



### 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

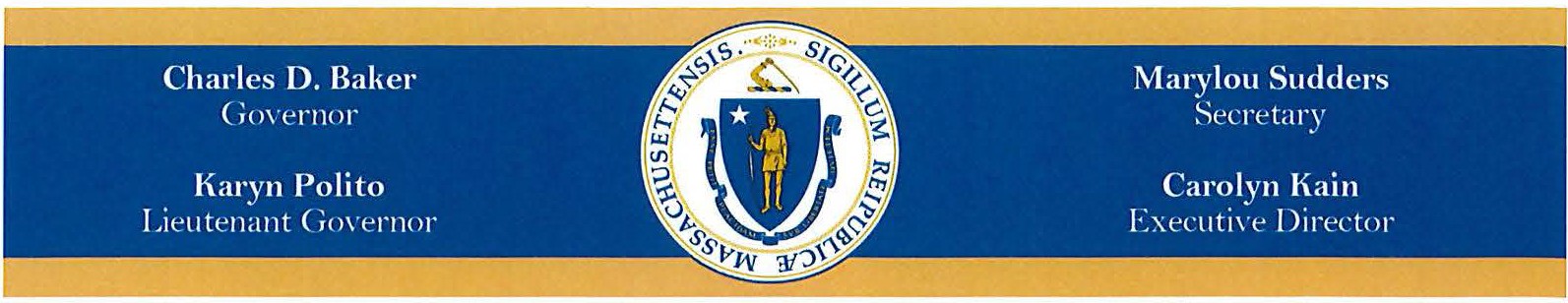
**Re: 2016 Annual Report of the Autism Commission**

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.

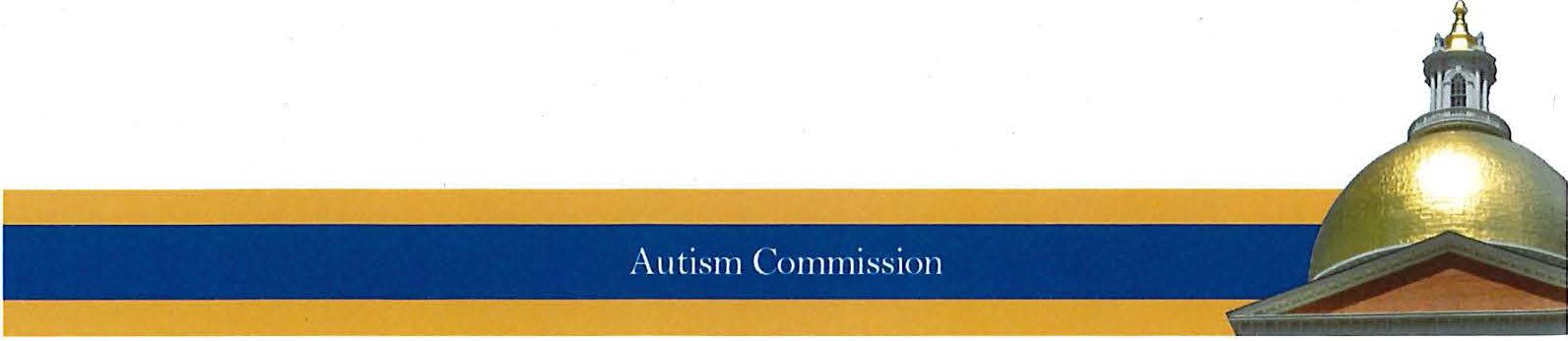
Sincerely,

### Executive Director Autism Commission



THE MASSACHUSETTS AUTISM COMMISSION ANNUAL REPORT

October 24, 2016



## State Legislative Members

### Senator Barbara L'ltalien, 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 Mass Health

Laura Conrad, Mass Health 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

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## 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, 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 n'eeds 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 1in 68, with four times as many boys being diagnosed with ASD than girls (1 in 42 boys, and 1in 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

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

2 1bid.

### 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

1. key recommendations.

Those recommendations were as follows:

* 1. Expand eligibility criteria for the Department of Developmental Services so that individuals with autism who have !Qs 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.

* 1. 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.
  2. Expand insurance coverage for autism treatments.

1. 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.
2. Determine the number of people with autism in Massachusetts and their support needs by implementing a plan for consistent statewide data collection.
3. 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.
4. Increase employment opportunities for individuals with autism by providing a

range of job training, job development, and employment opportunities.

1. Increase capacity to provide educational supports and services necessary to meet the needs of all students with autism.

### Increase availability of augmentative and alternative communication methods, devices and services for individuals with autism.

1. Increase the range of housing options for individuals with autism.
2. 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.

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**

5 Chapter 226 of the Acts of 2014, Section 1(b)

### 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.

1. 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 wenc promulgated on April22, 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 and functional impairments (in three or more of seven life areas), and 4 individuals metthe 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.

1. 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.
2. Coverage of Medically Necessary Treatments by Mass Health. 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. Mass Health is working to implement Outside Section 89 of the FY17 budget.
3. 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.

1. 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 ofthe 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)**

* 1. 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.

* 1. 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)**

1. 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 !SA 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.

1. 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.

1. 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

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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.

1. 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.

1. 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.

1. 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

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program information is available in eleven (11) languages on the DDS website to address any language barriers.

#### Recommendation # 3 Adnlts

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

1. 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.

1. 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.

1. 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.**

1. 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.**

1. 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)

1. 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%.

1. 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)

1. 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.

1. Private Insurance EOHHS and DOl 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.

1. 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.

1. **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.

1. **Early Interventi.on** To assist families transitioning from El to utilize all their available resources, El 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

Enti!;y(ies)Responsible: **Executive Office of Health and Human Services (EOHHS)**

##### DDS, MassHealth

1. 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.

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**2016 Update:** DDS' Division of Autism has primary responsibility for the provision of services for eligible individuals with autism.

1. 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.

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

**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.

1. 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.

1. 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.

1. Increase DDS's funding for family support programs.

**2016 Update:** The budget for *F¥17* includes a $5mil increase of funding for family support

##### services.

1. 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.

1. 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.

1. 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.

* 1. 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)

* + 1. 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.

* + 1. 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)

1. If a child is exhibiting symptoms of autism but does not have an autism diagnosis, El will provide some Autism Specialty Services to the child.

2016 Update: Early Intervention (E.!.) Staff work with families to help them obtain a diagnosis when signs of autism exist. E.!. staff also work to provide services for all of a child's needs while a diagnosis of ASD is being sought.

1. 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.

1. DPH, DDS, EEC, and DESE will continue to support and partner with the MAAct 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.

1. 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. TheM-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.

1. 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.!. 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)**

1. 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 April2016 that is processed 88,508 new claims for SSI/SSDI.

1. 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

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are under the age of 30. *A* total of 184 consumers with Autism achieved successful employment outcomes.

1. 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.

1. 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.

1. 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)**

1. 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.

1. 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.

1. 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.**

1. 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.

1. 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 oftransition 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.

1. 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.

1. 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:l. The Team discusses the student's transition needs annually,.beginning no Iaterthan when the studentis 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 ofM.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.

1. 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.

1. 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.

1. Increase state funding for disability services at Community Colleges.

**2016 Update:** Increased funding is required.

jJ 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 ofEOE. Increased funding is required. Bridgewater State University enrolled two students from the MAJCEI 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

Entit;y(ies)Responsible: **Massachusetts Rehabilitation Commission (MRC), DDS, DESE**

1. 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.

1. 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.

1. 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.

1. 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.

1. 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

1. 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.

1. 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.

1. The DHCD will develop a formal, statewide housing policy to establish priorities for individuals with autism.

##### 2016 Update:

1. 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.

##### 2016Update: Recommendation# 12

Entity Responsible: State Legislature

1. 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.

1. 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 ofMCPAP to restore their coverage to 100o/o.There are six regional hubs located at academic medical centers. Each regional Hub has; **1**FTE child psychiatry, 1FTE licensed therapist, 1FTE care coordinator, and 1Program administrator.

1. 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.

1. 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.

1. 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.