is defined as:

> *"…an infrastructure that operates across service sectors. It facilitates the integration of services in several dimensions— including organization, delivery, and financing. The development of community-based systems of services is a response to the complexity and fragmentation of services for CSHCN and their families. Multiple service programs—each with its own funding streams, eligibility requirements, policies, procedures, and service sites—serve CSHCN. It is clear that communities and their resources affect the way families of children with special health needs find and use services. Therefore, the health of communities themselves can have a positive effect on the growth and development of CSHCN."* [112]

According to MCHB, care coordination and family-centered care should be treated as integral parts of systems of care for children and youth with autism, as well as CYSHCN in general. The MCHB defines care coordination as "a process that links CYSHCN to services and resources in a coordinated effort to maximize the potential of children and provide them with optimal health care."[113] Family-centered care is defined as "an approach to the planning, delivery, and evaluation of health care whose cornerstone is active participation between families and professionals. Family-centered care helps support the family's relationship with the child's health care providers and recognizes the importance of the family's customs and values in the child's care. More information on care coordination and family-centered care is also discussed in the Medical Home section.

MCHB has set the targets presented in the table below as key Maternal, Infant and Child Health (MICH) outcomes of Healthy People 2020 for an accessible community-based service system. The

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[112] http://mchb.hrsa.gov/cshcn0910/core/pages/co5/co5cbs.html

[113] American Academy of Pediatrics Committee on Children with Disabilities. Care coordination: Integrating health and related systems of care for children with special health care needs. *Pediatrics* 1999; 104(4):978-981.

MCHB national target-setting method is a goal of 10% improvement over baseline. For the purposes of this report, we will consider this goal for children with autism specifically.

MICH-31[114]*: Increase the proportion of children with special health care needs who receive their care in family-centered, comprehensive, and coordinated systems.*

Maternal Infant & Child Health Indicator #	Baseline	Nat'l Target
MICH-31.1: Increase the proportion of children aged 0 to 11 years with special health care needs who receive their care in family-centered, comprehensive, and coordinated systems.	20.4 percent of children aged 0 through 11 years with special health care needs received their care in family-centered, comprehensive, and coordinated systems in 2005–06.	22.4 %
MICH-31.2: Increase the proportion of children aged 12 to 17 years with special health care needs who receive their care in family-centered, comprehensive, coordinated systems.	13.8 percent of children aged 12 through 17 years with special health care needs received their care in family-centered, comprehensive, and coordinated systems in 2005–06.	15.1 %

To assist policy makers, practitioners, state programs, researchers and families in implementing community-based systems of care, Perrin et al. (2007)[115] presented a conceptual definition of the system of community-based services for CYSHCN that included coordination of child and family services, effective communication among providers and the family, family partnership in care provision, and flexibility. The conceptual definition was intended to help measure development and assessment of how well systems work and achieve their goals. The authors describe a responsive system of services as providing a seamless and transparent spectrum of services that are accessible, flexible, responsive, and targeted to address the child's mental, physical, emotional and social needs. It includes all possible systems that could service CYSHCN such as: Medical home, other medical, education, social services, public health, insurance/financing, mental health, transportation, vocational services, housing, and others. It should be organized to be cost-effective, sustainable, equitable and universal. It would require changes on the macro level (state and local) and micro level (community service systems). It allows for measurement of all domains with implementation of standardized eligibility protocols, ability to access all services regardless of the point of entry, would have methods to blend funding from several sources, measures to avoid duplication of effort, interagency agreements, and waivers of program and financing rules to enhance seamlessness. Potential challenges include boundary-related concerns, regulatory impediments, availability of adequate funding, evidence to develop a cost-effective delivery system, and of particular importance to Massachusetts, balancing the privacy of the person and the family with provider needs for information. Thus, to achieve measurable health outcomes for CYSHCN with autism, the institution, coordination and measurement of process outcomes for related community-based systems of care is necessary as well.

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114 National Survey of Children with Special Health Care Needs (NS-CSHCN), HRSA/MCHB and CDC/NCHS. Source: https://www.healthypeople.gov/2020/topics-objectives/topic/maternal-infant-and-child-health/objectives

[115] Perrin J, Romm D, Bloom S, Homer C, Kuhlthau K, Cooley C, Duncan P. (2007). A family-centered, community-based system of services for children and youth with special health care needs. Archives of Pediatrics, 161, 933.

Summary of State Environment: Access to Care

To understand access for CYSHCN with autism to community-based systems of care in Massachusetts in the current state environment, it is essential to review recent history that has resulted in sweeping changes in the state. By looking at the Massachusetts Autism Commission that met from 2011-2013, the follow-up Autism Omnibus Bill of 2014 that acted on the top priorities set by the Commission, and the 2016 Annual Report of the permanently appointed Autism Commission that brings their activities up to the present day, the reader will gain insight into how the various systems of care in Massachusetts impact CYSHCN with autism, where the baseline of known state data was originally set, and how far the needle has moved over the past five years.

Massachusetts Autism Commission Report 2013[116]

EXECUTIVE SUMMARY FROM THE REPORT. The Special Commission Relative to Autism was established by Legislative Resolve and approved by Governor Deval Patrick on April 22, 2010. The Mission of the bipartisan Commission was:

> *"To investigate and study current support and services, identify gaps and make recommendations for strategies that will support the development of appropriate, collaborative and timely supports and services across the lifespan of individuals on the [autism] spectrum."*

The mission charged the Commission to focus on:

- Best practices
- Increased coordination among state agencies
- Maximization of federal reimbursement and other resources
- Approaches to better serve individuals on the spectrum and their families

Per the Legislative Resolve, the Commission was directed to focus its work on issues affecting all individuals on the autism spectrum, including, but not limited to, classic autism, Asperger's syndrome, High Functioning Autism and Pervasive Developmental Disorder, not otherwise specified.

The Resolve directed the Commission to investigate issues including, but not limited to:

- Coordination of state human service agencies
- Issues related to access for families of children with autism spectrum disorders and adults who are from linguistically and culturally diverse communities
- Provision of adult human services
- Behavioral services based on best practices to ensure emotional well-being
- Mental health services
- Public education
- Mechanisms to ensure maximization of federal reimbursement
- Post-secondary education
- Job attainment and employment, including supported employment
- Housing
- Independent living
- Community participation
- Social and recreational opportunities

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[116] http://www.mass.gov/anf/docs/mddc/autism-commission-report-full.pdf

Throughout its work, the Commission focused on developing recommendations related to these issues.

PROCESS. Acknowledging the broad range and diversity of issues and needs affecting individuals on the autism spectrum throughout their lifespan, the Commission established sub-committees to provide the opportunity for in-depth analyses and the development of recommendations on specific issues affecting the following groups:

- Birth to Five
- School Age
- Transition to Adulthood
- Adults

Sub-committees were chaired by leaders in the autism community who were joined by numerous professionals, parents, self-advocates, and others with specific interests and expertise in these areas. State agencies from four Secretariats were represented on the Commission and these representatives served as valuable resources to the citizen members.

The findings and recommendations in the Commission's 2013 report were independently formulated by the citizen members and did not imply the endorsement of any specific agency or the Patrick Administration at the time. More than forty personal experiences and stories were also submitted by members of the public at the request of the Commission. These vignettes were inserted throughout the report to illustrate some of the key findings and recommendations of the Commission.

FINAL AUTISM COMMISSION REPORT RECOMMENDATIONS. Using the State Agency reports and the work of the sub-committees as a foundation, the Commission prioritized its findings and recommendations into the following 13 categories:

1.) Expand eligibility criteria for the Department of Developmental Services so that individuals with autism who have IQs over 70 and have substantial functional limitations have access to services.
2.) Assure that those with autism and a co-occurring mental health condition have equal access to and appropriate services from the Department of Mental Health.
3.) Expand intensive services in the home and community for individuals with autism through the Children's Autism Medicaid Waiver, the Adult Medicaid Waivers, and the Department of Elementary and Secondary Education/Department of Developmental Services Residential Placement Prevention Program.
4.) Expand insurance coverage for autism treatments.
5.) Increase and fortify supports and resources that make it possible to maintain the family unit and assist individuals with autism to live in the community.
6.) Determine the number of people with autism in Massachusetts and their support needs by implementing a plan for consistent statewide data collection.
7.) Improve access to autism screening, diagnosis, and Autism Specialty Services through Early Intervention for children diagnosed with autism and those considered at high risk for autism.
8.) Increase employment opportunities for individuals with autism by providing a range of job training, job development, and employment opportunities.
9.) Increase capacity to provide educational supports and services necessary to meet the needs of all students with autism.
10.) Increase availability of augmentative and alternative communication methods, devices and services for individuals with autism.

11.) Increase the range of housing options for individuals with autism.
12.) Improve the delivery of health care services for individuals with autism.
13.) Assure that the Autism Commission's Recommendations are implemented and outcomes are monitored for effectiveness.

Wherever appropriate, this report will connect its findings to these recommended state priorities.

Autism Omnibus Bill of 2014

The Autism Omnibus Bill of 2014 (Chapter 226 of the Acts of 2014) [117,118] was responsible for a number of positive developments in policies that provide access to services and supports for people with autism in Massachusetts. All of the parts of this important bill were prioritized follow-up actions from the 2013 Commission Report.

The bill included the following key provisions:

- *"A requirement that MassHealth cover medically necessary treatments for children with ASD who are under 21 years old – including ABA therapies as well as dedicated and non-dedicated AAC devices;*
- *Extension of Department of Developmental Services (DDS) eligibility to many persons with Autism, Prader Willi Syndrome and Smith-Magenis syndrome;*
- *The creation of an Autism Endorsement for special education teachers to enable them to voluntarily gain in-depth knowledge about the complexities of educating students with ASD;*
- *The creation of tax-free saving accounts (called "Achieving a Better Life Experience" or ABLE) to help families cover anticipated disability-related expenses for individuals with ASD and other physical and developmental disabilities;*
- *Requiring DMH and DDS to develop and implement a plan to provide services to individuals who have both a mental illness and a developmental disability; and*
- *Establishing the Autism Commission as a permanent entity."*

2016 Annual Report of the Autism Commission

In 2015, the Autism Commission became a permanent entity under the aforementioned Omnibus Bill and by early 2016, Carolyn Kain was appointed as its Executive Director. She and the new Commission members submitted its first annual report to Governor Charles Baker on October 24, 2016. The report includes updates on the 2013 Report recommendations and outlines "current unmet needs and trends in autism services, supports, and treatments for individuals with autism, with any recommendations for regulatory or legislative action necessary to provide or improve such support and services."[119] Much of the information in this report draws from the monthly meetings of the Commission starting in January 2015, as well as materials shared with our project team by the Commission's Executive Director. (See Appendix for full report).

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[117] http://www.mass.gov/eohhs/consumer/disability-services/services-by-type/intellectual-disability/newsroom/hb4047-autism-omnibus.pdf
[118] https://malegislature.gov/Laws/SessionLaws/Acts/2014/Chapter226
[119] Kain, C. (October 24, 2016). *The Massachusetts Autism Commission Annual Report*. Commonwealth of Massachusetts.

Identified Needs: Access to Care

Quantitative Findings

National Survey Data and Outcomes

Within Massachusetts, there are few quantitative measures that currently exist to substantiate the current status of criteria for an accessible community-based system of care. However, the 2009-10 National Survey of Children's Health Care Needs (NS-CSHCN) survey may provide some insights. It describes the "overall system of care" as a summary measure using low-threshold criteria for meeting each Healthy People 2020 core outcome calculated by evaluating the number of CSHCN meeting all age-appropriate core outcomes: Outcomes #1-5 for CSHCN age 0-11 and Outcomes #1-6 for CSHCN age 12-17.

The core outcomes are:

1.) Early and Continuous Screening (Early Identification)
2.) Medical Home
3.) Ease of Community-Based Service Use (Access)
4.) Partners in Decision Making (Family Involvement)
5.) Adequate Health Insurance
6.) Transition to Adulthood (ages 12-17 only)

The survey results break down the success of meeting these criteria by 0-2, 3-4, 5 or 6 outcomes met.

The following NS-CSHCN tables will share data estimating the access to community-based systems of care for all children with special health care needs (CSHCN) with or without. For more information about this survey, please refer to "Understanding Healthy People 2020 and Outcome Indicators for CYSHCN" in the Overview Section of this report.

It should be noted that while national surveys provide estimates of children with ASD in the state, they are based on parent report and cannot be confirmed by medical records. In addition, these surveys represent low sample sizes of children with ASD and thus, their statistical significance is greatly reduced. Weighted population estimates, as well as 95% confidence intervals (Cis) and their associated ranges will be important for the reader to keep in mind. Wherever the state findings trend with national estimates, we note these patterns for the reader.

See each report section for more information about each core outcome indicator for CYSHCN with autism in Massachusetts. In addition, tables with more information about the findings can be found in the Appendix under "Access to Care Data".

Meeting the Criteria for an Accessible System of Care for State CYSHCN with Autism

AGES BIRTH TO 11. Table AC-1 indicates that Massachusetts CSHCN with autism aged 0-11 years achieved far fewer outcomes for systems of care than all other CSHCN in Massachusetts. The survey estimates that between 46.4% and 77.3% achieved only 0-2 outcomes, and only between 0% to 8.4% achieved 5 or more outcomes. Massachusetts CSHCN in general shared a much better picture since between 18.5% and 28.1% achieved 5 or more outcomes, and between 40.7% and 53.4% achieved 3-4 outcomes. These results trended similarly to U.S. CSHCN findings.

Table AC-1. Ages 0-11 years meeting criteria for system of care, NS-CSHCN 2009-10

		0-2 outcomes achieved	3-4 outcomes achieved	All 5 outcomes achieved	Total
All U.S. CSHCN	*%*	31.37%	48.47%	20.15%	
	C.I.	(30.2 - 32.6%)	(47.3 - 49.7%)	(19.2 - 21.1%)	
	n	6,201	10,753	4,894	21,848
	Pop. Est	1,957,934	3,024,590	1,257,169	6,239,693
All U.S. CSHCN with ASD	*%*	56.5%	35.0%	8.5%	
	C.I.	(52.4 - 60.7%)	(31.0 - 38.9%)	(6.3 - 10.7%)	
	n	928	675	163	1,766
	Pop. Est	286,764	177,257	43,162	507,183
All MA CSHCN	*%*	29.6%	47.1%	23.3%	
	C.I.	(23.3 - 35.9%)	(40.7 - 53.4%)	(18.5 - 28.1%)	
	n	111	191	105	407
	Pop. Est	39,733	63,119	31,209	134,061
*All MA CSHCN with ASD**	*%*	61.8%	34.7%	3.5%	
	C.I.	(46.4 - 77.3%)	(19.6 - 49.8%)	(0.0 - 8.4%)	
	n	25	16	2	43
	Pop. Est	6,498	3,641	368	10,507

C.I. = 95% Confidence Interval. Percentages are weighted to population characteristics.

n = cell size. Use caution in interpreting cell sizes less than 50

Note: Given the range of the estimates, it appears that the sample size may be too small to meaningfully estimate whether all criteria for system of care was met for children ages 0-11 years with ASD within Massachusetts.

Frequency missing = 410

AGES 12 TO 17. The sample sizes for Massachusetts CYSHCN with autism aged 12-17 from national surveys are too small to draw meaningful results. U.S. results indicate older children with autism may experience systems of care that meet more of the quality criteria, but that there are still substantial disparities compared to other CYSHCN.

Table AC-2. Ages 12-17 meeting criteria for system of care, NS-CSHCN 2009-10

		0-2 outcomes achieved	3-4 outcomes achieved	5 outcomes achieved	All 6 outcomes achieved	Total
All U.S. CSHCN	*%*	26.5%	38.4%	21.4%	13.6%	
	C.I.	(25.1 - 27.9%)	(37.1 - 39.8%)	(20.3 - 22.6%)	(12.7 - 14.5%)	
	n	3,379	5,861	3,614	2,479	15,333
	Pop. Est	1,062,882	1,541,674	859,379	546,136	4,010,071
All U.S. CSHCN with ASD	*%*	40.8%	42.1%	12.0%	5.2%	
	C.I.	(35.5 - 46.0%)	(36.9 - 47.2%)	(8.8 - 15.1%)	(3.2 - 7.2%)	
	n	413	436	146	55	1,050
	Pop. Est	106,843	110,233	31,330	13,678	262,084

C.I. = 95% Confidence Interval. Percentages are weighted to population characteristics.

ALL AGE RELEVANT OUTCOMES. Whether comparing CYSHCN with autism to other CYSHCN in general in the state or in the country, it is consistently clear that they access fewer of the core outcomes for a health system of care than other CYSHCN. CYSHCN in Massachusetts and the U.S. fare slightly better, but overall, the health care system is not achieving nearly enough of the age-relevant core indicators needed for a high standard of care. Again, these results are too small to be reliable or precise but they trend similarly to U.S. CSHCN findings.

Table AC-3. System of care for all CSHCN - met all age relevant outcomes (age 2-17), NS-CSHCN 2009-10

		2 or more age-relevant core outcomes NOT achieved	1 age-relevant core outcome NOT achieved	All age-relevant core outcomes achieved	Total
All U.S. CSHCN	*%*	57.9%	24.5%	17.6%	
	C.I.	(57.0 - 58.8%)	(23.7 - 25.3%)	(16.9 - 18.35%)	
	n	20,232	9,576	7,373	37,181
	Pop. Est	5,937,670	2,508,790	1,803,305	10,249,765
All U.S. CSHCN with ASD	*%*	77.4%	15.2%	7.4%	
	C.I.	(74.9 - 80.0%)	(13.0 - 17.4%)	(5.8 - 9.0%)	
	n	2,146	452	218	2,816
	Pop. Est	595,639	116,788	56,841	769,268
All MA CSHCN	*%*	53.2%	24.7%	22.1%	
	C.I.	(49.5 - 57.9%)	(20.7 - 28.7%)	(18.5 - 25.8%)	
	n	374	183	175	732
	Pop. Est	127,748	59,295	53,187	240,230
*All MA CSHCN with ASD**	*%*	78.7%	18.6%	2.7%	
	C.I.	(66.5 - 90.9%)	(6.7 - 30.5%)	(0.0 - 5.8%)	
	n	53	10	3	66
	Pop. Est	15,147	3,582	522	19,251

C.I. = 95% Confidence Interval. Percentages are weighted to population characteristics.

n = cell size. Use caution in interpreting cell sizes less than 50

Note: Given the range of the estimates, it appears that the sample size may be too small to meaningfully estimate whether all age relevant criteria for system of care was met for children ages 2-17 years with ASD within Massachusetts.

Frequency missing = 85

Specialty Services Access

ACCESSING SPECIALTY CARE. The NSCH reported that overall, between 32-81% of Massachusetts children with autism and 68% (C.I. 65.6-71.1%) of all Massachusetts children indicated that they did not need or receive specialty care. About a quarter of both groups indicated that they needed or received specialty care without a problem. However, it is estimated that between 0 – 34% of Massachusetts children with ASD needed or received specialty care but had a problem, compared with just 5.6% (C.I. 4.2-7.0%) of all Massachusetts children. Small sample sizes can provide only wide estimates, but these estimates do not show any significant differences from national findings.

ACCESSING MENTAL HEALTH TREATMENT OR COUNSELING. Despites small sample sizes resulting in wide estimate ranges, the NSCH also reported that significantly more Massachusetts children with autism received mental health treatment or counseling (46.4%, C.I. 20.5-72.3%) than Massachusetts children in general (13.3%, C.I. 11.2-15.5%). Mental health utilization rates for children in general in MA were significantly higher than national rates (9.4%, C.I. 8.9-9.8%); patterns for children with autism were not significantly different between state and national trends.

Effect on Family Members

Two additional measures of access to community-based systems of care are related to the amount of care that a family member must dedicate to their child or adolescent with autism due to a lack of supports for the caregiver and whether that becomes a hardship to the family.

The NS-CSHCN asks parents whether they or other family members provide health care at home for the child or youth with autism. Although not statistically significant, the trend for 46.5% of Massachusetts parents of CYSHCN with autism who provide health care at home is comparable to all 43.2% of U.S. CSHCN with autism, and in fact, closely aligned to all 46.7% CSHCN for Massachusetts and 49.6% of U.S CSHCN. The result is split down the middle. The more important question is what factors created the situation, how much of a hardship it is and what can be done to address it. The answer would require more investigation and monitoring.

Table AC-4. Do you (parent) or other family members provide health care at home for your child?, NS-CSHCN 2009-10

		No	Yes	Total
All U.S. CSHCN	*%*	50.3%	49.6%	
	C.I.	(49.4 - 51.2%)	(48.7 - 50.5%)	
	n	20891	19132	40,023
	Pop. Est	5551596	5475296	11,026,892
All U.S. CSHCN with ASD	*%*	46.7%	43.2%	
	C.I.	(43.6 - 50.0%)	(50.1 - 56.4%)	
	n	1516	1527	3,043
	Pop. Est	391293	445432	836,725
All MA CSHCN	*%*	53.1%	46.7%	
	C.I.	(48.6 - 57.6%)	(42.2 - 51.3%)	
	n	433	352	785
	Pop. Est	137,089	120,681	257,770
*All MA CSHCN with ASD**	*%*	43.5%	46.5%	
	C.I.	(29.4 - 57.6%)	(42.4 - 70.7%)	
	n	37	37	74
	Pop. Est	9,215	11,967	21,182

C.I. = 95% Confidence Interval. Percentages are weighted to population characteristics.

n = cell size. Use caution in interpreting cell sizes less than 50

Note: Given the range of the estimates, it appears that the sample size may be too small to meaningfully estimate whether or not care is provided at home in MA.

Frequency missing = 33

In terms of determining how much of a hardship the level of at-home care described above might be for the family, the question about whether parents have needed to stop work due to the child's condition sheds more light. The results are fairly close again. For 40.9% of Massachusetts parents of CYSHCN with autism, they report having to stop working due to the need to care for their child with autism compared to 38.2% of U.S. parents of CSHCN with autism. Conversely, only 16.5% of Massachusetts parents of CSHCN and 15.1% of U.S CSHCN have had to stop working. Roughly 25% more family members of children with autism cannot work compared to those with special health care needs. Again, the question is what can be done to address these hardships and this would also require more investigation and monitoring.

Table AC-5. Have you (parent) or other family members stopped working due to your child's health condition?, NS-CSHCN 2009-10

		No	Yes	Total
All U.S. CSHCN	*%*	84.9%	15.1%	
	C.I.	(84.2 - 85.6%)	(14.4 - 15.7%)	
	n	34,911	5,060	39,971
	Pop. Est	9,357,340	1,659,267	11,016,607
All U.S. CSHCN with ASD	*%*	61.6%	38.2%	
	C.I.	(58.3 - 64.8%)	(35.0 - 41.57%)	
	n	1,971	1,063	3,034
	Pop. Est	514,693	319,734	834,427
All MA CSHCN	*%*	83.2%	16.5%	
	C.I.	(79.2 - 87.2%)	(12.53 - 20.4%)	
	n	676	108	784
	Pop. Est	214,581	42,461	257,042
*All MA CSHCN with ASD**	*%*	55.1%	40.88%	
	C.I.	(39.7 - 70.5%)	(25.3 - 56.5%)	
	n	49	24	73
	Pop. Est	11,669	8,660	20,329

C.I. = 95% Confidence Interval. Percentages are weighted to population characteristics.

n = cell size. Use caution in interpreting cell sizes less than 50

Note: Given the range of the estimates, it appears that the sample size may be too small to meaningfully estimate whether or not family members have stopped work.

Frequency missing = 34

When considering how accessible systems of care are for families who support CYSHCN with autism compared to other CYSHCN, the difference is clear: families of children with autism access fewer of the core outcomes for a health system of care than other CYSHCN. The health care system is not achieving enough of the age-relevant core indicators needed for a high standard of care. Moreover, families also report experiencing some difficulty accessing specialty care, a high need for mental health services and personal hardships supporting their family members.

In addition to understanding the results of this category in general, it is important to note that assessment within demographic or other subgroups of CSHCN is critical to developing appropriate interventions and policy responses. More investigation and analysis of these critical questions is needed for Massachusetts children and youth with autism due to the small sample size.

State Data

Access to Early Identification

Starting in late 2013, the Massachusetts Act Early program conducted two surveys, the *Pediatric Provider Survey* and the *Wait Time Survey*, to better understand screening, diagnosis and referral practice and timelines for both general and specialty pediatric providers. Each survey will first be presented separately with the most pertinent findings and then a comparison of the two surveys. Given the dynamic nature of regional capacity building and change, these regional findings may have grown or diminished since the surveys were administered. Most importantly, evaluation wait times are ever-changing, requiring ongoing monitoring.

Pediatric Provider Survey 2013-2014

PURPOSE. From August 2013 through January 2014, the Massachusetts Act Early State Team's Early Identification Task Force members produced a pediatric provider survey to better understand developmental and autism screening practices in Massachusetts. This collaborative group represented backgrounds in pediatrics, autism family support, Early Intervention specialty services, special education, and research. The survey polled state-based pediatricians on such areas as: the types of screening tools used, if any; the scoring and review processes; comfort level with screening; the process of referral for a positive screen; evaluation wait times; and the screening and referral process for working with non-English speaking families.

METHODS. An invitation to the survey (online via Survey Monkey) was disseminated in three email waves to 1,600 Massachusetts pediatricians in August 2013, November 2013 and January 2014 using an email marketing service, Health Data Solutions. A total of 106 pediatricians responded (6.6% response rate) from the following regions: Metro Boston (50%), Northeast (17%), Western (14%), Central, (12%), Southeast (10%). They reported working in the following settings: Urban (50%), Suburban (49%), Rural (2%).

FINDINGS. Selected findings include:

- 34% of pediatricians reported that greater than or equal to 51% of their patients use MassHealth, which confirms MassHealth utilization reports.
- Pediatricians reported using certain MassHealth approved screening tools over others:
    - For developmental screening, 74% preferred the Parent's Evaluation of Developmental Status (PEDS) compared to 6% who reported preferring the Ages and Stages Questionnaires (ASQ-3 or ASQ:SE). (This survey preceded the most recent changes to the list of MassHealth-approved tools and may no longer reflect current practice).
    - 91% of the respondents overwhelmingly reported using the Modified Checklist of Autism in Toddlers (M-CHAT). Again, this may no longer reflective current usage pending the recent revised version of the M-CHAT-R/F.
- Pediatricians reported conducting routine Level 1 developmental screening at the well child visit ages of 12 months (35%), 18 months (93%), and 24 months (88%).
- 93% have access to an interpreter and 40% report having a bilingual provider in the practice.
- Possible reasons that children may be referred for diagnosis later than usual included:
    - Parents unaware of developmental milestones/red flags (83%)

    - Family's cultural background (65%)

- Other important barriers/needs cited included:
    - Families are unable to complete English screener (76%)
    - Providers do not screen when patient does not speak English (20%)
    - Providers cited time as a barrier to formal screening (92%)
- Reported overall needs included:
    - Better availability of diagnostic specialists (80%)
    - Better communication with diagnostic specialists (43%)
    - Information needed on when/how to refer (35%)

Wait Time Survey 2015

PURPOSE: In their December 2014 quarterly meeting of the Massachusetts Chapter of the American Academy of Pediatrics (MCAAP) Children's Mental Health Task Force (CMHTF), members shared concerns with this report's project director about the length of time that their patients with developmental concerns had to wait for a diagnostic evaluation following their referrals. Several community pediatricians stated that they delivered the diagnosis themselves instead of referring to diagnostic specialists due to the wait time delays that their patients commonly experience. In response, our project team conducted a *Wait Time Survey* modeled in part after the Massachusetts Act Early *Pediatric Provider Survey* in March 2015 to learn more from diagnostic specialty clinics about the typical length for a child to be seen by their practices.

METHODS. An email invitation to take the online survey was disseminated to 40 diagnostic clinic directors and/or private specialists across the state on March 4, 2015. Of the 26 survey respondents (65% response rate), 18 (69%) provided contact information for further follow-up. Most major medical centers and several private practices were represented by location across 5 regions (Metro Boston, North Shore, Southeast/Cape Cod, Central and Western Massachusetts) totaling 45 locations and 122 specialists altogether: BayState Medical, Boston Medical Center, Children's Hospital, MGH Lurie Center, Tufts Medical Center, UMass CANDO, and UMass Memorial Medical Center. Many small clinics or individuals were represented but not all were identified. Smaller or less known centers may not have responded (16).

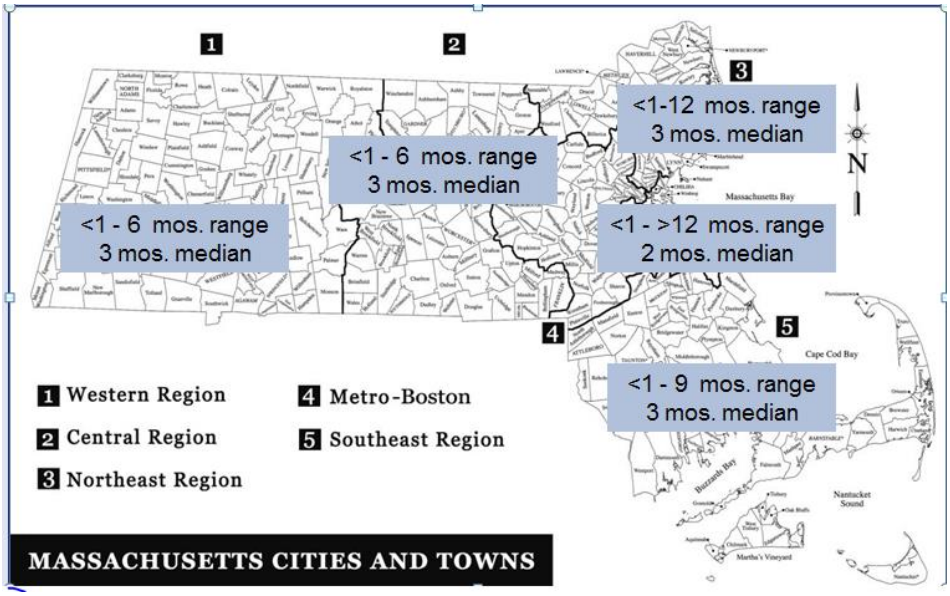
The survey polled the specialty clinic directors on areas such as: demographic data, estimated wait times, reasons for and needs to improve delays in referrals, and how evaluations are delivered when working with non-English speaking families.

DEMOGRAPHICS. All regions of the state were covered. Several practices had a number of locations across multiple regions. Metro Boston had 38% of all practices, Southeast/Cape Cod and the Islands had 16%, Central Massachusetts had 13%, and Western Massachusetts had 9%. Diagnostic specialists included: psychologists (23%), developmental behavioral pediatricians (22%), psychiatrists (21%), neuropsychologists (19%) and neurologists (11.5%).

The number of practices accepting MassHealth was 54%; 46% did not accept it. Practices estimated their percentage of patients covered by MassHealth as: 57% with 25-50% of patients covered, 29% with 51-75% covered, and 14% of practices with greater than 75% covered.

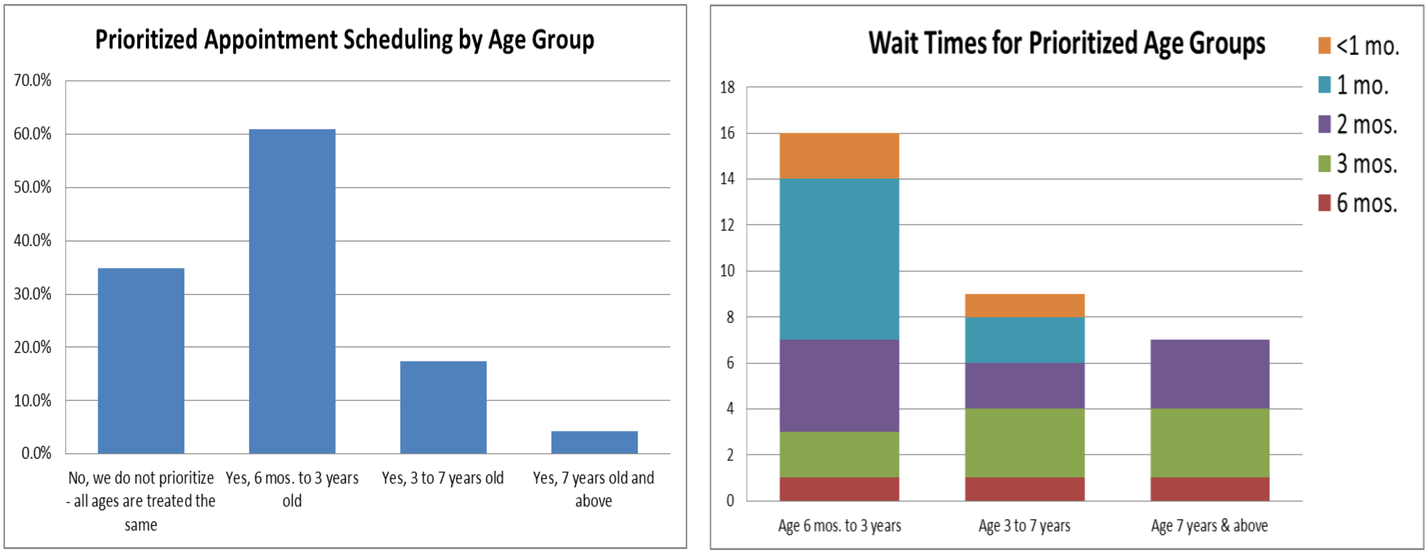
REGIONAL WAIT TIMES. The graphic below shows the median wait times for practices in March 2015 located in the five predominant regions in the state. The ranges within each region vary broadly and therefore may be too small of a sample size to meaningfully estimate average wait times. Of reasons given for long wait times, responses included: demand from referrals versus the supply of clinicians (n=10), lengthy evaluations, reduced capacity and related costs (n=6), small practice size (n=3), practice is one of only a few accepting MassHealth (n=3), practice prioritizes younger patients (n=3), and poor reimbursement/financial concerns (n=3).

Table AC-6. Diagnostic Wait Times by Region in Massachusetts, March 2015.



Prioritization to reduce wait times. Practitioners were asked if their practices prioritized patients based on the age of the children referred for evaluation. Figure AC-7 provides estimates of appointment prioritization by age group. Prioritized age groups included: 6 months to 3 years (61%), no prioritization due to all ages treated equally (35%), 3 to 7 years old (17%), and 7 years and older (4%).

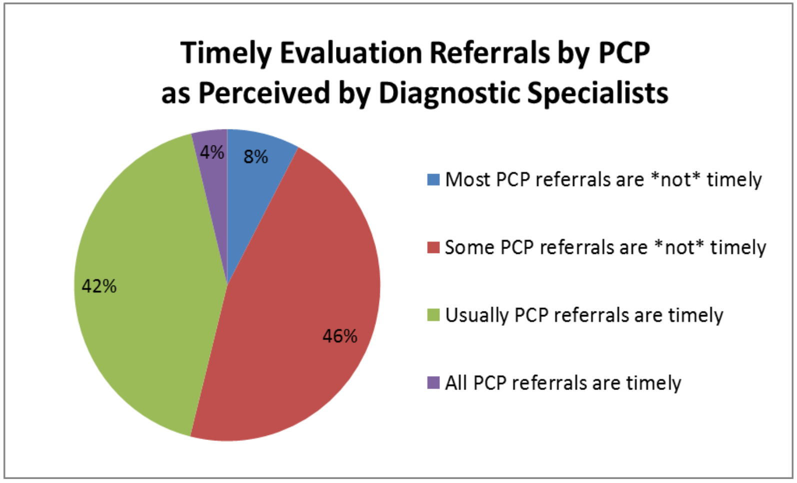
Figure AC-7. Wait Times & Prioritized Appointment Scheduling for Different Age Groups



The wait times by age were stratified by age with the vast majority of children seen within one month as the ages between 6 months to 3 years. The reasons for prioritization included: EI/early identification (n=19), more resources MassHealth for older/limited English proficiency (n=1), priority determined by provider availability (n=1) and do not need as much testing time as older children (n=2).

PERCEPTIONS OF LATE REFERRALS. Specialists were asked "Are children typically referred in a timely manner to your practice for a comprehensive autism or developmental evaluation by their PCP's office?" The responses included: some NOT timely (46%), usually timely (42%), mostly NOT timely (8%), and <u>all</u> are timely (4%).

Table AC-8. Perceptions of Timely Evaluation Referrals by PCPs



When asked for all possible reasons that specialists thought children might be referred later than average for a comprehensive autism or developmental evaluation, the responses were:

- Parent(s) unaware of typical developmental milestones/red flags for delays (77%)
- Family's primary language not English (59%)
- PCP did not screen in accordance with AAP timelines (55%)
- Family's lower socio-economic status (SES) (55%)
- Parent(s) caregiving ability limited (e.g., mental health issues, addictions, etc.) (55%)
- Family's cultural background (50%)
- Family's racial background (23%)

REGIONAL NEEDS AND CHALLENGES. When asked if there are enough diagnostic specialists in a region, 58% responded "no" and only 13% responded "yes", while 29% did not know. Metro Boston practices reported the most "yes" replies (6 of 17 replies for the region).

The reasons for regional shortages included: Lack of reimbursement, lack of paid positions/recruitment, and disparities for practices not accepting MassHealth creating a "two-tiered system". The regional challenges experienced by families as reported by clinicians included transportation, poverty, immigrant priorities differ, rural accessibility, lack of access to providers in rural regions, and provider lack of familiarity/qualifications.

OVERALL NEEDS. The following needs were shared by respondents to the Wait Time Survey.

- Need to improve screening & referral:
    - Regional networking between PCPs, EI programs, early childhood programs and diagnostic specialists for early identification pipelines
    - Training PCPs about how to screen & refer
    - Public awareness outreach to early childhood programs about development,
- Need to improve detection in practices overall:
    - Better communication with referring entities (e.g., pediatric practices, early intervention, early childhood programs, etc.
    - Improved reimbursement for evaluation practices
- Plans:
    - Expand/add/recruit clinical providers to diagnostic practices
- Challenges:
    - Reimbursement/insurance
    - Families may avoid diagnosis
    - Non-culturally competent tools & clinicians

Comparison of Pediatric Primary Care Provider (PCP) to Specialty Provider Surveys

There was general agreement between the two surveys regarding: the estimated wait times for evaluation, the top reasons for referral delays, and the needs cited to promote effective and timely evaluations. It was widely agreed that delays might be caused by parents being unaware of developmental milestones, not speaking English, and being from lower incomes. Training pediatricians how to screen and refer is desirable, as well as having better availability of specialists, and conducting outreach to early childhood professionals for further referral and support needs. The following tables compare results of the two surveys and show similarities and differences.

WAIT TIME ESTIMATES. A timely referral for diagnostic evaluation was defined in both surveys as no longer than one month. Perceptions of the average wait times in March 2015 for children to be seen align for pediatric providers and diagnostic specialists were less than a 6 month window (49% vs. 46%), but 33% of pediatricians estimated longer average wait times than specialists (18% over 6 months). Closing the loop on timely referrals (within one month) varied between professionals as well with 66% of pediatricians agreeing that they receive timely feedback on evaluation results from specialists but only 46% of specialists reporting that timely referrals from PCPs.

Table AC-9. Wait times and timely referrals (pediatricians vs. specialty diagnostic clinics)

	Pediatricians	Specialty Diagnostic Clinics
# locations	103	45
Wait times	2 months = 26% 3 months = 23% 6 months = 33%	2 months = 22% 3 months = 24% 6 months = 18%
Timely referral	*Re: Timely Diagnosis feedback* Strongly disagree = 0% Disagree = 12.5% Neutral = 23% Agree = 44% Strongly agree = 20%	*Re: PCPs referrals* Most PCP are NOT timely = 8% Some NOT timely = 46% Usually timely = 42% Always timely = 4% *defined as within one month

REFERRAL REASONS & DETECTION NEEDS. Reasons for late referrals were consistent and closely aligned between both pediatric PCPs and diagnostic specialists respectively on the topics of the need for creating parental awareness of developmental milestones (88% & 77%), linguistic needs (61% & 59%), and needs related to income level and poverty (60% & 55%). Both groups aligned on the need for early identification training of PCPs (40% & 44%), and the importance of communication and networking as well.

Table AC-10. Top reasons for late referral and top 3 detection needs (pediatricians vs. specialty diagnostic clinics)

	Pediatricians	Specialty Diagnostic Clinics
Top reasons late referral:	Parents unaware of milestones/red flags (88%)	Parents unaware of milestones/red flags (77%)
	Primary language not English (61%)	Primary language not English (59%)
	Lower SES (60%)	Lower SES (55%)
Top 3 detection needs:	Train PCPs screen/refer (40%)	Train PCPs screen/refer (44%)
	Better availability of ASD Dx specialists (80%)	Outreach of PCPs to early childhood programs (44%)
	Better communication w/ ASD Dx specialists (43%)	Regional networking re: Early ID between EC, EI, PCP & Dx (52%)

CULTURAL AND LINGUISTIC COMPETENCE IN SCREENING AND EVALUATION. Table AC-11 compares both surveys related to cultural and linguistic competence in practice. General pediatric providers estimate serving more non-English speaking patients than specialty diagnostic providers (13% pediatric providers have practices with over 50% non-English speaking patients compared to only 4% of specialists). They also have access to more interpreters than specialists (93% compared to 58%).

Table AC-11. Cultural and linguistic competence (pediatricians vs. specialty diagnostic clinics)

Category	Pediatric Providers	Specialty Diagnostic Clinics
% non-English speaking patients	**<20% = 61%** 21-50% = 24% 51-80% = 13%	**<25% = 81%** 25-50% = 12% 51-75% = 4%
I have access to…	**Interpreters = 93%** Translators = n/a Cultural liaisons = 9% Bilingual providers = 40%	**Interpreters = 58%** Translators = 23% Cultural liaisons = 15% Bilingual providers = 15%
I do not have access to language services	**N/A**	**35%**

Category	Pediatric Providers	Specialty Diagnostic Clinics
What do you do when patient's family does not speak English?	**Re: Screening**: Use translated measure (45%) Perform w/ interpretation (70%) **Do not screen (20%)**	**Re: Evaluation**: Use translated measure (23%) Perform w/ interpretation (62%) **Do not evaluate (35%)**

A concerning result for both pediatricians and diagnostic clinics was that if parents do not speak English, screening and evaluation may be jeopardized. When asked what they do when the patient's family does not speak English, 20% of pediatric providers do not screen and 35% of specialists do not evaluate. This may require further examination to determine what these practices do instead when a parent does not speak the same language and whether there are further follow-up steps taken for a child. Similarly, consideration is needed on how to support practices in this work to reduce cultural and linguistic disparities.

These two studies indicate that wait times fluctuate across the state, requiring a data system that can conduct ongoing time studies to measure and monitor the critical points of screening, diagnosis and referral to evaluation and intervention. Special attention should be paid to building regional workforce capacity both for having enough specialists, as well as opening up better access for providers to accept MassHealth for those families who rely on it.

Education and training as well as resource materials, such as that offered by the CDC's "Learn the Signs. Act Early." program and the local Massachusetts Act Early program, is needed to build parent awareness of the importance of monitoring developmental milestones and red flags, as well as PCP confidence in screening and referral practice. Finally, there is a great need for strengthening cultural and linguistic competence among providers through workforce development. The Massachusetts Act Early program has developed a curriculum entitled "Considering Culture in Autism Screening" that is equipped to train providers for this purpose. More information on these programs can be found in the Early Identification section under "Resources."

Access to Health Care Services

Little information about access to health care services exists specifically for children, youth and young adults with autism and other developmental disabilities. A combination of measures are offered in this section of the report to provide some possible ways to measure access to health care services using other models, information about access to specialists, and regional access to key medical centers.

National Health Care Quality and Disparities Report

Because it is not expected that people with autism experience any fewer barriers to accessing health care and could possibly have more, the following information about the general population may inform useful targets for consideration about improving health service access in the state. In some cases, the measures are shown by subgroups of people in the state, the most common set of subgroups are organized by type of medical insurance including commercial plans, Medicare managed care, Medicare fee-for-service or Medicaid. Benchmarks shown in this table are from the *National Health Care Quality and Disparities Reports*, and are created from the performance of top-performing states in an effort to derive achievable benchmarks. The measures below could be used for CYSHCN with autism as well.

Table AC-12. National Health Care Quality and Disparities Report (AHRQ 2015)

National Health Care Quality and Disparities Report (AHRQ 2015)					
Measure[120]	**Subgroup**	**Estimate**	**Benchmark**	**Distance to Benchmark**	**Status**
Adults who had a doctor's office or clinic visit in the last 12 months whose health providers sometimes or never spent enough time with them	Commercial Plans	8.5	6.07	40%	Needs Improvement
	Medicare fee-for-service	5.64	3.97	42%	Needs Improvement
	Medicare managed care	5.37	4.97	8%	Close to benchmark
	Medicaid, last 6 months	10			N/A
Adults who had an appointment for routine health care in the last 12 months who sometimes or never got appointments for routine care as soon as wanted	Commercial Plans	13.8	9.3	48%	Needs Improvement
	Medicare managed care	12.3	9.73	26%	Needs Improvement
	Medicaid, last 6 months	20.4			N/A
Adults who needed care right away for an illness, injury, or condition in the last 6 months who sometimes or never got care as soon as wanted, Medicaid		14.4			N/A
Adults who needed to see a specialist in the last 12 months who sometimes or never found it easy to see a specialist	Commercial Plans	16.2	10	62%	Needs Improvement
	Medicare fee-for-service	9.32	5.61	66%	Needs Improvement
	Medicare managed care	8.56	6.13	40%	Needs Improvement
	Medicaid, last 6 months	18.6	18.1	3%	Close to benchmark
Adult hospital patients who sometimes or never had good communication about medications they received in the hospital	about medications they received in the hospital	10.4	9.62	8%	Close to benchmark
	with doctors in the hospital	4.4	3.26	35%	Needs Improvement
	with nurses in the hospital	3.9	3.08	27%	Close to benchmark
Adult hospital patients who strongly disagree or disagree that they understood how to manage their health after discharge		3.5	2.58	36%	Close to benchmark
Adult hospital patients who strongly disagree or disagree that they understood the purpose for taking each of their medications after discharge		2.9	1.9	53%	Close to benchmark
Adults who had a doctor's office or clinic visit in the last 12	Commercial Plans	5.2	3.13	66%	Needs Improvement
	Medicare fee-for-service	4.28	3.21	33%	Needs Improvement

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[120] Source: National Healthcare Quality and Disparities Reports, AHRQ, 2015, https://nhqrnet.ahrq.gov/inhqrdr/Massachusetts/benchmark/table/All_Measures/All_Topics#achieved

National Health Care Quality and Disparities Report (AHRQ 2015)					
Measure[120]	**Subgroup**	**Estimate**	**Benchmark**	**Distance to Benchmark**	**Status**
months whose health providers sometimes or never explained things in a way they could understand	Medicare managed care	5.13	3.44	49%	Needs Improvement
Adults who had a doctor's office or clinic visit in the last 12 months whose health providers sometimes or never listened carefully to them	Commercial Plans	6.9	3.7	86%	Needs Improvement
	Medicare fee-for-service	3.97	3.29	21%	Close to benchmark
	Medicare managed care	4.33	3.54	22%	Close to benchmark
	Medicaid, last 6 months	9.8	N/A	N/A	N/A
Adults who had a doctor's office or clinic visit in the last 12 months whose health providers sometimes or never showed respect for what they had to say	Medicare fee-for-service	3.88	2.32	67%	Needs Improvement
	Medicare managed care	3.94	2.67	47%	Needs Improvement
	Medicaid, last 6 months	6.2	N/A	N/A	N/A
Rating of health care 0-6 on a scale from 0 to 10 (best grade) by adults who had a doctor´s office or clinic visit in the last 12 months	Commercial Plans	10.4	7.57	37%	Needs Improvement
	Medicaid	14.2	N/A	N/A	N/A
	Medicare fee-for-service	9.39	9.04	4%	Close to benchmark

Any of the above categories could be targeted to CYSHCN and their families or autistic young adults entering adult health care with appropriate estimates and benchmarks determined and set. Since most statuses were rated as "needs improvement" for the general population, emphasis would need to be placed in particular on providers spending enough time, explaining things in a way the patient can understand, and making it easy to see a specialist, among others.

Specialty Services Access

ACCESS TO BEHAVIORAL INTERVENTION. The Autism Omnibus Bill of 2014 included the following key provision[121]:

- *"A requirement that MassHealth cover medically necessary treatments for children with ASD who are under 21 years old – including ABA therapies as well as dedicated and non-dedicated AAC devices"*

Relative to other states, Massachusetts has a high number of programs that train therapists (BCBA programs), and a relatively high number of therapists per capita.[122] However, Massachusetts still does not have enough ABA therapists to meet the demand of families limiting access to ABA services and raising concerns about network adequacy for autism treatment.

CONSUMER PROTECTIONS FOR BEHAVIORAL INTERVENTIONS. As of June 2015, regulations governing licensure eligibility, the application process, and standards of practices for Applied

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[121] http://massadvocates.org/mac-victory-autism-omnibus-bill/

[122] Verbal communication with the Massachusetts Autism Insurance Resource Center, based on their conversations with state residents accessing their support services.

Behavior Analysts (ABAs) and Assistant Applied Behavior went into effect in Massachusetts.[123] These laws provide greater customer protection for people seeking autism treatment services within the state. For two years after the start of the regulations (until June 5, 2017), therapists may be grandfathered into ABA or AABA licensure if they meet certain criteria including Board certification. The license must be renewed every two years, and includes a requirement for continuing education units. The impact of these regulations upon the volume of available therapists in the state has not been assessed.

It is important to measure and monitor this particular workforce due to supply and demand, particularly in regions experiencing shortages such as Cape Cod. Additionally, workforce estimates should take into account the language needs of families seeking services.

Regional Access to Boston Medical Centers

Boston is a mecca for medical services for CYSHCN across the state, as well as across the Northeast region and the U.S. Within Massachusetts, getting to the Boston area for services can result in hardships on families, including transportation needs, travel time, time off from work and other hurdles.

A 2012 data analysis conducted by local organization Exceptional Lives (more information in the Resources section) looked at the estimated number of children with autism by age group within three regional catchment areas representing commuting distance to Boston. The aims were:

1.) To set the lower and upper limits by age and by catchment area and
2.) Estimate total children with autism in New England potentially needing local services and supports from medical centers in the Greater Boston area.

For the lower limit, the analysis used data from each New England state's Department of Public Health's (DPH) Early Intervention program and from each Department of Education (DOE) (now DESE for Massachusetts) Special Education program for the 2010-2011 school year. For the upper limit, the 2008 CDC prevalence estimate of 1 in 88 children was paired with the total population from the 2010 U.S. Census data to compute the total children with autism. In most states, data for low individual city/town were suppressed due to privacy policies which slightly depressed the overall total for those states. Tables AC-13 and 14 provide both sets of ranges of children and youth with autism by age and catchment area.

Table AC-13: Range of ASD population estimates by age & CA

Catchment Area (CA) # hrs to Boston	Total: Age group 0-2	Total: Age group 3-5	Total: Age group 6-21	Overall total: 0-21
CA1 (1 hr or less)	746 – 2,097	1,725 – 2,142	7,976 – 9,211	10,447 – 13,450
CA2 (1-2 hrs)	854 – 1,685	1,232 – 1,820	8,019 – 8,352	20,552 – 25,307
CA3 (2-4 hrs)	1,066 – 1,661	1,073 – 1,789	6,038 – 7,894	28,729 – 36,651

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[123] http://www.mass.gov/ocabr/docs/dpl/boards/mh/mh-astnt-applied-behavior-analyst-faq.pdf

Table AC-14: Catchment Areas by Commuting Time to Boston

CA#	Commute	Cities/States
CA1	1 hour or less	**Boston, MA; Worcester, MA;** Providence, RI; Nashua, NH; Salem NH
CA2	1-2 hours	**Cape Cod, MA; New Bedford, MA; Fall River, MA; Springfield MA**; New London, CT; Manchester, NH; Concord, NH; Portsmouth, NH; Kennebunk, ME
CA3	2-4 hours	Bridgeport, CT; New Haven, CT; Hartford, CT; Albany, NY; Montepelier, VT; Burlington, VT; Portland, ME; Augusta, ME; Bangor, ME

*Massachusetts cities are **bolded**

CA2 for Southern Massachusetts/Cape Cod and Springfield are notable regional results because often families cannot access services, particularly specialized services, locally and must take the time to travel to Boston. Many providers in these regions may not accept MassHealth, so families experience additional health care access-related disparities. These radiuses provide a conservative estimate of the distance families must travel to receive appropriate care for their child. Other burdens include time off from work, lost wages, childcare expenses, stress and long term impacts.

These data speak to the need for expansion of workforce capacity into the furthest regions of the state, as well as more providers accepting MassHealth in their regional practices.

Community Services & Supports Access

One of the top priorities recommended by the Massachusetts Autism Commission (2013) was to:

> *"Increase and fortify supports and resources that make it possible to maintain the family unit and assist individuals with autism to live in the community."*

To understand whether individual and family needs are being met, reviewing state agency data can serve as a baseline for future monitoring.

Department of Developmental Services (DDS)

For the families of CYSHCN with autism who have some of the most intensive needs, the Department of Developmental Services (DDS) serves as a cog in the system of care at the state level.

DDS AUTISM SERVICES. The seven community-based Autism Support Centers funded by the Department of Developmental Services (DDS) Autism Division serve as prominent sources of services and supports, as well as information and referral, for CYSHCN with autism and their families.

Although the Department of Developmental Services (DDS) does not track sources, the department receives referrals for service requests from a variety of avenues.[124] Many come from Early Intervention programs (EIPs) encouraging families to apply for autism waivers. Most come from pediatric offices from major medical centers. Ultimately, all are referred out to the local/regional area offices and autism support centers across the state that often serve as the front door and "one-stop shopping" for family support and community-based services such as information and referral,

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[124] From key informant Interview with Cariann Harsh, former Director of DDS Autism Division, 3/2/15.

training, support and family events. Because of this, these centers may be the among the best sources of data collection since they track the numbers of children and families served annually, though diagnostic information may not be available.

DDS area offices are found across the state in 23 locations. Autism Service Coordinators have been added to each office. DDS also has four regional offices and a Central Office that support autism services and supports.

There are 7 Autism Support Centers located across the state:

Table AC-15. Massachusetts Autism Support Centers

Pathlight/Autism Connections (Formerly ACL/Community Resources for People with Autism) 116 Pleasant Street Easthampton, MA, 01027 Serving Western, MA	Advocates/Autism Alliance of MetroWest (AAMW) 1881 Worcester Road Suite 100A Framingham, Ma, 01701 Serving Metro West of Boston
Community Autism Resources (CAR) 33 James Reynolds Rd, Unit C Swansea, MA 02777 Serving Southeastern, MA	HMEA/ Autism Resource Central 71 Sterling Street West Boylston, MA 01583 Serving: Central, MA
NEARC/The Autism Support Center: 6 Southside Road Danvers, MA 01923 Serving Northeastern, MA	TILL, Inc./Autism Support Center 20 Eastbrook Road Dedham, MA 02026 Serving Greater Boston
The Arc of South Norfolk/The Family Autism Center 789 Clapboardtree Street Westwood, MA 02090 Serving Norfolk County Area	

Although not part of the DDS Autism Support Center system, it should be mentioned here that the Asperger/Autism Network (AANE) is another valuable local support center serving the population of CYSHCN with autism in the community, as well as adults. AANE works with individuals, families, and professionals to help people with Asperger profiles or similar autism spectrum profiles by providing information, education, community, support, and advocacy.

DDS also relies on community advocacy through health care organizations and other family support organizations across the state to collaborate with them on outreach efforts to families to share information about their center services and waiver program. Examples of these contacts include: the Massachusetts Chapter of the AAP (MCAAP), the Massachusetts League of Community Health Centers, major medical centers that house autism specialists (formerly part of the Autism Consortium), the Federation for Children with Special Needs, Family Voices of Massachusetts, the Developmental Disabilities Council (MDDC), Arc of Massachusetts and Massachusetts Advocates for Children, among others through these partnerships.

In addition, DDS maintains connections with the DPH, DESE, DCF, DMH and MassHealth, and have worked with community health centers particularly to find harder-to-reach families. DDS has actively worked to establish connections with Spanish and Vietnamese-speaking family support groups. In using medical interpreters with families, DDS has found that while the interpreters have knowledge of medical terminology, they may not be as knowledgeable about autism. Training resources for interpreters interested in learning more about autism may be beneficial. In spite of these helpful connections, real challenges persist in tracking children and youth and communicating and collaborating across multiple agencies. The collection of and access to data about services and outcomes needs to be improved. Other states may provide clues on how to coordinate, monitor and improve access to services and supports.

DDS CHILDREN'S AUTISM HOME AND COMMUNITY-BASED WAIVER PROGRAM. The Children's Autism Home and Community-Based Services Waiver Program at the DDS Autism Division has been in operation since 2007 and is renewed every five years. Effective October 2016, the Waiver has expanded its availability to serve 385 children. (See the Appendix under "Access to Care Data" for a table with all cities and towns participating in the HCBS Waiver Program).

The 2013 Commission Report stated that the support available through the Children's Autism Waiver is a commendable example of the positive impact that this type of service can have for to service navigation. The program serves children under age 9 with autism who meet the eligibility criteria as specified in the waiver for ASD and MassHealth. To determine eligibility, the Division performs two clinical assessments that measure the child's deficits in the areas of socialization, communication and behavior. All waiver services require that the child (and the child's family) continues to meet the financial and clinical eligibility requirements for the Waiver Program, 300% of the Federal Poverty Level (FPL).

The latest Renewal Autism Waiver Program designated ten slots for three year olds transitioning out of Early Intervention - a statewide service available to families of children between birth and three years of age through the Department of Public Health (DPH). As part of the FY 16 budget, the number of slots has been expanded to 20 statewide slots.[125] This provided the opportunity for families with younger children to access the program and to continue with an in-home support program model. The renewal Waiver also built in a Step-Down Program after three years of intensive in-home supports that allows families to receive behavioral consultation services and other ancillary supports until the child reaches his/her ninth birthday.[111] To date the Autism Division has held six Open Request Periods which have consistently resulted in high numbers of interested families.

On their web site, DDS has offered their Waiver Program Eligibility Request Forms to families in a number of predominant languages in the state: Arabic, Chinese, French, Haitian-Creole, Khmer, Portuguese, Russian, Spanish, Thai, and Vietnamese. Applications come from across the state and often in languages other than English, requiring translation and interpretation support from DDS. The most recent open request period that ended October 30th, 2015 yielded 749 applications. The Autism Division has established that on an annual basis going forward, the last two weeks of October every year will be the open request period. [111] The program is now exploring additional methods to insure that families from diverse backgrounds can effectively participate in the program. This will involve using interpreters at initial contact and developing a pilot to create a pool of family partners to assist new families in the program.

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[125] MA Autism Commission by DDS Commissioner Elin Howe. January 12, 2016.

AUTISM WAIVER PROGRAM ELIGIBILITY DATA. From January to November 2015, the Division processed 204 Waiver applications with 77 determined to be eligible and 73 found ineligible.[126] The processing of applications includes finding children on the list that are over the age of nine, are not on MassHealth Standard and are not eligible to enroll in MassHealth Standard, and identifying families who elect to not participate in the eligibility process despite repeated attempts to connect by phone and mail. More current data is available in the Autism Commission's recent 2016 Annual Report (see Appendix).

ACTIVE PARTICIPANTS IN THE DDS AUTISM WAIVER PROGRAM. In Calendar Year 2015 (January 1, 2015- November 15, 2015), approximately 77% of participants were males and 23% were females and this follows the national trend that indicates boys are much more likely to receive an autism diagnosis than girls. [111]

As of November 15, 2015, the DDS Autism Waiver Program served a wide range of ages of children between two and until the child turns 9 years of age.

Table AC-16. Age of 278 Participants as of 11/15/15:

Age Group	No. of Participants	% of Participants	Age Group	No. of Participants	% of Participants
Age 2	0	0%	Age 6	47	17%
Age 3	13	5%	Age 7	57	21%
Age 4	26	9%	Age 8	46	17%
Age 5	54	19%	Age 9	30	11%

DDS WAIVER DIAGNOSTIC INFORMATION. Approximately 5% of the children served in the Autism Waiver have diagnosed co-morbid conditions that are identified in the child's medical record. These conditions include metabolic, genetic, and physical disorders. In some cases, these conditions require multiple hospitalizations and intensive nursing. Scheduling of in-home services can be more challenging when dealing with these conditions compared to cases where autism is the sole diagnosis. In 2015, the references in the medical records to the presence of a co-morbid psychiatric condition meeting diagnostic criteria was small. The section on Medical Home shares information from the NSCH and the NS-CSHCN that can provide further insights into the extent of co-morbid medical conditions CYSHSN with ASD may have that could be used in combination with the DDS data to set a baseline and measure progress. In addition, the Medical Home section discusses needs surrounding patient care and emergency department use by this population.

DDS WAIVER CULTURAL AND LINGUISTIC INFORMATION. The 278 children served in the Waiver Program in CY 15 represent a wide range of linguistic and cultural backgrounds as identified by the Autism Clinical Managers and Parents/Guardians. If a family requires the use of an interpreter, the DDS Autism Division provides interpreters and translations, including a procurement to select a telephonic service. They have increased resources for face-to-face interpretation and written translation.[127] Of the 278 Waiver Program participants, the main languages spoken are English 67%, Non-English Primary Language 33%, Spanish 23%, and Portuguese 5%. One percent or fewer of the following participants speak the following languages: Haitian-Creole, Vietnamese, Mandarin, Russian, Cape Verde Creole, Cantonese, and Egyptian Arabic. Fifteen percent of the total

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[126] Commonwealth of Massachusetts, Department of Developmental Services, *Autism Waiver Program 2015 Legislative Report*, November 15, 2015

[127] Personal Communication, DDS 2016

participants or 37% of Non-English speaking participants need an interpreter. (See the Appendix under "Access to Care Data" for a table with cultural information for participants for CY15).

DDS FAMILY FACTORS AND MENTAL HEALTH. In some instances, the support needs of the service recipients may be complicated by social factors about their living environments, including poverty and family instability such as involvement from the Department of Children and Families or parental substance abuse. A portion of the children served to date have mental health needs. For those with the most substantial mental health support needs, in-state inpatient specialized capacity for children with autism is lacking. For most children needing this type of treatment, out of state options are used in either Connecticut or New Hampshire due to this limited capacity.

DDS AUTISM WAIVER OPEN REQUEST PERIOD DEMOGRAPHICS - OCTOBER 2015. Of 749 applicants, male/female distribution was about 78% of applicants males (n=587) and 22% females (n=162).[128] The numbers of applicants by age are presented in Table AC-17.

Table AC-17. Ages of Applicants CY 15

Age group	No. of Applicants	% of Applicants	Age group	No. of Applicants	% of Applicants
Age 1	9	1%	Age 6	99	13%
Age 2	80	11%	Age 7	88	12%
Age 3	152	20%	Age 8	42	6%
Age 4	139	19%	Age 9+	15	2%
Age 5	125	17%			

AUTISM WAIVER PROGRAM PROVIDER INFORMATION. At the outset of the Autism Waiver Program, a major outreach effort took place to locate and qualify potential providers of services offered through the Program. This outreach included: all Early Intervention providers in the Commonwealth, all Special Education Departments in schools districts across the state, all major providers of autism and related services and Colleges/Universities with majors/minors in the disability education field. The Autism Support Brokers do a concerted outreach effort to try and obtain new providers about every 12-18 months or as needed to meet an individual family's needs.

All identified potential providers were added to a Master Provider List (MPL) that consists of Agencies, Independent Contractors and Employees. As of October 31, 2015, the list of unique providers totaled 660, an increase over the previous year. Many providers deliver more than one service. The MPL, which is an online web-based listing, is available to families in their geographic region and is utilized by the Autism Support Brokers at initial meetings with every new family. Due to the flexibility of the Waiver Program's service design, many of these providers are new to DDS. Table AC-18 presents providers by type of services.

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[128] Commonwealth of Massachusetts Department of Developmental Services Autism Waiver Program 2015 Legislative Report, November 15, 2015

Table AC-18. Provider Totals (As of November 15, 2015):

Service Type	Description of Provider Duties	Total #
Expanded Habilitation, Education: *Senior Level Therapists*	Responsible for the creation and oversight of the in-home support plan	248
Step Down Program *(after 3 years): Behavioral Consultants*	Responsible for providing technical assistance for the continuation of the in-home support plan	41
Expanded Habilitation, Education: *Therapists*	Responsible for carrying-out the in-home plan with the child on a one-to-one basis	328
Expanded Habilitation, Education: *Direct Supports*	Responsible for carrying-out the in-home plan with the child on a one-to-one basis	451
Habilitation, Community Integration	Responsible for helping the child to participate in activities and other programs provided in community settings	255
Family Training	Responsible for teaching families about a variety of topics based on needs, such as autism in general, working on safety or reinforcing the work of the in-home service providers	155
Respite	Responsible to provide respite care of the child, allowing the parent or guardian to get out of the house for a short period of time	456
Total Unique Providers Services		**660**

PARTICIPANT BUDGETS BY SERVICE TYPE. The majority of service provision funding is spent on the Waiver's intensive in-home support program, Expanded Habilitation Education. Children receive an average of between 6 to 10 hours a week of intensive in-home support services provided by a variety of therapists and based on a set of goals developed with input from the parent/guardian. Families also prioritize respite and community integration as important services. From the almost $5 million budget, the percentages allocated to services breaks down as follows: Expanded Habilitation, Education (87%), Respite (includes related workers comp costs) (5%), Behavioral Consultation (Step Down Program) (3%), Habilitation, Community (2%), Goods and Services/Homemaker (2%), Home/Vehicle and Adaptive (>1%), and Family Training (>1%).

Of the 278 Waiver Program participants from January 2015-November 15, 2015, 171 children (61.5%) received over $20,000 worth of services and supports, while another 50 (18%) received services and supports between $10,000 and $20,000. There were 5 participants with budgets under $10,000 and the majority of these participants turned 9 during CY 15 and therefore had prorated budgets to reflect their shortened time in the program. Most participants in the Program are also receiving ancillary services such as goods and services to purchase safety equipment, home/vehicle adaptations and community integration services in order to increase the child's ability to participate in community activities. Most families are also receiving a respite service, providing critical relief to families. In CY 15, 52 children were enrolled in the Step Down program, receiving $5,500 of supports.

DDS Autism HBCS Waiver Program baseline measures are monitored annually and contribute to a general understanding of the needs for this vulnerable age group and their families. Comparing these needs as part of an overall system of care will be a critical piece of the puzzle.

DESE/DDS Program (Ages 6-22)

A longstanding program between the Department of Elementary and Secondary Education (DESE) and DDS is designed to provide in-home and community bases therapeutic supports to students ages 6 to 22 who demonstrate a need for services to prevent a more restrictive out of home residential placement. About 85% of the participants in the DESE program have ASD and ID.[129] Information on this program is beyond the purview of this report, but is indicative of another collaborative partnership in the overall system of care for CYSHCN with autism. Understanding the baseline of need for this program and monitoring demand and successful outcomes in the future could provide further insights into high quality care for this population.

Department of Children and Families (DCF)

No data is currently available for foster CYSHCN with autism served by the Department of Children and Families (DCF) at this time.[130] Information on this program is beyond the purview of this report, but is an important subset of CYSHCN with autism to measure prevalence and monitor in the future, given the extreme disparities they face and the need for supports required to care for them. Homelessness is a major concern, particularly as they transition to adult life without a full system of care to draw upon (See section on Housing for more information).

Qualitative Data

Focus Groups

The research team asked questions about accessible community-based systems in all of the focus groups. This includes parent leaders, autism professionals, medical professionals, and culturally diverse families. Please refer to the Methods section for more information on these groups. The following themes cut across all groups.

WHAT HAS WORKED TO IMPROVE ACCESS TO SERVICES?

Participants almost unanimously emphasized the importance of working within local communities with parent groups, businesses, and cultural groups to network with families, build trust, share information, and ultimately connect families who have children with autism with community services. For example, a local group in Western Massachusetts, No Small Victories collaborates with the local YMCA to open their swim program to families and kids with autism. They also offer trainings to community businesses where families frequent, like barber shops, on how to work with children who have autism. When working with cultural communities, participants stated that offering services in native languages was an effective strategy for expanding access. Offering professional speakers at local parent groups also helped to educate parents about available services and provide guidance on applying/accessing these services.

> "The families that have the most, can access the most. Services tend to go to people who can advocate well, who are more affluent, etc. And yet, the families in Boston who need it more than most families in Bedford, won't get it."
>
> – Attorney and Parent Advocate

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[129] From MA Autism Commission presentation by Elin Howe, 1/12/16.

[130] Source: MA Autism Commission, Executive Director Carolyn Kain, September 2016, non-published.

BARRIERS TO ACCESSING EXISTING SERVICES. One barrier frequently mentioned by focus group participants is the complexity of the existing service system. It was generally felt that many families, especially low-income or non-English speaking parents, have trouble navigating services. As one EI Director with a statewide perspective shared, "The child gets diagnosed and the family flounders to get a long list of services recommend by the developmental specialist. As the child ages, parents are given mores lists of resources and they are overwhelmed. They don't know how to prioritize." Sometimes there are different organizations that provide different servicers (i.e. one organization for respite, one for ABA) and families may not know to access both. When asked whether families had access to needed services, one pediatrician responded that, "It's not clear where there are enough services. There is great variability in skills and training of those providing home-based services."

Participants stated that there is great variability and acceptance by community organizations from town to town. As one program director of a large network of programs and services for children with autism states, "It is so hard to figure out how one family comes and they have every service under the sun and another family comes and they have no services at all. So it is hard to figure out how families access services."

Once parents are aware of existing services, many are not able to advocate for the amount or type that their child needs. Many families cannot pay out-of-pocket for professional advocates and they may not know what services their child is entitled to. Families may lack the sophistication to advocate well.

Access to home care services was continuously raised as a large need across professional focus groups due to a lack of state funding.

Geographic access was another major area of concern. The following comments share the difficulties with obtaining services for families from Cape Cod:

> *"The Cape is sorely neglected. We just don't have what they have in the rest of the state…We have so little in terms of diagnosis. And once you have a diagnosis then you have trouble getting and keeping staff."*
>
> *"Things are tough on the Cape, but my heart breaks for the folks on the Islands because they are really in bad shape."*
>
> *"People who live in Provincetown, Truro and so forth, it's really far for them to get even here. It takes them as long to get here as it does to get to Boston."*

Similar concerns were voiced in the Western region:

> *"[A barrier to diagnosis is] distance. Families who have to go to Worcester or Boston. Or families in the Berkshires who need to come out to Springfield."*
>
> *"There aren't a lot of hospitals in the region. We've seen hospitals open developmental centers but they've folded. It's a real financial liability. And even BayState is struggling….We say go to Boston like it's no big thing. But for families, yikes! And bringing kids! And if you're relying on public transportation you might as well be going to the moon."*

Disparities resulting from poverty can have an overwhelming effect on access:

> *"We see a lot of (homeless) families in hotels and they are just trying to get through. And they need the diagnosis but where they are living is horrendous. But they need that outreach to help prioritize the services they need."* – Public health expert from Western region.
>
> *"Some (homeless) people in this community may be working hard to get back to their home community. And (diagnosis) may not be their priority at this point."* – Specialty school provider

Access to providers who accept MassHealth for the many families who rely on it is a huge barrier to care. One EI professional shared that although 38% of CYSHCN in the state have MassHealth coverage, that percentage rises to 50% for those children receiving EI services.

> *"About 70% of our clients use MassHealth. But we are limited because no diagnostic providers take it."* – Community support agency professional from Cape Cod.
>
> *"It is just so hard that a lot of these families just give up. We work with DDS a lot and there is a new testing for adult eligibility but we don't know who does it locally. We don't know anyone who has MassHealth to cover it."* – Family support specialist.

Other barriers identified by focus group participants:

- Many families have high co-pays for home-based therapies.
- There is a lack of psychiatrists, therapists, and social workers who are skilled in working with people who have autism.
- High turnover of ABA staff, particularly in some areas of the state. This high turnover was attributed to high living costs in relation to local pay, lack of mileage reimbursement to travel long distances, and lack of reimbursement for travel time.

Identified Needs:

Focus group participants identified the following recommendations based on their needs to improve access:

- Increase the number of bilingual and bicultural therapists (ABA, play, etc.), or provide interpreters so that parents can better participate in the therapy.
- Provide incentives for professionals, especially from minority cultures, to enter the field.
- Provide funds to support families in accessing educational advocates.
- Provide family trainers or paraprofessionals who can provide assistance with understanding health benefits.
- Increase the capacity of middle and high school counselors who are skilled in autism.
- Increase the availability of respite care options.
- Increase opportunities for social and recreation.
- Increase capacity for home-based services, i.e. ABA providers.
- More support groups and support systems for parents and youth.

"Our ABA service providers are wonderful but we aren't able to communicate with them. We have no access to them because they're monolingual and they don't speak Chinese….We would benefit so much more and get so much more from ABA if we could communicate with them."

– Chinese parent of a six year old child with Autism.

Future possibilities: Access

INDEX

INDEX[131], a project of the Eunice Kennedy Shriver Center at the University of Massachusetts Medical School, helps people with disabilities find the information they need. They collect and keep up-to-date information on programs, providers and services in Massachusetts that have something to offer to people with disabilities. Their mission is to improve the lives of people with disabilities and those that serve them by providing information and referral; technical assistance; training; online education; and technology services. They provide to the public for free, information about programs, providers, and services for people with disabilities living in Massachusetts.

INDEX coordinates a state-wide information system known as the Massachusetts Network of Information Providers for People with Disabilities.[132] The MNIP provides a connection to a local source of information and referral to people with disabilities; their friends and families; and professionals working with them. The MNIP also supports the collaboration of its members in solving information and referral problems.

INDEX also provides Technical Services that build and host web-based applications and online-learning solutions, all accessible to people with disabilities, for nonprofits and government agencies in Massachusetts and throughout the United States. The INDEX platform facilitates dissemination of disability-related resources, program, and service data by storing them in a single repository and extending the data by combining it with other services such as:

- record updating
- call center for consumer support
- text simplification
- data maintenance
- client support
- training and learning management system hosting
- technology consulting
- data mashups

In cases where clients want a subset of the data to be available to their users, INDEX can provide a search interface and a filter for that specific client's set of records. This will lead to consumers having better access to higher quality data resulting in consumers making better decisions about the services they receive. The robust platform also allows INDEX to create data mashups with other data sources such as geolocation and social media. The INDEX platform enables clients to become more agile by providing shared resources to help clients quickly scale operations while decreasing costs over traditional platforms.

In terms of full access for people with disabilities, their families and the autism community-at-large to find specific disability information and resources germane to the autism community, INDEX is fully equipped, local, and unique. In terms of future access at the systems level, they are also prepared to provide the services and supports to leverage and monitor data sources and could potentially assist with the single port of entry that has been a goal for the autism community.

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[131] https://www.disabilityinfo.org/Index.aspx
[132] https://www.disabilityinfo.org/Resources/MNIP/

Medicaid Information Technology Architecture

The Medicaid Information Technology Architecture (MITA) initiative is a federal initiative to stimulate integration of business and IT platforms across all Medicaid services in each state, based on national guidelines. In Massachusetts, there has been a multi-year MITA initiative, supported at least in part through federal grants, to design and develop a new information system for use by all state agencies under EOHHS providing Medicaid-funded services. Currently, each agency has its own data system, and these systems are not formally linked. However, under plans for the MITA system, each person receiving Medicaid services would have a centralized record, likely containing information about the person's eligibility-related diagnoses that would be visible only to agencies providing services to or assessing eligibility for the person. Such a system has the potential to improve cross-agency communication, but also to provide more comprehensive data on Medicaid-funded service recipients within the state including autistic people. For DDS, this system is planned to replace the agency's current Meditech system that is currently used to house the primary record on each service recipient and to handle billing for Medicaid waiver services.

Since 2007, the Commonwealth has been actively engaged in identifying, defining, and developing the Commonwealth's Business, Infrastructure, and Technical Architecture, specifically as it relates to MassHealth and the Commonwealth's Medicaid Enterprise, (MassHealth and Massachusetts agencies supporting the Medicaid Title XIX and Title XXI populations). The original scope of the initial State Self-Assessment (SS-A), using CMS's MITA Framework 2.0, was to define a common EOHHS business information and technical model so that all future systems developments can re-use components and create system interoperability. Due to the complexity of the Enterprise, however, in 2008 the Commonwealth decided to split the SS-A process into three components. The initial endeavor, defined as the MITA Component One Project, was the collecting, cataloguing and identifying of the 78 business processes as defined by MITA 2.0, plus the identifiable State Specific Processes, and the identification of the Enterprise's Business and Technical Capabilities as centered on the Center for Medicare and Medicaid Services (CMS) MITA 2.0 Framework. [133]

The exact status of the MITA project was unclear at the time of our initial review (October 2013). In March 2016, Massachusetts, together with New Hampshire and Rhode Island through a New England MITA collaborative, issued a Request for Proposal (RFP) for consultation services to conduct a State Self-Assessment using the national Framework 3.0 and develop a Five Year Strategic Plan for improving MITA maturity levels across the Medicaid Enterprise in each state with a target completion date for both components of June 30, 2017. A data infrastructure that links data about Medicaid-related services across service agencies has the potential to greatly improve the feasibility of measuring service needs, referrals and service outcomes for people with autism and other conditions and to permit greater statewide planning regarding service capacity in alignment with needs.

Standards for Systems of Care for Children and Youth with Special Health Care Needs

The Association of Maternal & Child Health Programs (AMCHP), with support from the Lucille Packard Foundation for Children's Health, released a groundbreaking set of standards and companion background white paper in March 2014[134] designed to help communities, states, and the

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[133] http://www.dhhs.nh.gov/business/rfp/documents/rfp-2016-ois-01-mita.pdf

[134] Association of Maternal & Child Health Programs (AMCHP). (March, 2014). *Standards for Systems of Care for Children and Youth with Special Health Care Needs: A Product of the National Consensus Framework for Systems of Care for CYSHCN Needs Project*.

nation build and improve systems of care for children and youth with special health care needs (CYSHCN). The standards address the core components of the structure and process of an effective system of care for CYSHCN and are intended for use or adaptation by a wide range of stakeholders at the national, state, and local levels. The standards were derived from a comprehensive review of the literature, early guidance during the project from more than 30 key informants, case studies of standards currently in use within selected sites, and input and guidance from a national work group comprised of national and state leaders representing state Title V CYSHCN programs, health plans, state Medicaid and CHIP agencies, pediatric providers, children's hospitals, insurers, health services researchers, families/consumers, and others. Several experts from Massachusetts participated on the National Work Group including Dr. Richard Antonelli of Boston Children's Hospital, Meg Comeau of the Catalyst Center, and Nora Wells of Family Voices.

The Standards of Care framework could be used by Massachusetts as an excellent tool that employs structure and process standards to advance a comprehensive system of care to improve health outcomes for CYSHCN with autism.

Resources: Access

The following resources can assist with understanding and monitoring a variety of types of access for individuals and families as well as the larger autism community at the systems level. Both state and national resources are shared. This list represents only a few out of many more available and can provide a starting point in thinking about how to measure access to services and supports.

Autism Consortium

Over the eight years from 2006 through 2015, 100+ researchers and clinicians from 17 Boston-area institutions comprised the Autism Consortium to accelerate research to understand Autism and develop new treatments. Under the philosophy that scientific collaboration accelerates research progress, the Autism Consortium facilitated autism research by:

- Bringing scientists and clinicians together across disciplines and institutions.
- Making targeted investments in collaborative projects.
- Making available their local repository of 1,500 biological samples with associated phenotype data.
- Hosting an annual Research Symposium to showcase new research and foster collaboration.

In addition, the Autism Consortium supported autism clinics and families by:

- Providing a team of autism resource specialists to serve as family navigators in five hospital clinics.
- Providing quality resources so families could take the critical steps after diagnosis.
- Raising awareness of opportunities to participate in autism research.

The Consortium offered quality resources for families and clinicians through their website:

- A comprehensive Parent Information Packet translated into six languages.
- A searchable on-line Resource Database of services.
- An online calendar of events for parents and professionals.

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http://www.amchp.org/AboutAMCHP/Newsletters/member-briefs/Documents/Standards%20Charts%20FINAL.pdf

- A comprehensive manual on Transitioning Teens with Autism Spectrum Disorders.

Their team of Autism Resource Specialists served over 10,000 families at Boston Children's Hospital, Boston Medical Center, the Lurie Center at Mass General Hospital, the Floating Hospital for Children at Tufts Medical Center, and UMass Medical Center. Most are still in place serving at these medical centers.

The Autism Consortium informally assessed the effectiveness of the Autism Resource Specialist role on clinic efficiency and waiting lists. They found anecdotally that patient flow within the clinics improved as valuable clinician time was freed up by presence and work of these specialists.

When the Consortium began in 2006, they identified about 160 researchers involved in slightly more than 300 autism-related collaborations. When it concluded its work in 2015, the number of researchers involved with autism research increased to over 270 with Boston's basic science, translational, and clinical researchers engaged in more than 1,545 autism-related collaborative efforts – a more than five-fold increase. The major hospital clinics evolved into interdisciplinary centers, improving both care and treatment of impacted families. Moreover, families became increasingly engaged in the research process as educated consumers and participants. Activities resulting from these and related collaborations brought funding in excess of $100 million from government, philanthropy, and industry to Greater Boston area institutions. This funding continues to multiply as more investments are made in the brain sciences in the region.

The brain trust and workforce resulting from the Autism Consortium distinguishes Massachusetts as a research and treatment leader serving people with autism and their families, not only locally but nationally and internationally. In terms of understanding needs, addressing services and supports, and expanding workforce capacity, the network and knowledge base they created could still be of use in gathering data, measuring progress and expanding infrastructure in the state.

Exceptional Lives[135]

Exceptional Lives is an online resource designed to help families of children with disabilities gain better access to services and supports. The founders discovered that much of the available disability information was too general, overwhelming, or inaccessible for families who needed it. To solve this problem, they collaborated on technology to empower families. In 2013, they launched Exceptional Lives.

Exceptional Lives uses web-based software to produce free online Guides and other tools that help parents navigate the complex processes they face in caring for family members with disabilities. As parents walk through a Guide, they answer questions that lead them down an individualized path of actionable steps. All content is sourced from subject matter experts, presented in plain language, and displayed so parents see only what is relevant to them.

Parents and caregivers open free accounts so they can save and return to their Guides and at any time, on any device. Free phone and online support is also available. Exceptional Lives hold free workshops for parents and caregivers of children and adults with disabilities throughout the year.

As of October 2016, the following Guides are available: How to Create an Effective IEP, How to Access Special Education, How to Apply for SSI, How to Optimize your Health Insurance, and How to Navigate Guardianship. Future Guides in 2017 are planned for early childhood and transition

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[135] http://exceptionallives.org/

topics. From November 2015 through October 2016, Exceptional Lives had 20,000 visitors to its Guides with 2,500 accounts opened (a 13% conversion rate).

Exceptional Lives reports that parents commonly use their Guides between the hours of 10 pm to 1 am to answer disability-related questions around caring for their children with special needs.[136] Recent surveys show that 90% of parents and 95% of professionals said they would recommend an Exceptional Lives Guide to another parent they knew who was navigating one or more of these processes.

In addition, the organization acquired the online Resource Directory previously managed by the Autism Consortium. It is being redesigned and relaunched via the Exceptional Lives website by January 2017.

The Guides and Resource Directory provide easy access to disability-related information for parents, saving them time and lowering the stress that often results from navigating systems of care among other parental responsibilities. Exceptional Lives' online (high tech) access complements the family navigation (high touch) services that autism specialists – like those set up originally by the Autism Consortium – provide.

Data gleaned from these efforts can also provide insights into community needs and usage in the future.

Autism CARES Act and Related State and National Resources

In addition to state and local resources that can provide greater access, it is important for Massachusetts state agencies and other organizations that serve people with autism and developmental disabilities and their families to be aware of national resources that can assist states as potential sources for technical assistance, research, and training to address state needs.

In August 2014, the bipartisan Autism Collaboration, Accountability, Research, Education and Support Act—Autism CARES Act—was signed into law under Public Law 113–157[137]. The Act, a reauthorization of the Combating Autism Act, supports a number of national autism resources for participating states to utilize by investing in research, prevalence monitoring, and services for both children and adults on the autism spectrum. Of particular note, the autism programs they support address the needs of underserved populations and barriers to evidence-based interventions.

The Autism CARES Act funds Autism State Systems programs administered by HRSA-MCHB such as State Implementation Grants (SIGs), the State Public Health Coordinating Center, and State Planning Grants (SPGs), among its many programs.

- State Implementation Grants (SIGs) aim to improve access to care through referrals, timely diagnosis and feedback, and entry into quality, coordinated care across systems for children with ASD/DD.
- The State Public Health Coordinating Center coordinates with the SIGs to develop and implement a strategy for defining, supporting, and monitoring the role of state public health systems in assuring that children and youth with autism receive early and timely identification, diagnosis, and intervention.

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[136] Source: 9/23/16 interview with co-founder Anne Punczak Marcus
[137] http://mchb.hrsa.gov/maternal-child-health-initiatives/autism

- State Planning Grants (SPGs) help states with planning and implementation activities designed to improve state systems of care and access to care for children with ASD/DD.

This report is the outcome of the SPG grant to UMass Medical School-E.K. Shriver Center through the Massachusetts Act Early program with the support of the Center for Developmental Disabilities Evaluation and Research (CDDER).

The Autism CARES Act also supports a number of technical assistance programs that can assist states in meeting their early identification goals:

- The State Public Health Autism Resource Center (SPHARC) hosted by the Association of Maternal & Child Health Programs (AMCHP) is a comprehensive web-based resource center intended to provide ongoing technical assistance and facilitate cross-state learning to increase the capacity of states, particularly Title V programs, in developing and implementing systems of care for children and youth with autism spectrum disorders and other developmental disabilities (ASD/DD) through resource development, technical assistance and peer learning. The SPHARC offers state systems grants related to autism.
    - Massachusetts Act Early has had two state systems grants so far: one for the Considering Culture in Autism Screening Guide and Kit (2011-2012) and most recently for the Developmental Monitoring in State Systems Cable TV Project (2016-2018). (For more information, see the Early Identification Section on Massachusetts Act Early below).

- Leadership Education in Neurodevelopmental Disabilities (LEND) programs that provide interdisciplinary training to enhance the clinical expertise and leadership skills of professionals dedicated to caring for children with neurodevelopmental and other related disabilities, including autism. There are 43 LEND programs in the country.
    - Massachusetts has two programs at the University of Massachusetts Medical School-E.K. Shriver Center LEND and at the Institute for Community Inclusion/Boston Children's Hospital LEND.

- The Developmental-Behavioral Pediatric (DBP) programs train the next generation of leaders in developmental-behavioral pediatrics and provides pediatric practitioners, residents, and medical students with essential biopsychosocial knowledge and clinical expertise. There are 10 DBP programs in the country.
    - Massachusetts has a DBP at Boston Children's Hospital.

- The Interdisciplinary Technical Assistance Center (ITAC) on Autism and Developmental Disabilities at the Association of University Centers on Disability (AUCD) provides technical assistance to LEND and DBP interdisciplinary training programs to train professionals to use valid and reliable screening tools to diagnose or rule out and provide evidence-based interventions for children with ASD and other developmental disabilities.

- The Autism Intervention Research Network on Physical Health (AIR-P Network) focuses on research around interventions, improvement of care and services, guideline development and information dissemination.
    - The coordinating center for these projects is located at Massachusetts General Hospital in Boston.

- The Healthy Weight Research Network for Children with Autism Spectrum Disorder and Developmental Disabilities (HWRN-ASD/DD) aims to increase the understanding of factors contributing to the possible increased risk of overweight and obesity among children with autism and other special health needs.
  - The HWRN is led by the UMass Medical School-E.K. Shriver Center.

Lastly, the Autism CARES Act funds the activities of the national autism awareness campaign "Learn the Signs. Act Early." A detailed review of the campaign under our local state chapter, Massachusetts Act Early, can be found in the chapter on Early Identification under Resources. This project is directed by the Massachusetts Act Early Program at UMass Medical School-E.K. Shriver Center LEND in collaboration with the Center for Developmental Disabilities Evaluation and Research (CDDER).

The national and state-based resources made possible by the Autism CARES Act can serve as technical assistance resources in locating, understanding, analyzing and monitoring a variety of locally sourced data, learning from other states about different models and approaches used successfully in other parts of the country, and training and expanding the local workforce to better serve and provide great access to people with autism and their families.

These programs can contribute greatly to the Autism Commission's mission of maximizing federal reimbursement and resources.

Recommendations: Access to Care

The core outcome indicator, Access to Community-Based Systems of Care is one of the six indicators with the greatest level of need for CYSHCN with autism in Massachusetts.

Within the state, there are few quantitative measures that exist to substantiate the current status of criteria for an accessible community-based system of care. National surveys, while limited, indicate that when considering how accessible systems of care are for families who care for CYSHCN with autism compared to other CYSHCN, families of children with autism access fewer of the six core outcomes indicator domains within the health care system than other CYSHCN. Thus, the state's health care system is not achieving enough of the age-relevant core indicators needed for a high standard of care. Moreover, families also report experiencing some difficulty accessing specialty care, having a high need for mental health services, and experiencing personal hardships supporting their family members. Assessment within demographic or other subgroups of CSHCN with autism is critical to develop appropriate interventions and policy responses.

Discrete areas of need for access include diagnostic wait times for evaluation and referral to intervention, which fluctuate across the state. Special attention should be paid to building regional workforce capacity both for having enough specialists, as well as opening up better access for providers to accept MassHealth for those families who rely on it. Education and training as well as resource materials are needed to build parent awareness of the importance of monitoring developmental milestones and red flags, as well as PCP confidence in screening and referral practice. There is also a great need for strengthening cultural and linguistic competence among providers through workforce development. Massachusetts still does not have enough ABA therapists to meet the demand of families, limiting access to ABA services and raising concerns about network adequacy for autism treatment. Southern Massachusetts/Cape Cod and Western Massachusetts experience regional disparities because often families cannot access services locally and must take the time to travel to Boston. Many providers in these regions may not accept MassHealth locally, so families experience additional health care access-related disparities. Restrictions to access for families living in poverty are significant.

1.) OBTAIN DATA TO MEASURE AND MONITOR ACCESS TO CARE

Currently, the state does not use the sort of operational definition of the community-based system of services described by Perrin et al. (2007) to help ensure the breadth, comprehensiveness, and organization of services that will benefit CYSHCN and their families. No information is known at present about how accessible community-based systems have been measured for children with autism and DD in Massachusetts. Moreover, focus group feedback overwhelmingly cites access to care as the most predominant need and perceives state systems as working in silos.

The Massachusetts Autism Commission's 2013 report priorities and recommendations go far in outlining a state plan to begin this process. One key recommendation that was echoed by several of the Commission's subcommittees was the need for a single point of entry to services in the state. All stakeholders should be included in attempting to measure these data across systems. It should include information reported by race, culture, ethnicity, immigrant status, age, mental health status, region, and income level.

It is important to monitor processes to insure that access to systems of care for CYSHCN with ASD is timely and effective. Systems of care measurement and monitoring might include:

- Publicizing core outcomes for all six indicators (and others) using an online dashboard to communicate targets, progress and outcomes to the public (see Recommendations in the Population & Prevalence Data Section as well).
- Conducting time studies of diagnostic wait times – from screening to evaluation to referral to intervention – to address fluctuating wait times across the state.
- While acknowledging the challenge of tracking children and youth across multiple agencies, determining the feasibility of coordinating public program databases such as MITA and the use of the SASID.
- If pediatric practices and diagnostic clinics do not screen or evaluate when a parent does not speak English, examining whether there are further follow-up steps taken for a child.
- Increasing the number of providers who accept MassHealth, especially in regional practices, for those families who rely on it.
- Making telehealth reimbursable as modeled by other states; testing its use for ABA, pediatrics, etc.

2.) OBTAIN A LARGER DATA SAMPLE FOR NATIONAL SURVEY QUESTIONS RELATED TO ACCESS TO CARE FOR CYSHCN WITH ASD

One way to achieve Recommendation 1 may be to utilize national survey questions related to access to care for CYSHCN with ASD. For the section on Access to Community-Based Systems of Care, this recommendation is made in two parts: a) measuring the system of care overall and b) measuring discrete items such as access to specialty care and the effect of lack of access on family members.

Initial results of the NS-CSHCN survey indicate that in Massachusetts two or more age-relevant core outcomes were <u>not</u> achieved for the overall system of care (out of 6 possible Healthy People 2020 indicators) for almost 80% of CYSHCN with ASD compared with 53.2% of all CSHCN in general, though more data is needed to establish a reliable baseline from which to monitor future progress.

Initial results for access to specialty care and the effect of lack of access on family members also require more investigation and analysis of these questions due to the small sample size.

While the national CAHMI children's health surveys (NSCH and NS-CSHCN) ask important and relevant questions about access to systems of care, the state sample sizes are quite limited such that any estimates for CYSHCN with autism are based on very little information and therefore subject to error. However, the questions and survey structure are useful, and a state supplement or coordinated efforts with the funder of the survey, Health Resources & Services Administration (HRSA), may be beneficial to oversample children in Massachusetts for the purpose of improving the precision of these estimates. In addition to enlarging the state data set for the Access to Care core outcome indicator, this would apply to all six Healthy People indicators to provide a fuller picture of how all systems of care serve CYSHCN with autism in Massachusetts.

By using quality measures such as the national surveys across all relevant state agencies and other partners within the entire system of care for CYSHCN with autism, it can facilitate the establishment of common aims, shared metrics and measurement systems, coordinated strategies, and continuous communication at the state level in the care and management of CYSHCN with autism, ultimately helping the state achieve collective impact in serving this population.[138]

3.) SET ACCESS TO CARE TARGETS AND MONITOR PROGRESS ON AN ANNUAL BASIS.

While it is challenging to set targets with little data available about Access to Care in the state, the national Maternal, Infant & Child Health (MICH) Outcome Indicators for Access to Community-Based Systems of Care may be useful to Massachusetts in setting targets and monitoring progress by related indicator criteria. To review, the indicators are:

- **MICH-31.1**: Increase the proportion of children aged 0 to 11 years with special health care needs with autism who receive their care in family-centered, comprehensive, and coordinated systems.
  - National Baseline: 20.4% of U.S. CSHCN with autism aged 0 through 11 years (National target = 22.4%)
- **MICH-31.2**: Increase the proportion of children aged 12 to 17 years with special health care needs with autism who receive their care in family-centered, comprehensive, coordinated systems.
  - National Baseline: 13.8% of U.S. CYSHCN with autism aged 12 through 17 years (National target = 15.1%)

As stated earlier, the MCHB national target should be a goal of 10% improvement over baseline.

Other possible targets to benchmark and monitor are some of those included in the National Health Care Quality and Disparities Report from AHRQ (2015). For example, one measure could read "CSHCN with autism who had a pediatric visit or clinic visit in the last 12 months (or other appropriate interval) whose health providers sometimes or never spent enough time with them." The statement would be followed by an estimate and a benchmark, with the distance to the benchmark indicated and the status of "needs improvement" or "close to benchmark." (See section on page 110).

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[138] Kuo DZ, Houtrow AJ, AAP Council on Children with Disabilities. (2016). Recognition and Management of Medical Complexity. *Pediatrics*, *138*(6):e20163021

The Massachusetts Autism Commission could consider whether these national targets are appropriate for the state, whether any other systems-level targets should be considered, and determine how and which data sources can be used to measure and monitor possible targets for this core outcome indicator.

4.) BUILD AND MONITOR WORKFORCE CAPACITY AND DEVELOPMENT FOR ACCESSIBLE COMMUNITY-BASED SYSTEMS.

Several needs for better detection of autism in young children were raised in the Pediatric Provider Survey and the Wait Time Survey. They included: 1) training PCPs to screen and refer, 2) better availability of diagnostic specialists, and 3) better communication between PCPs and diagnostic specialists, 4) outreach to early childhood programs by PCPs, and 5) regional networking on the topic of early identification between early childhood, providers, PCPs and diagnostic specialists.

It is important to build and measure workforce capacity and to monitor workforce development through training to meet the Access to Care core outcome indicator.

Some workforce development considerations might include:

- Recruiting diagnostic specialists across all regions.
- Building networking opportunities for all professionals through promotion of the Massachusetts Act Early state team, which leverages cross-system collaboration and collective impact
- Strengthening cultural competence among providers through workforce development using a curriculum such as the Massachusetts Act Early Program's "Considering Culture in Autism Screening".
- Measuring and monitoring the number of ABA providers available by region.
- Using telehealth to provide regional access to training.

5.) EDUCATE PARENTS ABOUT NAVIGATING AND ACCESSING SUPPORT SYSTEMS

From the moment a child is born, families of both typically developing children and those with developmental concerns must learn how to traverse many systems of care. Supporting families through this process is of paramount importance, especially when the child has a disability such as autism.

For those parents whose children eventually have developmental concerns requiring follow-up for evaluation, pediatricians and diagnostic specialists both agree that late referrals for diagnoses may be attributable to: 1) parents' lack of awareness of developmental milestones and red flags for concerns, 2) parents' primary language not being English, and 3) parents' low socio-economic statuses. Coaching programs such as Thrive in 5's Screen to Succeed campaign, CFCE's use of the ASQ questionnaires, and the CDC's online "Watch Me!" curriculum as well as their "Milestones in Action" tools are meant to educate parents on the importance of developmental monitoring and what to do when they have a concern. To address physician concerns about late referrals, these programs might be supported for full dissemination of materials and training to young parents across the state.

Once diagnosed, accessing systems of care can be one of the most daunting tasks for parents of children with autism. Educating parents how to navigate systems is of critical importance in empowering them to care for their child with autism. Providing navigation services either online (e.g., INDEX, Exceptional Lives guides) or in person (e.g., family navigators, care coordinators, family-to-family support networks, community support lines, etc.) can be worth their weight in gold for busy, challenged families getting started in obtaining services and supports.

Our focus groups also spoke to several access needs that parents have. There may be a need for further workforce development to assess educators' skills in working with families. Educating community organizations on how best to work with families whose children have autism could also have benefits. In addition, the full list of family focus group recommendations is listed below:

- Increase the number of bilingual and bicultural therapists (ABA, play, etc.), or provide interpreters so that parents can better participate in the therapy.
- Provide incentives for professionals, especially from minority cultures, to enter the field.
- Provide funds to support families in accessing educational advocates.
- Provide family trainers or paraprofessionals who can provide assistance with understanding health benefits.
- Increase the capacity of middle and high school counselors who are skilled in autism.
- Increase the availability of respite care options.
- Increase opportunities for social and recreation.
- Increase capacity for home-based services, i.e. ABA providers.
- Offer more support groups and support systems for parents and youth.

FAMILY INVOLVEMENT

Healthy People 2020 Core Outcome Indicator #4

Families of CSHCN will partner in decision-making regarding their child's health

The following section will share information about the involvement and engagement of families as full partners and decision makers in the care of children and youth with autism and other developmental disorders by looking at data related to practices, projects and programs in Massachusetts that empower families and give them a voice. We include autistic self-advocates in our discussion as well. We will present identified needs using national and state quantitative data findings first looking at the state environment. We will then provide qualitative insights from focus groups. Lastly, we will offer future possibilities and recommendations that arise from this assessment.

Background

The core MCHB indicator for family involvement is described as:

> *"Families of children and youth with special health care needs partner in decision making at all levels and are satisfied with the services they receive."*

The U.S. Maternal and Child Health Bureau (MCHB) defines family-centered care as an approach to care that "assures the health and well-being of children and their families through a respectful family-professional partnership. It honors the strengths, cultures, traditions, and expertise that everyone brings to this relationship [and is] the standard of practice which results in high quality services".[139] Implicit in this definition are the core tenets of family-centered care which include regarding the family unit as a constant in the child's life, building on family strengths, empowering families to advocate for their child's and their own needs, involving families in decision making about care, providing continuity of care, promoting parent-professional partnership and collaboration, developing cultural competence, ensuring equity, understanding the importance of community-based services, and generally improving services to CSHCN and their families.[140]

When considering family-centered care in the context of policies and procedures for organizations that work with families, the Maternal & Child Health Bureau states:

> *"Family-centered care is a process to ensure that the organization and delivery of services, including health care services, meet the emotional, social, and developmental needs of children; and that the strengths and priorities of their families are integrated into all aspects of the service system….Family-centered care recognizes that families are the ultimate decision-makers for their children, with children gradually taking on more and more of this responsibility as they mature."*[141]

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[139] McPherson, 2005; also, National Center for Family-Centered Care, 1989

[140] Bishop, Woll & Arango, 1993; MCHB, 2005

[141] http://mchb.hrsa.gov/cshcn0910/core/pages/co1/co1dm.html

Kuhlthau et al.[142] conducted a systematic review of evidence for family-centered care focusing specifically on family-provider partnerships. They found positive associations of family-centered care with efficient use of services, health status, satisfaction, access to care, communication, systems of care, family functioning, and family impact/cost. Many elements of family-centered care dovetail with the medical home and issues related to transition age youth.

In their 1999 book *Essential Allies: Families as Advisors*,[143] the Institute for Family-Centered Care offered additional roles for family members as partners in the overall system of care based on the wisdom they bring from lived experiences as parents of CSHCN, such as autism. At the organization or systems levels, families can play a role as advisors and partners in policy and practice. Examples of such types of family involvement include: task force members, advisory board members, program evaluators, in-service trainers, family mentors, family navigators, fundraisers, and many others. Over the past few decades, a movement of recognizing the added value that family members bring in tandem with their various professional skillsets, creating opportunities to take advantage of their expertise, and instituting family/professional partnerships at all levels has become a prevailing trend. Measuring the types and levels of activities that include families of children and youth with autism is another way to think about and monitor state outcomes for family involvement.

Separate from families, and equally as important, is the act of seeking out and including the voices of people with disabilities, specifically those with autism, for the most personally-informed counsel and participation of all. Here, family-centeredness gives way to person-centeredness and should start at transition age to gain and operationalize important insights as autistic youth become adults. The limitless opportunities above are exactly the same for autistic people and should be measured and monitored to chart meaningful progress (as they define it) in reaching for the best possible quality of life outcomes as they enter their adult years. According to journalist and author Steve Silberman, "in recent years, a growing alliance of autistic self-advocates, parents, and educators who have embraced the concept of neurodiversity have suggested a number of innovations that could provide the foundation of an open world designed to work with a broad range of human operating systems."[144] He then goes on to share roles that autistic people have played in areas such as environmental design, computer design, policy, science, health care, education, and others; as well as the need to "build a world suited to the needs and special abilities of all kinds of minds" with the possible returns on and innovations from these investments as "practical and immediate."

The principle "Nothing about us without us" should be rigorously applied without exception in including all those who have or care for someone with autism, be they self-advocates or family members.

Massachusetts will need to consider whether setting target goals for this indicator might be appropriate for the state including both populations and determine how data collection can be used to understand how the state's CYSHCN with autism, young adults, and families are being included respective to this indicator.

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[142] Kuhlthau KA, Bloom S, Van Cleave J, Knapp AA, Romm D, Klatka K, Homer CJ, Newacheck PW, Perrin JM. Evidence for family-centered care for children with special health care needs: a systematic review. Acad Pediatr. 2011 Mar-Apr; 11(2):136-43. PMID: 21396616.

[143] Institute for Family-Centered Care, 1999, Essential Allies: Families as Advisors

[144] Silberman, S. (2015) *Neurodiversity: The Legacy of Autism and the Future of Neurodiversity.* New York: Penguin Random House.

Summary of State Environment: Family & Self-Advocate Involvement

Family and Self-Advocate Involvement at the Systems Level in Massachusetts

Family Involvement

At the systems level throughout the state, there is no question that families are becoming more and more involved as advisors and professional staff in health care, education, family support and a host of other specialties. There are countless examples of family members participating in key roles across the state. We are a far cry from the late 1980's when families advocated tirelessly to be included and to have influence over critical decisions that impact their children's and families' lives.

Many LEND trainees from the two Massachusetts university-affiliated programs at UMass Medical School-Shriver and the Institute for Community Inclusion/Boston Children's Hospital are family fellows who have contributed greatly to systems for children and youth with autism across the state. Health care organizations have included family members as autism specialists in their diagnostic clinics through the former Autism Consortium with many serving in these roles to this day. Many members of the Massachusetts Autism Commission and committees are family members. Several local legislators are family members with children with a variety of disabilities including autism. The principal investigator of this report is the parent of a son with autism.

Advocacy organizations such as Advocates for Autism of Massachusetts (AFAM), Asperger/Autism Network (AANE), and Massachusetts Advocates for Children (MAC) have many family members in key roles, often educating many other families getting started in leadership and advocacy through workshops and conferences. Family leadership has been cultivated through efforts such as the DPH Family Leadership Institute, the Early Intervention Parent Leadership Project (EIPLP), and Massachusetts Families Organizing for Change (MFOFC). The Federation for Children with Special Needs (FCSN) holds conferences and support groups throughout the year that offer education and training to all parents with important outreach to bi-cultural/bi-lingual communities.

Family Networks

The Thrive in 5 program hires and trains family members to coach other parents from their community about developmental monitoring using the Ages and Stages Questionnaire. This helpful model breaks down cultural barriers in diverse communities by providing opportunities for peer-to-peer screening where parent leaders can play mentoring roles. (More information is available in the Early Identification section). Similarly, Family TIES of Massachusetts provides a statewide family-to-family volunteer network of experienced parents of children with special health care needs, including autism, who are trained to help families get started on the road to serving their children by carefully matching parents by disability and other needs. In addition, self-organizing groups such as Parent Advisory Councils (PACs) that advise school district Special Education Departments play a critical advocacy role in education.

Self-Advocate Involvement

Autistic self-advocates lead and participate in a number of organizations. Some provide a forum for advocacy and leadership. Others help them gain critical advocacy skills. These include the local chapter of the Autistic Self-Advocacy Network (ASAN), AANE, Arc of Massachusetts, Easter Seals, MAC, the Institute for Human-Centered Design (IHCD), Mass Advocates Standing Strong (MASS), Massachusetts Developmental Disabilities Council (MDDC), and Partners for Youth with Disabilities (PYD), among others.

These organizations only scratch the surface of the myriad efforts across the state that serve as models to add to the high quality of advocacy and services for children and youth with autism in Massachusetts. Understanding how broadly families and autistic people are involved in state systems and policies can help set the course for further capacity building in the state with a workforce that understands disability-related issues from people's direct experiences.

Identified Needs: Family Involvement

Quantitative Findings

National Survey Data about Massachusetts Family Involvement

The 2009-10 National Survey of Children with Special Health Care Needs (NS-CSHCN) asks questions about the family's role in decision making about a child's health, and also includes questions about whether the children in the family have autism. It can allow for the examination of family involvement in decision making specifically for children with autism. More information on autistic youth and their roles in their own health care and adult life will be discussed in the Transition section.

While the NS-CSHCN contains state-level data, its sample size is too small to provide reliable estimates for children with autism in Massachusetts. It can provide meaningful benchmarks for state data comparisons, particularly starting in 2017 when it will be combined into a single survey with the National Survey of Children's Health (NSCH). Comparisons to state data will be made where meaningful, and full tables of survey data on all relevant indicators below can be found in the Appendix under "Family Involvement Data".

The family partnership outcome for the NS-CSHCN was established by using a series of questions about families' role in decision-making:

- how often doctors discuss a range of treatment options with families,
- how often they encourage parents to ask questions about their child's care,
- how often they make it easy for parents to ask questions, and
- how often doctors respect parents' choices about their child's health care.

If parents answered "usually" or "always" to all four of these questions, the standard was met for family partnership. If they answered "sometimes" or "never," the standard was not met.

HOW OFTEN DOCTORS DISCUSS TREATMENT OPTIONS. Parents of 62.6% (C.I. 48.3-80.0%) of CSHCN with autism in Massachusetts and 67.4% (C.I. 64.2-70.6%) CSHCN with autism in the U.S. report that their doctor usually or always discusses a range of treatment options. The trend is lower than for all CSHCN: the parents of 83% (C.I. 79.2-86.2%) of CSHCN in Massachusetts and 81.1% (C.I. 80.3-81.8%) in the U.S. report their doctor usually or always discussing such options with them.

HOW OFTEN DOCTORS ENCOURAGE PARENTS TO ASK QUESTIONS OR RAISE CONCERNS. Parents of 69.6% (C.I. 53.4-85.7%) of CSHCN with autism in Massachusetts and 71% (C.I. 68.3-74.6 %)

CSHCN with autism in the U.S. report that their doctor usually or always encourages them to ask questions or raise concerns. The trend is lower than for all CSHCN: the parents of 84% (C.I. 80.5-88.0%) of CSHCN in Massachusetts and 81% (C.I. 80.4-81.9%) in the U.S. report their doctor usually or always encourages them to share their concerns.

HOW OFTEN DOCTORS MAKE IT EASY FOR PARENTS TO ASK QUESTIONS. Parents of 79.5% (C.I. 66.7-92.4%) of CSHCN with autism in Massachusetts and 76.8% (C.I. 73.7-79.9%) CSHCN with autism in the U.S. report that their doctor usually or always makes it easy for them to ask questions. The trend is lower than for all CSHCN: the parents of 89.5% (C.I. 86.6-92.4%) percent of CSHCN in Massachusetts and 86% (C.I. 85.3-86.7%) in the U.S. report their doctor usually or always making it easy to share their questions.

HOW OFTEN DOCTORS RESPECT PARENTS' CHOICES ABOUT THEIR CHILD'S HEALTH CARE. Parents of 76.6 (C.I. 61.9-91.2%) CSHCN of children with autism in Massachusetts and 76.7% (C.I. 73.6-79.7%) CSHCN with autism in the U.S. report that their doctor usually or always discusses a range of treatment options. The trend is lower than for all CSHCN: the parents of 88% (C.I. 85.1-91.2%) of CSHCN in Massachusetts and 84% (C.I. 83.4-84.8%) in the U.S. report their doctor usually or always discussing such options with them.

Of the four items that make up the family involvement standard on the NS-CSHCN, all four were partially met for all CSHCN with autism in Massachusetts (between 60-90% satisfaction) aligning closely with U.S. children with autism. In all four measures, disparities were seen for children with autism compared to all CSHCN in Massachusetts and nationally suggesting room for improvement.

HOW OFTEN DOCTORS MAKE PARENTS FEEL LIKE PARTNERS IN THEIR CHILD'S CARE. Similarly, the NSCH inquired how often their child's physician makes the parent feel like a partner in the past 12 months. Parents of 94.7% (C.I. 88.1-100%) of children with autism in Massachusetts and 76.3% (C.I. 70.8-81.7%) children with autism in the U.S. report that their doctor usually or always makes them feel like a partner in their child's care. The trend is similar for all children: the parents of 89.6% (C.I. 87.6-91.5%) of children in Massachusetts and 84.0% (C.I. 83.5%-84.6%) in the U.S. report their doctor usually or always makes them feel like a partner in their child's care.

Qualitative Findings

Focus Groups

The research team did not directly ask questions about family involvement in health care or other core outcome indicators in any of the focus groups, and no significant evidence of family involvement emerged unprompted from these groups. Any discussion about family involvement had to do with working with the child's school.

LACK OF FAMILY INVOLVEMENT AT SCHOOL. Many focus group participants described a lack of involvement with the school system. This sometimes took the form of excluding families from school grounds, classrooms, or meetings:

> *"The biggest problem I've seen with this is schools pulling kids age 14, 15 or 16 aside and saying your parents don't need to be involved in this anymore, you can sign for this. And they begin to have IEP meetings without the parent. And I've seen that happen quite a few times. And most of these kids really need support from their parents." – President of a large agency providing services to children with autism.*

Exclusion left parents feeling distant and frustrated. As one minority parent of an 8-year-old stated,

> *"I feel like during the meetings, the providers would give the report, and it would be the first time I'm hearing about this very specific information and data, and I really don't understand them, and then when I try to [bring up concerns] the team will say 'No, he's having no problem' and then I'm pushed out of the meeting."*

Culturally diverse participants unanimously stated that they felt "ignored'" by schools or "not taken seriously" because of their culture. This was especially felt by parents who speak other languages.

> *"As one diverse parent stated, "We ask them to send home documents in our language. But if you ask for translated documents, they ignore you."*

ADVOCACY. Many parents discussed the importance of support groups to help families feel more supported and together. These groups were able to provide resources, training, and education to families on the effect of advocacy with school systems and organizations.

Future Possibilities: Family & Self-Advocate Involvement

Citizen's Jury

Using deliberative methods to help make effective decisions about health policy, a "Citizen's Jury" project convened in 2015 to consider and make recommendations about the sharing of data among state agencies about people with autism and the pros and cons of a possible future integrated confidential data system among state agencies to track diagnosis, treatment services and outcomes of people with autism. The Citizen's Jury reflected on concerns about maintaining individual privacy and clarifying the specific intent of the data.

The project was spearheaded by Alixe Bonardi, MHA, OTR/L of Human Services Resource Institute (HSRI) and the UMass Medical School-Shriver in conjunction with the Minnesota-based Jefferson Center and the Boston chapter of the Autistic Self-Advocacy Network (ASAN) and funded by a grant from the Agency for Healthcare Research and Quality (AHRQ).

The Citizen's Jury allowed the research team to include the input of individuals who will be directly affected by the collection, storage, and usage of this data in the future. Participants were recruited through an online survey asking their feelings about autism data collection that included whether they would be interested in more detailed discussion. The 19-person jury included autistic adults, family members, and professionals from Massachusetts. Over the course of the deliberation in a Boston hotel over two separate weekends in September and October, 2015, jury members came to understand the need to both express their own feelings on the subject and value the opinions of others.

Findings from the Citizen's Jury have been compiled into a report, and Bonardi is now focused on presenting those findings and determining how best to integrate the jury's recommendations into the eventual development and rollout of any future autism data collection system in Massachusetts.

Recommendations: Family & Self-Advocate Involvement

The principle "Nothing about us without us" should be rigorously applied without exception in including all those who have or care for someone with autism, be they self-advocates or family members. Massachusetts rates highly in this area when considering the many opportunities available for families to participate as advisors and experts on committees and task forces as well as family professional employees in human service organizations. Opportunities for autistic self-advocates are not as prevalent.

The national NS-CSHCN survey shows that the four components indicating whether providers meet the family involvement standard were likely to be met for all CSHCN with autism in Massachusetts (between 70-90% satisfaction) aligning closely with U.S. children with autism, as well as all CSHCN in Massachusetts and nationally. Nonetheless, family partnership for Massachusetts CSHCN with autism was still reported less often than CSHCN in general by about 10-20%, indicating improvement may be needed. More is needed to be known about this indicator in general.

1.) SET FAMILY INVOLVEMENT TARGETS AND MONITOR PROGRESS ON AN ANNUAL BASIS.

The national Maternal, Infant & Child Health (MICH) Outcome Indicators for Healthy People 2020 under CSHCN does not include targets related to Family Involvement. Prior to this, Healthy People 2010 shared the following targets, but without specific baselines or numerical targets.

- **MICH 1.1**: Increase the percentage of families reporting satisfaction with the quality of primary care, obtaining referrals, needed services, coordination among providers.
- **MICH 1.2**: Increase the percentage of parents who report satisfaction with their level of involvement in setting concerns/priorities about their child's care.

Given the high level of satisfaction with family involvement within health care as reported in the NS-CSHCN and the less favorable level of satisfaction within schools shared anecdotally by our focus groups, the Massachusetts Autism Commission could consider whether these national targets are appropriate for the state and applicable to education as well, and if so, determine how and which data sources can be used to measure and monitor these core outcomes.

2.) OBTAIN A LARGER DATA SAMPLE FOR NATIONAL SURVEY QUESTIONS RELATED TO FAMILY INVOLVEMENT.

The NS-CSHCN survey indicates that satisfaction with the involvement of families of CYSHCN with autism in their children's health care is encouraging, though not as high as for CSHCN in general. Families report usually or always being able to discuss treatment options and raise questions or concerns with their child's doctor, as well as feeling respected and like a partner in their child's care. This outcome aligns closely with national results. While the NS-CSHCN survey asks very important and relevant questions about family involvement, the state sample sizes are quite limited such that any estimates may be subject to error. However, the questions and survey structure are useful, and a state supplement or coordinated efforts with the funder of the survey, Health Resources & Services Administration (HRSA), may be beneficial to oversample families in Massachusetts to improve the precision of these estimates. This would apply to all six Healthy People indicators to provide a fuller picture of how all systems of care serve CYSHCN with autism in Massachusetts.

3.) BUILD AND MONITOR FAMILY & SELF-ADVOCATE WORKFORCE CAPACITY AND DEVELOPMENT

Understanding how broadly families and autistic people are involved in state systems and policies can help set the course for further capacity building in the state with a workforce that understands disability-related issues from people's direct experiences. Examples of engaged citizenry projects and programs such as the Citizen's Jury as well as the many other initiatives presented herein could serve as helpful models and may produce relevant data to share for this purpose. Family members and self-advocates directly contributing to policy and practice, as well as serving on focus groups can also help determine which data should be prioritized across indicators and which should be monitored over time to gauge progress. The Massachusetts Autism Commission could consider leveraging these resources and others to measure and monitor the state's formal and informal workforce capacity that are capable to increasing quality and saving costs by providing helpful insights based on lived experience.

TRANSITION TO ADULTHOOD

Healthy People 2020 Core Outcome Indicator #5

Youth with Special Health Care Needs Receive the Services Necessary to Make Transitions to Adult Health Care

While this report focuses primarily on health-related core outcome indicators under Healthy People 2020 goals for CYSHCN with autism, the Transition to Adulthood section addresses a critical milestone for youth that encompasses other quality of life indicators as post-secondary education, employment, housing, community living and mental health in addition to health care. Because of this, we split this section into two complementary parts:

1.) Transition to adult health care
2.) Transition to adult life through education, employment and adult services

In each section, we share national and state findings related to transition for autistic teens and young adults. We look at background information from a national perspective, at a summary of the state environment, and any quantitative data that can define the state of need. We then provide qualitative insights from focus groups and autistic self-advocates. We provide any resources that we have found in our research. Lastly, we consider future possibilities and offer recommendations that arise from this assessment.

We use respectful identity-first language in this section to honor the preference of many adult autistics who embrace autism and neurodiversity as a central part of their identities. (For more information on identity-first language, please see the Overview section).

In Massachusetts, graduation numbers have grown in recent years to approximately 1,000 autistic students per year.[145] To put that into perspective, about 50,000 autistic youth in the U.S. graduate high school annually. Some graduates will enter post-secondary education and some will seek employment, but most will continue to need some type of services or supports regardless of their level of function. A study by Shattuck et al.[146] found that nearly 40% of autistic youth do not receive any clinical services, such as mental health counseling, speech therapy, case management, or medical services related to their disability once they reach adulthood. Lower income households experience greater disparities in receiving services. In truth, services for young people on the autism spectrum often seem least available when they are most needed. This explains a popular saying by parents that compares their child's transition to falling off a cliff. The situation in Massachusetts is no different.

Compared to other core outcome indicators, transition to adult life is one of the areas of greatest need in Massachusetts. In addition to health care, it is also important to address education, housing, transportation, mental health, and the social and emotional lives of transition age youth. The Massachusetts Autism Commission's report (2013)[147] focused mainly on post-secondary

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[145] MA Department of Elementary & Secondary Education (DESE), reported to Massachusetts Autism Commission Executive Director Carolyn Kain, September 2016

[146] Shattuck, PT, Roux, AM, Hudson, LE, Lounds, J, Maenner, MJ, & Trani, JF. (2012). Services for Adults with an Autism Spectrum Disorder, *Can J Psychiatry, 57* (5):284-291. doi: 10.1177/070674371205700503

[147] Massachusetts Autism Commission (March 2013). *Report of the Massachusetts Special Commission Relative to Autism*. http://www.mass.gov/anf/docs/mddc/autism-commission-report-full.pdf

employment, education and independence rather than health care transition. It found that older autistic youth ages 14-22 frequently do not receive the assessments and services needed to successfully transition to further education, employment, and independent living when they exit special education. Many autistic youth require instruction in the community to learn independent travel, communication, employment and daily living skills necessary to succeed.

Autistic adult self-advocates interviewed for this report have stressed that autism does not end when children reach adulthood, as popular culture leads people to think, but lasts for a person's entire lifetime. Although transition is one of the most critical times in a young adult's life, there is little we know about this indicator at present. As seen with other Healthy People 2020 indicators, by gathering and monitoring related data, we will be able to demonstrate progress in each essential quality of life area. It is important to track outcomes longitudinally, especially since the outcomes of unemployment and lack of continued postsecondary education are measurable. Factors that lead to positive post-transition adult outcomes need to be better understood by monitoring them over the life course of autistic people.

> "Autism is often thought to be a childhood disorder. That is untrue; it affects people across the lifespan. We need to cover services for adults starting at 18, 19, 20."
>
> –Autistic adult self-advocate

TRANSITION TO ADULT HEALTH CARE

Background

As part of the health care transition (HCT) process, autistic youth typically transition from pediatric or family health care provider to an adult health care provider by the time they are 22.

According to the Maternal & Child Health Bureau, recent medical advances have made it possible for more than 90 percent of youth with special health care needs (YSHCN) to reach adulthood, and yet these youth are much less likely to complete high school, attend college, get jobs, or live independently than other youth without disabilities:

> *"Few coordinated services have been available to assist them in their transition to adult-oriented care. Transition planning must begin early in order to move children and families along in a developmentally appropriate fashion. One of the greatest challenges in planning is how to make a successful transition from the pediatric to the adult model system of care. Health care professionals, on both the pediatric and adult sides, may lack the training, support, and opportunities they need to promote the development of youth with special health care needs as partners in health care decision-making. Some adult health care providers may not be prepared to treat patients with complex medical conditions that begin in childhood. The challenge remains to improve the system that serves youth with special health care needs while simultaneously preparing youth and their families with the knowledge and skills necessary to promote self-determination, wellness, and successful navigation of the adult service system."*[148]

MCHB has set the targets presented in the table below as key Maternal, Infant and Child Health (MICH) outcomes of Healthy People 2020 for health care transition (HCT) for youth with special health care needs. The MCHB national target-setting method is a goal of 10% improvement over baseline. For the purposes of this report, we consider this goal for autistic youth specifically.

DH-5: Increase the proportion of youth with special health care needs whose health care provider has discussed transition planning from pediatric to adult health care.

Maternal & Infant Child Health Indicator #	Baseline	Nat'l Target
DH-5: Increase the proportion of youth with special health care needs whose health care provider has discussed transition planning from pediatric to adult health care.	41.2 percent of youth with special health care needs had a health care provider who discussed transition planning from pediatric to adult health care in 2005–06.	45.3 %

Massachusetts will need to consider whether this national target might be appropriate for the state and determine how data collection can be used to understand how the state's children are being served respective to this measure.

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[148] U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. *The National Survey of Children with Special Health Care Needs Chartbook 2009–2010.* Rockville, Maryland: U.S. Department of Health and Human Services, 2013. http://mchb.hrsa.gov/cshcn0910/core/pages/co6/co6tahc.html

The Center for Child and Adolescent Health Policy at Mass General Hospital for Children[149] compiled a comprehensive literature review of what is currently known about YSHCN transitioning from pediatric to adult health care. They found serious gaps in outcomes, particularly if the youth's disorder affected the nervous system as many autistic youth experience. Bridging activities and the use of care coordinators appear to improve outcomes, but the evidence on programs to facilitate health care transition was weak and inconclusive.

Got Transition™ Six Core Elements of Health Care Transition

One emerging support framework based on research evidence is Got Transition™. The Got Transition™ National Center for Health Care Transition[150] aims to improve pediatric to adult health care transition through the use of the *Six Core Elements of Health Care Transition* in pediatric, family medicine, and internal medicine in partnership with youth and families.

Got Transition™? Six Core Elements of Health Care Transition	
1. Transition Policy	Create a written practice policy on transition including timeframes for when youth leave practice.
2. Transition Tracking & Monitoring	Track health care transition progress among all youth ages 12 and older, with and without chronic conditions.
3. Transition Readiness	Assess youth's transition readiness and self-care skills.
4. Transition Planning	Plan for transition as a collaborative and continuous process with youth and families.
5. Transfer of Care	Creating a transfer of care checklist for the practice, preparing a transfer package for youth leaving the practice, and communicating with the new adult provider.
6. Transfer Completion	Confirming transfer completion, arranging for pediatric consultation (as needed), and assessing youth and family experience with transition support

The six core *Got Transition™* elements provide a framework for practices to assist with the health care transition process and possible measurement of transition outcomes. Massachusetts may find this resource useful in implementation of pediatric medical homes future monitoring.

National Autism Indicators Report: Transition into Young Adulthood

Anne Roux, PhD, Paul Shattuck, PhD and their colleagues at Drexel University are the authors of *The National Autism Indicators Report*, a publication series produced by the AJ Drexel Autism Institute's Life Course Outcomes Research Program. The first volume of this report, *Transition into Young*

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[149] Bloom S, Kulthau K, Van Cleave J, Knapp A, Newacheck P, & Perrin JM. (2012). Health Care Transition for Youth With Special Health Care Needs. *Journal of Adolescent Health 51*, 213–219.

[150] http://www.gottransition.org/; http://www.gottransition.org/researchpolicy/index.cfm

Adulthood[151] was written in response to the call in the Autism Collaboration, Accountability, Research, Education, and Support Act of 2014 (Autism CARES Act of 2014) for more research on transition. Their findings are from their analyses of national-level data from the National Longitudinal Transition Study-2 (NLTS2) and the 2011 Survey of Pathways to Diagnosis and Services. In this section and in the section on Transition to Adult Life, we share their analyses based on these two national surveys as transition indicators for Massachusetts to consider monitoring in the future.

The *National Autism Indicators Report* presents evidence about a wide range of experiences and outcomes of young adults on the autism spectrum between high school and their early 20s. When addressing what is known nationally about the experience of health care transition for autistic transition age youth, the research team revealed the following findings:

Table HCT-1. National Indicator Findings for Health, Mental Health & Health Care

Health, Mental Health & Health Care	• 60% of youth had at least two health or mental health conditions in addition to autism spectrum disorder. • Three-quarters of youth on the autism spectrum took at least one kind of prescription medication on a regular basis for any type of health or mental health issue. • Nearly all had health insurance, and over 75% received needed treatments and services. • One in three parents said their pediatrician alerted them to the need to eventually change to an adult physician.

Similar to earlier report findings on the presence of two or more chronic conditions, the *National Indicator Report* confirms the level of need for CYSHCN with autism including prescription and health care utilization. These data have application for benchmarking and future monitoring in Massachusetts.

Summary of State Environment: Transition to Adult Health Care

Very little is known at present about state practices and data collection for youth transitioning to adult health care. The section on Identified Needs: Transition to Adult Health Care, hopes to shed initial light on the state of HCT for autistic YSHCN in Massachusetts through the NS-CSHCN and building upon national insights shared by the *National Autism Indicators* project above.

Identified Needs: Transition to Adult Health Care

Quantitative Findings

Provision of Anticipatory Health Care Transition Guidance

The 2009-10 National Survey-Children with Special Health Care Needs (NS-CSHCN) estimated the achievement of effective transitions to adult health care for autistic youth and others. Health care providers (and the overall system) were considered to have achieved the outcome for working with

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[151] Roux, Anne M., Shattuck, Paul T., Rast, Jessica E., Rava, Julianna A., and Anderson, Kristy, A. *National Autism Indicators Report: Transition into Young Adulthood*. Philadelphia, PA: Life Course Outcomes Research Program, A.J. Drexel Autism Institute, Drexel University, 2015.

autistic youth with special health care needs (YSHCN) toward an effective health care transition to adult life if their parents reported that they had provided their child with anticipatory guidance in three areas:

- Changing needs approaching adulthood
- Making the shift to adult provider, if needed
- Insurance coverage as they become adults

Drawing conclusions from the data collected for Massachusetts is problematic due to the low sample sizes, however we share the results here along with the national results in the hope that it can provide some insights into areas to investigate, benchmark, and monitor in the future. (See Appendix for tables with more information on all findings below under "Health Care Transition Data").

DOCTOR DISCUSSED CHANGING NEEDS AS YOUTH BECOMES AN ADULT. About half (46.5%) of Massachusetts autistic YSHCN nationally report that their doctor discussed their changing needs as they become adults. Sample sizes for this survey question for MA were extremely small and the range of the resulting estimate is too small to be meaningful. National patterns show almost 10% fewer providers discussed changing health care needs for autistic YSHCN as compared to all YSHCN.

DOCTOR DISCUSSED MAKING THE SHIFT TO ADULT PROVIDER. Nationally, only 35.8% of U.S. autistic YSHCN and 43.9% of U.S. YSHCN in general reporting that doctors discussed moving to adult providers with them. It is estimated that 45% (C.I. 32.2-57.7%) of Massachusetts YSHCN have had this conversation based on national trends. Sample sizes for this survey question for MA were extremely small and the range of the resulting estimate for youth with autism in MA is too small to be meaningful.

DOCTOR DISCUSSED INSURANCE COVERAGE AS YOUTH BECOMES AN ADULT. Of all Massachusetts YSHCN, 31.5% (C.I. 23.2-39.8%) of parents reported that their doctor discussed their insurance coverage as they become adults. These findings align closely with national findings of 35.1% (C.I. 33.3-36.7%) of all U.S. YSHCN and 28.2% (C.I. 22.3-33.4%) of U.S. autistic YSHCN discussing insurance coverage with their doctors. The NS-CSHCN preceded changes to Massachusetts insurance law from the ARICA legislation of 2011 and the Affordable Care Act of 2010. Additionally, sample sizes for this survey question for MA were extremely small and the range of the resulting estimate for youth with autism in MA is too small to be meaningful. Thus, these results tell us very little.

ALL 3 CRITERIA MET FOR HEALTH CARE TRANSITION OUTCOMES. Based on the above findings, Table HCT-2 shares the outcome of all three components of overall HCT anticipatory guidance being met for autistic YSHCN. In Massachusetts, all three transition outcome criteria were met for only 16.9% (C.I. 0.0-35.9%) of autistic youth compared to 40.9% (C.I. 33.3 - 48.5%) of all YSCHCN in the state aged 12-17 years. While this data suggests a possible disparity for youth with autism, the difference is not statistically significant, although it is close to significant, and should be used with caution. In comparison, almost 25.6% (C.I. 21.3-30.0%) of U.S. autistic youth met the standard compared with 36.8% (C.I. 35.4 - 38.2%) of all U.S. YSHCN, representing a statistically significant evidence of a disparity for youth with autism. Clearly, this is an area of much needed change in health care for autistic YSHCN, not only in Massachusetts, but across the country and provides an opportunity to gather data and monitor progress in the future.

National findings provide the best subgroup estimates. U.S. YSHCN in general whose conditions consistently affect their daily lives were half as likely as those whose conditions never affect their daily activities to achieve this objective (25.5 vs. 52.0 %). Children living in poverty were also half as likely as those with greater financial means to receive transition services (25.4 vs. 52.2%).[152] For Massachusetts, it will also be important to understand the provision of anticipatory guidance for these categories and also for youth from all racial and ethnic backgrounds.

Much more is needed to be known about this important indicator.

Table HCT-2. Doctor met all 3 transition components, NS-CSHCN 2009-10

		No	**Yes**	**Total**
All U.S. children	*%*	63.2%	36.8%	
	C.I.	(61.8 - 64.6%)	(35.4 - 38.2%)	
	n	8042	5627	13,669
	Pop. Est	2324437	1353458	3,677,895
All U.S. children with ASD	*%*	74.4%	25.6%	
	C.I.	(70.1-78.7%)	(21.3-30.0%)	
	n	714	285	999
	Pop. Est	185,709	63,880	249,589
All MA children	*%*	59.1%	40.9%	
	C.I.	(52.5 - 66.7%)	(33.3 - 48.5%)	
	n	157	113	270
	Pop. Est	52,670	36,404	89,074
*All MA children with ASD**	*%*	83.1%	16.9%	
	C.I.	(64.1-100.0%)	(0.0-35.9%)	
	n	20	5	25
	Pop. Est	7,474	1,524	8,998

C.I. = 95% Confidence Interval. Percentages are weighted to population characteristics.

n = cell size. Use caution in interpreting cell sizes less than 50

Frequency missing = National, 26626; MA, 818

In addition, the NS-CSHCN health care transition questions also included whether their providers usually or always encouraged youth to take responsibility for their health and health care.

DOCTOR ENCOURAGING YOUTH TO ENGAGE IN SELF-CARE. YSHCN in general were encouraged more frequently by their health care provider to take responsibility for their own self-care: 81.4% (C.I. 76.7-86.2%) of YSHCN in Massachusetts and 78.0% (76.8-79.2%) in the U.S., respectively. Rates are lower for of autistic YSHCN nationally at 48.1% (C.I. 43.1-53.0%). Sample sizes for this survey question for MA were extremely small and the range of the resulting estimate for youth with autism in MA is too small to be meaningful. However, data does suggest similar disparities may exist for children and youth with autism in Massachusetts.

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[152] http://mchb.hrsa.gov/cshcn0910/core/pages/co6/s.html

The reasons for all of these disparities in anticipatory guidance for autistic youth in Massachusetts are unknown, but worth investigating and measuring to promote a better experience of transitioning to adult health care for all autistic youth in the state. The gap is wide between autistic YSHCN and YSHCN more generally with much opportunity for measurement and improvement.

Qualitative Findings

The research team conducted one focus group specifically on the topic of Health Care Transition. Questions about transition were also asked in each of the Parent Leader, Autism Services Professional, and Medical Professional focus group as well as across the culturally-diverse focus groups. (Please refer to the Methods section for more details on these groups).

Researchers asked questions about current experiences with health care transition (HCT) for focus group participants and other people they know, as well as input on ideal states, and barriers to adult health care transition. In addition, interviews with self-advocates deepened emerging themes through insights from personal and shared lived experiences.

Focus Group Interviews

The following findings cut across all of the focus groups. These were opinions expressed not only by the group specific to health care transition, but by parents and professionals in other focus groups as well.

Participants expressed concern that transition to adult health care is not happening in a timely manner due to the following barriers:

- Parental/child attachment to the pediatrician and a hesitancy to transition to adult health care.
- Lack of adult health care providers with experience or training in autism.
- Lack of sufficient mechanisms for adult providers to adequately bill for longer medical appointments that are often needed by autistic adults.
- Lack of adult providers trained in mental health needs of autistic youth and adults.

> "The biggest problem I see is not talking all along. This isn't a one-time conversation, it's a process."
>
> ~ Program Director, large service agency for children with ASD

MEDICAL PROVIDER PERSPECTIVES. The research team conducted a focus group with pediatric and adult health care providers at a Boston community health center to better understand the medical provider perspective.
The most commonly heard themes related to transition were:

- Hesitancy among parents to transition their child from pediatrician to adult health care.
    - As one pediatrician stated, *"We've been talking care of their child for a long time and parents don't want to leave."*
- Few opportunities to plan for transition.
    - *"The child turns 19 and has this normal adolescent experience of fading away from urgent issues. We may send letters, but they don't get them. Transition doesn't get to happen because the person removed themselves from access."*
      - Family medicine nurse practitioner

- Little opportunity to plan for adult transition.
    - "*This may also be a time when undiagnosed medical issues surface without a clear path of what 'to do' in adult services, (i.e. whether the teen may qualify for mental health services vs. DDS services).*"–Family medicine physician
- Physicians feel limited in their ability to help autistic patients.
    - As one family medicine physician stated, "*There is not the expertise, not the training [to help kids get services]. Kids are not getting services they need out there so it feels like we are treading water. We fill out the form for special education so they get services, but in the current financial systems that's not a big whoopee. These kids don't have a lot of primary medical issues. They just need services.*"
- Time-consuming to see an autistic patient with little room to discuss transition.
    - As one seasoned family medicine physician stated, "*Time to see autistic patients with autism takes double the time and is not reimbursed. One patient with autism shoots my whole day seeing other patients.*"
- Hesitancy among adult providers to care for autistic people, and consequentially, to think about the topic of transitioning to adult health care.
    - "*It's hard to find adult providers to care for people with autism. Maybe they feel they don't have the training to take care of people with autism, that it's just like other adult diseases. They don't feel comfortable taking care of the patient.*"– Pediatrician
- Significant barriers connecting and working with schools and adult services.
    - "*We just don't know what's happening out there.*"
- Provider's confusion about how to work with guardians to plan for transition.
    - "*Who does what? What is the role of the PCP?*"

Self-Advocate Interviews

Four autistic key informants were interviewed separately and shared a number of concerns about health care transition for autistic youth and young adults. These self-advocates were well-networked within the autism community and able to represent not only their own personal needs, but also speak for others on the spectrum.

NAVIGATING HEALTH CARE. When asked about their greatest health care needs, self-advocates identified navigating the adult health care system as a top concern. They shared the need to assist autistic adults with navigating, applying for and managing their own health care coverage independent of their parents, as well as dealing with ongoing necessities such as scheduling annual check-ups, managing co-payments, and other tasks that require facility with executive function. All mentioned that autism is often thought of as a childhood disorder. This creates the need to raise awareness of adult issues, including insurance coverage starting as early as age 18.

GENDER AND SEXUAL IDENTITY. Issues of gender and sexual identity arose as an area of particular importance. One key informant cited the emergence of empirical research that shows that autistic people have a higher rate of having non-binary, gender non-conforming, transgender identities than the general population. Moreover, gender issues fit with other diversity issues.

> *"The idea that we are all equal and treat everyone as a blank slate – all the same – is doing nobody a service. For example, transgender people have different support needs so you can't treat all the same. You have to recognize that there's more than one way to access and impact someone's identity or experience." (See section on Cultural & Linguistic Diversity).*

Another key informant expanded on the outcomes for autistic LGBTQ adults by citing that, "*research shows that autistics are 2% more likely to be LGBT and 7% more likely to be transgender. [Because of this], they are more likely to be on the street."* (See section on Housing).

> *"To find a therapist who is culturally competent in so many different areas is hard due to my issues of LGBT, autism and race. So many therapists would not take my plan. Tufts has better networks….BCBS might work but not those on the insurance marketplace."*

COMMUNICATION. As part of health care and general speech/language needs, the topic of accessing assistive technology was raised. The need to provide AT devices to people all along the spectrum could assist those "*who speak differently or want to communicate but can't as readily."*

> *"Often, it's defined as if you can speak, you don't need it. An SLP must prescribe. Some speaking people do get overwhelmed and can't speak or may have sensory issues. They can be ignored. Some may need noise cancelling headphones and that may not have been thought about before."*

In addition, insurance tends to cover only more expensive, complex tools such as Dynavoxes but may not be necessary for the range of needs, however less costly, more user-friendly and readily available tools such as iPads and iPhone apps are not typically covered.

> *"These would allow us to communicate, but insurers get caught up on the idea that they will fund old-fashioned devices even though technology has moved forward…Autistics are never asked about these things. Not everyone needs an iPad and an iPhone may be enough. There are multiple needs that need to be taken into account. Some things may not be affordable for disability coverage… It is impossible to get A/T if you are not a kid in school."*

When asked what might help with communication, responses included:

- *"To have medical sheets to tell doctors about their condition."*
- *"They should be able to talk to doctors using AT devices & apps. On the doctor's end, they need to learn how to treat autistic patients by using iPads with communication apps, etc."*

ADULT HEALTH CARE INDEPENDENCE. When asked what it is like for autistic young adults to separate from their parents, the key informants focused mainly on transition to adult health care.

- *"For some people it's hard; for others, it's not. It depends on the person. Some want to give permission for parents to be involved… We need to gradually work with parents to pull back. We need to help people advocate in the health setting. Doctors need to involve parents if we want them to be involved, but not as the default medical advocate. Youth should start to* *advocate to doctors in their teens. Some may have a hard time verbalizing. They may be non-speaking. Others may have a harder time noting in words."*

- *"It is difficult living with parents if you can't get your own health care because autistics become dependent on parents and become dependent minors without their own benefits and health care. The parents can dictate who the doctor or therapist can be. They can get too much medical info on their children who are like captives based on this dependence."*

ADULT HEALTH CARE PROVIDERS. Finding and using adult health care providers can be challenging for many reasons. Common experiences include:

- *"My impression is that people have a hard time explaining their symptoms. Even though they may be very well meaning, doctors don't get it. So they end up thinking we are overwhelmed, we have different communication styles, that autism is a childhood condition, that we have "behaviors", and that they can't talk to a 25 year-old with autism."*

- *"Finding doctors is a challenge. There are so many variables. Do they take insurance? So many doctors don't take MassHealth. It must be a big name insurer. Even Connector plans are limited on the doctors you can see. There are fewer choices. Aetna & BCBS have more options than NHP, Fallon, etc."*

- *"I had a hard time [finding a therapist last year] because they are all in private practice. I couldn't find one through the Connector. They might take Tufts Health Plan, but eventually I went to Fenway Health and they took all plans so it turned out well, but they had a long waiting list."*

Future possibilities: Transition to Adult Health Care

It is clear that much workforce training and development is needed if Massachusetts autistic YSHCN are to successfully transition to the adult health care system. Much is needed to be understood about their needs and monitored in the future. The following projects and programs might help.

Local Transition Training for Pediatric Providers

OPERATION HOUSE CALL. Operation House Call (OHC) of the Arc of Massachusetts teaches young medical professionals essential skills to enhance the health care of persons with intellectual/developmental disability. OHC works with many families of transition age youth and individual self-advocates as educators as part of its overall program. (More information on OHC is available in the Medical Home section under Future Possibilities).

SPECIAL HOPE FOUNDATION PROJECT. Nurses do not often play a significant role in transitional medical homes, even though they are ideally suited to coordinate such care. As a result, they may lack the knowledge about both autism and the concept of transition from adolescent to adult health care services. To address these gaps, the UMASS Medical School-Shriver Center in collaboration with the UMASS Medical School Graduate School of Nursing and Operation Housecall is developing an innovative training curriculum to prepare graduate-level family nurse practitioner students to provide patient-centered health care for autistic transition-aged youth under a grant from the Special Hope Foundation.

By studying and measuring the efficacy of the Got Transition^{TM} Six Core Elements in practice in tandem with the OHC model and classroom didactics, the project team hopes to equip graduate family nurse practitioners with information to improve access for and provide skilled primary care to autistic young adults.

The curriculum will address effective transition from pediatric to adult health care for autistic YSHCN in the areas of:

1.) Misconceptions and attitudes about autism;
2.) Lack of knowledge about common comorbidities; and
3.) Lack of training and experience to provide primary and emergency care to autistic people.

By doing so, this project will increase the pool of trained nurse practitioners and improve health care delivery by potentially streamlining transition, reducing stigma, treating comorbidities, improving access for family advocacy, improving safety, and reducing costs overall. This pilot promises to be the first of many more and will serve to measure and document the efficacy of the OHC model in affecting positive change in workforce development and capacity building in the state.

Resources: Transition to Adult Health Care

Got Transition^{TM} National Center

Got Transition^{TM} Center for Health Care Transition Improvement is a cooperative agreement between the Maternal and Child Health Bureau and The National Alliance to Advance Adolescent Health. Their aim is to improve transition from pediatric to adult health care through the use of new and innovative strategies for health professionals and youth and families. With a broad range of partners, they are working to:

- Expand the use of the Six Core Elements of Health Care Transition in pediatric, family medicine, and internal medicine practices;
- Partner with health professional training programs to improve knowledge and competencies in providing effective health care transition supports to youth, young adults, and families;
- Develop youth and parent leadership in advocating for needed transition supports and participating in transition quality improvement efforts;
- Promote health system measurement, performance, and payment policies aligned with the Six Core Elements of Health Care Transition; and
- Serve as a clearinghouse for current transition information, tools, and resources.

This national resource could be used toward workforce development to promote better HCT practices and measurement in Massachusetts. More information and HCT tools and process measures are available at: http://www.gottransition.org

Division of Maternal and Child Health Workforce Development (DMCHWD)

The Division of MCH Workforce Development provides national leadership and direction in educating and training our nation's future leaders in maternal and child health. Special emphasis is placed on the development and implementation of interprofessional, family-centered, community-based and culturally competent systems of care across the entire life course with experiences in one life stage shaping health in later stages.

The Division, part of HRSA's Maternal and Child Health Bureau, supports programs established in federal legislation (Title V of the Social Security Act and the Autism CARES Act) to complement state and local health agency efforts. In partnership with state MCH programs, academic institutions, and professional organizations, the Division collaborates with other health training programs of the federal government to ensure that MCH initiatives are based on emerging and evidence-based practices.

Recommendations: Transition to Adult Health Care

While the 2013 Massachusetts Autism Commission Report prioritized transition age issues prominently in its examination and recommendations, health care transition (HCT) was not included among the other categories of education, employment, independent living and self-determination. The HCT core outcome indicator is an area of great need compared to other Healthy People 2020 goals for autistic YSHCN in Massachusetts. Anticipatory guidance for HCT is not being met for autistic YSHCN in Massachusetts. It is an area of much needed change in health care for autistic YSHCN, just only in Massachusetts but across the country and provides an opportunity to gather data and monitor progress in the future.

Among focus group participants, medical providers expressed great hesitance when working with transition age patients with autism. When asked about their greatest health care needs, self-advocates identified navigating the adult health care system as a top concern. Issues of sexuality, gender and sexual identity also arose as areas of particular importance. Communication and independence in working with providers were also raised as needs.

Thus, this report attempts to fill in some of the unknowns on this important topic for autistic youth and yet, there is still much to be understood about this particular area for youth.

1.) SET HEALTH CARE TRANSITION TARGETS AND MONITOR PROGRESS ON AN ANNUAL BASIS.

The national Maternal, Infant & Child Health Outcome Indicators for Transition to Adult Health Care (HCT) may be useful to Massachusetts in setting targets and monitoring progress by related indicator criteria. To review, the transition indicator is:

- **MICH DH-5**: Increase the proportion of youth with special health care needs whose health care provider has discussed transition planning from pediatric to adult health care.
    - National Baseline: 41.2% of U.S. YSHCN with autism (National target = 45.3%)

As stated earlier, the MCHB national target should be a goal of 10% improvement over baseline.

The Massachusetts Autism Commission should consider whether this national target is appropriate for the state, whether any other HCT targets should be considered, and determine how and which data sources can be used to measure and monitor possible targets for this core outcome indicator.

2.) OBTAIN A LARGER DATA SAMPLE FOR NATIONAL SURVEY QUESTIONS RELATED HEALTH CARE TRANSITION FOR AUTISTIC YSHCN.

Initial results of the NS-CSHCN survey estimate that very few doctors met all three HCT components in giving autistic YSHCN anticipatory guidance about transitioning to adult health care compared with 40.9% of all YSHCN in general in Massachusetts, though more data is needed to establish a reliable baseline from which to monitor future progress. The survey explored the following three components of transition anticipatory guidance from doctors or health care providers with autistic patients: changing needs as youth become adults (18-80%), making the shift to adult provider (48-100%), and insurance coverage as youth become adults (0-28% prior to ARICA).

The state sample sizes for these questions are quite limited such that any estimates for autistic YSHCN with autism are based on very little information and therefore subject to error. However, the questions and survey structure are important and useful, and a state supplement or coordinated efforts with the funder of the survey, Health Resources & Services Administration (HRSA), may be beneficial to oversample children in Massachusetts for the purpose of improving the precision of these estimates.

It seems that the gap is wide between autistic YSHCN and YSHCN more generally with much opportunity for measurement and improvement to fill in the gaps in baseline data and to set progress goals for future monitoring purposes.

3.) BUILD AND MONITOR WORKFORCE CAPACITY AND DEVELOPMENT FOR HEALTH CARE TRANSITION.

Workforce preparation to work with transition age autistic youth moving onto adult health care is an area of great need. It is important to build and measure workforce capacity and to monitor workforce development through training to meet the Transition to Adult Health Care outcome indicator. Some of the major concerns for this population that arose in health care provider focus groups included: few opportunities to plan for adult transition, medical appointments take longer, reimbursement does not cover the time needed, and few adult health care providers have experience or training in medical, behavioral and mental health care. Some of the needs that arose in self-advocate interviews included: care coordination to address and support their executive function and communication needs in navigating adult health care, as well as providers who are culturally competent and knowledgeable about topics such as sexuality and gender identity.

Some workforce development considerations might include:

- Incorporating autism knowledge into medical and nursing school curricula by enlisting local training resources such as Operation House Call for pediatric residents and nurses and the Special Hope Foundation Project for nursing students to develop a more informed workforce on the topic of transition.
- Using telehealth as a platform for accessible, flexible, remote continuing medical education for pediatric and family practice providers and their clinical staffs.
- Working with local pediatric and adult health care practice administration to create, measure and monitor processes for care coordination and anticipatory guidance that lead to greater HCT participation in practices by using resources such as the Got Transition™ tools and framework.
- Finding practice champions who can share lessons learned in working with this population to train others.

- Piloting a statewide professional HCT coalition that engages in a collective impact approach (i.e., share a common agenda, employ common progress measures, participate in mutually reinforcing activities, engage in regular communication, supported by a backbone organization).
- Training about the presence of eating disorders, self-medication, and gender identity in this population.
- Addressing emergency department challenges (e.g., behavioral disturbance assessment and management, placement needs, adequate backdoor to specialized outpatient providers, insurance coverage and communication, training of ED providers).

4.) EDUCATE TRANSITION AGE YOUTH AND FAMILIES ABOUT HEALTH CARE TRANSITION.

The transition to adult health care requires that youth and, if necessary, their caregivers develop the skills to become self-sufficient in navigating, self-advocating and being knowledgeable of the adult service system that will support their health care needs. Better understanding is needed of the existence, number and location of HCT training resources in the state that can assist youth and families.

Some other youth and caregiver considerations might include:

- Creating online access to HCT training resources for autistic youth and families.
- Sharing the Got Transition™ framework with youth and families.
- Developing youth and parent leadership in advocating for needed transition supports and participating in quality improvement efforts.

5.) INCREASE EFFORTS TO SUPPORT AND INCENTIVIZE ADULT HEALTH CARE PROVIDERS TO ACCEPT YOUNG ADULTS AS PATIENTS. CONSIDER EFFORTS TO TRACK PROVIDER NETWORK CAPACITY FOR ADULTS WITH DEVELOPMENTAL AND INTELLECTUAL DISABILITIES.

While Massachusetts has a wealth of health care providers, finding adult health care providers that are willing to take on new patients with autism is a challenge reported by both pediatric providers and youth and families. Adult providers may not have received formal training about autism during their medical education, and may be hesitant to take on new patients because of this. Adult providers may also be disincentivized to take on new patients that require extended medical appointments due to complex needs if there are not payment mechanisms to support these services.

- Ensure curriculum is available to adult health care providers, particularly in primary care, about transition for youth with autism and about taking new patients with autism that provide free Continuing Medical Education credits.
- Allowing for flexible billing and insurance to accommodate extended medical and follow-up appointments if needed to provide anticipatory guidance to autistic YSHCN on HCT. For example effective January 1, 2017, providers may use CPT Code 96160 to be reimbursed for the administration of patient-focused health risk assessment instruments (e.g., Transition Readiness Assessment tools for HCT planning) with scoring and documentation, per standardized tool. For more information, visit http://www.aappublications.org/news/2016/11/04/Coding110416.

- Use models to support the provision of care coordination for autistic young adults in adult practices that address issues such as scheduling check-ups, managing co-payments, finding a provider, and communication needs.

6.) IMPROVE LONG-TERM PLANNING FOR HEALTH CARE TRANSITION AND THE USE OF EVIDENCE-BASED GUIDES AND MODELS

Discussions related to transition should begin well before children are of transition age. Additionally, enhanced use of evidence-based guides and models for transition can help families understand how to plan for the transition, what to expect, and how to make successful transitions. These resources can also be beneficial for health care providers on the pediatric and adult sides to aid their patients in successful transitions. Specific suggestions include:

- Incorporating the discussion of aging into adulthood as early as age 12, far ahead of the age of majority and consent for both medical providers and educators.
- Using Got Transition^{TM} tools, MGH Autism Care Plan and other models to aid communication with parents at medical encounters, ER visits, etc.

TRANSITION TO ADULT LIFE

Youth with special health care needs will receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, [153]*and independence.*[154]

Background

Although the purpose of this report is to examine the six core health outcome indicators for autistic YSHCN, equally important for youth on the spectrum is to consider the transition to the adult service system as part of overall well-being. Secondary and post-secondary education, employment, mental health and other domains are critical to their success. Here, we review state agency environments and other local data sources.

While there are no MCHB core outcome indicators transitioning to adult life separate from health care, it is an equally important area for which to set goals, establish baseline data, and conduct ongoing monitoring to measure progress. National studies can provide some important data findings and insights to assist with identifying transition measures to capture locally. Several national organizations have compiled their findings into major reports and web sites with rich information to help. Their work may have important implications for Massachusetts autistic transition age youth.

Question: "Do autistic youth and/or parents need additional supports to navigate the transition to adulthood?" Answer: "Yes, yes & yes! Without reservation, yes!"

– Adult autistic self-advocate

National Autism Indicators Report: Transition to Young Adulthood

In addition to the key national findings related to health care transition presented in the previous section, the *National Autism Indicators Report* by the research team at A.J. Drexel Autism Institute presents evidence using transition planning, services access, adult outcomes and disconnection, postsecondary education, and employment as quality of life indicators for the transition to young adulthood.

Table TA-1 shares several key findings common to autistic youth transitioning to adult life in the U.S. All are measurable and may be worth establishing and monitoring in Massachusetts to understand the needs of and outcomes for successful transitions.

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[153] Roux AM, Shattuck PT, Rast JE, Rava JA, and Anderson KA. *National Autism Indicators Report: Transition into Young Adulthood*. Philadelphia, PA: Life Course Outcomes Research Program, A.J. Drexel Autism Institute, Drexel University, 2015.

[154] U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. *The National Survey of Children with Special Health Care Needs Chartbook 2009–2010.* Rockville, Maryland: U.S. Department of Health and Human Services, 2013.

Table TA-1. Selected Findings from the National Autism Indicators Report: Transition to Young Adulthood

Transition Planning	• 58% of autistic youth had a transition plan in place by the federally required age according to special education teachers. • 60% of parents participated in transition planning. Over 80% felt the planning was useful. • One-third of the group of autistic youth who were capable of responding to the survey said they wanted to be more involved in transition planning.
The Services Cliff	• During high school, over half of youth received speech-language therapy, occupational therapy, social work, case management, transportation, and/or personal assistant services. • However, receipt of these services decreased dramatically for youth between high school and their early 20s. • Approximately 26% of young adults on the autism spectrum received no services – services which could help them become employed, continue their education, or live more independently. • 28% of young adults who were not employed and also not attending higher education had no services.
Adult Outcomes & Disconnection	• Over one-third of young adults were disconnected during their early 20s, meaning they never got a job or continued education after high school. • Young adults on the autism spectrum had far higher rates of disconnection than their peers with other disabilities. Less than 8% of young adults with a learning disability, emotional disturbance, or speech-language impairment were disconnected, compared to 37% of those with autism.
Postsecondary Education	• 36% of young adults on the autism spectrum never attended postsecondary education of any kind between high school and their early 20s, including 2-year or 4-year colleges or vocational education. • Of those who continued their education, 70% attended a 2-year college at some point – making 2-year colleges the major gateway to continued education for this group. • About 40% of those who disclosed their disability to their postsecondary school received accommodations or some type of help.
Employment	• 58% of young adults on the autism spectrum worked for pay outside the home between high school and their early 20s – a rate far lower than young adults with other types of disabilities. • Four in every 10 young adults on the autism spectrum never worked for pay between high school and their early 20s. • Those who got jobs tended to work part-time in low-wage jobs. • Approximately 90% of autistic youth who had a job during high school, also had a job during their early 20s – compared to only 40% of those who did not work during high school.

Similar to the core outcome indicator for Accessibility to Community-Based Systems of Care, the criteria in table TA-1 touch many of the different systems of care that impact the lives of youth and young adults with autism as they bridge the transition to adulthood. The *National Indicator Report* presents critical findings for the nation's CYSHCN with autism that may have application for benchmarking and future monitoring in Massachusetts.

National Longitudinal Transition Study-2 (NLTS2)

The National Longitudinal Transition Study-2 (NLTS2)[155] was the second phase of a 10-year longitudinal study with five waves ranging from 1990 to 2009 using a nationally representative sample of 11,280 students who were ages 13 to 16 at the start of the study. The study provides a national picture of transition planning goals, transition plan participants, postsecondary education experiences and post-high school employment experiences.

Some of the most concerning transition research findings exist in the autism category. For example, clear transition progress had been made in postsecondary education enrollment which had doubled over 15 years from 1990 to 2005. The highest gains were made among students with learning disabilities who were now at the same educational level as their same-age peers, however the categories of autism, ID and multiple disabilities had the lowest gains.

In a related 2012 study by Shattuck et al.[156] that profiled youth who exited high school, only 6% had competitive jobs, 21% had no employment or education at all, 80% were living with their parents, and 40% reported having no friends. In the first two years after high school more than half of autistic individuals did not work or attend school, a lower rate of participation than any other disability group studied. The situation improved somewhat with time, yet more than six years after leaving high school some 35% of those with autism still had no work or further education. The findings suggest that current transition planning for autistic young people is inadequate. Given its growing prevalence, the struggles facing autistic youth are particularly troubling.

> "There are multiple needs that need to be taken into account….We need to say what is needed. It's making the person fit the program when it should be the program working for the person. MRC asks what do you need to work? DDS will only serve you if you have behavior problems or are not independent through long term supports. It's hard to get on disability if you have autism because it is an invisible disability. It feels as if everything becomes a weird Catch 22."
>
> – Adult autistic self-advocate

National Technical Assistance Center for Transition (NTACT)

The National Technical Assistance Center for Transition (NTACT) (formerly known as the National Secondary Transition Technical Assistance Center - NSTTAC)[157] is the national technical assistance and dissemination center funded by the U.S. Department of Education's Office of Special Education Programs (OSEP). NTACT's purpose is to assist State Education Agencies, Local Education Agencies, State VR agencies, and VR service providers in implementing evidence-based and promising practices ensuring students with disabilities, including those with significant disabilities, graduate prepared for success in postsecondary education and employment. In this role, NTACT has conducted an extensive and rigorous review of the literature in secondary transition to identify 33

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[155] Newman L & Cameto R, SRI International; Leuchovius, D., PACER Center. (May 31, 2012). *National Perspective: Student & Family Transition Plan Participation, Postsecondary Education, and Employment National Longitudinal Transition Study 2.* [Presentation at the National Transition Conference, Washington, DC]. www.nlts2.org

[156] Shattuck PT, Narendorf SC, Cooper B, Sterzing PR, Wagner M & Taylor JL. (2012). Postsecondary Education and Employment Among Youth With an Autism Spectrum Disorder. *Journal of Pediatrics*, DOI: 10.1542/peds.2011-2864.

[157] National Technical Assistance Center for Transition (NTACT), http://transitionta.org/

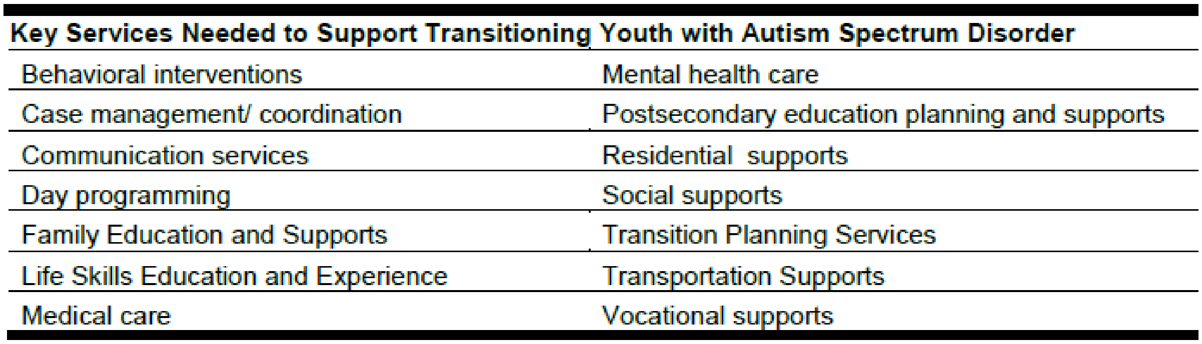
evidence-based practices and 16 predictors correlated to improved post-school outcomes in education, employment, and/or independent living. Among the list of predictors[158], transition programming emerged as having significant importance with the following included: inclusion in general education, paid work experience, vocational education, independent living skills, self-advocacy, self-determination, social skills, parental involvement, career awareness, student support, interagency collaboration, occupational courses, program of study, community experiences, and exit exam requirements/high school diploma status. Any and all of these should apply to autistic transition age youth and are highly measurable using school self-assessments of predictor implementation.[159] The website is a rich resource that can provide insight on numerous measurable targets for transition age youth that could assist Massachusetts in setting its priorities.

2016 GAO Youth with Autism Report

In November 2016, the U.S. Government Accountability Office (GAO) released *Youth with Autism: Roundtable Views of Services Needed During the Transition to Adulthood*[160], a report that studied the services and supports autistic youth need during the transition to adulthood. Previous GAO work has shown that students with disabilities who are transitioning to adulthood face challenges identifying and obtaining adult services.

GAO studied (1) the services and supports transitioning autistic youth need to attain their goals for adulthood, (2) the characteristics of these services and supports, and (3) how autistic youth can be fully integrated into society. To address these objectives, GAO convened a roundtable discussion on March 3 and 4, 2016. The panel described the services and supports that autistic youth may need to help them achieve five goals for adulthood: postsecondary education; employment; maximizing independent living; health and safety; and maximizing community integration.

For each goal, the panel described services and supports that autistic youth (ages 14-24) transitioning to adulthood may need to address autism characteristics and other health conditions that affect their ability to attain the goal. GAO grouped these services into 14 broad categories.



Key Services Needed to Support Transitioning Youth with Autism Spectrum Disorder

Behavioral interventions	Mental health care
Case management/ coordination	Postsecondary education planning and supports
Communication services	Residential supports
Day programming	Social supports
Family Education and Supports	Transition Planning Services
Life Skills Education and Experience	Transportation Supports
Medical care	Vocational supports

Source: GAO analysis of roundtable discussion. | GAO-17-109

Although GAO analyzed the transcripts of the panel as well as documents provided by panelists, GAO did not make recommendations in this report. The report is the first in a series on autistic

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[158] Rowe DA, Alverson CY, Unruh D, Fowler CH, Kellems R, & Test DW. (2013). *Operationalizing evidence- based predictors of post- school success: A delphi study.*

[159] http://kl55z182axe1ezol670tdk15.wpengine.netdna-cdn.com/files/2014/03/Predictor-Implementation-School-District-Self-Assessment.pdf

[160] http://www.gao.gov/products/GAO-17-109

youth who are transitioning to adulthood. The GAO report categories may have application for benchmarking and future monitoring in Massachusetts.

Summary of State Environment: Transition to Adult Life

The following section shares current state agency practices with regards to servicing autistic transition age youth. This information has been compiled from key informant interviews, agency data sharing, and from both the 2013 Massachusetts Autism Commission report as well as from records of presentations made to the permanent Commission in 2016. This section should serve as a repository for Autism Commission information that may be used for future planning. We have also added the 2016 Massachusetts Autism Commission Annual Report to the Appendix since it is an important complementary document that was published upon this report's completion. In addition to providing background on how these state agencies serve transition age youth, the data shared can inform the reader of the current baseline statistics that can be monitored for progress over time. The following is not comprehensive, but provides insights into the state environment with more needed to be investigated and understood.

State Agencies

Department of Elementary & Secondary Education (DESE)

Amendments to the Individuals with Disabilities Education Act (IDEA) in 2004 emphasized the importance of transition assessment, planning, services and post-secondary goals in the areas of education/training, employment, and independent living skills. As advances in research and practice are made in response to the policies and legal mandates set forth in IDEA 2004, professionals and parents alike are working hard to stay abreast of these positive developments for transition age youth with disabilities.

According to Massachusetts state law, "beginning at age 14 or sooner if determined appropriate by an individualized education program team, school age children with disabilities shall be entitled to transition services or measurable postsecondary goals, as provided under the federal Individual Disabilities with Education Act, 20 USC sec. 1400, et sec." (MGL Ch. 71B, §2). Special education transition planning and services are completed by age 22 or by a student's graduation from high school, whichever comes first.

A number of secondary transition technical assistance advisories have been issued by the Massachusetts Department of Elementary and Secondary Education (ESE) in recent years. All build upon each other in the context of previous ESE advisories. The following are excerpts that summarize each advisory:

Technical Assistance Advisory SPED 2009-1: Transition Planning to Begin at Age 14, September 3, 2008

- On August 6, 2008, the Massachusetts Legislature approved Chapter 285 of the Acts of 2008, which amends Section 2 of c.71B (the Massachusetts Special Education Statute) by adding the following paragraph:
    - Beginning at age 14 or sooner if determined appropriate by an individualized education program team, school age children with disabilities shall be entitled to transition services and measurable postsecondary goals, as provided under the federal Individual with Disabilities Education Act, 20 USC sec. 1400, et sec.

- The Department has developed a training module on the transition planning process that schools may use to assist staff in understanding this process.
    - The Department expects districts to conduct training as needed and to initiate transition planning for all 14 year olds eligible for special education during the course of the 2008-2009 school year. Therefore, by the end of this school year all students with disabilities aged 14 years or older should have a completed Transition Planning Form that will be updated annually. The Department will begin monitoring of transition planning for 14 year olds as of the 2009-2010 school year.

Technical Assistance Advisory SPED 2013-1: Postsecondary Goals and Annual IEP Goals in the Transition Planning Process, September 14, 2012

The purpose of this advisory is to:

1.) Highlight the central role of appropriate measurable postsecondary goals and annual IEP goals in the transition planning process for students with IEPs, ages 14-22.
2.) Provide guidance to school districts concerning the inclusion of postsecondary goals in the Transition Planning Form (TPF) (28M/9) and the inclusion of postsecondary goals and annual goals in the IEP.

Technical Assistance Advisory SPED 2014-4: Transition Assessment in the Secondary Transition Planning Process, April 9, 2014

The purpose of this advisory is to:

a. Clarify the purpose of transition assessment in the secondary transition planning process.
b. Provide guidance to school districts concerning the selection and use of transition assessments.

Technical Assistance Advisory SPED 2016-2: Promoting Student Self-Determination to Improve Student Outcomes, September 18, 2015

The purpose of this advisory is to:

1.) Highlight the fundamental importance of supporting and encouraging student self-determination to promote successful adult outcomes.
2.) Provide guidance to school districts on multiple means of advancing student self-determination skills.

Technical Assistance Advisory SPED 2017-1: Characteristics of High Quality Secondary Transition Services, July 14, 2016

The purpose of this advisory is to help school districts improve outcomes for students with IEPs and to promote compliance with state and federal special education law by highlighting three characteristics of appropriate high quality secondary transition service delivery:

1.) Transition Services should be coordinated.
2.) Transition services should be provided based on the needs, strengths, preferences, and interests of individual students.
3.) Transition services should be results oriented.

For statistics related to all autistic students receiving Special Education services, including those who are transition age youth, please refer to the section on Education and the Appendix.

Bureau of Transitional Planning, Executive Office of Health and Human Services

Massachusetts Chapter 688 of the Acts of 1983, also known as the "Turning 22" law, stipulates that students receiving special education who will require continued disability-related services upon exiting school (by graduating or turning 22 years of age, whichever occurs first) shall be entitled to formal transitional planning. The primary function of the Bureau of Transitional Planning (BTP) is to coordinate and monitor implementation of the formal transition planning process.

Children receiving special education services must have a 688 form[161] completed no later than 2 years prior to their planned transition from secondary education (generally via graduation). This form includes two fields for the child's diagnosis (primary and secondary) related to their need for support, and this is where an autism diagnosis would be recorded. The reliability of the accurate coding of autism on these forms has not been formally assessed; however the eligibility process does include psychological testing which likely adds to the accuracy of diagnostic information in the record system.

Currently, the process for applying for adult services is handled through a paper system. Across the Commonwealth, each health and human service agency has delegated authority to review and refer 688 applications. The Massachusetts Rehabilitation Commission (MRC) is the default service provider in the state, so if one of the other service agencies receive a referral that is found ineligible for their own agency's services, this referral would be passed to either BTP or MRC. Select cases, usually those considered to be more difficult to accurately review and refer, are handled by the BTP Central Office through the Transitional Advisory Committee including representation with MRC, DDS, DMH and DCF. It has been verbally reported that a large proportion of the cases reviewed in 2013-2014 by this committee were for autistic young adults. Each agency with delegated authority may maintain their own electronic databases of referred young adults, however these systems do not generally connect across agencies and may exist in different formats. The current situation presents challenges to gaining a comprehensive picture of young adults referred for services and the services they receive, and in turn presents challenges for resource monitoring, planning and projection.

In the 2016-2017 school year, the BTP will enter the final stages of development and testing for a paperless referral process for all Chapter 688 submissions on behalf of students with disabilities.[162] This includes submissions directly to human service agencies as well as to the BTP. During this phase-in of the electronic referral process, EOHHS agencies and the BTP will be working with all school districts to provide information and technical assistance, with the goal of no longer accepting paper referral packets beginning with the 2017-2018 school year.

It is not known whether the public secondary education identification numbers, known as the State Assigned Student Identifier (SASIDs), of students within the ESE information system will be captured in the new electronic BTP system for 688 referrals. If the SASID is captured in the BTP system, it has the possibility to permit a greater longitudinal perspective from youth through adulthood.

In conversations with BTP staff between 2014 and 2015, some areas for potential improvement in transition were identified. For example, incarcerated youth are educated in separate educational systems and there are known weaknesses in transition planning within this system. Additionally, the parents or guardians of young adults in secondary education are generally the group that initiates the completion of the 688 forms related to transition, and it is the secondary school's responsibility

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[161] Available on the DESE website at http://www.doe.mass.edu/sped/28mr/28m11.pdf

[162] http://www.mass.gov/eohhs/consumer/family-services/youth-services/youth-with-disabilities/bureau-of-transitional-planning-.html, Accessed 10/9/16.

to follow up with parents who do not complete the forms; however school follow-up has been reported to be variable. Some children each year do 'fall through the cracks' and do not receive full transition planning prior to leaving secondary school. Lastly, there are some autistic young adults that have support needs, but have historically not met eligibility criteria for state services. Recent changes to eligibility criteria and determination processes within DDS and DMH, discussed below, likely address some of these service gaps. However, the new electronic BTP referral system should improve the state's ability to measure and learn more about the extent of service needs for this group of young adults.

Tables TA-2, TA-3 and TA-4 represent the number of individuals leaving special education and entering DDS services under "Turning 22" each fiscal year noted. The annual report on this program notes that each year experiences a higher number of individuals with complex clinical profiles who have intensive support needs due to medical and behavioral needs:

Table TA-2. DDS Turning 22 Census by Fiscal Year over last 3 fiscal years

	2014	2015	2016
FY Census	804	809	855

Source: FY 14-16 Legislative Reports for the DDS Turning 22 Program. (December 4, 2015).

Table TA-3. DDS Turning 22 Community Based Residential Services by Region over last 3 fiscal years

Region	Central/West	Metro Boston	Northeast	Southeast	Total
FY Census 14	64	63	60	53	240
FY Census 15	77	49	51	56	233
FY Census 16	70	57	58	52	237

Source: FY 14-16 Legislative Reports for the DDS Turning 22 Program. (December 4, 2015).

Table TA-4. Remaining Turning 22 Students by DDS Region over last 4 fiscal years

Region	Central/West	Metro Boston	Northeast	Southeast	Total
FY Census 14	216	120	125	103	564
FY Census 15	210	124	138	104	576
FY Census 16	213	140	129	108	590

Source: FY 14-16 Legislative Reports for the DDS Turning 22 Program. (December 4, 2015).

The changes above signify an important opportunity for more comprehensive and detailed monitoring of Massachusetts autistic transition-aged students seeking and being referred for services across the health and human service system.

Department of Developmental Services (DDS)[163]

Autism Omnibus Legislation of 2014

The Autism Omnibus Bill (Ch. 226 of the Acts of 2014) expands the Department of Developmental Services (DDS) eligibility criteria for autistic individuals beyond a person's IQ to functional needs. As a result of the Autism Omnibus bill, the eligibility definition for DDS services has been expanded to

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[163] Howe, E. (January 12, 2016). Department of Developmental Services presentation to Massachusetts Autism Commission.

include autism spectrum disorder (ASD), Prader-Willi syndrome (without ID) and Smith-Magenis Syndrome in the presence of functional support needs across two areas of living.

To be eligible for services, youth must have a diagnosis of ASD based on criteria in the Diagnostic and Statistical Manual of Mental Disorders (DSM) fourth or third editions and made by a medical professional. Functional abilities are assessed with a range of tools including the Vineland, ABAS and the Major Life Activity Questionnaire (MLAQ). Although eligibility for adult services currently begins at age 22, the redrafted regulations cover the 18-22 age group if they have graduated from high school, are no longer receiving special education services, and have passed MCAS. If individuals are still in school, they fall under the education system, but if they have graduated, they are treated as adults. For autistic people to be eligible for DDS services, they must be domiciled in Massachusetts, have a documented diagnosis, and have three adaptive functional limitations (two standard deviations below the norm) as measured by the above-mentioned tools.

As of 12/31/15, 505 adults (aged 18 years and older) have been found eligible for DDS services with 494 having autism without an intellectual disability, five having both autism and an intellectual disability, four with Prader-Willi syndrome, one with Smith-Magenis Syndrome and one with autism, Prader-Willi Syndrome and intellectual disability.[164] Many of these adults were currently still in school and are not requesting DDS services at that time. Others were receiving a total of 524 services broken out on the following chart, with many receiving more than one service. To date, the average FY16 cost per individual is $22,289.

Table TA-5. Adult Autism Services Enrolled (Age 18+)

Categories	Enrolled Q1	Enrolled Q2
3150 SHARED LIVING/HOME SHARE	3	3
3153 RESIDENTIAL SUPPORTS	4	7
3163 COMMUNITY BASED DAY SUPPORTS	19	39
3164 MASS HEALTH DAY HABILITATION	5	9
3168 EMPLOYMENT SUPPORTS	15	35
3170 CLINICAL TEAM	1	6
3174 M.S.A.SUPPORT SERVICES	1	1
3180 CEIS-COMPETITIVE INTEG EMP SRV	5	7
3181 GROUP SUPPORTED EMPLOYMENT	10	25
3182 RESPITE FACILITY	2	2
3196 TRANSPORTATION	11	24
3285 DAY HAB SUPPLEMENT	5	5
3700 FAMILY SUPPORT NAVIGATION	13	44
3703 INDIVIDUAL HOME SUPPORTS	11	22
3707 ADULT COMPANION	2	8
3731 Respite in Recipient's Home	8	17
3759 RESPITE - ADULT - SITE-BASED	2	2
3770 FAMILY SUPPORT CENTERS	4	33
3779 STIPENDS	21	59
3780 FINANCIAL ASSISTANCE	3	7

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[164] FY16 Quarter Two Report on the Department of Developmental Services for Newly Eligible Individuals with Autism, Smith-Magenis Syndrome, and Prader-Willi Syndrome. February 2016

Categories	Enrolled Q1	Enrolled Q2
3781 FINANCIAL ASSISTANCE ADMIN	29	60
3798 INDIV SUPPORT AND COMM HAB	6	21
5283 ISO-ASSITIVE TECHNOLOGY	1	1
5300 NON-WAIVER	9	11
5400 NON - WAIVER FINANCIAL	10	12
5703 INDIVIDUAL HOME SUPPORTS - SO	2	4
57041NDIVIDUAL DAY SUPPORTS - SO	2	2
5710 BEHAVIORAL SUPP&CONSULT - SO	1	1
5728 INDIVIDUAL GOODS AND SERVICES	1	6
6703 INDIVIDUAL HOME SUPPORTS - AWC	1	9
6704 INDIVIDUAL DAY SUPPORTS - AWC	2	5
6707 ADULT COMPANION - AWC	2	6
6753 AGENCY WITH CHOICE ADMIN FEE	5	20
6780 FINANCIAL ASSISTANCE - AWC	3	11
Total Enrollments	219	524
Avg Cost	*$14,800*	*$22,289*

As of May 2016, the number of newly eligible individuals 18 years and over was 690. Eighty percent (80%) are males. Between 40-60 new people seek services per month, and over 800 new service recipients have been added in the last year.[165] Newly eligible applicants were distributed across the state, not culturally diverse, and not low income. Many of those in their late 20's and early 30's had fallen outside of the service system since high school.[166]

People who have started receiving services under the expanded eligibility tend to have different and higher level of support needs than other DDS service recipients. These adults tend to have more mental health support needs ranging from anxiety disorders, depression and major mental illness, and are more likely to be forensically involved. As compared to other DDS service recipients, they are more likely to be their own guardians, and more likely to exercise their choice to refuse certain treatment. The majority are likely to reside with their families or live independently.[167] Applicants for these services are most often covered by their family's medical insurance, and do not receive public insurance support (such as Medicaid).

Some early concerns have included difficulty reaching this population to encourage them to apply for eligibility. DDS staff has had to take time to build rapport with these individuals; unfortunately, this has resulted in their needs being underrepresented in the initial enrollment numbers for annual reporting purposes. Currently, the services that DDS offers may not address the needs of this population in the areas of mental health, employment, transportation, driver education, residential support, health care, and other areas. Although this first cohort is highly complex, it is expected that over time the presentation of their needs will even out and normalize. To date, access to psychiatric care in the community and inpatient care has been challenging for this newly DDS-eligible population. As the population increases, DDS anticipates that there may be a waiting list for services.[146]

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[165] Personal communication, DDS 2016

[166] J. George, DDS, presentation at AANE/NESCA Transition Roundtable Meeting, October 7, 2015

[167] FY16 Autism Omnibus Bill Report, February 2016, Department of Developmental Services

The number of adults traditionally eligible for DDS services who had an intellectual disability and autism have not historically been tracked based on their ASD diagnoses. Since individuals were required to have an intellectual disability to be eligible for DDS services prior to the 2014 Omnibus Law, there is no data on the number of autistic adults with ID being served by DDS prior to 2014. DDS will collect data on these individuals who will become eligible for services going forward.

Process Changes

Following the law's enactment, DDS embarked on a regulatory review process that led to many eligibility and process changes in serving transition age youth on the spectrum. The new DDS regulations provide the administrative framework for the statute and DDS has strengthened its infrastructure to support the new populations. DDS has designed a number of new materials including new applications, fact sheets, and assessment processes to support this expansion and has trained its Regional Eligibility Teams in these new activities.

Staffing upgrades took place, such as autism service coordinators being added to each of the 23 area offices. These individuals have the targeted case management responsibility for adults with autism and have been trained to support the expansion population. Service Coordinators deliver and manage the service delivery at the local level. DDS has added four (4) Eligibility Specialists, one (1) to each of the Regional Eligibility Teams and is in the process of increasing Psychologist capacity as well. To date, DDS has added one (1) FTE psychologist and is in the process of adding two (2) additional psychologists to assess and evaluate potential applications. Additionally, the Department has hired one (1) additional legal counsel to support both the eligibility process and service delivery concerns as they arise. The Department has hired two Contract Specialists and intends to hire two (2) more. Four (4) Program Coordinators have been added. In total, the Department intends to hire thirty-eight full and half full-time equivalents (39 FTES) FTES to support the new population.[168]

DDS has established an Autism Implementation Working Group chaired by the Deputy Commissioner, with monthly meetings designed to gather feedback from the field, review clinical needs, monitor expenditures, identify service needs and gaps, identify risk factors, and identify training needs. This includes gathering feedback from the field about newly eligible individuals, reviewing all clinical needs, monitoring services delivered, identifying services for the unique needs of the population, and identifying training opportunities, among other considerations. To this end, a data management system has been developed that tracks eligible individuals on a monthly basis, as well as individuals served and individuals in planning. A fiscal monitoring system has been put in place to monitor the $12.6 million appropriation in the dedicated Adult Autism account.

DDS's Collaboration with Department of Mental Health (DMH)

The Autism Omnibus Bill of 2014 was also responsible for a number of positive developments in policies that provide access to mental health services and supports for autistic people in Massachusetts.

The bill included the following key provisions[169]:

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[168] FY16 Autism Omnibus Bill Report, February 2016, Department of Developmental Services

[169] http://massadvocates.org/mac-victory-autism-omnibus-bill/

- *"Requiring DMH and DDS to develop and implement a plan to provide services to individuals who have both a mental illness and a developmental disability."*

The provision requires DMH and DDS to develop a plan to provide services to individuals with both severe mental illness and a developmental disability who are eligible for services from both agencies. Prior to the new law, DMH services were not designed to address behavioral support for people.[170] Collaborative activities have included an autism survey, a task force, its final report and 10 related recommendations shared with the legislature in December 2015, and a resulting DMH/DDS Interagency Service Agreement (ISA) to collaborate in the development and funding of supports and services to individuals who are eligible for services in both systems. DMH has worked with DDS, DCF, DYS, schools and community agencies.[171]

DDS has worked closely with the Department of Mental Health (DMH) to establish a shared training agenda to support the autistic population, to clarify eligibility between the agencies and determine how to support those individuals who have both a diagnosis of ASD as well as significant mental health needs.[172]

The DDS/DMH ISA was shared with the Legislature in late December 2015. The agencies meet regularly to learn about how each agency functions, the services it offers and has developed a broad based agenda to increase the working knowledge and relationships through regular meetings at the local, regional and central offices. A joint steering committee was formed between DMH and DDS. The agencies have committed to joint trainings in areas such as each agency's eligibility processes, service design and mutual consultation based on the respective knowledge of the two agencies. DDS has determined that it needs added clinical support from DMH.

Through the ISA, DDS has committed to purchasing two (2) psychiatric fellowships (one at Mass General, the other at UMass Medical), short-term psychiatric consultations, and forensic risk consultations. DDS has also procured certain services from DMH including services in the community-based Clubhouse model.

DMH Activities Relative to ASD[173]

Prior to the Omnibus Bill's passage, the Department of Mental Health (DMH) conducted an ASD Survey in January 2014 with 142 responses from a variety of DMH employees including clinicians, case managers, and administrators. Seventy percent (70%) of the respondents work in adult services; 30% work in children services. Fifteen percent (15%) have specialized credentials or training to work with people with ASD. The survey results estimated that out of the nearly 21,000 individuals with severe and persistent mental illness and serious emotional disturbance (SPMI/SED) who are approved for DMH services, between 500 and 1,000 have co-occurring ASD. Forty percent (40%) are age 18 or younger. The respondents estimated that about 865 individuals with ASD are served annually. Information from the Mental Health Information Systems (MHIS) cited 556 autistic individuals served in 2013. The survey's outcomes identified needs in training, services, and state

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[170] Massachusetts Autism Commission (March 2013). *Report of the Massachusetts Special Commission Relative to Autism*. http://www.mass.gov/anf/docs/mddc/autism-commission-report-full.pdf

[171] February 25, 2016 presentation to Autism Commission by DMH Deputy Commissioner Kathy Sanders, MD

[172] FY16 Autism Omnibus Bill Report, February 2016, Department of Developmental Services

[173] Howe, E. (January 12, 2016). Department of Developmental Services presentation to Massachusetts Autism Commission.

agency resources. In 2015, the agency estimated that it served between 500-800 autistic people in the state.[174]

To be eligible for DMH services, individuals must have a SPMI that is impairing their ASD. Historically, autistic people seeking services from DMH were largely referred to DDS. While the DMH eligibility has not changed, the agency has started to screen a growing number of autistic people for eligibility. In addition, some people may become dually eligible for both DDS and DMH support, which generally did not occur prior to the Omnibus Bill.

DMH suggests the need for more evidence-based practices in supporting autistic people, and additional service model options. One possibility may be an autism health home through MassHealth as a way to improve integrated and coordinated care, as has been created for other chronic illnesses such as Serious Emotional Disturbance and Serious and Persistent Mental Illness in the state.[174] In this model[175], six services are provided to eligible Members including comprehensive care management, care coordination and health promotion, comprehensive transitional care, patient and family support, referral to community and social support services, and use of health information technology, as feasible and appropriate.

Massachusetts Rehabilitation Commission (MRC)

The Massachusetts Rehabilitation Commission's has three divisions: Vocational Rehabilitation (VR), Community Living (CL) and Disability Determination Services (DDS) with 24 Area VR Offices as points of service delivery, CL Offices and CL staff located in Lawrence and Malden VR offices, and 2 MRC DDS offices located in Boston and Worcester. MRC's federally-funded Vocational Rehabilitation ("VR") Services are designed as short-term methods of assistance that help individuals locate employment that is terminated 90 days after employment starts. There has been a steady increase in individuals with a primary or secondary diagnosis of ASD served by the VR Division. There are currently 1,100 people with diagnoses of ASD who are actively receiving services; this represents 4% of the total VR client base. This increase is in large part due to MRC's enhanced outreach to transition age populations. Current agency data indicates that over 65% of the autistic individuals served are under the age of 20 which highlights the increased collaboration that is occurring between MRC and local school systems in addition to a number of other programs for autistic transition age youth. However, because many autistic individuals often have difficulty maintaining a job once obtained and VR services cease 90 days after employment, federally funded VR services, as currently designed, do not meet the needs of many people in the autism community.

According to data received from the Autism Commission in September 2016, MRC served 1,704 autistic individuals during FY15. Since MRC also serves individuals ages 14-22, their data may be duplicative of the numbers reported by DESE.[176]

A presentation to the new Massachusetts Autism Commission on April 12, 2016 by Commissioner Adelaide 'Nicky' Osborne, Deputy Commissioner Kasper Goshgarian, VR Assistant Commissioner Joan Phillips, CL Assistant Commissioner Joshua Mendelsohn, DDS Assistant Commissioner Patricia Roda shared information about MRC's autism services and capacity. According to this presentation, MRC's autism demographics includes the following[177]:

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[174] Personal communication, DMH May 2015

[175] http://www.mcaap.org/HealthHomesRFIFINAL%206%2010%2013%20(2)(1).pdf

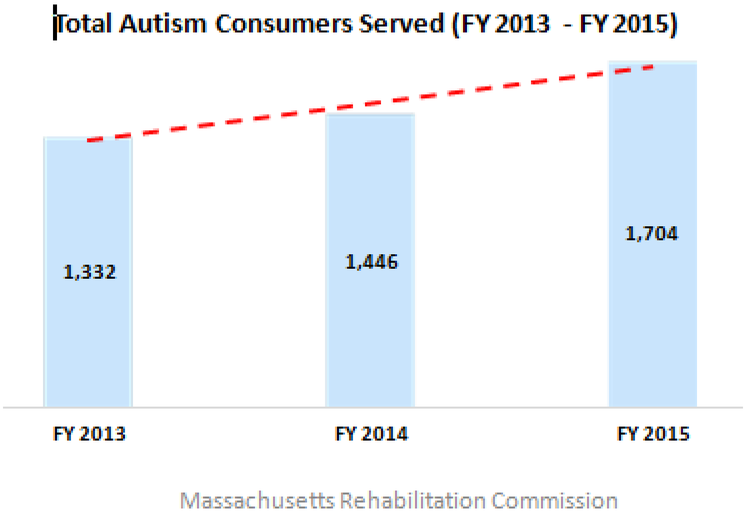
[176] Source: MA Autism Commission, Executive Director Carolyn Kain, September 2016, non-published.

[177] MRC Presentation to MA Autism Commission, 4/12/96

- MRC served 1,704 autistic individuals, accounting for 6% of all consumers served by the MRC during FY 2015.
- MRC consumers with autism are predominately Male (84.4%) and White (92.3%).
- Approximately 89% of autistic consumers served by MRC are under the age of 30.
- 50% of autistic consumers have less than high school education when entering MRC's VR program.
- A total of 184 autistic consumers achieved successful employment outcomes, accounting for 4.9% of all total successful closures.
- Successfully employed autistic consumers worked an average of 23 hours/week and had an average hourly wage of $11.25.
- The current data for MRC's Community Living Division identified 115 autistic consumers served through its Transition to Adulthood Program (TAP).
- Additionally, 37.5% out of all consumers receiving Transitional Advisory Committee (TAC) services through the Community Living Division are autistic individuals.
- The current proportion of autistic consumers served by the Independent Living Centers (ILCs) is approximately 3% to 5%.

Regionally, the largest proportion of MRC VR autistic consumers as a primary or secondary disability were in the MRC's North District (679, or 40%), followed by the South District (572, or 34%) and the West District (453, or 26%). The Lowell, Framingham, and Salem offices served the highest percent of autistic consumers of offices in the North District. The Downtown Boston, Taunton, Braintree, Cape and Islands offices served the highest percent of autistic consumers of offices in the South District. The Worcester, Milford, and Springfield offices served the highest percent of autistic consumers of offices in the West District.

Figure TA-6.



- In FY 2013, MRC VR served a total of 1,322 autistic consumers which accounted for 4.7% of all active cases during this period.
- In FY 2014, MRC VR served 1,446 autistic consumers, representing 5.1% of all active cases during this period, a total increase of 1% from FY 2013.
- In FY 2015, MRC VR served 1,704 autistic consumers, constituting 6.0% of all active cases during this period.
- Between FY 2013 and FY 2015 the number of autistic individuals served increased by 28%.

MRC FY 2013 DATA. Data tables describing active cases of autistic consumers were provided to this project team by MRC in SFY 2013. (See Appendix for all relevant tables for more information under "Transition Data"). The current 2016 Autism Commission annual report data should supplant this information, but the information below might be useful for benchmarking and monitoring the progress for autistic individuals in the future.

In SFY 2013, the vast majority of autistic consumers (61%) received training and education that year with another 7.6% listed as "job ready" and 2.1% in job placements.

Table TA-7. Active Cases w/ Autism as a Primary or Secondary Disability by Current Status, as of 12/31/2013

Status	# of Consumers	% of Consumers
10 (Eligibility)	294	21.7%
12 (IPE Completed)	24	1.8%
16 (Restoration)	53	3.9%
18 (Training and Education)	837	61.8%
20 (Job Ready)	103	7.6%
22 (Job Placement)	28	2.1%
24 (Interrupted Services)	15	1.1%
Total	1354	100.0%

To further understand outcomes for MRC autistic consumers, it would be useful to know the level of education both at the time of application and at the time of job placement. The table below provides information on incoming applications in SFY2013, with 22.4% having a high school education or equivalent, 13.% having some college, 4.0% having a Bachelor's degree, and 0.8% having a Master's degree or higher. This information in Table TA-8 might also be useful for benchmarking and monitoring the progress for autistic individuals in the future.

Table TA-8 Level of Education at Application, SFY 2013 Actively Served Consumers w/ Autism as a Primary or Secondary Disability by Area Office, as of 12/31/2013

Education Level	# of Consumers	% of Consumers
Less Than High School	733	55.4%
Special Education Certificate	54	4.1%
HS Diploma or Equivalent	296	22.4%
Some College	176	13.3%
Bachelor's Degree	53	4.0%
Master's Degree or Higher	10	0.8%

Consistent with SFY 2016 findings on race/ethnicity, the vast majority of autistic consumers were White (92.4% in SFY 2013 versus 92.3% in SFY 2016). For autistic consumers from minority groups, 5.6% were Black, 3.0% were Hispanic, 2.3% were Asian/Pacific Islander, and 0.1% were Native American. This is not consistent with either EI or DESE data. More needs to be known about any possible disparities in these populations receiving MRC services.

MRC AUTISM PROGRAMS. The MRC VR Division has developed two programs to address the needs of MRC autistic consumers.

Asperger/Autism Network (AANE):

- The program currently works with individuals, families, and professionals to improve employment outcomes for autistic people by providing training on autism to MRC staff and training for consumers.
- AANE LifeMAP provided coaching services to 110 individuals throughout the state, exceeding the projected number of 90. More than 25% found employment and a sizeable number received on-the-job assistance once employed.
- Additionally, AANE's training series allowed MRC counselors to select among various types of training opportunities. AANE provided six workshops (including in September 2015) that reached more than 118 MRC staff from field offices across the state.
- AANE has successfully recruited new coaches from consumers' communities and now employs 60 coaches, all of whom have expertise in working with autistic consumers.
- AANE currently serves 101 consumers through its LifeMAP program throughout the Commonwealth.
- AANE and MRC are piloting an autism assessment instrument.

Northeast ARC:

- The Northeast ARC provided staff trainings on autism and summer internships and training to MRC consumers. The program was designed to enhance vocational opportunities for teens and young adults with Autism Spectrum Disorder, including Asperger's Syndrome, and other related conditions.
- Northeast ARC currently provides employment supports through MRC's Competitive Integrated Employment Services (CIES) program. Furthermore, they were recently selected through a procurement, "High School Pre-Employment Transition Service Program – Workforce Innovation & Opportunity Act RFR", to provide Pre- Employment Transition services to high school students with disabilities.

MRC AND DDS COLLABORATION: MRC and DDS are working on collaborative efforts to serve transition aged youth, including autistic individuals.

MRC FUTURE EFFORTS:

- Continue to research best practice models to serve autistic consumers. (e.g. customized employment).
- Evaluate AANE and MRC assessment tool.
- Continue to explore additional collaboration with other agencies for autistic consumers.

Employment Population Statistics for People with Disabilities in Massachusetts

The National Report on Employment Services and Outcome[178] is an annual report written by the Institute on Community Inclusion at UMass Boston. Although their data is not specifically targeted to autistic adults, they are included in these numbers that help paint a picture of employment status,

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[178] Butterworth J, Winsor J, Smith FA, Migliore A, Domin D, Ciulla Timmons J, & Hall AC. (2015). StateData: The national report on employment services and outcomes. Boston, MA: University of Massachusetts Boston, Institute for Community Inclusion.

income and to some extent, disability type compared to the general population. Tables for Massachusetts are presented below.

From the period of 2007 through 2013, both the state population and the unemployment rate were steadily growing, starting with the financial crisis of 2008 and leveling off to 7.1% in 2013.

Table TA-9. Demographic Trends over last 4 biannual cycles, Source: U.S. Bureau of Labor Statistics

	2007	2009	2011	2013
State population (in thousands)	6,468	6,594	6,588	6,693
State Unemployment Rate	4.4%	8.4%	7.0%	7.1%

Although people with disabilities face significant employment disparities lagging an average of 40% behind the general population, people with cognitive disabilities face greater challenges at almost 50% behind the general population of employed people. It can be assumed the autistic adults are included in this category.

Table TA-10. % Employment Participation for Working Age People (Ages 16-64) over last 4 years, Source: American Community Survey

	2010	2011	2012	2013
Percentage of people with no disability who are employed	73.8%	74.6%	74.9%	75.9%
Percentage of people with any disability who are employed	32.3%	31.4%	32.3%	33.8%
Percentage of people with a cognitive disability who are employed	22.4%	23.6%	23.4%	25.7%

Similarly, the percentage of people with cognitive disabilities correlates most highly with poverty averaging in the 30th percentile range compared to people with disabilities at over 25% and people without disabilities at around 9% through 2013. These tables provide data that could apply to autistic young adults in Massachusetts and should be monitored in the future.

Table TA-11. % Employment Outcomes for Working Age People (Ages 16-64) over last 4 years, Source: American Community Survey

	2010	2011	2012	2013
Percentage of people with no disability living below the poverty line	9.1%	9.2%	9.4%	9.4%
Percentage of people with any disability living below the poverty line	27.7%	27.2%	28.5%	28.3%
Percentage of people with a cognitive disability living below the poverty line	34.6%	32.3%	32.8%	35.0%

Higher Education

Higher Education serves as an important transition point for many autistic youth and young adults. The 2013 Massachusetts Autism Commission Report[179] states that 10,240 students with disabilities attended public higher education in 2013. It is estimated that 70% of those students with disabilities attended Massachusetts community colleges. It is also estimated that 582 students who attended public higher education had autism, with a possible 450 enrolled at community colleges. As mentioned previously in research findings by Shattuck et al.[180], 36% of U.S. autistic young adults have ever attended postsecondary education; 70% of this group have attended two-year community colleges, which serve as a major gateway to continued education.

It should be noted that Massachusetts Community Colleges[181] have consistently participated on the Massachusetts Autism Commission since 2011 and offer numerous programs developed with autistic students in mind. Other colleges that have disability services specifically targeted to autistic students include Boston University, UMass Lowell, Emerson College, Middlesex Community College, Lesley University, and others.

Currently there is no consistent way to measure and monitor outcomes for this population of students. The best attempts have been able to gather data for public higher education, but little is known about private postsecondary colleges and universities. Many autistic students have complex needs that extend beyond providing learning supports as typically offered in the post-secondary setting. Self-advocates point to the need for executive function and social supports. This is an area that should be investigated further. (More information is available in the Education section and in our qualitative findings in the Transition to Adulthood section as shared in Self-Advocate interviews).

Mobile Crisis Units (MCI) through the Autism Law Enforcement Coalition (ALEC)[182]

Autism and mental health co-morbidity have been found to be as high as 70% in some populations. Lack of training for providers has been cited anecdotally, as well as in the literature as a statistically significant barrier to the prevention of autistic individuals being able to access appropriate mental health care. Workforce development is one effective way to build statewide capacity in supporting autistic people.

To address this concern, a 2015 project to train mental health professionals working on Massachusetts Mobile Crisis Units (MCI) with clients with co-occurring of autism and mental health concerns was led by former Shriver Center LEND Fellow and parent Carrie Noseworthy in partnership with Bill Cannata of the Autism Law Enforcement Coalition (ALEC) and Shelly Baer, Director of Emergency Mental Health Services for the Massachusetts Behavioral Health Partnership (MBHP).

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[179] Massachusetts Autism Commission (March 2013). *Report of the Massachusetts Special Commission Relative to Autism*. http://www.mass.gov/anf/docs/mddc/autism-commission-report-full.pdf

[180] Roux AM, Shattuck PT, Rast JE, Rava JA, and Anderson KA. *National Autism Indicators Report: Transition into Young Adulthood*. Philadelphia, PA: Life Course Outcomes Research Program, A.J. Drexel Autism Institute, Drexel University, 2015.

[181] http://www.masscc.org/

[182] ALEC Mobile Crisis Initiative, Carrie Noseworthy, 2016.

ALEC is a non-profit, state-funded organization that uses first responders such as firefighters and police officers who are parents of children with autism to conduct autism trainings free of charge at the location of requesting organizations. Mobile Crisis often works in conjunction with first responders to de-escalate their clients in crisis. Using first responders as instructors offers another layer of consistency and firsthand knowledge of the field. There are currently 21 MCI units statewide. Seventeen fall under the MBHP and four fall under the Massachusetts Department of Public Health.

On Friday, February 12, 2016, Bill Cannata and Carrie Noseworthy co-presented the ALEC training to the monthly statewide director's meeting to be held at Worcester PolyTechnical Institute in Worcester, Massachusetts. The goals of the training were two-fold:

1.) Present autism training to statewide Mobile Crisis Directors to focus on awareness and training to bridge the gap between mental health training and autism training.
2.) Generate the statewide directors' interest in site specific training to a larger audience of their extended staff who provide direct care.

At the end of the training, presenters encouraged directors to utilize the ALEC autism training as a topic to comply with their mandated need for training in cultural competence. The long term goals were to increase safety and access to mental health services for autistic individuals, increase the quality of mental health service, decrease overall costs of services, decrease unnecessary escalations and hospitalizations, provide appropriate services, and increase the safety of providers including first responders.

Table TA-12. On-site MCI Autism Trainings (eff. October 2016)

Location	Estimated # trained
Boston Medical Center	16-20 staff
Milford	6
Pittsfield	3-5
New Bedford	TBD - pending
Statewide Directors	40

To build workforce capacity, approximately 70 staff have been "autism trained" so far. Participating locations have requested future training to reach greater numbers of staff. For FY 2017, ALEC has the following trainings planned: 45 police, 40 Firefighter/EMS, 9 Mobile Crisis, 4 hospital trainings, 3 parent trainings.

One barrier to increasing the trainings is that there is no current mandate for autism training, but there is a mandate for mobile crisis staff to maintain cultural competence. It is within this scope that autism training for mental health providers makes sense to help provide mental health equity for autistic individuals.

Another barrier is that training on-site mobile crisis units presents logistical challenges similar to those presented when training police, i.e. (8 hour shifts, staff called out to emergencies, staff changes prior to training); possible ways to address this are multiple on site trainings, training multiple mobile crisis units by geographical location, and of course, trainings mandated by leadership.

Feedback from pre- and post-training surveys from all locations has yielded positive results. The majority of respondents said they would recommend the training to colleagues.

Identified Needs: Transition to Adult Life

Quantitative Findings

In recent years, two local independent surveys, one producing state-level data and the other town-level data, were conducted to shed light on the need for and evidence of transition planning, assessments, services and supports for youth with special education needs, many of whom were autistic. The two surveys provide ways to engage the community in better understanding of the needs of transition age autistic youth as a way to gather and analyze data and disseminate findings, as well as how to objectively and effectively advocate for services and supports for this population using data and monitoring progress as well.

Federation for Children with Special Needs (FCSN) Transition Experiences Survey

From July 2009 to June 2010, the Federation for Children with Special Needs (FCSN) conducted the *Transition Experiences Survey*[183] of people working with Massachusetts students ages 14 to 22 on Individualized Education Programs (IEPs) during the 2008-2009 school year. It explored the transition preparation process of these students with a particular focus on the Transition Planning Form (TPF). Three hundred and twenty-nine (329) surveys were fully completed, of which 298 respondents were parents (90.6%), 20 were educational advocates (6.1%), 5 were students on IEPs (1.5%), and 6 fell into "other." Of these, nearly a quarter of the respondents (79) identified as school or related professionals who were also reporting as parents.

The survey polled all IEP disability categories to describe a student that the respondent was working with of which the most prevalent category at 40.7% was autistic students (n=134) with an additional 31.6% for students with developmental delays (n=104). Respondents could identify more than one category to describe a student. Within the 2008-2009 school year, almost half of the students were 16-18 years old (46.5%, n=153), 31.6% were between 13-15 years old (n=104), 20.4% were between 19-22 years old (n=67), and an additional 1.5% were over 22 years old (n=5). The following tables provide some of the highlights of the study and should represent autism with 41% of autistic transition age students in the results.

Close to one-third of students represented had had a neuropsychological evaluation (31%). For the 134 autistic students (41%), only 20% had completed an independent living assessment (n=27) and fewer than 10% had undergone an assistive technology evaluation. Most respondents (37%) had not reported having completed a transition assessment, though many commented that they arranged testing at their own expense. Table TA-13 displays the transition assessments complete by students.

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[183] Gorman, MA. (May, 2012). *The Transition Experience Survey*. Boston, MA: Federation for Children with Special Needs.

Table TA-13. Which transition assessments has the student had to help the Team decide on the appropriate Transition services? (Multiple responses allowed).

Type	Number	Percent
Individual interest inventory	92	28.2%
Vocational evaluation	81	24.8%
Functional behavioral evaluation	55	16.9%
Independent living assessment	27	8.3%
Recreation assessment	9	2.8%
Assistive technology evaluation	34	10.4%
Neuropsychological evaluation	102	31.3%
No assessment reported	119	36.5%
Total respondents	326	100%

At the time of the survey, transition planning had been reported not to have begun for up to 34% of 16-18 year olds and up to 14% of 19-22 year olds, as shown in Table TA-14.

Table TA-14. Has transition planning begun? (By student age)

Age	Transition Planning Has Not Begun (# Students)	Row %	Transition Planning Has Begun (# Students)	Row %	Not Sure	Row %
13-15	55	53%	38	37%	11	11%
16-18	34	22%	100	66%	18	12%
19-22	6	9%	57	86%	3	5%
Over 22	0	0%	5	100%	0	0%

Of those students on IEPs who reported not yet having had a transitional planning form (TPF) introduced by the school, 56% were over the age of 16. Seventeen parents of students on IEPs (over the age of 16) reported introducing the form themselves.

Table TA-15. Has school introduced the TPF? (By student age)

Age	School has not introduced the TPF (# Students)	Row %	School has introduced the TPF (# Students)	Row %	Respondent introduced the TPF (# Students)	Row %
13-15	65	64%	29	28%	8	8%
16-18	59	39%	79	53%	12	8%
19-22	24	36%	37	56%	5	8%
Over 22	1	25%	2	50%	0	25%

If the TPF had been introduced, there was a much likelier chance that the student's IEP had transition goals in it (80%) compared to 69% not having transition goals if the TPF had not been used, as shown in Table TA-16.

Table TA-16. Does the IEP have transition goals? (By whether school has introduced IEP)

TPF Introduced	IEP does not have transition goals (# Students)	Row %	IEP has transition goals (# Students)	Row %
School has not introduced TPF	102	69%	46	31%
School has introduced TPF	30	20%	117	80%
Respondent has introduced TPF	11	42%	15	58%

Similarly as shown in Table TA-17 if the TPF had been introduced, 81% of students had a vision-based set of transition goals compared with only 52% having vision-based goals if it had not been introduced. These data indicate the tool's effectiveness in supporting a positive outcome for students.

Table TA-17. Are transition goals in the IEP vision? (By whether the school has introduced the TPF)

TPF Introduced	Transition goals are not vision-based (# Students)	Row %	Transition goals are vision-based (# Students)	Row %
School has not introduced TPF	29	48%	32	52%
School has introduced TPF	22	19%	96	81%
Respondent has introduced TPF	4	24%	13	76%

Other noteworthy findings included 17% of respondents reporting that transition goals and services in the IEP were based on the availability of existing programs rather than on individual vision or need. This was echoed in one of this report's focus groups when participants described students learning cashiering skills as a group regardless of individual interests. Another finding shared that transition IEP goals and services were not developed due to a school's claim that "transition services that are not academic are not the responsibility of the school." Given that executive function, social skills and independent living needs are common to many autistic people, this reported misconception is of particular concern.

Secondary to post-secondary education transition outcomes should have improved since the publication of the original report due to changes in the law that include the endorsement of the training of transition and autism specialists in school systems and the previously shared Transition Advisories by DESE. These changes are worth monitoring again asking similar questions.

In the report's conclusion, the Federation called for immediate attention to be paid to special education transition planning in Massachusetts, noting that services vary considerably based on resources of school districts. It highlights the need for approaching transition in an "individualized 'results-oriented' manner…, rather (than) in a generic 'process-oriented' fashion." The report makes recommendations "to ensure the rights of students with disabilities are preserved".

LexSEPAC Transition Report and Activities, 2012-2014

Another independent survey was conducted by the principal investigator of this report and other parents in the Lexington Special Education Parent Advisory Council (LexSEPAC) to serve as a needs assessment in advocating for services.

BACKGROUND. In an effort to understand and address local transition practice in the Lexington Public Schools (LPS), the Lexington Special Education Parent Advisory Council (LexSEPAC) formed a Transition Subcommittee from 2011-2013 to assess and report on the collective needs of Lexington transition age youth in all disability categories, specifically with an eye toward timely transition assessments, services, and IEP transition goals to prepare students for adult life. The subcommittee presented a transition needs assessment report with the intention of helping to shape a coherent, collaborative approach to transition planning with LPS. The report did not seek to evaluate Lexington's compliance with current regulations, but to start a collaborative process between LPS and the LexSEPAC that led to greater cohesion and consistency in planning and delivering transition services grounded in evidenced-based practice.

The report[184] was comprised of three major sections:

- Transition-Related Legislation and Case Law
- Best Practices
- Transition Needs Assessment Survey Results

METHODS: To compile the needs assessment, the Transition Subcommittee invited parents to complete an online transition needs assessment survey from March 2- 13, 2012. Of the 367 LPS transition age students who were on IEPs in March 2012, a total of 94 eligible parents (26.4%) received and responded to the PAC's survey invitation; and 38 (10.4%) completed the survey in its entirety.

The needs assessment survey captured parent input about:

1.) How parents perceive transition assessment, planning and goal setting for their transition age child,
2.) How they perceive their own family involvement in the transition process,
3.) What current student needs they have identified for their child, and
4.) What recommendations can be made to respond to parent concerns.

The survey was adapted from the five data tools listed below:

- National Secondary Training and Technical Assistance Center's (NSTTAC) Indicator 13 Checklist,
- Massachusetts Department of Elementary and Secondary Education's (DESE) Indicator 8 (Family Involvement) and Indicator 13 (Transition) Checklists
- University of Kansas' Parents Needs Survey and
- Delaware Department of Education Parents Needs Survey.

OUTCOMES: The LexSEPAC Transition Subcommittee offered their report to the LPS School Committee and Special Education Administration for careful consideration and action in late 2012. The SEPAC recommended and received approval for the *formation of a Transition Task Force* of LPS administrators and transition-related staff working in partnership with the Lexington SEPAC

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[184] Gabovitch E, Baci L, Boker H, Hausslein E, & Sackton E. (Oct. 11, 2012). *Lexington Special Education Parent Advisory Council Report on Transition to Lexington Public Schools 2012*.

Transition Subcommittee to address transition policy, practice, and programming for students with IEPs attending Lexington Public Schools. The task force used the SEPAC Transition Report[185] and existing LPS reports and related data as tools to better understand current transition practice in the district through a comprehensive review followed by a timely, responsive action plan to explore and address a variety of transition areas.

The task force ultimately recommended the creation of a *fulltime Transition Coordinator position* to the LPS Superintendent and School Committee to be voted upon in the 2014-2015 School Budget. In early 2014, the position was approved. The position serves to educate teachers and parents about transition, promote family involvement in transition planning, cultivate community partnerships with higher education, local employers, and adult service agencies, monitor efficient and effective system-wide transition timelines and processes, and share evidence-based practices and predictors of post-secondary success to drive programming and outcomes, among other responsibilities.

As a follow-up measure, the SEPAC distributed a summative needs assessment survey to all parents of transition age students receiving special education services in April 2014 which received a total response of 77 parents.

Between the formative and summative surveys, the project attempted to chart progress and establish ongoing needs. Autistic transition age students were included in these results; thus a process like this could measure transition baselines and progress for all students including those with autism as part of SPED and PAC collaborations in the future.

An overview of the report is available at: http://lexsepta.org/

Qualitative Findings

The Transition focus group was comprised of transition professionals and served as the main focus group to address this topic. Questions about transition were also asked in the Parent Leader, Autism Professional and Medical Professional groups, as well as across culturally-diverse focus groups. (Please refer to the Methods section for more details on these groups).

In addition, interviews with self-advocates deepened emerging themes through insights from personal and shared lived experiences.

> What will life look like after 22? It's challenging for schools to have 40 custom fit shoes. There is no 'one size fit all' with transition.
>
> – Transition Specialist

Focus Group Results

The following findings cut across all of the focus groups. These were opinions expressed not only by the group specific to transition, but by other parents and professionals as well.

TRANSITION PROCESS. Focus group participants unanimously expressed concern that the transition process in education begins too late for many autistic youth. Typically this process should start at age 14. Participants felt that many parents and schools lack a clear understanding about when transition should begin. Additionally, the majority of participants described inconsistences across

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[185] An overview of the report is available at: http://lexsepta.org/. The full report can be obtained by contacting Elaine.Gabovitch@umassmed.edu.

schools in terms of when they begin their transitioning planning, whether transition forms are used, and how involved the child is with the process.

PARENT DRIVEN. The process was described as "parent-driven" by several participants and dependent on parents' ideas of what was possible for their child.

Different cultural perspectives and socioeconomic statuses may affect this involvement.

> *"It [transition] is really parent driven. In Asian cultures, the parents will usually just keep the kids with them until they pass away. When I work with families who have kids who are 13 or 1, I begin to inform them. You first need to make sure that your child is independent enough that when he transitions from the school to adult system that he can have more support."*
> –Parent outreach coordinator

TRANSITION & IEP FORMS: Some participants described experiences from families whereby the transition forms were completed in advance of meetings or boxes on the forms were routinely checked off by the school team even if the process was not followed. Some parents shared that they were asked to sign IEP forms they didn't understand due to language or cultural barriers.

Challenges may be especially prevalent for low income families who are not aware of the process and for parents for whom English is not their first language. Western Massachusetts, in particular, was an area identified as needing more transition services. Examples were shared of parents were either being excluded from the IEP before the age of majority or when the student turned 18 with no preparation. Participants also felt that parents and school lacked clarity about whose responsibility it was to start the transition process and which role each should play.

WHAT HAPPENS DURING TRANSITION: There was consensus among participants that teens are not being asked about their vision/goals for the future and are not learning age-appropriate skills needed for adult life.

> *"The biggest problem is that the folks doing transition for your child have no idea what adult services look like. Families don't know what to expect or what's available in adult services."* -– Attorney and parent advocate

Participants expressed concern that adult services exist in silos and are not always easy to access or easy for parents to understand eligibility criteria of various agencies. Additionally, several participants expressed concerns about the availability of services for young adults/adults, including:

- Mental-health services
- Appropriate residential options
- Job supports
- Inclusive community-based programs
- ABA services/staff
- Post-secondary educational opportunities for autistic people

"… parents can't imagine what is out there, what they don't know. For the children of families in the Greater Boston area they cannot even make a living; they cannot even make a meal [for themselves]. And so they say 'we will just keep them with me, and get SSI.' Those families cannot imagine that the child can live independently because they don't think they have the resources and also they don't have the language skills."

– Parent Coordinator

Focus Group Recommendations

Focus group participants stated the following recommendations based on needs for successfully transitioning youth to adult life and adult services:

- Provide clear guidance to families and schools about roles and responsibilities in the transition process.
- Start the transition conversations earlier than age 14 (e.g., age 12).
- Train parents on transition starting in elementary school (e.g., asking "what do you want to be when you grow up," helping with household chores, etc.).
- Inform schools about post-secondary programs such as Inclusive Concurrent Enrollment (ICE) done in partnership with community colleges that they may not be aware of.
- Help parents connect with, and apply to, adult services.
- Create more adult services, especially post-secondary educational opportunities, meaningful day activities, and mental health.
- Provide access to training and resources on young adult, autism topics such as sexuality training, social skill training, recovering from trauma (sexual) or other victimization, mental health needs.
- Train college guidance counselors about the autism experience.
- Fund local organizations to do grass roots initiatives, for example, skills training for young adults, job preparation, budgeting, time management, and socialization.
- Fund more transition specialists in school systems.
- Map out the coordination of services for a timely IEP/TPF process.
- Provide flexible adult services.

Self-Advocate Interviews

Four autistic self-advocates served as key informants and shared a number of concerns about the greatest transition needs young adults experience.

EMPLOYMENT. Among the highest needs of autistic young adults, employment was cited as the top concern.

> *"The biggest issue for us is jobs, jobs, jobs. People are steered to jobs that don't match their skills….The main thing is to do the thing you want to do or are good at, you need to get support for retail, to be a lawyer, to be a theater director. Whatever skills you have. Employment is one of the biggest things that stands in the way. Talented people with skills are eager to join the workforce, but have a hard time getting and keeping jobs. Statistics show that autistic people are less likely to find employment."*

> "Employment is the biggest thing that stands in the way. Talented people with skills are eager to join the workforce but have a hard time getting and keeping jobs. Statistics show that they are less likely to find employment."
>
> – Adult autistic self-advocate

One key informant provided some insights for employers to know that highlight the strengths and aptitudes of autistic workers, many who have natural talents with jobs that stress intricacy and precision. The following questions provide other insights that would require "thinking out of the box" and promoting non-traditional occupations:

- *"Why is no one looking into working with unions for autistics since they have good wages and job security? Raising union saturation helps all Americans. We are very detail and rule oriented as a rule.*

- *Why is no one looking at aiming us toward inspector jobs (e.g., elevators, housing, food, ADA, etc.)? We tend to be very logical, objective and fair-minded.*
- *What about aiming us as Hazmat technicians and/or EMTs?*
- *Teach us crafts – many of us would be good at that.*
- *Also, look to jobs working for other disabled folks who are likely to be much more accepting."*

One key informant followed up the interview with further commentary and advice about the viability of employment for certain people on the spectrum as part of the transition process from secondary education to post-secondary life with a viewpoint based on autism acceptance of neurodiversity:

- *"Focus less on making us appear normal and controlling us, as that is for the comfort of others, and more on teaching us transitioning skills (how to live independently - assume always that this will be the end goal); this is more important than job skills as most of us will not work no matter how good we appear."*
- *"We have a social disability. Please stop being so insistent on employment. We do not read body language properly. Eye contact makes us upset and even can cause physical pain. Worse than not reading body language, we do not give off the correct response to others body language. This drops our employment options through the floor. We are literally being demanded to fail. This is cruel."*
- *"With the social sections of our brains under-developed, other sections are over-developed. Often these areas are: memory, creativity, pattern recognition, cooperation, understanding animals, radical thinking, and non-linear thought processes. There are SO many ways we can be productive, even without working. We can be consultants on our condition and needs. We are often big or little picture people. Often certain environments or groups of people will stimulate us and bring us out of our shell."*

EXECUTIVE FUNCTION SUPPORT AND TRAINING. All of the self-advocate interviewees put assistance with executive function high on the list of needs. Each was very specific about what types of needs could be addressed:

- Learning skills
  - *"NT's don't know how to teach people practical adult skills. We need to focus on:*
    - *What a full life looks like*
    - *Teach skills on how to live in the world*
    - *How to file taxes*
    - *Banking – how to handle a bank account*
    - *How to balance finances*
    - *How to set up multiple bank accounts*
    - *The Fair Housing Act of 1975"*
- Case management to guide people through the transition to adulthood.
  - *"Mentoring services would be helpful. People need help with:*
    - *How to apply to college*
    - *How to deal with applying for a job*
    - *How to deal with applying for insurance*
    - *How to communicate with the doctor who previously communicated with parents; or instead of parents*

        - *How to self-advocate in general*
        - *How to navigate services in the adult system*
        - *How to navigate DDS"*

- Executive Function *supports*
    - *Switching from entitlement to adult service system. Affects:*
        - *VR, DDS Services*
        - *Employment, housing, behavioral health access*
        - *Higher ed accommodations*
        - *SSI, SSDI applications*
        - *Medicaid enrollments*

Other comments had to do with the practical application of executive function skills on the job.

- *Autistics can get retail and food service jobs, but they become overloaded due to executive function and social issues, like the social pecking order of managers & employees. For many, things move too fast to process. But some autistics are doing fine at retail too since everyone is different.*

SELF-ADVOCACY. The facility with self-advocacy was one that came up often as a critical area to master.

- *"For example, if you have a PCA and you're uncomfortable, you need to be able to set boundaries. If you have a job, you need to be able to speak up for yourself. You should be able to say 'this is not right. I'm not ready for this. I don't want this. It's not right for me."*

- *"We are taught from a young age not to say no to adults. We train disabled kids to comply and in doing so, we are setting them up for abuse and exploitation. There have been studies with service animals that use "intelligent disobedience." We don't do that for kids with autism."*

When asked how to best address the need to self-advocate, the following suggestions were made:

- *"Two things: peer training and peer mentorship. They are different. Peer training is done for a limited, specified time. Peer mentorship is an ongoing relationship. Older PWD's = peers. Youth with self-advocacy skills = peer."*

Along with the ability to self-advocate, suggestions included having a safe and supportive environment and system that provide opportunity to participate but not pressure youth.

- *"We won't feel the full benefit of services if pressured. It may not be effective. If opportunity and information are pitched at the person's level and pace, what is helpful or not, can help them decide on most appropriate services for them."*

As for the places that assist with self-advocacy in varying degrees, the following were mentioned:

- *I've been here in Massachusetts for 4 years. For many people, (secondary) schools are not respecting people's self-determination. Not colleges, unless it's the disability office that's clueless (only complaint I hear at college).*
- *The ILCs help TAY and are geared to self-advocates. BCIL has a youth program. National ILC is focused on youth and transition.*
- *PTIC – Parent Training and Assistance Centers at the FCSN are doing this for families.*

ADULT SERVICE SYSTEM. When asked what the most pressing issues are for autistic teens and young adults in this state, interviewees focused on state agencies and the existing system of services:

- *Insurance companies are not covering enough.*

- *There's a lack of coordination and parity between DDS, Behavioral Health (DMH) and general health (MassHealth). EOHHS had meetings last year but has not resulted in much.*
- *It's better with DDS recently due to the change in IQ requirement. That's really good for people with DD without ID, but they still struggle with 2 things: Activities of Daily Living (ADL's) and Instrumental Activities of Daily Living (IADL's). But people also hear that they're too high-functioning for services. Some people might have a PhD, they're literal rocket scientists who can hold and keep a job but their house may be a disaster so they need help.*
- *As for DDS, I don't know many using it. More use MRC who is usually giving help. People worry that they will be turned away from DDS because they're too high-functioning.*
- *Regarding MRC, many people say they're not getting help finding appropriate jobs. It's hit or miss.*

> "They're all giant bureaucracies. Without executive function, you're screwed. Even with high intellectual skills, without executive function you can't turn in forms. It's many steps to do any of these things and without supports, it's almost impossible."
>
> – Adult autistic self-advocate

- *Many are dissatisfied with services. I know one person happy with OneCare. Others think it's terrible. All others are dissatisfied with housing, health care, transition. Some are mildly dissatisfied, others say "f--- everything."*
- *ILC's are doing better for people with IDD now, especially BCIL. The struggle with IDD is that historically ILCs knew physical disabilities, but not IDD. There's a need for technical assistance. To bring people with IDDs into their organizations. 51% of employees must be PWD. Hire more with IDD. May know nothing about IDD. I'm a policy wonk and community organizer but they call me and ask me to help them understand the long term support world for IDD. That's not my training but there is a need.*

Self-Advocate Recommendations

- Access to older people on spectrum who can assist by providing supports.
  - *"We need access to older adults and it does not have to be too much older – could be that you are 17 and the person is 18-25. You can't get the same lived experience and info from parents or teachers no matter how open or informed they may be. The person must be where you are and understand the hurdles you will need to get through. It could also be an elder. This person could help you learn to self-advocate. If you have the same disability they can be an incredible support and can be validating. These older peers can help you imagine yourself in the future. They can show you that you can have a satisfying life that is relatively happy with doing the things you want to be doing. This is an opportunity to be with older people who exist outside of Sped or medical contexts."*

Future possibilities: Transition to Adult Life

Autism Higher Education Foundation (AHEF)

The Autism Higher Education Foundation (AHEF) works with high schools, community colleges, colleges and universities, as well as other educational institutions and professional associations, that utilize technological and programmatic innovation for autistic individuals such as music and fine arts education, training, assistance, and support protocols for educators and administrators in effective educational/behavioral techniques, as well as advocacy and outreach for families to promote access to new educational and vocational opportunities.

One area of particular importance is their development of training protocols for specific vocational tracks. The *Paralegal Assistant Training Program (PLAT)* works in collaboration with the Massachusetts Probate & Family Courts to provide non-paid internship opportunities for autistic students between the ages of 18 and 21 in paralegal assistant work in participating Courts in Massachusetts. The course provides the student with valuable job readiness and vocational training in paralegal assistant skills, including, scanning, filing, data entry as well as exposure to the workings of the Court. In collaboration with visionary law firms, AHEF aspires to then match students who have successfully completed their court internships with appropriately paid employment throughout the legal community. In addition to youth gaining experience, this program also serves to build greater understanding of this population with the Massachusetts Probate & Family Court System.

Massachusetts Advocates for Children Transition Task Force

Mass Advocates for Children (MAC) has hosted a Transition Task Force for several years geared toward the development and proposal of data fields and programming design to share with DESE to be used in a future online database-driven Individualized Education Program (IEP). If the proposed IEP data elements which include the Transition Planning Form (TPF) embedded into its design, this instrument could be a powerful tool to help understand the current and future needs of students on IEPs, including autistic youth from all cultures, races, regions and backgrounds. Aggregating the data would be critical but the information offered by this collaborative community development group could be helpful to future baseline setting and progress monitoring.

In addition, MAC's Autism Center provides training to parents statewide regarding services and programs necessary for children on the spectrum to reach their potential and the legal right to obtain these services. With an emphasis on the requirement that children with ASD receive educational opportunities which reflect competency and potential, MAC's workshop addresses current trends, legal standards, discussion of court cases, and special education service options for children with ASD.

The Autism Center also offers trainings for medical professionals and educators (e.g., neuropsychologists, occupational therapists, physicians, teachers) who conduct evaluations of children with ASD on legal requirements and effective strategies to secure the full range of educational services necessary for children with autism to reach their potential and demonstrate competence.

Transition Outcomes of High-Functioning Students with Autism: How and When Students Learn the Skills Necessary for Self-Management of Daily Responsibilities

Gael Orsmond, PhD of Boston University is conducting a study[186] entitled *Transition Outcomes of High-Functioning Students with Autism: How and When Students Learn the Skills Necessary for Self-Management of Daily Responsibilities* to (1) understand the programs and strategies that parents and special educators use to teach students with high-functioning autism spectrum disorders (HFASD) how to manage daily life tasks and (2) examine how the ability to self-manage daily life tasks is associated with successful transition outcomes for students with HFASD. Research has shown that although students with HFASD have similar levels of academic achievement as their

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[186] http://ies.ed.gov/funding/grantsearch/details.asp?ID=1896

peers, they also exhibit significant impairments in their ability to manage daily life tasks, which are a strong predictor of poor adult outcomes. There is a need to better understand the factors that account for the poor transition outcomes of students with HFASD. This study aims to inform the development and refinement of interventions and supports that will facilitate the ability of students with HFASD to self-manage daily life tasks and thus prepare for life after high school.

Project Activities: The research team will explore malleable factors related to improved transition outcomes for students with HFASD. In Phase 1, the research team will conduct focus groups with high school special education personnel knowledgeable about direct services provided to high school students with HFASD. The research team will also distribute web-based surveys to a larger group of high school special education personnel informed by the focus group results to more broadly identify existing services. In Phase 2, the research team will collect data from students with HFASD and their parents regarding students' self-management of daily life tasks—as well as additional data that will be used to identify malleable factors, moderators, and mediators of transition outcomes—during their final year of high school. Transition outcome data (i.e., independent living, post-secondary education, employment, and vocational training) will be collected at the time of the post-test and 18 months later as a follow-up to assess how students have transitioned out of high school.
Products: The primary product of this study is an understanding of how self-management of daily life relates to transition outcomes for students with HFASD. The team will also disseminate findings through peer-reviewed publications and presentations.

Professional Organization Trainings by a Self-Advocate/Autism Consultant

Some good examples of the benefits of working with autistic self-advocates to better understand their needs and to design meaningful measures for services and supports comes from local autistic self-advocate Kate Ryan, a 2015-2016 UMMS-Shriver Center LEND fellow who developed a LEND Capstone project to educate vocational rehabilitation professionals and employment specialists about autism from the autistic perspective.

Kate’s presentation entitled *Autism: What Vocational Rehabilitation Professionals Need to Know* explains from her point of view as a person with autism why autistic clients might behave in puzzling ways to their neuro-typical peers, job coaches, or supervisors. The presentation is designed to bridge gaps between the disabled and the non-disabled and has been successfully applied to several local non-profits. Kate is also a certified Massachusetts Access Monitor, able to measure facilities to ensure that they are complying with local and federal access laws, and offer suggestions on how to make a space autism-friendly. Kate is actively involved with the Massachusetts Chapter of ASAN and the Massachusetts Developmental Disabilities Council.

Resources: Transition to Adult Life

Transition Guides

Guide	Authors
A Family Guide to Transition Services in Massachusetts	Federation for Children with Special Needs
Important Transition Information Every Family Should Know: Transition Information Fact Sheets, April 2015	Massachusetts Department of Developmental Services
“Planning for Life After Special Education”: A	Disability Law Center

Guide	Authors
Transition Services Online Manual	
The Road Forward Transition Guide	Massachusetts Department of Developmental Services
Transitioning Teens with ASD: Resources and Timeline Planning for Adult Living	Autism Consortium
Transition Timelines	The Arc of Massachusetts
Transition Toolkit	Autism Speaks

Youth, Young Adult and Family Transition & Self-Advocacy Training Programs

Program	Provider
Life MAPS Program	AANE/MRC
Youth Leadership Program and Network	Easter Seals
The Full Life Ahead Workshop Series	Massachusetts Families Organizing for Change
ASPIRE Program	Mass General Hospital Lurie Center
Transition Services and Coaching	NESCA-Newton
Peer Mentoring Program	Partners for Youth with Disabilities
Access to Theater Program	Partners for Youth with Disabilities

Workforce Development Programs

Program	Provider
First Responder Training & Mobile Crisis Unit training	ALEC
Webinars, conferences and support services	AANE
Autism: What Vocational Rehabilitation Professionals Need to Know	Kate Ryan, Self-Advocate & Consultant/Trainer
Paralegal Assistant Training Program (PLAT)	Autism Higher Education Foundation (AHEF)

Recommendations: Transition to Adult Life

While there are no MCHB core outcome indicators transitioning to adult life separate from health care, it is an equally important area for which to set goals, establish baseline data, and conduct ongoing monitoring to measure progress. Little is known about this particular indicator, leaving much room for future investigation and monitoring. Similar to the Access to Care indicator, Transition to Adult Life is one of the areas in this report showing the greatest level of need for YSHCN with autism in Massachusetts.

Due to new collaborative efforts between state agencies, adults that serve autistic young adults based on the legislative change prompted by the Autism Omnibus Bill of 2014, there is hopeful progress being made that is still in need of published target goals and outcomes. More evidence-based practices are needed in supporting autistic people, and additional service model options. Workforce development and capacity building are needed to help more professionals understand how to support and include this community in transitioning from secondary to post-secondary life accessing the full complement of educational supports, accessing adult services, gaining job experience and employment, staying safe when interacting with law enforcement, and living high quality adult lives in general. For those systems that fall outside of state government or that present challenges with tracking adult activities such as higher education, there is no consistent way to measure and monitor outcomes for this population. Autistic adult self-advocates describe needs with employment, executive function, learning to self-advocate, and navigating the adult service system as high priorities.

1.) SET TRANSITION TO ADULTHOOD TARGETS AND MONITOR PROGRESS ON AN ANNUAL BASIS.

While there are no MCHB core outcome indicators for transitioning to adult life in general other than for health care transition, it is an all-encompassing quality of life domain for which to establish baselines, set targets, and conduct ongoing monitoring to measure progress.

The aforementioned national studies and technical assistance centers are resources that can provide important insights to assist with identifying possible transition baseline measures to capture locally from which to benchmark targets and monitor future progress:

- National Autism Indicators Report for Transition in Young Adulthood
- National Longitudinal Transition Study (NLTS-2)
- National Secondary Transition Technical Assistance Center (NSTTAC) (now closed)

The Massachusetts Autism Commission should consider whether a target(s) for transition to adulthood is appropriate for the state and determine how and which data sources can be used to measure and monitor possible targets for this core outcome indicator.

2.) USE EMERGING STATE ELECTRONIC RESOURCES AND OTHER MODELS TO GATHER MORE INFORMATION ABOUT TRANSITION TO ADULTHOOD FOR AUTISTIC YOUTH.

While there are no national surveys that share data specific to Massachusetts about transitioning to adult life in the areas of postsecondary education, employment, independently living, and self-determination, there are multiple promising databased projects emerging in the state that could serve as data sources from which to gather robust and integrated data to serve autistic youth and young adults.

- Currently, DESE is building an online, database-driven IEP form that will incorporate transition-specific data fields that could embed the Transition Planning Form (TPF) and other transition elements into its design. This instrument could be a powerful tool to help understand the current and future needs of students on IEPs, including autistic youth from all cultures, races, regions and backgrounds. Aggregating the data would be critical but the information offered by this tool could be helpful to future baseline setting and progress monitoring.

- The new paperless system for the Bureau of Transitional Planning (BTP) is due to be completed by the end of the 2016-2017 school year and to be implemented starting in 2017-2018. It holds promise for coordinating the various systems of care toward the successful transition of autistic youth (and all others receiving special education services). Although it is not known whether the SASID will be the vehicle that informs transition from secondary to postsecondary life, this student identifier could be another important use for this data source and could assist with providing a longitudinal view of transitional outcomes for autistic youth.

- In addition, more needs to be known about the extent to which the many best practice-related transitional advisories issued by DESE have resulted in positive student outcomes for transition age autistic students across all regions of the state. Measuring and monitoring the extent to which these processes are adhered to by the various school systems across the state is critical so that students do not fall through the cracks. The BTP electronic referral system might be able to assist with these questions.

- The Mental Health Information System (MHIS) may be able to provide information that reveals differences in needs based on race, ethnicity and socio-economic status of DMH clients.

- Likewise, the previous section on Transition to Adult Health Care identifies a need to prepare autistic youth with complex medical and behavioral needs for the move to the adult health care system. The BTP referral system signifies an important opportunity for more comprehensive and detailed monitoring of Massachusetts autistic transition age youth seeking and being referred for services across the health and human service system.

- Specific data measurement is needed to better understand the outcomes for autistic youth and young adults (as well as all adults) including:

  - Process outcomes for transition planning, assessments, job placements and internships, and full participation of the student and family on the IEP/transition team.
  - Process outcomes for the coordination of services for a timely IEP/TPF process.
  - Results outcomes for postsecondary transition planning and activities that start at the age of 14 for autistic students.
  - Results outcomes for non-English speaking parents to be fully informed about the content of the IEP and TPF both written and verbally in their own languages and cultures.
  - Employment outcomes for autistic adults.
  - Enrollment and graduation rates for autistic college students from institutes of higher education.

3.) BUILD AND MONITOR WORKFORCE CAPACITY AND DEVELOPMENT FOR TRANSITION TO ADULTHOOD.

Workforce preparation for those who work with autistic transition-age youth and young adults in the state service system and in the larger community is another area of need. It is critical to build workforce capacity and infrastructure through cross system planning across all regions, as well as strengthen, measure and monitor workforce development through trainings. Some examples of professionals who might benefit from such capacity-building and training efforts are: first responders such as police and mental health crisis units; college guidance counselors; behavioral clinicians, case managers and administrators; vocational rehabilitation counselors; service coordinators and support brokers; and legal and judicial professionals such as advocates, prosecutors, state lawyers, legal aid officers, judges, magistrates and other adjudicators.

Some workforce development considerations might include:

- Adding more transition specialists in school systems.

- Training transition specialists in the public schools as well as families about the adult service world.
- Enlisting local training resources such as DDS autism support centers, AANE, the ARCs, ALEC, AHEF including their PLAT Program, and other community partners could serve to educate those that are beginning to serve the broader autistic community.
- Finding local champions, including self-advocates and family members, who can share lessons learned in working with this population to train others.

4.) EDUCATE YOUTH AND PARENTS ABOUT TRANSITION TO ADULTHOOD.

Both professional and family focus group participants and self-advocate interviews perceived gaps in the following areas of need for autistic youth and families in training to prepare for the transition to adult life:

- Students and parents need a clear understanding about when transition begins, the process, inclusion of the student in their IEP team meetings, roles and responsibilities in the transition process and all related details.
- Parents should not be excluded from IEP meetings that discuss transition unless the student is the age of majority and does not give permission.
- Students and parents should be given notice well in advance and prepared to handle the shift in responsibility at the age of majority.
- Parents should know whose responsibility it is to start the transition process.
- The Team should actively involve the student in their vision and goals for the future starting at age 14 or earlier.
- Students should learn age-appropriate skills for adult life starting at age 14.
- Students and families should learn about the adult service world starting at age 14.
- Train parents on transition starting in elementary school (e.g., asking "what do you want to be when you grow up," helping with household chores, etc.).
- Train students and parents connect with, and apply to, adult services.

Specific recommendations from autistic self-advocate interviews for self-advocacy youth training include:

- Executive function training and support (e.g., topics such as how to bank, file taxes, apply to college, apply for a job, navigate the adult service system, etc.).
- Self-advocacy training (e.g., topics such as how to say "no" and how to manage anxiety proactively).
- Peer training and peer mentorship.
- Funding for non-profit organizations such as ASAN or AANE to offer self-advocacy training programs.
- sexuality training, social skill training, recovering from sexual trauma or other victimization, mental health needs.

School and community programs that can strengthen and empower autistic individuals and their families in these areas are recommended. Consider funding local organizations to do grass roots initiatives around skills training for young adults, job preparation, budgeting, time management, and socialization. Measuring and monitoring the presence of such training programs in the state is also recommended.

5.) FORM A STATEWIDE TRANSITION COALITION.

Both professional and family focus group participants and self-advocate interviews expressed concern that transitional and adult services exist in silos and are not always easy to access or easy for consumers to understand various agencies' eligibility criteria. Concerns were shared about the availability of services for young adults/adults, including mental-health services, appropriate residential options, job supports, inclusive community-based programs, and post-secondary educational opportunities for autistic people.

To break down perceived silos and allow for a broader statewide dialogue around transition, piloting a Statewide Transition Coalition that engages in a collective impact approach is recommended to set measurable goals and to monitor progress across agencies and organizations (i.e., share a common agenda, employ common progress measures, participate in mutually reinforcing activities, engage in regular communication, supported by a backbone organization). The current collaborative climate between state agencies fostered by the Autism Commission bodes well for the utility of collective impact in building capacity and linkages to better understand and serve autistic consumers. The previously-recommended HCT coalition could be added as a special interest group within this model. Both self-advocates and family members should be well-represented and fully included in such an effort.

Moreover, creating a learning community within this model that researches and shares best practice models to serve autistic consumers can elevate statewide competencies and expertise further. Models for providing more flexible adult services and additional offerings of post-secondary educational opportunities, meaningful day activities, and mental health for youth with autism could be explored. Partnerships between secondary education schools and community colleges, such as the Inclusive Concurrent Enrollment (ICE), hold promise as transition models. Such a learning community would require combining resources, but is worth considering as a way to build capacity.

INSURANCE

Healthy People 2020 Core Outcome Indicator #6

Families of CSHCN Have Adequate Private and/or Public Insurance to Pay for Needed Services

The following section will review what's known about insurance covering CYSHCN with ASD in Massachusetts. We will present national survey data and state findings first and then provide qualitative insights from focus groups and self-advocates. We will discuss needs, future possibilities, gaps and recommendations at the end.

Background

This MCHB core indicator addresses adequate private and/or public insurance to pay for the services that CYSHCN with ASD and DD need. Health insurance, whether financed through the public or private sector, is essential for children to access needed care. Without health insurance, children are more likely to forgo necessary preventive care, and acute health care when children are sick can leave their families with overwhelming medical bills.

Summary of State Environment: Insurance

In 2006, the state of Massachusetts mandated Universal Healthcare via the Chapter 58 of the Acts of 2006 of the Massachusetts General Court, "An Act Providing Access to Affordable, Quality, Accountable Health Care". The law mandated that nearly every resident of Massachusetts obtain a minimum level of insurance coverage, provided free health care insurance for residents earning less than 150% of the federal poverty level (FPL) and mandated employers with more than 10 "full-time" employees to provide health care insurance. The Massachusetts law was amended once in 2008 and twice after the federal Affordable Care Act was passed in 2010 to make it consistent with the federal act including expansion of Medicaid coverage to cover children aged one to 18 years living at 150% of the federal poverty level (FPL), all adults living at 133% FPL and higher FPL limits for infants and pregnant women.

In Massachusetts, Medicaid and the Children's Health Insurance Program (CHIP) are combined into one program called MassHealth, which covers 38% of state families including CYSHCN and low-income families. About 96% of the population have health insurance, however pockets of the population (e.g., immigrants, minorities) remain uninsured.[187]

For example, a recent report from the Blue Cross Blue Shield of Massachusetts Foundation found that there were two such groups in East Boston with over 20% uninsured. In the Maverick Square neighborhood of East Boston, the average estimated rate is 23.7 %, and in one section of New Bedford, the uninsured rate is 22.1%. These two census tracts (a statistical subdivision with 1,200 to 8,000 people) have the highest rates of uninsured individuals in the state, substantially higher than the 4% uninsured rate found in the state on average. In contrast, 10 census tracts around the state are estimated to have an uninsured rate of zero. These tracts are in the wealthier cities and towns of Duxbury, Groton, Lincoln, Newton (two tracts), Southborough, Sutton, Walpole, Westwood, and Wilmington.

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[187] Blue Cross Blue Shield of Massachusetts Foundation "The Geography of Uninsurance in Massachusetts, 2009-2013.

Autism-Specific Insurance Coverage

In 2010, *An Act Relative to Insurance Coverage for Autism* (ARICA) was passed in Massachusetts. Beginning in 2011, state-regulated health insurance plans, including private insurers, employees and retirees under the state plan, hospital service plans and HMOs[188] were required to cover medical services for ASD related to its diagnosis and treatment including habilitative, rehabilitative, pharmacy, psychiatric, psychological, and therapeutic services. ARICA specified that state-regulated health insurance plans could not limit coverage based upon the age of the person, or due to the amount of funding paid for similar services over their lifespan.

It is important to note that ARICA does not apply to some types of health insurance used by people in Massachusetts, for example, people covered under federally-regulated insurance plans. According to the Autism Insurance Resource Center (AIRC),"many employers have "self-funded" plans, which are regulated under a federal law and not subject to ARICA." However, these plans may choose to cover some or all services related to the diagnosis and treatment of ASD, and may impose their own limitations on coverage. While some have voluntarily adopted coverage, many have not, making it difficult for some to obtain services paid for through insurance.

Additionally, ARICA did not affect MassHealth. However, as of 2015, MassHealth has expanded the services under the Autism Omnibus bill (passed in Massachusetts in 2014) and now covers Applied Behavior Analysis (ABA) therapy for children under age 21 with MassHealth Standard and MassHealth CommonHealth; and under age 19 with MassHealth Family Assistance.[189]

Autism Insurance Resource Center (AIRC)

The Autism Insurance Resource Center[190] based at the Eunice Kennedy Shriver Center at the University of Massachusetts Medical School is a state resource that assists consumers, families and providers with information on insurance coverage for autism in Massachusetts. The web site is a rich source for specialized information related to the state's Act Relative to Insurance Covering Autism (ARICA) that became law in 2011 (see the Insurance section for more information). One unique feature there is the easy to use screening tool "Am I Covered?" that determines if a person's insurance is subject to the Massachusetts Autism Insurance Law (ARICA). In addition, AIRC provides webinars, trainings and telephone support to families and support specialists across the state. (See the section on Insurance for more information).

The AIRC is responsible for opening up access for countless families to adequate insurance coverage for their loved ones with autism. To date, the AIRC has had over 3,000 contacts with people seeking information about autism insurance coverage.

The AIRC helps parents navigate health insurance plans to identify resources available for treating autism, and also provides assistance to other connected groups such as health care professionals seeking reimbursement for services related to ASD diagnosis and treatment.

The AIRC has also trained providers in how to navigate and administer complex insurance systems through their workforce development efforts. At a systems level, the AIRC has influenced many local companies with self-funded insurance plans to offer coverage to their employees to stay competitive.

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[188] https://www.disabilityinfo.org/ARICA/aricafaqs.aspx#faq1
[189] https://www.disabilityinfo.org/ARICA/insuranceinfo.aspx
[190] https://www.disabilityinfo.org/arica/

Continuing to monitor AIRC's activities including the numbers of families served, the number of companies offering insurance benefits under ARICA as a baseline, monitoring the growth of these efforts as more are added in the future, and tracking workforce development and training efforts can assist the state in understanding access process outcomes in the future.

The availability of insurance coverage under ARICA, and the assistance to gain access to it provided by the AIRC has a substantial impact on families, as described in this note from a parent sent to the AIRC in 2012:

> *…I am very thankful for the guidance and information [AIRC] provided recently to [provider] with regard to the full denial [insurer] placed on my son's services at the one year review... As I briefly mentioned to you, the outcome was that the denial was reversed…*
>
> *…The treatment now available under [ARICA] is an integral reason my son continues to have the…opportunity to live at home, stay in his community and remain in his school. Period. Other than maybe donating a lifesaving organ to somebody, I don't know how much more 'real' or meaningful it gets when it comes to the wellbeing of a child and family in chronic crisis. How do you thank somebody for that? …My thanks, my appreciation, my gratitude for all that has been done and continues to be done by you and others making a difference.*

MassHealth (Medicaid)

According to information about children enrolled in Medicaid in Massachusetts around 2012, about 6% were reported to have some type of disability which may include many children with ASD.

Table IN-1. MassHealth FY 2012 Enrollment

MA Health Enrollment[191]	**Massachusetts % or #**
All Children	547,232
Children without Disabilities	516,410 (94%)
Children with Disabilities	30,772 (6%)

MassHealth reported that a scan of ASD diagnosis codes using 2012 fiscal year claims data of 14,755 recipients having at least one ASD diagnosis code.[192] This total, which also included recipients dually eligible for both Medicaid and Medicare (later determined to total 1,914), excluded 182 members identified as being members of the state's Autism Home and Community-based Services Medicaid Waiver. The MassHealth information was broken down by age group and the number of claims generated by age group.

The age distribution of the subgroup is shown in Table IN-2 with age calculated as of June 30, 2012. The subgroup is predominantly male (77%). Figure IN-3 shows the distribution of this group among the MassHealth enrollment categories. (Please note that this measures the total number of member enrollment days in each plan type, not individual members, since members often shift between plans).

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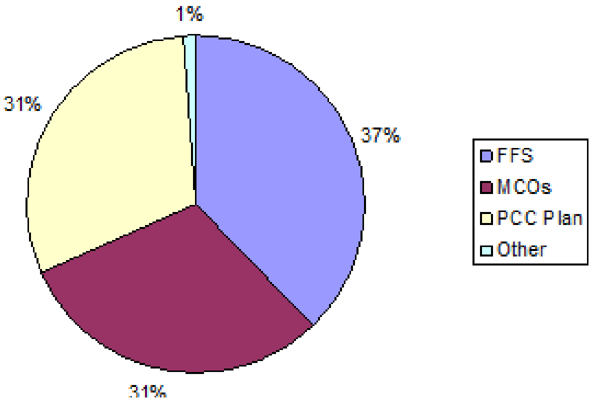
[191] MA Budget & Policy Ctr, 2012

[192] It is important to note that this methodology may include people who do not have autism but may have been evaluated for an autism diagnosis. It may also exclude people who have autism but who did not receive medical services that were coded as being related to their autism diagnosis during the year.

Table IN-2. MassHealth FY 2012, people with ASD-related medical service utilization[193]

Age Group	No. Members	Percent by Age Group
0-2	*533*	*3.6%*
3-8	*4,057*	*27.5%*
9-13	*3,117*	*21.1%*
14-21	*3,140*	*21.3%*
22+	*3,908*	*26.5%*
Total	*14,755*	*100%*

Figure IN-3. MassHealth FY 2012 Enrollment by Category



Identified Needs

Quantitative Findings

Important Notes about National Surveys:

At least two national surveys, the National Survey of Children's Health (NSCH) and the National Survey of Children with Special Healthcare Needs (NS-CSHCN), ask questions about health insurance coverage for children and families, and include questions about whether the children have autism. The inclusion of these two sets of questions allows the surveys to inform insurance coverage and adequacy patterns specifically for children with autism. **While the surveys do contain both national- and state-level data, the state sample sizes are generally too small (between 31–74 children) to provide reliable estimates, specifically for children with ASD**. Comparisons to state data will be made where meaningful, and full tables of survey data on relevant indicators can be found in the Appendix under "Insurance Data." National data trends may provide further insights.

The most recently available data is 2009-10 for NS-CSHCN and is 2011-12 for NSCH.

NS-CSHCN outcomes above predate universal health care in Massachusetts, the Massachusetts autism insurance law "An Act Relative to Insurance Covering Autism," (ARICA) enacted in January 2011, and the passage of the federal Patient Protection and Affordable Care Act (ACA) (Association of Maternal and Child Health Programs, 2012). All of these laws are particularly beneficial to children with ASD and developmental disabilities in Massachusetts. Therefore, these surveys can provide important baseline measures, but likely do not reflect the current state or national environment.

Since 2012, these two surveys have been integrated into a single National Survey of Children's Health. Data are being collected in 2016 and will be available for analysis in 2017. For more information on the integration, visit: http://mchb.hrsa.gov/data/national-surveys

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[193] Reported by P. Kirby, MassHealth Office of Clinical Affairs, 6/1/15.

Insurance Coverage

The 2011-12 NSCH survey asked parents of young children whether their child had insurance in the past 12 months and what kind of insurance they had. Health insurance was defined as private insurance provided through an employer or union or obtained directly from an insurance company; public insurance, such as Medicaid, the Children's Health Insurance Program (CHIP), military health care (TRICARE, CHAMPUS, or CHAMP-VA); or some other plan that pays for health services obtained from doctors, hospitals, or other health professionals.[194] The proportion of the population that was uninsured in 2011-12 was smaller in Massachusetts (between 0.4% - 1.7%) than observed nationally (between 5.18 - 5.94%). Even prior to the health insurance reform in Massachusetts discussed above, the 2009-10 NS-CSCHN estimated that children in Massachusetts had lower rates of being uninsured (0.1 - 1.5%) than national patterns (3.19% - 3.97%), which also held for children with autism in Massachusetts (0.0% - 0.6%).

The NSCH estimates that between 16.8%-27.7% of children with autism nationally have public insurance such as Medicaid or SCHIP, 70.8%-81.7% have private health insurance and 0.5 – 2.5% are currently uninsured demonstrating that children with autism are significantly more likely to be covered by public insurance and significantly less likely to be uninsured than children nationally. Similarly, these surveys also suggest that more children with autism in Massachusetts are on public insurance and fewer on private insurance than children without autism in the state, however the state findings were not statistically significant, likely due to the small number of children with ASD in the state included in the survey.

Nationally, the percentage of CSHCN without insurance varies by race/ethnicity. Hispanic children were the most likely to have been uninsured at some point in the past year (15.9 %), and this percentage was even higher for those children whose primary language was Spanish (22.7%). Among non-Hispanic Black children, 10.0% were uninsured at some point during the year, as were 7.2% of non-Hispanic White children and 9.6 % of children of other races. While the sample sizes are too small to assess this in the state for children with ASD, the national statistics may provide a useful benchmark.

Consistency of health insurance coverage

Children in Massachusetts were significantly more likely to have consistent health insurance coverage in the 2011-2012 NSCH (93.0 - 96.1%) than children nationally (88.21 - 89.23%). Specifically for CSHCN with autism, those in Massachusetts were significantly more likely to have consistent health insurance coverage in the 2009-10 NS-CSHCN (81.2 – 100%) than children with autism nationally (66.56 – 77.05%). While not statistically significant, this pattern was also evident in the 2011-2012 NSCH with 92.8 - 100% of children with autism in Massachusetts with consistent coverage, compared to 89.6 – 94.0% of children with autism nationally.

Adequacy of Insurance

In the NS-CSHCN, parents of CSHCN with health insurance were asked three questions about their children's coverage:

- Does the plan offer benefits and cover services that meet their needs?
- Does the plan allow the child to see the health care providers that s/he needs?

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[194] http://mchb.hrsa.gov/cshcn0910/core/pages/co3/co3ai.html

- Are the costs not covered by the plan reasonable?

If parents answered "usually" or "always" to all three of these questions, then the child's coverage was considered to be adequate. All others were considered to have inadequate insurance coverage. A similar strategy is used in the NSCH.

Nationally, about half of CYSHCN with autism (53.45 – 64.59%) in the NS-CSHCN were reported by their parents to have adequate insurance coverage, compared with about two-thirds (75.85 - 77.12%) nationally in the 2011-12 NSCH. The rates of adequacy improved significantly from findings in the 2009-2010 NS-CSHCN for all children as well as for children with autism at both the state and national levels. When examined by type of insurance (public vs. private), the rates of adequacy were substantially higher for public insurance coverage for children in general and for children with autism at both the state and national levels. Nationally, adequacy of coverage was reported for 66.2-79.6% of children on public insurance, and 40.5-55.2% of children on private insurance demonstrating a statistically significant difference in the 2011-12 NSCH. Massachusetts state estimates for children with autism showed very similar patterns.

Of the three items that make up the adequacy standard, the one most likely to be met is that the child's insurance allows them to see needed providers. Massachusetts scored better on this indicator than national patterns, with 89.4-93.8% of all CSHCN in the state reporting they could usually or always see the needed providers with their coverage compared to 85.7-87.1% nationally in the 2009-2010 NS-CSHCN. However, CSHCN with ASD both nationally and in Massachusetts appeared to report being able to see needed medical providers with their coverage less frequently: 74.7% - 93.0% of CSHCN with autism in Massachusetts usually or always could see needed providers, as well as 74.1 – 79.1% nationally, a difference of about almost 15, a difference of about almost 15% compared to all CSHCN. Findings were similar in the 2011-2012 NSCH survey.

In assessing whether the child's health insurance met their needs, there were few differences observed between CSHCN with ASD in Massachusetts and other CSHCN in the state with 85.1 – 90.9% reporting their insurance usually or always met the child's needs in the 2009-2010 NS-CSHCN. While there were not statistically significant differences between CSHCN with ASD in Massachusetts and nationally, the available data suggested that CSHCN with autism in Massachusetts may have their needs met by their insurance more than CSHCN with autism nationally in the 2009-2010 NS-CSHCN. However, in the 2011-2012 NSCH estimates for children with autism in Massachusetts fell slightly to become similar to national patterns for children with autism though changes were not statistically significant.

Of the insurance adequacy questions, non-covered insurance charges and out-of-pocket expenses presented the largest burden for children with autism in Massachusetts and nationally. In the 2009-2010 NS-CSHCN, roughly a third (23.0-48.8%) of CSHCN with autism in Massachusetts reported that their non-covered medical charges were never or sometimes reasonable, compared with 34.6 – 40.6% of CSHCN with autism nationally. For CSHCN without autism in the state and nationally, only about a quarter reported the charges were never or sometimes reasonable. In quantifying out-of-pocket costs, more than half of families of CSHCN with autism surveyed in the 2009-10 NS-CSHCN reported paying more than $1,000 in out-of-pocket costs for the child's medical expenses in the last year, estimating that 35.9 - 65.5% of CSHCN with autism have similar costs throughout the state. *It is important to note that this survey occurred before changes to public and private insurance coverage specifically for ASD-related diagnosis and treatment in the state.* In the 2011-2012 NSCH, the burden of out-of-pocket costs for children with autism in Massachusetts appeared to improve to be similar to or better than children without autism, however the small sample sizes limit generalizability. Roughly half of the children with autism in Massachusetts (23.9 – 71.5%) of children were estimated to have no out-of-pocket medical costs.

Although it is notable that these findings preceded changes to insurance coverage for autism in Massachusetts, the questions about the ability to see needed providers compared to other CSHCN and the estimate of out-of-pocket costs for families of children with autism are still important to monitor and understand. More importantly, there is a need to understand the percentage of children with autism not covered under ARICA or by MassHealth, but by self-funded plans. This subset could experience significant insurance disparities that are worth further investigation.

Qualitative Findings

Ongoing Consumer Assistance Needs

As demonstrated by the volume of informational requests experienced by the state's Autism Insurance Resource Center, even with the recent policy improvements for insurance coverage for children with autism in the state assistance, is frequently needed to navigate the system of coverage. Additionally, despite the expansion of coverage the need for information and consultation from the center has not slowed. The AIRC reports that complexity of the cases of parents contacting the center has increased, and the challenges shared by parents have allowed the AIRC to identify systemic barriers to coverage, for example, with particular insurers in the state. The AIRC also provides assistance to families to work with federally-regulated employers, which are not covered by ARICA in the state, to provide and maintain coverage for ASD diagnosis and treatment. This type of family-based support resource will likely be a continued need to aid families in navigating insurance and medical systems, as well as to learn about potential areas of consumer protection needs throughout the state.

Focus Group Themes

The topic of insurance came up frequently in the focus groups when participants discussed access to community resources and access to appropriate diagnosticians. The following are the most commonly-identified themes.

MASSHEALTH. The biggest areas of need identified by focus group participants are to expand services that are covered by MassHealth, increase the number and availability of providers who accept MassHealth, and educate parents about insurance options and services.

> "I have MassHealth and I've wanted ABA at home for my daughter since she was 3 and she is 5 now. I've wanted it so bad. I cannot afford private insurance myself."
>
> – Parent of young child

MassHealth is heavily utilized in some areas of the state and this creates long waiting periods for families trying to access a limited number of providers. MassHealth may also limit coverage for certain specialties, i.e. psychiatry, and may not cover other services that are needed for children with ASD such as nutrition and sensory integration therapy. Some focus group participants describe what they see as inequity across the state in terms of services a family can get for their child with autism. This inequity is attributed to the difference between having MassHealth or having private insurance.

> *"My biggest concern is the vast difference money makes. For low income families, so few providers take MassHealth. I see what the families with regular insurance can get compared to*

> *[the families who have] MassHealth. And the area just lost another therapist who took MassHealth. She explained that it was just not cost effective."*
> – Central/West inclusion consultant with many year of experience

> "All of this increase in access has led to problems in capacity. We need to increase capacity in a great way."
>
> – Autism resource specialist

Using private insurance can be cumbersome. As one parent of a school aged child with autism explains, "Even if you have private insurance, it's a very complicated and long process. You have to go through the PCP and the PCP sends over their referral. Then the insurance company will ask for more information, like the evaluation report or more information from the specialist. [After all that], you get the authorization, but then you have to find a provider that accepts your insurance."

CAPACITY. Due to recent changes in insurance practice, families can now obtain coverage for Applied Behavioral Analysis (ABA) services through private insurance and MassHealth. Most focus group participants agreed that this has created problems with capacity; the demand is very high for ABA services and providers are struggling to keep up.

According to one resource specialists, an unintended consequence of this new coverage is that schools limit the services they provide.

> *"Schools look at a child with an ASD diagnosis and say they don't qualify for anything, or will allocate 1-2 hours of speech a week, or a half-day program 2-3 weeks. In the past, it would be 4 or 5 full days. They usually accompany this with 'you can access your insurance.'* – Resource specialist.

Or, schools will set up their own program.

> *"It's an ABA-based therapy that's not actually ABA. There's no data collection, baseline testing, or graphing of results. Children are not getting intensive services."* – Resource specialist.

INCONSISTENCIES WITH ARICA. Other participants described the barriers in accessing ARICA. As one program director of a large service agency described, "Even though ARICA is there and in place, they (insurance companies) are real sticklers about how they will provide it. One insurance will only allow it at home when the parent is here. Another won't allow it at school, or anywhere else."

PARENT KNOWLEDGE AND TRAINING. Parents need knowledge about coverage options and MassHealth advocacy as well as training on the availability of additional MassHealth services, (i.e. in-home services, PCA, etc.).

TREATMENT RESOURCES. Since the improvements in coverage for autism-related diagnosis and treatment, concerns about network adequacy for these services have increased. Relative to other states, Massachusetts has a high number of programs to train therapists (e.g., BCBA programs), and a relatively high number of therapists per capita.[195] However, low therapist volume has still been reported to limit access relative to the demand for services related to ASD.

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[195] Verbal communication with the Massachusetts Autism Insurance Resource Center, based on their conversations with state residents accessing their support services.

As suggested by the focus groups, other medical resource needs likely exist, particularly for children on public insurance in remote areas or in areas with a high proportion of children on Medicaid. These treatment resources also likely exist for certain specialties. Unfortunately, data was not found in the course of this project that could adequately inform these needs.

COVERAGE GAPS. While recent policy changes have greatly expanded coverage for autism-related services, some significant gaps in coverage persist, including variable coverage and coverage limits in federally-regulated insurance plans. For example, some plans do provide some coverage but only for very limited age groups (e.g. 3-6 years). In addition, some insurers operating in the state have argued that autism treatments are not medically necessary; skilled advocacy may be needed to facilitate payment for services.

In some cases, a co-payment burden can exist for some therapies that are delivered with a high frequency (e.g. weekly) and require co-pays at each session. This type of co-payment may present particular burdens for families on Medicaid and others with relatively low incomes.

Lastly, there is no insurance coverage for care coordination services. However, these services are frequently part of models to provide comprehensive, integrated care for families (e.g. the medical home model). The lack of insurance payment for these services makes them difficult to fund and maintain, including the ability to consistently offer them to families in need. Thus, effective programs such as Family Navigation and the use of community health workers are typically only carried out on a short-term basis because they rely on grant funding to employ these care coordination professionals over the course of the grant period.

Future possibilities: Insurance

Medical Billing (Claims) Data

The Commonwealth of Massachusetts has a legislatively-formed All Payer Claims Database (APCD), which is the most comprehensive source of health claims data from public and private payers in Massachusetts. The Center for Health Information and Analysis (CHIA) is a state agency charged with monitoring the Massachusetts health care system, and is the group that operates the APCD in Massachusetts. Massachusetts General Laws Chapter 12C section 10 provides broad authority for CHIA to collect information from private and public health care payers, including third-party administrators. Section 12 outlines certain governance requirements and conditions for use and release of such data. CHIA's regulations governing carrier reporting requirements and the disclosure of certain carrier data are found at 957 CMR 8.00 (APCD and Case Mix Data Submission) and 957 CMR 5.00 (Health Care Claims Data Release), respectively.

The database contains information on the vast majority of Massachusetts residents and enables CHIA and other groups that apply for access to the data to conduct research and analyses that support state agency operations and enhance the ability of payers and providers to deliver care.[196] CHIA's enabling statute allows for the collection of data from commercial payers, third party administrators and public programs (Medicare and MassHealth, Massachusetts' Medicaid program), however it does not include payments from Workers' Compensation, TRICARE and the Veterans Health Administration, and Federal Employees Health Benefit Plan. These data sets come both from

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[196] Overview of the MA All Payer Claims Database, Sept 2016, http://www.chiamass.gov/assets/docs/p/apcd/APCD-White-Paper-2016.pdf

medical insurers and from specialty insurers and administrators of "carved-out" services including pharmacy, mental health/chemical dependency, dental, and vision. The Massachusetts APCD is somewhat unique from other state APCDs due to the infrastructure offered by CHIA to work collaboratively with payers to improve data quality and completeness and having the specialized staff needed to normalize data across payers to support cross-payer analyses. These functions substantially improve the quality of the data within the database, and have also enabled the creation of certain additional features, such as a way to link records across payers for a single individual enabling analyses that account for changes in people's insurance coverage.

This database represents an important source of data within the state that can inform health care utilization for people with autism within the state. The data may also offer ways to help confirm the number of people with autism within the state, especially for younger people (due to generational effects of autism diagnosis).

It was beyond the scope of this Needs Assessment to pursue and analyze this data, as substantial resources are needed to plan and conduct valid analyses. Use of this data requires special considerations. For example, this data was collected for the use of facilitating medical payments, and therefore the structure of the data and use of certain diagnostic and procedural codes may be influenced by this purpose. There are also important considerations about how people with autism may be identified within this data, as health care providers are less likely to include medical codes for ASD for certain types of health care utilization, such as Emergency Department visits. Use of this data for analyses of people with ASD requires important considerations in order to avoid including people who are being screened for ASD vs. those that have been diagnosed with ASD, as well as to avoid missing people with ASD that do not have utilization associated with this diagnosis over short time periods. Best practices do exist to provide longitudinal perspectives on ASD code use and other strategies to address these areas of informational risk.

The Omnibus Law requires the Massachusetts Autism Commission to "review the rise in prevalence of autism spectrum diagnoses among children in the past thirty years and make estimates of the number of children, aged 21 or younger, who will become adults in the coming decades…" The Autism Commission has identified medical data as a possible source of monitoring ASD counts, but recognizes that more work must be done to understand and assess this data's ability to answer such questions.[197]

Recommendations: Insurance

National survey findings preceded changes to insurance coverage for autism in Massachusetts, and yet the questions about the ability to see needed providers compared to other CSHCN and the estimate of out-of-pocket costs for families of children with autism are still important to monitor and understand. More importantly, there is a need to understand the percentage of children with autism not covered under ARICA or by MassHealth, but by self-funded plans. This subset could experience significant insurance disparities that are worth further investigation. Although the small sample sizes preclude using these data for meaningful conclusions, these surveys could be the source of helpful information if sample sizes were larger.

More information is needed regarding network adequacy for various specialties within various types of insurance coverage, particularly with the expanded efforts for purchase of health insurance

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[197] Source: Massachusetts Autism Commission, Executive Director Carolyn Kain, September 2016.

through the health exchanges, and as some insurers transition to managed care and other new models. Particularly, some of the network adequacy measures required of insurers, for example those specified by federal guidance for Medicaid managed care models[198], may be insufficient if they do not specifically consider the needs of children with special health care needs like autism. Specifically, more information is needed regarding network adequacy for children on Medicaid in remote areas or in areas with a high proportion, and particularly for specialists.

There have been numerous recent policy changes in the state related to insurance coverage in general, and specifically for children with autism. These represent important opportunities for the state to measure their impact for children with autism in the state to ensure they are functioning as intended, are adequately addressing identified or known gaps, and do not have other unintended consequences. The measures discussed in this section are only able to inform a portion of the insurance-related experiences necessary to inform these questions.

1.) SET INSURANCE TARGETS AND MONITOR PROGRESS ON AN ANNUAL BASIS.

The national Maternal, Infant & Child Health (MICH) Outcome Indicators for Healthy People 2020 under CSHCN does not include targets related to Insurance. Prior to this, Healthy People 2010 shared the following targets for this indicator:

- Increase the percentage of CSHCN with adequate public and/or private insurance to pay for the services they need.
  - Baseline and target: No data specified.

  The questions that support this statement are:
  - Child has private or public health insurance at the time of the interview
  - Child had no gaps in coverage during past 12 months
  - Health insurance covers services that meet the child's needs

Given the high level of insurance coverage in Massachusetts in general and recent changes in insurance practice to cover more children under the ARICA law for private insurance and MassHealth expansion, the Massachusetts Autism Commission should consider whether this national target is appropriate for the state, and if so, determine how and which data sources can be used to measure and monitor these core outcomes.

2.) LEVERAGE EXISTING ELECTRONIC RESOURCES AND/OR OBTAIN A LARGE DATA SAMPLE RELATED TO INSURANCE COVERAGE AND NETWORK ADEQUACY.

Use existing electronic information resources in the state, like the All Payer Claims Database, to monitor insurance coverage and network adequacy. Consider data linkages between state resources to enhance the ability of these data sources to inform questions related to insurance coverage.

While the national surveys regarding children's health ask very important and relevant questions about insurance coverage, the state sample sizes are quite limited such that any estimates for children with ASD are based on very little information and therefore subject to error. However, the questions and survey structure are useful, and a state supplement or coordinated efforts with the funder of the survey, Health Resources & Services Administration (HRSA), may be beneficial to

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[198] Centers for Medicare & Medicaid Services (CMS), Medicaid and CHIP Managed Care Final Rule, April 25, 2016, https://www.medicaid.gov/medicaid/managed-care/guidance/index.html#

oversample children in Massachusetts for the purpose of improving the precision of these estimates. In addition to enlarging the state data set for the Insurance core outcome indicator, this would apply to all six Healthy People indicators to provide a fuller picture of how all systems of care serve CYSHCN with autism in Massachusetts.

More information is needed regarding network adequacy for various specialties within various types of insurance coverage, particularly with the expanded efforts for purchase of health insurance through the health exchanges, and as some insurers transition to managed care and other new models. Particularly, some of the network adequacy measures required of insurers, for example those specified by federal guidance for Medicaid managed care models[199], may be insufficient if they do not specifically consider the needs of children with special health care needs like autism. Specifically, more information is needed regarding network adequacy for children on Medicaid in remote areas or in areas with a high proportion, and particularly for specialists.

More information is needed to understand non-covered insurance charges and out-of-pocket expenses for families of children with autism. There is also a need to understand the percentage of children with autism not covered either under ARICA or by MassHealth, but by self-funded plans. Focus group results indicate that children with autism covered by self-funded plans may experience significant gaps in coverage, such as age limitations and treatments deemed as not medically necessary. This subset of insured children with autism could experience significant insurance disparities that are worth further investigation.

3.) BUILD AND MONITOR WORKFORCE CAPACITY AND DEVELOPMENT FOR INSURANCE.

According to focus group reports, the biggest areas of need are to expand services that are covered by MassHealth and increase the number and availability of providers who accept MassHealth. This requires expanding workforce capacity of those providers who accept MassHealth by region and comparing it against the number of families of children with autism in a region who rely on MassHealth coverage.

In addition, recent changes in insurance practice to cover ABA services through private insurance and MassHealth have resulted in needs for a greater supply of providers to meet the demand. Expanding workforce capacity is needed to address this shortage.

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[199] Centers for Medicare & Medicaid Services (CMS), Medicaid and CHIP Managed Care Final Rule, April 25, 2016, https://www.medicaid.gov/medicaid/managed-care/guidance/index.html#

SUPPLEMENTAL REPORT SECTIONS

Baseline Findings

Education

Housing

Cultural Considerations

EDUCATION

The following section shares information about education for Massachusetts children and youth with autism. We first present identified needs using state and national data findings touching upon the Early Intervention, Elementary and Secondary Education, and Higher Education systems and then provide qualitative insights from focus groups. We discuss future possibilities and recommendations at the end.

Background

Children and youth with autism are served by the state's education system often from the moment of diagnosis leading to Early Intervention and pre-school services, through elementary and secondary education, and possibly into higher education for some. When considering the whole person, education plays a critical role in supporting children and youth with autism and is one of the most prominent systems in their lives. In addition to students' rights to a free and appropriate public education, most interventions and supports for children with autism are offered through special education until a student's graduation from high school at age 18 or no later than age 22.

Although this report is primarily meant to address core health outcome indicators under Healthy People 2020, education is also included as a supplemental topic since it factors heavily into one's life course outcomes. We dedicate this section in recognition of the central role education plays in the lives of children and youth with autism and the critical work that teachers, school clinicians and administrators contribute to their formative years.

Summary of State Environment: Education

MDPH Early Intervention Program

The Massachusetts Department of Public Health (DPH) collects data on children from birth to three years old who receive Early Intervention services. (More information can be found in the sections on Early Identification and Accessible Community-Based Systems of Care).

DESE Elementary and Secondary Education Program

The Massachusetts Department of Elementary and Secondary Education (DESE) collects data on children in the public school districts across Massachusetts, excluding children enrolled in private schools or home schooled that do not receive public funds for education, who are incarcerated or who attend out-of-state schools. Each district uses independent data collection and reporting methods. Districts may have coded students with autism under any of 13 disability categories when submitting special education data to DESE, including categories such as "multiple disabilities", "developmental delay" or "intellectual disability". Children with IEPs are categorized for the purpose of receiving special education services, and while multiple categories can be used, only the primary category is counted in aggregate DESE reports. Until recently, only a single category could be used to classify student need. Case verification for the use of disability categories has not been confirmed with psychiatric, medical or clinical records, and only those students with IEPs would be counted.[200] Possible discrepancies for disability category totals may reflect differences in definitions of disabilities

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[200] "Prevalence Estimates of Autism and Autism Disorder in Massachusetts", Final Report December 2005, Center for Environmental Health, Environmental Epidemiology Program, Massachusetts Department of Public Health

and use of other disability categories to classify students with autism (e.g., neurological disability listed as a primary and autism as a secondary disability). Categorization may also reflect differences in district practices, and differences in parent preference for classifications. DSM-5 definitions are not used to code for autism and may be inconsistent with other state agency definitions. As a result, these data may underrepresent the number of students with autism[201] in some areas, and may over-represent the number of students with autism in other areas as two types of misclassification are possible within the system. Therefore, it is important that these figures are not used without verification to estimate autism prevalence, particularly at local levels.

Identified Needs: Education

Quantitative Findings

Early Intervention Estimates

In FY 2015, there were 38,478 children enrolled in the DPH's Early Intervention system of which 2,036 had diagnoses of autism (5.3%) and were enrolled in Specialty Service Programs[202], a 47% increase over the FY 2011 total of 1,381 children with autism served by Early Intervention specialty services.[203] The DPH reported to the Massachusetts Autism Commission that for FY16 the number of children with autism was 2,052 (0.79% increase over FY15).

Elementary and Secondary School Estimates

The 2011-12 National Survey of Children's Health (NSCH) survey indicates that the vast majority (96.5%, C.I. 91.2 - 100.0%) of parents of children with autism in Massachusetts responded that their children receive services through Individualized Education Programs (IEPs).

Table ED-1. Child has Individualized Education Program or IEP, ages 6-17 years, NSCH 2011-12

		No	Yes	Total
All MA children	*%*	85.1%	14.9%	
	C.I.	(82.5 - 87.7%)	(12.3 - 17.5%)	
	n	1,093	189	1,282
	Pop. Est	818,664	143,230	961,894
*All MA children with autism**	*%*	3.5%	96.5%	
	C.I.	(0.0 - 8.8%)	(91.2 - 100.0%)	
	n	2	27	29
	Pop. Est	858	23,384	24,242

C.I. = 95% Confidence Interval. Percentages are weighted to population characteristics.
n = cell size. Use caution in interpreting cell sizes less than 50
Note: Given the range of the estimates, it appears that the sample size may be too small to meaningfully estimate the number of students with autism on IEPs within Massachusetts.

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[201] "Prevalence Estimates of Autism and Autism Disorder in Massachusetts", Final Report December 2005, Center for Environmental Health, Environmental Epidemiology Program, Massachusetts Department of Public Health; and M. Mittnacht, presentation to Autism Commission, May 17, 2016.
[202] DPH Early Intervention Program data, 2016, n.p., personal interview.
[203] 2013 Massachusetts Autism Commission Report, p. 9 & 55; U.S. Census Bureau for 2012 at http://quickfacts.census.gov/qfd/states/25000.html

STUDENT POPULATION INCREASES. Massachusetts Department of Elementary and Secondary Education (DESE) data from 2012 through 2016 show a continuing annual increase of students with autism. Autism as a primary disability category has grown from 4,080 in SY 2003[204] to 13,228 in SY 2012 (8.1%) and most recently to 18,572 in SY 2016 (11.2%).[205] Over the same time period, the use of other less specific disability categories has dropped. This compares to the U.S. Department of Education's Office of Special Education Programs (OSEP) SY 2015 *IDEA Part B Child Count and Educational Environments* report estimating approximately 14,500 students between the ages of 6 to 21 years old within the Autism Disability category for Special Education in Massachusetts.[206]

Information provided by DESE at the request of Massachusetts Autism Commission members by Marcia Mittnacht, DESE Director of Special Education[207] gave enrollment data from SY 2003 through SY 2015 to estimate adult outcomes and needs. These data are notable for the shift in student percentages across grade levels with a higher percentage of the total students by year enrolled in lower grades closer to 2003 and shifting distribution over time toward the middle and upper grades. Percentages stabilize by grade level starting in 2009-2010 through 2015. Nonetheless, there is an overall average increase per year of total students with autism at 12%. (The table with full details can be found in the Appendix under "Education Data").

Another way to examine the data is by following a class across the years to see changes in percentages between years where one can assume that increases might represent new diagnoses or reclassifications of disability categories in IEPs. For example, the graduation class of 2014 would have been in first grade in 2003. The average increase in student count per year averaged 8% through 11th grade. However in 12th grade that number increased sharply by 19%. This pattern may be worth following to see if there is an uptick in reclassifications in diagnoses for students with autism on IEPs as they prepare for transition to adult services.

RACE, CULTURE & LANGUAGE. Regarding the number and percentage of students with autism in SY 2016 for English Language Learners (ELL) as well as across races and ethnicities,[188] DESE data report that of all 18,572 students enrolled during SY 2016, 4.6% (n=862) across all races and ethnicities did not speak English as their primary language. The vast majority of students with autism are White (56-80%), followed by Hispanic students (7-22%), African American/Black 6-10%), Asian (3-8%), multi-race/non-Hispanic (1.5-4.5%), Native American (0.2%) and Native Hawaiian/Pacific Islander (0.1%). These ranges are notable for the shift in percentages across grade levels with more minority students appearing in the younger age groups and more White students appearing in the upper grades. This could represent greater awareness and acceptance of autism in minority cultures in the state in recent years and could explain increases in the total numbers of students with autism on IEPs more recently as well. (The table with full details can be found in the Appendix under "Education Data"). The SY 2015 Massachusetts autism data shared by the U.S. DOE also breaks out student data by race and ethnicity in the year prior. Minority populations with autism experienced increases to 15% for SY 2016 over 12% in SY 2015 (a 26% difference) in the following student categories: Hispanic, Asian, African American/Black, and multi-race/non-Hispanic. There was

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[204] MA Student Information Management System (SIMS), 2013.

[205] M. Mittnacht, presentation to Autism Commission, May 17, 2016.

[206] U.S. Department of Education, EDFacts Data Warehouse (EDW): "IDEA Part B Child Count and Educational Environments Collection," 2014-15. Data extracted as of July 2, 2015 from file specifications 002 and 089.

[207] MA Department of Elementary & Secondary Education (DESE), reported to Massachusetts Autism Commission Executive Director Carolyn Kain, September 2016.

no change for Native American and Native Hawaiian/Pacific Islander (no percentage change). White students decreased by approximately 6% from 72% in SY 2015 to 67.6% in SY 2016.

Comparing students with autism to all SY 2015 disabilities in the table below, disparities are possible and worth examining and monitoring in two categories: Hispanic/Latino students at 12% for autism compared to 21% for all disabilities as a possible underdiagnosed group versus White students at 72% for autism compared to 62% for all disabilities.

Table ED-2: U.S.DOE IDEA Part B Child Count 2014-15, Massachusetts ASD vs. All Disabilities[208]

School Year	**2014-15**				
Collection	Part B Child Count and Educational Environments				
Developed	11/1/2015				
Revised	N/A				
Ages	**6 through 21**				
Massachusetts	**No. Students, All disabilities**[2]	**% of students with disabilities**	**No. Students, Autism**	**% of students with autism**	**Autism as % of all disabilities for racial group**
American Indian of Alaska Native	468	<1%	19	<1%	4.1%
Asian	4,258	3%	711	5%	16.7%
Black or African American students	1,603	10%	1,123	8%	7.2%
Hispanic/Latino students	31,629	21%	1,807	12%	5.7%
Two of More Races	4,581	3%	430	3%	9.4%
Native Hawaiian or Other Pacific Islander	140	<1%	15	<1%	10.7%
White	94,404	62%	10443	72%	11.1%
Total	**151,083**	**100%**	**14,548**	**100%**	

A five year look at changes in placement for students with autism shows greater inclusion and within-district placements over time and fewer substantially separate and out of district placements. To present the full picture, programmatic and methodological changes would be worth examining to monitor quality standards.

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[208] U.S. DOE Office of Special Education Programs (OSEP). *2014-15 Part B Child Count and Educational Environments 6 Through 21.*; www2.ed.gov/programs/osepidia/618-data/static-tables/index.htr

Table ED-3: Educational Environment Placement for Students with Autism: Ages 6-21 ¥

Placement	*SY 2011***	*SY 2016**
Full inclusion	35.9%	40.4%
Partial inclusion	15.6%	14.4%
Substantially separate	31.3%	30.0%
Out of district program £	17.2%	14.8%

** SY 2016 (M. Mittnacht, presentation to Autism Commission, May 17, 2016)*

*** SY 2011 (2013 Autism Commission Report, p.88)*

£ Includes public day, private day, private residential, homebound or hospital and correctional facilities

¥ Difficult to distinguish actual students with ASD due to 13 IEP categories

MCAS scores for students with autism fall significantly behind other student disability categories. Due to the broad range of functional abilities across the spectrum, this category should be reviewed by level of severity.

Table ED-4: 2015 Grade 10 MCAS Performance Comparisons *

	Autism		*Other Disabilities*	
Subjects	*Total*	*CPI*	*Total*	*CPI*
Math	849	79.0	10,893	68.9
English Language Arts	834	87.3	10,854	88.1

** SY 2016 (M. Mittnacht, presentation to Autism Commission, May 17, 2016)*

Higher Education Estimates

In response to a 2011 survey by the Massachusetts Department of Higher Education, 26 public institutions of higher learning reported a total of 582 autistic students (5.6% of all students receiving disability services) during the 2009-2010 academic year. Because there is currently no system for collecting disability incidence data in state public higher education, these findings should be considered as anecdotal.

Respondents reported a total enrollment of 246,248 students with an estimated 10,240 students receiving disability services (4%). Of these students, 72% attended community colleges (n=7,374), 6% attended state universities (n=1,512), and 13% attended the University of Massachusetts. Of the 582 estimated autistic students, 77% n=(450) attended community colleges, while the remainder, 11% and 12% respectively, attended state universities and the University of Massachusetts. It is important to note that because autistic students represent only 25% of 1% of the total enrollment, the survey results likely understates the true prevalence of autism in the college population (Massachusetts Department of Higher Education, HEIRS Database, 2011).

The 26 respondents provided further insights about the data shared. The vast majority positively reported that the enrollment of autistic students had increased in the five years prior (96%) as well as that of students with disabilities in general (92%). Most felt that student disability is underreported (69%), though some felt that they were unable to determine this (11.5%). This implies that the incidence of autism and disability in general is higher than the report estimates. Among the many insights that respondents shared in their qualitative responses, the need for greater services for students, faculty and staff were apparent, however, resources to provide them are limited (Massachusetts Autism Commission Report, 2013, p. 94).

Qualitative Findings

Focus Groups

The research team did not ask specifically about the education system in our focus groups. However, in almost every focus group, it was one of the first topics that participants brought up – sometimes as soon as in the opening introductions. Education was a topic parents spoke passionately about. At times, it was difficult to refocus the discussion to the health outcome indicators that the project team was exploring due to the desire of parents to share many concerns. Most of the concerns came from the multicultural focus groups.

LANGUAGE AND TRANSLATION. One of the most common educational themes was around language and translation. Many participants expressed a need for translation in educational documents, such as IEPs and progress reports. Parents are legally entitled to have educational documents translated into their native language. Anecdotally, the team heard stories from participants that this is not always happening and that some documents, such as daily notebooks and behavior logs, assessments, etc. are not being translated. When considering the ease with which English-speaking parents can exchange daily written communications with teachers to act as partners with their child's education team, the disparity that exists for non-English speaking families is apparent.

The project team also heard anecdotal stories of IEP-related documents being translated by bi-lingual cafeteria workers, thus jeopardizing the student's privacy. Stories about parents being pressured to sign IEPs following an education plan meeting were also shared, without translation being offered.

APPROPRIATE, INDIVIDUALIZED TRANSITION SERVICES. The education and transition planning that youth receive in preparation for adult life begins in high school but needs to continue through the 18-22 year old period. Adequate and high quality job training and skill building are needed. Unfortunately, these needs are highly variable and individual. The project team heard anecdotal stories from non-English speaking parents about their youth learning only clerical and/or retail skills as part of transition services as part of the school's programming instead of gaining skills as defined by the student's vision. Anecdotal information was also shared with the project team from a range of sources that the quality and availability of job training and skill training varied greatly between school districts.

The team recommends establishing a *Parents Bill of Rights*. (More information is available in the Cultural Considerations section).

Future Possibilities: Education

State Assigned Student Identifier (SASID) tracking

According to the Massachusetts Department of Elementary and Secondary Education's web site,[209] a State Assigned Student Identifiers (SASID) is:

> *"a unique identifier given to each student receiving a publicly funded education in Massachusetts. The SASID number remains with the student throughout his or her educational life in grades pre-K through 12, even as the student transfers from one district or school to another. If the student*

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[209] http://www.doe.mass.edu/infoservices/data/sims/sasid/

> *leaves the state and returns, the student will receive his/her original SASID. Districts can apply for a SASID using the Single Student Registration (SSR) or the Multiple Student Registration (MSR) applications. Once the SASID is assigned, districts can retrieve the unique identifier using the Publish Manager application."*

A memorandum of understanding has been in process between the Department of Public Health and the Department of Elementary and Secondary Education to assign SASID IDs to children when they enter EI services instead of when they first enter the school system, allowing better tracking across systems.

This is a promising practice that could assist in data collection by producing accurate coding for ASD at an earlier age, traveling with the child over the course of early childhood and school years, reflecting adjustments in diagnostic classifications and related public services, and more accurately monitoring outcomes and forecasting needs.

Massachusetts Advocates for Children (MAC) and DESE Collaboration

There is currently a survey being developed between DESE and MAC pending about opening up the autism specialist endorsement in the Autism Omnibus legislation to all educators. More information is needed.

DESE and DDS Collaboration

DESE may be working on including multiple diagnoses such as ID in Special Education data to assist with eligibility for DDS. More information is needed.

Recommendations: Education

In almost every focus group, education was one of the first topics that participants brought up and spoke passionately about – sometimes as soon as in the opening introductions. Most of the concerns came from the multicultural focus groups.

One of the most common educational themes was around language and translation. Many participants expressed a need for appropriate translation of educational documents, such as IEPs and progress reports by skilled professional bicultural, bilingual translators as well as language interpretation also needed by interpreters with the same skills and backgrounds. Families requested that they receive many more materials in their languages than just the IEP and progress reports, but also daily communication notes.

The quality of education and transition planning that youth receive in preparation for adult life begins in high school, but needs to continue through the 18-22 year old period. Adequate job training and skill building are needed. Unfortunately, these needs are highly variable and individual.

At the systems level, sharing data systems with the education system was also an area of need between state agencies.

1.) SET EDUCATION TARGETS AND MONITOR PROGRESS ON AN ANNUAL BASIS.

Education is a supplemental category added to this report and thus does not fall under the Maternal, Infant & Child Health (MICH) Outcome Indicators for Healthy People 2020 under CSHCN. It does not have targets related to its outcomes.

Given the frequency with which parents in the various focus groups highlighted the educational needs of their children with autism, there is a need to understand this population better during all phases of education: early intervention, elementary and secondary education, and higher education by continuing to track the trajectory of how and when young children and students with ASD are being identified in addition to their functional outcomes over the long-term.

Assigning SASID numbers and tracking outcomes longitudinally could assist in accurate data analysis, monitoring outcomes and forecasting needs through secondary graduation. Continuing to monitor school-age enrollment information through DESE could also help to see where new diagnoses and reclassification of disability categories are trending and could be linked to race, culture or language to examine differences.

Though more difficult, establishing a system to routinely monitor the number of transition age students with autism who are enrolled in state colleges and universities and comparing their graduation rates to the general population, could provide insights into the outcomes of previous educational investments made following IEP.

The Massachusetts Autism Commission should consider whether setting targets for the different levels of education would be useful, and if so, determine how and which data sources can be used to measure and monitor these core outcomes.

2.) MEASURE, MONITOR AND ADDRESS CULTURAL EQUITY FOR TRANSLATED SPECIAL EDUCATION DOCUMENTS AND COMMUNICATIONS WITH FAMILIES.

Non-English speaking parents have requested reliable translated education documents and materials such as IEPs and progress reports to be received in a timely and appropriate manner. Understanding how universally available these translated documents are in school systems that serve diverse populations is recommended to promote and support a positive family-school relationship working together on behalf of all students.

HOUSING & HOMELESSNESS

The following section will discuss housing and homelessness for Massachusetts autistic transition age youth and young adults. We will present national data and state survey findings first and then provide qualitative insights from focus groups and self-advocate interviews. We will discuss needs, future possibilities and recommendation at the end.

Background

Household circumstances are important to transition success. Having a residence can lead to success with independence[210,211,212]. As it gets more difficult for youth in the general population to transition from high school to adulthood than in the past[213,214,215] (Shanahan, 2000), the same is more difficult for youth with disabilities. The National Longitudinal Transition Survey 2 (NLTS2) has examined such trends among youth with disabilities over several cycles. Descriptive findings are reported for young adults with disabilities as a whole and for those who differed in their primary disability category, years since leaving high school (up to 8 years), highest level of educational attainment, and selected demographic characteristics.

Summary of State Environment: Housing & Homelessness

In Massachusetts, the leading organization specializing in housing options for autistic people with autism and other developmental disabilities and their families is the non-profit organization Autism Housing Pathways (AHP), incorporated in June 2010. The organization was formed by a concerned group of parents whose children were approaching transition age and recognized the need and the challenge of providing appropriate, secure housing options in the state for adults with autism. AHP has become a family-driven, membership-based organization with the following core goals:

- Build the capacity of families to find or create housing solutions for their family members with disabilities;
- Improve the professional development of direct support staff;
- Conduct research on the housing needs and resources of the Massachusetts autism community;
- Build the capacity of the housing sector to meet the residential needs of autistic individuals

AHP provides information, education, support and resources for families who seek to create and maintain secure, self-directed, supported housing for their adult children with disabilities using a person-centered approach that supports their residential, recreational and community needs.

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[210] Arnett JJ. (2000). Emerging adulthood: A theory of development from the late teens through the twenties. *American Psychologist, 55*(5): 469-480. http://dx.doi.org/10.1037/0003-066X.55.5.469

[211] Rindfuss RR. (Nov., 1991).The Young Adult Years: Diversity, Structural Change, and Fertility. *Demography, 28*(4):493-512.

[212] Settersten RA. (2006). *New Directions in the Sociology of Aging*. Panel on New Directions in Social Demography, Social Epidemiology, and the Sociology of Aging; Committee on Population; Division on Behavioral and Social Sciences and Education; National Research Council; Waite LJ, Plewes TJ, editors. Washington (DC): National Academies Press (US); 2013 Dec 26.

[213] Furstenberg FF & Kennedy S. (n.d.). *The Changing Transition to Adulthood in the U.S.: Trends in Demographic Role Transitions and Age Norms since 2001*. paa2013.princeton.edu/papers/132789.

[214] Mortimer JT & Larson RW. (2002). *The Changing Adolescent Experience: Societal Trends and the Transition to Adulthood*. U.K.: Cambride University Press.

[215] Shanahan MJ. (2000). Pathways to Adulthood in Changing Societies: Variability and Mechanisms in Life Course Perspective. *Annual Review of Sociology, 26*: 667-692. DOI: 10.1146/annurev.soc.26.1.667

Identified Needs: Housing

Quantitative Findings

National Studies

National Longitudinal Transition Study (NLTS2)

According to the National Longitudinal Transition Study (NLTS2)[216]:

> *Within 8 years of leaving high school… 59 percent of young adults with disabilities had lived independently at some time since high school. Fewer young adults had lived semi-independently since leaving high school (4 percent, p < .001)—a transitional living arrangement between "leaving the parental home and establishing an independent residence" (Goldscheider and Davanzo 1986, p. 187), including in a college dormitory, military housing, or a group home. When young adults with disabilities who were living independently or semi-independently were asked about their satisfaction with their living arrangement, 69 percent reported being satisfied with their residential arrangement, 24 percent said they would prefer living elsewhere, and 7 percent were ambivalent. The rates of living independently were significantly lower for young adults with autism at 17%, living semi-independently at 3.4%, and satisfaction of young adult living independently or semi-independently (45.8% vs. 76.7 for ID and 79.7 for TBI). Compared to young adults with other neurological disabilities such as ID (36%) or TBI (42.8%), young adults with autism were less likely to live independently (17%).*

National Autism Indicators Report on Transition to Young Adulthood

According to the *National Autism Indicators Report on Transition to Young Adulthood*, some people on the autism spectrum will eventually live independently as adults, but not all. Some will continue to need significant help. Even of those living independently, many still require some degree of support.

Table HO-1. Findings from the National Autism Indicators Report: Transition to Young Adulthood [217]

Living Arrangements	• One in five young adults on the autism spectrum never lived independently (away from parents without supervision) between high school and their early 20s. • Most (87%) of those with autism lived with their parents at some point between high school and their early 20s - a far higher percentage than in the general population of young adults. • Far fewer autistic young adults never lived independently after high school (19%) compared to over 60% of their peers with speech-language impairment or emotional disturbance and nearly 80% of those with learning disabilities.

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[216] Newman L, Wagner M, Knokey AM, Marder C, Nagle K, Shaver D, & Wei X. (September, 2011). In Chapter 5. Household circumstances of young adults with disabilities. *The Post-High School Outcomes of Young Adults With Disabilities up to 8 Years After High School: A Report From the National Longitudinal Transition Study-2 (NLTS2)*. U.S. Department of Education: National Center for Special Education Research (NCSER) 2011-3005.

[217] Roux AM, Shattuck PT, Rast JE, Rava JA & Anderson KA *National Autism Indicators Report: Transition into Young Adulthood*. Philadelphia, PA: Life Course Outcomes Research Program, A.J. Drexel Autism Institute, Drexel University, 2015.

State-Based Data

The Massachusetts child count of students with autism continues to grow (over 17,000 ages 3-21 in 2014), and at this point the Autism Housing Pathways (AHP) estimates the number of individuals likely to need affordable housing beyond that provided by Department of Developmental Services (DDS) over the next 20 years is most likely over 14,000.[218] Only about 13% of autistic individuals are likely to be DDS Priority One, 2% are likely to live completely independently, and about 85% need affordable, supported housing.

A 2012 AHP Housing Survey study reported an estimate of 12,000 Massachusetts students with autism using 2010 IDEA headcounts. Combined with the estimated fulltime employment rate for autistic adults at about 10%, there is an implied need for approximately 8-10,000 units of affordable housing over the next 20 years for autistic adults beyond housing provided by DDS.

Over the years, the AHP study has experienced limitations since the survey reflects a time when an IQ of 70 was still a bright line cut-off for DDS eligibility. However, while people with higher IQs and an autism diagnosis can now be found eligible, the Department is not budgeting for housing for those with autism without an ID. Another limitation was the absence of reliable state data on the total number of autistic people, which underscores the need to improve data collection in Massachusetts to understand this transitional need further. This concurs with a comprehensive 2009 report[219] by the Arizona collaborative, Opening Doors, that called for data collection to determine housing market needs for autistic people. The report cited challenges with projecting the size of the autism/DD population because most autistic adults live with their parents and, as a result, very little is known about the demographics and corresponding market demand. This could also be assumed for Massachusetts.

The 2012 AHP Housing Survey yielded a sample of 276 responses from email lists, organization membership outreach, and community outreach at autism-related events. Of the individuals described:

- 61% of 18 or older not eligible for services from DDS, but not able to live independently
- 42% of 18 or older not eligible for DDS or MassHealth state plan services, but not able to live independently

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[218] Personal interview, Catherine Boyle, Autism Housing Pathways, October 28, 2016.

[219] Resnik, D. & Blackbourn, J. (2009). *Opening Doors: Discussion Of Residential Options For Adults Living With Autism And Related Disorders*. Phoenix, AZ: Southwest Autism Research & Resource Center (SARRC).

Table HO-2. AHP Housing Survey Finding by Group

Key findings:	**Group 1 (ID)**	**Group 2 (No ID, prompts for 1+ ADLs)**	**Group 3 (help for 1+IADLs)**	**Group 4 (need quality control with 1+ IADLs)**	**Group 5 (independent in ADLs & IADLs)**
Group eligibility	DDS eligible	Possibly DDS eligible[220]; MassHealth: Adult foster care, family care, group adult foster care	No support service eligibility	No support service eligibility	Independent living
% Group Ages 18+	37%	19%	28%	14%	2%
Able to live independently	1.3%	3.7%	3%	16%	na
Able to live independently with periodic monitoring &/or assistance	6.3%	18.5%	45.5%	76%	na
Can be left alone up to 3 hours	7.5%	6.2%	13.6%	0%	na
Need someone present at all times, 1:8 staff: resident	10%	19.8%	15.2%	4%	na
Need someone present at all times, s2:4 staff: resident/day; 1:4 ratio at night	35%	27.2%	15.2%	0%	na
Need 3:5 staff:resident for behavior; overnight awake staff	33.8%	18.5%	1.5%	0%	na
Housing Type	33% favor group home owned/leased by families	21% favor group home owned/leased by families	14% favor group home owned/leased by families	Private home or condo	na

Other notable AHP Housing Survey findings include:

- The most popular living arrangements are living with parents or group living across the board.
- More restrictive preferences shared for Groups 1 & 2 versus less restrictive preferences for Group 3 & 4.
- A family-style living situation is more popular in Groups 1-3; more privacy is preferred for Group 4.
- A walkable location is most popular for most. Public transportation is more important for Groups 3 & 4.

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[220] With recent expansions in DDS eligibility

- A large percentage of respondents not aware of benefits (e.g., adult family care, adult foster care, group adult foster care, PCA services, public housing, Section 8 housing, public housing, food stamps).
- Evidence exists that respondents may believe they are ineligible for benefits when they are indeed eligible.

In the summer of 2016, AHP queried families online via the Facebook page *Massachusetts Autism Housing Think Tank*[221] to compile a list of 20 Housing Consensus Principles. A short sampling of the principles includes: a spectrum of adult living arrangements and supports; living arrangements should not be based on ability to participate in types of programming or employment; residential placement based on one's vision using a person-centered plan; ability to stay put in one's residence when providers change; choice and personal decision making should be supported. The full list may be found at their web site.

Homelessness for Youth with Autism in Massachusetts

"The State and Federal Policy Story of Homeless, Unaccompanied Youth Report" (Ferrier, 2015) states that homeless, unaccompanied youth are ineligible for almost all housing services and adult homeless shelters are not considered a safe and appropriate option. Such youth are defined as "a person 24 years of age or younger who is not in the physical custody or care of a parent or legal guardian, and who lacks a fixed, regular, and adequate nighttime residence" (EOHHS Special Commission for Homeless, Unaccompanied Youth, 2014).

The report found that Massachusetts does not have nearly enough resources to respond to the need of the estimated 5,000 homeless, unaccompanied youth who attend high school and the unaccounted youth who do not and the lack of housing options for these youth has hit a crisis level. Youth in foster care and the mental health system who are diagnosed with autism are far more susceptible to homelessness than the general population with many in the clinical "borderline functioning range." For those youth who reside in the Department of Children and Families (DCF) residential placements, a significant 38% have been diagnosed with autism (Ferrier, 2013, State System Shortchanges Youth with Autism). A recent survey of clinicians found that out of the 650 DCF/DMF shelter beds they monitor, 35% were occupied by autistic youth across all programs (Justice Resource Institute, n.d.). These numbers are expected to grow in the future.

> "Homelessness is becoming a problem. There is research that homelessness and living in shelters can be lethal for someone with a social disability like autism, more than for the general population. Research shows that autistics are 2% more likely to be LGBT and 7% more likely to be transgender. They are more likely to be on the street. Canadian studies have looked at this. Older autistics, over 22 years old tend to vanish from our awareness as adults because autism is associated with children. The thinking is that we are cured as adults."
>
> – Adult autistic self-advocate

For autistic youth, transition age is a critical developmental stage for executive function, which governs one's ability to "plan, organize, strategize, pay attention to and remember details, and manage time and space"[222]. Many experience executive functioning for their entire lives. When applied to seeking housing, it can compound their ability to overcome homelessness. The

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[221] https://www.facebook.com/MAAutismHousingThinkTank/

[222] National Center for Learning Disabilities website at http://www.ncld.org/.

implications include such risks as dropping out of high school or college, mental illness, sexual exploitation, chronic adult homelessness, and death.

Qualitative Findings

Self-Advocate Interviews

Self-advocate key informants shared a number of concerns about their housing needs. Housing was identified as a leading problem for autistic people. Affordable housing and voucher priorities stood out as priorities. Homelessness was mentioned as a particularly challenging concern.

An important need that often goes unrecognized for more independent people pertains to executive function challenges, such as navigating listings, finding landlords, living with others, and related social issues. Advocating for housing services and the money to pay for housing is difficult. Un- and under-employment add to this. For those who live alone, there are long waiting lists and they may end up in an isolated area because it costs a lot to live in the city. Many people do not drive due to spatial awareness issues and also must live in the city where it's more expensive. Additionally, housing providers may not be aware of one's autism. For many, challenges with self-advocacy skills can make it hard to express oneself and lead to melt down.

> "Accessibility needs for housing are not well known or understood for autistic adults as a physical disability would be. This varies significantly. A wheelchair user needs rooms to be a certain size to have clearance to turn with wider hallways, and so forth. This is standard. But autism is not standard. There is no standard list of accommodations. There are individual needs, not a baseline. You might need extra space for a PCA, lightbulbs switched from fluorescents, an apartment that is not on the street level due to noise. But this is less understood, even if you have affordable housing."
>
> – Adult autistic self-advocate

Housing accessibility needs were stressed as not well known or understood for autistic people as for those with physical disabilities. Physical accommodations, such as the amount of clearance needed to turn wheelchairs, are well-understood and thus, standard. Because the needs for autistic people are individual and not standard, there is no standard list of accommodations. For example, one might need extra space for a PCA, lightbulbs switched from fluorescents, an apartment not on the street due to noise, but this is less understood.

Self-advocate interviews revealed a need for a service to help find affordable housing to assist with executive function limitations. Other recommendations included training for housing agencies, public housing, and providers that include housing services. Training self-advocacy skills for transition whether a person needs to be supported or independent may help to identify the needs one has. Peer mentorship and making professionals aware could help.

Resources: Housing & Homelessness

Accessibility for autistic adults is neither well understood nor standardized, however there is a growing literature on architectural design for autistic people. According to Catherine Boyle of AHP, it is far enough advanced that designers and contractors can be educated about the most common accommodations, with checklists of additional features that might relate to certain individuals.

Three significant publications in this area are:

- Ahrentzen and Steele: "Advancing Full Spectrum Housing: Designing for Adults with Autism Spectrum Disorders" (https://stardust.asu.edu/docs/stardust/advancing-full-spectrum-housing/full-report.pdf)
- Brand: "Living in the Community: Housing Design for Adults with Autism" (http://www.kingwood.org.uk/downloads/research/living-in-the-community-housing-design-for-adults-with-autism.pdf)
- Braddock and Rowell: "Making Homes That Work: A Resource Guide for Families Living with Autism Spectrum Disorder and Co-occurring Behaviors" (http://parenttoparentnys.org/images/uploads/pdfs/Making_Homes_That_Work_A_Resource_Guide_(2).pdf)

Work is also being done in the UK on homelessness. They have developed a training tool for frontline staff, http://www.homeless.org.uk/sites/default/files/site-attachments/Autism%20%26%20HomelessnesOct%202015.pdf.

Additionally, a readily-available ten question screening tool, the Autism Quotient (AQ10), has been developed in the UK that could be used to start to quantify the numbers of autistic people who are homeless. It is available at: http://docs.autismresearchcentre.com/tests/AQ10.pdf.

Recommendations: Housing & Homelessness

For autistic youth, transition age is a critical developmental stage for executive function, which governs one's ability to "plan, organize, strategize, pay attention to and remember details, and manage time and space". Many experience executive functioning challenges for their entire lives. When applied to seeking housing, it can compound their ability to overcome homelessness. The implications include such risks as dropping out of high school or college, mental illness, sexual exploitation, chronic adult homelessness, and death. More state data is needed to be measured and monitored for the status of housing and homelessness for transition age youth and young adults with autism.

1.) Set Housing Targets and Monitor Progress on an Annual Basis.

Housing is a supplemental category added to this report and thus does not fall under the Maternal, Infant & Child Health (MICH) Outcome Indicators for Healthy People 2020 under CSHCN. It does not have targets related to its outcomes. The Massachusetts Autism Commission might consider setting targets for housing and homelessness based on the implications listed below, and if so, determine how and which data sources can be used to measure and monitor these core outcomes.

According to the 2012 AHP Housing Study, there is a disconnect between existing need and available services, particularly for those with intensive behaviors, but no ID; those who need constant supervision, but can perform ADLs; and those who might be able to function well enough to afford market rate housing with the provision of life coaching.

Housing implications include:

- Autistic individuals and their families need better education about supports, particularly MassHealth state plan services.
- Training residential staff in autism-specific supports is essential to successful outcomes.
- Modifying the built environment can improve outcomes.

Homelessness implications include:

- Homelessness is likely to be a serious issue. Better numbers are needed. Use of the Autism Quotient (AQ10) tool by shelters and hospitals may help, as would a question in the homeless census.

2.) BUILD AND MONITOR WORKFORCE CAPACITY AND DEVELOPMENT.

It is important to measure workforce capacity and to monitor workforce development through training to meet the outcome indicator listed above. In particular, training staff at the Department for Children and Families (DCF) in early preparation for transition in youth with ASD could prevent needless homelessness in this vulnerable population.

3.) CONSIDER RESEARCHING AND INVESTING IN PROMISING NEW HOUSING MODELS FOR FAMILIES OF CHILDREN AND YOUTH WITH AUTISM, AS WELL AS ADULTS WITH AUTISM.

- Legislative and administrative initiatives can help: a loan program for families to create accessory apartments, and zoning reform to permit such units by right. There is a need for a MassHealth state plan service to cover drop-in cueing services, and for MassHealth to cover assistive technology, including apps.
- In the absence of new funding, it is not scalable to fully mitigate the larger potential housing crisis over the next 20 years without development of "off the shelf" models.
- There is interest in, and potential for, "out of the box" solutions such as family-driven group homes and mixed income housing.
- For the younger population with autism who are less likely to have ID, it is even more urgent to develop additional residential supports beyond those provided by DDS; better data are needed to establish the actual need.
- MassHealth state plan services are needed that are a better fit with the support needs of the population.
- A range of affordable housing options is needed that meets the sensory and support needs of people not likely to be prioritized by DDS. This must include ways to empower families to create options, such as accessory units, on their own.
- Training for landlords and property managers is needed in how to relate to autistic tenants, and training for autistic people in the hidden curriculum of being a tenant.

CULTURAL CONSIDERATIONS

Throughout this report, racial, cultural and linguistic disparities across all six core outcome indicators for Healthy People 2020 have emerged as one of the largest areas of need for CYSHCN with autism. The following section will share information about cultural and linguistic considerations for serving children and youth with autism in Massachusetts. We will present qualitative insights from focus groups and adult self-advocate key informant interviews. Lastly, we will offer recommendations.

Background

The American Community Survey (ACS) data collected between 2010 - 2014 shows that 15.3% of people in Massachusetts are foreign born[223], and that number may likely increase in the future. In their December 23, 2015 state-level release, the U.S. Census Bureau estimated that the Massachusetts population had increased by 39,298 people from July 1, 2014 to July 1, 2015. Massachusetts experienced more births than deaths for a positive net natural increase of 17,813 persons (i.e., the difference between births and deaths). However, a larger share of this population growth was attributed to the positive net migration of 21,703 persons.[224]

Because it is essential to include the perspective of growing foreign-born and minority populations, the research team conducted six, 90-minute focus groups across the state with culturally and linguistically diverse parents of children and youth with autism across the state to better understand the effects of race, culture & language on the six core indicators. Two focus groups were held with Hispanic participants and one focus group each with Chinese, Haitian-Creole, Vietnamese, and African-American parents. Participants were recruited through local organizations.

Focus group questions were primarily about Early Identification, Access to Community Based Services, Medical Home, and Transition. Questions were translated into parents' native language, if necessary, and provided to participants in advance. Questions were translated ahead of time and culturally competent interpreters were provided on the day for all non-English speaking groups.

Identified needs: Cultural Considerations

Qualitative Findings

Focus Groups

The most commonly occurring themes across cultures were in the areas of Early Identification (EI), Access to Community Based Services, and language/culture barriers in communicating with schools and health care providers.

EARLY IDENTIFICATION. Participants consistently discussed language and cultural barriers to screening and diagnosis. Currently, screening forms given by health care providers to parents are primarily in English and this makes it difficult for parents to accurately complete the forms if their first language is not English.

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[223] http://www.census.gov/quickfacts/table/POP645214/25

[224] http://www.massbenchmarks.org/statedata/data/mdc2015/UMDI%20Summary%20US%20Census%202015%20MA%20MCD%20Population%20Estimates.pdf

Cultural differences may contribute to delayed screening or referrals. The African-American focus group members felt their children received delayed diagnoses because symptoms were incorrectly characterized as behavioral problems or ADHD, and not autism. There was great concern about not understanding racial differences in school systems.

Some participants described hesitancy on the part of the parents to mention early symptoms to the pediatrician due to pressure from within the culture or from interfamily blame and stigma.

> *"[In our culture] because it's so often boys, the men don't want to see anything wrong with them so that kind of hinders the moms [from seeking a diagnosis]." - African American parent of a youth with autism*

> *"In our community, if the child is delayed there is a belief that it's because the mother is not teaching the child. Another issue is that there are often many generations living in the same household, the parents might not be the decision makers. So the grandparents might want to wait [to mention symptoms to the PCP or follow-up with screening visits], not knowing about autism, and they might be blaming the mother for not teaching their child." - Vietnamese focus group*

Participants consistently identified daycare as a place where their child's autism symptoms were first identified. This was a comment unique to the cultural groups that was not heard from other parent groups with as much frequency.

Another common theme was the importance of the trust relationship with the child's PCP. This trust was enhanced by having a PCP who spoke the parents' language and/or who was culturally competent. This trust allowed parents to share concerns about their child's development.

ACCESS TO COMMUNITY BASED SERVICES. Culturally diverse participants consistently emphasized the importance of their cultural community. However, many participants expressed the isolation they felt from their family and community post-diagnosis. This was sometimes attributed to a misunderstanding in the cultural community about autism or a lack of knowledge about autistic traits.

> *"After I received the diagnoses, my family told me, 'Oh, it's no big deal, he'll be fine, the doctor will just give him medication and he'll be fine.' But it wasn't fine."*

The community response may not have been as helpful as many participants had hoped. They were frustrated further by trying to locate resources/services within their communities that were offered in their languages and which were easy to access. The majority of resources described by participants are in English. Other barriers to access included times that were not convenient for parents, difficulty with transportation, and cost.

Additionally, many participants reported that resource information provided post-diagnosis by the pediatrician was primarily in English.

> *"After my child was diagnosed, the doctor printed out some Google stuff for me and asked, 'Can you access Google stuff at home? How much English do you understand?' - Parent of a young adult with autism.*

The sense among participants was that this wasn't particularly helpful.

Some participants, especially those in and around Boston, explained the difficulties they had maintaining steady employment, housing, and transportation. This sometimes interfered with their ability to access services as those are most often scheduled during the day and would require the parent taking time off from work to attend.

> *"For a lot of families, Autism is not the priority; they are trying to get a roof over their heads"*
> *Cultural Liaison*

Smaller minority groups in general, including the Haitian and Vietnamese communities, felt there were not sufficient resources put towards support services such as case management.

> *"If you know there are services and ask for them, they will not give them. No reason why. They shut you out – schools and hospitals". –Parent of a transition-aged youth with autism.*

The expectation among participants was that a resource located in a majority-minority community (such as Chinatown or Lawrence) would provide sufficient bilingual and bicultural resources to the community. This includes positions funded for a sufficient amount of time (i.e., fulltime, not part-time). This was not often realized.

For African-American focus group members, there was great concern that most systems of care do not fully understand racial differences for CYSHCN with autism and do not address their needs appropriately.

LANGUAGE AND CULTURAL BARRIERS IN COMMUNICATING WITH SCHOOLS. Parents most frequently discussed education in the focus groups and it was often the first topic on their minds. Many parents described difficulties receiving educational documents in their native languages,

> *"They used to do the IEP in English. But then weeks later send it home in Spanish. But they had me sign at the meetings [in English]. But when I showed it to someone they said that's not right." – Parent of a school-aged child*

Parents described growing pressure from schools to speak to their children in English at home. Some participants reported that doctors also told them the reason their child had language problems was because a different language other than English was spoken at home, in spite of the fact that research shows that speaking one's own native language at home does not cause language disorders though it may delay language only slightly. Research confirms that learning English is best done by native English speakers such as teachers. Parents are encouraged to speak their own native language at home to model it in its best form.

Participants consistently reported difficulties obtaining translators and interpreters for educational and medical appointments.

> *"Sometimes we ask for the translator 3 weeks in advance, but at the last minute they tell us that there is no translator. So in that moment they continue to roll on, they have the meeting without a translator." -Parent of a school-aged child.*

Two different groups in two different areas of the state mentioned that schools relied on any available staff who spoke the language to translate in IEP meetings. In both instances, this was the cafeteria staff.

> *"In this area, many of the families were not successful in school and so school is not a happy place. And it turns out that the lunch ladies were doing the translating. Translation is a really a big skill [and the lunch ladies were not necessarily skilled translators with vocabulary for all situations and/or cultural nuance]. And people don't want to talk about their own experiences for fear that the lunch ladies would spread the information." -Parent of teenager with autism and advocate.*

In another instance, a parent described having to rely on the district speech language pathologist to interpret.

> *"I felt like she wasn't a nonpartisan third person, and so I feel like there was a bit of a conflict of interest and if I had had a non-partisan third party than they wouldn't have stake either way and I might have known all my rights" -Parent of a transition-age youth.*

Some participants described feeling 'ignored' or 'not taken seriously' by the schools because of their minority culture.

> *"The school is supposed to send home the documents interpreted. They ignore us or they translate it with Google Translate and it's not understandable…sometimes we have to read the documents 5-6 times and we still don't know what they mean" -Parent of a school-age child.*

Many participants described a growing trend within the medical and education communities to rely on Google translate to translate important documents. However, that translation may not be very accurate.

> *"80% of the IEP's I read appear to have been translated by google translate. The translation is not very good or very clear." - Cultural Specialist and Educational Advocate.*

WHAT DO YOU NEED? The research team covered many themes with culturally-diverse participants, but ultimately wanted to get to the bottom line on prioritizing needs. At the end of each focus group, the research team asked, 'What do parents of children with autism/DD need most?'

> ***HIGH-QUALITY, APPROPRIATE INTERPRETERS.*** Parents strongly responded that there is a critical need for high-quality, appropriate interpreters in the public school system so that all parents can fully participant in their child's IEP. This applies to the daily communication logs between home and school as well.
>
> ***BILINGUAL, BICULTURAL PROFESSIONALS FOR HOME-BASED SERVICES.*** Additionally, there is need for bilingual, bicultural professionals for home-based services such as ABA therapy or speech language therapy.
>
> *"Because of the language difference, the therapist did not include the family. Bilingual professionals are critical so that parents can understand the message and bring the therapy back home." -Parent Leader*

BILINGUAL/BICULTURAL PROFESSIONALS. Parents also felt strongly that bilingual/bicultural professionals are needed to inform communities about early signs of Autism and to communicate resources, offer support, and help advocate.

"There is a great need for training programs about what is autism because there are a lot of myths about what autism is. There needs to be family-friendly materials that cross the life span. This would help break up myths across the community." -Parent Leader

Other needs mentioned:

- Autism information given to parents in their language at the time of diagnosis.
- Services for high-functioning autism, especially in non-white cultures.
- Social skills training for parents on how to help their children with autism.
- Education about their parental rights.
    - *"They used to do the IEP in English. But then weeks later send it home in Spanish. But they had me sign at the meetings [in English] but when I showed it to someone they said that's not right." ~ Parent*
- School advocates who speak their language/know their culture.
- Basic training on autism for parents new to the system but also more advanced training on subjects such as educational rights for more experienced parents.

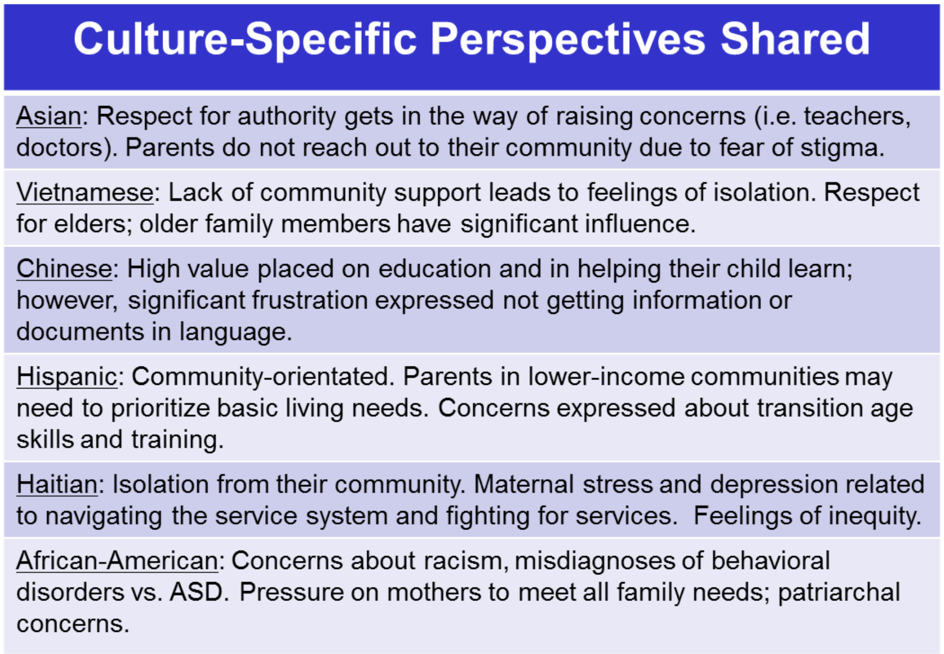
"Language barriers are serious. People from Brazil, the Dominican Republic, Haiti, need additional cultural competence with disability. How much their issues are autism or culture shock or a language barrier is hard to peel apart. There's a lot of under-diagnosis in other cultures, but also for U.S. people of color and immigrants on top of that."

– Adult autistic self-advocate who represents a self-advocacy network

Comparative Findings across Focus Groups

Each focus group had their own unique concerns about their interactions as family members with the various service systems for CYSHCN with autism, as well as their own extended families and communities, based on their cultural or racial backgrounds and experiences. The table below highlights some of the predominant findings from focus group transcripts. These findings speak to the participants' most prized values and beliefs and their deepest concerns about how systems interact with their children and families.

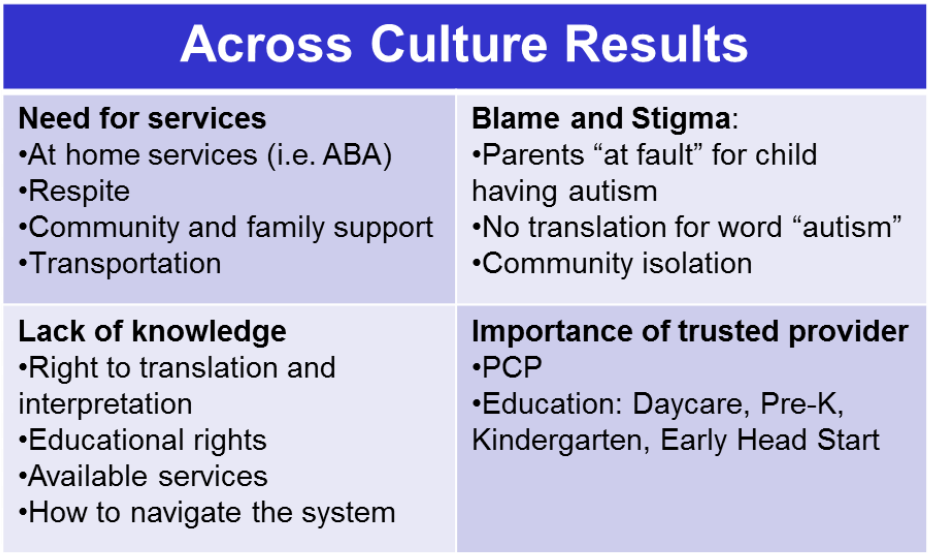
Table CL-1. Culture-Specific Perspectives Shared Within Focus Groups.



Culture-Specific Perspectives Shared
Asian: Respect for authority gets in the way of raising concerns (i.e. teachers, doctors). Parents do not reach out to their community due to fear of stigma.
Vietnamese: Lack of community support leads to feelings of isolation. Respect for elders; older family members have significant influence.
Chinese: High value placed on education and in helping their child learn; however, significant frustration expressed not getting information or documents in language.
Hispanic: Community-orientated. Parents in lower-income communities may need to prioritize basic living needs. Concerns expressed about transition age skills and training.
Haitian: Isolation from their community. Maternal stress and depression related to navigating the service system and fighting for services. Feelings of inequity.
African-American: Concerns about racism, misdiagnoses of behavioral disorders vs. ASD. Pressure on mothers to meet all family needs; patriarchal concerns.

There were a number of common themes that emerged from the focus groups as well. The table below highlights four predominant themes that arose from the focus group transcripts: the need for services, community blame and stigma, families' lack of knowledge, and the importance of trusted providers.

Table CL-2. Across Culture Focus Group Results



Across Culture Results

Need for services •At home services (i.e. ABA) •Respite •Community and family support •Transportation	**Blame and Stigma**: •Parents "at fault" for child having autism •No translation for word "autism" •Community isolation
Lack of knowledge •Right to translation and interpretation •Educational rights •Available services •How to navigate the system	**Importance of trusted provider** •PCP •Education: Daycare, Pre-K, Kindergarten, Early Head Start

Self-Advocate Interviews

Self-advocates weighed in on issues of culture, language and diversity as well. When addressing adults' needs, it is important to consider the multi-layered nature of diversity. As one self-advocate stated,

> *"Being CLD is different than being white. Recognizing real cultural differences and life perspectives can be different in seeing systems. This is tied to experiences culturally. Gender issues and culture can be completely different experiences as well. The idea that we are all equal and treat everyone as a blank slate – all the same – is doing nobody a service. For example, transgender people have different support needs so you can't treat all the same. You have to recognize that there's more than one access point to identity or experience and this impacts individuals greatly."*

Several self-advocates commented on the prevalence of people with autism who have gender differences.

> *"There has been empirical research that autism people at a higher rate have non-binary, gender non-conforming, transgender identities. There are many theories about this. All have a basis in truth."*

Recommendations: Cultural Considerations

There were a number of common themes that emerged in cultural focus groups. Four predominant themes included: the need for services, community blame and stigma, families' lack of knowledge, and the importance of trusted providers. Family members from the same culture also expressed a number of culture-specific needs. The most common categories of disparities included: early identification, access to community-based services, language and cultural barriers in communicating with schools, as well as high quality interpreters, home-based services and bi-lingual, bi-cultural professionals.

Predominant expressed needs included: information given to parents in their language at the time of diagnosis; services for high-functioning autism, especially in non-white cultures; social skills training for parents on how to help their children with autism; education about their parental rights; school advocates who speak their language/know their culture; and basic training on autism for parents new to the system but also more advanced training on subjects such as educational rights for more experienced parents.

1.) SET REDUCTION OF CULTURAL DISPARITIES TARGETS AND MONITOR PROGRESS ON AN ANNUAL BASIS.

Race, culture and language are components of a supplemental category added to this report and thus do not fall under the Maternal, Infant & Child Health (MICH) Outcome Indicators for Healthy People 2020 under CSHCN. They do not have targets related to outcome measures. The Massachusetts Autism Commission might consider setting targets for reducing possible disparities for these subpopulations within each of the six core outcome indicators and other supplemental categories such as education and housing based on the implications raised in this section. If so, reviewers should determine how and which data sources can be used to measure and monitor these core outcomes, as well as set appropriate targets for achievement.

These subcategories of data are available through the national surveys which would require a larger data sample, but should also be drilled down in the various state-based data sources presented in this report for better understanding.

2.) BUILD AND MONITOR WORKFORCE CAPACITY AND DEVELOPMENT.

To build better cultural competence across the state, it is important to build and measure workforce capacity and to monitor workforce development through training.

Early Childhood programs such as the state's CFCEs and the Thrive in 5 Program are well-positioned to assist parents from all cultures in learning about developmental monitoring and what to do when there is a concern. Focus group participants commented in particular on the help they get in daycare and early childhood education centers. Strengthening this workforce could assist many families from minority communities.

Increasing the workforce of interpreters and translators who not only speak a family's language, but understand the culture is essential when assisting them to access critical information about their child in settings such as schools and health care practices. Moreover, these professionals should also have some understanding of the terminology unique to autism and development as appropriate.

Bilingual, bicultural professionals for home-based services such as ABA or speech therapy or in-patient settings such as pediatric offices and hospitals are much needed.

The "Considering Culture in Autism Screening" curriculum was designed by Massachusetts Act Early to address these needs and is flexible enough to adapt to a variety of professions outside of screening. It may have some application in building a more informed, culturally competent workforce.

Being able to measure the number of trained professionals and monitor progress in this regard are important, though may be difficult requiring innovation in determining a method for data capture.

3.) ADDRESS RELATED ISSUES FOR CULTURAL AND LINGUISTIC ACCESS.

Culturally and linguistically competent information, resources, and services are essential to help families of children with autism move beyond common obstacles to meeting their needs. At present, state service and support systems may not be fully structured to accommodate diverse needs.

- A one stop, multilingual online information & referral source for families and professionals that explains systems & processes, such as the state information & referral site INDEX.
- Adherence of IEPs and related communications to federal law for translations.
- Promotion of the CDC's Act Early campaign that provides developmental milestones information in multiple languages.
- Recruitment of trained bi-cultural and bi-lingual professionals from the fields of health care, education, advocacy, and clinical therapy.
- Training to promote cultural competence in the medical home.
- Improve interpretation services.
- Cultural 'hubs' in majority-minority communities like Chinatown or Lawrence to provide sufficient bilingual and bicultural resources to the community.

FINAL RECOMMENDATIONS

Healthy People 2020 State Autism Roadmap

Overarching Recommendations

Certain recommendations cut across several of the core outcome indicators. The following represent the main recommendations of this report based on the needs shared in each of the report sections:

1.) Set targets and monitor progress for Healthy People 2020 indicators and other topics that do not have indicators.

2.) Obtain large data samples to better understand needs and inform policy and resource planning needs.
   a. Either oversample national survey data for Massachusetts or conducting a similar survey in the state
   b. Leverage existing and emerging electronic data resources in the state
   c. Investigate linking state databases, particularly emerging ones

3.) Build and monitor workforce capacity, training and development.
   a. Monitor the number of pediatric and specialty physicians in the state for capacity building
   b. Invest in workforce development to increase the number of trained professionals across indicators

4.) Prioritize understanding racial, cultural and regional disparities.

5.) Share Massachusetts MCHB Core Outcome Indicator Data online with the public.

6.) Employ innovative practices to approaching data collection and analysis.
   a. Fully engage community organizations, families and self-advocates
   b. Review the intersection of government and university research
   c. Invite other states to share promising practices
   d. Conduct focus groups to monitor public response

APPENDICES

Prevalence Data

Early Identification Data

Medical Home Data

Access to Care Data

Family Involvement Data

Insurance Data

Education Data

Healthy People 2020 State Autism Roadmap Fact Sheet

Glossary

Acronyms

2016 Annual Report of the Autism Commission

Massachusetts Autism Omnibus Law Fact Sheet

Healthy Vermonters 2020 Dashboard Example

State Public Health Autism Resource Center Fact Sheet

Prevalence Data

Table P-8. Children currently have autism or autism spectrum disorder, age 2-17, NSCH, 2011-2012

		Do not have ASD	Currently have ASD
U.S.	*%*	97.8%%	1.8%
	C.I.	(97.6-98.0%)	(1.6-2.0%)
	n	83,515	1,624
	Pop. Est	64,0002,605	1,174,871
Massachusetts	*%*	97.4%	2.2%
	C.I.	(96.4 - 98.5%)	(1.2 - 3.2%)
	n	1,609	31
	Pop. Est.	1,223,664	27,7618

C.I. = 95% Confidence Interval. Percentages are weighted to population characteristics.

n = cell size. Use caution in interpreting cell sizes less than 50

Frequency Missing = 214

Table P-9. CSHCN age 2-17 have with Autism, Asperger, PDD or other ASD (NS-CSHCN, 2009-10)

		Do not have ASD	Currently have ASD
U.S.	*%*	89.7%	7.9%
	C.I.	(89.1 - 90.2%)	(7.4-8.4%)
	n	34,791	3,055
	Pop. Est	9,487,574	839,275
Massachusetts	*%*	88.7%	8.6%
	C.I.	(85.6 - 91.8%)	(6.2-11.1%)
	n	667	74
	Pop. Est	217,627	21,183

C.I. = 95% Confidence Interval. Percentages ae weighted to population characteristics.

n = cell size. Use caution in interpreting cell sizes less than 50

Frequency missing = 31

Table P-10. CYSHCN who currently have autism by age, NS-CSHCN 2009-10

		0-5 years old	6-11 years old	12-17 years old	Total
All U.S. CSHCN	*%*	20.8%	38.7%	40.6%	
	C.I.	(20.0-21.5%)	(37.8 - 39.5%)	(39.7 - 41.4%)	
	n	7,294	15,834	17,114	40,242
	Pop. Est	2,307,940	4,292,126	4,501,684	11,101,750
All U.S. CSHCN with ASD	*%*	18.12%	46.44%	35.44%	
	C.I.	(15.6 - 20.6%)	(43.2 - 49.6%)	(32.5 - 38.4%)	
	n	460	1,416	1,179	3,055
	Pop. Est	152,075	389,769	297,431	839,275
All MA CSHCN	*%*	16.7%	38.4%	44.9%	
	C.I.	(13.4- 20.1%)	(33.9 - 42.9%)	(40.4 - 49.4%)	
	n	128	301	359	788
	Pop. Est	43,271	99,381	116,034	258,686
*All MA CSHCN with ASD**	*%*	12.0%	41.1%	47.0%	
	C.I.	(3.5-20.4%)	(27.5-54.7%)	(31.8-62.1%)	
	n	11	34	29	74
	Pop. Est	2,535	8,702	9,946	21,183

C.I. = 95% Confidence Interval. Percentages ae weighted to population characteristics.

n = cell size. Use caution in interpreting cell sizes less than 50

Note: Given the range of the estimates, it appears that the sample size may be too small to meaningfully estimate the percentage of children by age with ASD in Massachusetts.

Frequency missing = 31

Table P-11. CYSHCN who currently have autism by race/ethnicity, NS-CSHCN 2009-10

		Hispanic	**White, non-Hisp**	**Black, non-Hisp**	**Other, non-Hisp**	**Total**
All U.S. CSHCN	*%*	16.8%	59.3%	16.1%	7.8%	
	C.I.	(16.0 - 17.2%)	(58.4 - 60.2%)	(15.4 - 16.9%)	(7.4 - 8.2%)	
	n	4,479	27,989	4,010	3,764	40,242
	Pop. Est	1,859,879	6,579,873	1,790,890	871,109	11,101,751
All U.S. CSHCN with ASD	*%*	16.4%	62.7%	10.4%	10.6%	
	C.I.	(13.9 - 18.9%)	(59.4 - 66.0%)	(8.4 - 12.3%)	(7.7 - 13.3%)	
	n	340	2,202	212	301	3,055
	Pop. Est	137,642	526,045	87,003	88,585	839,275
All MA CSHCN	*%*	14.5%	72.2%	6.7%	6.6%	
	C.I.	(10.4 - 18.6%)	(67.5 - 76.9%)	(3.9 - 9.5%)	(4.4 - 8.7%)	
	n	80	625	30	53	788
	Pop. Est	37,550	186,746	17,368	17,022	258,686
*All MA CSHCN with ASD**	*%*	13.4%	77.6%	0.0%	9.0%	
	C.I.	(0.9-25.9%)	(63.5-92.7%)	-	(0.05 - 17.9%)	
	n	6	63	0	5	74
	Pop. Est	2,844	16,437	0	1,902	21,183

C.I. = 95% Confidence Interval. Percentages ae weighted to population characteristics.

n = cell size. Use caution in interpreting cell sizes less than 50

Note: Given the range of the estimates, it appears that the sample size may be too small to meaningfully estimate the percentage of children with ASD by race/ethnicity within Massachusetts.

Frequency missing = 31

Table P-12. CYSHCN with ASD by specified level of income according to the Federal Poverty Level, NS-CSHCN 2009-10

		0-99% FPL	**100-199% FPL**	**200-399% FPL**	**400% FPL or greater**	**Total**
All U.S. CSHCN	*%*	22.2%	21.9%	28.5%	27.4%	
	C.I.	(21.5-23.0%)	(21.1 - 22.6%)	(27.7 - 29.3%)	(26.7 - 28.2%)	
	n	6,899	7,722	12,572	13,049	40,242
	Pop. Est	2,469,569	2,425,959	3,163,784	3,042,439	11,101,751
All U.S. CSHCN with ASD	*%*	18.9%	21.7%	31.7%	27.7%	
	C.I.	(16.4 - 21.4%)	(19.2 - 24.2%)	(28.6 - 34.8%)	(24.9 - 30.5%)	
	n	489	639	984	943	3,055
	Pop. Est	158,820	181,789	266,256	232,410	839,275
All MA CSHCN	*%*	14.1%	15.9%	27.8%	42.2%	
	C.I.	(10.05 - 18.15%)	(11.96 - 19.77%)	(23.89 - 31.77%)	(37.96 - 46.43%)	
	n	77	84	217	410	788
	Pop. Est	36,483	41,039	72,007	109,157	258,686
*All MA CSHCN with ASD**	*%*	8.4%	11.9%	36.2%	43.5%	
	C.I.	(0.0 - 19.9%)	(2.4 - 21.5%)	(21.4 - 50.9%)	(29.5 - 57.5%)	
	n	3	7	27	37	74
	Pop. Est	1,771	2,529	7,667	9,215	21,182

C.I. = 95% Confidence Interval. Percentages ae weighted to population characteristics.

n = cell size. Use caution in interpreting cell sizes less than 50

Note: Given the range of the estimates, it appears that the sample size may be too small to meaningfully estimate the percentage of children with ASD by FPL % within Massachusetts.

Frequency missing = 31

Table P-13. Would you (parent) describe child's Autism or ASD as mild, moderate or severe? (NSCH, 2011-12)

		Does not have ASD	Current ASD, mild	Current ASD, moderate or severe
U.S.	*%*	98.2%	`0.9%	0.9%
	C.I.	(98.1 – 98.4%)	(0.8-1.0%)	(0.7-1.0%)
	n	83,858	889	726
	Pop. Est.	64,263,099	607,450	562,594
Massachusetts	*%*	97.8%	1.2%	1.0%
	C.I.	(96.7 -98.8%)	(0.5 – 2.0%)	(0.3 – 1.7%)
	n	1616	17	14
	Pop. Est.	1,228,250	15,339	12,279

C.I. = 95% Confidence Interval. Percentages are weighted to population characteristics.
n = cell size. Use caution in interpreting cell sizes less than 50
Frequency missing = 214

Table P-14. Would you (parent) describe child's Autism or ASD as mild, moderate or severe? (NS-CSHCN, 2009-10)

		Does not have ASD	Current ASD, mild	Current ASD, moderate or severe
U.S.	*%*	92.1%	3.9%	4.0%
	C.I.	(91.6-92.6%)	(3.6-4.2%)	(3.6-4.3%)
	n	35,658	1,587	1,450
	Pop. Est.	9,740,195	411,861	420,213
Massachusetts	*%*	91.4%	3.6%	5.1%
	C.I.	(88.9-93.8%)	(2.3-4.8%)	(2.9-7.2%)
	n	863	37	37
	Pop. Est.	224,177	8,729	12,454

C.I. = 95% Confidence Interval. Percentages are weighted to population characteristics.
n = cell size. Use caution in interpreting cell sizes less than 50
Frequency missing = 31

Early Identification Data

Developmental Screening

Table EI-22. How old was your child when a doctor or other health care provider first told you that s/he had autism or ASD? NSCH 2011-12

		Diagnosed at birth to 2 years of age	Diagnosed at 3-5 years of age	Diagnosed at 6-10 years of age	Diagnosed at 11-17 years of age	Total
All U.S. CSHCN with ASD	*%*	26.2%	39.4%	26.8%	7.5%	
	C.I.	(22.1-30.4%)	(34.7-44.2%)	(22.3-31.3%)	(5.5-9.6%)	
	n	448	780	566	210	2,004
*All MA CSHCN with ASD**	*%*	20.3%	52.8%	20.0%	6.9%	
	C.I.	(0.0-60.3%)	(0.0-100%)	(0.0-49.7%)	(0.0-20.9%)	
	n	7	16	7	1	31

C.I. = 95% Confidence Interval. Percentages ae weighted to population characteristics.

n = cell size. Use caution in interpreting cell sizes less than 50

Note: Given the range of the estimates, it appears that the sample size may be too small to meaningfully estimate the percentage of children with ASD by FPL % within Massachusetts.

Table EI-23. How old was your child when a doctor or other health care provider first told you that s/he had autism or ASD? NS-CSHCN 2009-10

		Diagnosed at birth to 2 years of age	Diagnosed at 3-5 years of age	Diagnosed at 6-10 years of age	Diagnosed at 11-17 years of age	Total
All U.S. CSHCN with ASD	*%*	26.9%	44.7%	22.0%	6.4%	
	C.I.	(23.9-29.9%)	41.5-47.9	(19.6-24.4%)	(5.1-7.7%)	
	n	713	1,298	790	229	3,030
	Pop. Est	224,010	372,355	183,371	53,170	832,906
*All MA CSHCN with ASD**	*%*	25.2%	43.4%	19.9%	11.5%	
	C.I.	(14.2-36.3%)	(28.4-58.5%)	(10.2-29.6%)	(0.0-23.2%)	
	n	23	27	17	7	74
	Pop. Est	5,340	9,203	4,209	2,431	21,183

C.I. = 95% Confidence Interval. Percentages ae weighted to population characteristics.

n = cell size. Use caution in interpreting cell sizes less than 50

Note: Given the range of the estimates, it appears that the sample size may be too small to meaningfully estimate the percentage of children with ASD by FPL % within Massachusetts.

Frequency missing = 31

Table EI-24. What type of doctor or other health care provider first told you your child had ASD? Massachusetts Data (NSCH, 2011-2012)

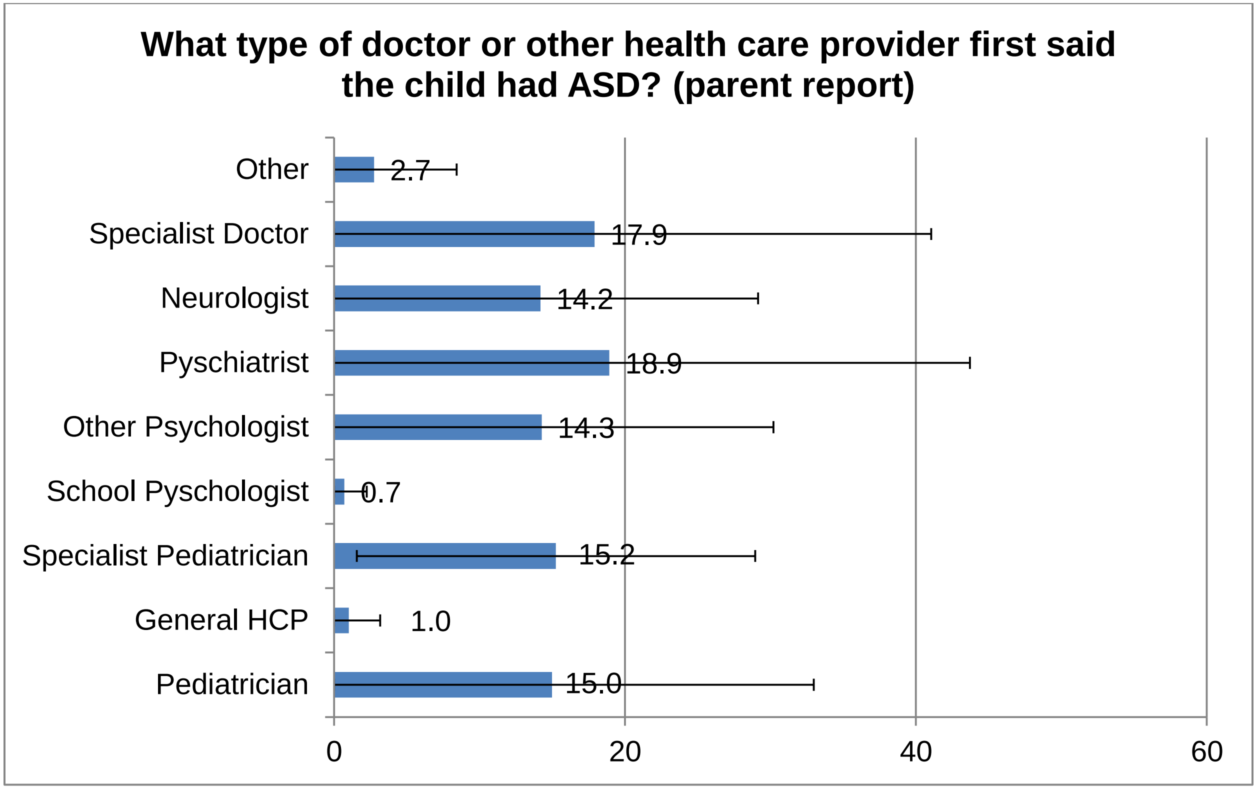


Table EI-25. Type of doctor or other health care provider who first told you child had autism or ASD, NSCH 2011-12

	National			Massachusetts		
Type	**n**	**%**	**C.I.**	**n**	**%**	**C.I.**
Pediatrician or other general pediatric H.C. provider	407	21.55%	(17.75 - 25.35%)	5	15.0%	(0.0 - 32.9%)
Another type of H.C. provider	46	2.35%	(0.99 - 3.71%)	1	1.0%	(0.0 - 3.2%)
Specialist pediatrician such as DBP	304	15.78%	(12.19 - 19.37%)	7	15.3%	(1.6 - 28.9%)
School psychologist - counselor	130	6.40%	(3.09 - 9.75%)	1	0.7%	(0.0 - 2.2%)
Other psychologist (non-school)	308	13.29%	(10.29 - 16.29%)	5	14.3%	(0.0 - 30.2%)
Psychiatrist (medical doctor)	303	12.13%	(9.55 - 14.72%)	2	18.9%	(0.0 - 43.7%)
Neurologist	209	10.53%	(8.04 - 13.02%)	5	14.2%	(0.0 - 29.2%)
School nurse	6	0.48%	(0.0014 - 0.96%)	na		
PT, OT, SLP or other therapist	47	1.73%	(0.82 - 2.64%)	na		
Specialist doctor other than DBP, psychiatrist, or neurologist	152	10.42%	(6.54 - 14.28%)	4	17.9%	(0.0 - 41.1%)
Other	52	2.36%	(0.0 - 8.42%)	1	2.74%	(0.0 - 8.42%)
Was not told by doctor or other health professional	41	1.63%	(1.02 - 3.70%)	na		
Don't know	33	1.16%	(0.74 - 2.52%)	na		
Refused	3	0.17%	0.50 - 1.73%)	na		
Total	2,041			31		

C.I. = 95% Confidence Interval. Percentages ae weighted to population characteristics.

n = cell size. Use caution in interpreting cell sizes less than 50

Note: Given the range of the estimates, it appears that the sample size may be too small to meaningfully estimate the types of physicians diagnosing within Massachusetts.

Table EI-26. EI Catchment areas and % of Population served

EI Catchment Areas		Birth Population (2012+ 2013+ 2014)	Early Intervention			% of Population Served by EI		No. of EI Centers
	Cities and Towns		Total Served	ASD Served	% Served for ASD	Total Served	ASD Served	
	Totals	***215,941***	***38,478***	***2,036***	***5.29%***	***17.82%***	***0.94%***	***60***
1	Acton, Bedford, Boxborough, Carlisle, Concord, Lincoln, Littleton, Maynard, Stow	2,420	428	26	6.07%	17.69%	1.07%	1
2	Ashburnham, Barre, Gardner, Hardwick, Hubbardston, New Braintree, Oakham, Princeton, Rutland, Templeton, Westminster, Winchendon	2,159	300	32	10.67%	13.90%	1.48%	1
3	Ashby, Ayer, Berlin, Bolton, Clinton, Fitchburg, Groton, Harvard, Lancaster, Leominster, Lunenberg, Pepperell, Shirley, Sterling, Townsend	5,638	810	59	7.28%	14.37%	1.05%	1
4	Ashland, Dover, Framingham, Holliston, Hopkinton, Natick, Sherborn, Sudbury, Wayland	6,312	907	60	6.62%	14.37%	0.95%	2
5	Attleboro, Foxboro, Mansfield, North Attleboro, Norton	3,915	756	32	4.23%	19.31%	0.82%	1
6	Auburn, Boylston, Holden, Leicester, Paxton, Shrewsbury, West Boylston, Worcester.	10,120	1,999	108	5.40%	19.75%	1.07%	4
7	Barnstable, Bourne, Brewster, Chatham, Chilmark, Dennis, Eastham, Edgartown, Falmouth, Gay Head, Harwich, Mashpee, Nantucket, Oak Bluffs, Orleans, Provincetown, Sandwich, Tisbury, Truro, Wellfleet, West Tisbury, Yarmouth	5,519	765	24	3.14%	13.86%	0.43%	1
8	Beacon Hill , Charlestown, Chelsea, East Boston, North End, Revere, Winthrop	8,430	935	57	6.10%	11.09%	0.68%	1
9	Becket, Cheshire, Dalton, Hancock, Hinsdale, Lanesborough, Lee, Lenox, Peru, Pittsfield, Richmond, Tyringham, Washington, Windsor	2,132	373	9	2.41%	17.50%	0.42%	1
10	Belchertown, Chicopee, Granby, Holyoke, Ludlow, Monson, Palmer, South Hadley, Southampton, Ware	5,969	1,208	123	10.18%	20.24%	2.06%	2
11	Bellingham, Blackstone, Douglas, Franklin, Grafton, Hopedale, Medway, Mendon, Milford, Millbury, Millville, Northbridge, Sutton, Upton, Uxbridge	5,918	922	83	9.00%	15.58%	1.40%	1
12	Acushnet, Dartmouth, Fairhaven, Gosnold, Marion, Mattapoisett, New Bedford, Rochester, Wareham	6,085	1,162	66	5.68%	19.10%	1.08%	2
13	Belmont, Waltham, Watertown	4,776	673	30	4.46%	14.09%	0.63%	1
14	Berkley, Dighton, Lakeville, Middleboro, Raynham, Rehoboth, Seekonk, Taunton	4,243	840	36	4.29%	19.80%	0.85%	1
15	Beverly, Essex, Gloucester, Hamilton, Ipswich, Manchester, Rockport, Topsfield, Wenham	3,018	615	32	5.20%	20.38%	1.06%	1
16	Billerica, Chelmsford, Dracut, Dunstable,	9,862	2,483	105	4.23%	25.18%	1.06%	3

EI Catchment Areas		Birth Population (2012+ 2013+ 2014)	Early Intervention			% of Population Served by EI		No. of EI Centers
	Cities and Towns		Total Served	ASD Served	% Served for ASD	Total Served	ASD Served	
& 17	Lowell, Tewksbury, Tyngsborough, Westford							
18	Boston (except Beacon Hill, Charlestown, East Boston), Brookline	22,004	2,923	192	6.57%	13.28%	0.87%	5
19	Braintree, Cohasset, Hingham, Hull, Norwell, Scituate. Weymouth	4,900	685	29	4.23%	13.98%	0.59%	1
20	Brimfield, Brookfield, Charlton, Dudley, East Brookfield, Holland, North Brookfield, Oxford, Southbridge, Spencer, Sturbridge, Wales, Warren, Webster, West Brookfield	3,570	753	28	3.72%	21.09%	0.78%	2
21	Abington, Avon, Bridgewater, Brockton, East Bridgewater, Easton, Holbrook, Rockland, Stoughton, West Bridgewater, Whitman	9,233	1,956	60	3.07%	21.18%	0.65%	2
22	Cambridge, Somerville	6,727	797	34	4.27%	11.85%	0.51%	2
23	Adams, Clarksburg, Florida, New Ashford, North Adams, Savoy, Williamstown	769	230	6	2.61%	29.91%	0.78%	1
24	Canton, Dedham, Medfield, Millis, Norfolk, Norwood, Plainville, Sharon, Walpole, Westwood, Wrentham	5,409	1,047	64	6.11%	19.36%	1.18%	2
25	Carver, Duxbury, Halifax, Hanover, Hanson, Kingston, Marshfield, Pembroke, Plymouth, Plympton	4,493	713	29	4.07%	15.87%	0.65%	1
26	Danvers, Lynn, Lynnfield, Marblehead, Middleton, Nahant, Peabody, Salem, Saugus, Swampscott	10,390	2,187	108	4.94%	21.05%	1.04%	2
27	East Longmeadow, Hampden, Longmeadow, Springfield, Wilbraham	7,767	2,161	168	7.77%	27.82%	2.16%	3
28	Everett, Malden, Medford	6,617	816	53	6.50%	12.33%	0.80%	2
29	Fall River, Freetown, Somerset, Swansea, Westport	4,519	1,329	29	2.18%	29.41%	0.64%	1
30	Hudson, Marlborough, Northborough, Southborough, Westborough	3,417	645	23	3.57%	18.88%	0.67%	1
31	Melrose, North Reading, Reading, Stoneham, Wakefield	3,880	582	29	4.98%	15.00%	0.75%	1
32	Milton, Quincy, Randolph	5,729	852	59	6.92%	14.87%	1.03%	1
33	Needham, Newton, Wellesley, Weston	4,064	622	32	5.14%	15.31%	0.79%	1
34	Agawam, Blanford, Chester, Granville, Huntington, Middlefield, Montgomery, Russell, Southwick, Tolland, West Springfield, Westfield	3,407	703	31	4.41%	20.63%	0.91%	1
35	Alford, Egremont, Great Barrington, Monterey, Mount Washington, New Marlborough, Otis, Sandisfield, Sheffield, Stockbridge, West Stockbridge	388	71	6	8.45%	18.30%	1.55%	1
36	Amesbury, Boxford, Georgetown, Groveland, Haverhill, Merrimac, Newbury, Newburyport, Rowley, Salisbury, West Newbury	4,593	1,209	32	2.65%	26.32%	0.70%	1

EI Catchment Areas		Birth Population (2012+ 2013+ 2014)	Early Intervention			% of Population Served by EI		No. of EI Centers
	Cities and Towns		**Total Served**	**ASD Served**	**% Served for ASD**	**Total Served**	**ASD Served**	
37	Amherst, Ashfield, Athol, Bernardson, Buckland, Charlemont, Chesterfield, Colrain, Conway, Cummington, Deerfield, Easthampton, Erving, Gill, Goshen, Greenfield, Hadley, Hatfield, Hawley, Heath, Leverett, Leyden, Monroe, Montague, New Salem, Northampton, Northfield, Orange, Pelham, Petersham, Phillipston, Plainfield, Rowe, Royalston, Shelburne, Shutesbury, Sunderland, Warwick, Wendell, Westhampton, Whately, Williamsburg, Worthington	4,141	640	28	4.38%	15.46%	0.68%	2
38	Andover, Lawrence, Methuen, North Andover	7,254	1,339	65	4.85%	18.46%	0.90%	2
39	Arlington, Burlington, Lexington, Wilmington, Winchester, Woburn	6,154	1,042	49	4.70%	16.93%	0.80%	1

EI Referral Data for Children with ASD by Catchment Area FY15 & 16 (**July 1, 2014 to June 30, 2016)**
Source: EARLY INTERVENTION INFROMATION SYSTEM

Table EI-27. EI Catchment areas and % of children served with ASD by Race

EI Catchment Areas		Percent of Children Served with ASD by Race					
	Cities and Towns	**White**	**Black**	**Hispanic**	**Asian**	**Multi-Race**	**Am Ind/ Pac Isl**
	Totals	54%	9%	26%	7%	3%	0%
1	Acton, Bedford, Boxborough, Carlisle, Concord, Lincoln, Littleton, Maynard, Stow	56%	<14.81%	<14.81%	30%	<14.81%	<14.81%
2	Ashburnham, Barre, Gardner, Hardwick, Hubbardston, New Braintree, Oakham, Princeton, Rutland, Templeton, Westminster, Winchendon	90%	<6.45%	<6.45%	<6.45%	<6.45%	<6.45%
3	Ashby, Ayer, Berlin, Bolton, Clinton, Fitchburg, Groton, Harvard, Lancaster, Leominster, Lunenberg, Pepperell, Shirley, Sterling, Townsend	63%	<4.3%	28%	<4.3%	<4.3%	<4.3%
4	Ashland, Dover, Framingham, Holliston, Hopkinton, Natick, Sherborn, Sudbury, Wayland	64%	<4%	7%	22%	<4%	<4%
5	Attleboro, Foxboro, Mansfield, North Attleboro, Norton	86%	<9.52%	<9.52%	<9.52%	<9.52%	<9.52%
6	Auburn, Boylston, Holden, Leicester, Paxton, Shrewsbury, West Boylston, Worcester.	51%	12%	26%	8%	<2.31%	<2.31%
7	Barnstable, Bourne, Brewster, Chatham, Chilmark, Dennis, Eastham, Edgartown, Falmouth, Gay Head, Harwich, Mashpee, Nantucket, Oak Bluffs, Orleans,	69%	<11.11%	22%	<11.11%	<11.11%	<11.11%

EI Catchment Areas		Percent of Children Served with ASD by Race					
	Cities and Towns	White	Black	Hispanic	Asian	Multi-Race	Am Ind/ Pac Isl
	Provincetown, Sandwich, Tisbury, Truro, Wellfleet, West Tisbury, Yarmouth						
8	Beacon Hill , Charlestown, Chelsea, East Boston, North End, Revere, Winthrop	37%	5%	49%	5%	4%	<3.48%
9	Becket, Cheshire, Dalton, Hancock, Hinsdale, Lanesborough, Lee, Lenox, Peru, Pittsfield, Richmond, Tyringham, Washington, Windsor	63%	<25%	<25%	<25%	<25%	<25%
10	Belchertown, Chicopee, Granby, Holyoke, Ludlow, Monson, Palmer, South Hadley, Southampton, Ware	40%	3%	54%	<1.83%	2%	<1.83%
11	Bellingham, Blackstone, Douglas, Franklin, Grafton, Hopedale, Medway, Mendon, Milford, Millbury, Millville, Northbridge, Sutton, Upton, Uxbridge	75%	<2.92%	11%	7%	7%	<2.92%
12	Acushnet, Dartmouth, Fairhaven, Gosnold, Marion, Mattapoisett, New Bedford, Rochester, Wareham	55%	10%	34%	<3.92%	<3.92%	<3.92%
13	Belmont, Waltham, Watertown	48%	<8%	24%	14%	<8%	<8%
14	Berkley, Dighton, Lakeville, Middleboro, Raynham, Rehoboth, Seekonk, Taunton	84%	<7.02%	<7.02%	<7.02%	<7.02%	<7.02%
15	Beverly, Essex, Gloucester, Hamilton, Ipswich, Manchester, Rockport, Topsfield, Wenham	80%	<8.7%	<8.7%	<8.7%	<8.7%	<8.7%
16 & 17	Billerica, Chelmsford, Dracut, Dunstable, Lowell, Tewksbury, Tyngsborough, Westford	58%	6%	17%	17%	<2.33%	<2.33%
18	Boston (except Beacon Hill, Charlestown, East Boston), Brookline	22%	31%	38%	7%	<1.48%	<1.48%
19	Braintree, Cohasset, Hingham, Hull, Norwell, Scituate. Weymouth	75%	<6.78%	<6.78%	12%	<6.78%	<6.78%
20	Brimfield, Brookfield, Charlton, Dudley, East Brookfield, Holland, North Brookfield, Oxford, Southbridge, Spencer, Sturbridge, Wales, Warren, Webster, West Brookfield	71%	<7.69%	21%	<7.69%	<7.69%	<7.69%
21	Abington, Avon, Bridgewater, Brockton, East Bridgewater, Easton, Holbrook, Rockland, Stoughton, West Bridgewater, Whitman	62%	24%	8%	<3.88%	<3.88%	<3.88%
22	Cambridge, Somerville	42%	20%	14%	13%	11%	<5.63%
23	Adams, Clarksburg, Florida, New Ashford, North Adams, Savoy, Williamstown	100%	0%	0%	0%	0%	0%
24	Canton, Dedham, Medfield, Millis, Norfolk, Norwood, Plainville, Sharon, Walpole, Westwood, Wrentham	74%	5%	9%	9%	<4.17%	<4.17%
25	Carver, Duxbury, Halifax, Hanover, Hanson, Kingston, Marshfield, Pembroke, Plymouth, Plympton	93%	<9.3%	<9.3%	<9.3%	<9.3%	<9.3%
26	Danvers, Lynn, Lynnfield, Marblehead, Middleton, Nahant, Peabody, Salem, Saugus, Swampscott	58%	8%	27%	3%	4%	<2.56%
27	East Longmeadow, Hampden, Longmeadow, Springfield, Wilbraham	26%	9%	63%	<1.52%	<1.52%	<1.52%

EI Catchment Areas		Percent of Children Served with ASD by Race					
	Cities and Towns	White	Black	Hispanic	Asian	Multi-Race	Am Ind/ Pac Isl
28	Everett, Malden, Medford	51%	18%	14%	11%	6%	<4.55%
29	Fall River, Freetown, Somerset, Swansea, Westport	90%	<9.52%	<9.52%	<9.52%	<9.52%	<9.52%
30	Hudson, Marlborough, Northborough, Southborough, Westborough	63%	<10%	13%	18%	<10%	<10%
31	Melrose, North Reading, Reading, Stoneham, Wakefield	91%	<7.41%	<7.41%	<7.41%	<7.41%	<7.41%
32	Milton, Quincy, Randolph	38%	12%	12%	26%	11%	<4.94%
33	Needham, Newton, Wellesley, Weston	54%	<9.76%	<9.76%	24%	<9.76%	<9.76%
34	Agawam, Blanford, Chester, Granville, Huntington, Middlefield, Montgomery, Russell, Southwick, Tolland, West Springfield, Westfield	68%	<12.9%	19%	<12.9%	<12.9%	<12.9%
35	Alford, Egremont, Great Barrington, Monterey, Mount Washington, New Marlborough, Otis, Sandisfield, Sheffield, Stockbridge, West Stockbridge	88%	<50%	<50%	<50%	<50%	<50%
36	Amesbury, Boxford, Georgetown, Groveland, Haverhill, Merrimac, Newbury, Newburyport, Rowley, Salisbury, West Newbury	68%	<6.35%	24%	<6.35%	<6.35%	<6.35%
37	Amherst, Ashfield, Athol, Bernardson, Buckland, Charlemont, Chesterfield, Colrain, Conway, Cummington, Deerfield, Easthampton, Erving, Gill, Goshen, Greenfield, Hadley, Hatfield, Hawley, Heath, Leverett, Leyden, Monroe, Montague, New Salem, Northampton, Northfield, Orange, Pelham, Petersham, Phillipston, Plainfield, Rowe, Royalston, Shelburne, Shutesbury, Sunderland, Warwick, Wendell, Westhampton, Whately, Williamsburg, Worthington	67%	<9.3%	16%	<9.3%	<9.3%	<9.3%
38	Andover, Lawrence, Methuen, North Andover	27%	<3.57%	63%	5%	<3.57%	<3.57%
39	Arlington, Burlington, Lexington, Wilmington, Winchester, Woburn	66%	<5.06%	<5.06%	14%	9%	<5.06%

Source: EARLY INTERVENTION INFROMATION SYSTEM

Table EI-28. EI Catchment areas and Age at Diagnosis

EI Catchment Areas		Age at Diagnosis of Children with ASD Served by EI					
	Cities and Towns	7 to 12 months	13 to 18 months	19 to 24 months	25 to 30 months	31 to 35 months	Unknown
	Totals	<0.123%	2%	33%	43%	13%	<0.123%
1	Acton, Bedford, Boxborough, Carlisle, Concord, Lincoln, Littleton, Maynard, Stow	<14.81%	<14.81%	41%	37%	<14.81%	<14.81%
2	Ashburnham, Barre, Gardner, Hardwick, Hubbardston, New Braintree, Oakham, Princeton, Rutland, Templeton, Westminster, Winchendon	<6.45%	<6.45%	42%	40%	13%	<6.45%
3	Ashby, Ayer, Berlin, Bolton, Clinton, Fitchburg, Groton, Harvard, Lancaster, Leominster, Lunenberg, Pepperell, Shirley, Sterling, Townsend	<4.3%	<4.3%	26%	52%	16%	<4.3%
4	Ashland, Dover, Framingham, Holliston, Hopkinton, Natick, Sherborn, Sudbury, Wayland	<4%	<4%	36%	38%	20%	<4%
5	Attleboro, Foxboro, Mansfield, North Attleboro, Norton	<9.52%	<9.52%	24%	50%	24%	<9.52%
6	Auburn, Boylston, Holden, Leicester, Paxton, Shrewsbury, West Boylston, Worcester.	<2.31%	10%	25%	49%	13%	<2.31%
7	Barnstable, Bourne, Brewster, Chatham, Chilmark, Dennis, Eastham, Edgartown, Falmouth, Gay Head, Harwich, Mashpee, Nantucket, Oak Bluffs, Orleans, Provincetown, Sandwich, Tisbury, Truro, Wellfleet, West Tisbury, Yarmouth	<11.11%	<11.11%	28%	44%	17%	<11.11%
8	Beacon Hill , Charlestown, Chelsea, East Boston, North End, Revere, Winthrop	<3.48%	8%	44%	37%	10%	<3.48%
9	Becket, Cheshire, Dalton, Hancock, Hinsdale, Lanesborough, Lee, Lenox, Peru, Pittsfield, Richmond, Tyringham, Washington, Windsor	<25%	<25%	44%	31%	<25%	<25%
10	Belchertown, Chicopee, Granby, Holyoke, Ludlow, Monson, Palmer, South Hadley, Southampton, Ware	<1.83%	<1.83%	36%	43%	14%	<1.83%
11	Bellingham, Blackstone, Douglas, Franklin, Grafton, Hopedale, Medway, Mendon, Milford, Millbury, Millville, Northbridge, Sutton, Upton, Uxbridge	<2.92%	7%	32%	44%	17%	<2.92%
12	Acushnet, Dartmouth, Fairhaven, Gosnold, Marion, Mattapoisett, New Bedford, Rochester, Wareham	<3.92%	<3.92%	31%	35%	25%	<3.92%
13	Belmont, Waltham, Watertown	<8%	10%	22%	38%	28%	<8%
14	Berkley, Dighton, Lakeville, Middleboro, Raynham, Rehoboth, Seekonk, Taunton	<7.02%	<7.02%	40%	42%	<7.02%	<7.02%
15	Beverly, Essex, Gloucester, Hamilton, Ipswich, Manchester, Rockport, Topsfield, Wenham	<8.7%	11%	39%	41%	<8.7%	<8.7%
16	Billerica, Chelmsford, Dracut, Dunstable, Lowell, Tewksbury, Tyngsborough, Westford	<2.33%	<2.33%	33%	47%	11%	<2.33%
17	Boston (except Beacon Hill, Charlestown,	<1.48%	<1.48%	32%	45%	16%	<1.48%

EI Catchment Areas		Age at Diagnosis of Children with ASD Served by EI					
	Cities and Towns	7 to 12 months	13 to 18 months	19 to 24 months	25 to 30 months	31 to 35 months	Unknown
	East Boston), Brookline						
18	Braintree, Cohasset, Hingham, Hull, Norwell, Scituate. Weymouth	<6.78%	<6.78%	42%	44%	<6.78%	<6.78%
19	Brimfield, Brookfield, Charlton, Dudley, East Brookfield, Holland, North Brookfield, Oxford, Southbridge, Spencer, Sturbridge, Wales, Warren, Webster, West Brookfield	<7.69%	<7.69%	23%	52%	<7.69%	<7.69%
20	Abington, Avon, Bridgewater, Brockton, East Bridgewater, Easton, Holbrook, Rockland, Stoughton, West Bridgewater, Whitman	<3.88%	<3.88%	33%	41%	19%	<3.88%
21	Cambridge, Somerville	<5.63%	<5.63%	25%	52%	15%	<5.63%
22	Adams, Clarksburg, Florida, New Ashford, North Adams, Savoy, Williamstown	<57.14%	<57.14%	<57.14%	71%	<57.14%	<57.14%
23	Canton, Dedham, Medfield, Millis, Norfolk, Norwood, Plainville, Sharon, Walpole, Westwood, Wrentham	<4.17%	<4.17%	38%	44%	13%	<4.17%
24	Carver, Duxbury, Halifax, Hanover, Hanson, Kingston, Marshfield, Pembroke, Plymouth, Plympton	<9.3%	<9.3%	33%	51%	<9.3%	<9.3%
25	Danvers, Lynn, Lynnfield, Marblehead, Middleton, Nahant, Peabody, Salem, Saugus, Swampscott	<2.56%	<2.56%	37%	45%	10%	<2.56%
26	East Longmeadow, Hampden, Longmeadow, Springfield, Wilbraham	<1.52%	<1.52%	38%	38%	16%	<1.52%
27	Everett, Malden, Medford	<4.55%	<4.55%	32%	45%	14%	<4.55%
28	Fall River, Freetown, Somerset, Swansea, Westport	<9.52%	<9.52%	<9.52%	40%	29%	<9.52%
29	Hudson, Marlborough, Northborough, Southborough, Westborough	<10%	<10%	38%	43%	<10%	<10%
30	Melrose, North Reading, Reading, Stoneham, Wakefield	<7.41%	<7.41%	33%	54%	<7.41%	<7.41%
31	Milton, Quincy, Randolph	<4.94%	<4.94%	25%	47%	20%	<4.94%
32	Needham, Newton, Wellesley, Weston	<9.76%	<9.76%	41%	34%	<9.76%	<9.76%
33	Agawam, Blanford, Chester, Granville, Huntington, Middlefield, Montgomery, Russell, Southwick, Tolland, West Springfield, Westfield	<12.9%	19%	45%	26%	<12.9%	<12.9%
34	Alford, Egremont, Great Barrington, Monterey, Mount Washington, New Marlborough, Otis, Sandisfield, Sheffield, Stockbridge, West Stockbridge	<50%	<50%	<50%	<50%	<50%	<50%
35	Amesbury, Boxford, Georgetown, Groveland, Haverhill, Merrimac, Newbury, Newburyport, Rowley, Salisbury, West Newbury	<6.35%	<6.35%	40%	35%	<6.35%	<6.35%
36	Amherst, Ashfield, Athol, Bernardson, Buckland, Charlemont, Chesterfield, Colrain, Conway, Cummington, Deerfield, Easthampton, Erving, Gill, Goshen, Greenfield, Hadley, Hatfield, Hawley, Heath, Leverett, Leyden, Monroe,	<9.3%	<9.3%	35%	47%	12%	<9.3%

EI Catchment Areas		Age at Diagnosis of Children with ASD Served by EI					
	Cities and Towns	7 to 12 months	13 to 18 months	19 to 24 months	25 to 30 months	31 to 35 months	Unknown
	Montague, New Salem, Northampton, Northfield, Orange, Pelham, Petersham, Phillipston, Plainfield, Rowe, Royalston, Shelburne, Shutesbury, Sunderland, Warwick, Wendell, Westhampton, Whately, Williamsburg, Worthington						
37	Andover, Lawrence, Methuen, North Andover	<3.57%	<3.57%	30%	40%	23%	<3.57%
38	Arlington, Burlington, Lexington, Wilmington, Winchester, Woburn	<5.06%	<5.06%	28%	51%	16%	<5.06%

Table EI-29. Monthly free online CDC Autism Case Training (ACT) by MA health care providers[225]

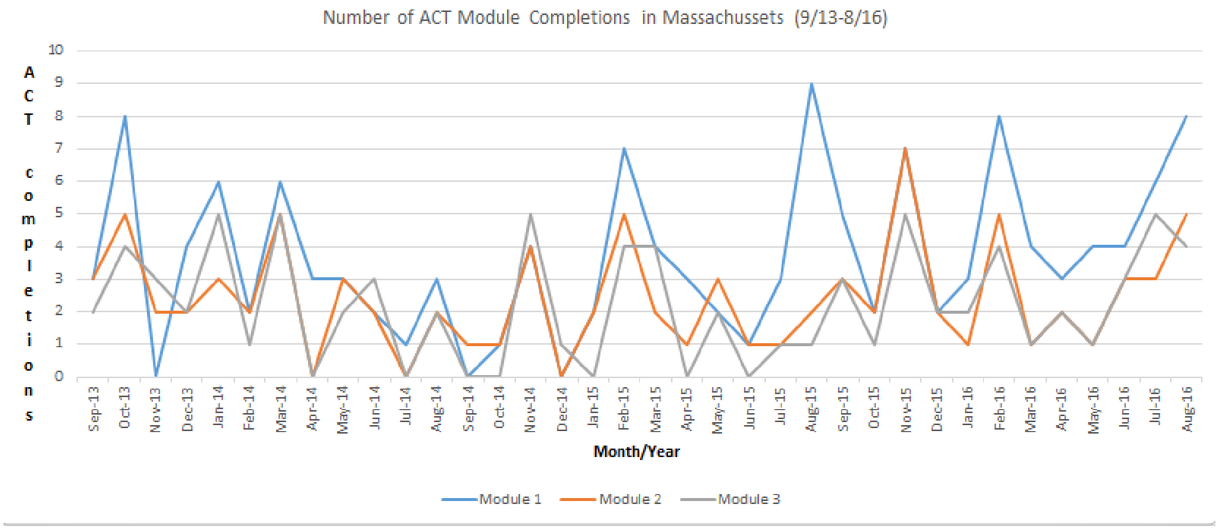


Table EI-30. MA Completions (Passed) of ACT Curriculum Modules, 2013-2106, CDC 2016				
Year	Module 1	Module 2	Module 3	Notes:
2013	15	12	11	Sept-Dec 2013
2014	31	23	24	
2015	47	31	23	
2016	40	21	22	Jan-Aug 2016
Total	133	87	80	

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[225] CDC LTSAE Program, 2016

Table EI-31. Monthly free online CDC Watch Me! Training by MA early childhood educators

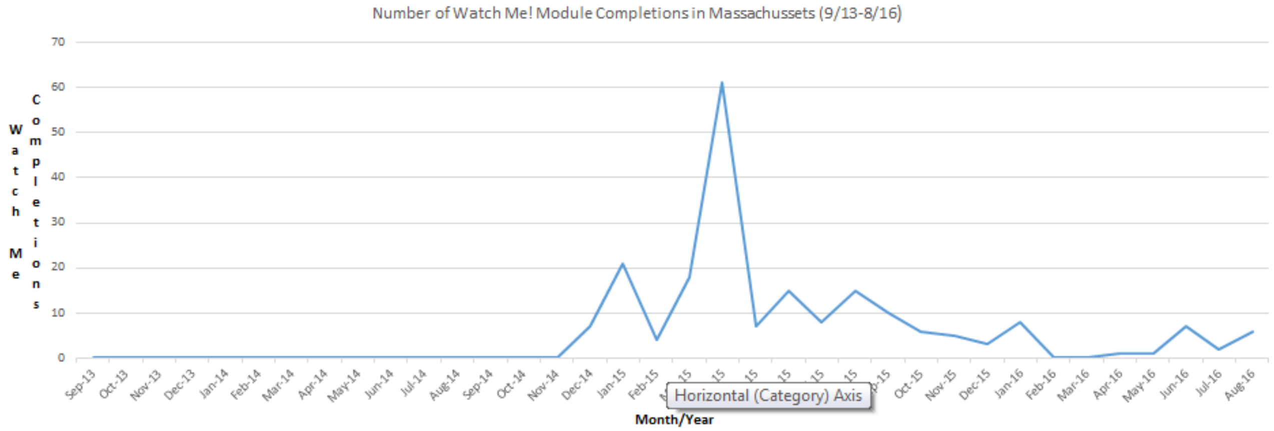
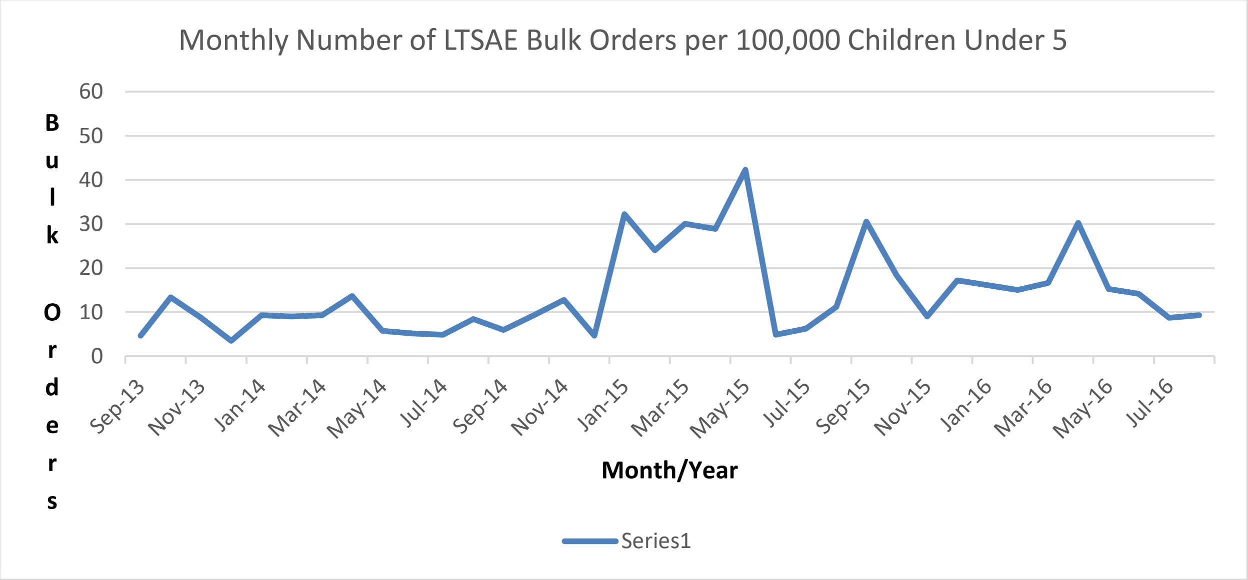


Table EI-32: CDC LTSAE Watch Me Module Completions by Month, 12/15-8/16

	2014	2015	2016	Total
Jan		21	8	
Feb		4	0	
Mar		18	0	
Apr		61	1	
May		7	1	
Jun		15	7	
Jul		8	2	
Aug		15	6	
Sep		10		
Oct		6		
Nov		5		
Dec	7	3		
Total	7	173	23	205

Table EI-33. Monthly orders of free CDC LTSAE bulk order materials for families by MA web visitors[68]



Medical Home Data

Table MH-12. Children with usual sources for sick care as subcomponent of Medical home composite measure, NSCH 2011-12

		Does not have usual sources for sick care	Child does have usual source for sick care	Total
All U.S. children	*%*	8.6%	91.4%	
	C.I.	(8.26 - 9.07%)	(90.93 - 91.84%)	
	n	5,811	89,687	95,498
	Pop. Est	6,335,023	6,721,297	13,056,320
All U.S. children with ASD	*%*	7.0%	93.0%	
	C.I.	(3.86 - 10.12%)	(89.87 - 96.14%)	
	n	101	1,514	1,615
	Pop. Est	81,807	1,088,237	1,170,044
All MA children	*%*	5.0%	95.0%	
	C.I.	(3.55-6.39%)	(93.60-96.45%)	
	n	71	1,787	1,858
	Pop. Est	69,341	1,324,529	1,393,870
*All MA children with ASD**	*%*	10.1%	89.9%	
	C.I.	(0.0 - 26.84%)	(73.15 - 100.0%)	
	n	3	28	31
	Pop. Est	2,793	24,825	27,618

C.I. = 95% Confidence Interval. Percentages are weighted to population characteristics.

n = cell size. Use caution in interpreting cell sizes less than 50

Note: Given the range of the estimates, it appears that the sample size may be too small to meaningfully estimate the percentage of children with ASD with usual sources for sick care within Massachusetts.

Table MH-13. Is there a place that your child USUALLY goes when s/he is sick or you (parent) need advice about his/her health care?, NS-CSHCN 2009-10

		Yes	There is no place	There is more than one place	Total
All U.S. CSHCN	*%*	96.3%	2.5%	1.2%	
	C.I.	(96.0 - 96.6%)	(2.2 - 2.8%)	(1.0 - 1.3%)	
	n	38,894	849	470	40,213
	Pop. Est	10,691,599	276,429	127,585	11,095,613
All U.S. CSHCN with ASD	*%*	95.2%	3.4%	1.4%	
	C.I.	(93.7 - 96.6%)	(2.1 - 4.7%)	(0.7 - 2.1%)	
	n	2,930	75	48	3,053
	Pop. Est	798,870	28,760	11,439	839,069
All MA CSHCN	*%*	98.7%	0.3%	1.0%	
	C.I.	(97.86 - 99.6%)	(0.0 - 0.7%)	(0.2 - 1.8%)	
	n	777	3	8	788
	Pop. Est	255,218	812	2,655	258,685
*All MA CSHCN with ASD**	*%*	98.7%	1.3%	0.0%	
	C.I.	(96.3 - 100.0%)	(0.0 - 3.7%)	0.00%	
	n	73	1	0	74
	Pop. Est	20917	265	0	21182

C.I. = 95% Confidence Interval. Percentages are weighted to population characteristics.

n = cell size. Use caution in interpreting cell sizes less than 50

Note: Given the range of the estimates, it appears that the sample size may be too small to meaningfully estimate the presence of medical homes for children and youth with ASD within Massachusetts.

Frequency missing = 31

Table MH-14. CSHCN receiving coordinated, ongoing, comprehensive care within a Medical Home, NS-CSHCN 2009-10

		Care DOES NOT meet medical home criteria	**Care MEETS medical home criteria**	**Total**
All U.S. CSHCN	*%*	57.0%	43.0%	
	C.I.	(46.2 - 57.9%)	(42.1 - 43.8%)	
	n	20,671	18,279	38,950
	Pop. Est	6,126,183	4,613,661	10,739,844
All U.S. CSHCN with ASD	*%*	76.1%	23.9%	
	C.I.	(73.6 - 78.7%)	(21.3 - 26.4%)	
	n	2,187	769	2,956
	Pop. Est	617,755	193,514	811,269
All MA CSHCN	*%*	52.9%	47.1%	
	C.I.	(48.3 - 57.5%)	(42.5 - 51.7%)	
	n	382	381	763
	Pop. Est	132,549	117,885	250,434
*All MA CSHCN with ASD**	*%*	70.2%	29.8%	
	C.I.	(57.7 - 82.7%)	(17.3 - 42.3%)	
	n	45	23	68
	Pop. Est	13,794	5,846	19,640

C.I. = 95% Confidence Interval. Percentages are weighted to population characteristics.

n = cell size. Use caution in interpreting cell sizes less than 50

Note: Given the range of the estimates, it appears that the sample size may be too small to meaningfully estimate whether all components of a Medical Home were met for children and youth with ASD within Massachusetts.

Frequency missing = 56

Table MH-15. Family-centered care as a sub-component of a Medical Home, NS-CSHCN 2009-10

		Does NOT have family-centered care	**Yes, has family centered care**	**Total**
All U.S. CSHCN	*%*	35.3%	64.5%	
	C.I.	(34.4 - 36.2%)	(63.6 - 65.3%)	
	n	12,579	27,106	39,685
	Pop. Est	3,878,340	7,073,553	10,951,893
All U.S.CSHCN with ASD	*%*	50.8%	48.9%	
	C.I.	(47.5 - 53.0%)	(45.7 - 52.1%)	
	n	1,440	1,558	2,998
	Pop. Est	418,409	402,966	821,375
All MA CSHCN	*%*	28.5%	71.5%	
	C.I.	(24.4 - 32.5%)	(67.4-75.6%)	
	n	209	572	781
	Pop. Est	73,281	184,100	257,381
*All MA CSHCN with ASD**	*%*	41.4%	58.6%	
	C.I.	(26.4 - 56.3%)	(43.7 - 73.6%)	
	n	31	41	72
	Pop. Est	8,605	12,199	20,804

C.I. = 95% Confidence Interval. Percentages are weighted to population characteristics.

n = cell size. Use caution in interpreting cell sizes less than 50

Note: Given the range of the estimates, it appears that the sample size may be too small to meaningfully estimate whether family-centered care was met as a subcomponent of a Medical Home for children and youth with ASD within Massachusetts.

Frequency missing = 38

Table MH-16. Children (ages 0 - 17) receiving coordinated, ongoing, comprehensive care within a Medical Home, NSCH 2011-12

		Care DOES NOT meet medical home criteria	**Care MEETS medical home criteria**	**Total**
All U.S. children	*%*	45.6%	54.4%	
	C.I.	(44.8 - 46.3%)	(53.7 - 55.1%)	
	n	36,493	56,257	92,750
	Pop. Est	32,537,906	38,826,906	71,364,812
All U.S. children with ASD	*%*	71.0%	29.0%	
	C.I.	(66.3 - 75.8%)	(24.21 - 33.74%)	
	n	1,044	530	1,574
	Pop. Est	811,849	331,192	1,143,041
All MA children	*%*	37.3%	62.7%	
	C.I.	(34.4 - 40.3%)	(59.7 - 65.6%)	
	n	638	1,171	1,809
	Pop. Est	506,586	850,290	1,356,876
*All MA children with ASD**	*%*	69.85%	30.14%	
	C.I.	(46.7 - 93.0%)	(7.0 - 53.3%)	
	n	22	8	30
	Pop. Est	18,755	8,093	26,848

C.I. = 95% Confidence Interval. Percentages are weighted to population characteristics.

n = cell size. Use caution in interpreting cell sizes less than 50

Frequency missing = all MA, 52; all MA ASD, 1

Note: Given the range of the estimates, it appears that the sample size may be too small to meaningfully estimate the percentage of children with ASD with a Medical Home within Massachusetts.

Table MH-17. CSHCN receiving coordinated, ongoing, comprehensive care within a Medical Home, NS-CSHCN 2009-10

		Care DOES NOT meet medical home criteria	Care MEETS medical home criteria	Total
All U.S. CSHCN	*%*	57.0%	43.0%	
	C.I.	(46.2 - 57.9%)	(42.1 - 43.8%)	
	n	20,671	18,279	38,950
	Pop. Est	6,126,183	4,613,661	10,739,844
All U.S.CSHCN with ASD	*%*	76.1%	23.9%	
	C.I.	(73.6 - 78.7%)	(21.3 - 26.4%)	
	n	2,187	769	2,956
	Pop. Est	617,755	193,514	811,269
All MA CSHCN	*%*	52.9%	47.1%	
	C.I.	(48.3 - 57.5%)	(42.5 - 51.7%)	
	n	382	381	763
	Pop. Est	132,549	117,885	250,434
*All MA CSHCN with ASD**	*%*	70.2%	29.8%	
	C.I.	(57.7 - 82.7%)	(17.3 - 42.3%)	
	n	45	23	68
	Pop. Est	13,794	5,846	19,640

C.I. = 95% Confidence Interval. Percentages are weighted to population characteristics.

n = cell size. Use caution in interpreting cell sizes less than 50

Note: Given the range of the estimates, it appears that the sample size may be too small to meaningfully estimate whether all components of a Medical Home were met for children and youth with ASD within Massachusetts.
Frequency missing = 56

Table MH-18. Top 30 Principal Diagnoses Associated with Hospital Claims by ASD Members

Diagnosis	Description	Frequency	Percent	Frequency	Percent
29690	Episodic mood disord NOS	777	17.74	777	17.74
29980	Pervasv Dev Dis - Cur NEC	298	6.8	1075	24.54
29900	Autistic disord - current	256	5.84	1331	30.39
30981	Posttraumatic stress dis	246	5.62	1577	36
29680	Bipolar disorder NOS	188	4.29	1765	40.3
29990	Pervasv dev dis-cur NOS	164	3.74	1929	44.04
31401	Attn deficit w hyperact	95	2.17	2024	46.21
311	Depressive disorder NEC	92	2.1	2116	48.31
29570	Schizoaffective dis NOS	90	2.05	2206	50.37
30000	Anxiety state NOS	79	1.8	2285	52.17
2989	Psychosis NOS	78	1.78	2363	53.95
3079	Special symptom NEC/NOS	76	1.74	2439	55.68
29690	Episodic mood disord NOS	73	1.67	2512	57.35
78609	Respiratory abnorm NEC	58	1.32	2570	58.68
3432	Congenital quadriplegia	53	1.21	2623	59.89
31381	Opposition defiant disor	50	1.14	2673	61.03
3439	Cerebral palsy NOS	46	1.05	2719	62.08
3129	Conduct disturbance NOS	45	1.03	2764	63.11
3149	Hyperkinetic synd NOS	42	0.96	2806	64.06
85400	Brain injury NEC	39	0.89	2845	64.95
27709	Cystic fibrosis NEC	38	0.87	2883	65.82
78039	Convulsions NEC	38	0.87	2921	66.69
75610	Anomaly of spine NOS	37	0.84	2958	67.53
27651	Dehydration	34	0.78	2992	68.31
46619	Acu brnchlts d/t oth org	31	0.71	3023	69.02
29530	Paranoid schizo-unspec	30	0.68	3053	69.7
V5789	Rehabilitation proc NEC	30	0.68	3083	70.39
30400	Opioid dependence-unspec	28	0.64	3111	71.03
30480	Comb drug dep NEC-unspec	28	0.64	3139	71.67
2967	Bipolar I current NOS	26	0.59	3165	72.26

Table MH-19. Top 30 Secondary Diagnoses Associated with Hospital Claims by ASD Members

Diagnosis	Description	Frequency	Percent	Frequency	Percent
31401	Attn deficit w hyperact	204	7.31	204	7.31
29980	Pervasv Dev Dis - Cur NEC	160	5.73	364	13.04
29900	Autistic disord - current	146	5.23	510	18.27
30981	Posttraumatic stress dis	130	4.66	640	22.93
29900	Autistic disord - current	108	3.87	748	26.8
29690	Episodic mood disord NOS	90	3.22	838	30.03
+	Missing	89	3.19	927	33.21
31381	Opposition defiant disor	74	2.65	1001	35.87
29980	Pervasv Dev Dis - Cur NEC	58	2.08	1059	37.94
V6284	Suicidal ideation	58	2.08	1117	40.02
31400	Attn defic nonhyperact	56	2.01	1173	42.03
78039	Convulsions NEC	55	1.97	1228	44
29990	Pervasv Dev Dis - Cur NOS	54	1.93	1282	45.93
30000	Anxiety state NOS	54	1.93	1336	47.87
29990	Unspecified pervasive developmental disorder cur	51	1.83	1387	49.7
25001	Diabetes wo cmp nt st uncntrl	43	1.54	1430	51.24
3149	Hyperkinetic synd NOS	41	1.47	1471	52.71
75569	Lower limb anomaly NEC	36	1.29	1507	53.99
29680	Bipolar disorder NOS	31	1.11	1538	55.11
317	Mild Intellectual Disabilities	26	0.93	1564	56.04
V5873	Aftercare following surgery of the circulatory system, NEC	25	0.9	1589	56.93
32723	Obstructive sleep apnea	24	0.86	1613	57.79
3129	Conduct disturbance NOS	23	0.82	1636	58.62
3481	Anoxic brain damage	21	0.75	1657	59.37
7061	Acne NEC	21	0.75	1678	60.12
45341	Ac DVT/emb prox low ext	20	0.72	1698	60.84
3158	Development delays NEC	16	0.57	1714	61.41
30002	Generalized anxiety dis	14	0.5	1728	61.91
V469	Unspecified machine dependence	14	0.5	1742	62.41
3090	Adjustmnt dis w depressn	13	0.47	1755	62.88

Access to Care Data

Table AC-19. Children with problems accessing specialty care, NSCH 2011-12

		Did not need or receive specialty care	**Needed or received/no problem**	**Needed or received/had a problem**	**Total**
All U.S. children	*%*	72.9%	20.7%	6.4%	
	C.I.	(72.3 - 73.5%)	(20.2 - 21.3%)	(6.0 - 6.7%)	
	n	67,967	21,920	5,613	95,500
	Pop. Est	53,622,528	15,233,324	4,693,535	73,549,387
All U.S. children with ASD	*%*	50.96%	30.86%	18.17%	
	C.I.	(45.4 - 56.5%)	(23.2 - 35.5%)	(13.8 - 22.6%)	
	n	750	570	292	1,612
	Pop. Est	595,795	360,925	212,495	1,169,215
All MA children	*%*	68.3%	26.1%	5.6%	
	C.I.	(65.6- 71.1%)	(23.5 - 28.7%)	(4.2- 7.0%)	
	n	1,251	502	107	1,860
	Pop. Est	956,622	365,262	77,968	1,399,852
*All MA children with ASD**	*%*	56.7%	26.9%	16.4%	
	C.I.	(32.0 - 81.4%)	(7.0 - 46.8%)	(0.0 -34.0%)	
	n	16	10	5	31
	Pop. Est	15,656	7,420	4,541	27,617

C.I. = 95% Confidence Interval. Percentages are weighted to population characteristics.

n = cell size. Use caution in interpreting cell sizes less than 50

Frequency missing = 1

Note: Given the range of the estimates, it appears that the sample size may be too small to meaningfully estimate the percentage of children with ASD with problems accessing specialty care within Massachusetts.

Table AC-20. During past 12 mos., person has received treatment or counseling from mental health professional, NSCH 2011-12

		No	Yes	Total
All U.S. children	*%*	90.5%	9.4%	
	C.I.	(90.1 - 91.0%)	(8.9 - 9.8%)	
	n	77,192	8,350	85,542
	Pop. Est	59,340,210	6,137,616	65,477,826
All U.S. children with ASD	*%*	45.89%	54.06%	
	C.I.	(40.36 - 51.41%)	(48.53 - 59.58%)	
	n	706	906	1,612
	Pop. Est	536,935	632,534	1,169,469
All MA children	*%*	86.6%	13.3%	
	C.I.	(84.40 - 88.69%)	(11.17 - 15.45%)	
	n	1,421	227	1,648
	Pop. Est	1,088,714	167,466	1,256,180
*All MA children with ASD**	*%*	53.6%	46.4%	
	C.I.	(27.74 - 79.53%)	(20.46 - 72.25%)	
	n	18	13	31
	Pop. Est	14,614	12,804	27,418

C.I. = 95% Confidence Interval. Percentages are weighted to population characteristics.

n = cell size. Use caution in interpreting cell sizes less than 50.

Note: Given the range of the estimates, it appears that the sample size may be too small to meaningfully estimate the percentage of CYSHCN with ASD who have received mental health treatment or counseling within Massachusetts.

Table AC-21 Children served in DDS's Autism children's HCBS waiver by city and town, 2015:

Town	#	Town	#	Town	#	Town	#	Town	#
Adams	1	Dorchester	16	Leicester	1	Norwood	1	Wareham	1
Agawam	1	Dudley	2	Leominster	3	Palmer	1	Watertown	1
Allston	1	East Bridgewater	2	Littleton	3	Peabody	3	Webster	1
Amherst	1	East Boston	2	Lowell	5	Plymouth	2	West Bridgewater	1
Arlington	1	East Taunton	1	Ludlow	3	Quincy	2	West Roxbury	4
Attleboro	1	East Walpole	1	Lynn	7	Reading	1	West Yarmouth	1
Auburn	2	Everett	8	Malden	4	Revere	2	Westborough	1
Barre	2	Fall River	7	Mansfield	2	Roslindale	1	Westfield	2
Bellingham	1	Fitchburg	1	Marlborough	1	Roxbury	1	Weymouth	1
Beverly	3	Florence	1	Mashpee	1	Salem	1	Wilbraham	1
Billerica	1	Framingham	6	Mattapan	4	Sharon	1	Winchendon	1
Boston	3	Franklin	1	Mattapoisett	1	Shrewsbury	1	Woburn	3
Bourne	1	Gloucester	2	Medford	2	Somerville	1	Worcester	22
Brighton	1	Greenfield	1	Methuen	3	South Boston	1	**Total:**	**278**
Brimfield	1	Hampden	1	Milford	5	South Easton	1		
Brockton	5	Haverhill	3	Millville	1	Southbridge	5		
Burlington	2	Holyoke	8	Natick	1	Springfield	22		
Cambridge	4	Hopedale	1	New Bedford	18	Stoughton	2		
Chelsea	1	Hyde Park	1	Newtonville	1	Taunton	2		
Chicopee	6	Indian Orchard	2	North Adams	1	Wakefield	1		
Clinton	1	Jamaica Plain	2	North Dartmouth	1	Waltham	1		
Dedham	1	Lawrence	5	Northborough	1	Ware	1		

Table AC-22 Applications for DDS's Autism children's HCBS waiver by city and town, 2015:

Town	#	Town	#	Town	#	Town	#	Town	#
Adams	1	Dorchester	36	Hyde Park	12	Oxford	2	West Boylston	1
Agawam	4	Douglas	2	Indian Orchard	4	Palmer	2	West Springfield	5
Allston	4	Dracut	1	Jamaica Plain	4	Peabody	3	Wakefield	1
Arlington	2	Dudley	1	Lanesboro	1	Pittsfield	4	Watertown	1
Ashburnham	1	Duxbury	1	Lawrence	15	Plymouth	3	Ware	1
Ashland	2	East Boston	11	Lenox	1	Princeton	1	Wareham	1
Assonet	1	East Brookfield	2	Leominster	6	Quincy	14	Webster	5
Athol	1	East Longmeadow	1	Lexington	1	Randolph	6	Wellfleet	5
Attleboro	4	East Wareham	1	Lowell	29	Raynham	2	West Roxbury	1
Auburn	1	Eastham	1	Ludlow	1	Reading	1	Westborough	3
Bedford	1	Easthampton	5	Lunenburg	1	Revere	11	Westfield	10
Belchertown	2	Essex	1	Lynn	11	Rockland	1	Westford	3
Bellingham	2	Everett	9	Malden	5	Roslindale	8	Weymouth	4
Berkley	1	Fairhaven	3	Mansfield	2	Roxbury	9	Whitinsville	3
Beverly	2	Fall River	6	Marblehead	1	Russell	2	Wilbraham	1
Billerica	2	Fitchburg	11	Marlborough	1	South Yarmouth	1	Winchendon	1
Blackstone	1	Forestdale	1	Mattapan	3	Salem	8	Winchester	1
Boston	25	Foxboro	4	Medfield	1	Saugus	3	Winthrop	2
Boxborough	2	Framingham	11	Medford	8	Seekonk	1	Woburn	3
Bradford	2	Franklin	1	Melrose	3	Sheffield	1	Worcester	46
Braintree	2	Gardner	1	Methuen	2	Shirley	1	**Total:**	**749**
Brewster	1	Gloucester	2	Middleboro	1	Shrewsbury	1		
Brighton	4	Grafton	1	Milford	1	Somerset	1		
Brockton	13	Granby	2	Millbury	2	Somerville	15		
Brookline	2	Greenfield	1	Millville	1	South Boston	2		
Buzzard's Bay	1	Groton	2	Milton	2	South Dennis	1		
Cambridge	7	Hadley	1	Monson	1	south Easton	1		
Centerville	1	Halifax	1	North Brookfield	1	South Hadley	2		
Charlestown	2	Hanscom	2	North Weymouth	1	Southwick	1		
Chelmsford	1	Harvard	1	New Bedford	26	Spencer	2		
Chelsea	8	Haverhill	6	Newburyport	2	Springfield	57		
Cheshire	1	Hingham	1	Newton	1	Stoneham	1		
Chestnut Hill	4	Holden	3	North Adams	2	Stoughton	3		
Chicopee	12	Holliston	2	North Andover	2	Sunderland	1		
Clinton	2	Holyoke	17	North Attleboro	3	Swampscott	2		
Concord	1	Hopkinton	2	North Easton	1	Taunton	13		
Danvers	1	Hudson	1	Northampton	2	Tewksbury	2		
Dedham	2	Hull	1	Norton	1	Townsend	1		
Deerfield	1	Hyannis	3	Norwood	3	Tyngsboro	2		
Dighton	1	Hyannisport	1	Orange	3	Uxbridge	3		

Table AC-23. Cultural Information for Participants, CY 15

Ethnicity	**# of Participants**	**%**
Caucasian	103	37%
Latino/Hispanic	78	28%
African American	30	11%
Portuguese	27	10%
Dominican	8	3%
Haitian	6	2%
Middle Eastern	6	2%
Chinese	4	1%
Vietnamese	3	1%
Greek	2	1%
Moroccan	2	1%
Cape Verdean	2	1%
Russian	2	1%
Nigerian	1	<1%
Egyptian	1	<1%
Ghana	1	<1%
Indian	1	<1%
Puerto Rican	1	<1%
TOTAL	**278**	100%

Family Involvement Data

Table FI-1. During the past 12 months/since birth, how often did your child's doctors or other health care providers discuss with you (parents) the range of options to consider for your child's health care or treatment?, NS-CSHCN 2009-10

		Never	**Sometimes**	**Usually**	**Always**	**No Options to Consider**	**Don't Know**	**Total**
All U.S. CSHCN	*%*	5.4%	12.8%	20.6%	60.5%	0.5%	0.1%	
	C.I.	(5.0 - 5.9%)	(12.2 - 13.5%)	(19.8 - 21.3%)	(59.6 - 61.4%)	(0.4 - 0.6%)	(0.5 - 0.2%)	
	n	1,772	4,632	8,541	24,924	225	57	40,151
	Pop. Est	599,704	1,421,454	2,277,100	6,705,822	57,368	14,579	11,076,027
All U.S. CSHCN with ASD	*%*	9.9%	21.9%	23.1%	44.3%	0.6%	0.1%	
	C.I.	(7.9 - 12.0%)	(18.9 - 24. 8%)	(20.5 - 25.7%)	(41.2 - 47.5%)	(0.3 -1.0%)	(0.0 - 0.3%)	
	n	254	630	760	1,372	25	4	3,045
	Pop. Est	83,117	183,135	193,079	370,777	5,176	1,079	836,363
All MA CSHCN	*%*	2.7%	13.9%	21.2%	61.5%	0.7%	0.1%	
	C.I.	(1.1 - 4.2%)	(10.7 - 17.1%)	(17.7 - 24.7%)	(57.1 - 65.8%)	(0.1 - 1.2%)	(0.0 - 0.2%)	
	n	18	98	170	494	7	1	788
	Pop. Est	6,871	3,012	54,814	159,033	1,763	193	225,686
*All MA CSHCN with ASD**	*%*	3.2%	30.8%	19.0%	43.6%	3.4%	0.0%	
	C.I.	(0.0 - 6.8%)	(16.8 - 44.7%)	(9.4 - 28.6%)	(28.7 - 58.6%)	(0.0 - 8.5%)		
	n	3	20	17	32	2	-	74
	Pop. Est	673	6,521	4,028	9,238	721	-	21,181

C.I. = 95% Confidence Interval. Percentages are weighted to population characteristics.

n = cell size. Use caution in interpreting cell sizes less than 50

Note: Given the range of the estimates, it appears that the sample size may be too small to meaningfully estimate how often parents were given options to discuss their child's healthcare within Massachusetts.

Frequency missing = 31

Table FI-2. How often did your child's doctors or other health care providers encourage you to ask questions or raise concerns?, NS-CSHCN 2009-10

		Never	**Sometimes**	**Usually**	**Always**	**Total**
All U.S. CSHCN	*%*	7.1%	11.5%	14.4%	66.8%	
	C.I.	(6.5 - 7.6%)	(10.9 - 12.1%)	(13.8 - 15.0%)	(65.9 - 67.6%)	
	n	2,228	4,307	6,186	27,323	40,044
	Pop. Est	782,495	1,273,845	1,594,584	7,396,069	11,046,993
All U.S. CSHCN with ASD	*%*	10.7%	17.5%	17.3%	54.1%	
	C.I.	(7.9 - 13.5%)	(15.3 - 19.8%)	(15.0 - 19.6%)	(50.9 - 57.4%)	
	n	271	508	535	1,717	3,031
	Pop. Est	89,213	146,685	144,752	452,754	833,404
All MA CSHCN	*%*	4.8%	10.6%	14.3%	70.0%	
	C.I.	(2.5 - 7.1%)	(7.4 - 13.8%)	(11.5 - 17.1%)	(65.8 - 74.2%)	
	n	29	68	127	563	787
	Pop. Est	12,471	27,404	37,006	180,997	257,878
*All MA CSHCN with ASD**	*%*	5.5%	25.0%	18.2%	50.9%	
	C.I.	(0.6 - 10.4%)	(8.4 - 41.5%)	(8.7 - 28.6%)	(36.1 - 65.8%)	
	n	5	11	15	43	74
	Pop. Est	1,160	5,288	3,943	10,792	21,183

C.I. = 95% Confidence Interval. Percentages are weighted to population characteristics.

n = cell size. Use caution in interpreting cell sizes less than 50

Note: Given the range of the estimates, it appears that the sample size may be too small to meaningfully estimate how often parents are encouraged to ask questions or raise concerns about children and youth with ASD within Massachusetts.
Frequency missing = 31

Table FI-3. How often did your child's doctors or other health care providers consider and respect what health care and treatment choices you thought would work best for your child?, NS-CSHCN 2009-10

		Never	Sometimes	Usually	Always	Total
All U.S. CSHCN	*%*	3.9%	11.6%	19.8%	63.3%	
	C.I.	(3.4 - 4.4%)	(11.0 - 12.2%)	(19.1 - 20.5%)	(63.4 - 65.2%)	
	n	1,127	4,129	8,493	26,261	40,010
	Pop. Est	433,182	1,285,951	2,194,024	7,123,440	11,036,597
All U.S. CSHCN with ASD	*%*	6.3%	16.4%	24.3%	52.4%	
	C.I.	(3.7 - 8.9%)	(14.2 - 18.6%)	(21.7 - 26.8%)	(49.2 - 55.6%)	
	n	128	501	793	1,609	3,031
	Pop. Est	52,766	136,812	203,035	438,329	830,942
All MA CSHCN	*%*	1.7%	9.9%	19.2%	69.0%	
	C.I.	(0.5 - 2.8%)	(6.9 - 12.7%)	(16.1 - 22.3%)	(64.9 - 73.1%)	
	n	11	69	169	538	787
	Pop. Est	4,314	25,540	49,562	178,474	257,890
*All MA CSHCN with ASD**	*%*	1.0%	22.5%	29.3%	47.2%	
	C.I.	(0.0 - 2.9%)	(7.8 - 37.1%)	(15.7 - 42.9%)	(32.7 - 61.8%)	
	n	1	14	20	39	74
	Pop. Est	207	4,757	6,211	10,007	21,182

C.I. = 95% Confidence Interval. Percentages are weighted to population characteristics.

n = cell size. Use caution in interpreting cell sizes less than 50

Note: Given the range of the estimates, it appears that the sample size may be too small to meaningfully estimate how respected parents feel in their health care choices for children and youth with ASD within Massachusetts.
Frequency missing = 31

Table FI-4. How often did child’s doctor or other health care providers make it easy for you to ask questions or raise concerns, NS-CSHCN 2009-10

		Never	**Sometimes**	**Usually**	**Always**	**Total**
All U.S. children	*%*	3.10%	10.70%	14.81%	69.68%	
	C.I.	(2.70-3.5%)	(10.9 - 11.3%)	(14,81 - 16.07%)	(69.68 - 71.37%)	
	n	951	3786	6708	38643	50088
	Pop. Est	343743	1185546	1710612	7813284	11053185
All U.S. children with ASD	*%*	5.7%	17.3%	19.4%	57.4%	
	C.I.	(3.98 - 7.51%)	(14.42 - 20.09%)	(16.95 - 21.89%)	(54. - 60.6%)	
	n	130	476	656	1775	3037
	Pop. Est	48093	144351	162430	479816	834690
All MA children	*%*	1.5%	8.9%	18.3%	71.2%	
	C.I.	(0.53 - 2.46%)	(6.19 - 11.75%)	(14.96 - 21.57%)	(67.15 - 75.24%)	
	n	12	60	146	569	787
	Pop. Est	3,871	23,214	47,260	184,170	258,515
*All MA children with ASD**	*%*	2.3%	18.2%	27.1%	52.4%	
	C.I.	(0.0 - 5.51%)	(5.46 - 30.84%)	(12.11 - 42.12%)	(37.41-67.44%)	
	n	2	11	16	45	74
	Pop. Est	488	3846	5744	11105	21183

C.I. = 95% Confidence Interval. Percentages are weighted to population characteristics.

n = cell size. Use caution in interpreting cell sizes less than 50

Interpretation:

Note: Given the range of the estimates, it appears that the sample size may be too small to meaningfully estimate how respected parents feel in their health care choices for children and youth with ASD within Massachusetts.

Table FI-5. Doctor makes parent feel like partner in child's care in past 12 mos., NSCH 2011-12

		Sometimes/Never	Always/Usually	Skip, did not need	Total
All U.S. children	*%*	11.8%	84.0%	4.2%	
	C.I.	(113 - 12.3%)	(83.5 - 84.6%)	(3.9 - 4.2%)	
	n	9,044	83,374	2,955	95,373
	Pop. Est	8,654,330	61,794,789	3,079,968	73,529,087
All U.S. children with ASD	*%*	22.2%	76.3%	1.5%	
	C.I.	(16.8 - 27.7%)	(70.8 - 81.7%)	(0.5 - 2.5%)	
	n	271	1,319	18	1,608
	Pop. Est	259,574	890,936	17,410	1,167,920
All MA children	*%*	8%	90%	3%	
	C.I.	(6.2 - 9.5%)	(87.6 - 91.5%)	(1.5 - 3.7%)	
	n	144	1,680	31	1,855
	Pop. Est	109,157	1,248,835	36,257	1,394,249
*All MA children with ASD**	*%*	5%	95%		
	C.I.	(0.0 - 11.9%)	(88.1 - 100.0%)		
	n	4	27	na	31
	Pop. Est	1,456	26,162		27,618

C.I. = 95% Confidence Interval. Percentages are weighted to population characteristics.

n = cell size. Use caution in interpreting cell sizes less than 50

Note: Given the range of the estimates, it appears that the sample size may be too small to meaningfully estimate the percentage of parents of children with ASD who feel like a partner in their child's care within Massachusetts.

Transition Data

Table HCT-3. Doctor talked about changing needs as youth becomes adult, if helpful, NS-CSHCN 2009-10

		No	**Yes**	**Total**
All U.S. YSHCN	*%*	41.0%	59.0%	
	C.I.	(39.4 - 42.6%)	(57.4 - 60.6%)	
	n	4,572	7,787	12,359
	Pop. Est	1,368,844	1,970,605	3,339,449
All U.S. YSHCN with ASD	*%*	53.5%	46.5%	
	C.I.	(47.9-59.2%)	(40.8-52.1%)	
	n	438	464	902
	Pop. Est	123,437	107,101	230,538
All MA YSHCN	*%*	41.1%	58.9%	
	C.I.	(32.6 - 49.5%)	(50.5 - 67.4%)	
	n	85	153	238
	Pop. Est	32,920	47,272	80,192
*All MA YSHCN with ASD**	*%*	51.0%	49.0%	
	C.I.	(19.8 - 82.2%)	(17.8 - 80.2%)	
	n	11	10	21
	Pop. Est	4,056	3,896	7,952

C.I. = 95% Confidence Interval. Percentages are weighted to population characteristics.

n = cell size. Use caution in interpreting cell sizes less than 50

Note: Given the range of the estimates, it appears that the sample size may be too small to meaningfully estimate if doctor discussed changing needs as youth becomes adults in Massachusetts.

Frequency missing = National, 27883; MA, 550.

Table HCT-4. Doctor discussed shift to adulthood, NS-CSHCN 2009-10

		No	**Yes**	**Total**
All U.S. YSHCN	*%*	56.1%	43.9%	
	C.I.	(53.5 - 58.8%)	(41.2 - 45.5%)	
	n	2,455	2,151	4,606
	Pop. Est	757,723	592,407	1,350,130
All U.S. YSHCN with ASD	*%*	61.0%	35.8%	
	C.I.	(52.9 - 69.1%)	(30.9 - 47.1%)	
	n	272	152	424
	Pop. Est	66,707	42,684	109,391
All MA YSHCN	*%*	55.0%	45.0%	
	C.I.	(42.2 - 67.8%)	(32.2 - 57.7%)	
	n	62	49	111
	Pop. Est	20,798	17,001	37,799
*All MA YSHCN with ASD**	*%*	28.8%	71.2%	
	C.I.	(0.0 - 59.2%)	(40.8 - 100.0%)	
	n	6	5	11
	Pop. Est	1,424	3,513	4,937

C.I. = 95% Confidence Interval. Percentages are weighted to population characteristics.

n = cell size. Use caution in interpreting cell sizes less than 50

Note: Given the range of the estimates, it appears that the sample size may be too small to meaningfully estimate whether doctor discussed the "shift to adulthood" with provider.

Frequency missing = 677

Table HCT-5. Has anyone's Doctor talked about insurance coverage as youth becomes adult, if needed, NS-CSHCN 2009-10

		No	Yes	Total
All U.S. YSHCN	*%*	64.9%	35.1%	
	C.I.	(63.2 - 66.6%)	(33.3 - 36.7%)	
	n	6,545	3,868	10,413
	Pop. Est	1,931,147	1,042,613	2,973,760
All U.S. YSHCN with ASD	*%*	71.8%	28.2%	
	C.I.	(66.6 - 77.0%)	(22.3 - 33.4%)	
	n	629	246	875
	Pop. Est	162,594	63,853	226,447
All MA YSHCN	*%*	68.5%	31.5%	
	C.I.	(60.2 - 76.8%)	(23.2 - 39.8%)	
	n	139	64	203
	Pop. Est	45,961	21,151	67,112
*All MA YSHCN with ASD**	*%*	90.2%	9.8%	
	C.I.	(71.9 - 100.0%)	(0.0 - 28.1%)	
	n	22	1	23
	Pop. Est	7,874	854	8,728

C.I. = 95% Confidence Interval. Percentages are weighted to population characteristics.

n = cell size. Use caution in interpreting cell sizes less than 50

Note: Given the range of the estimates, it appears that the sample size may be too small to meaningfully estimate if doctor discussed insurance coverage needs as youth becomes adults in Massachusetts.

Frequency missing = National, 29877; MA, 585

Table HCT-6. Doctor met all 3 transition components, NS-CSHCN 2009-10

		No	**Yes**	**Total**
All U.S. children	*%*	63.2%	36.8%	
	C.I.	(61.8 - 64.6%)	(35.4 - 38.2%)	
	n	8042	5627	13,669
	Pop. Est	2324437	1353458	3,677,895
All U.S. children with ASD	*%*	74.4%	25.6%	
	C.I.	(70.1-78.7%)	(21.3-30.0%)	
	n	714	285	999
	Pop. Est	185,709	63,880	249,589
All MA children	*%*	59.1%	40.9%	
	C.I.	(52.5 - 66.7%)	(33.3 - 48.5%)	
	n	157	113	270
	Pop. Est	52,670	36,404	89,074
*All MA children with ASD**	*%*	83.1%	16.9%	
	C.I.	(64.1-100.0%)	(0.0-35.9%)	
	n	20	5	25
	Pop. Est	7,474	1,524	8,998

C.I. = 95% Confidence Interval. Percentages are weighted to population characteristics.

n = cell size. Use caution in interpreting cell sizes less than 50

Frequency missing = National, 26626; MA, 818

Table HCT-7. Doctor encouraged youth to engage in appropriate self-care, NS-CSHCN 2009-10

		Never/Sometimes	Usually/Always	Total
All U.S. YSHCN	*%*	22.0%	78.0%	
	C.I.	(20.8 - 23.2%)	(76.8 - 79.2%)	
	n	3,442	13,608	17,050
	Pop. Est	987,176	3,496,770	4,483,946
All U.S. YSHCN with ASD	*%*	51.9%	48.1%	
	C.I.	(47.0 - 56.9%)	(43.1 - 53.0%)	
	n	597	571	1,168
	Pop. Est	152,768	141,514	294,282
All MA YSHCN	*%*	18.6%	81.4%	
	C.I.	(13.8 - 23.4%)	(76.6 - 86.2%)	
	n	68	291	359
	Pop. Est	21,561	94,472	116,033
*All MA YSHCN with ASD**	*%*	37.4%	62.6%	
	C.I.	(12.8 - 61.8%)	(38.2 - 87.1%)	
	n	12	17	29
	Pop. Est	9,946	21,561	31,507

C.I. = 95% Confidence Interval. Percentages are weighted to population characteristics.

n = cell size. Use caution in interpreting cell sizes less than 50

Note: Given the range of the estimates, it appears that the sample size may be too small to meaningfully estimate if doctor encouraged self-care as youth becomes adults in Massachusetts.

Frequency missing = National, 23192; MA, 429

Table HCT-8. How often do your child's doctors or other health care providers encourage him/her to take responsibility for his/her health care needs?, NS-CSHCN 2009-10

		Never	Sometimes	Usually	Always	Total
All U.S. YSHCN	*%*	13.7%	16.0%	19.9%	48.8%	
	C.I.	(13.0 - 14.5%)	(15.4 - 16.7%)	(19.1 - 20.6%)	(48.8 - 50.7%)	
	n	4,241	5,589	7,434	17,406	34,670
	Pop. Est	1,287,768	1,506,564	1,866,492	4,673,487	9,334,311
All U.S. YSHCN with ASD	*%*	38.0%	20.2%	16.7%	23.8%	
	C.I.	(34.5 - 41.5%)	(17.7 - 22.6%)	(14.3 - 19.1%)	(21.1 - 26.4%)	
	n	975	615	492	656	2,738
	Pop. Est	287,696	152,656	126,343	179,899	746,594
All MA YSHCN	*%*	10.7%	17.7%	23%	49%	
	C.I.	(7.9 - 13.4%)	(14.5 - 20.9%)	(18.7 - 26.4%)	(44.1 - 53.7%)	
	n	78	133	159	329	699
	Pop. Est	24,539	40,675	51,803	112,241	229,258
*All MA YSHCN with ASD**	*%*	36%	19%	23%	22%	
	C.I.	(21.4 - 50.9%)	(8.9 - 28.5%)	(11.0 - 35.1%)	(6.7-37.5%)	
	n	24	15	16	12	67
	Pop. Est	7,186	3,721	4,583	4,397	19,887

C.I. = 95% Confidence Interval. Percentages are weighted to population characteristics.

n = cell size. Use caution in interpreting cell sizes less than 50

Note: Given the range of the estimates, it appears that the sample size may be too small to meaningfully estimate how ,much providers have spoken with parents about obtaining or keeping health insurance coverage for youth with ASD within Massachusetts.

Frequency missing = 90

MRC 2013 Data Tables

Table TA-18. Summary of SFY2013 Actively Served Consumers w/ Autism as a Primary or Secondary Disability Massachusetts Rehabilitation Commission, Vocational Rehabilitation Program Total # of Current Active Cases w/Autism as a Primary or Secondary Disability (as of 12/31/2013)

Primary or Secondary Disability	1354	100%	5.3%	of Active Cases, Statuses 10-24
Primary Disability	1163	85.9%	4.5%	of Active Cases, Statuses 10-24
Secondary Disability	191	14.1%	0.7%	of Active Cases, Statuses 10-24

Table TA-19. Active Cases w/ Autism as a Primary or Secondary Disability by Current Status, as of 12/31/2013

Status	# of Consumers	% of Consumers
10 (Eligibility)	294	21.7%
12 (IPE Completed)	24	1.8%
16 (Restoration)	53	3.9%
18 (Training and Education)	837	61.8%
20 (Job Ready)	103	7.6%
22 (Job Placement)	28	2.1%
24 (Interrupted Services)	15	1.1%
Total	1354	100.0%

Table TA-20. Gender, SFY2013 Actively Served Consumers w/ Autism as a Primary or Secondary Disability by Area Office, as of 12/31/2013

Gender	# of Consumers	% of Consumers
Female	195	14.8%
Male	1127	85.2%

Table TA-21. Gender, Race/Ethnicity, SFY2013 Actively Served Consumers w/ Autism as a Primary or Secondary Disability by Area Office, as of 12/31/2013

Race/Ethnicity	# of Consumers	% of Consumers
White	1222	92.4%
Hispanic	39	3.0%
Black	74	5.6%
Asian/Pacific Islander	31	2.3%
Native American	1	0.1%
**Multiple category field, may add up to over 100%*		

Table TA-22. Gender Age at Application, SFY2013 Actively Served Consumers w/ Autism as a Primary or Secondary Disability by Area Office, as of 12/31/2013

Age At Application	# of Consumers	% of Consumers
Under 20	813	61.5%
20-29	385	29.1%
30-39	77	5.8%
40-49	29	2.2%
50-59	16	1.2%
60 and up	2	0.2%

Table TA-23. Current Age, SFY2013 Actively Served Consumers w/ Autism as a Primary or Secondary Disability by Area Office, as of 12/31/2013

Current Age	# of Consumers	% of Consumers
Under 20	101	7.6%
20-29	1034	78.2%
30-39	124	9.4%
40-49	36	2.7%
50-59	24	1.8%
60 and up	3	0.2%

Table TA-24. Level of Education at Application, SFY2013 Actively Served Consumers w/ Autism as a Primary or Secondary Disability by Area Office, as of 12/31/2013

Education Level	# of Consumers	% of Consumers
Less Than High School	733	55.4%
Special Education Certificate	54	4.1%
HS Diploma or Equivalent	296	22.4%
Some College	176	13.3%
Bachelor's Degree	53	4.0%
Master's Degree or Higher	10	0.8%

Insurance Data

Table IN-4. Type of insurance coverage and current health insurance status, NSCH 2011-12

		Public insurance such as Medicaid or SCHIP	Private health insurance	Currently uninsured	Total
All U.S. children	*%*	36.36%	57.36%	5.57%	
	C.I.	(36.36 – 37.80%)	(56.63 - 58.08%)	(5.18 - 5.94%)	
	N	27,381	63,079	4,040	94,500
	Pop. Est	26,941,410	41,674,400	4,044,605	72,660,415
All U.S. children with ASD	*%*	43.6%	54.6%	1.7%	
	C.I.	(38.03 - 49.23%)	(49.03 - 60.24%)	(0.5 - 2.9%)	
	N	726	845	32	1,603
	Pop. Est	508,679	637,002	20,130	1,165,811
All MA children	*%*	32.5%	66.46%	1.0%	
	C.I.	(29.5 - 35.5%)	(63.4 - 69.5%)	(0.4 - 1.7%)	
	N	441	1,390	15	1,846
	Pop. Est	451,413	923,519	14,579	1,389,511
*All MA children with ASD**	*%*	53.5%	46.5%	0%	
	C.I.	(29.9 - 79.1%)	(22.9 - 70.1%)	N/A	
	n	14	17	0	31
	Pop. Est	14,769	12,848		27,617

C.I. = 95% Confidence Interval. Percentages are weighted to population characteristics.

n = cell size. Use caution in interpreting cell sizes less than 50

Note: Given the range of the estimates, it appears that the sample size may be too small to meaningfully estimate the type of insurance coverage for CYSHCN with ASD within Massachusetts.

Table IN-5. Type of insurance coverage (ages 2-17), NS-CSHCN 2009-10

		Public insurance such as Medicaid or SCHIP	Private health insurance	Both Public & Private	Currently uninsured	Total
All U.S. children	*%*	35.85%	52.36%	8.20%	3.58%	
	C.I.	(34.94 - 36.76%)	(51.45 - 53.27%)	(7.68 - 8.72%)	(3.19 - 3.97%)	
	n	11,362	23,315	2,910	1,149	38,736
	Pop. Est	3,848,567	5,621,137	880,494	384,698	10,734,896
All U.S. children with ASD	*%*	33.72%	45.85%	17.67%	2.7%	
	C.I.	(30.46 - 36.97%)	(42.68 - 49.02%)	(14.97 - 20.37%)	(1.9 - 3.6%)	
	n	876	1,523	470	86	2,955
	Pop. Est	274,230	372,898	143,687	22,505	813,320
All MA children	*%*	24.4%	63.6%	11.2%	0.8%	
	C.I.	(19.7 - 29.0%)	(58.8 - 68.4%)	(8.0 - 14.5%)	(0.1 - 1.5%)	
	n	141	552	68	9	770
	Pop. Est	61,662	160,974	28,475	2,095	253,206
*All MA children with ASD**	*%*	18.7%	58.1%	23.0%	0.2%	
	C.I.	(5.7 - 31.7%)	(42.1 - 74.0%)	(7.3 - 38.8%)	(0.0 - 0.6%)	
	n	11	49	11	1	72
	Pop. Est	3,861	11,998	4,760	43	20,662

C.I. = 95% Confidence Interval. Percentages are weighted to population characteristics.

n = cell size. Use caution in interpreting cell sizes less than 50

Note: Given the range of the estimates, it appears that the sample size may be too small to meaningfully estimate the type of insurance coverage for CYSHCN with ASD within Massachusetts.

Table IN-6. Consistency of health insurance coverage during last 12 mos., NSCH 2011-12

		Currently uninsured or periods w/ no coverage during year	Consistently insured throughout past year	Total
All U.S. children	*%*	11.28%	88.72%	
	C.I.	(10.78 - 11.79%)	(88.21 - 89.23%)	
	n	8,212	86,929	95141
	Pop. Est	8,252,803	64,907,362	73,160,165
All U.S. children with ASD	*%*	10.67%	89.31%	
	C.I.	(6.01 – 15.36%)	(89.64 - 93.99%)	
	N	126	1485	1611
	Pop. Est	124,884	1,043,889	1,168,774
All MA children	*%*	5.5%	94.5%	
	C.I.	(3.9 - 7.0%)	(93.0 - 96.1%)	
	N	79	1,777	1,856
	Pop. Est	76,189	1,319,032	1,395,221
*All MA children with ASD**	*%*	2.9%	97.1%	
	C.I.	(0.0 - 7.5%)	(92.8 – 100%)	
	N	2	29	31
	Pop. Est	798	26,820	27,618

C.I. = 95% Confidence Interval. Percentages are weighted to population characteristics.

n = cell size. Use caution in interpreting cell sizes less than 50

Note: Given the range of the estimates, it appears that the sample size may be too small to meaningfully estimate the consistency of insurance coverage for CYSHCN with ASD within Massachusetts.

Table IN-7. Consistency of health insurance coverage during past 12 months (ages 2-17), NS-CSHCN 2009-10

		Insured entire year	**NOT insured at some point during year**	**Total**
All U.S. children	*%*	64.9%	35.06%	
	C.I.	(63.26 - 66.62%)	(33.38 - 36.74%)	
	n	6,545	3,868	10,413
	Pop. Est	1,931,147	1,042,613	2,973,760
All U.S. children with ASD	*%*	71.8%	28.20%	
	C.I.	(66.56 – 77.05%)	(22.95 - 33.45%)	
	n	629	246	875
	Pop. Est	162,594	63,853	226,447
All MA children	*%*	94.4%	5.6%	
	C.I.	(91.3 - 97.5%)	(2.5 - 8.7%)	
	n	756	31	787
	Pop. Est	243,936	14,559	258,495
*All MA children with ASD**	*%*	92.7%	7.3%	
	C.I.	(81.2 - 100%)	(0.0 - 18.8%)	
	n	71	3	74
	Pop. Est	19,629	1,554	21,183

C.I. = 95% Confidence Interval. Percentages ae weighted to population characteristics.

n = cell size. Use caution in interpreting cell sizes less than 50

Frequency missing = 32

Note: Given the range of the estimates, it appears that the sample size may be too small to meaningfully estimate the percentage of children with ASD without insurance in the past 12 month period within Massachusetts.

Table IN-8. Health insurance benefits meets child's needs (ages 2-17), NS-CSHCN 2009-10

		Never/sometimes	Usually/always	Skipped, uninsured	Total
All U.S. children	*%*	12.71%	83.80%	3.49%	
	C.I.	(12.05 - 13.38%)	(83.06 - 84.54%)	(3.10 - 3.86%)	
	N	4,532	34,351	1,149	40,032
	Pop. Est	1,403,859	9,250,036	384,698	11,038,593
All U.S. children with ASD	*%*	25.01%	72.28%	2.7%	
	C.I.	(22.27 - 27.75%)	(69.47 - 75.08%)	(1.9 - 3.5%)	
	N	750	2,206	86	3,042
	Pop. Est	207,943	600,866	22,505	831,314
All MA children	*%*	11.2%	88.0%	0.1%	
	C.I.	(8.4-14.0%)	(85.1 - 90.9%)	(0.1-1.5%)	
	N	84	692	9	785
	Pop. Est	28,863	226,466	2,095	257,424
*All MA children with ASD**	*%*	17.2%	82.6%	0.2%	
	C.I.	(8.4 - 25.9%)	(73.9 - 91.5%)	(0.0 - 0.6%)	
	n	16	57	1	74
	Pop. Est	3,633	17,507	43	21,183

C.I. = 95% Confidence Interval. Percentages are weighted to population characteristics.

n = cell size. Use caution in interpreting cell sizes less than 50

Note: Given the range of the estimates, it appears that the sample size may be too small to meaningfully estimate how often insurance benefits CYSHCN with ASD within Massachusetts.

Table IN-9. Non-covered insurance charges are reasonable (ages 2-17), NS-CSHCN 2009-10

		Never/sometimes	Usually/always	Skipped, uninsured	Total
All U.S. children	*%*	27.74%	68.77%	3.12%	
	C.I.	(26.93 - 28.54%)	(67.93 - 69.60%)	(3.11 - 3.87%)	
	n	11,147	27,605	1,149	39,901
	Pop. Est	3,051,819	7,566,172	384,698	11,002,689
All U.S. children with ASD	*%*	37.56%	59.72%	2.7%	
	C.I.	(34.56 - 40.55%)	(56.68 - 62.77%)	(1.9 - 3.6%)	
	n	1,171	1,774	86	3,031
	Pop. Est	311,132	494,781	22,505	828,418
All MA children	*%*	28.6%	70.6%	0.8%	
	C.I.	(24.6 - 32.7%)	(66.5 - 74.6%)	(0.1-1.5%)	
	n	233	539	9	781
	Pop. Est	73,609	181,531	2,095	257,235
*All MA children with ASD**	*%*	35.9%	63.9%	0.2%	
	C.I.	(23.0 - 48.8%)	(51.0 - 76.9%)	(0.0 - 0.6%)	
	n	31	41	1	73
	Pop. Est	7,532	13,418	43	20,993

C.I. = 95% Confidence Interval. Percentages are weighted to population characteristics.

n = cell size. Use caution in interpreting cell sizes less than 50

Note: Given the range of the estimates, it appears that the sample size may be too small to meaningfully estimate how reasonable non-covered charges are for CYSHCN with ASD within Massachusetts.

Table IN-10. Out-of-pocket expenses for child's medical expenses (ages 2-17), NS-CSHCN 2009-10

		Less than $250	$250-500	$501-1,000	More than $1,000	Total
All U.S. children	*%*	44.60%	21.45%	11.84%	22.11%	
	C.I.	(43.69 - 45.51%)	(20.72 - 22.18%)	(11.28 - 12.39%)	(21.42 - 22.80%)	
	n	15,400	8,859	5,238	10,144	39,641
	Pop. Est	4,875,280	2,344,614	1,293,968	2,416,952	10,930,814
All U.S. children with ASD	*%*	36.78%	20.06%	9.70%	33.45%	
	C.I.	(33.72 - 39.89%)	(16.96 - 23.16%)	(8.11 - 11.30%)	(30.55 - 36.36%)	
	n	988	554	371	1,099	3,012
	Pop. Est	303,209	165,347	79,998	275,771	824,325
All MA children	*%*	38.0%	22.9%	13.3%	25.7%	
	C.I.	(33.3 - 42.7%)	(19.5 - 26.4%)	(10.3 - 16.4%)	(22.1 - 29.4%)	
	n	249	205	105	220	779
	Pop. Est	97,101	58,542	34,087	65,743	255,473
*All MA children with ASD**	*%*	20.9%	15.5%	13.0%	50.7%	
	C.I.	(6.0 - 35.8%)	(6.9 - 24.1%)	(4.6 - 21.2%)	(35.9 - 65.6%)	
	n	13	14	10	36	73
	Pop. Est	4,250	3,144	2,624	10,310	20,328

C.I. = 95% Confidence Interval. Percentages are weighted to population characteristics.

n = cell size. Use caution in interpreting cell sizes less than 50

Note: Given the range of the estimates, it appears that the sample size may be too small to meaningfully estimate out-of-pocket medical expenses for CYSHCN with ASD within Massachusetts.

Note: Autism requires a number of services beyond traditional medical expenses such as ABA, tutoring, social skills therapy, speech therapy, OT, etc. As well, parents often pay out of pocket for special education advocates and legal services.

Table IN-11. Insurance allows child to see needed providers (ages 2-17), NS-CSHCN 2009-10

		Never/ sometimes	Usually/always	Skipped, uninsured	Total
All U.S. children	*%*	10.11%	86.40%	3.48%	
	C.I.	(9.50 - 10.72%)	(85.71 - 87.09%)	(3.10 - 3.86%)	
	N	3,509	35,404	1,149	40,062
	Pop. Est	1,117,110	9,543,097	384,698	11,044,905
All U.S. children with ASD	*%*	20.68%	76.61%	2.70%	
	C.I.	(18.26 - 23.11%)	(74.09 - 79.14%)	(1.9 - 3.5%)	
	N	605	2,353	86	3,044
	Pop. Est	172,688	639,552	22,505	834,745
All MA children	*%*	7.6%	91.6%	0.8%	
	C.I.	(5.5 - 9.7%)	(89.4 - 93.8%)	(0.1 - 1.5%)	
	N	65	712	9	786
	Pop. Est	19,697	236,408	2,095	258,200
*All MA children with ASD**	*%*	15.9%	83.9%	0.2%	
	C.I.	(6.8 -25.1%)	(74.7 - 93.0%)	(0.0 - 0.6%)	
	n	13	60	1	74
	Pop. Est	3,374	17,765	43	21,182

C.I. = 95% Confidence Interval. Percentages are weighted to population characteristics.

n = cell size. Use caution in interpreting cell sizes less than 50

Note: Given the range of the estimates, it appears that the sample size may be too small to meaningfully estimate how well insurance allows child to see needed providers for CYSHCN with ASD within Massachusetts.

Table IN-12. Meets outcome indicator for adequate insurance to pay for services needed (ages 2-17), NS-CSHCN 2009-10

		Did not meet insurance outcome	Met insurance outcome	Total
All U.S. children	*%*	39.44%	60.56%	
	C.I.	(38.55 - 40.33%)	(59.66 - 61.44%)	
	N	14,880	24,840	39,720
	Pop. Est	4,316,749	6,626,999	10,943,748
All U.S. children with ASD	*%*	50.63%	49.37%	
	C.I.	(47.42 - 53.84%)	(46.16 - 52.58%)	
	N	1,524	1,497	3,021
	Pop. Est	417,748	407,378	825,126
All MA children	*%*	37.8%	62.2%	
	C.I.	(33.3 - 42.4%)	(57.6 - 66.7%)	
	N	285	493	778
	Pop. Est	96,870	159,209	256,079
*All MA children with ASD**	*%*	51.3%	48.7%	
	C.I.	(36.3 - 66.2%)	(33.8 - 63.7%)	
	n	41	32	73
	Pop. Est	10,765	10,229	20,994

C.I. = 95% Confidence Interval. Percentages are weighted to population characteristics.

n = cell size. Use caution in interpreting cell sizes less than 50

Note: Given the range of the estimates, it appears that the sample size may be too small to meaningfully estimate if the insurance outcome indicator has been met for CYSHCN with ASD within Massachusetts.

Table IN-13. Adequacy of insurance coverage during last 12 mos., NSCH 2011-12

		Current insurance adequate for child's needs	Current insurance NOT adequate for child's needs	Total
All U.S. children	*%*	76.49%	23.51%	
	C.I.	(75.86 - 77.12%)	(22.87 - 24.14%)	
	N	70,451	20,810	91,261
	Pop. Est	53,003,373	16,290,222	69,293,595
All U.S. children with ASD	*%*	59.02%	40.98%	
	C.I.	(53.45 - 64.59%)	(35.41 - 46.56%)	
	N	961	620	1,581
	Pop. Est	678,218	470,999	1,149,217
All MA children	*%*	78.7%	21.3%	
	C.I.	(76.3 - 81.1%)	(18.9 - 23.7%)	
	N	1,436	407	1,843
	Pop. Est	1,087,374	294,000	1,381,374
*All MA children with ASD**	*%*	65.5%	34.5%	
	C.I.	(43.9 - 87.0%)	(13.0 - 56.1%)	
	N	15	16	31
	Pop. Est	18,079	9,538	27,617

C.I. = 95% Confidence Interval. Percentages are weighted to population characteristics.

n = cell size. Use caution in interpreting cell sizes less than 50

Note: Given the range of the estimates, it appears that the sample size may be too small to meaningfully estimate the adequacy of insurance coverage for CYSHCN with ASD within Massachusetts.

Table IN-14. Adequacy by type of insurance coverage, NSCH 2011-12

		Public insurance such as Medicaid or SCHIP			Private health insurance			**Total**
		Adequate	**NOT Adequate**	**Total**	**Adequate**	**NOT Adequate**	**Total**	
All U.S. children	*%*	82.14%	17.86%		72.86%	27.14%		
	C.I.	(81.13 - 83.15%)	(16.85 - 18.87%)		(72.05 - 73.66%)	(26.33 - 27.95%)		
	N	22,991	4,366	27357	46,793	16,243	63036	90393
	Pop. Est	22,116,700	4,808,758	26,925,458	30,342,154	11,303,093	41,645,247	68,570,705
All U.S. children with ASD	*%*	72.92%	27.08%		47.84%	52.16%		
	C.I.	(66.22 - 79.62%)	(20.38 - 33.77%)		(40.46 - 55.23%)	(44.77 - 59.54%)		
	n	522	204	726	434	411	845	1,571
	Pop. Est	370,951	137,727	508,678	304,759	332,243	637,002	1,145,680
All MA children	*%*	85.4%	10.4%		75.4%	24.6%		
	C.I.	(81.1 - 89.6%)	(10.4 - 18.9%)		(72.5 - 78.3%)	(21.7 - 27.5%)		
	n	369	72	441	1,056	334	1,390	1,831
	Pop. Est	385,396	66,017	451,413	696,349	227,170	923,519	1,374,932
*All MA children with ASD**	*%*	79.7%	20.3%		49.1%	50.9%		
	C.I.	(54.1 - 100.0%)	(0.0 - 45.9%)		(16.9 - 81.3%)	(18.7 - 83.1%)		
	n	9	5	14	6	11	17	31
	Pop. Est	11,771	2,998	14,769	6,308	6,540	12,848	27,617

C.I. = 95% Confidence Interval. Percentages are weighted to population characteristics.

n = cell size. Use caution in interpreting cell sizes less than 50

Note: Given the range of the estimates, it appears that the sample size may be too small to meaningfully estimate the adequacy of each type of insurance coverage for CYSHCN with ASD within Massachusetts.

Education Data

Table ED-5. Before age 3, did the child receive EI Services? (2011 Pathways to Diagnosis & Services)

		Yes, child received EIS	No, child did not receive EIS	Total
Nationwide	*%*	44.5	55.5	
	C.I.	(39.8 - 49.3)	(50.7 - 60.2)	
	n	531	792	1,323
	Pop. Est.	271,551	338,564	610,115
Northeast	*%*	56.6	43.4	
	C.I.	(46.8 - 66.5)	(33.5 - 53.2)	
	n	148	119	267

Table ED-6. Does the child have a written plan called an Individualized Education Plan? (2011 Pathways to Diagnosis & Services)

		Yes, child has an IEP	No, child does not have IEP	Total
Nationwide	*%*	84.5	15.5	
	C.I.	(80.5 - 88.5)	(11.5 - 19.5)	
	n	1,169	175	1,344
	Pop. Est.	522,155	95,595	617,750
Northeast	*%*	85.6	14.4	
	C.I.	(78.8 - 92.5)	(7.5 - 21.2)	
	n	233	36	269
	Pop. Est.	114,112	19,148	133,260

Table ED-7. DESE Autism Data: # of students in Grades Pre-Kindergarten through 12+ by Year

	Autism Grade by Year																									
	Oct-03		Oct-04		Oct-05		Oct-06		Oct-07		Oct-08		Oct-09		Oct-10		Oct-11		Oct-12		Oct-13		Oct-14		Oct-15	
GR	#	%	#	%	#	%	#	%	#	%	#	%	#	%	#	%	#	%	#	%	#	%	#	%	#	%
PK	725	14.9%	766	14.0%	950	14.7%	950	14.7%	1212	14.0%	1297	13.2%	1376	12.8%	1460	12.1%	1568	11.9%	1716	11.6%	1920	11.8%	2002	11.5%	2140	11.5%
K	438	9.0%	450	8.2%	558	8.6%	558	8.6%	768	8.9%	805	8.2%	860	8.0%	881	7.3%	888	6.7%	948	6.4%	1059	6.5%	1130	6.5%	1270	6.8%
1	413	8.5%	520	9.5%	519	8.0%	519	8.0%	696	8.0%	820	8.4%	869	8.1%	962	8.0%	964	7.3%	1018	6.9%	1092	6.7%	1152	6.6%	1198	6.5%
2	418	8.6%	425	7.8%	564	8.7%	564	8.7%	699	8.1%	799	8.2%	877	8.1%	979	8.1%	1049	7.9%	1075	7.3%	1132	7.0%	1197	6.9%	1233	6.6%
3	395	8.1%	427	7.8%	491	7.6%	491	7.6%	646	7.5%	754	7.7%	824	7.6%	928	7.7%	1037	7.8%	1119	7.6%	1130	7.0%	1200	6.9%	1276	6.9%
4	411	8.4%	412	7.5%	483	7.5%	483	7.5%	682	7.9%	694	7.1%	814	7.6%	944	7.8%	1027	7.8%	1152	7.8%	1231	7.6%	1223	7.0%	1270	6.8%
5	384	7.9%	448	8.2%	472	7.3%	472	7.3%	602	6.9%	717	7.3%	723	6.7%	888	7.4%	1004	7.6%	1157	7.9%	1243	7.7%	1331	7.7%	1279	6.9%
6	389	8.0%	394	7.2%	447	6.9%	447	6.9%	572	6.6%	630	6.4%	743	6.9%	755	6.3%	912	6.9%	1069	7.3%	1196	7.4%	1303	7.5%	1336	7.2%
7	291	6.0%	376	6.9%	419	6.5%	419	6.5%	512	5.9%	603	6.2%	660	6.1%	751	6.2%	800	6.0%	958	6.5%	1122	6.9%	1202	6.9%	1323	7.1%
8	221	4.5%	282	5.2%	393	6.1%	393	6.1%	517	6.0%	546	5.6%	637	5.9%	719	6.0%	801	6.1%	856	5.8%	1032	6.4%	1147	6.6%	1251	6.7%
9	229	4.7%	259	4.7%	318	4.9%	318	4.9%	460	5.3%	547	5.6%	549	5.1%	644	5.3%	743	5.6%	873	5.9%	920	5.7%	1068	6.2%	1196	6.4%
10	163	3.3%	246	4.5%	259	4.0%	259	4.0%	402	4.6%	494	5.0%	545	5.1%	612	5.1%	652	4.9%	776	5.3%	882	5.4%	918	5.3%	1093	5.9%
11	143	2.9%	153	2.8%	252	3.9%	252	3.9%	354	4.1%	418	4.3%	511	4.7%	565	4.7%	628	4.7%	683	4.6%	795	4.9%	894	5.1%	894	4.8%
12	179	3.7%	209	3.8%	216	3.3%	216	3.3%	326	3.8%	425	4.3%	507	4.7%	620	5.1%	732	5.5%	795	5.4%	867	5.3%	950	5.5%	1098	5.9%
+	77	1.6%	100	1.8%	136	2.1%	136	2.1%	220	2.5%	244	2.5%	286	2.7%	350	2.9%	423	3.2%	541	3.7%	624	3.8%	648	3.7%	715	3.8%
Total	**4,876**	**100.0%**	**5,467**	**100.0%**	**6,477**	**100.0%**	**6,477**	**100.0%**	**8,668**	**100.0%**	**9,793**	**100.0%**	**10,781**	**100.0%**	**12,058**	**100.0%**	**13,228**	**100.0%**	**14,736**	**100.0%**	**16,245**	**100.0%**	**17,365**	**100.0%**	**18,572**	**100.0%**

Source: MA Department of Elementary & Secondary Education (DESE), 9/19/16

Table ED-8. DESE Autism Data: # of students with ELL and by Race/Ethnicity 2015-2016

Autism ELL and Race/Ethnicity 2015-2016																	
	Autism	ELL		African American/Blk		Asian		Hispanic		Multi-Race, Non-Hispanic		Native American		Native Hawaiian, Pacific Islander		White	
GR	#	#	% in grade	#	% in grade	#	% in grade	#	% in grade	#	% in grade	#	% in grade	#	% in grade	#	% in grade
PK	2,140	182	8.5%	197	9.2%	179	8.4%	469	21.9%	78	3.6%	3	0.1%	0	0.0%	1,214	56.73%
K	1,270	122	9.6%	123	9.7%	79	6.2%	302	23.8%	51	4.0%	2	0.2%	0	0.0%	713	56.1%
1	1,198	112	9.3%	115	9.6%	98	8.2%	248	20.7%	52	4.3%	3	0.3%	0	0.0%	682	56.9%
2	1,233	98	7.9%	119	9.7%	85	6.9%	256	20.8%	53	4.3%	2	0.2%	0	0.0%	718	58.2%
3	1,276	70	5.5%	122	9.6%	80	6.3%	235	18.4%	41	3.2%	1	0.1%	0	0.0%	797	62.5%
4	1,270	61	4.8%	115	9.1%	66	5.2%	196	15.4%	45	3.5%	2	0.2%	1	0.1%	845	66.5%
5	1,279	41	3.2%	97	7.6%	64	5.0%	181	14.2%	57	4.5%	0	0.0%	1	0.1%	879	68.7%
6	1,336	29	2.2%	77	5.8%	80	6.0%	170	12.7%	40	3.0%	1	0.1%	2	0.1%	966	72.3%
7	1,323	33	2.5%	117	8.8%	79	6.0%	154	11.6%	39	2.9%	3	0.2%	1	0.1%	930	70.3%
8	1,251	34	2.7%	89	7.1%	51	4.1%	119	9.5%	30	2.4%	3	0.2%	0	0.0%	959	76.7%
9	1,196	21	1.8%	82	6.9%	54	4.5%	132	11.0%	29	2.4%	2	0.2%	3	0.3%	894	74.7%
10	1,093	20	1.8%	76	7.0%	38	3.5%	114	10.4%	33	3.0%	2	0.2%	2	0.2%	828	75.8%
11	894	10	1.1%	58	6.5%	29	3.2%	65	7.3%	24	2.7%	1	0.1%	0	0.0%	717	80.2%
12	1,098	21	1.9%	67	6.1%	48	4.4%	99	9.0%	23	2.1%	1	0.1%	1	0.1%	859	78.2%
+	715	8	1.1%	59	8.3%	36	5.0%	60	8.4%	11	1.5%	2	0.3%	2	0.3%	545	76.2%
Total	**18,572**	862	4.6%	1,513	8.1%	1,066	5.7%	2,800	15.1%	606	3.3%	28	0.2%	13	0.1%	12,546	67.6%

University of Massachusetts
UMASS Medical School

Fact Sheet

Eunice Kennedy Shriver Center
Healthy People 2020 Roadmap for Massachusetts Children & Youth with ASD/DD: Understanding Needs and Measuring Outcomes

General Information:

A major 2013 report by the Massachusetts Autism Commission called for a comprehensive statewide approach to respond to the needs of people with autism spectrum (ASD) and other developmental disorders (DD) in the state. One major priority called to "determine the number of people with autism in Massachusetts and their support needs by implementing a plan for consistent statewide data collection."

In response, the UMass Medical School-E.K. Shriver Center is conducting a needs assessment project funded under a federal grant by HRSA-MCHB to understand current state-level data collection and to establish a future outcome monitoring plan for systems of services for Massachusetts children and youth with ASD/DD. The Shriver Center project team will gather information about current data systems in place across through a structured review process, and develop and implement a future surveillance strategy for ASD/DD outcomes to inform policy and practice.

Specifically, the project aims to:

1. Understand the utility of existing state data to inform the needs of Massachusetts children and youth with ASD and DD that align with six MCHB core indicators (i.e., early identification, medical home, access to community-based systems of support, family involvement, transition to adulthood, and insurance); Set a state baseline from what we learn about each of the six categories;
2. Refine the existing state plan originally recommended by the Massachusetts Autism Commission to address identified needs; and
3. Outline a comprehensive evaluation plan and program outcome monitoring strategy to track and report on future state ASD/DD outcomes by building upon what has been learned through the initial needs assessment. The plan will focus on children and youth by race, culture, language, immigrant status, region, transition age, insurance coverage, level of function, and mental health status.

We will ask state agencies and related organizations to be involved in refining state-level approaches to identify the population with ASD and to monitor a number of outcomes including development, health, education, and transition in this population using existing data and surveillance systems within the state. We will explore data linkages and specific approaches to mining existing data to inform best practices. Our data interpretation will carefully consider any limitations in the existing data to deem its utility and usability in informing the state's policy questions.

Project Questions and Answers:

What is expected of state agencies and organizations that choose to participate?

No new data collection will be performed as part of this pilot work. Rather, we will ask participating state agencies and organizations to assist the Shriver Center with locating and providing their own organization's *existing* data resources. They will advise us on how these sources can inform health and developmental surveillance for this population either on their own or through linkage with other data resources. In addition, we will ask agencies to share information about how data may be abstracted, both currently and for ongoing surveillance, including necessary approvals and protocols.

If we choose to participate, what is our responsibility?

As much as possible, the Shriver Center project team will manage the data exploration and analysis process and attempt to minimize the effort required of agency staff. The Shriver Center will be responsible for information gathering and review of data dictionaries or other available sources. Interface with state agency staff will be necessary to document issues regarding data quality, methods of collection, access to data and local data collection processes, as well as interpretation of the data.

How will the UMMS-Shriver Center deal with the fact that state agencies may use different eligibility criteria for autism spectrum disorder services?

In an effort to establish a uniform operational definition of ASD for the project, the Shriver Center proposes a broad definition framework for use in health and development surveillance against which each system's definition may be compared and which may be used to inform design of the sample frame. This pilot project will include the development of a Best Practices Report in using the definition framework to enhance comparability of data across systems.

Is this research that needs to be IRB approved?

This work is considered public health practice directed towards expanded surveillance for people with autism spectrum disorders and not research. However, in cases where Personal Health Information (PHI) may need to be shared for secondary data analysis or linkage to create a final de-identified state-level dataset, all necessary data-sharing agreements will be put in place by the Shriver Center team. If review by an IRB is deemed necessary, the Shriver Center will manage the process.

What benefit would participation in this project bring to my agency?

We expect that participating state agencies and organizations will benefit in a number of ways:

- Have an opportunity to lend their perspectives and experience about the interpretation of the data.
- Receive shared findings including comparative benchmarks, as permitted.
- Learn promising strategies for monitoring future outcomes arising from the analysis.
- Gain information that can help target local improvements in service delivery and support quality.
- Benefit from any insights gained during this process in addressing policy questions that are important to them.

How will the data gathered in this project be stored and used?

This could vary according to agencies' restrictions or requirements, but it is anticipated that de-identified data will be stored in UMMS's secure data networks as a state organization. *This will ensure the security and confidentiality of all data using integrated, rigorously enforced IT security controls as set forth in Federal Information Processing Standards (FIPS) Act 199, Standards for Security Categorization of Federal Information and Information Systems*. The data will be used only to evaluate their potential value in the establishment of a health and development surveillance system for people with ASD. Data use agreements will be instituted as needed.

How will the privacy of state residents be protected?

The protection of individuals' privacy is critically important. Therefore, information will be stored in a de-identified manner for analysis. In addition, sensitive fields, particularly those with small cell counts (rare conditions, for example) will have limited use and will be combined with other variables to prevent inadvertent identification of individuals.

For more information, please contact: Elaine.Gabovitch@umassmed.edu, 774-455-6531

Glossary

Term	Definition	Source
An Act Relative to Insurance Coverage for Autism ("ARICA")	2010 Law in Massachusetts requiring private insurers to cover medically necessary treatment for autism.	Report from the Governor's Special Commission Relative to Autism
APCD	APCDs are large-scale databases that systematically collect health care claims data from a variety of payer sources which include claims from most health care providers.	APCD Council, http://www.apcdcouncil.org/apcd-council-frequently-asked-questions
Applied Behavior Analysis ("ABA")	An evidence- based treatment for individuals with autism that utilizes positive reinforcement to encourage positive behavior while at the same time reducing interfering behaviors. ABA can also help children and adults with autism learn new skills.	Report from the Governor's Special Commission Relative to Autism
Asperger Syndrome	One of the autism spectrum disorders (see definition below) characterized by normal intelligence.	Report from the Governor's Special Commission Relative to Autism
Autism Spectrum Disorder	A developmental disability significantly impacting verbal and nonverbal communication and social interaction. Autism Spectrum Disorders, as defined by the DSM-IV, include Autism, Pervasive Developmental Disorder-Not Otherwise Specified, Asperger Syndrome, Rett Syndrome and Childhood Disintegrative Disorder.	Report from the Governor's Special Commission Relative to Autism
CDHP	A Consumer-Directed Health Plan (CDHP) is a plan that is desiend to return control of health care dollars to the person who uses them, the consumer. The consumer is given a financial incentive to control costs and as a result tend to become more directly involved in the selection and usage of health care services. CDHP's consist of three parts: 1) A health plan with a relatively high deductible level that provides financial security for more severe illnesses. Preventive care services are typically covered with only a small copayment. 2) A health fund that the consumer controls. Employers can make contributions into the health fund of their employees. Funds in the account can be used to pay for expenses before the deductible is met. Any unused funds typically roll over from year to year and can accumulate into a significant balance. 3) Information tools are provided to the consumer to help them make better health care decisions. These may include health and wellness information and information on providers and the cost of services.	http://www.siho.org/en/CDHP/qa.html
Child or children	A person 14 years and under	Hill & Hill. The People's Law Dictionary
Children with Special Health Care Needs (CSHCN)	Children with special health care needs are defined by the US Maternal and Child Health Bureau as those who have, or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions and who require health and related services of a type or amount beyond that required by children generally (USDHHS, MCHB, 1997).	MHI: Pediatric
Children's Autism Medicaid Waiver	The Children's Autism Waiver Program is a Medicaid Home & Community Based Wavier program that provides intensive in-home and community based services to MassHealth eligible children under age 9 who have an autism diagnosis and are at risk for institutionalization. The Waiver Program is administered by the Department of Developmental Services' Autism Division, and up to 157 children may participate in the Waiver program at any given time. Over the course of the Waiver year, 205 children may be served. The federal government reimburses Massachusetts at 50% of the cost of the Waiver Program. Children chosen to participate in the Waiver program are eligible for up to $25,000 a year of services for a three year period up until their 9th birthday. All staff working with the waiver have extensive experience working with children with autism.	Report from the Governor's Special Commission Relative to Autism

Glossary

Term	Definition	Source
Community health centers	Health centers are community-based and patient-directed organizations that serve populations with limited access to health care. Health Center Program Fundamentals: --Located in or serve a high need community (designated Medically Underserved Area or Population). Find MUAs and MUPs --Governed by a community board composed of a majority (51% or more) of health center patients who represent the population served. More about health center governance --Provide comprehensive primary health care services as well as supportive services (education, translation and transportation, etc.) that promote access to health care. --Provide services available to all with fees adjusted based on ability to pay. --Meet other performance and accountability requirements regarding administrative, clinical, and financial operations.	HRSA, http://bphc.hrsa.gov/about/
Community-based systems of services	A system of care builds not only on the strengths of the child and family, but also on the strengths of the community where that family lives. Providing community-based services means having high quality services accessible to families in the least restrictive setting possible. A community-based system of care requires systems to see the home, school, and neighborhood of the family from an asset perspective, and to identify the natural supports in these familiar surroundings as part of a strengths-based approach. Services, programs and resources are provided where and with whom young children and their families live, attend school and/or spend time. The system fosters the capacity of communities to support young children and their families.	Administration for Children and Families, USHHS, https://www.childwelfare.gov/management/reform/soc/history/community.cfm
Co-Morbid Disorder	The appearance of two more illnesses at the same time, such as the co-occurrence of autism and schizophrenia.	Report from the Governor's Special Commission Relative to Autism
Continuity of care	Systems promote consistency among caregivers. To the extent pennitted by federal and state privacy and confidentiality laws, there is consistent and rellable communication among various providers with individual families and that services and supports are coordinated across programs and settings, especially when children are at risk of disrupted services related to transiency .	
Developmental Disability	A severe, chronic disability of an individual 5 years of age or older that: 1. Is attributable to a mental or physical impairment or combination of mental and physical impairments; 2. Is manifested before the individual attains age 22; 3. Is likely to continue indefinitely; 4. Results in substantial functional limitations in three or more of the following areas of major life activity; (i) Self-care; (ii) Receptive and expressive language; (iii) Learning; (iv) Mobility; (v) Self-direction; (vi) Capacity for independent living; and (vii) Economic self-sufficiency. 5. Reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, supports, or other assistance that is of lifelong or extended duration and is individually planned and coordinated, except that such term, when applied to infants and young children means individuals from birth to age 5, inclusive, who have substantial developmental delay or specific congenital or acquired conditions with a high probability of resulting in developmental disabilities if services are not provided.	DD act

Glossary

Term	Definition	Source
Early Intervention ("EI")	EI in Massachusetts is a statewide, integrated, developmental service available to families of children between birth and three years of age. Children may be eligible for EI if they have developmental difficulties due to identified disabilities, or if typical development is at risk due to certain birth or environmental circumstances. Children with autism are automatically eligible for Early Intervention services. EI provides family-centered services that facilitate the developmental progress of eligible children. EI helps children acquire the skills they will need to continue to grow into happy and healthy members of the community.	Report from the Governor's Special Commission Relative to Autism
Equitable	Quality services and resources designed for families with young children are accessible regardless of where the family lives, their socia-economic status, disabIlities, race? ethnicity, primary language, or their knowledge about how to access information.	
ERISA	The Employee Retirement Income Security Act of 1974 (ERISA) (Pub.L. 93–406, 88 Stat. 829, enacted September 2, 1974, codified in part at 29 U.S.C. ch. 18) is a federal law that establishes minimum standards for pension plans in private industry and provides for extensive rules on the federal income tax effects of transactions associated with employee benefit plans, including health insurance. ERISA does not require that an employer provide health insurance to its employees or retirees, but it regulates the operation of a health benefit plan if an employer chooses to establish one. Self-funded health plans are regulated by this federal law. ERISA plans are not subject to State laws.	
Evidence-based	In the health care field, evidence-based practice (or practices), also called EBP or EBPs, generally refers to approaches to prevention or treatment that are validated by some form of documented scientific evidence.What counts as "evidence" varies. Evidence often is defined as findings established through scientific research, such as controlled clinical studies, but other methods of establishing evidence are considered valid as well. Evidence-based practice stands in contrast to approaches that are based on tradition, convention, belief, or anecdotal evidence.	Massachusetts School of Professional Psychology http://msppinterface.org/guides/evidence SAMHSA Guide To Evidence-Based Practices (EBP) on The Web http://www.samhsa.gov/ebpWebguide/index.asp
Family Navigators	A Family Navigator is a parent who has cared for a child with special needs and has been trained to help other families. Navigators know about the services in a particular area and in their community, and how to apply for them. A Family Navigator can listen to concerns, attend meetings, when possible, assist with completing forms, explain rights, and make connections to appropriate services	Adapted from Maryland definition
Family Support Specialist	A Family Support Specialist is a trained resource who can support parents in learning to promote their child's developmental well-being, and act as a liaison with parents regarding programs and services.	Adapted from various sources
Family-Centered Care	Family-centered care assures the health and well-being of children and their families through a respectful family-professional partnership. It honors the strengths, cultures, traditions and expertise that everyone brings to this relationship. Family-centered care is the standard of practice which results in high quality services. Family Centered services are both a goal and process by which families are recognized	US Maternal and Child Health Bureau, 2004

Glossary

Term	Definition	Source
FERPA	The Family Educational Rights and Privacy Act (FERPA) (20 U.S.C. § 1232g; 34 CFR Part 99) is a Federal law that protects the privacy of student education records. The law applies to all schools that receive funds under an applicable program of the U.S. Department of Education. FERPA gives parents certain rights with respect to their children's education records. These rights transfer to the student when he or she reaches the age of 18 or attends a school beyond the high school level. Students to whom the rights have transferred are "eligible students." Parents or eligible students have the right to inspect and review the student's education records maintained by the school. Schools are not required to provide copies of records unless, for reasons such as great distance, it is impossible for parents or eligible students to review the records. Schools may charge a fee for copies. Parents or eligible students have the right to request that a school correct records which they believe to be inaccurate or misleading. If the school decides not to amend the record, the parent or eligible student then has the right to a formal hearing. After the hearing, if the school still decides not to amend the record, the parent or eligible student has the right to place a statement with the record setting forth his or her view about the contested information. Generally, schools must have written permission from the parent or eligible student in order to release any information from a student's education record. However, FERPA allows schools to disclose those records, without consent, to the following parties or under the following conditions (34 CFR § 99.31): School officials with legitimate educational interest; Other schools to which a student is transferring; Specified officials for audit or evaluation purposes;	US Dept of Ed http://www.ed.gov/policy/gen/guid/fpco/ferpa/index.html
Focus group	A focus group is a group of people that are asked about their perceptions, opinions, beliefs, and attitudes towards a service, concept, or idea. Questions are asked in an interactive group setting where participants are free to talk with other group members. Focus groups are generally used in qualitative research that seeks to learn more about why and how things happen.	Adapted from Wikipedia
HIPAA	The Health Insurance Portability and Accountability Act of 1996 (HIPAA) required the creation of rules for the privacy, security and handling of a breach of personal health information. The Standards for Privacy of Individually Identifiable Health Information (“Privacy Rule”) establishes, for the first time, a set of national standards for the protection of certain health information and was developed in response to the requirements of HIPAA. The Privacy Rule standards address the use and disclosure of individuals’ health information—called “protected health information” by organizations subject to the Privacy Rule — called “covered entities,” as well as standards for individuals' privacy rights to understand and control how their health information is used. Within HHS, the Office for Civil Rights (“OCR”) has responsibility for implementing and enforcing the Privacy Rule with respect to voluntary compliance activities and civil money penalties. A major goal of the Privacy Rule is to assure that individuals’ health information is properly protected while allowing the flow of health information needed to provide and promote high quality health care and to protect the public's health and well being. The Rule aims to strike a balance that permits important uses of information, while protecting the privacy of people who seek care and healing. Given that the health care marketplace is diverse, the Rule is designed to be flexible and comprehensive to cover the variety of uses and disclosures that need to be addressed.	HHS http://www.hhs.gov/ocr/privacy/hipaa/understanding/summary/privacysummary.pdf

Glossary

Term	Definition	Source
HMO	A health maintenance organization (HMO) is an organization that provides or arranges managed care for health insurance, self-funded health care benefit plans, individuals and other entities in the United States and acts as a liaison with health care providers (hospitals, doctors, etc.) on a prepaid basis. The Health Maintenance Organization Act of 1973 required employers with 25 or more employees to offer federally certified HMO options if the employer offers traditional healthcare options.[1] Unlike traditional indemnity insurance, an HMO covers care rendered by those doctors and other professionals who have agreed by contract to treat patients in accordance with the HMO's guidelines and restrictions in exchange for a steady stream of customers. HMOs cover emergency care regardless of the health care provider's contracted status.	
IEP	Each public school child who receives special education and related services must have an Individualized Education Program (IEP). Each IEP must be designed for one student and must be a truly individualized document. The IEP creates an opportunity for teachers, parents, school administrators, related services personnel and students (when appropriate) to work together to improve educational results for children with disabilities. By law, the IEP must include certain information about the child and the educational program designed to meet his or her unique needs. This information covers topics such as current performance, annual goals, special education and related services, accommodations, participation in state and district-wide tests, needed transition services and measured progress.	National Center for Learning Disabilities http://www.ncld.org/students-disabilities/iep-504-plan/what-is-iep
Individual Support Plan (ISP)	In a process chaired by the DDS Service Coordinator, the chair helps the DDS team work with the individual to plan his or her life. The ISP addresses areas of life which are important to the individual.	Report from the Governor's Special Commission Relative to Autism
Individualized Education Plan ("IEP")	The IEP is a written statement signed by the parent that lists services designed to meet the unique needs of eligible children. It can also contain "related services" to help the child access the general curriculum. Review all the potential services listed on an IEP grid. An IEP is legally enforceable.	Report from the Governor's Special Commission Relative to Autism
Key informant	Someone who is regarded as an expert in the field of focus, or who is regarded as having important knowledge in a particular area. Key informants in this project will be interviewed about particular topics of interest such as a source of data or challenges facing people with autism from the perspective of a particular field.	
Managed care	Managed care plans are a type of health insurance. They have contracts with health care providers and medical facilities to provide care for members at reduced costs. These providers make up the plan's network. How much of your care the plan will pay for depends on the network's rules.	Medline http://www.nlm.nih.gov/medlineplus/managedcare.html
Massachusetts Act Early Program	This state program aims to educate parents and health care, early childhood and educational 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. It is an affiliate of the CDC "Learn the Signs, Act Early" program to promote early, periodic developmental screening of all children. www.maactearly.org	Report from the Governer's Special Commission Relative to Autism
Massachusetts Child Psychiatric Access Program ("MCPAP")	This program provides psychiatric expertise to help primary care physicians recognize the signs of mental illness in children and help them provide care to children with mental health issues in their practices.	Report from the Governor's Special Commission Relative to Autism
MassHealth	MassHealth is a public health insurance program offered by the state to low- to medium-income residents of Massachusetts, including individuals with disabilities. The Commonwealth is reimbursed approximately 50% of the cost of the MassHealth program by the federal government.	Report from the Governor's Special Commission Relative to Autism

Glossary

Term	Definition	Source
Medical Home	A medical home is a community-based primary care setting which provides and coordinates high quality, planned, patient/family-centered: health promotion (acute, preventive) and chronic condition management (© CMHI, 2006).	MHI: Pediatric
Medical Home Family Index (MHFI)	A companion survey to the MHI, the MHFI is intended for use with a cohort of practice families (particularly those who have children/youth affected by a chronic health condition). The MHFI is to be completed by families whose children receive care from a practice with whom their child has been seen for over a year. The Medical Home Family Index provides the practice team with a valuable parent/consumer perspective on the overall experience of care.	MHI: Pediatric
Medical Home Index (MHI)	A validated self-assessment and classification tool designed to translate the broad indicators defining the medical home (accessible, family-centered, comprehensive, coordinated, etc.) into observable, tangible behaviors and processes of care within any office setting. It is a way of measuring and quantifying the "medical homeness" of a primary care practice. The MHI is based on the premise that "medical home" is an evolutionary process rather than a fully realized status for most practices. The MHI measures a practice's progress in this developmental process.	MHI: Pediatric
MSW	Masters-level social workers (MSW) have advanced training and generally do either of two main types of social workers: direct-service social workers, who help people solve and cope with problems in their everyday lives, and clinical social workers, who diagnose and treat mental, behavioral, and emotional issues. Social workers work in a variety of settings, including mental health clinics, schools, hospitals, and private practices.	Bureau of Labor Statistics
Nurse Practitioner	A nurse practitioner (NP) is a nurse who has completed advanced didactic and clinical education beyond that required of the generalist registered nurse (RN) role. Nurse practitioners utilize extended and expanded skills, experience and knowledge in assessment, planning, implementation, diagnosis and evaluation of the care required. Nurses practicing at this level are educationally prepared at the post-graduate level and may work in either a specialist or generalist capacity.	Adapted from Wikipedia
OT	Occupational therapists (OT) treat patients with injuries, illnesses, or disabilities through the therapeutic use of everyday activities. They help these patients develop, recover, and improve the skills needed for daily living and working. They require a masters degree in occupational therapy.	Bureau of Labor Statistics
Parents	Children have a variety of diverse family constellations. The term ''parents'' recognizes and is inclusive of grandparents, foster parents or other individuals acting as a parent or serving as a child's legal guardian.	
Pediatrician	A primary care physician who specializes in in the medical care of children (up to age 18).	
PPO	A preferred provider organization (or PPO, sometimes referred to as a participating provider organization or preferred provider option) is a managed care organization of medical doctors, hospitals, and other health care providers who have covenanted with an insurer or a third-party administrator to provide health care at reduced rates to the insurer's or administrator's clients.	

Glossary

Term	Definition	Source
Practice-Based Care Coordination	Care and services performed in partnership with the family and providers by health professionals to: 1) Establish family-centered community-based Medical Homes for CSHCN and their families. -Make assessments and monitor child and family needs -Participate in parent/professional practice improvement activities 2) Facilitate timely access to the Primary Care Provider (PCP), services and resources -Offer supportive services including counseling, education and listening -Facilitate communication among PCP, family and others 3) Build bridges among families and health, education and social services; promotes continuity of care -Develop, monitor, update and follow-up with care planning and care plans -Organize wrap around teams with families; support meeting recommendations and follow-up 4) Supply/provide access to referrals, information and education for families across systems. -Coordinate inter-organizationally -Advocate with and for the family (e.g. to school, day care, or health care settings) 5) Maximize effective, efficient, and innovative use of existing resources -Find, coordinate and promote effective and efficient use of current resources -Monitor outcomes for child, family and practice	MHI: Pediatric
Primary Care Provider (PCP)	Physician or pediatric nurse practitioner who is considered the main provider of health care for the child	MHI: Pediatric
PT	Occupational therapists treat patients with injuries, illnesses, or disabilities through the therapeutic use of everyday activities. They help these patients develop, recover, and improve the skills needed for daily living and working. Physical therapists typically need a doctoral degree in physical therapy. All states require physical therapists to be licensed.	Bureau of Labor Statistics
Respect for diversity	Policies, systems, programs and staff are knowledgeable about and responsive to the diversity of families, with regard to their needs, culture, etbnicity, language, economics, and family structure.	
Self-Funded Insurance Plans	Pursuant to the federal Employee Retirement Income Security Act ("ERISA"), certain "self-funded" or "self-insured" insurance plans are subject only to federal law and exempt from state insurance regulations, including mandates. In those instances where employers bear the entire risk for employee insurance claims, such plans are exempt from state regulation. As a result of ERISA, many employees are unable to access benefits required by An Act Relative to Insurance Coverage for Autism "ARICA" unless their employer volunteers to comply.	Report from the Governer's Special Commission Relative to Autism
Speech pathologist	Speech-language pathologists diagnose and treat communication and swallowing disorders in patients. Most speech-language pathologists work in schools or healthcare facilities. Some work in patients' homes. Speech-language pathologists typically need at least a master's degree.	Bureau of Labor Statistics
State agencies	A state agency is a permanent or semi-permanent organization in the state government that is responsible for the oversight and administration of specific functions.	Adapted from Wikipedia

Glossary

Term	Definition	Source
The Department of Elementary Secoand ndary Education/Department of Developmental Services Residential Placement Prevention Program ("DESE/DDS" Program)	The DESE/DDS program provides supports to families to keep children at home and reduce the risk for residential placement of students who are in school and DDS eligible. It also provides supports to families who opt to bring their children home from a residential placement. Children must be 6-17 years of age at the time of enrollment in the Program. The DESE/DDS Program is funded by the state through funds allocated to Department of Elementary and Secondary Education and administered by the Department of Developmental Services. There are currently 485 students receiving services through the DESE/DDS program, 75% of whom have an autism diagnosis.	Report from the Governer's Special Commission Relative to Autism
Transition Coordinators	The primary link to information and assistance from a state agency during the transition from special education to adult life. They help individuals and the families understand what state agencies can offer and assist with identifying and securing requested supports. The Transition Service Coordinator will also chair the Individual Transition Plan (ITP) meeting. From this meeting, they will develop a document that specifies what kinds of support the student/family is requesting upon leaving special education. Soon after graduation or when an individual leaves school and transitions into adult supports, an individual's case will be transferred to an adult service coordinator within the area office.	Report from the Governor's Special Commission Relative to Autism
Transition Planning	Helping an individual with disabilities move from the school setting into adult services. Areas to be considered include: post-secondary education options, housing, employment, public benefits, recreation and social interests.	Report from the Governor's Special Commission Relative to Autism
Underserved	Those living in the United States who do not have adequate access to health care services. They share one or more of these characteristics: they may be poor; uninsured; have limited English language proficiency and/or lack familiarity with the health care delivery system; or live in locations where providers are not readily available to meet their needs. A group of people who, for a variety of reasons, do not have equal access to health and health care services.	Adil Moiduddin, Jonathan Moore. The Underserved and Health Information Technology: Issues and Opportunities. November, 2008. Office of the Assistant Secretary for Planning and Evaluation (ASPE), U.S. Department of Health and Human Services (HHS) http://aspe.hhs.gov/sp/reports/2009/underserved/report.html http://www.endowmentforhealth.org/grant-center/glossary.aspx
Understandable and user-friendly	Services, programs and resources are easily accessible, understandable and presented in a variety of formats and languages to meet individual family needs.	
Vocational Rehabilitation Division	A division within Mass Rehabilitation Commission ("MRC"), it provides counseling, assessment, training and job placement support as well as assistance with adaptations and accommodations that will ultimately result in competitive employment for the individual with a disability	Report from the Governor's Special Commission Relative to Autism
Youth	A period between childhood and adulthood. Often roughly considered to be between the ages of 15 and 24 years.	

Acronyms	Full Title
AANE	Asperger's Association of New England
AAP	American Academy of Pediatrics
ABA	Applied Behavioral Analysis
ACA	The Affordable Care Act
AIRC	Autism Insurance Resource Center
APCD	Massachusetts All-Payer Claims Database
ARICA	An Act Relative to Insurance Coverage for Autism
ASD/DD	Autism Spectrum Disorder/ Developmental Disability
ASQ	Autism Screening Questionnaire developmental screening tool
ASQ:SE	Ages & Stages Questionairre: Social-Emotional Version developmental screening tool
BITSEA	The Brief Infant-Toddler Social and Emotional Assessment developmental screening tool
BMC	Boston Medical Center
BPHC	Boston Public Health Commission
BPHC CHAP Bureau	Boston Public Health Commission, Child Health Assessment and Planning (CHAP)
BUSPH	Boston University School of Public Health
CBHI	Children's Behavioral Health Initiative
CDC	Center for Disease Control
CDDER	Center for Developmental Disability Evaluation and Research
CDHP	Consumer Directed Health Care Plans
CFCE	Coordinated Family & Community Engagement Programs
CHIPRA	Children's Health Insurance Program Reauthorization Act
CHIPRA sites	Children's Health Insurance Program Reauthorization Act Initiative - 13 sites
CSHCN	Children with Special Health Care Needs
CSHCN in MA	Children with Special Health Care Needs in Massachusetts
CYSHCN	CYSHCN - Children and Youth with Special Health Care Needs
DDS	Department of Developmental Services
DESE	Massachusetts Department of Elementary and Secondary Education
DMH	Department of Mental Health
DPH	Department of Public Health
DPH MECCS	Department of Public Health Massachusetts Early Childhood Comprehensive Systems
DPH/EI	Department of Public Health/ Early Intervention
DTA	Department of Transitional Assistance
EBD	Emotional and behavioral disorders
EEC	Massachusetts Department of Early Education and Care
EEC-HMG	Department of Early Education & Care's Help Me Grow Program
EI	Early Intervention
EOHHS	Executive Office of Health and Human Services
EPSDT	Early and Periodic Screening, Diagnosis, and Treatment
ERISA	Employee Retirement Income Security Act
FCC	Federal Communications Commission
FCSN	Federation for Children with Special Needs
FPL	Federal Poverty Level
GLM	General linear models (statistical term)
HMEA-ARC	Horace Mann Educational Association - Autism Resource Center of Central MA
HMG	Help Me Grow
HRSA-MCHB	Health Resources and Services Administration, Maternal and Child Health Bureau
I/DD	Intellectual/Developmental Disabilities
ICI	Institute for Community Integration
IDDRC	Intellectual and Developmental Disabilities Research Center (IDDRC)
IDEA Data Accountability Center	The Individuals with Disabilities Education Act
IEP	Individual Education Plan
ISP	Individual Service Plan
LEND	Leadership Education in Neurodevelopmental and Related Disabilities
LTSAE	Learn the Signs Act Early
MA DESE	Massachusetts Department of Elementary and Secondary Education

MA EOHHS PCMHI	Mass Executive Office of Health and Human Services Patient Centered Medical Home Initiative
MA Family TIES	Massachusetts Family TIES organization
MassPAC	Massachusetts special education parent advisory councils (PACs)
MCAAP	The Massachusetts Chapter of the American Academy of Pediatrics
M-CHAT	Modified Checklist for Autism in Toddlers autism screening tool
MCHB	Maternal and Child Health Bureau
MDDC	Massachusetts Developmental Disabilities Council
MHI	Medical Home Index
ML CHCs	Massachusetts League of Community Health Centers
MOUs	Memorandum of Understanding
MRC	Massachusetts Rehabilitation Commission
NCCC	National Center on Cultural Competence at Georgetown University
NCQA	National Committee for Quality Assurance
NE Arc-ASC	Northeast Arc - Autism Support Center
NHIS	National Health Interview Survey
NIH	National Institutes of Health
NLTS-2	National Longitudinal Transition Study-2
NSCH	National Survey of Children's Health
NS-CSHCN	National Survey of Children with Special Health Care Needs
NSTTAC	National Secondary Transition Technical Assistance Center
OSEP, U.S.DOE	Office of Special Education Programs
PAG	Project Advisory Group
PCMH	Patient Centered Medical Home
PEDS	Parent's Evaluation of Developmental Status developmental screening tool
PPAL	Parent / Professional Advocacy League
Shriver AIRC	Shriver Autism Insurance Resource Center
SWYC	Survey of Wellbeing of Young Children developmental screening tool
U.S. HHS	United States Health and Human Services
UCEDD	University Centers for Excellence in Developmental Disabilities
UMMS	University of Massachusetts Medical School
UMMS-CANDO	UMass Medical School - Center for Autism and Neurodevelopmental Disorders
VR Division	Vocational Rehabilitation Division
YSHCN	Youth with Special Health Care Needs

The Autism Center
MASSACHUSETTS ADVOCATES *for* CHILDREN

Autism Omnibus Bill

Ch.226 of the Acts of 2014, *An Act Relative to Assisting Individuals with Autism and other Intellectual or Developmental Disabilities*, addresses the following recommendations of the Massachusetts Autism Commission:

- ***Require MassHealth to cover medically necessary treatments for children with ASD who are under 21 years old – including ABA therapies as well as dedicated and non-dedicated AAC devices.*** This is an important equity and legal issue, ensuring that families who are low-income can access treatments that are now available to families covered by private insurance plans subject to the state's autism insurance law (ARICA).

- ***Change eligibility criteria for The Department of Developmental Services (DDS) to include adults with Autism Spectrum Disorder,*** *Prader-Willi, and Smith-Magenis syndrome.* Many individuals with autism do not have an IQ lower than 70 (currently required for DDS eligibility) but do have significant functioning limitations (self care issues, mobility, unable to live independently, learning issues.) Rather than relying solely on an IQ criteria, DDS would be required to use the federal definition of "developmental disability" to expand eligibility to adults with ASD and PW who meet conditions for "substantial functional limitations".

- ***Create tax-free saving accounts*** **(called *"Achieving a Better Life Experience" or ABLE*)** to help families cover anticipated disability- related expenses for individuals with autism and other physical and developmental disabilities. The ABLE accounts are similar to the "529 plan" education savings accounts which encourage parents to save money for future college costs and are modeled on a federal bill pending in Congress.

- ***Create Autism Endorsement for special education teachers***, which is a voluntary credential for special education teachers to gain in-depth knowledge about the complexities of educating students with ASD. This will help to ensure that the growing number of students with autism receive appropriate educational services by increasing the capacity of school districts to meet their complex and unique needs.

- ***Require Department of Mental Health and Department of Developmental Services to develop and implement a plan to provide services to individuals who have both a mental illness and a developmental disabilities***

- ***Establish the Autism Commission as a permanent entity*** responsible for overseeing the implementation of the original Commission's recommendation and monitoring the implementation of government policies impacting individuals with ASD, with an executive director and 34 commission members who will investigate and report on the range of services and supports necessary for individuals with ASD to achieve full potential across their life spans.

Early Childhood Screening

INDICATORS/GOALS

✪ statistically better than US ✗ statistically worse than US

Increase % of babies –

• who are screened for hearing loss by 1 month of age	2020 Goal	100%
	VT 2009	95% ✪
	US 2007	82%
• who need and receive an audiological evaluation by 3 months of age	2020 Goal	55%
	VT 2009	48% ✗
	US 2007	66%
• with hearing loss who receive intervention services by 6 months of age	2020 Goal	55%
	VT 2009	50%
	US 2007	50%

Increase % of children –

• who are screened for Autism Spectrum Disorder and other developmental delays by 24 months of age	VT/2020 Goal	* * *
	US 2007	20%
• with Autism Spectrum Disorder diagnosis who have first evaluation by 36 months of age	VT/2020 Goal	* * *
	US 2006	39%
• who are ready for school in five domains of healthy development	2020 Goal	65%
	VT 2010	56%
	US data not available	
• age 10-17 who have had a wellness exam in the past 12 months	2020 Goal	65%
	VT 2010-11	57%
	US data not comparable	

Decrease % of students absent from school due to illness/injury	VT/2020 Goal	* * *
	US 2008	5%
Increase % of middle schools that require newly hired staff who teach Health Education to be State licensed or endorsed	VT/2020 Goal	* * *
	US 2006	51%

• Newborn Screening for Hearing

At least one in six Americans has a sensory or communication impairment or disorder. Even when temporary and mild, such disorders can affect health. Any barrier to physical balance and communication with others can make a person feel socially isolated, have unmet health needs, and limited success in school or on the job. Very early screening and intervention for hearing loss improves physical development, language, learning and literacy for these children.

• Well Child Ready for School

Social and emotional development in early childhood is strongly connected with later academic achievement. Early and continuous developmental screening results in timely identification and referral. This is important so that children arrive at Kindergarten competent in all five developmental domains.

• Wellness Check-ups for Adolescents

High quality preventive services for school-age youth include annual well exams, with assessments of physical activity, nutrition, sexual behavior, substance abuse and behaviors that can result in injuries.

• Quality Early Health Education

Health education by qualified teachers builds the knowledge, attitudes and skills that students need to make healthy decisions, become health literate, and look out for the health of others. Curricula should address tobacco/alcohol/drug use, nutrition, mental and emotional health, physical activity, safety and injury prevention, sexual health and violence prevention.

Five Domains of Healthy Development:

- Social-Emotional Development
- Approaches to Learning
- Communication
- Cognitive Development
- Wellness

Well children demonstrate age-appropriate self-help skills, and seldom or never appear to be inhibited by illness, fatigue or hunger.

Vermont's Statewide Report on Kindergarten Readiness 2011-2012

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* * * *Vermont data not available and goal to be developed*

3 WAYS

The State Public Health Autism Resource Center (SPHARC)

Can help improve your state's Autism Spectrum Disorder and/or Developmental Disabilities (ASD/DD) program.

Click on graphics for more!

SPHARC
State Public Health Autism Resource Center

is a comprehensive web-based resource center for state programs, including Title V.

OUR AIM

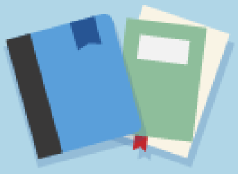
is to help increase state capacity to implement systems of care for children and youth with ASD/DD.

Here are three ways we can help **YOU** to improve your state's ASD/DD program.

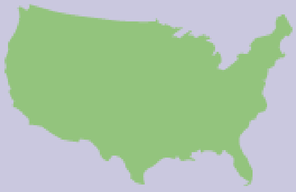
1 Resource Development

Find resources developed by SPHARC and state grantees using the search engine!

Title V MCH National Performance Measure 6 Developmental Screening Tools



Publications



State Profiles of ASD/DD programs and grantees

Title V Action Planning

Case Examples on Using CYSHCN Standards and SPHARC Tools

Children and Youth with Special Health Care Needs

Roles for State Title V Programs in Building ASD/DD Systems of Care

Environmental Scan: State Strategies and Initiatives

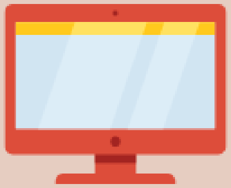
State Autism Grantee Spotlight Interactive Map

National Landscape: Developmental and Autism Screening Programs and Initiatives

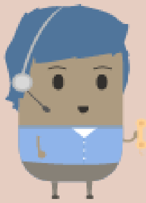
91% of responding state implementation and planning grantees said they applied one or more concepts learned from SPHARC.

2 Technical Assistance

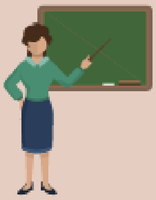
SPHARC has supported 30 HRSA State Autism Systems Grantees, including 12 Title V Programs!



SPHARC Webinars that feature topic area experts



One-on-One calls with SPHARC staff that focus on your state's area of need



Learning Modules around six critical indicators for CYSHCN

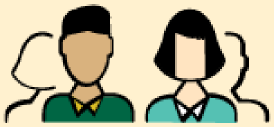
3 Peer Learning

See resources from past Peer-to-Peer Exchanges on topics like....

- Addressing Gaps in ASD/DD Diagnosis
- Considering Culture
- Screening and Beyond

Site Visits that delve into one another's programs, successes, and lessons learned

Peer-to-Peer Exchange for states to learn from each other on a specific topic



Learning Community that facilitates collective problem solving, sharing, and replication of best practices

THE BOTTOM LINE

SPHARC is a great resource for you and your state.

We are here to SERVE!

For more information, go to www.amchp.org/SPHARC.

AMCHP's State Public Health Autism Resource Center is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under grant number U01MC11069 - Partnership for State Leadership Cooperative Agreement. This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government.

AMCHP
ASSOCIATION OF MATERNAL & CHILD HEALTH PROGRAMS

October 24, 2016

The Honorable Charles D. Baker
Governor of Massachusetts

The Joint Committee on Children, Families and
Person with Disabilities
Senator Jennifer L. Flanagan, Chairperson
Representative Kay Kahn, Chairperson

The Joint Committee on Healthcare Financing
Senator James T. Welch, Chairperson
Representative Jeffrey Sanchez, Chairperson

Re: 2016 Annual Report of the Autism Commission

Dear Governor Baker and Committee Chairpersons:

In accordance with M.G.L. c.6 § 217(c), I respectfully submit the attached 2016 Annual Report on behalf of the Autism Commission.

Sincerely,

Carolyn J Kain

Carolyn J. Kain
Executive Director
Autism Commission

Charles D. Baker
Governor

Karyn Polito
Lieutenant Governor

Marylou Sudders
Secretary

Carolyn Kain
Executive Director

THE MASSACHUSETTS AUTISM COMMISSION ANNUAL REPORT

October 24, 2016

State Legislative Members

Senator Barbara L'Italien, Andover
Senator Richard Ross, Wrentham
Representative Garrett Bradley, Hingham
Representative Kimberly Ferguson, Holden

State Agency Members and Designees

Marylou Sudders, Secretary of Health and Human Services, Chair

Monica Bharel, MD, Commissioner of the Department of Public Health
Ron Benham, Director Bureau of Family Nutrition and Health, *Designee*

Elin Howe, Commissioner of the Department of Developmental Services

Joan Mikula, Commissioner of the Department of Mental Health
Kathy Sanders, M.D., Deputy Commissioner for Clinical and Professional Services, *Designee*

Linda Spears, Commissioner of the Department of Children and Families
Danielle Ferrier, MBA, LICSW, Deputy Commissioner for Clinical Services and Program Operations, *Designee*

Mitchell Chester, Commissioner of Elementary and Secondary Education
Marcia Mittnacht, State Director of Special education Planning and Policy, *Designee*

Chrystal Kornegay, Undersecretary of the Department of Housing and Community Development
Ayana Dilday Gonzalez, Supportive Housing and Special Projects Manager, *Designee*

Adelaide Osborne, Commissioner of the Massachusetts Rehabilitation Commission
Kasper Goshgarian, Deputy Commissioner, *Designee*

Carlos Santiago, Commissioner of Higher Education
Dr. Patricia Marshall, Deputy Commissioner of Academic Affairs and Student Success, *Designee*

Patricia A. Gentile, Ed.D., President, North Shore Community College

Dan Tsai, M.D., Assistant Secretary of MassHealth
Laura Conrad, MassHealth Program Manager, Children's Behavioral Health, *Designee*

Jane Ryder, Department of Developmental Services, Director of the Division of Autism

Janet George, Ed. D., Representative with Clinical knowledge of Smith-Magenis Syndrome

Other Commission Members

Cathy Boyle, Parent, Autism Housing Pathways

Michelle Brait, Parent

Dan Burke, Arc of Massachusetts representative

Rocío Calvo, Ph.D., Boston College School of Social Work, *Designee*

Rita Gardner, CEO Melmark

Todd Garvin, Self-Advocate

Christine Hubbard, AFAM representative

Dania Jekel, MSW, AANE representative

Patricia Jennings, Parent

Julia Landau, Esq., Massachusetts Advocates for Children representative

Susan Loring, RN, Director Autism Resource Central

Deidre Phillips, Consultant/Coach to Non-Profit Organizations

Chris Supple, Esq.

Judith Ursitti, Autism Speaks representative

Ann M. Neumeyer, M.D., Representative of the Lurie Center

Teresa Schirmer, LICSW, Boston College School of Social Work

Vincent Strully, Jr., Chief Executive Officer New England Center for Children

Amy Weinstock, Autism Insurance Resource Center representative

Carolyn Kain, Executive Director of the Autism Commission

This annual report is being submitted by the Autism Commission and its Executive Director to the Governor, the joint committee on children, families and persons with disabilities, and the joint committee on health care financing in accordance with Section 217 (c) of Chapter 226 of the Acts of 2014. On August 5, 2014, the Commonwealth of Massachusetts enacted Chapter 226 of the Acts of 2014 the "Autism Omnibus Law", which continued the previous work completed by the 2010 "Special Commission", and established the Autism Commission as a permanent entity.

The Autism Commission is charged with making recommendation on policies impacting individuals with autism spectrum disorders and Smith-Magenis syndrome. The Commission is required to investigate the range of services and supports necessary for such individuals to achieve their full potential across their lifespan, including but not limited to, investigating issues related to public education, higher education, job attainment and employment, including supported employment, provision of adult human services, post-secondary education, independent living, community participation, housing, social and recreational opportunities, behavioral services based on best practices to ensure emotional well-being, mental health services and issues related to access for families of children with autism spectrum disorder and adults who are from linguistically and culturally diverse communities. [1]

This report includes updates on: the statutory requirements of the Autism Omnibus Law: providing updates on the recommendations set forth in the 2013 report by the 2010 "Special Commission"; and outlining current unmet needs and trends in autism services, supports and treatments for individuals with autism spectrum disorder, with any recommendations for regulatory and legislative action necessary to provide or improve such supports and services. [2]

History

In 2010, the prevalence of autism spectrum disorder ("ASD") for eight (8) year olds was reported by the CDC to be 1 in 68, with four times as many boys being diagnosed with ASD than girls (1 in 42 boys, and 1 in 189 girls). That same year, the Commonwealth of Massachusetts by Legislative Resolve established a "Special Commission Relative to Autism". This Special Commission was charged with investigating and studying the range of supports and services necessary for individuals with ASD to achieve their full potential across their lifespan. The types of supports and services issues covered a wide range of issues including; public education, job attainment and employment, supported employment, adult human services, post-secondary education, independent living, community participation, housing, social and recreational opportunities, behavioral services based on best practices to ensure emotional well-being, mental health services, and access to services for families of children and adults with ASD who are from linguistically and culturally diverse communities. The Special Commission was also charged with addressing mechanisms to ensure maximization of federal reimbursement

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[1] Chapter 226 of the Acts of 2014, Section 1(c)
[2] Ibid.

and coordination of state human services. [3] The most recent data released by the CDC in March of 2016 maintains the same rates for the prevalence of autism. While the prevalence data was established by looking at eight year olds, many of the individuals who were included in the first ASD prevalence study by the CDC (in 2007) are entering adulthood.

The Special Commission established sub-committees to expand its ranks and to conduct more in-depth analyses and to make specific recommendations on issues affecting individuals with ASD. The sub-committees were assigned specific age groups: 1) Birth to Five Years Old; 2) School Aged individuals; 3) Transition to Adulthood; and 4) Adults. While the State agencies and Secretariats and/or their designees were represented and served as valuable members of the Commission, the findings and recommendations ultimately produced by the Commission in its 2013 report were independently formulated by its non-governmental Commission and sub-committee members. [4]

In March 2013, based on a combination of its own work, reports that were submitted by State agencies to the Commission, and the work performed by and reports developed by the sub-committees, the Commission issued an extensive report that prioritized thirteen (13) key recommendations.

Those recommendations were as follows:

1. Expand eligibility criteria for the Department of Developmental Services so that individuals with autism who have IQs over 70 and have substantial functional limitations have access to services.
2. Assure that those with autism and a co-occurring mental health condition have equal access to and appropriate services from the Department of Mental Health.
3. Expand intensive services in the home and community for individuals with autism through the Children's Autism Medicaid Waiver, the Adult Medicaid Waivers, and the Department of Elementary and Secondary Education/Department of Developmental Services Residential Prevention program.
4. Expand insurance coverage for autism treatments.
5. Increase and fortify supports and resources that make it possible to maintain the family unit and assist individuals with autism to live in the community.
6. Determine the number of people with autism in Massachusetts and their support needs by implementing a plan for consistent statewide data collection.
7. Improve access to autism screening, diagnosis, and Autism Specialty Services through Early Intervention for children diagnosed with autism and those considered high risk for autism.
8. Increase employment opportunities for individuals with autism by providing a range of job training, job development, and employment opportunities.
9. Increase capacity to provide educational supports and services necessary to meet the needs of all students with autism.

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[3] Chapter 2 of the 2010 Acts and Resolves

[4] Ibid.

10. Increase availability of augmentative and alternative communication methods, devices and services for individuals with autism.
11. Increase the range of housing options for individuals with autism.
12. Improve the delivery of healthcare services for individuals with autism.
13. Assure that the Autism Commission's Recommendations are implemented and outcomes are monitored for effectiveness.

The 2010 Special Commission made recommendations that were broad and extensive, and their report acknowledged that many of their recommendations would require legislative actions, statutory changes and/or increased financial resources. The recommendations were categorized based on specific state agencies' respective areas of responsibility, and designated as short, medium or long term goals.

Chapter 226 of the Acts of 2014 resumed the work of the previous Special Commission and established the Autism Commission as a permanent entity, comprised of 35 members including; State Legislators, State Secretariats, State Agencies, Autism advocates and service organizations, and 14 individuals appointed by the Governor. The Secretary of Health and Human Services is the designated Chair of the Commission. The Legislation also authorized the appointment of an Executive Director by the Governor from candidates recommended by the Commission. The duties of the Executive Director include: (1) reporting on the progress of the implementation of the recommendations of the March 2013 report with periodic benchmarks and cost estimates; (2) coordination of Commission meetings; (3) coordination with relevant state agencies; and (4) completion of the annual report. [5]

The Autism Omnibus Law incorporated some of the 2013 recommendations as statutory mandates. The statute required: a) the creation of tax-free "ABLE" accounts for qualified disability expenses; b) a comprehensive program of community developmental disability services by the Department of Developmental Services; c) the Department of Developmental Services ("DDS") issuing of licenses to providers for individuals with developmental disabilities for a term of two years; d) the creation of an autism endorsement for special education teachers by the Board of Elementary and Secondary Education; e) Coverage by MassHealth of medically necessary treatments under the age of 21 including ABA services and augmentative and alternative communication devices; f) a plan between DDS and the Department of Mental Health to provide services to individuals who have both a developmental disability and a mental illness; g) and further investigation and study by the Commission on the issues of employment and higher education, and housing and h) Commission recommendations for plans of action for the Commonwealth on higher education and employment, and housing for individuals with ASD.

Updates on Autism Omnibus Law Mandates

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[5] Chapter 226 of the Acts of 2014, Section 1 (b)

I. ABLE accounts. The Massachusetts Autism Omnibus Law enacted in August 2014 called for the establishment of "Achieving a Better Life" or "ABLE" savings accounts for individuals with disabilities for qualified disability expenses. Six months later in December 2014, the Federal government passed the ABLE Act amending Section 529 of the Internal Revenue Service Code of 1986 to create tax-free accounts for individuals with disabilities. In June 2015, the Department of the Treasury issued proposed regulations regarding ABLE accounts, and additional revisions to those proposed regulations were issued in January 2016. The final federal regulations are expected to be issued later in 2016.

The total annual contributions by all participating individuals, including the beneficiary, family and friends is $14,000 (the federal gift tax exclusion-this will be adjusted annually for inflation). The total contribution that can be made to an ABLE account over time is tied to the individual state's maximum amount for 529 accounts (typically around $250,000 to $350,000). The first $100,000 in ABLE accounts is exempted from the SSI $2,000 individual resource limit.

In July 2016, a Massachusetts FY17 budget amendment further amended G.L. c. 15c, Sec. 29 and Section 23 of Ch. 226 of the Acts of 2014, in response to the Federal ABLE Act. In Massachusetts the Massachusetts Educational Financing Authority ("MEFA"), is the authority for 529 college accounts and has also been designated as the authority for ABLE accounts in Massachusetts. MEFA has reported that they do not intend to issue separate regulations regarding ABLE accounts, and will rely on the Federal regulations for the establishment and administration of these accounts. MassHealth will review the final federal rules once they are promulgated to determine if any changes will be necessary to MassHealth regulations. MEFA has reported that they do not expect ABLE accounts to be available in the Commonwealth until 2017. MEFA is currently in the process of designating an administrator for ABLE accounts. Massachusetts residents can presently use the ABLE account websites of Ohio, Nebraska or Tennessee to establish an account, and then transfer those funds in an out-of-state account to Massachusetts once ABLE account are available here.

II. Department of Developmental Services. The Department of Developmental Services ("DDS") was directed to develop a comprehensive program of community developmental disability services and to issue licenses to providers for a term of two years. DDS was also required to file annual reports reviewing its progress on the implementation of the law. The most recent DDS report was filed with the Legislature in February 2016.

Since November 2014, DDS has been accepting applications for individuals with Autism Spectrum Disorder, Prader-Willi Syndrome, and Smith-Magenis syndrome. DDS also revised its regulations to provide the administrative framework for the implementation of the Autism Omnibus Law. Those regulations were promulgated on April 22, 2016. From November 2014 to June 2016, DDS has determined that 686 individuals with ASD met the criteria for eligibility as a person with autism <u>and</u> functional impairments (in three or more of seven life areas), and 4 individuals met the criteria for Prader-Willi-Syndrome. DDS provides the following services: Service Coordination, a variety of Employment Supports and Activities during the Day, a variety of Family support for individuals residing in family homes including companions, respite, flexible funding, and a variety of individual supports for individuals who live independently, a variety of short term services related to vocational interests, and social skills.

In order to meet the needs of these "newly eligible" individuals DDS has increased its infrastructure by hiring twenty-three (23) Autism Service Coordinators, four (4) Eligibility Specialists, additional psychologists, legal counsel, and program coordinators. DDS has also expanded the capacity of its seven (7) Autism Support Centers and its Family Support Centers to meets the additional needs of Adults with Autism who have become eligible for services as a result of the Autism Omnibus Law. DDS Service Coordinators have been working with newly eligible individuals to provide the types of supports and services requested by the individuals and their families. DDS has provided services from its existing service menu including, among others, individual supports, companion supports, various types of employment supports (both group and individual), behavioral supports, transportation and services offered by the Autism Resource Centers and Family Support Centers including family training, respite services and flexible funding. These services have been provided either through the DDS community provider system or through self-direction using either a fiscal employer agent or an agency with choice model. DDS has also developed a new service, coaching, which has been requested by newly eligible individuals. This service will be available in the fall of 2016. DDS has explored with DMH how to best use their Club House model for individuals who may be interested. DDS has been collecting information on the types of services that individuals are requesting that DDS does not currently provide. Services such as a housing search, specialized employment services and opportunities for socialization are among important future services to be developed.

Many of the newly eligible individuals have not requested services yet because they are still enrolled in their public school districts. In April 2015, DDS developed and distributed facts sheets on important transition topics. These facts sheets were developed in direct response to concerns from families about the need for clearer communication around Chapter 688 and transition issues. These facts sheets are available on the DDS website and were presented at a full-day training for family support center staff to assist families through the complex process of transitioning between special education and the adult service system. DDS' ongoing efforts to obtain input and feedback from families include meetings with the Statewide Family Support Council, the Statewide

Advisory Council and Citizen Advisory Boards, and meetings with representatives of family and individual advocacy organizations. The information garnered through these on-going communications is supporting the development of current and future services offered by DDS.

III. Autism Endorsement. The Board of Elementary and Secondary Education was directed to provide an endorsement in autism for licensed special education teachers, which included both coursework and field experience working with students with autism. The Board promulgated regulations for this endorsement in June 2015, under 603 CMR 7.14(5). Educators receiving this endorsement will need to renew it every five (5) years. The Department of Elementary and Secondary Education (DESE) has issued draft guidelines for this endorsement and is in the process of receiving and reviewing public input on these guidelines. DESE will begin accepting Higher Education proposals for the coursework required for this endorsement this fall. Additionally, individuals with at least three years of experience working with students with autism who are licensed special educators and can demonstrate subject matter knowledge can directly apply for the autism endorsement, under the grandfathering provision, if they apply by December 31, 2016. The Board has also recently requested that a survey be conducted and based on the results thereof they will consider expanding the endorsement to general education teachers.

IV. Coverage of Medically Necessary Treatments by MassHealth. The 2014 Autism Omnibus Law in Section 25 of Chapter 226 of the Acts of 2014, amended G.L. c. 118E, for MassHealth to cover, subject to federal financial participation, medically necessary treatments for persons younger than 21 years, including ABA services and supervision by a BCBA, and dedicated and non-dedicated augmentative and alternative communication devices, including but not limited to medically necessary tablets. MassHealth implemented statewide ABA services as of 6/15. Outside Section 89 of the FY17 budget amended this provision to require coverage of AAC devices not eligible for FFP if the total cost incurred by the state for such a device is not more than the state share of a comparable device eligible for FFP. MassHealth is working to implement Outside Section 89 of the FY17 budget.

V. DDS and the Department of Mental Health ("DMH"). DDS and DMH were required to develop a plan to provide services to individuals who have both a mental illness and a developmental disability. A task force was established with representatives of DMH and DDS in January 2014, to study best practices related to understanding individuals with autism and a co-occurring severe mental illness. The task force was made up of key autism experts in the community from Massachusetts General Hospital, Lurie Center, UMass Medical School, private psychiatrist(s), DMH medical staff, and DDS participants. The task force issued a report in January 2015, which took into consideration the requirements of the Autism Omnibus Law in August 2014. The Task Force's report included survey information from DMH clinicians, case managers, and administrators, which resulted in recommendations for staff training and services for individuals with co-occurring autism and severe mental illness. DDS and DMH entered into an Inter-Agency Agreement to collaborate in the development and funding of supports and services to individuals who are eligible for services in both agencies. DDS and DMH meet regularly and have committed to join trainings, service design, and mutual consultation based on the respective knowledge of both agencies. A number of training sessions have been and will continue to be offered jointly to DDS and DMH. In recognition of DDS' need for additional clinical support from DMH the Inter-Agency Agreement provides for two fellowships funded by DDS, one at UMass Medical Worcester and one at Mass General, for short term psychiatric consultations and forensic risk consultations. DDS and DMH are also working to add a third Fellowship at Boston Medical Center/Boston University for a Transition Aged Youth Fellowship.

VI. Further Investigations and Studies by the Commission. The Omnibus Law also requires the Commission to further investigate and study the needs of individuals with autism in the areas of employment and higher education, and housing and to make recommendations in regards thereto. These studies encompass the current needs of individuals who have been diagnosed with autism spectrum disorder, as well as, an examination by the Commission of the number of individuals with autism who will become adults in future decades as a result of the increase in the prevalence of autism over the last thirty years. With input from the Commission, the Executive Director of the Commission has established separate sub-committees for employment and higher education, and housing, and each Sub-Committee includes Commission members and other stakeholders who work with individuals with autism, to examine the current and future needs for individuals with ASD and to develop recommendations to meet the on-going needs in these areas.

Updates on March 2013 Recommendations of the 2010 Special Commission

There has been and there continues to be a great deal of collaboration between state agencies and a broad range of individualized services developed for individuals on the autism spectrum since the Special Commission issued its report in 2013. The Autism Commission has reconstituted Sub-Committees for; Adults, Data, Employment and Higher Education, Housing, Birth to Three Year Olds, 3-14 Year Olds, and 14-22 Year Olds to review the progress that has been made, to identify any unmet needs and trends in autism services, and to make recommendations regarding policies, legislative or regulatory action necessary to provide or improve services and supports.

Recommendation # 1

Entity Responsible: **Department of Developmental Services (DDS)**

a) DDS will no longer use an IQ based eligibility requirement for adult services.

2016 Update: DDS revised regulations were issued on April 22, 2016. DDS expanded eligibility to include individuals with the developmental disabilities of Autism, Prader-Willi Syndrome and Smith-Magenis Syndrome. DDS began admitting individuals in November 2014 prior to the promulgation of the regulations based on the Autism Omnibus Statute.

b) On a quarterly basis, DDS will report to the Autism Commission the number of individuals with autism applying for services that are found to be ineligible.

2016 Update: DDS is currently verifying the total number of individuals who have been found ineligible. In July, 2016, three adult individuals were found ineligible.

Recommendation # 2

Entity Responsible: **Department of Mental Health (DMH)**

a) Primary diagnosis of autism will not be used as grounds to find an adult ineligible for DMH services.

2016 Update: DMH's clinical requirements for service authorization still focus on the primary cause of the person's functional impairment to be due to severe and persistent mental illness. DMH has made changes in its authorization process so that DMH now has the ability to recognize those with both autism and a severe and persistent mental illness resulting in functional impairment to enable a person to receive services from both DMH and DDS. The agencies are meeting at the regional level to establish positive working relationships, discuss complex cases, and establish how DDS eligibility staff and DMH service authorization staff will determine how best to serve individuals who are dually eligible. DDS and DMH have also established dedicated individuals to be the point person to facilitate these eligibility processes. Each DDS region and DMH area has established lines of communication to review applications whenever one agency believes that the applicant is dually eligible. Through the ISA with DMH, DDS has been able to obtain expert consultation and a plan for treatment for individuals who are both dually eligible and for those who only meet DDS eligibility but who have significant mental health or forensic issues.

b) On a quarterly basis, DMH will report to the Autism Commission the number of individuals with autism applying for services that are found to be ineligible.

2016 Update: DMH does not currently have the ability to track this information. Only individuals deemed eligible for DMH services are entered into DMH's database.

c) DMH will increase its level of clinical expertise on the treatment needs of individuals with co-occurring mental illness and autism.

2016 Update: DDS and DMH have an Inter-Agency Agreement which includes expanding clinical expertise through 2 Fellowships, one at UMass Medical and one at Mass general hospital. Additionally, DDS and DMH are starting collaboration with Boston Medical Center/Boston University to create a Transition Age Youth focused Autism Fellowship. Through the Inter-Agency Agreement, DDS is also purchasing forensic capacity.

d) DMH will develop more services that are aimed at meeting the needs of individuals with autism and co-occurring mental illnesses.

2016 Update: The DMH Research Center of Excellence associated with the University of Massachusetts medical center at Worcester is in the final stages of developing a document that reviews best clinical practices for those with ASD and mental illness. DMH has started to work with its providers that are also serving DDS contracts to engage in the process of identifying new services that can be developed for this population, which will be supported by the best practices research.

Recommendation # 3 Children's

Entity Responsible: **Department of Developmental Services (DDS)**

a) Increase the appropriation for the Children's Autism Waiver Program.

2016 Update: CMS approved an amendment to the Children's autism waiver in January 2013, increasing the waiver program capacity to 157. A renewal application was submitted in September 2015. Additionally as part of the FY16 budget the Autism Division received an increase in funding and these funds allowed the waiver program to expand to provide services to 260 children at a point in time. From January, 2015 to January 2016, 278 children participated in the waiver program.

b) Amend the Waiver and initially expand the number of children (ages birth through age 8 years) served from 157 to 500.

2016 Update: The number of children has been expanded from 157 to 260 in FY16. A total of 278 children have participated in the waiver program from January 2015 to January 2016.

c) Designate at least two enrollment periods per year to allow parents to plan accordingly.

2016 Update: There has been one enrollment period per year. The enrollment period in October 2015 yielded 749 applicants. DDS is committed to offering an annual request period for enrollment the last two weeks of October. The next enrollment period is scheduled for October 17, 2016 through October 31, 2016.

d) When the Autism Waiver is renewed in two years, DDS will expand the Waiver to create Waiver Services for children ages 9-22.

2016 Update: The Waiver Program has not been expanded to cover children 9-22 years. Additional funding would be required for this expansion to occur. The current waiver program information is available in eleven (11) languages on the DDS website to address any language barriers.

Recommendation # 3 Adults

Entity Responsible: **Department of Developmental Services (DDS)**

a) Assuming expanded eligibility will be implemented, it will be necessary to increase the number of waiver slots to ensure waiver services for those newly eligible.

2016 Update: DDS has not amended its HCBS waivers to include newly eligible adults. The Department and EOHHS are reviewing options for inclusion of this population on existing or new waivers.

b) Provide intensive case management by adding a group of trained workers with extensive autism experience to assist with development of individual support plans.

2016 Update: To assist in development of plans and services for individuals with Autism, DDS has hired 23 adult service coordinators who have experience in serving individuals with Autism as well as 4 Autism regional coordinators with extensive autism expertise and experience.

c) Increase the availability and expertise of Behavior Support Consultation for DDS eligible adults.

2016 Update: DDS provides behavioral supports and services to adults with autism using services of its private sector providers, independent consultants and Area Office psychologists. The Department is continually working to increase service capacity in this area.

d) Expand and develop additional specialty day and employment programs tailored to meet the needs of adults with autism, including those with severe challenging behaviors.

2016 Update: DDS has been providing services to adults with autism based on their individual needs and the services requested by the individual and their families. The Department has been engaged with the Association of Developmental Disability Providers in review of existing day and employment services and in discussion of future planning for services.

e) Direct transition coordinators in school districts to provide written information to families of students with autism transitioning into adult services about the availability of the three adult waivers.

2016 Update: Individuals with Autism but no Intellectual Disability are not eligible for HCBS waiver services. Information on the transition process and available services is provided to families.

Recommendation # 3

Entity Responsible: **Department of Elementary and Secondary Education (DESE) and Department of Developmental Services (DDS)**

a) Since there is currently no wait list, DDS will initiate a new application process and expand the number of slots available for students requiring these services.

2016 Update: In FY 16 the DDS/DESE residential prevention program serviced 572 children. In late winter DDS will conduct a new open request period for participation in the DESE/DDS program. Based on past experience, DDS anticipates receiving approximately 600-750 requests for participation. From that group DDS will likely serve @ 50-70 new participants. Although the funding for the program has remained stable, DDS has been able to serve more students in FY 16 than in previous years through a combination of case management and collaboration with school districts, private insurers offering benefits under ARICA and through the expanded state plan ABA benefit. The combination of these efforts has allowed DDS to serve many more students while maintaining a success rate of preventing residential placements in the high 90%.

b) Increase funding for the DDS/DESE program in order to serve more individuals in this program.

2016 Update: DDS accepts new individuals into this program when funding is available. 85% of the 572 individuals currently served by the DDS/DESE program have autism.

Recommendation # 4

Entity(ies) Responsible: **Executive Office of Health and Human Services (EOHHS)**
MassHealth, Department of Public Health (DPH)

a) **Private Insurance** EOHHS will reach out to large self-funded employers to educate them about the insurance law.

2016 Update: No formal outreach on this issued has occurred.

b) **Private Insurance** EOHHS and DOI will explore ways to recoup from self-funded employers the additional direct costs incurred by the State due to lack of coverage for autism treatment.

2016 Update: Legislation filed in 2015 (S.1516) would have required corporations applying for tax credits to indicate whether their employees' health coverage included the same benefits in the State's minimum benchmark plan, adopted under the ACA. Bill was heard by the Revenue Committee and sent to study. It is unclear whether it will be re-filed in the next legislative session.

c) **Mass Health** Require Mass Health to take action necessary to cover medically necessary treatments for individuals with autism.

2016 Update: The 2014 Autism Omnibus Law in Section 25 of Chapter 226 of the Acts of 2014, amended G.L. c. 118E, for MassHealth to cover, subject to federal financial participation, medically necessary treatments for persons younger than 21 years, including ABA services and supervision by a BCBA. MassHealth implemented statewide ABA services as of 6/15.

d) **MassHealth** Require MassHealth to revise regulations to cover both dedicated and non-dedicated (e.g., tablets), for people who require Augmentative and Alternative Communication.

2016 Update: The 2014 Autism Omnibus Law in Section 25 of Chapter 226 of the Acts of 2014, amended G.L. c. 118E, for MassHealth to cover, subject to federal financial participation (FFP), dedicated and non-dedicated augmentative and alternative communication devices (AAC), including medically necessary tablets.

MassHealth covers medically necessary AAC, including tablets, eligible for FFP that meet the federal and state definitions of Medicaid Durable Medical Equipment (DME), i.e., devices whose functionality is medical or "dedicated" to a medical purpose. Tablets with unrestricted functionality, such as commercially available iPads, are not eligible for FFP.

Outside Section 89 of the FY17 budget amended this provision to require coverage of AAC devices not eligible for FFP if the total cost incurred by the state for such a device is not more than the state share of a comparable device eligible for FFP.

MassHealth is working to implement Outside Section 89 of the FY17 budget.

e) **Early Intervention** To assist families transitioning from EI to utilize all their available resources, EI will train their staff about the autism insurance law, and develop tools to help staff and families navigate insurance options for behavioral treatments after age 3.

2016 Update: DPH has provided training to its Early Intervention providers on the ARICA Law to assist families with navigating insurance options.

Recommendation # 5

Entity(ies)Responsible: **Executive Office of Health and Human Services (EOHHS)**
DDS, MassHealth

a) EOHHS will designate DDS's Division of Autism as the single agency dedicated as a source of information and referral for individuals with autism throughout their lives.

2016 Update: DDS' Division of Autism has primary responsibility for the provision of services for eligible individuals with autism.

b) Funding for the Autism Support Centers will be increased to ensure consistency of the Centers' quality of services and information and to prepare the Centers to serve individuals of all ages.

2016 Update: DDS funds seven (7) autism support centers across Massachusetts. Funding for the Autism Support Centers was increased by $822,580., with 9 additional FTEs added.

c) The Division of Autism with support from EOHHS will create a website and telephone number mirroring 1-800-AGE-INFO.

2016 Update: The DDS Division of Autism does not maintain a separate website. Information on DDS' services for individuals with autism is available on the DDS website and direct contact information under Autism Spectrum Services to link directly to or call the Autism Support Centers.

d) EOHHS shall form an inter-agency/inter-department committee amongst DCF, DPH, DDS, MRC, LTSS, DMH and DESE to develop policies to better coordinate overall services and improve cross-agency and cross-Secretariat communication.

2016 Update: DDS has inter-agency agreements with DMH and MRC aimed at the coordination of services for individuals with autism who are eligible for each agency's services. EOHHS has representatives on the Autism Commission's sub-committees, which are aimed at the coordination of services for individuals with autism.

e) DDS shall promulgate regulations to change how case management services are delivered to adults with autism who are eligible for DDS by using the Children's Autism Waiver as the model for adult case management.

2016 Update: DDS revised its regulations to reflect its services to adults with autism who are newly eligible, and case management is done with a person-centered approach based on the needs of the individual. The Children's Autism Waiver was not used as the model to address adult service needs.

f) DDS will increase cross-agency training and technical assistance efforts so that the state workforce has a better understanding of the needs of adults with autism.

2016 Update: DDS collaborates with and participates in trainings with DMH and MRC to coordinate services to individuals with autism.

g) Increase DDS's funding for family support programs.

2016 Update: The budget for FY17 includes a $5mil increase of funding for family support services.

h) Autism Division and Autism Clinical Managers will work with paraprofessional training programs to develop a program to train people to work as direct support providers for people with autism.

2016 Update: DDS has offered an array of trainings for family support and autism support centers. DDS has explored various web-based training programs for direct service providers and is going to pilot an online web-based direct support autism program in the fall of 2016. At the conclusion of the pilot which will run for approximately 6 months, DDS will assess the effectiveness of the pilot and make a determination about recommending its adoption for future use.

i) Autism Division and Autism Clinical Managers will create paraprofessional training for direct support providers program in school districts, community colleges and vocational high schools.

2016 Update: This recommendation has not been implemented. DDS does not currently provide trainings for school personnel. DESE provides professional development and trainings for school districts including vocational high schools and many districts have chosen autism as the area of focus for professional development under DESE's 274 grants. DDS is piloting on-line forty (40) hour autism training course in October 2016 for direct service providers, this may be a training opportunity for school personnel in the future.

j) Revise MassHealth regulations to broaden Adult Foster Care and Personal Care Assistant ("PCA") services to better meet the needs of individuals with autism and expand access to respite care for families of adults with autism.

2016 Update: Adults with autism are currently eligible to receive medically necessary adult foster care AFC and PCA services, as a result, an expansion of those services is not necessary. Adults with autism may also be eligible for certain MassHealth 1915(c) Home and Community-Based Services (HCBS) waivers, some of which cover respite services.

k) DDS will examine current staffing credentials, staffing levels at group homes, and supportive living arrangements for adults with autism.

2016 Update: DDS staffing is based on the individual's needs and is reflected in the rates paid for the services. DDS is currently expanding its shared living option for individuals with Autism. DDS is working with its provider organization ADDP, to determine what types of training may be necessary to increase knowledge among staff. A number of provider organizations will be participating in the web-based pilot for Direct Support Professionals.

l) Autism Division will establish and maintain a database of institutions offering courses, certifications and degree programs in autism and autism related fields.

2016 Update: A database with this information has not been established. The new sub-committee on workforce development has begun looking at this issue at the community colleges. DDS currently includes information in both its community college programs and its university programs about Autism Spectrum Disorders.

Recommendation # 6

Entity Responsible: **Executive Office of Health and Human Services (EOHHS)**

a) EOHHS will make recommendations to the Autism Commission for overcoming data collection issues in Massachusetts.

2016 Update: The IT Bond Bill authorized funding for a study of current data collection systems in MA and models in other states. Funds have not been allocated by A&F. UMass Medical School's Shriver Center convened a Citizen's Jury in 2015 to examine issues around data collection and to inform this process. A report is expected in the next few months.

b) EOHHS will establish and manage an integrated confidential data system among state agencies and stakeholders.

2016 Update: The IT Bond Bill authorized funding to establish and manage a data system. Funds have not been allocated by A&F.

Recommendation # 7

Entity Responsible: **Department of Public Health (DPH)**

a) If a child is exhibiting symptoms of autism but does not have an autism diagnosis, EI will provide some Autism Specialty Services to the child.

2016 Update: Early Intervention (E.I.) Staff work with families to help them obtain a diagnosis when signs of autism exist. E.I. staff also work to provide services for all of a child's needs while a diagnosis of ASD is being sought.

b) DPH will require medical professionals to follow AAP and Centers for Disease Control and Prevention's recommendations (CDC) to screen all children for developmental delays.

2016 Update: DPH supports the AAP and CDC recommendations to screen all children for developmental delays at 18 months and 24 months. However, DPH does not have any direct authority over medical professionals.

c) DPH, DDS, EEC, and DESE will continue to support and partner with the MA Act Early program's efforts to increase the availability of clinicians who are trained to provide comprehensive evaluations of young children at risk for autism.

2016 Update: A DPH staff person is currently on the MA ACT EARLY Steering Committee and participates in ongoing discussions to strategize ways to increase the current work force.

The Mass Early Act website provides a list of thirty-seven (37) clinics and private practices and their contact information for diagnostic services of autism spectrum disorders and developmental disorders.

d) DPH shall continue to support MA Act Early program's efforts to create culturally competent screening protocols and kits for community health centers, pediatric practices, and other clinicians in languages other than English.

2016 Update: The MA Act Early Campaign has "Culturally competent screening tools" on its website. The M-CHAT screening tool is available in English, Spanish, Chinese, Haitian Creole and Vietnamese. DPH also has a staff member on the MA ACT EARLY Steering Committee.

e) DPH, in partnership with MA Act Early, MCAAP, Mass League of Community Health Centers, MA Medical Schools, MA Neuropsychology Society (MNS), and MA Psychological Association (MPA), and other related associations shall develop a coordinated plan aimed at increasing the availability of clinicians who are trained to provide comprehensive evaluations of young children at risk for autism.

2016 Update: Limited progress has been made in this area, specifically as it relates to infants and toddlers. The state's Early Intervention Program has strong ties to Act Early, Massachusetts Chapter of the American Academy of Pediatrics but more efforts need to be directed to the articulation of a more comprehensive approach across the broader range of stakeholders. MA DPH staff are in discussions with Roula Chouieri, MD from UMass Medical School to collaborate with trained E.I. staff in administering a level 2 screening tool RITA-T which will expedite a diagnosis of ASD in participating diagnostic centers, thus increasing capacity to diagnosis more children with a shorter wait time.

The Mass Early Act website provides a list of thirty-seven (37) clinics and private practices and their contact information for diagnostic services of autism spectrum disorders.

Recommendation # 8

Entity(ies)Responsible: **Massachusetts Rehabilitation Commission (MRC)**

a) MRC will collect, monitor, and analyze data from the Social Security Administration (SSA) and report data regarding the outcomes and ongoing status of the disability claims for SSDI and SSI to the Autism Commission.

2016 Update: MRC reported to the Autism Commission in April 2016 that is processed 88,508 new claims for SSI/SSDI.

b) MRC shall analyze and report data to the Autism Commission concerning the approximately 20,000 individuals who receive MRC services each year including number of individuals with autism served.

2016 Update: MRC reports that is served 1,704 individuals with Autism accounting for 6% of all consumers served by MRC during FY2015. 89% of consumers with Autism served by MRC are under the age of 30. A total of 184 consumers with Autism achieved successful employment outcomes.

c) MRC shall expand upon existing staff training initiatives on autism to ensure that all staff are competent in addressing the needs of this population.

2016 Update: 118 MRC counselors received training from Asperger's Association of New England (AANE) through various workshops on working with individuals with autism. AANE and MRC are piloting and autism assessment instrument to support their work with individuals with Autism.

d) MRC shall seek funding to increase the number of job coaches employed by MRC and continue to increase collaboration with other disability agencies

2016 Update: In FY2015 MRC Voc. Rehab. served 1,704 consumers with Autism. This represents a 28% increase in the number of individuals with autism served since FY2013.

e) Increase funding for MRC's Supported Employment Supports program.

2016 Update: MRC recently awarded a contract to the Northeast Arc for employment services.

f) MRC shall also reach out to private non-profits, such as Asperger's Association of New England, to help fund coaching programs.

2016 Update: The Northeast ARC provided staff trainings on autism and summer internships and training to MRC consumers. This ARC currently provides employment supports through MRC's competitive employment services program and provides pre-employment transition services to high school students with disabilities.

g) MRC shall continue to work with AANE, and other providers, to establish one or more employment pilot programs dedicated to connecting adults with autism with employment opportunities.

2016 Update: MRC and DDS are working on a collaborative effort to serve transitioned aged youth with autism and other disabilities. The Northeast ARC provides competitive employments services and AANE continues to provide coaching services to MRC consumers.

Recommendation # 9

Entity(ies)Responsible: **Department of Elementary and Secondary Education (DESE)**

a) DESE shall hire autism specialists who will help ensure the state's policies and practices meet the needs of students with autism.

2016 Update: This recommendation has not been implemented. DESE does not have an autism specialist(s). DESE reports that it is trying to assist school districts with building internal expertise on autism. The DESE Fund Code 274 is available for school districts and many districts have chosen working with students with autism as the area for professional development.

b) DESE will develop and implement a state autism Discretionary Grant Program for local school districts to increase their capacity to educate students with autism in a manner consistent with their potential and in the least restrictive environment.

2016 Update: DESE has the Fund Code 274 grants to support professional development in school districts. Many districts have selected autism as their area of focus for professional development, which will increase their capacity to educate students with autism effectively.

c) DESE will take steps to ensure that school districts have access to the number of appropriately qualified interpreters and translators necessary to provide communications in parents' primary languages.

2016 Update: DESE does not provide school district with interpreters. DESE refers District to neighboring school districts or community organizations for the sharing of interpretation services.

d) DESE will fund pilot programs for school districts working in partnership with community organizations throughout the Commonwealth to demonstrate best practices to overcome cultural and linguistic barriers faced by parents and children with autism.

2016 Update: A pilot program has not been established.

e) DESE will develop a competency based Autism Endorsement for licensed teachers so that teachers can obtain competencies necessary to educate students with autism in a manner consistent with their potential in the least restrictive environment.

2016 Update: The Board promulgated regulations for this endorsement in September 2015, under 603 CMR 7.14(5). The Department of Elementary and Secondary Education (DESE) has issued guidelines for this endorsement and anticipate programs will begin submitting applications for program approval this fall.

f) (i) Require that the new transition specialist endorsement competencies include experience working with youth and adults with autism.

2016 Update: No action has been taken on this recommendation. DESE reports that this would require a regulatory change.

(ii) Work with autism experts to establish best practice guidelines for providing transition assessments based on The National Secondary Transition Technical Assistance Center (NSTACC) and shall conduct professional development necessary to establish a pool of transition evaluators with autism-specific expertise.

2016 Update: On July 14, 2016, DESE issued a Technical Assistance Advisory regarding high quality transition services. The purpose of the advisory is to help school districts improve outcomes for students with IEPs, and focuses on Service Coordination, system level coordination, Individual coordination (including the results of transition assessments including the use of the Massachusetts Work-Based Learning Plan), individualization of transition services, and the need for them to be results oriented.

(iii) Develop an IEP model form for transition age youth that addresses the unique and complex needs of youth with autism.

2016 Update: DESE has issued an RFI for the development of a new IEP system that will include an improved Secondary Transition planning process.

(iv) Support development of model transition practices which successfully promote employment, further education, and independent living.

2016 Update: On July 14, 2016, DESE issued a Technical Assistance Advisory regarding high quality transition services. The purpose of the advisory is to help school districts improve outcomes for students with IEPs, and focuses on Service Coordination, system level coordination, Individual coordination (including the results of transition assessments including the use of the Massachusetts Work-Based Learning Plan), individualization of transition services, and the need for them to be results oriented.

(v) Improve state monitoring of transition requirements of special education law pursuant to recommendation G below.

2016 Update: As Part of its Coordinated Program Review Process SE6 covers transition services; "**Determination of transition services:1.** The Team discusses the student's transition needs annually, beginning no later than when the student is 14 years old, and documents its discussion on the Transition Planning Form. 2. The Team reviews the Transition Planning Form annually and updates information on the form and the IEP, as appropriate. 3. Reserved, 4. For any student approaching graduation or the age of 22, the Team determines whether the student is likely to require continuing services from adult human service agencies. In such circumstances, the administrator of special education makes a referral to the Bureau of Transitional Planning in the Executive Office of Health and Human Services in accordance with the requirements of M.G.L. c. 71B, §§12A-12C (known as Chapter 688). 5. In cases where the IEP included needed transition services and a participating agency other than the school district fails to provide these services, the Team reconvenes to identify alternative strategies to meet the transition objectives. 6. The district ensures that students are invited to and encouraged to attend part or all of Team meetings at which transition services are discussed or proposed." **State Requirements Federal Requirements:**M.G.L.c.71B, Sections 12A-C 34 CFR 300.320(b); 300.321(b); 603 CMR 28.05(4)(c) 300.322(b)(2); 300.324(c) SE 6 is related to State Performance Plan Indicators 1, 13, and 14.

g) DESE will develop a more responsive and effective system for state monitoring of compliance with requirements of special education laws, including an improved system for conducting coordinated program reviews and responding to individual complaints.

2016 Update: DESE's Program Quality Assurance Services include Coordinated Program Reviews of School Districts' special education programs. Individual complaints are managed by DESE's Problem Resolution System.

h) Change special education law and practice to require that a professional with the new state autism endorsement participates in the IEP Team meetings of all students with autism.

2016 Update: This recommendation would require changes to state law as it is not required under the IDEA. It is also unknown whether there will be enough teachers who qualify for the new autism endorsement to participate in every Team meetings for students with autism.

i) Increase state funding for disability services at Community Colleges.

2016 Update: Increased funding is required.

j) EOE and DHE shall work together to expand the Inclusive Concurrent Enrollment program to all colleges in the Commonwealth to increase opportunities to meet the needs of transition age youth with autism, including expansion to support inclusion in resident life(dormitory) of the college.

2016 Update: The ICEI program was moved under the jurisdiction of EOE. Increased funding is required. Bridgewater State University enrolled two students from the MAICEI program into the residence life of its school in September 2016.

k) Higher education institutions will design innovative services, supports and programming, based upon current research and best practices in the field of disability services and autism studies, for students with autism.

2016 Update: No action has been taken on this recommendation.

Recommendation # 10

Entity(ies)Responsible: **Massachusetts Rehabilitation Commission (MRC), DDS, DESE**

a) Increase funding for MRC's AT Regional Centers, in partnership with Institutes of Higher Education where appropriate.

2016 Update: MRC reports that $1.2 million dollars is currently earmarked for assistive technology. MRC contracts with three agencies MA Easter Seals, United Cerebral Palsy of Berkshire County, and the University of MA Dartmouth Center for Rehabilitation Engineering for the provision of AT assessments, purchase and set-up of equipment, training, and follow up.

b) Establish one or more additional AT Regional Centers in other areas of the state and fund one or more mobile AT Regional Centers.

2016 Update: DDS opened an additional AT Center in Worcester.

c) Increase funding for DDS's AT Centers across the state in order to increase the capacity of these centers to match individuals who need assistive technology with the proper equipment.

2016 Update: DDS has added an additional AT Center in Worcester. DDS has three AT Centers; Northampton, Hawthorne, and Worcester. DDS also provides information on 18 other agencies that perform mobility and assistive technology services.

d) Revise the Massachusetts education licensure regulations to require that general education teachers and specialists receive sufficient coursework and practical experience in methods of augmentative and alternative communication.

2016 Update: This recommendation has not been implemented. However, DESE has offered a number of hybrid online and face-to face courses in assistive technology, including augmentative and alternative communication free of charge to Massachusetts Educators to assist with non-verbal students with ASD.

e) Revise Massachusetts education licensure regulations to require that all teachers address use of assistive technology and augmentative and alternative communication.

2016 Update: The licensure regulations have not been revised to include this requirement. DESE has offered a number of hybrid on-line and face-to-face course in assistive technology including augmentative and alternative communication to educators, including recent summer institutes course offerings. DESE has also developed a multi-year RFR for a graduate level Massachusetts Focus Academy Course (MFA) course: *Understanding the Academic and Non-Academic Needs of Students with Autism Spectrum Disorder.* This RFR has not yet been put out to bid.

Recommendation # 11

Entity(ies)Responsible: State Legislature, DHCD

a) The State Legislature will amend M.G.L. Chapter 40B (affordable housing) to redefine housing for low-income people with disabilities to count as affordable housing, with each bedroom in a multi-residential house counting as one affordable unit.

2016 Update: M.G.L. Chapter 40B has not been amended.

b) Increase funding for MRC's MassAccess website to ensure individuals with disabilities including adults with autism can continue to access current information on affordable and accessible housing available in Massachusetts.

2016 Update: The MassAccess website is available to individuals with autism with information on affordable housing.

c) The DHCD will develop a formal, statewide housing policy to establish priorities for individuals with autism.

2016 Update:

d) The Interagency Council on Housing and Homelessness will work with DHCD and assist them in determining how to effectively serve adults with autism who are at risk for homelessness.

2016 Update:

Recommendation # 12

Entity Responsible: State Legislature

a) Provide state funding to the University of Massachusetts Medical School in order to establish Operation House Call program as part of the curriculum.

2016 Update: Operation House call is a course formed in partnership with the ARC of Mass. This course is currently taught at B.U., Tufts University, University of Mass. Medical School, Yale school of Nursing and Simmons Graduate Program of Allied Health Professionals.

b) Expand funding for the Massachusetts Child Psychiatry Access Project to augment autism expertise within the program.

2016 Update: SIM grant funds have enabled the regional hubs of MCPAP to restore their coverage to 100%.There are six regional hubs located at academic medical centers. Each regional Hub has; 1 FTE child psychiatry, 1 FTE licensed therapist, 1 FTE care coordinator, and 1 Program administrator.

c) Identify medical practitioners across the Commonwealth who have received training and consider themselves specialists in the healthcare of individuals with autism and develop specialty provider lists that will be available on the Autism Resource Center websites.

2016 Update: The Mass Act Early website provides a list of 37 clinics and private practices that offer diagnostic services for autism. This information needs to be expanded to include more providers across the Commonwealth who accept private insurance and those who accept MassHealth.

d) In order to increase the number of medical providers who are knowledgeable in autism.

2016 Update: The Mass Act Early campaign held a summit in Spring 2016 on the CDC's "Learn the Signs. Act Early." The presentations included diagnostic tools and a number of other topics for medical providers and families. The Mass Act Early website directly links to the CDC's Autism Training Curriculum for medical providers.

e) Promote additional specialized training on autism through medical continuing education programs for primary care physicians, neurologists, psychiatrists, dentists, emergency room personnel and other medical specialists.

2016 Update: The Mass Act Early Campaign provides a free 40 minute webinar, MassHealth approved CBHI screening materials, and a link to CDC materials including; A clinical resource to assist in the recognition, evaluation, and ongoing management of autism spectrum disorder throughout the patient's lifespan from the American Academy of Pediatrics (AAP).

f) Encourage hospitals to develop an "autism team" who could be called upon should a patient with autism enter the emergency room, need tests or X-rays, need to be admitted, etc.

2016 Update: The Commission is exploring additional training opportunities for emergency room personnel through the ALEC program.

Recommendation # 13

Entity Responsible: State Legislature

a) The Autism Commission will be a permanent entity responsible for overseeing the implementation of the Commission's recommendations and analyzing issues facing the autism community not discussed in the report.

2016 Update: On August 5, 2014, the Commonwealth of Massachusetts enacted landmark legislation, known as the "Autism Omnibus Bill" or Chapter 226 of the Acts of 2014. This legislation established the Autism Commission as a permanent entity.