



March 7, 2018

The Honorable Charles D. Baker
Governor of Massachusetts

The Joint Committee on Children, Families and
Person with Disabilities
The Honorable Joan Lovely, Chairperson
The Honorable Kay Khan, Chairperson

The Joint Committee on Healthcare Financing
The Honorable James T. Welch, Chairperson
The Honorable Jeffrey Roy, Vice Char

Re: 2017 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 2017 Annual Report on behalf of the Autism Commission.

Sincerely,

Carolyn J. Kain
Executive Director
Autism Commission

(Attachments)

Charles D. Baker
Governor

Karyn Polito
Lieutenant Governor



Marylou Sudders
Secretary

Carolyn Kain
Executive Director

THE MASSACHUSETTS AUTISM COMMISSION ANNUAL REPORT

March 2018

Autism Commission



State Legislative Members

Senator Barbara L'Italien, Andover

Senator Richard Ross, Wrentham
Jessica Katon, Director of Constituent Services, *Designee*

Representative Kimberly Ferguson, Holden

Representative Christine P. Barber, Somerville

State Agency Members and Designees

Marylou Sudders, Secretary of Health and Human Services, Chair

Carolyn J. Kain, Executive Director of the Autism Commission

Monica Bharel, MD, Commissioner of the Department of Public Health
Ron Benham, Director Bureau of Family Nutrition and Health, *Designee*

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
Paola Ferrer, Chief of Staff for Clinical Services & Program Operations, *Designee*

Russell Johnston, Senior Associate Commissioner, District Support for Elementary &
Secondary Education
Teri Williams Valentine, 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*

Toni Wolf, 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
Carolyn S. Langer, MD, MPH, JD, Chief Medical Office, MassHealth, Dir. Office of Clinical
Affairs, *Designee*

Jane F. Ryder, Commissioner Department of Developmental Services

Janet George, Ed. D., Representative with Clinical knowledge of Smith-Magenis Syndrome

Rosalin Acosta, Secretary of Labor and Workforce Development

Jason Albert, Manager Special Grants, *Designee*

Other Commission Members

Cathy Boyle, Parent, Autism Housing Pathways

Michelle Brait, Parent

Dan Burke, Arc of Massachusetts representative

Rocio Calvo, Ph.D., Boston College School of Social Work, *Designee*

Rita Gardner, Chief Executive Officer, 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

Chris Supple, Esq.

Judith Ursitti, Autism Speaks representative

Ann M. Neumeyer, M.D., Lurie Center representative

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

In accordance with Section 217 (c) of Chapter 226 of the Acts of 2014, “the Autism Omnibus Law”, the Executive Director submits this annual report on behalf of the Autism Commission to the Governor, the Joint Committee on Children, Families and Persons with disabilities, and the Joint Committee on Health Care Financing.

The 2014 Autism Omnibus Law 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 first Executive Director of the Commission was appointed in April 2016. Following the appointment of the Executive Director eight (8) subcommittees were created; 1) Birth to Three years of age; 2) 3-14 years of age; 3) 14-22/employment; 4) Adults; 5) Data; 6) Housing; 7) Workforce Development and 8) 22+ years of age. After several meetings the 22+ years of age was combined with the 14-22/employment subcommittee. The subcommittees meet monthly or bi-monthly, and each subcommittee is chaired by a member of the Commission or the Executive Director. Over one hundred (100) persons participate on the Commission’s subcommittees and have a broad range of experience with and expertise on autism.

The Autism Commission is charged with making recommendations 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 provides previous and recent updates on the recommendations of the March 2013 report by the 2010 Special Commission, and updates on the requirements of the Autism Omnibus Law.

Autism Prevalence

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). The most recent data released by the CDC in March of 2016 maintains the same rates for the prevalence of autism.

The 2014 Autism Omnibus Law

¹ Chapter 226 of the Acts of 2014, Section 1(c)

The 2014 Autism Omnibus Law 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, subject to federal financial participation; 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

- I. ABLE accounts. The Massachusetts Autism Omnibus Law called for the establishment of “Achieving a Better Life” or “ABLE” savings accounts for individuals with disabilities for qualified disability expenses. In May 2017, Massachusetts launched its ABLÉ accounts known as “The Attainable Savings Plan”, established and will be maintained by the Massachusetts Education Financing Authority (MEFA) and by Fidelity Investments. The Attainable Plan is available to individuals with disabilities nationwide and allows qualified individuals with disabilities to save up to \$14,000 a year without jeopardizing their Social Security and Medicaid benefits.

- 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 January 2017.

Since November 2014, DDS has been accepting applications for individuals with Autism Spectrum Disorder, Prader-Willi Syndrome, and Smith-Magenis syndrome. DDS revised its regulations to provide the administrative framework for the implementation of the Autism Omnibus Law on April 22, 2016. From November 2014 to December 2017, 1,463 “newly eligible” individuals with ASD only met the DDS criteria for eligibility as a person with autism and functional impairments (in three or more of seven life areas). Of the 1,463 individuals eligible 719 are enrolled in DDS services.

Individuals with an intellectual disability (ID) and ASD are also eligible for DDS services. Since eligibility was expanded for individuals with ASD, DDS also began separately tracking the number of individuals with co-occurring ASD and ID. The number of new individuals with ID and ASD as of December 2017 is 504.

The FY18 the “Turning 22 budget” was increased to \$23.1 million. There are 190 individuals with ASD only in this year’s Turning 22 class, which is 17.6% of the FY18 Turning 22 class. There are also 62 individuals with ASD and ID, which is an additional 6% of the FY18 Turning 22 class.

- III. Autism Endorsement. The Board of Elementary and Secondary Education was directed to provide an autism endorsement 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). In 2017, the ESE Board voted to expand the autism endorsement to general educators.
- 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. MassHealth FY17 spending on ABA; 1) Age 0-5, 2,094 children received ABA; 2) Age 6-12, 826 children received ABA; and 3) Age 13-20, 213 children received ABA. Total spent by ABA codes \$46,954,350.

MassHealth has long covered medically necessary “dedicated” devices that meet the federal definition of a medical device and qualify for FFP. Effective March 1, 2017, MassHealth instituted guidelines for medical necessity for Augmentative and Alternative Communication Devices and Speech Generation Devices that cover “non-dedicated” devices for individuals 1) under the age of 21 years; 2) with a diagnosis of autism spectrum disorder; 3) who meet MassHealth’s prior authorization requirements; 4) only if the total cost to MassHealth for a comparable non-covered, non-dedicated device is equal to or less than the net cost of the approved, covered (dedicated) AAC device. MassHealth has approved one device and has three additional requests that are in the review process.

- 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. 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 from both agencies. The agencies are engaged in regular meetings and joint trainings. DDS and DMH have an Inter-Agency Agreement which expanded clinical expertise through 2 Fellowships in July 2016, one at UMass Medical and one at Mass General Hospital. The first year of fellowships provided 30 consultations resulting in diagnostic clarification, service needs, and treatment planning

suggestions for individuals with ASD and mental health issues. DDS and DMH have expanded the fellowship sites to include Boston Medical Center (BMC). BMC has developed collaboration between the Child Psychiatry and Developmental Behavioral Pediatrics Departments to work with ASD transition age youth (TAY). DDS and DMH provided the funding for BMC to create and produce a web based curriculum to Transition Aged Youth with ASD, with plans to have this internet accessible curriculum be used throughout BMC (medical students, residents in various disciplines and staff) as well as available to other medical schools and psychiatry residences in Massachusetts. DDS and DMH will continue to explore the use of this curriculum for emergency service providers and inpatient psychiatric units.

VI. Further Investigations and Studies by the Commission.

- a) The Omnibus Law also required the Commission to further investigate and study the higher education opportunities, employment training opportunities, and employment opportunities available to person with autism spectrum disorder, and to determine the current status of such higher education opportunities, employment training opportunities and employment opportunities, but not limited to vocational training programs for teen-aged and young adult persons with ASD and make recommendations for providing appropriate higher education, employment training and employment opportunities for the population of residents in the commonwealth diagnosed with ASD.

The 14-22/employment subcommittee of the Commission has begun to study the higher education opportunities, employment trainings opportunities and employment opportunities for persons with ASD. MRC currently serves 562 VR consumers with ASD enrolled in post-secondary education. MRC has over 30 providers of pre-employment services (Pre-ETS), which provide job exploration counseling, workplace readiness trainings, workplace learning experiences, counseling in post-secondary training opportunities and self-advocacy. In FY17 MRC referred 422 consumers with ASD to its Pre-ETS vendors. In FY17, MRC received 143 referrals through the 688 process for individuals with ASD, and served 115 individuals with ASD in its Transition to Adulthood (TAP) program. In October 2017, DDS reports that 219 individuals with ASD have selected and receive community-based day supports, employment supports, or competitive integrated employment services.

- b) Additionally, the commission shall review the rise in the prevalence of autism spectrum disorder diagnoses among children in the past 30 years and shall make estimates of the number of children, aged 21 or younger, with autism spectrum disorder who will become adults in the coming decades and the resulting need for employment training and employment opportunities for those individuals and shall recommend a plan-of-action for the commonwealth in regard thereto.

The commission has not yet reviewed the rise in prevalence of autism spectrum disorder diagnoses among children in the past 30 years to make estimates of the number of children aged 21 or younger who will become adults in the coming decades to recommend a plan-of-action for the resulting need for training and employment opportunities.

The Commission has not yet developed recommendations for providing appropriate higher education, employment training, and employment opportunities for the population of residents in the commonwealth diagnosed with ASD.

- c) The commission on autism shall make an investigation and study of the present, and anticipated future, statewide affordable supportive housing needs for the commonwealth's population of persons with autism spectrum disorder. The commission shall develop and conduct a statewide housing survey to determine the current status of affordable supportive housing stock for adults with autism spectrum disorder and shall make recommendations in regard thereto.

The Housing Subcommittee with funding from DDS commissioned a state-wide housing survey by Technical Assistance Collaborative (TAC), which was completed in June 2017, to determine the current status of affordable housing stock for adults with ASD. This survey, as well as, information provided by the Housing Think Tank and other resources will provide the framework for the housing subcommittee to develop recommendations for the Autism Commission. The subcommittee is currently meeting with state agencies to gain their input and feedback on the recommendations of the Housing Think Tank.

- d) Additionally, the commission shall review the rise in the prevalence of autism spectrum disorder diagnoses among children in the past 30 years and shall make estimates of the number of children, aged 21 or younger, with autism spectrum disorder who will become adults in the coming decades and the resulting need for affordable supportive housing for those individuals and shall recommend a plan-of-action for the commonwealth in regard thereto.

The commission has not yet reviewed the rise in prevalence of autism spectrum disorder diagnoses among children in the past 30 years to make estimates of the number of children aged 21 or younger who will become adults in the coming decades to recommend a plan-of-action for the resulting need for affordable supportive housing.

Recommendation # 1

Entity Responsible: **Department of Developmental Services (DDS)**

- a) DDS will no longer use an IQ based eligibility requirement for adult services.

Update: Completed. DDS revised regulations were issued on April 22, 2016.

- 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.

Update: At the end of December 2017, 177 adult individuals with autism only (no ID) have been found ineligible, and 1,463 have been found eligible. Eligibility broken down by Region and based on decision date is set forth below. There are 719 individuals enrolled in services.

Eligibility Decision by FY	CW	ME	NE	SE	Total Adult Eligible
FY15	93	64	52	45	254
FY16	125	108	122	132	487
FY17	190	71	134	92	487
FY18	77	42	65	51	235
Total	485	285	373	320	1,463
By Age					
18-21	256	128	169	129	
22+	229	157	204	191	

***FY18 through End December 2017**

* This does not necessarily reflect the entire applicant pool as some additional individuals either did not complete the application process or withdrew their applications.

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.

Update: 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 engaged in regular meetings and joint trainings.

- 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.

Update: DMH does not maintain this information. Only individuals deemed eligible for DMH services are recorded within 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.

Update: DDS and DMH have developed an Inter-Agency Agreement which expanded clinical expertise through two Fellowships, one at UMass Medical and one at Mass General Hospital. These programs began in July 2016, and have provided 30 consultations resulting in diagnostic clarification, service needs, and treatment planning suggestions for individuals with ASD and mental health issues. DDS and DMH have expanded the fellowship sites to include Boston Medical Center (BMC). BMC has developed collaboration between the Child Psychiatry and Developmental Behavioral Pediatrics Departments to work with ASD transition age youth (TAY). DDS and DMH provided the funding for BMC to create and produce a web based curriculum to Transition Aged Youth with ASD, with plans to have this internet accessible curriculum be used throughout BMC (medical students, residents in various disciplines and staff) as well as available to other medical schools and psychiatry residencies in Massachusetts. DDS and DMH will continue to explore the use of this curriculum for emergency service providers and inpatient psychiatric units.

d) DMH will develop more services that are aimed at meeting the needs of individuals with autism and co-occurring mental illnesses.

Update: The DMH Research Center of Excellence associated with the University of Massachusetts Medical Center at Worcester has gathered data on best clinical practices for those with ASD and mental illness for dissemination. DMH has initiated work with its providers that also have DDS contracts to engage in the process of identifying services and best practices for this population.

Recommendation # 3 Children's

Entity Responsible: Department of Developmental Services (DDS)

a) Increase the appropriation for the Children's Autism Waiver Program.

Update: Funding for this waiver program has remained at \$5.8 million.

b) Amend the Waiver and initially expand the number of children (ages birth through age 8 years) served from 157 to 500.

Update: In the waiver year ending 9/30/17, DDS received 817 requests for participation in the Autism Waiver program. Current enrollment is 260, over the course of the waiver year DDS served 315 children with ASD. This waiver can serve up to 385 children in the waiver year.

Children's Autism Waiver Enrollment Data

Autism Participants by DDS Region and Age*

DDS Region	Age Range	Number
Central (79 total)	0 -2 years old	0
	3-5 years old	24
	6-8 years old	47
	turned 9 in 2017	8
Metro (67 total)	0 -2 years old	0
	3-5 years old	14
	6-8 years old	40
	turned 9 in 2017	13
Northeast (64 total)	0 -2 years old	0
	3-5 years old	11
	6-8 years old	40
	turned 9 in 2017	13
Southeast (53 total)	0 -2 years old	0
	3-5 years old	13
	6-8 years old	34
	turned 9 in 2017	6
West (52 total)	0 -2 years old	0
	3-5 years old	14
	6-8 years old	35
	turned 9 in 2017	3
Total		315

* All data is for Calendar Year 2017, as of 12/31/17

c) Designate at least two enrollment periods per year to allow parents to plan accordingly.

Update: There has been one enrollment period per year.

d) When the Autism Waiver is renewed in two years, DDS will expand the Waiver to create Waiver Services for children ages 9-22.

Update: The Waiver Program has not changed to date.

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.

Update: DDS has not amended its HCBS waivers to include newly eligible adults with ASD only.

b) Provide intensive case management by adding a group of trained workers with extensive autism experience to assist with development of individual support plans.

Update: DDS has recruited 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.

Update: As of December 2017, DDS provides behavioral supports and consultation to 32 individuals with ASD only over the age of 22 years, and to 18 individuals with ASD only ages 18-21.

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.

Update: This has not been fully implemented. DDS has been providing services to adults with autism based on their individual needs and the services requested by the individual and their families. DDS provides forty-five (45) different services to individuals with ASD, including; community based day supports, employment supports, competitive integrated employment supports, and coaching services. A complete list of the services being provided by DDS to this “newly eligible” group of ASD without ID is attached. (*Appendix A*)

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.

Update: Individuals with Autism but no Intellectual Disability are not eligible for HCBS waiver services. ESE works closely with district personnel, BPT, MRC, DDS, MCB and other adult serving agencies on the development and distribution of resources on secondary

transition for students with IEPs. In addition, ESE has a contract with the Federation for Children with Special Needs to provide parent workshops on transition, and to create family brochures on transition, translated into five languages. The Autism Commission has developed a brochure for transition aged youth and is working with DESE to disseminate this information to school personnel and families to inform them about the services available to individuals 14 years of age and older, through ESE's Regionals meetings with Special Education Directors.

Recommendation # 3

Entity Responsible: **Department of Elementary and Secondary Education (DESE) and Department of Developmental Services (DDS)**

- a) DDS will initiate a new application process and expand the number of slots available for students requiring these services.

Update: In FY17 the DDS/DESE residential prevention program served 570 children. DDS accepts new applications as funding becomes available.

- b) Increase funding for the DDS/DESE program in order to serve more individuals in this program.

Update: Funding for this program remains \$6.5 million. DDS accepts new individuals into this program as funding becomes available, 85% of the 570 individuals currently served by the DDS/DESE program have autism. In FY18, 29 children are expected to age out of this program.

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.

Update: EOHHS is in active discussion with DOI regarding compliance with parity laws.

- 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.

Update: Some self-funded employers have voluntarily expanded insurance coverage for autism treatment.

- c) **Mass Health** Require Mass Health to take action necessary to cover medically necessary treatments for individuals with autism.

Update: As of June 2015, MassHealth covers statewide ABA services for persons younger than 21 years old with MassHealth coverage and who were diagnosed with an autism spectrum disorder by a licensed physician or a licensed psychologist.

- 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.

Update: Effective March 1, 2017, MassHealth instituted guidelines for medical necessity for Augmentative and Alternative Communication Devices and Speech Generation Devices that cover non-dedicated devices for individuals 1) under the age of 21 years; 2) with a diagnosis of autism spectrum disorder; 3) who meet MassHealth's prior authorization requirements; 4) only if the total cost to MassHealth for a comparable non-covered, non-dedicated device is equal to or less than the net cost of the approved, covered (dedicated) AAC device. MassHealth has approved one (1) device and has three (3) additional requests in the review process. MassHealth is providing support to implement this added benefit and has created an FAQ to provide support with the authorization process.

- 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.

Update: DPH has provided training to its Early Intervention providers on the ARICA Law to assist families with navigating insurance options. The Autism Insurance Resource Center provides information to families on the ARICA Law and MassHealth. The Autism Commission has developed a turning three brochure to educate families on the transition from EI to the public school system and information about the Autism Support Centers, which provide information and resources for families of individuals with ASD.

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.

Update: Completed. 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.

Update: DDS funds seven (7) autism support centers across Massachusetts. Funding for the Autism Support Centers was increased by \$822,580.

- c) The Division of Autism with support from EOHHS will create a website and telephone number mirroring 1-800-AGE-INFO.

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. Information concerning Autism Spectrum Services includes a link to information on the Autism Support Centers. Additionally, information on the Autism Support Centers and other resources are available on the Autism Commission's website.

- 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.

Update: The Secretary of EOHHS is the chair of the Autism Commission and representatives from DDS, DCF, DPH, MRC, MassHealth, DESE, DHCD, EOLWD, are members of the Autism Commission and the Autism Commission's sub-committees. The Secretariat takes the recommendations of the Commission and incorporates them, as appropriate, into operational policies within EOHHS, and discusses them with other cabinet level agencies.

- 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.

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.

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.

Update: The budget for FY17 included a five million dollar (\$5M) increase of funding for family support services; that funding was fully annualized for FY18.

- 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.

Update: DDS provides on-line learning opportunities about autism for its employees. The Provider's Council also offers on-line training courses about autism to its members.

- 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.

Update: This recommendation has not been implemented. School district personnel access professional training, including trainings on autism, through the Department of Elementary and Secondary Education.

- 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.

Update: Adults with autism are currently eligible to receive medically necessary adult foster care AFC and PCA services. 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.

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. The Executive Director of the Commission and DDS are meeting with the Provider's Council for a demonstration of their Provider's eAcademy and to discuss training for service providers.

- l) Autism Division will establish and maintain a database of institutions offering courses, certifications and degree programs in autism and autism related fields.

Update: Institutions offering course, certification, and degree programs in autism and autism related fields include; Bay Path University, Boston College, Cambridge College, Elms College, Endicott College, Lesley University, Regis College, Salem State, Simmons College, UMass Amherst, UMass Lowell, and Wheelock College.

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.

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 appropriated. UMass Medical School's Shriver Center convened a Citizen's Jury in 2015 to examine issues around data collection and to inform this process. Upon completion, the data subcommittee of the Commission will meet to discuss the findings of the Citizen's Jury. Additionally, the Executive Director of the Autism Commission collected available data from DPH, MassHealth, DDS, DESE and MRC on the number

of individuals with autism served by each of these respective agencies. The information provided by DESE includes 2003 to 2016 and also indicates the level of need based on the individual number of service hours. Data collected is attached hereto. (*Appendix B*)

- b) EOHHS will establish and manage an integrated confidential data system among state agencies and stakeholders.

Update: The IT Bond Bill authorized funding to establish and manage a data system. Funds have not been appropriated.

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.

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.

Update: DPH supports this recommendation. The Mass Act Early website provides free information to health care providers on the early signs of autism. Mass Act Early is creating seven (7) different culturally and linguistically diverse television shows (English, Spanish, Arabic, Brazilian Portuguese, Haitian Creole, Mandarin Chinese and Vietnamese) to educate parents and caregivers on the early signs of autism and to address cultural barriers. The focus of the shows will be on children ages birth to 3 with information on what to do when concerned, and where parents and caregivers can contact for more information either on-line or by phone at Family Ties of Massachusetts.

- 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.

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 an on-line Autism Case Training Curriculum (ACT) for primary health care providers to gain knowledge and skills to improve early identification of children with ASD. The three modules help providers to 1) identify ASD; 2) assist families through the diagnostic process and 3) care for patients with ASD.

- 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.

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.

Update: The Mass Early Act website provides a list of clinics and private practices along with 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.

Update: From October 2016-September 2017, MRC processed 87,054 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 the number of individuals with autism served.

Update: In FY17, MRC served 2,513 individuals with autism. MRC received 422 referrals for individuals with autism for its (pre-employment) Pre-ETS services. MRC's Transition to Adulthood Program served 115 individuals with autism.

MRC shall expand upon existing staff training initiatives on autism to ensure that all staff are competent in addressing the needs of this population.

Update: 118 MRC counselors received training from Asperger's Association of New England (AANE) on working with individuals with autism. The Federation for Children with Special Needs (FCSN) and MRC are working on a webinar on autism for MRC's pre-ETS vendors that will be available through the Federation's LINK center.

- c) MRC shall seek funding to increase the number of job coaches employed by MRC and continue to increase collaboration with other disability agencies

Update: In FY17, MRC served 2,513 consumers with either a primary or secondary diagnosis of autism. This represents a 32% increase in the number of individuals with autism served since FY15.

d) Increase funding for MRC's Supported Employment Supports program.

Update: Under the Workforce Innovative and Opportunity Act (WIOA), MRC is required to spend 15% of its funding on transition aged youth. MRC has over 30 providers of pre-employment (pre-ETS), services include job exploration counseling, workplace readiness, work-based learning experiences, counseling in post-secondary training opportunities and self-advocacy. IN FY17, MRC referred 422 consumers with autism to its pre-ETS services.

e) MRC shall also reach out to private non-profits, such as Asperger's Association of New England, to help fund coaching programs.

Update: The Northeast ARC provided staff trainings on autism, 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.

f) 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.

Update: MRC and DDS are working collaboratively to serve transitioned aged youth with autism and other disabilities. MRC has over 30 pre-ETS vendors and referred 422 consumers with autism to these providers. MRC also received 143 referrals of individuals with autism through the Chapter 688 referral process.

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.

Update: This recommendation has not been implemented as written. Rather, ESE special education staff members are responsible for supporting the specific needs of students in all disability categories through state policies and practice, and identifying focused needs of specific populations as appropriate, including students with autism. Working with stakeholders, ESE helped to develop the criterion for the Autism Endorsement for educators working with this student population.

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.

Update: This has not been fully implemented. DESE has several discretionary grant programs that may be used to support program improvement focused on educating students with autism.

- 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.

Update: This has not been fully implemented. While DESE does not provide school district with interpreters, DESE makes available its required IEP forms in multiple languages for district use. Additionally, through its Coordinated Program Review process, DESE monitors the extent to which local education agencies are using interpreters and translators to provide communications in parents' primary languages, and requires corrective action whenever noncompliance is detected. Finally, DESE encourages school districts to share translation and interpretation resources with each other, and to partners with community organizations for these 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.

Update: Though funding has not been available to develop this specific pilot program, DESE is supporting many programs focusing on reducing and eliminating culture and linguistic barriers faced by students and their families, regardless of disability designation. This has not been fully implemented.

- 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.

Update: Completed. 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 at present time, approximately 750 individuals have received the endorsement. In addition, nearly 500 other individuals have applied for the endorsement and received feedback from ESE on the specific steps they need to complete to finalize their endorsement.

- f) (i) Require that the new transition specialist endorsement competencies include experience working with youth and adults with autism.

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.

Update: This has not been fully implemented. 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.

Update: DESE is currently seeking a vendor to assist with project planning and development to further advance the new IEP project. The new IEP development process will include an improved Secondary Transition planning process and special considerations regarding identifying and implementing the needs of students with autism at all stages, not just for transition aged youth.

(iv) Support development of model transition practices which successfully promote employment, further education, and independent living.

Update: This has not been fully implemented. 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.

Update: This has not been fully implemented. 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.

Update: DESE's Public School Monitoring (PSM) office conducts Coordinated Program Reviews of School Districts' special education programs. Starting in with a self-assessment process during school year 2017-18, PSM has instituted a new system for conducting its monitoring reviews of special education services through a tiered and focused approach. This improved monitoring system will provide more concentrated analyses and targeted assistance for LEAs that struggle to implement effective special education procedures so that LEAs can create sustainable systems that provide students and their families with the full requirements of special education. ESE currently includes in its special education monitoring protocol specific examination of evidence that IEP Teams consider the specific needs of individuals with autism as set for in G.L. c. 71B, §3. 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.

Update: There has been no change to state law. This recommendation would require changes to state law as it is not required under the IDEA, nor are districts required to employ one or more staff members who have the Autism Endorsement credential. 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.

Update: There is no dedicated funding stream for these services.

- 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.

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.

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.

Update: \$1.2 million dollars is currently appropriated 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.

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.

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.

Update: This has not been implemented. The subject matter knowledge (SMKs) requirements for certain Massachusetts educators' licenses are currently under review. Once this review of SMKs is completed, the DESE will consider this recommendation. 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.

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.

Update: M.G.L. Chapter 40B has not been amended. There are alternative ways to achieve this outcome.

- 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.

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.

Update: DHCD is unable to implement a housing priority specifically for individuals with Autism at this time given restrictions on priorities or preferences that target individuals with specific disabilities or diagnoses under civil rights laws, including the Americans with Disabilities Act and Section 504 of the Rehabilitation Act of 1973 and implementing federal regulations, particularly in the absence of certain statutory authorization and/or approval from the U.S. Department of Housing and Urban Development Office of General Counsel's Office of Fair Housing and Equal Opportunity.

- 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.

Update: The Executive Director of the Autism Commission has met with the Interagency Council on Housing and Homelessness, the Unaccompanied Homeless Youth Commission, MassHousing and DCF about trainings on autism. The Executive Director is working with DDS to develop more trainings on autism to assist these entities, state agencies, and their respective stakeholders.

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.

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.

Update: Massachusetts Child Psychiatry Access Project (MCPAP) provides autism expertise in its program.

- 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.

Update: This has not been fully implemented. The Mass Act Early website provides a list of 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 including primary care physicians, nurses, dentists, physical therapists, occupational therapists, speech therapists, and other specialists, the legislature will establish a fund to provide scholarships for students attending state schools including state run nursing and schools of dentistry who are either studying issues related to autism and/or plan to work with individuals upon graduation.

Update: This has not been implemented.

- 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.

Update: The Mass Act Early campaign held a summit in Spring 2017 on the CDC's "Early Identification & Intervention of Neurodevelopmental Disabilities and Autism in Underserved and Culturally Diverse Children." 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. 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). The Adult subcommittee of the Commission also developed and piloted an emergency fact sheet to facilitate better understanding and knowledge of individuals with autism to assist with interactions with an emergency department for general medical or behavioral health care.

- 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.

Update: DDS, DMH, and the Autism Commission's Executive Director met with Massachusetts General Hospital (MGH) Boston to learn about their hospital wide training on autism, and MGH's effort to designate certain units as "autism friendly". Additionally, through an ISA between DMH and DDS that established two clinical fellowships in July 2016, one at UMass Worcester and one at MGH, 30 consultations have been provided for diagnostic clarification, service needs, and treatment planning. An additional fellowship at BMC was added this year. BMC was also engaged to produce training videos for medical staff, with plans to use this web-based curriculum throughout BMC, as well as, other medical schools and psychiatry residencies.

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.

Update: Completed. 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.