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The entire report is available online at **www.mass.gov/hhs/autismcommission.**

March 2013

The Honorable Deval L. Patrick
Governor of Massachusetts

The Honorable Therese Murray
Senate President

The Honorable Robert A. DeLeo
Speaker of the House

Re: Report of the Special Commission Relative to Autism

Dear Governor Patrick, Senate President Murray and Speaker DeLeo:

On behalf of the Massachusetts Autism Commission, I am proud to present the Priorities, Findings and Recommendations of the Governor's Special Commission Relative to Autism. Enacted in April of 2010, the Commission was directed to determine the current status of available services and supports, to identify gaps and to make recommendations to better serve individuals on the Autism Spectrum. Our commitment was to examine the issues for people of all ages–children and adults alike–along the entire spectrum from classic Autism to Asperger's syndrome.

The Commission began meeting in October of 2010 and assembled bipartisan members of the MA State Legislature to work in collaboration with relevant state agency representatives, leading medical practitioners, educators, advocates and parents. In addition, we expanded our ranks with input from four hard working subcommittees, which provided in-depth study and evaluation of the issues that individuals with Autism encounter throughout their lifespan.

The work of this Commission is the next major step for the Commonwealth of Massachusetts, which has been a national leader on Autism issues with the establishment of the Division of Autism, the passage of the ARICA Autism Medical Insurance Law, the Autism IEP Act, the development of the Children's Autism Medicaid Waiver Program, and the actions taken to ensure the protection of students with Autism from bullying.

Despite all of these efforts, the Autism Commission has determined that tremendous gaps in services and supports still persist and that there is a critical need to develop a comprehensive statewide approach that will respond to the needs of this burgeoning population. For example, our findings confirmed that many children and their families continue to struggle to receive the educational, behavioral, social and emotional supports necessary to transition to adulthood at age 22 and often leaves many without the specialized programming and assistance that is essential to ensuring success in the community. Beyond this, three critical needs were identified: individuals with Autism of all ages need a single entity to provide comprehensive information and referral support, mental health services are difficult to access and need to be widely available and tailored to the unique needs of this population, and eligibility for adult services needs to be based on functional ability rather than IQ. In addition, many adults need housing, job coaching to obtain and retain employment, and case management to assist in realizing their potential.

The Commission has created a ten year roadmap to achieve our goal of developing comprehensive supports and services for our children and adults with Autism. We strove to set pragmatic timelines to achieve our goals. We recognized that there are certain expansions that could be quickly and easily achieved and others that are more complex that will take much longer. We looked to build upon programs with a record of proven success for which an investment of money will produce an immediate positive impact, such as the DESE/DDS Residential Placement Prevention Program, the Children's Autism Medicaid Waiver Program and the Autism Support Centers; and, we have also recognized that some improved outcomes do not need additional funding, but merely require better coordination and collaboration among our state agencies.

While many of our recommendations do require additional financial resources to be implemented, our recommendations also call for leveraging federal funding and we have already begun planning to seek out private foundation funding where appropriate.

Given that Autism prevalence is increasing at an alarming rate, the Commonwealth must move forward with a plan to better manage services and supports for people on the Autism Spectrum so that they can realize their potential and participate fully in the community. The Commission is committed to continuing its work in partnership with the Governor, the Legislature and state agencies in order to accomplish these goals.

Respectfully submitted,

Barbara A. L'Italien

Chairperson, Massachusetts Autism Commission

II LIST OF COMMISSION MEMBERS

State Legislature Members

Senator Jennifer Flanagan, Leominster
Senator Richard Ross, Wrentham
Representative Garrett Bradley, Hingham
Representative Bradford Hill, Ipswich

State Agency Members and Designees

John Polanowicz, Secretary of Health and Human Services
Rosalie Edes, Deputy Assistant Secretary, Office of Disability Policies & Programs, Designee

Lauren Smith, Interim Commissioner Department of Public Health
Ron Benham, Director, Bureau of Family Health & Nutrition, Designee

Elin M. Howe, Commissioner Department of Developmental Services
Janet George, Asst. Commissioner, Policy Planning & Children's Services, Designee

Marcia Fowler, Commissioner of Department of Mental Health
David Hoffman, Senior Psychiatrist, Metro-Southeast Area, Designee

Angelo McClain, Commissioner Department of Children and Families
Jan Nisenbaum, Assistant Commissioner, Clinical & Program Services, Designee

Matthew H. Malone, Secretary of Education
Marissa Cole, Deputy Chief of Staff, Designee

Aaron Gornstein, Undersecretary, Department of Housing & Community Development
Alana Murphy, Director of Policy, Designee

Joanne F. Goldstein, Secretary of Labor and Workforce Development
Leslie Seifried, Designee, Department of Career Services

Charles Carr, Commissioner of the Massachusetts Rehabilitation Coalition

Sherri Killins, Commissioner of Department of Early Education and Care
David McGrath, Designee, EEC

Mitchell D. Chester, Commissioner of Elementary and Secondary Education
Marcia Mittnacht, State Director of Special Education, Designee

Richard M. Freeland, Commissioner of Higher Education
Shelley Tinkham, Director for Academic, P-16, and Veterans Policy, Designee Freeland

Wayne Burton, President, North Shore Community College

Ann L. Hartstein, Secretary of Elder Affairs
Ken Smith, Director, MassHealth Office of Long Term Services & Supports, Designee

Citizen Commission Members

Margaret Bauman, MD, Lurie Center for Autism, MGHfC

Rita Gardner, MPH, BCBA, Executive Director, Melmark New England

Dania Jekel, MSW, Executive Director, Asperger's Association of New England ("AANE") and AANE representative

Julia Landau, J.D., Director, Autism Special Education Legal Support Center of Massachusetts Advocates for Children ("MAC")

Karen Levine, PhD., Helping Children with Challenges

Barbara L'Italien, Chair and Parent

Sherry Amaral-Lopez, Community Autism Resources

Sue Loring, RN, Advocates for Autism of Massachusetts ("AFAM") representative

Gerard McCarthy, Executive Director, Northeast Arc, Inc.

Margaret McPhee, PhD., Murphy and Dwyer Academy, Inc.

Evelyne Milorin, Parent

Daniel Rosenn, MD, Harvard Medical School

Amy Weinstock, AFAM representative

Michael Wilcox, CFA, AANE representative

Subcommittee Co-Chairs

Gloria Castillo, Transition Subcommittee Chair

Ann Guay, Adult Subcommittee Co-Chair

Dave Harmon, Adult Subcommittee Co-Chair

Louann Larson, Birth to Five Subcommittee Co-Chair

Richard Martin, Schoolage Subcommittee Co-Chair

Linda Schaeffer, Birth to Five Subcommittee Co-Chair

Judith Ursitti, Schoolage Subcommittee Co-Chair

III EXECUTIVE SUMMARY

Purpose of the Legislative Commission

The Special Commission Relative to Autism was established by Legislative Resolve and approved by Governor Deval Patrick on April 22, 2010. The Mission of the bipartisan Commission was "To investigate and study current support and services, identify gaps and make recommendations for strategies that will support the development of appropriate, collaborative and timely supports and services across the lifespan of individuals on the [autism] spectrum."

The mission charged the Commission to focus on:

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

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

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

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

Process

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

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

Sub-committees were chaired by leaders in the Autism Community who were joined by numerous professionals, parents, self-advocates, and others with specific interests and expertise in these areas.

State Agencies from four Secretariats were represented on the Commission and these representatives served as valuable resources to the citizen members. The findings and recommendations were ultimately independently formulated by the citizen members and do not imply the endorsement of any specific agency or the Patrick Administration.[1]

More than forty personal experiences and stories were also submitted by members of the public at the request of the Commission. These vignettes describe how lives have been impacted by autism, (both positively and negatively), concerns, frustrations, hopes and aspirations and they have been inserted throughout the report to illustrate some of the key findings and recommendations of the Commission.

[1]State Agency representatives have appreciated the opportunity to be active participants in the Commission proceedings and look forward to continuing their work with this group, but have recused themselves from any of the final decisions on the findings and recommendations that are included in this report since most of the recommendations are for action steps to be taken by the Administration. Upon the filing of the Report, the state agencies will share the recommendations with others in the Administration and determine what action steps are possible. The Administration has deep appreciation for the dedicated and comprehensive work that went into this effort as well as the spirit of the recommendations and looks forward to its continued work with the Commission on this critical issue.

Using the State Agency reports and the work of the sub-committees as a foundation, the Commission prioritized its findings and recommendations into the following thirteen categories:

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

The Recommendations are diverse and extensive. It is understood and acknowledged that implementation of many of these recommendations will require legislative actions, statutory changes and/or financial resources and that some will take more time to implement than others. They are, by intent, broad and ambitious. But collectively, they represent a vision and blueprint for Massachusetts to address the needs of all individuals and families affected by autism.

IV AUTISM IN MASSACHUSETTS

What is Autism?

Autism is a developmental disability that can cause significant social, communication and behavioral challenges.[2] Autism includes Asperger Syndrome and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS).[3] According to the CDC, "Diagnosing autism can be difficult since there is no medical test, like a blood test, to diagnose the disorders. Doctors look at the child's behavior and development to make a diagnosis."[4] EVERY individual with autism is impacted differently by it and has unique needs.

> *"I am a single mom of two teen sons with autism. My 13 year old son has severe autism, bi-polar, mood disorder and Celiac sprue. He is non-verbal and very active. He needs close watch and help with activities of daily living including feeding himself. He is very friendly and sweet. He attends a private school in Andover, MA and loves it. My oldest son has ADHD and a mild case of Asperger syndrome. He is lovable and sweet and does well in the public high school he attends. He enjoys his friends and is active in chess club and forensics debating team. My sons keep me very busy, but it's very rewarding when you see how happy they both are."*
>
> ***Parent of two children with Autism, Worcester, MA***

The Prevalence of Autism in Massachusetts[5]

The CDC estimates that 1 in 88 children have an autism spectrum disorder or approximately 1.1% of the population.[6] No comparable data are broken out for Massachusetts by the CDC. But, this statistic, applied to the Massachusetts population of 6,646,144[7] suggests that around 75,000 people in Massachusetts have autism.

This estimate assumes that prevalence is consistent across age groups. Yet we know from the CDC numbers that rates of diagnosis have risen dramatically in recent years, stimulating lively debate over whether this reflects a true increase in the prevalence of autism, or better screening and diagnostic procedures, or a combination of the two.
The Commission was not charged with resolving this dispute and has simply taken the 75,000 estimate as a guideline for determining how many individuals in Massachusetts have autism.

Prevalence of Autism in the Massachusetts School-Age and Higher Education Populations

According to US Census data, 21.3% of the State's population is under age 18. This suggests that potentially 16,000 Massachusetts children under the age of 18 have autism.

[2] http://www.cdc.gov/ncbddd/autism/index.html
[3] Ibid.
[4] Ibid.
[5] In the absence of explicit and accurate data, the Commission has gathered what is available.
[6] http://www.cdc.gov/mmwr/preview/mmwrhtml/ss5810a1.htm
[7] The US Census Bureau estimate for 2012 http://quickfacts.census.gov/qfd/states/25000.html

In a study cited by the Commission's School-age Sub-committee, in the 2010-2011 school year approximately 12,000 students aged 6 to 17 were identified as having an autism diagnosis.[8] The difference of about 4,000 likely represents pre-school children (under age 6) with autism. Another report by the Department of Elementary and Secondary Education ("DESE"), from the same time period, stated approximately 10,000 children aged 6-21 "were found eligible for special education due to disability on the autism spectrum."[9] Such relatively small discrepancies likely reflect different data collection and reporting mechanisms, different definitions of disabilities, and utilizing different disability categories (such as neurological disability) to classify children with autism.

In a survey conducted by the Department of Higher Education[10] 26 public institutions of higher learning reported 582 students identified as having autism. This figure represents only about 25% of 1% of the total enrollment of students with autism, so it likely understates the true prevalence of autism in the college population.

[8] See School-age sub-committee report in Appendix F
[9] See Department of Elementary and Secondary Education's report in Appendix E
[10] See Department of Higher Education's report in Appendix E

V PRIORITIES, FINDINGS AND RECOMMENDATIONS

Introduction

The Commonwealth of Massachusetts is a leader among states in providing services to individuals with disabilities. In recent years, rates of diagnosis of autism in both children and adults have increased dramatically. The spike in the number of individuals diagnosed with autism has placed strain on an already stressed system that was not originally designed to serve the growing number of individuals living with autism in Massachusetts. While demand for services has increased, government programs designed to assist individuals with autism have not kept pace for a number of reasons: (1) fallout from the economic downturn, resulted in cuts in funding for services and prevented the expansion of programs which successfully serve children and adults with autism, (2) lack of autism expertise among staff in government agencies, and (3) insufficient capacity to meet increased demand for services.

Children and adults with autism have a very broad range of needs, which vary from person to person as well as over the course of an individual's lifespan. Meeting the diverse needs of this population is a challenge that requires creative solutions, new programs, systemic changes, and additional financial resources. In the long run, improving autism services will benefit the Commonwealth as a whole. With appropriate supports and services, individuals with autism will become more productive, more self-sufficient, and more fully-integrated members of society.

The Massachusetts Autism Commission has developed the following Priorities, Findings, Recommendations and Implementation Steps to help Massachusetts improve and expand existing autism services to better meet the needs of our residents with autism. By implementing the recommended changes, the Commonwealth will continue to be a leader among states in providing services to individuals with autism and their families and providers.

State Agency representatives have appreciated the opportunity to be active participants in the Commission proceedings and look forward to continuing their work with this group, but have recused themselves from any of the final decisions on the findings and recommendations that are included in this report since most of the recommendations are for action steps to be taken by the Administration. Upon the filing of the Report, the state agencies will share the recommendations with others in the Administration and determine what action steps are possible. The Administration has deep appreciation for the dedicated and comprehensive work that went into this effort as well as the spirit of the recommendations and looks forward to its continued work with the Commission on this critical issue.

> *"He needs oversight, management and someone to advocate for him; services currently provided by his aged parents. In the not so distant future someone else will have to pick up that role. His siblings will do some of it but what they can do is limited. He needs support and a place in society."*
>
> ***Parents of 54 year old man with Autism, Lexington, MA***

Priority #1 Expand eligibility criteria for the Department of Developmental Services so that individuals with autism who have IQs over 70 and have substantial functional limitations have access to services.

Findings

The Department of Developmental Services ("DDS") has two different sets of eligibility criteria for children and adults seeking services through the Department. Because there are two sets of criteria, even if individuals apply and are found eligible for DDS before the age of 18, these same individuals must apply for eligibility before he or she turns 18. The DDS eligibility criterion for individuals 18 and over is twofold: the individual must have an IQ of 70 or lower and significant limitations in adaptive functioning. Many individuals with autism do not have an IQ lower than 70 but do have significant adaptive functioning limitations. Despite this, if individuals have IQs higher than 70, they are currently found ineligible for services through DDS. In the first quarter of 2012, 25% of individuals who applied for adult services through the Department of Developmental Services were found ineligible; 41% of the individuals who were found to be ineligible had an autism diagnosis.[11]

> *"His most recent round of testing showed huge variation among subscores but an overall IQ of 72. This is a young man who cannot be outside independently. He has no judgment and no sense of propriety so that he continually gets into trouble when he is unsupervised. He has little ability to care for himself inside the home and requires supervision. We applied to DDS, went through every level of appeal. In the final report they agreed with the notion that our son is not functional enough but his IQ was too high and he was found ineligible for DDS services."*
>
> ***Parents of a 21 year old with Autism, Newton, MA***

Recommendations

Entity Responsible: DDS, State Legislature

A) DDS will no longer use an IQ-based eligibility requirement for adult services. Rather, eligibility will be determined by using the federal Developmental Disability Act definition of a developmental disability that takes into account a range of limitations in adaptive functioning skills.[12] *Short-term*[13]; *amend statute and regulations; DDS will need an increase in financial resources to support more individuals*

B) On a quarterly basis, DDS will report to the Autism Commission the number of individuals with autism applying for services who are found to be ineligible. *Short-term*

[11] Department of Developmental Services.
[12] Public Law 106 (8)
(A) The term "developmental disability' means a severe, chronic disability of an individual that:
(i) is attributable to a mental or physical impairment or combination of mental and physical impairments;
(ii) is manifested before the individual attains age 22;
(iii) is likely to continue indefinitely;
(iv) results in substantial functional limitations in 3 or more of the following areas of major life activity:
(I) Self-care.
(II) Receptive and expressive language.
(III) Learning.
(IV) Mobility.
(V) Self-direction.
(VI) Capacity for independent living.
(VII) Economic self-sufficiency; and
(v) reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.
[13] Despite this recommendation needing both financial resources and updated statutes and regulations to be implemented, the Commission labeled it as "Short-term" because the Commission believes it can be implemented during the 188th legislative session, January 1, 2013 to December 31st, 2014 due to recent discussions about eligibility at the DDS.

Priority #2 Assure that those with autism and a co-occurring mental health condition have equal access to and appropriate services from the DMH.

> *"Since S.G.'s IQ tested well above the 70 point cut-off for DDS services, they turned to DMH. After both a prolonged application and an appeal, they were told that S.G. is not eligible for DMH because he is on the autistic spectrum. Despite his significant depression, Mood Disorder NOS, rage reactions, and a host of other psychiatric symptoms, they were told by DMH that he did not have a major mental disorder which would qualify him for their services."*
>
> ***Professional, Boston Metro Area***

Findings

Many individuals with autism have co-occurring mental health diagnoses. In a study of 112 children diagnosed with autism, 70% of children had at least one comorbid disorder and 41% of the same sample had at least two comorbid disorders.[14] Some research has studied the likelihood of adults with autism developing psychotic symptoms and schizophrenia.[15] This same research discussed the difficulty practitioners have distinguishing between autistic symptoms in adults and some non-psychotic symptoms of schizophrenia.[16] The high number of individuals with autism who have mental health issues, combined with the difficulties of properly identifying these issues, makes it difficult for many people with autism to receive accurate diagnoses and effective treatment.

The Department of Mental Health ("DMH") is the state agency responsible for providing assistance to individuals with mental health issues. The application for services through DMH is a two-step process. First, individuals must meet DMH's clinical criteria to receive services, which differ for children and adults. In order to meet the clinical criteria for DMH services, children must have a serious emotional disturbance that results in functional impairment. The emotional disturbance does not have to be the primary cause of functional impairment.[17] Thus, so long as a child's functional impairment is not solely the result of autism, a child with co-occurring serious emotional disturbance and autism may be eligible for DMH services.

To meet the clinical criteria for adult DMH services, an adult must have a serious mental illness that is determined to be the primary cause of his or her functional limitations.[18] An adult whose functional limitations are primarily due to an autism spectrum disorder may be found ineligible for DMH services, even if he or she has a secondary serious mental illness diagnosis. Due to different clinical eligibility criteria for adults and children, an adult who received DMH services as a child, but who does not have a serious mental illness as an adult, or whose serious mental illness is not the primary cause of his or her functional impairment, may not be approved for DMH adult services. The differences in clinical eligibility criteria for adults and children can potentially disrupt treatment for individuals with autism.

[14] Simonoff, E., Pickles, A., Charman, T., Chandler, S., Loucas, T., & Baird, G. (2008). Psychiatric disorders in children with autism spectrum disorder: prevalence, comorbidity, and associated factors in a population derived sample. *Journal of the Academy of Child and Adolescent Psychiatry, 47*(8), 921-929.
[15] Nylander, L. (2008). Autism spectrum disorders and schizophrenia spectrum disorders – is there a connection? A literature review and some suggestions for future clinical research. Clinical Neuropsychiatry,(5)43-54.
[16] Ibid.
[17] DMH Regulations: 104 CMR 29.00 Clinical Criteria to receive DMH services as a child http://www.mass.gov/eohhs/gov/laws-regs/dmh/regulations.html
[18] DMH Regulations: 104 CMR 29.00 ***Eligibility for Adult Services*** http://www.mass.gov/eohhs/gov/laws-regs/dmh/regulations.html

Second, the individual must be in need of a service that DMH provides and has available. Consistent with DMH's primary mission to serve individuals with serious and persistent mental illness DMH's community services are designed to meet the needs of this population. Those services are often not suitable for individuals with autism who require specialized services to address their mental health needs since they are individuals with a developmental disability. As a result, individuals with autism may be found ineligible because their needs cannot be met by currently available DMH services.[19] It is also important to note that individuals with autism who are eligible to receive services through DDS are "categorically excluded from consideration of DMH services."[20] This practice creates some challenges in meeting the needs of individuals with autism who have co-occurring mental illness and significant mental health service needs.

> *"After one exceptionally troubling episode when he angrily entered his parents' bedroom in the middle of the night, he was hospitalized for 24 hours, and discharged on increased medications. When his private psychiatrist tried to dissuade the discharging psychiatrist from sending him home so soon (where he might attack his parents again and, because of pending charges, end up in jail) the hospital psychiatrist told him, "Going to jail might teach him a lesson."*
>
> ***Professional, Boston Metro Area***

Recommendations

Entity Responsible: DMH; DDS; State Legislature

A) Applicable statutes, regulations and policies will be revised to state that a primary diagnosis of autism will not be used as grounds to find an adult ineligible for DMH services.[21] *Short-term*[22]*; regulations and statutes need to be updated; DMH will require increased financial resources*

B) On a quarterly basis, DMH will report to the Autism Commission the number of individuals with autism applying for services who are found to be ineligible. *Short-term*

C) DMH will improve its level of clinical expertise regarding the treatment needs of individuals with co-occurring mental illness and autism. *Short-term*

D) DMH will develop more services that are tailored to meet the needs of individuals with autism and co-occurring mental illnesses. *Medium-term; Increased financial resources will be needed*

[19] Autism Commission Report-State Agency Section (July 2012) Department of Mental Health section. "Individuals with autism and co-occurring mental health diagnoses are not able to access mental health services through Department of Mental Health because the department's services are not designed to address the behavioral support needs of this population."

[20] Information found on page 12 of the Department of Mental Health's *Interpretative Guidelines for 104 CMR 29.00 Determining Service Authorization for Children, Adolescents and Adults December 2009 (revised November 17th, 2010)* http://www.lawlib.state.ma.us/docs/interpretive_guidelines.pdf

[21] See DMH Regulations: 104 CMR 29.00 Section 29.04:Application for DMH Services; Clinical Criteria and Determination of Need (2) Clinical Criteria for DMH Services. (a) To meet the clinical criteria to receive DMH services, an adult must have a mental number 2. Mental illness is the primary cause of a functional impairment that substantially interferes with or limits the performance of one or more major life activities, and is expected to do so in the succeeding year

[22] Despite this recommendation requiring statutes and regulations to be changed as well as funding it is labeled "Short-term" because increasing access to DMH services for individuals with autism is a priority for the Commission.

Priority #3 Expand intensive services in the home and community for individuals with autism through the (3A) Children's Autism Medicaid Waiver and Adult Medicaid Waivers and the (3B) DESE/DDS program

3A) Medicaid Waivers

Children's Autism Waiver Program

Findings

The Children's Autism Waiver Program is a Medicaid program that provides intensive in-home and community based services to MassHealth eligible children under age 9 who have an autism diagnosis and are at risk for institutionalization. The Waiver Program is administered by the Department of Developmental Services' Autism Division, and up to 157 children may participate in the Waiver program at any given time. Over the course of the Waiver year, 205 children may be served even though it is estimated that there are approximately 6,000 low-income children with autism receiving MassHealth. The federal government reimburses Massachusetts at 50% of the cost of the Waiver Program. Children chosen to participate in the Waiver program are eligible for up to $25,000 a year of services for a three year period up until their 9th birthday.

Upon completion of three years of intensive home-based services, children enrolled in the Waiver may receive supplemental services, including respite and home consultation services to assist with the transition from the Waiver Program. During the most recent open enrollment period in April 2012, more than 800 families applied for the Waiver.

Recommendations

Entity Responsible: DDS; State Legislature

A) Increase the appropriation for the Children's Autism Waiver Program. *Short-term; increased resources*

B) Amend the Waiver and initially expand the number of children (ages birth through age 8) served from 157 to 500. To ensure adequate funding for expansion of waiver services, establish a DDS retained revenue account which retains Medicaid Reimbursement fees for waiver services. *Short-term; increased resources*

C) Designate at least two enrollment periods per year to allow parents to plan accordingly. *Short-term*

D) When the Autism Waiver is renewed in two years, DDS will expand the Waiver to create Waiver Services for children ages 9-22. For this older cohort, the Commission recommends that the waiver offer a broad array of flexible in-home and out-of-home services. *Medium-term; increased resources*

Adult Waiver Program

Findings

Massachusetts has three adult waivers that serve DDS eligible adults, including many with autism who meet the current DDS eligibility criteria.

- The Residential Waiver provides supports to eligible adults who require 24 hours per day of support. Many of them have serious medical, behavioral and/or physical needs. They are not able to live at home and require round the clock support. There is no dollar limit for services. Current capacity is 8,200 adults.

- The Community Living Waiver provides services to DDS-eligible adults who require a moderate level of assistance and live in their own home or with a provider. They do not require round the clock support. The dollar limit of support under this waiver is $65,000 annually. Services include supported employment, day habilitation supplement, transportation, homemaker services, assistive technology and behavioral supports consultation. Capacity is 2,300 adults.
- The Adult Supports Waiver provides services to eligible adults who require supports to reside successfully in the community. Services can be client-directed or offered through a traditional provider-based system. The dollar limit is $28,000 per year. Services include group or center based day supports, individual support, community habilitation, respite, supported employment, family navigation and transportation. Capacity is 2,800.

These three waivers will be renewed in the spring of 2013 for a five year period commencing July 1, 2013.

Recommendations

Entity Responsible: DDS

Since the Adult Waiver Programs are up for renewal in 2013, immediate steps should be taken to expand and improve the specialized services available for adults with autism enrolled in the Waiver Programs:

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. *Short-term; increased resources*

B) Provide intensive case management by adding a group of trained workers with extensive autism experience to assist with development of individual support plans provide on-going support and technical assistance for in-home behavioral supports and coordinate and organize services. There will need to be a sufficient number of case managers to meet the increased demand for services due to changes in eligibility criteria. *Long-term; increased resources*

C) Increase the availability and expertise of Behavior Support Consultation for DDS eligible adults and reframe behavioral service delivery in group homes to meet the behavioral needs of adults with autism. *Medium-term; increased funding*

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. *Long-term; increased resources; structural changes; research and development*

E) Require school districts to provide written information to families of students with autism transitioning into adult services about the availability of the three adult waivers. *Short-term*

3B) The DESE/DDS Residential Placement Prevention Program

Findings

The DESE/DDS Residential Placement Prevention Program ("DESE/DDS Program") provides supports to families to keep children at home and reduce the risk for residential placement of students who are in school and DDS eligible. It also provides supports to families who opt to bring their children home from a residential placement. Children must be 6-17 years of age at the time of enrollment in the Program. The Program is well-suited for children with autism and provides additional resources to families. The DESE/DDS Program is funded by the state through funds allocated to DESE and administered by the DDS. According to DDS, "The DESE/DDS Program currently serves 485 participants across the Commonwealth; approximately **90%** of participants have an autism spectrum diagnosis." DDS closed the waiting list for DESE/DDS and stopped taking new applications in 2009. In FY 12, DDS eliminated the waiting list and fully funded all but 20 participants, who received partial funding; DDS expects to fully fund them all in FY 13.

> *"He is a participant in the DESE/DDS program. This provides resources which we utilize to support his opportunities to participate and integrate him into our family and community. Through the program, he attends a specialized day school where he receives an education which meets his unique educational needs. He also receives Personal Care Attendant services to help him attend successfully to dressing and grooming."*
>
> ***Mother of a 14 year old with Autism, Sterling, MA***

Recommendations

Entities Responsible: State Legislature, DDS, and the DESE

A) Since there is currently no wait list, DDS will initiate a new application process and expand the number of slots available for students requiring these services. DDS will then maintain a wait list of students who are found eligible but for whom funding is not available. The Autism Commission will receive annual updates from DDS regarding the number of students on the wait list. *Short-term*

B) Increase funding for the DESE/DDS program in order to serve more individuals in this program. *Short-term*

Priority #4 Increase insurance coverage for autism treatments.

Findings

ARICA, the 2010 law in Massachusetts requiring private insurances to cover autism treatment is starting to have a major effect on people's ability to access treatment, especially behavioral treatment. However, the law only applies to state-regulated plans. Many large employers have self-funded plans, which are federally regulated, and exempt from state law. While some have voluntarily adopted coverage, many have not, making it very difficult for some to obtain services paid for through insurance.

In addition, MassHealth is not subject to ARICA. While MassHealth covers some treatments (some children are covered under the Autism Waiver), there is generally less autism coverage available, including coverage of ABA services, for MassHealth clients than for people who have private coverage. Only 157 recipients are covered under the Autism Waiver, while there are approximately 6,000 low-income children with autism enrolled in MassHealth.

> *"MassHealth won't pay for ABA services, which I think would benefit my child a great deal, and she doesn't qualify for the autism waiver, because she is 9 years old."*
>
> ***Parent of a 9 year old with Autism, Athol, MA***

The Department of Public Health's Early Intervention ("EI") program provides access to comprehensive services and treatment for all children prior to age three. The DPH pays all costs that are not covered by insurance and for eligible children who have no insurance. [23] Transitioning from EI to the early childhood education system can be stressful for families. The frequency, intensity and quality of services after EI often depends on the child's Individual Education Plan, the capacity of the local school district, and the type of insurance the child has. Some parents are able to access autism services through their health insurance. Access to insurance that provides coverage for autism treatment to children transitioning from EI is a crucial piece to enabling continued progress for them. Unfortunately, many families insurance plans do not cover these services.

MassHealth currently covers dedicated communication devices for people who require Augmentative and Alternative Communication ("AAC"). These devices can be quite expensive, cumbersome, and require significant maintenance to keep them working properly. In recent years, with the development and proliferation of tablets and associated specialized software to support AAC, some families who are able to afford them purchase them for their children. But current MassHealth regulations do not cover non-dedicated communication devices (i.e.: tablets), despite the significantly lower cost, greater functionality, and reliability.

> *"The insurance company will not deny services but it's impossible to get them. They told me they are on a committee to define services to be covered with the state. I pray all the fighting for the ARICA law was not wasted. Social skills being one of the biggest issues with autism the social skills groups which help with this should be covered. Most service providers for groups do not bother taking insurance because the battle is so exhausting. I have to work full-time to have the insurance coverage which leaves me without the time to fight the insurance company on a daily basis and care for our family."*
>
> ***A parent of a 12 year old with Autism, Worcester, MA***

Recommendations

Entities Responsible: EOHHS; DOI; MassHealth; DPH

Private Insurance

A) EOHHS will reach out to large self-funded employers to educate them about the insurance law, and the importance of covering autism treatment for their employees. *Short-term*

B) 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. *Short-term*

MassHealth

C) Require MassHealth to take action necessary (including approval from the Centers for Medicare and Medicaid Services, if required) to cover medically necessary treatments for individuals with autism, including, but not limited to, Applied Behavior Analysis, supervised by a Board Certified Behavior Analyst (BCBA). *Medium-term, legislation needs to be filed*

D) Require MassHealth to revise regulations to cover both dedicated and non-dedicated (e.g., tablets), for people who require Augmentative and Alternative Communication. *Short-term; update MassHealth Regulations*

[23] http://www.mass.gov/eohhs/consumer/community-health/family-health/early-childhood/ei/who-pays.html

Early Intervention

E) 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. Families that have limited or no options for behavioral treatments under their current insurance will be referred to resources for information on possible alternatives for obtaining coverage. This should take place before the child turns 2 (or as soon as possible if the diagnosis comes later). *Short-term*

Priority #5 Increase and fortify supports and resources that make it possible to maintain the family unit and assist individuals with autism to live in the community.

Findings

To maximize a family's ability to properly care for a loved one with autism in the community or for an individual with autism to live as independently as possible in the community, it is critical that they have access to information about state service options and assistance with navigating both the private and public sector service system. Locating information on state service options is a particularly time consuming task and many families report that there is an overwhelming and confusing presentation of information about state services that can be difficult to decipher. The different application procedures and eligibility requirements at every state agency are not only confusing but they can also delay access to services.

There are a limited number of state programs that provide information and referral for this population. The programs that are best suited to the needs of families with individuals with autism are the seven community-based Autism Support Centers funded by the DDS Autism Division; these Centers provide information and support to families on both state and private resources. Due to the limited resources available, these Centers currently only serve children with autism and their families. They do not have the capacity to work with all current DDS-eligible children with autism as well as adults with autism.

As to service navigation, the supports available through the Children's Autism Waiver are a commendable example of the positive impact that this type of service can have. Families who participate in this Waiver benefit from the support of a clinical case manager as well as an autism support broker who attend to both the behavioral needs of the child as well as helping the family access services and supports. Unfortunately, these services are only available to the limited number of children who meet DDS's eligibility criteria for waiver services and are selected to be in the program.

> *"Because of the Asperger's diagnosis, the DMH intake coordinator said he did not qualify for DMH services. She did insist, however, that he would qualify for CBHI from MassHealth based solely on the fact that he had an IEP. At that point I had already submitted identical applications for MassHealth twice. They required us to submit an application which was first rejected based on our income. They never gave us an option to apply directly based on disability. We wasted 5 months of time waiting to be told we made too much money. All during that time, my son and our family struggled and suffered. I had to quit my job in order to support him emotionally. This took a terrible toll on me personally and our family's income."*
>
> ***Mother of an individual with Autism, Ludlow, MA***

Assistance with navigating the system is even more limited for individuals with autism who are not eligible for state services. Other constituencies have developed creative ways to disseminate information to broad groups of individuals who are not eligible for state services. For example, people looking for information on elder services in Massachusetts can use the 1-800-AGE-INFO number and/or website to locate information. A resource like this, with reliable information on autism services that could be accessed by individuals, regardless of their eligibility status for state agency services, would be beneficial to entire the autism community.

Perhaps more vital than navigating services and gathering information is the ability to access supports that are necessary to successfully function in the community outside of a structured school, day program, or employment environment. Those eligible for state services can be offered a range of in-home supports depending on need. DDS's Family Support program offers respite care, personal care assistance, medical equipment, therapies, training, support groups, recreational and social activities as well as flexible funding to pay for extraordinary expenses to those eligible for the program. Unfortunately, funding for Family Support services is not meeting the demand in the Commonwealth. Only 3.5% of DDS's funding is available for family support, while family caregivers represent 60% of the individuals receiving supports.[24]

> *"I do struggle with not having any babysitter for him or the money to pay for one so I never get a break. It's very hard working full-time and having a home and taking care of two kids on my own... especially one with low functioning autism."*
>
> ***Parent of an 11 year old with Autism, Danvers, MA***

Many families struggle to locate support providers who are knowledgeable about autism. The need to expand the number of staff who work with individuals with autism and improve their training is evident in homes where adults with autism reside without their families. Staff in adult DDS residences are required to be trained in the basics of residence safety and care as well as general information about the nature of developmental disabilities, but would benefit from specialized training on how to support residents with autism. Furthermore, staffing levels in many group settings are inadequate, both as to quantity and quality. Low compensation levels are a hindrance to attracting qualified staff. Turnover is often high, and training levels are low, which can lead to an unstable and potentially dangerous environment for residents and staff.

Recommendations

Entities Responsible: 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. Individuals with autism will be directed to the Division of Autism whether or not they are eligible for DDS. *Medium-Term, organizational changes and increased funding*

B) To assist the Division of Autism with its new designation as the single agency dedicated to offering information and referral to all people with autism, 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. DDS will determine what funding is required for each center to serve more individuals and will determine the need for additional resources for the Autism Division. *Medium-term increased funding*

C) The Division of Autism with support from EOHHS will create a website and telephone number mirroring 1-800-AGE-INFO that individuals with autism and their families can use to access information on state and private services that are available to assist them. *Medium-term*

D) EOHHS shall form an Interagency/inter-Secretariat Work Group to include DCF, DPH, DDS, MRC, MassHealth, DMH and DESE to develop policies to better coordinate overall services and improve cross-agency and cross-Secretariat communication. The Committee shall develop written recommendations which will address the gaps in services for adults and children with autism focusing on individuals who are served by more than one agency. A plan will be developed for better cross-agency care coordination and be submitted to the Autism Commission. *Short-term*

E) DDS shall promulgate regulations to improve 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. Under the new system, case management services will be provided by highly trained service coordinators specially trained in autism. *Long-term regulations change, structural changes and increased funding*

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. *Short-term*

G) Increase DDS's funding for family support programs. *Short-term*

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. *Medium-term*

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. *Medium-term*

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. *Short-term*; *Revise MassHealth regulations*

K) DDS will examine current staffing credentials, staffing levels at group homes, and supportive living arrangements for adults with autism and ensure that there are adequate staffing patterns and appropriately trained staff in order to meet the safety, behavioral and health needs of individuals with autism *Short-term*

L) Autism Division will establish and maintain a database of institutions offering courses, certifications and degree programs in autism and autism related fields, and provide public access via a centralized website and the Autism Support Centers' websites. *Medium-term*

[24] DDS *In their Own Words: The Need for Family Support Services* report

Priority #6 Determine the number of people with autism in Massachusetts and their support needs by implementing a plan for consistent statewide data collection.

Findings

State agencies utilize different, incompatible tracking systems, which makes it difficult to obtain comprehensive data on people with autism in the Commonwealth. For example, DMH, Department of Early Education and Care ("EEC"), Department of Higher Education ("DHE") and MassHealth have data on the number of individuals utilizing each service in their agency but none of these agencies maintain data on the total number of individuals with autism they serve. Department of Elementary and Secondary Education ("DESE") keeps data on the number of students with autism receiving special education services but these data under-reports the true incidence of autism, as it reflects individuals with autism designated as the category of disability on Individualized Education Plans ("IEP"), while many times schools will classify autism utilizing a different disability category, such as "neurological disability, developmental delay." DPH follows the number of children with autism utilizing Early Intervention services and Massachusetts Rehabilitation Commission ("MRC") tracks the number of individuals with autism receiving its services. DDS notes who is eligible for services and has begun tracking the number of people (including those with autism) who are found ineligible for services. Because each state agency maintains different criteria for collecting data, it is unfeasible to calculate a reliable number of people with autism utilizing state services in Massachusetts.

State agencies also struggle to find a balance between acquiring comprehensive and accurate data on the autism population while maintaining confidentiality of the individuals receiving services from state agencies. Federal regulations also make it difficult to share data between state agencies and create a comprehensive data collection system. The current lack of an organized data system makes it difficult to fully address urgent and critical planning and policy issues that concern the future of the autism population.

Recommendations

Entity Responsible: Executive Office of Health and Human Services ("EOHHS")

A) EOHHS will inventory current data tracking systems at DDS, DPH, DESE, EEC and MassHealth and review data tracking models in other states.[25] EOHHS will make recommendations to the Autism Commission to improve data collection in Massachusetts, and a plan will be developed for tracking data on the autism population while protecting the population's confidentiality. *Short-term*

B) EOHHS will establish and manage an integrated confidential data system among state agencies and stakeholders to track diagnosis, treatment, services and outcomes of individuals with autism in order to improve coordination of care and to disseminate information. *Short-term; Legislation needs to be drafted*

[25] New Jersey has developed an Autism Registry which takes steps to protect privacy and confidentiality but it does not include information on individuals with autism over age 22.

Priority #7 Improve access to autism screening, diagnosis, and Autism Specialty Services through Early Intervention for children diagnosed with autism and those considered at high risk for autism.

Findings

The American Academy of Pediatrics ("AAP") recommends all pediatricians screen infants for signs of autism with standardized instruments at the 18 and 24 month well baby visits.[26] Two of the barriers that are impeding the pediatric community from implementing the AAP's standardized autism screening at every 18 and 24 month visit are time limitations and reimbursement rates that fail to cover the cost of the screening.[27] The shortage of diagnosticians delays follow-up care for children who have an initial positive screening for autism.[28] This is a major barrier to obtaining time sensitive treatment such as Early Intervention through DPH.

The DPH's Early Intervention program offers a robust set of services to children under the age of three. Children diagnosed with autism are automatically eligible for EI services. Children who exhibit some of the signs of autism but do not have a formal autism diagnosis may be eligible for EI services. Only children with an autism spectrum diagnosis confirmed by a physician or licensed psychologist are eligible for EI's Autism Specialty Services. The average age children receive an autism diagnosis while enrolled in the EI program is 25.6 months. As a result of the delay in obtaining a formal autism diagnosis, many children do not receive Autism Specialty Services, which terminate at age 3.

> *""C" was diagnosed with PDD-NOS at 19 months and was prescribed 25-30 hours of behavioral therapy. We interviewed numerous therapy providers, and settled on a reputable provider, who offered just 10 hours per week of therapy. The weeks and months slipped by, "C" was getting older but his autism remained the same. At 22 months old, "C" started 28 hours per week of ABA therapy through a different home-based program. He made incredible progress. He began responding to his name and began to speak."*
>
> ***Parent of an 11 year old with Autism, Brookline, MA***

Recommendations

Entity responsible: DPH; MassHealth; DDS

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. *Medium-term*

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 at 9, 18, 24 and 30 months. In addition, all children will be given a standardized autism screening at 18 and 24 months.[29] *Medium-term; Educate Medical Providers*

[26] Early Intervention ("EI")American Academy Pediatrics "APA Recommends Autism Screening for All Infants". (2007, Oct 30). Available at www.medscape.org
[27] Center for Disease Control and Prevention CDC 24/7: (2012). "Autism A.L.A.R.M. Guidelines." Available at www.cde.gov/nbddd/autism/htp-recommendations/html
[28] Lipkin P., "Efforts must continue to improve screening rates, payment", (2011, Aug 11). AAP News, Vo 32. No. 8. Available at www.aapnews.org
[29] MassHealth through the Children's Behavioral Health Initiative requires medical professionals to use a behavioral health screening tool to check the child's behavioral health. Following this example, MassHealth will require all medical professionals in MA to screen for autism.

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. *Short-term*

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. *Short-term*

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. *Medium-term*

Priority #8 Increase employment opportunities for individuals with autism by providing a range of job training, job development, and employment opportunities.

Findings

MRC's federally-funded Vocational Rehabilitation ("VR") Services are designed as short-term methods of assistance that help individuals locate employment. These services are terminated 90 days after an individual's employment starts. Many individuals in the autism community require long-term (post-employment) support to have a successful employment experience; often these individuals are able to find employment but have difficulty maintaining a job. They may require specialized training in related areas, such as, social awareness and basic living skills. Federally-funded VR services, as currently designed, do not meet the needs of many people in the autism community.

By comparison, MRC's state funded Supported Employment Supports program provides job coaching and longer-term job supports. State funding for this program is limited and is insufficient to meet the needs of the growing population of adults with autism. In addition, despite admirable efforts by MRC to increase staff awareness and training, there is, nonetheless, a shortage of well-trained job coaches available to assist adults with autism seeking employment, as well as those already employed. According to MRC, "The steady increase in enrollment of consumers on the spectrum pushes the need for access to specialized consultants to assist counselors and program coordinators in assessing functional abilities and program-specific questions related to the Autism diagnosis." This lack of awareness also extends to the employer community (including state agencies). Many employers are ignorant about the special skills that employees with autism can bring to the workforce if they are placed in jobs for which they are suited and given an autism-friendly environment. This results in a shortage of suitable employment opportunities.

Transition services often fall short of meeting the needs of students with autism who need specialized guidance to help them choose educational, employment, and housing options that will provide a higher likelihood of success. MRC has established a Memorandum of Understanding with DDS to begin the process of increasing long-term supports for the intellectual disability/developmental disability populations who are transitioning from school to DDS and who would benefit from extended periods of support where MRC will train and place individuals into integrated competitive employment. DDS will provide the funding for ongoing supports.

> *"I qualify for Mass Rehab based on my disability, but the people there have basically said that they cannot help me as I am too high-functioning. They say that I interview well, that I present nicely, and am very qualified, but they don't know why employers never hire me, even after multiple interviews. I don't know, either – that's why I need help."*
>
> ***Individual with Autism, age 28, Arlington, MA***

> *"Our son is now in his own apartment and a few courses away from getting his four year degree. All those accomplishments started with those first steps with Mass Rehab and he would not be where he is today without their support."*
>
> ***Parent of a 26 year old with Autism, Shrewsbury, MA***

Recommendations

Entity Responsible: MRC; EOHHS

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. *Short-term*

B) MRC shall analyze and report data to the Autism Commission concerning the approximately 20,000 individuals who receive MRC services each year including number of individuals with autism served. *Short-term*

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

D) MRC shall seek funding to increase the number of job coaches employed by MRC and continue to increase collaboration with other disability agencies to expand supported employment options, and ensure that providers receive specialized training in how to meet the needs of adults with autism. *Medium-term*

E) Increase funding for MRC's Supported Employment Supports program. MRC will also explore and identify options for making available on-going employment supports to those consumers with autism who require them, including broadening the MRC/DDS Memorandum of Understanding to include consumers with autism. *Medium-term; increased funding*

F) MRC shall also reach out to private non-profits, such as Asperger's Association of New England, to help fund coaching programs (such as AANE's LifeMAP Program), so that wider access can be provided to people who cannot afford to pay fees for such services. *Medium-term; increased funding*

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.[30] *Medium-term; increased funding*

[30] Successful models that might be emulated are the Aspiritech company and the Autistic Self-Advocacy Network's work with federal agencies seeking to enhance the diversity of their workforce

Priority #9 Increasing capacity to provide educational supports and services necessary to meet the needs of all students with autism

Findings

The number of students with autism between the ages of 3 and 22 educated in Commonwealth schools increased 170% between FY 2003 and FY 2011.[31] This was the largest increase for any disability category during the same timeframe. School systems across the state struggle to develop programs and services to respond to the substantial increase in the number of students diagnosed with autism seeking educational services required under special education laws.The growing numbers of students with autism appear to be outpacing capacity, including the development of programs and the preparation of personnel experienced in the area of autism.

> *"I actually kept my son out of school another year so he could continue with ABA therapy at home because there was no one in the school that had ever been trained in ABA. I had to leave work and get a part-time job so I could work with my son and his therapists. It was a financial struggle working only part-time and paying for professional advocates to make sure my child received the services, that by law, I should not have to fight for."*
>
> ***Parent of a 6 year old with Autism, Danvers, MA***

Although state and federal laws (including the Autism IEP Act) require school districts to provide appropriate services/programs for the burgeoning numbers of students with autism, the state system to monitor and ensure compliance with these laws is inadequate due in part to lack of resources and structural capacity. As a result, students with autism often do not receive necessary special education services and programs There is wide disparity in the availability of appropriate educational services available for students with autism across the Commonwealth. For example, there is a growing need to address cultural and linguistic barriers faced by the increasing numbers of individuals with autism from immigrant communities. Older youth with autism ages 14-22 frequently do not receive the assessments and services needed to successfully transition to further education, employment, and independent living when they exit special education. Many youth with autism require instruction in the community to learn independent travel, communication, employment and daily living skills necessary to succeed.

Public higher education institutions also reported an increase in enrollment of students with autism between academic years 2004-2005 and 2009-2010.[32] Students with autism pursuing higher education require a different level of services than students with other disabilities.[33] For example, supports focused on improving and expanding means of social communication are not traditionally provided as a part of disability services in higher education, yet these services would benefit many students with autism. Faculty at institutions of higher education may lack information about and experience in teaching individuals with autism. Students transitioning to higher education campuses are often ill-prepared for self-advocacy in this environment and do not know how to access disability services. Meanwhile, limited available state and federal funding for public higher education campuses makes expanding resources for students with autism difficult.

[31] Data is from the Department of Elementary and Secondary Education.
[32] Autism Commission Report-State Agency Section Department of Higher Education, Data was collected via online questionnaires in spring 2011; questionnaires were completed by each responding institution's disability services director or similar position. This information should be considered anecdotal.
[33] Autism Commission Report-State Agency Section Department of Higher Education

The Commission has developed a comprehensive set of education recommendations, in recognition of the fact that the education system has a broad and inclusive mandate, as the only public entity that serves all individuals with autism, ages 3-22. It is critical to build the capacity of the Commonwealth's school systems, increasing funding, infrastructure, and expertise needed to meet the complex needs of students with autism.

> *"The classroom aide he had in first and second grade was critical to his development of appropriate classroom behaviors. He was pulled out for speech, but this really was an opportunity for social skills development. I also believe he was fortunate to have some truly exceptional teachers, who were able to look beyond his disability and see the endearing aspects of his personality."*
>
> ***Parent of a 17 year old with Autism, suburb of Boston***

Recommendations

Entities Responsible: DESE; DHE; State Legislature

A) DESE shall hire autism specialists who will help ensure the state's policies and practices meet the needs of students with autism. Autism specialists will also be available to provide technical assistance to local education agencies to aid in the development of appropriate programs for students with autism which educate students in a manner consistent with their potential and in the least restrictive environment. *Medium-term*

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. *Medium-term*

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. *Medium-term*

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. *Medium-term*

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. *Short-term*

F) DESE will take steps necessary to ensure that school districts provide the range of special education transition services necessary to promote employment, higher education, and independent living success for youth with autism by utilizing necessary community-based education and integrated paid employment experiences (including supportive employment) that specifically address social, communication, behavioral, academic, functional, independent living, and self-determination skills. To accomplish this, DESE will:

   (i) require that the new transition specialist endorsement competencies include experience working with youth and adults with autism. *Short-term*

   (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 DESE shall conduct professional development necessary to establish a pool of transition evaluators with autism-specific expertise. *Short-term*

   (iii) develop an IEP model form for transition age youth that addresses the unique and complex needs of youth with autism. *Short-term*

(iv) support development of model transition practices which successfully promote employment, further education, and independent living *Short-term*

(v) improve state monitoring of transition requirements of special education law pursuant to recommendation G below. *Short-term*

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. It will also create a data tracking system which will enable it to compile statistics on:

(i) the number of individual complaints filed by families of children with autism;

(ii) the number of BSEA hearing requests involving students with autism, identifying the town and age of the student;

(iii) BSEA decisions pertaining to students with autism;

(iv) findings from Coordinated Program Reviews that are relevant to students with autism.

DESE and the Division of Administrative Law Appeals shall amend their memorandum of understanding to the extent necessary for BSEA to furnish DESE with the data required in (ii) and (iii) above. DESE will file a bi-annual report detailing these findings with the Autism Commission and the Joint Committee on Education. *Short-term*

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. *Long-term*

I) Increase state funding for disability services at Community Colleges. *Short-term*

J) DESE 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. *Medium-term; financial resources*

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. *Medium-term*

Priority #10 Increasing availability of augmentative and alternative communication methods, devices and services for individuals with autism

Findings

Approximately 50% of individuals with autism are nonverbal or have limited speech. Federal and state special education laws require school districts to provide assistive communication technology necessary for students who are nonverbal or who have limited speech to receive an appropriate education. In many instances, Augmentative and Alternative Communication technology remains unavailable to children with autism, either because school districts lack expertise and resources to support appropriate assistive technology or students are not referred to appropriate specialists. Many adults with autism are also unable to access the AAC evaluations and devices essential to communicate. This has an impact on educational progress, health care attainment, employment and housing options, quality of life, and may increase behavioral difficulties.

> *"For years, my life was in silence. I was unable to communicate with people. I had my first steps but not my first words. It was very hard for me to get through life as a child but when I taught myself how to read, life began for me."*
>
> ***Individual with Autism, age 26, Hyde Park, MA***

Recommendations

Entity Responsible: State Legislature, MassHealth, MRC, DDS, DESE

A) Increase funding for MRC's Assistive Technology Regional Centers, in partnership with Institutes of Higher Education where appropriate, in order to enhance their ability to provide the training and courses on assistive technology to general and special educators, speech and language pathologists, paraprofessionals, parents, and other service providers in school districts in order to increase the school's capacity to refer, assess, and provide required AAC /assistive technology appropriate to meet the needs of children with autism who are nonverbal or have limited speech. Ensure the delivery in a variety of formats to meet the greatest number of people possible: online, video, in person, group trainings, etc. as well as ongoing individual support. *Medium-term; increase funding*

B) Establish one or more additional Assistive Technology Regional Centers in other areas of the state and fund one or more mobile Assistive Technology Regional Centers. *Medium-term; increased funding*

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. *Medium-term; increased funding*

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 to facilitate interaction of students with autism that are nonverbal or have limited speech, to ensure access to the general education curriculum, and to facilitate inclusion. *Short-term*

E) Revise Massachusetts education licensure regulations to require that all teachers address use of assistive technology and augmentative and alternative communication for students who are nonverbal or who have limited speech as a requirement for recertification, incorporating this requirement in educator's required individual professional development plan. *Short-term*

Priority #11 Increasing the range of housing options for individuals with autism.

Findings

Except in those instances when individuals are prioritized for housing, adults with autism and their families are largely responsible for locating and financing their own housing. Some adults with autism can live alone, but most independent housing that is available to adults is built and maintained by the private sector making it difficult for individuals with autism to be able to afford housing. Individuals, who meet the income criteria, may apply for federally funded housing assistance programs, like the Section 8 voucher program. Unfortunately, Section 8 income limits prohibit many adults with autism who are successfully employed from receiving financial assistance for housing. This presents a dilemma for some individuals with autism who, despite being employed, may continue to struggle to afford housing.

Housing capacity in existing programs is outstripped by demand. For those who are eligible for a Section 8 voucher, many spend years on waiting lists until vouchers become available. In addition, many adults with autism who are DDS eligible may not be prioritized for this level of service and do not receive such a placement until there is a family crisis. This can result in a sudden, traumatic change in living situation, with a loss of community ties and supports. The Commission has also heard testimony, which is corroborated by the personal knowledge of many of its members, from parents of adult children with autism who continue to live at home, under the care of their parents. These parents, many of whom are elderly, have few options for future housing and support, when they will be unable to care for their children. There is also an unknown backlog of people who would apply for aid if relevant programs existed. Lastly, the shortage of emergency housing for the general population affects individuals with autism-those with autism not eligible for services that do not have the support of family or loved ones are at a high risk for becoming homeless.

> *"S.G.'s father, who was considerably older than his wife, felt that an out of home placement was more and more essential. S.G.'s mother was increasingly afraid to be alone with her son, and they themselves were becoming symptomatic. They wanted to seek supervised therapeutic housing for their son, and wanted help in setting up a professional team that could support S.G and customize his needs. They found they could not afford to pay for private subsidized programming, even if S.G. were stable enough to enroll."*
>
> ***Professional, Metro Boston area***

Recommendations

Entity 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. *Short-term; Legislature*

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. *Short-term*

C) The DHCD will develop a formal, statewide housing policy to establish priorities for individuals with autism. *Short-term*

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. *Short-term*

Priority #12 Improve the Delivery of Healthcare Services for Individuals with Autism.

Findings

Individuals with autism are prone to a number of health complications including but not limited to musculoskeletal problems, gastro-intestinal issues, increased incidence of allergies/sensitivity to certain foods and increased chances of epilepsy.[34] Depending on the range of health complications an individual may need to see several doctors in order to receive adequate treatment for his or her medical issues.[35]

There are many factors that impede this population's access to appropriate health care and even when individuals with autism have insurance coverage for medical procedures, they can sometimes still struggle to receive adequate health care. Barriers to health care are created by the lack of medical providers knowledgeable about autism and/or lack of specialists available to diagnose and treat individuals with autism. This is particularly the case for young children since there is a dearth of diagnosticians which consequently delays formal diagnosis and access to treatment and services during critical developmental stages. Throughout their lifespan, miscommunication with the medical professionals can occur. This is especially problematic for individuals with autism who are unable to effectively communicate with medical professionals and also individuals who do not speak English.

There are both State and private sector programs in the Commonwealth that are working to increase access to medical services and the number of providers who are knowledgeable about autism and other developmental disabilities. Some examples of these programs are Operation House Call, which is a program offered through the Arc of Massachusetts that focuses on increasing medical students' knowledge about people with developmental disabilities and the Massachusetts Child Psychiatry Access Project, which is designed to assist primary care providers (PCPs) to meet the needs of children with psychiatric problems. This project provides an opportunity to better inform primary care providers about children with autism who have co-occurring psychiatric problems.

Recommendations

Entity Responsible: MassHealth, State Legislature

A) Provide funding to state schools in order to establish the Operation House Call program as part of the curriculum for medical, nursing, dentistry, physical therapy, occupational therapy, speech therapy, and other specialty degree programs. *Medium-term*

B) Expand funding for the Massachusetts Child Psychiatry Access Project to augment autism expertise within the program. *Medium-term*

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. *Short-term; increased funding*

[34] http://www.autismhelp.info/health/health-issues-specific-to-autism/categories, id, 466,1-1.aspx
[35] Please see section 4 for information and recommendations on access to health insurance coverage for individuals with autism.

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 with autism upon graduation. *Medium-term; increased funding*

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. *Short-term*

E) 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. This "team" would be knowledgeable about autism and communication difficulties many people with autism have and could advise MDs and staff how to communicate with the patient. *Short-term*

Priority #13 Assure that the Autism Commission's recommendations are implemented and outcomes are monitored for effectiveness.

"We have so much to offer society, IF WE CAN ONLY GET A CHANCE."

Individual with Autism, age 73, Worcester, MA

Findings

The members of the Autism Commission committed themselves to developing comprehensive recommendations designed to improve the lives of individuals with autism living in the Commonwealth. In order to ensure the recommendations fulfill this commitment, members agreed that the work of the Commission would not end with the filing of the final report. Rather, it was decided the Commission would continue to meet to both oversee the implementation of the Commission's final recommendations and discuss any other issues that are facing the autism community in Massachusetts.

Recommendation

A) The Autism Commission will continue to meet and be responsible for overseeing the implementation of the Commission's recommendations and analyzing issues facing the autism community not discussed in the report. *Short-term; Legislation*

VI IMPLEMENTATION CHART[36]

[36] Some of the recommendations were abbreviated to fit the chart format.

Priority	Recommendations	Entity(ies) Responsible	Required for Implementation	Legislation Filed	State Budget Line Item	Timeline
#1	A) DDS will no longer use an IQ-based eligibility requirement for adult services.	DDS; State Legislature	Change DDS statute and Regulations; Increase DDS resources	HD 2945 Rep. Bradley SD 777 Sen. Flanagan	5911-1003 (DDS Service Coordination, Admin.)	Short-term 1/1/13 to 12/31/14
	B) On a quarterly basis, DDS will report to the Autism Commission the number of individuals with autism applying for services who are found to be ineligible.					Short-term 1/1/13 to 12/31/14
#2	A) Primary diagnosis of autism will not be used as grounds to find an adult ineligible for DMH services.	State Legislature	Change DMH statute and Regulations; Increase DMH resources	HD 1658 Rep. Khan SD 781 Sen. Flanagan	5042-5000 (DMH child and adolescent services); 5046-0000 (DMH Adult Services)	Short-term 1/1/13 to 12/31/14
	B) On a quarterly basis, DMH will report to the Autism Commission the number of individuals with autism applying for services who are found to be ineligible.	DMH				Short-term 1/1/13 to 12/31/14
	C) DMH will increase its level of clinical expertise on the treatment needs of individuals with co-occurring mental illness and autism.	DMH; DDS				Short-term 1/1/13 to 12/31/14
	D) DMH will develop more services that are aimed at meeting the needs of individuals with autism and co-occurring mental illnesses.	EOHHS				Medium-term 1/1/15 to 12/31/16
	E) EOHHS will establish and manage an integrated confidential data system among state agencies and stakeholders.	EOHHS;State Legislature	Funding to initiate data collection; legislation	HD 2874 Rep. Bradley		Short-term 1/1/13 to 12/31/14

Priority	Recommendations	Entity(ies) Responsible	Required for Implementation	Legislation Filed	State Budget Line Item	Timeline
#3 Children's Autism Waiver	A) Increase the appropriation for the Children's Autism Waiver Program.	State Legislature	Funding Increased		5920-3010 (DDS Autism)	Short-term 1/1/13 to 12/31/14
	B) Amend the Waiver and initially expand the number of children (ages birth through age 8) served from 157 to 500…	State Legislature	Funding Increased		5920-3010 (DDS Autism)	Short-term 1/1/13 to 12/31/14
	C) Designate at least two enrollment periods per year to allow parents to plan accordingly.	DDS				Short-term 1/1/13 to 12/31/14
	D) When the Autism Waiver is renewed in two years, DDS will expand the Waiver to create Waiver Services for children ages 9-22. For this older cohort, the Commission recommends that the waiver offer a broad array of flexible in-home and out-of-home services...	DDS; State Legislature	Funding Increased	HD 2883 Rep. Bradley	5920-3010 (DDS Autism)	Medium-term 1/1/15 to 12/31/16
#3 Adult Waiver	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.	State Legislature	Funding Increased			Short-term 1/1/13 to 12/31/14
	B) Provide intensive case management by adding a group of trained workers with extensive autism experience to assist with development of individual support plan.	DDS	Funding Increased		5920-2000 (DDS Community Residential)	Long-term 1/1/17 to 12/31/18

Priority	Recommendations	Entity(ies) Responsible	Required for Implementation	Legislation Filed	State Budget Line Item	Timeline
#3 Adult Waiver *(cont.)*	C) Increase the availability and expertise of Behavior Support Consultation for DDS eligible adults.	DDS	Funding Increased		5920-2000 (DDS Community Residential)	Medium-term 1/1/15 to 12/31/16
	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.	DDS	Funding Increased; Organizational Changes; Research and Development			Long-term 1/1/17 to 12/31/18
	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.	DDS				Short-term 1/1/13 to 12/31/14
#3 DESE/DDS Program	A) Since there is currently no wait list, DDS will initiate a new application process and expand the number of slots available for students requiring these services.	DDS				Short-term 1/1/13 to 12/31/14
	B) Increase funding for the DDS/DESE program in order to serve more individuals in this program.	State Legislature	Increased Funding			Short-term 1/1/13 to 12/31/14

Priority	Recommendations	Entity(ies) Responsible	Required for Implementation	Legislation Filed	State Budget Line Item	Timeline
#4	**Private Insurance** A) EOHHS will reach out to large self-funded employers to educate them about the insurance law.	EOHHS				Short-term 1/1/13 to 12/31/14
	Private Insurance B) 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.	EOHHS; DOI				Short-term 1/1/13 to 12/31/14
	Mass Health C) Require Mass Health to take action necessary to cover medically necessary treatments for individuals with autism.	Mass Health; State Legislature	Legislation	HD 1780 Rep. Gregoire HD 2871 Rep. Bradley		Medium-term 1/1/15 to 12/31/16
	Mass Health D) Require Mass Health to revise regulations to cover both dedicated and non-dedicated (e.g., tablets), for people who require Augmentative and Alternative Communication.	Mass Health	Update Regulations			Short-term 1/1/13 to 12/31/14
	Early Intervention E) 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.	DPH				Short-term 1/1/13 to 12/31/14

Priority	Recommendations	Entity(ies) Responsible	Required for Implementation	Legislation Filed	State Budget Line Item	Timeline
#5	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.	EOHHS; DDS	DDS Organizational Change; Increased funding		5920-3010 (DDS Autism)	Medium-term 1/1/15 to 12/31/16
	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.	DDS	Increased funding		5920-3010 (DDS Autism)	Medium-term 1/1/15 to 12/31/16
	C) The Division of Autism with support from EOHHS will create a website and telephone number mirroring 1-800-AGE-INFO.	Division of Autism (DDS); EOHHS	Increased funding			Medium-term 1/1/15 to 12/31/16
	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.	EOHHS				Short-term 1/1/13 to 12/31/14
	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	EOHHS; DDS	Regulations changes; Organizational Changes; Funding increased		5911-1003 (DDS Service Coordination, Admin.)	Long-term 1/1/17 to 12/31/18
	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.	DDS				Short-term 1/1/13 to 12/31/14

Priority	Recommendations	Entity(ies) Responsible	Required for Implementation	Legislation Filed	State Budget Line Item	Timeline
#5 *(cont.)*	G) Increase DDS's funding for family support programs.	State Legislature	Increased funding		5920-3000 (DDS Family Services)	Short-term 1/1/13 to 12/31/14
	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.	DDS				Medium-term 1/1/15 to12/31/16
	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.	Autism Division				Medium-term 1/1/15 to 12/31/16 Update Regulations
	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.	MassHealth	Update Regulations			Short-term 1/1/13 to 12/31/14
	K) DDS will examine current staffing credentials, staffing levels at group homes, and supportive living arrangements for adults with autism...	DDS				Short-term 1/1/13 to 12/31/14
	L) Autism Division will establish and maintain a database of institutions offering courses, certifications and degree programs in autism and autism related fields…	Autism Division				Medium-term 1/1/15 to 12/31/16

Priority	Recommendations	Entity(ies) Responsible	Required for Implementation	Legislation Filed	State Budget Line Item	Timeline
#6	A) EOHHS will make recommend-ations to the Autism Commission for overcoming data collection issues in Massachusetts.					Short-term 1/1/13 to 12/31/14
	B) EOHHS will establish and manage an integrated confidential data system among state agencies and stakeholders.	EOHHS;State Legislature	Funding to initiate data collection; legislation	HD 2874 Rep. Bradley		Short-term 1/1/13 to 12/31/14
#7	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.	DPH	Increased Funding		4513-1020 (DPH Early Intervention)	Medium-term 1/1/15 to 12/31/16
	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.	DPH	Awareness Campaign			Medium-term 1/1/15 to 12/31/16
	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.	DPH; DDS				Short-term 1/1/13 to 12/31/14
	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 language other than English.	DPH				Short-term 1/1/13 to 12/31/14

Priority	Recommendations	Entity(ies) Responsible	Required for Implementation	Legislation Filed	State Budget Line Item	Timeline
#7 *(cont.)*	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.	DPH				Medium-term 1/1/15 to 12/31/16
#8	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.	MRC				Short-term 1/1/13 to 12/31/14
	B) MRC shall analyze and report data to the Autism Commission concerning the approximately 20,000 individuals who receive MRC services each year including number of individuals with autism served.	MRC				Short-term 1/1/13 to 12/31/14
	C) MRC shall expand upon existing staff training initiatives on autism to ensure that all staff are competent in addressing the needs of this population.					Short-term 1/1/13 to 12/31/14

Priority	Recommendations	Entity(ies) Responsible	Required for Implementation	Legislation Filed	State Budget Line Item	Timeline
#8 *(cont.)*	D) MRC shall seek funding to increase the number of job coaches employed by MRC and continue to increase collaboration with other disability agencies.	State Legislature; MRC	Increased funding			Medium-term 1/1/15 to 12/31/16
	E) Increase funding for MRC's Supported Employment Supports program.	State Legislature; MRC	Increased funding			Medium-term 1/1/15 to 12/31/16
	F) MRC shall also reach out to private non-profits, such as Asperger's Association of New England, to help fund coaching programs.	MRC	Increased funding			Medium-term 1/1/15 to 12/31/16
	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.	MRC	Increased funding			Medium-term 1/1/15 to 12/31/16
#9	A) DESE shall hire autism specialists who will help ensure the state's policies and practices meet the needs of students with autism.	DESE	Funding			Medium-term 1/1/15 to 12/31/16
	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.	State Legislature	Funding and legislation	Rep. Bradley HD 2863		Medium-term 1/1/15 to 12/31/16

Priority	Recommendations	Entity(ies) Responsible	Required for Implementation	Legislation Filed	State Budget Line Item	Timeline
#9 *(cont.)*	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.	DESE	Funding			Medium-term 1/1/15 to 12/31/16
	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.	DESE	Funding			Medium-term 1/1/15 to 12/31/16
	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.	DESE		Rep. Bradley HD 2870		Short-term 1/1/13 to 12/31/14
	F(i) require that the new transition specialist endorsement competencies include experience working with youth and adults with autism.	DESE				Short-term 1/1/13 to 12/31/14

Priority	Recommendations	Entity(ies) Responsible	Required for Implementation	Legislation Filed	State Budget Line Item	Timeline
#9 *(cont.)*	F(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.	DESE				Short-term 1/1/13 to 12/31/14
	F(iii) develop an IEP model form for transition age youth that addresses the unique and complex needs of youth with autism.	DESE				Short-term 1/1/13 to 12/31/14
	F(iv) support development of model transition practices which successfully promote employment, further education, and independent living.	DESE				Short-term 1/1/13 to 12/31/14
	F(v) improve state monitoring of transition requirements of special education law pursuant to recommendation G below.	DESE				Short-term 1/1/13 to 12/31/14
	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.	DESE				Short-term 1/1/13 to 12/31/14

Priority	Recommendations	Entity(ies) Responsible	Required for Implementation	Legislation Filed	State Budget Line Item	Timeline
#9 *(cont.)*	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.	State Legislature; DESE	Amend Special Education Law			Long-term 1/1/17 to 12/31/18
	I) Increase state funding for disability services at Community Colleges.	State Legislature	Increase funding			Short-term 1/1/13 to 12/31/14
	J) DESE 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.	DESE; DHE	Increase funding			Medium-term 1/1/15 to 12/31/16
	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.					Medium-term 1/1/15 to 12/31/16

Priority	Recommendations	Entity(ies) Responsible	Required for Implementation	Legislation Filed	State Budget Line Item	Timeline
#10	A) Increase funding for MRC's AT Regional Centers, in partnership with Institutes of Higher Education where appropriate.	State Legislature	Increased funding			Medium-term 1/1/15 to 12/31/16
	B) Establish one or more additional AT Regional Centers in other areas of the state and fund one or more mobile AT Regional Centers.	State Legislature	Increased funding			Medium-term 1/1/15 to 12/31/16
	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.	State Legislature	Increased funding			Medium-term 1/1/15 to 12/31/16
	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.		Revise Education Regulations	Rep. Bradley HD2869		Short-term 1/1/13 to 12/31/14
	E) Revise Massachusetts education licensure regulations to require that all teachers address use of assistive technology and augmentative and alternative communication.	State Legislature	Revise Education Regulations	Rep. Bradley HD2869		Short-term 1/1/13 to 12/31/14

Priority	Recommendations	Entity(ies) Responsible	Required for Implementation	Legislation Filed	State Budget Line Item	Timeline
#11	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.	State Legislature	Amend Existing Law	Rep. Lewis HD 2673		Short-term 1/1/13 to 12/31/14
	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.	State Legislature	Increase funding			Short-term 1/1/13 to 12/31/14
	C) The DHCD will develop a formal, statewide housing policy to establish priorities for individuals with autism.	DHCD				Short-term 1/1/13 to 12/31/14
	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.	DHCD; Interagency Council on Housing and Homelessness				Short-term 1/1/13 to 12/31/14

Priority	Recommendations	Entity(ies) Responsible	Required for Implementation	Legislation Filed	State Budget Line Item	Timeline
#12	A) Provide state funding to the University of Massachusetts Medical School in order to establish the Operation House Call program as part of the curriculum.	State Legislature	Increase funding			Medium-term 1/1/15 to 12/31/16
	B) Expand funding for the Massachusetts Child Psychiatry Access Project to augment autism expertise within the program.	State Legislature; DMH	Increase funding			Medium-term 1/1/15 to 12/31/16
	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.		Increase funding			Short-term 1/1/13 to 12/31/14
	D) In order to increase the number of medical providers who are knowledgeable in autism.	State Legislature	Legislation	Rep. Bradley HD 2872		Medium-term 1/1/15 to 12/31/16
	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.	State Legislature; draft legislation	Legislation	Rep. Bradley HD 2884		Short-term 1/1/13 to 12/31/14
	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.	State Legislature; draft legislation	Legislation	Rep. Bradley HD 2884		Short-term 1/1/13 to 12/31/14
#13	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.	State Legislature	Legislation	Rep. Bradley HD 2879		Short-term 1/1/13 to 12/31/14

VII APPENDICES

The entire report including the state agency and subcommittee reports is available online at **www.mass.gov/hhs/autismcommission.**

Appendix A: Legislative Resolve

RESOLVE PROVIDING FOR AN INVESTIGATION AND STUDY BY A SPECIAL COMMISSION RELATIVE TO AUTISM

Resolved, that a special Commission is hereby established to make an investigation and study relative to individuals with autistic spectrum disorders, which shall include, but not be limited to, Asperger's syndrome, High Functioning Autism and Pervasive Development Disorder. The Commission shall investigate and study the range of services and supports necessary for individuals to achieve their full potential across their lifespan, including, but not limited to, investigating issues related to public 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. The Commission shall address mechanisms to ensure maximization of federal reimbursement and coordination of state human service agencies. The special commission shall consist of 2 members of the Senate, 1 of whom shall be appointed by the minority leader; 2 members of the house of representatives, 1 of whom shall be appointed by the minority leader; the secretary of health and human services or a designee; the commissioner of developmental services or a designee; the commissioner of mental health or a designee; the secretary of education or a designee; the commissioner of education or a designee; the director of housing and community development or a designee; the secretary of labor and workforce development or a designee; the commissioner of the Massachusetts rehabilitation commission or a designee; the commissioner of early education and care or a designee; the commissioner of elementary and secondary education or a designee; the commissioner of higher education or a designee; the secretary of elder affairs or a designee; the commissioner of children and families or a designee; the commissioner of public health or a designee; 1 person appointed by the secretary of education; and 14 persons to be appointed by the governor, 10 of shall be representatives of statewide autism group, 2 of whom shall be representatives of Advocates for Autism of Massachusetts. The Commission shall report to the General Court the results of its investigation and study and its recommendations, if any, by filing the same with the Clerk of the Senate and the Clerk of the House of Representatives not later than January 2013.

Appendix B: Overview of Commission Process

The Autism Commission was signed into law in April 2010 (see section A of the appendix) and was charged to make an investigation and study of the lifespan needs of individuals with autistic spectrum disorders, including, but not limited to, Asperger's syndrome, High Functioning Autism and Pervasive Development Disorder. Members of the Commission were appointed based on their personal and professional expertise in various forms of autistic spectrum disorders. A description of the appointed members of the Commission and their affiliations can be reviewed in section C of the appendix.

The Autism Commission held its first meeting on October 25th, 2010 and met 24 times through January 2013. Every meeting was open to the public to attend. The public attending meetings were encouraged to participate in the Commission discussions. Specifically, four of the Commission meetings designated time on the agenda for the public to voice their thoughts and concerns about autism services in Massachusetts. To further include the voice of the public in the Commission's final report; in the spring of 2012 the Commission requested that members, professionals, and allies of the autism community submit stories about their experiences related to autism. The chosen vignettes were included in section V. of the report.

At the Commission meetings, members were educated on the state and private services available to children and adults diagnosed with autism in Massachusetts. Representatives from MassHealth, the Executive Office of Health and Human Services, the Department of Public Health, the Division of Early Education and Care, the Department of Elementary and Secondary Education, the Department of Children and Families, the Department of Developmental Services, the Children's Behavioral Health Initiative, the Department of Mental Health, the Massachusetts Rehabilitation Commission, and the Office of Long-term Care made presentations to the Commission on state services available to some individuals diagnosed with autism in Massachusetts. Citizen members presented on topics including but not exclusive to behavioral health and mental health issues in the autism community and access to health insurance coverage for autism treatments. Upon completion of each presentation, Commission members discussed the services detailed and what gaps continued to exist within the system of supports. All of these presentations can be viewed at http://www.mass.gov/hhs/autismcommission.

In addition to the work of the Commission, four sub-committees were created to analyze the needs of individuals with autism in certain age groups. The sub-committees met between January 2011 and August 2011. Each sub-committee drafted a report and made a presentation to the full Commission on their sub-committee's findings. The Commission used the information the sub-committees reported to help narrow its own priorities and recommendations. More information about the work of the sub-committees including each sub-committee's findings can be reviewed in section E. of the appendix.

Based on Commission's discussions at meetings between October 2010 and June 2011, a document containing key issues, recommendations and action steps was compiled and shared with the entire Commission. Using the content in this document, a survey was created and disseminated in July 2011. Commission members were asked to complete the survey and the results were used to

prioritize issues and recommendations. The entire Commission met in August 2011 for a working session to finalize the Commission's priorities for the final report. In October 2011, the Chair of the Commission created a writing group consisting of 6 Commission members and 2 staff to the Commission. The writing group met between October 2011 and November 2012 and drafted problem statements, recommendations and action steps based on the set priorities of the Commission. Throughout this time period, Commission members were updated on the progress of the report and gave feedback on the document. The final copy of the challenges, recommendations and action steps that the majority of the Commission endorsed[37] can be reviewed in section V. of this report.

[37] The State Agency representatives recused themselves from any of the final decisions on the findings and recommendations that are included in this report since most of the recommendations are for action steps to be taken by the Administration. Upon the filing of the Report, the state agencies will share the recommendations with others in the Administration and determine what action steps are possible.

Appendix C: Reports from State Agencies on the Delivery of Services and Supports for Individuals with Autism Spectrum Disorder

The following reports from the state agencies provide an overview of specific services that are currently being provided to children and adults with Autism Spectrum Disorder in the Commonwealth including the steps already being taken to support the recommendations of the Commission. As part of this report, state agencies have been asked to identify gaps in the current system and to put forth recommendations for system improvement as applicable.

Executive Office of Health & Human Services

1. Department of Public Health - Early Intervention Program
2. Department of Developmental Services
3. Massachusetts Rehabilitation Commission
4. Executive Office of Elder Affairs - MassHealth Office of Long Term Services and Supports
5. Department of Mental Health

Executive Office of Education

1. Department of Early Education and Care
2. Department of Elementary & Secondary Education
3. Department of Higher Education

Executive Office of Housing & Economic Development

1. Department of Housing and Community Development

EXECUTIVE OFFICE OF HEALTH & HUMAN SERVICES

EARLY INTERVENTION PROGRAM

MASSACHUSETTS DEPARTMENT OF PUBLIC HEALTH

Brief Description of Early Intervention Program & Mission

The Department of Public Health protects, preserves, and improves the health of all the Commonwealth's residents. The Early Intervention Program (EI) of the Division of Perinatal, Early Childhood, and Special Health Needs of the Bureau of Family Health and Nutrition provides family-centered services to help infants and toddlers with developmental concerns to develop the skills they will need to continue to grow into happy and healthy members of the community. Children with an Autism Spectrum Disorder are eligible for early intervention services and for additional specialty services that address the core symptoms of autism.

ASD Incidence and Related Data

- In FY'11, there were 1,381 children in the Early Intervention system with diagnoses on the autism spectrum enrolled in Specialty Service Programs for children with Autism Spectrum Disorders (ASD).
- 1/108 children in the birth to three age cohort are identified with an ASD in Massachusetts
- The average age of diagnosis of ASD for children enrolled in the Early Intervention system is 25.6 months.
- Racial/ethnic differences in the early diagnosis of ASD in the under three population have lessened in the last decade, but the incidence of ASD is still significantly lower among minority populations than the incidence reported for the non-Hispanic white population. Following is a comparison of the 2001 and 2005 birth cohorts for specific populations.

Birth Cohort	Non-Hispanic White	Non-Hispanic Black	Non-Hispanic Other, including Asian/Pacific Islanders	Hispanic Children of any race
2001	63/10,000	40/10,000	39/10,000	33/10,000
2005	95/10,000	87/10,000	80/10,000	96/10,000

Services and Programs Serving Children with ASD

- Children with an autism spectrum disorder diagnosis are automatically eligible for the Early Intervention Program.
- Any child enrolled in early intervention with a diagnosis on the autism spectrum confirmed by a physician or licensed psychologist is eligible for Specialty Service Programs for children with ASD. These intensive, individualized treatment programs promote social skills and communication and manage behavior that interferes with learning. As active participants in these programs, parents learn strategies that can help their children progress.
- Specialty Service Programs for children with ASD work in conjunction with community Early Intervention Programs to deliver comprehensive, coordinated service to children on the spectrum and their families.

Case Management and Training

- Each child enrolled in the Early Intervention Program is assigned a Service Coordinator who is responsible for assisting and enabling the child and the child's family to receive the rights, procedural safeguards, and services that are authorized to be provided under the state's Early Intervention system.
- All newly hired professionals working in the Early Intervention System are required to attend core trainings provided by the Department of Public Health. An overview of the signs and symptoms of diagnoses requiring specialty services (including ASD) and resources with more detailed information on screening for ASD are included in the core curriculum.
- The Early Intervention Training Center provides ongoing workshops and training that promote EI staff's ability to recognize early signs of ASD. The MA Act Early State team (an affiliate of the CDC "Learn the Signs, Act Early" program to promote early, periodic developmental screening of all children) includes active participants from the EI system. Recent initiatives include the "Considering Culture in Autism Screening" toolkit developed for primary care practices and a pilot project pairing pediatric practices, Early Intervention Programs, and autism diagnosticians in an effort to reduce the wait time between a positive screen for ASD and a diagnostic appointment.

Funding Specialty Services for Children with ASD

- Average annual cost of Specialty Services for ASD is $9,050/child (there is a significant range that contributes to this average cost since it is dependent on numerous factors, including intensity of service plan, age of child, length of enrollment in EI)
- Currently (through the close of FY12) 100% of the costs for Specialty Services are supported by DPH through federal and state allocations; the FY12 cost to DPH for these services is estimated to be $12,489,000. In contrast, regular EI services are supported by a variety of payers: MassHealth pays 46%, private insurers pay 33% and DPH, as the payer of last resort, pays 20%.
- Effective July 1, 2012, an 1115 Demonstration Waiver from the federal Centers for Medicare and Medicaid will authorize MassHealth coverage of ABA-based services for children with the ASD diagnosis who receive services in the Early Intervention system. This will mean that DPH's total direct cost for specialty services will be reduced.

Gaps and Challenges

- There is a limited pool of trained providers. This challenge has increased dramatically since the passage of the Commonwealth's ARICA (*An Act Relative to Insurance Coverage for Autism Spectrum Disorder)* legislation.
- There is limited evidenced based validation of the types and intensity of intervention that are appropriate for the very young toddler. Research investigating parent mediated programs and the impact of variations in service intensity are underway, but far from complete.
- Transition to community school services at age three is challenging for many families as the types of programming offered by the school may not replicate the intensity or type of service that has been successful for the child in EI.

Future Goals and Initiatives

The following initiatives would support the advancement of the Early Intervention service system and specifically enhance the services for children with ASD.

- Increase the capacity of an appropriately trained pool of providers in the Commonwealth in order to meet the service demand.
- Ensure that all children in the Commonwealth have access to early developmental screening that reflects the American Academy of Pediatrics recommendation to screen twice for ASD by the child's second birthday.
- Continue to address disparities in early diagnosis through increased outreach to non-English speaking and other underserved populations.
- Reduce wait time from positive screen for ASD to evaluation appointment with a trained diagnostician in order to maximize the opportunity for early treatment and the potential for positive outcomes for the child.

DEPARTMENT OF DEVELOPMENTAL SERVICES – AUTISM DIVISION

Brief Description of the Department of Developmental Services (DDS)

Massachusetts has a comprehensive system of specialized services and supports to give individuals with intellectual disabilities the opportunities to live the way they choose. DDS is the state agency that manages and oversees this service system. DDS is organized through a structure that includes a central office, four regional offices and twenty-three area offices. Every day, DDS provides these specialized services and supports to approximately 34,000 adults with intellectual disabilities and children with developmental disabilities. The types of specialized services and supports include day supports, employment supports, residential supports, family supports, respite, and transportation. DDS provides these services through facilities and community-based state operated programs and by contracting with 235 private provider agencies.

Most individuals and families have contact with DDS through their local area office. These 23 offices are located throughout Massachusetts. Area offices are responsible for managing and monitoring the services provided or for arranging services for individuals served and their families who live in the towns covered by the respective area office. Functions performed at an area office include information and referral, service coordination/case management, service planning, prioritization and arrangements, complaint resolution, and citizen and family involvement. Each area office reports to one of four regional offices. The regional offices are geographically located around the state: Central West Region, Northeast Region, Southeast Region, and Metro Region. The regional office provides management of the area offices and performs the following regional functions including intake and eligibility determinations, survey and certification of service providers, business, legal and administration, abuse and mistreatment investigations and informal conferences to resolve disputes about the identification, prioritization, or provision of services. The regional office administrators work directly with DDS's central office which oversees all functions and operations throughout the state and establishes statewide policies and procedures. These statewide functions and offices include the Commissioner's Office, community field operations, facilities management, finance, budget and contracts, human rights, investigations, legal, policy, planning and children's services, quality management, and volunteer and board membership. Within the Central Office, the primary staff includes the Commissioner, Deputy Commissioner, General Counsel, Assistant Commissioners, and the Statewide Directors for Investigations, Human Rights, and Citizen Leadership. The Autism Division is an entity under the Policy, Planning and Children's Services unit. This Division oversees two important core programs for this population: the Autism Support Centers and the Medicaid Home and Community Based Services Autism Waiver.

Case Management Services

Children's Case Management Services

Case management services are provided for children found eligible to receive services from the Department. Additionally, families of both children and adults are connected with one of thirty-three family support centers or to one of the ten culturally specific family support centers that help meet the needs of Hispanic, Vietnamese and Asian families. These centers offer Short-term and extended service navigation (a type of case management), for families who require a higher level of supports. Family Navigators assist with accessing supports and services that are specific to the child's needs.

For families experiencing a behavioral crisis with their family member, DDS offers an Intensive Family Flexible Support Services (IFFS) Program. These are time limited services and involve additional supports, problem solving with families and a greater level of Case Management than what is offered through the Family Support Centers. The goal is to stabilize the family/child and then gradually decrease supports, typically over a period of six months.

The Department also operates a program funded by the Department of Elementary and Secondary Education (DESE) which serves children at risk for residential services up through age 21. Family Navigation services for these participants are provided through a network of DDS qualified DESE/DDS Providers. The Navigation includes helping families create individualized support plans, budgets and on-going program maintenance throughout the year. Navigators also work closely with DDS Service Coordinators who help provide oversight, technical assistance and guidance.

Autism Case Management Services

Intensive case management supports are provided to assist families whose children are enrolled in the Autism Waiver Program, which is explained further below. Each family is assigned to work with a DDS Autism Clinical Manager who oversees the development of the individual plan of services, provides on-going support and technical assistance around the in-home behavioral supports and provides oversight and assistance to the Autism Support Brokers who are employed through the Autism Support Centers. These Brokers work directly with families to provide assistance with staffing, budgeting, paperwork and day-to-day guidance around program rules and regulations.

Adult Case Management Services

Individuals found eligible for the Department's services at age eighteen receive case management services from a DDS Adult Service Coordinator. Individuals who are 18-22 and still receiving supports through their local educational system are assigned to work with a Transition Service Coordinator. These Transition Coordinators are the primary link to information and assistance from DDS during the transition from special education to adult life. They help individuals and the families understand what DDS can offer and assist with identifying and securing requested supports. The Transition Service Coordinator will also chair the Individual Transition Plan (ITP) meeting. From this meeting, they will develop a document that specifies what kinds of support the student/family is requesting upon leaving special education. Soon after graduation or when an individual leaves school and transitions into adult supports, an individual's case will be transferred to an adult service coordinator within the area office.

The Adult Service Coordinator arranges, coordinates, and monitors the services and supports that the Department provides, purchases or arranges for an individual. The Service Coordinator will chair and develop an Individual Support Plan (ISP) which helps the DDS team work with the individual to plan his or her life. The ISP addresses areas of life which are important to the individual. The Service Coordinator is also responsible for completing a semi-annual report that discusses: the individual's satisfaction with the ISP; the effectiveness of the supports and the quality of the interventions being provided; any need for modification; and any issues that have arisen during the six month period. Portions of the services provided by the Service Coordinators are reimbursed through the Medicaid State Plan through CMS.

Training

Adult/Children's Service Coordinators

Case Management training for both Adult and Children's Service Coordinators is provided consistently through the Service Coordinator Institute. The initial six day training covers DDS structure and organization, Eligibility, Prioritization, Transition, Regulations and Policies, Services and Waivers, Benefits, Family Supports, Service Planning, Risk Management, and Complaint Investigations. The Service Coordinator Institute also offers an array of professional development trainings; the selection of the offerings is based on surveying the needs of the SC staff and changes to meet the organizational needs of the Department and the populations it serves. The Department also routinely distributes information of interest to its field staff that will inform practice. Most recently, the Department has distributed information about Autism Insurance coverage and services available through the Children's Behavioral Health Initiative.

For Children Served By Autism Waiver or Autism Support Centers

All staff members working within the Autism Waiver Program have extensive experience working with children with autism; it is a hiring requirement for both Autism Clinical Managers and Autism Support Brokers. The Autism Division provides on-going training and both technical assistance and clinical training as it relates to the operation of the Autism Waiver Program. The Autism Division also helps to fund a network of Autism Support Centers across the Commonwealth. These Centers house the Autism Support Brokers and have other staff with demonstrated expertise in autism. The Centers collaborate with DDS area offices, community organizations, medical professionals and schools to provide training on autism.

Eligibility for DDS

Current Department of Developmental Services Eligibility Criteria

The Department of Developmental Services' current regulations pertaining to eligibility consists of two distinct components: children and adults. All but the Autism 'Spectrum' Division can be found in the Department's regulations. The Autism definitions and processes are sub-regulatory.

Children's eligibility is further divided into three distinct components:

- Global Developmental Delay: birth through 4th birthday
- Developmental Disability: 5-17th birthday
- Autism Spectrum Disorder: birth through 17th birthday

Definition of Children's Eligibility for DDS

To meet the eligibility criteria as a child for DDS, the child must have a verified diagnosis of intellectual disability or a "closely related developmental condition". Children from birth to age 5, must have a developmental delay which means a substantial developmental delay or specific congenital or acquired condition with a high probability of resulting in a developmental disability if services are not provided.

A *Closely Related Developmental Condition* means genetic, neuro-developmental or physical disorders that have a significant overlap with intellectual disability, and result in similar support needs. For the purposes of 115 CMR 6.06(1), closely related developmental conditions may include:

(a) Williams Syndrome
(b) Prader-Willi Syndrome
(c) Lesch-Nyhan Syndrome
(d) Angelman Syndrome
(e) Cri du Chat Syndrome
(f) Down Syndrome
(g) Fragile X Syndrome
(h) Cerebral Palsy
(i) Pervasive Developmental Disorders including the following specified autism spectrum disorders: Autistic Disorder, Rett's Syndrome, Childhood Disintegrative Disorder and Pervasive Developmental Disorder-Not Otherwise Specified (NOS)
(j) Spina Bifida (Myelomeningocele type MMC)
(k) Tuberous Sclerosis
(l) Fetal Alcohol Syndrome or
(m) Any other developmental disorder that the Department determines to be a closely related developmental condition.

Child eligibility for the Autism Spectrum Division is limited to children with a verified diagnosis of Pervasive Developmental Disorders including Autistic Disorder, Pervasive Developmental Disorder Not Otherwise Specified, Rett's Disorder, Childhood Disintegrative Disorder, and Asperger's Disorder.

Adult Eligibility

All adults over the age of 18 must have an intellectual disability to be eligible for service. Intellectual disability means significantly sub-average intellectual functioning existing concurrently and related to significant limitations in adaptive functioning. Intellectual disability manifests before age 18. Full definition can be found in 115 CMR 2.0.

Data, Statistics and Incidence Information Related to the ASD Population

The Autism Division's Autism Support Centers provide information and referral resources to approximately 6,000 families of children with autism. These Centers also provide community based programs to a subset of around 2,000 per year that include social skills programs and family activities. In the future, the Department will develop methods to track ASD only children in our system of record. However, since ASD is considered a closely related developmental condition many children are found eligible using the developmental disability criteria.

DDS recently created a systematic process to collect information about the presence of ASD in adults at the time of eligibility determination for both those who are found eligible and those who are determined ineligible. This is a recent change and therefore historical data on adults with autism is not available. However, first quarter data from calendar year 2012 included the following:

- Of the adults found eligible in the first quarter of 2012, 32% of the individuals were individuals with both ID and an ASD diagnosis.
- In total, 76% of the individuals who applied were found eligible, conversely 24% were found ineligible.
- Of those found ineligible, 33% were individuals with ASD diagnosis.

Recent Family Support Efforts to Collect Family Feedback and Relevant Data

DDS is at an important juncture. There are more and more children and adults with intellectual and developmental disabilities (many with autism) living with their families resulting in a greater demand for family support services.

Twenty-six forums were held across the state to gain input from over 600 caregivers about what they need to support their family member at home and in their community. This input, and the information received from 747 caregivers through an online survey, form the basis of a report by DDS called *'In Their Own Words'* describing the need to make adequate family supports available to caregivers and the cost benefit of these supports to the Commonwealth.

Survey Highlights

The survey was designed to get input from those who are the primary caregivers of a child or adult with ID/DD who lives at home, and for whom they have day-to-day responsibility for providing care. Overall, respondents indicated that the person they care for is most likely to be male (69.3%), with 51.9% between the ages of 6-17 and an additional 39.2% between the ages of 18-39. Additionally 69.4% reported being eligible for services from DDS and 61% had a diagnosis of Autism or ASD. Those with a reported Autism diagnosis are more likely to be male and under age 18.

As a recent survey of families conducted for Family Support Program planning demonstrated, those services which families seek most are Respite, Recreation/Social/Life Skills Training, Personal Care Assistance, and Financial Assistance. While approximately 52% of the children represented in the sample were between the ages of 6 and 17, about 40% were between the ages of 18 and 39.

Survey Responses of Families of Children with Autism

- *"Respite funding has been invaluable in allowing our son to have a personal connection outside of his family circle with well trained, compassionate and understanding providers. This service has allowed him to enjoy peer experiences in the home and community."*
- *"Flexible Funding, Family Leadership, and Respite are the most beneficial"*
- *"Respite and skills instruction have been essential to progress our son has made and also the quality of his life."*

Overview of Programs and Services

Children's Services

DDS offers eligible children with an autism spectrum diagnosis a broad array of support and services that vary depending on whether the child meets the developmental disability criteria (DDS Children's Eligibility) or if the child does not meet this threshold and is deemed Autism Division Only Eligible.

For those children with ASD who meet the DDS Children's Eligibility, there are a variety of programs and services available through the network of 33 family support centers. These centers provide supports and services including information and referral, community based programs and services and access to individual financial assistance when funds are available. There are an additional ten family support centers that work specifically with culturally diverse families.

For families of children eligible for DDS that are experiencing severe stress, which can lead to the child being at-risk of an out-of-home placement, there is a service called the Intensive Flexible Family Supports (IFFS) Program. This service consists of an intensive case management service designed to help families integrate the variety of available resources to support their family member in crisis and flexible funding to purchase additional supports or goods. Annually, about 525-550 children between the ages of 3-18 and their families receive services through these 22 statewide programs. One IFFS program is run by a specialty service provider with demonstrated expertise in autism and therefore all the children served have an autism diagnosis. Overall, across the state IFFS providers estimate that 60% of the children receiving these resources have autism.

Perspectives on Family Supports

- *"Flexible Funding, Family Leadership, and Respite are the most beneficial for this family."*
- *"Most helpful: Respite Supports"*
- *"Most helpful support from DDS: The Support Group that I belong to."*

A subset of eligible children under the age of nine, who also have MassHealth Standard (with an annual income below 300% of the federal poverty level), may have access to the Autism Waiver Program. This is a Medicaid Home and Community Based Waiver that provides federal reimbursement to the state for the services offered through the program. This Waiver provides a robust set of in-home therapies designed to help remediate behaviors and alleviate some of social and communication deficits associated with autism. The Waiver also provides ancillary supports to families including respite services and access to community integration activities. The Program currently has the capacity to serve 205 children in a Waiver year.

Family Perspectives on the Autism Waiver Program

- *"Autism waiver most beneficial support my son has received and he made great progress…"*
- *"One Autism Clinical Manager shared that Joey's mom is thrilled that after years of unsuccessful potty training attempts on her own, Joey's in-home behavioral team created a plan that they helped mom institute and together they had him trained in just two months. Mom cannot wait for Joey to succeed at his other goals too."*

DDS also administers a residential prevention program known as the DESE/DDS Program. This program funded by DESE helps to maintain students in the family home through an integrated set of staffing and related supports. The program provides supports for DDS eligible children and young adults until the participant turns 22 as long as the individual meets the adult eligibility criteria for DDS services after the 17th birthday when the criteria for eligibility changes from a significant developmental disability to intellectual disability. The DESE/DDS Program currently serves 485 participants across the Commonwealth. In FY 12, the DESE/DDS program received an increase in its annual allocation to $6.5 million and this increase allowed 300 participants to move off the waiting list. Of these 300 participants, approximately 90% of them have a diagnosis on the autism spectrum. Overall, of the 485 participants served through the DESE/DDS Program, approximately 75% have an autism spectrum diagnosis. In response to the growing number of children with autism in the program, we have made programmatic changes to enhance growth and ensure that participants continue to develop skills and remediate difficult behaviors that often increase the likelihood of a residential placement.

Perspectives of Families in the DESE/DDS Program

- *"DMR/DOE saved our family and our son. Absolutely amazing."*
- *"The DESE program (is most helpful). I recently started the self-funding option and have seen progress as a result. This program has definitely helped to keep my son at home."*
- *"DDS/DESE program has been our saving grace…"*

Autism Specialty Program for Children

For children who are deemed "Autism Division Only Eligible", there is a network of seven Autism Support Centers across the Commonwealth that provide information and referral resources,

individualized clinics, social skills and related programs for individual children and family based activities. These Centers are also available for DDS eligible children with autism. At this time, there are thousands of families who frequently utilize these autism support centers.

Family Stories from the Autism Support Center Activities

- *"Thank you so much for putting together the puppet show and pizza activity for the kids. It's great to have these activities for Joey and the other kids. I appreciate all the time and effort you have put into creating opportunities for my children! For instance, Joey could never have gone to a My Gym class if not for the spring break camp and one-to-one that the Autism Alliance paid for. Now, a couple of years later, he participates almost independently in his weekly class."*
- *"David R. had never been to the circus before. Mom and Dad were anxious about how he would handle the noise and crowd but also felt that he might really like it. When they found out that we were offering a Family Fun Day activity to the Big Apple Circus, they decided to take a chance. After creating a social story for David, they made their way to Boston, where David's anxiety started to increase. He was fearful of the tall buildings and crowds. After some convincing, they made it to City Hall Plaza where David saw the Big Top. He froze! It was so tall! He told his parents that he "wasn't going in there"! After a few minutes, he agreed to move a little closer to the entrance and after about 20 minutes, made it inside the tent but didn't want to go into the seats. He watched a video about the circus that was playing in the lobby and agreed to go in a bit further. This led to his willingness to check out where his seat was and then he decided to see what the view would look like from his seat. After getting in his seat (along with the promise of cotton candy), he seemed to settle down. Once the lights went down and the performance started, he was enthralled with the action. He lasted the entire show and told his parents that he had fun. When asked if he would go again, he said 'We'll See'!"*
- *The staff at Community Autism Resources (CAR) did a family movie activity the involved creating a visual system for the child to review, a communication board and related activity sheets and dimmed lights and no trailers. Here is what families had to say about taking their children to this special showing:*
    - *"My son thoroughly enjoyed the movie and wants to go to the movies again. He really appreciated the sticker that was given him. The pictures were of great help. Thank you so much for putting this event together. We greatly appreciate it!" Thanks for all the great handouts and activity schedule – that really seemed to make the transition easy!"*
    - *"Thanks for offering this to CAR families – it was a really nice event and so excited to see my son enjoy the movie (without all the sensory overload)"*

The Division also helps fund the Autism Law Enforcement Coalition (ALEC) educational initiative that provides autism training to police, fire, EMTs and other hospital personnel. The program has trained over 6,000 first responders across the Commonwealth and has developed a relationship with FEMA and was recently highlighted on the Today show as an important endeavor.

The Department continues to have great success in working with autism and family support providers to create specialty vacation programs, swimming programs, social skills and sensory based activities and family friendly outings in the community.

Adult Services

Services for DDS eligible adults are expansive in their scope and availability. For those living in a family home, there are thirty-three family support centers offering a broad range of supports and services including information and referral, community based programs and services and access to individual financial assistance when funds are available. For young adults over the age of twenty-two there is also a broad array of day and employment options, transportation and related specialty support services. There are an additional ten family support centers that work specifically with culturally diverse adults and their family members. The network of Autism Support Centers also provides an additional level of information and referral resources for young adults up to the age of twenty-five.

The DDS Adult Service System provides a host of programs. For MassHealth Standard Eligible Adults, these programs are also able to receive Federal revenue because they are operating as Home and Community Based Services Waivers. These programs provide different intensities and types of services based on assessed needs of individuals.

The Adult Supports Program is for individuals who can live in their own home or apartment or family home due to a combination of strong natural/generic and Medicaid services in addition to day, employment and transportation supports.

The Community Living Program is for individuals who can live in their family home, in the home of someone else or their own home and do not need supervision 24 hours a day, seven days a week due to the combination of natural, generic and Medicaid services, in addition to a broad array of available day, in-home, employment, transportation, companion, community, behavioral, and therapeutic supports.

The Adult Residential Program is for individuals who need a residential placement that has supervision and staffing, 24 hours a day, seven days a week due to significant behavioral, medical, and/or physical support needs and the absence of available natural, generic and Medicaid services. In this program, individuals will have access to residential services, behavioral supports, day, employment, therapeutic, and transportation services.

Adult Specialty Programs

DDS and its network of providers of adult services continue to expand the development of programs specific to adults with autism and ID. This is true for group homes as well as day and employment services. DDS also recently developed a qualified list of providers who are available for Behavioral Support Consultation Services for DDS Eligible Adults.

The Department has a number of residential providers who have expertise in Autism. These homes have far more structured activities than a more typical residential program and focus on skill development, communication, and behavioral development. The programs also have a variety of clinical orientations. Some utilize Applied Behavioral Analysis (ABA) whereas others use the Higashi method.

Likewise, the Department offers some specialty day and employment programs which cater to individuals with autism. These programs are characterized by the skill and knowledge level of the staff about autism. These programs focus on staff consistency across both transportation and the actual activity. The staff also pays particular attention to the skills and talents of the individuals to match potential jobs with those particular individual attributes. In effect they use the "autism" to assist

the person in employment. Additionally, there recently has been interest in developing specialty day habilitation programs for individuals on the autism spectrum. Although these programs are not funded by the Department, DDS is very interested in their development.

Creative programs for social recreation opportunities and social skill building are also in place in a growing number of agencies. These programs provide appropriate opportunities for young adults to socialize and connect within safe and monitored environments.

Current DDS Autism Funding

In FY12, the Autism Division at DDS has a budget of $4.9 million. These funds cover the Autism Waiver Program that serves up to 205 children in a waiver year. Given that participation in the Autism Waiver ends on the child's 9th birthday, the Autism Division staff work closely with DDS Family Support services to enable a seamless transition from the Waiver to DDS Children's Services; however, the supports available through Family Support are much less than what is provided through the Waiver.

The Autism Division funding also supports the Autism Support Centers in providing community based services for children across the autism spectrum. Additionally, another $650,000 in funds to assist the Autism Center efforts comes from the DDS Family Support appropriation.

The DESE/DDS residential prevention program received $6.5 million in funds in FY 12. This program is funded by DESE and administered through DDS. This allowed for 485 children and young adults to receive a full set of supports and services. Until last fiscal year, this program had a waiting list of over 300; the current waiting list of 30 children demonstrates significant progress in delivering services to meet this critical need. As noted earlier, the majority of the children and young adults in this program have a diagnosis of autism.

For DDS eligible adults with autism there are a variety of supports available based on a prioritization of need. Some individuals receive community based supports such as day and employment services. More involved individuals may also qualify for residential supports and a more intensive level of supports during the day. The Department serves individuals who are MassHealth eligible through three different Home and Community Based Waivers (HCBS) that provide a varying level of supports based on assessed need. The value of these waiver programs are that they provide Federal revenue to the state for the services provided to these participants. DDS does not have the ability to isolate the amount of funding that specifically goes to serving adults with Autism and ID.

Future Goals and Initiatives

Additional funding for the Autism Division would provide the potential for growth in both the Autism Waiver Program and the Autism Support Centers. While the Autism Waiver Program can now serve 205 children in a waiver year, which is over twice as many as when the Waiver started back in October 2007, the 800 applications that were received in the most recent open request period provide evidence of the demand for expansion of these services to many more young children. The expansion of this program would undoubtedly have a positive impact since research has demonstrated that earlier intensive interventions lead to better outcomes. In addition to this program, there is also a need to continue some type of intensive in-home behavioral supports for many of these children beyond the age of nine.

The Autism Support Centers, while impressive with their outreach efforts, are limited by their current funding levels. By expanding the staffing and related resources of the current Autism Support Centers, these Centers would be able to provide more supports to families closer to their homes and local communities. Families often express concerns about traveling any type of distance with their child as this can be a prohibitive task.

The DESE/DDS Program is another area that could benefit from an increase in funds. This program has a long history of success in keeping children and young adults at home and out of residential schools. The in-home program and related supports per individual participant average around $25,000 a year, which is far less than the cost of a residential school placement that averages about $150,000 a year. While the program recently received funding to remove about 300 participants from the waiting list, there are many families in need. The Waiting List officially closed in 2009 when the number of families waiting hit over 300. Without additional resources, it will be difficult for DDS to open enrollment in any significant way to new families.

The IFFS Family Support Program, that was previously noted, is filled predominantly with individuals with autism and is also limited by the availability of funds. This Short-term intensive case management and related funding can be just what a family needs to help remediate a new behavioral issue with their son or daughter.

Gaps and Challenges

<u>Eligibility</u>
As DDS eligible children with developmental disabilities approach adulthood, which is at 18, they face a different criteria for DDS adult eligibility; the adult eligibility criterion requires that an individual be a person with an intellectual disability which requires both sub-average intellectual functioning existing concurrently and related to significant limitations in adaptive functioning. While many of these individuals have significant limitations in adaptive functioning, they do not have an Intellectual Disability. Therefore they are unable to continue receiving services from DDS. These young adults still require supports to remain at home and to remain as active members of their communities.

<u>Funding</u>
DDS continues to strive to meet the unique needs of the increasing number of children and adults with autism. The addition of the Autism Division is one example of creating a better system of supports for families. The Autism Waiver Program is another example of working to address a specific need, in this case young children with financial limitations and clinical needs for appropriate in-home supports and services. If the Autism Waiver was expanded beyond age nine, it would help to ensure a continuation of necessary in-home supports and services for these children and families.

The increase in the numbers of participants with autism in the DESE/DDS Program is another example of services shifting to meet needs of this growing population. The growth in the number of individuals needing the intensive Short-term supports offered through the IFFS Program also demonstrates how individuals with autism are growing throughout the DDS Family Support System and need additional supports to remain successful in helping families handle the often difficult behaviors and issues related to raising a child/young adult with autism.

For adults, DDS continues to find more appropriate Residential Homes, Day and Employment services that harness the capabilities and interests of individuals with autism, but the development and ongoing staffing of these programs will necessitate access to increased funding.

Workforce Development

These programs all require a robust workforce that can meet the specific behavioral, communication and social support needs of individuals with autism and this is a challenge for DDS and its network of providers. The demand is outpacing the growth in new staff that has experience within the autism arena.

However, by using training systems already in place within DDS and making use of the expertise of the Autism Support Centers, there is the opportunity to strengthen the current workforce so that these individuals may better understand the nuances of working within the autism arena.

Some efforts that are already in place include an internship at UMass Amherst for psychology majors that provides a specialized certificate in Development Disabilities. The program offers a specific course in behavioral theory and interventions. The certificate program requires students to complete an internship with either one of the Department's providers or in one of the Department's Area offices. UMass Lowell also offers a certificate program to better prepare students to work with individuals with autism at the undergraduate level and a masters level program as well. The UMass Lowell program also requires an internship which gives students real-life exposure to the field.

There is also a Community College initiative at eight of the community colleges that offers a course in behavioral interventions. These are examples of the post-secondary opportunities currently supported by the Department. Additionally, there are a number of private post-secondary institutions that are also creating programs to enhance the workforce. Although these efforts represent notable advances in the field, there is still a significant crisis in the ability to meet the Department's staffing needs for future services in this area.

MASSACHUSETTS REHABILITATION COMMISSION

Brief Description of the Massachusetts Rehabilitation Commission

The Massachusetts Rehabilitation Commission (MRC) is organized pursuant to M.G.L. Ch. 6 and operates programs authorized by State Law, the Federal Rehabilitation Act of 1973 as amended and by the Social Security Act. The agency provides a comprehensive array of services to individuals with disabilities intended to maximize their quality of life and economic self-sufficiency within the community. The MRC operates programs and services through three administrative divisions: the Disability Determination Services (DDS), Vocational Rehabilitation (VR) and Community Living (CL) Divisions.

1. *Disability Determination Services* conducts the disability eligibility evaluations for all Massachusetts residents applying for Social Security Disability Income or for Supplemental Security Income based on disability. The DDS works under the auspices of the federal Social Security Administration and its regulations, policies and guidelines. DDS processes over 80,000 claims per year.
2. The *Vocational Rehabilitation Division* operates out of 25 area offices and is funded through the federal Rehabilitation Services Administration. The primary goal of this Division is to provide counseling, assessment, training and job placement support as well as assistance with adaptations and accommodations that will ultimately result in competitive employment for the individual with a disability. Over 20,000 individuals receive services each year.
    - The *Supported Employment Services Department* that operates within the Division is state-funded and provides job coaching and longer term job support than what is allowed through federally funded Vocational Rehabilitation services. This program serves approximately 450 individuals each year.
3. The *Community Living Division* operates a range of services, some to targeted populations and others to cross-disability populations, but all services have the goal of enabling individuals to maximize their quality of life as well as their self-sufficiency and participation in their communities. The Community Living Division is divided into Departments for operational purposes:
    - *Brain Injury and Statewide Specialized Community Services (BISSCS)* including the Statewide Head Injury Program, the Nursing Home Initiative, Transition Services, and the Acquired Brain Injury Waivers Program;
    - *Independent Living (IL) and Assistive Technology* including the 11 Independent Living Centers across the state, Supported Living Programs for Adults and for Turning 22, Assistive Technology programs (including MassMatch, the Assistive Technology Loan Program, VR-IL Vehicle Modifications) and housing programs (including the Home Modification Loan Program, VR-IL Home Modifications, oversight of the Housing Access Registry and Community Based Housing development);
    - Additional programs include the *Home Care Assistance Program; Money Follows the Person Waivers Program; the Protective Services Department* and the *Consumer Involvement Department.*

Community Living programs are implemented through a vast network of community providers who receive on-going support, training and oversight from Department staff. Over 18,000 people with disabilities are served each year through these programs, some with a single service and others with multiple services through more than one program; the amount and type of services are dependent on

the extent of an individual's disability and related needs. Most people are provided assistance to assist them to remain in the community, but each year, a significant number of individuals are provided assistance to transition out of nursing homes or other institutional settings and return to the community. The Community Living programs are funded by a blend of state appropriations and federal funding including Medicaid dollars, federal grants and federal pass-through dollars for the Independent Living Centers.

Data, Statistics and Incidence Related to the ASD Population

There has been a steady increase in individuals with a primary or secondary diagnosis of ASD served by the VR Division. There are currently 1,100 people with diagnoses of ASD who are actively receiving services; this represents 4% of the total VR client base. This increase is in large part due to MRC's enhanced outreach to transition age populations. Current agency data indicates that over 65% of the individuals with ASD served are under the age of 20 which highlights the increased collaboration that is occurring between MRC and local school systems. The next significant cohort of individuals with ASD (26%) who are served are between the ages of 20 - 29. This data suggests that the number of individuals with autism requesting services will continue to increase in the future.

Within the Community Living Division, there has been a notable increase in the utilization of community programs by people with ASD., Reports from the Independent Living Centers, particularly the Transition to Adulthood Programs (TAP), show an overall increase of individuals with ASD; over 40% of the youth involved in the six TAP programs were reported to be individuals on the spectrum (174 out of 395) and overall, the Independent Living Centers report 3% of the over 19,000 consumers served in Federal Fiscal Year 2011 were individuals with ASD. The Assistive Technology-IL Program reports 6% of the consumers served were individuals with ASD. These individuals and their families received services such as: financial and technical assistance with communication devices including consultation on use of I-pads for the purposes of communication, personal organization, learning and working; financial assistance for home modifications for families including fencing and alarms to prevent children from wandering; and also the School Swap program, which provides a database of assistive technology that is available to school systems to meet the needs of their students. In addition, the Home Care Program provides services to about 35 individuals on the spectrum (just over 2% of total served); many of these individuals have a specific diagnosis of Asperger Syndrome and are able to live alone with minimal supports.

Services and Programs Serving Adults with Autism Spectrum Disorder

The MRC does not operate any programs specifically targeted to individuals on the Autism Spectrum, but there are many programs and services from which people with ASD currently can and do benefit and the agency has been working to improve services that respond to their unique needs. The success of this work is evidenced by the increased participation in both the VR and TAP programs. In the VR program, the goal of competitive employment can, at times, present a challenge for some individuals with ASD who need on-going employment supports as well as support with other aspects of their lives. Individuals with other disabilities including intellectual and mental health disabilities also encounter this type of challenge and MRC collaborates closely with the Departments of Mental Health and Developmental Services to address the ongoing needs of consumers through facilitating other community-based services and supports; some of these individuals also have a diagnosis of ASD. In addition, the Supported Employment Services Program has developed a pilot project in collaboration with the Asperger's Association of New England to develop services that are more appropriate for people with Asperger Syndrome.

Case Management and Training

The majority of individuals with disabilities come to MRC for specific services to address particular needs. Many of those served are adults with disabilities who are able to manage their own lives and direct the services and supports they utilize. The VR Division has Rehabilitation Counselors and the CL Division has numerous Program Coordinators who determine eligibility for a service and coordinate the service with a provider in conjunction with the consumer. Program Coordinators and Rehabilitation Counselors are knowledgeable about disability as well as the adjustments, accommodations, technology or other types of assistance that can enhance a person's functioning. These staff members work with consumers to educate them about their options and assist them in accessing the types of assistance they choose.

To be effective, MRC staff must be knowledgeable about the specific impacts of a wide range of disabilities. In response to the increased referrals of individuals with ASD, the Training Department has developed a staff training series with the help of Northeast Arc. Each of these sessions, which include consumers and family members as well as experts in the field as trainers, provides an overview of ASD and the employment and independent living support needs of these individuals. To date, 120 staff members have attended these trainings and more are scheduled; in addition, a training curriculum for employers is being developed. For ongoing support to staff, MRC has consultant neuro-psychologists who are able to offer insight and some limited assistance with service delivery issues related to an ASD diagnosis.

Gaps and Challenges

Most of the individuals with ASD who are served by MRC have entered from school programs into the VR program and some are also involved in the Independent Living Centers' Transition to Adulthood (TAP) programs. Current MRC programming is able to address some of their day/vocational needs, but, as previously mentioned, the VR Program's goal is to provide the services and supports necessary to enable an individual to prepare for entry-level competitive employment and the types of supports provided post-employment are time-limited. A small number of consumers are able to access long-term employment supports through the Supported Employment Services Department, but funding is very limited. MRC works closely with Department of Developmental Services and the Department of Mental Health to assist consumers who are eligible for their services to obtain long-term employment supports, if they are available. Many individuals on the Autism Spectrum require on-going supports to ensure their ability to maintain both their jobs and their community living status and the availability of these supports within any of the disability agencies is limited due to funding and eligibility constraints.

The steady increase in enrollment of consumers on the spectrum pushes the need for access to specialized consultants to assist counselors and program coordinators in assessing functional abilities and program-specific questions related to the Autism/ASD diagnosis. The availability of more specialized consultants would enhance the quality of services and complement the stellar training that is already in place within the agency.

Overall, in order to adequately and appropriately respond to the increased demand for services by individuals with ASD, MRC would require increased resources to collect and analyze data, increase training opportunities for staff, providers and employers, and to expand availability of relevant services in order to adequately meet the needs of the increasing population of individuals with ASD. Nonetheless, despite the current resource limitations, MRC does and will continue to do its best to ensure that those with autism spectrum disorders who come to us for services have an experience in which their needs are understood, their strengths are highlighted, and their ability to understand their own abilities and needs and to advocate for themselves is enhanced.

Future Goals and Initiatives

Even with existing challenges, MRC's goal is to build a collaborative working relationship with individuals with ASD in order to develop an appropriate system of services that are responsive to their needs; this is the same approach that the agency has used with individuals with other disabilities that make up its constituency. To advance and highlight the commitment to these efforts, the agency invited a leader in the national Autism Self-Advocacy Network to be a Keynote Speaker at the Consumer Conference that was held in June 2012. This was a symbolic kick-off to on-going work with individuals with autism and other disability leaders to analyze how current models of self-advocacy, skill-building, information and resource sharing, and peer supports, such as those offered through the Independent Living Centers, can be adapted in Massachusetts to best serve individuals on the spectrum.

Moreover, the agency intends to continue to learn from its experiences and develop best practices for working with those on the spectrum. Learning from successes is important as illustrated by the following case:

> *"AG was a college graduate, highly skilled in computer information systems, who could not land a job despite an extensive search. With the help of his MRC Vocational Rehabilitation Counselor who consulted with Asperger's Association of New England, he received vocational counseling, a vocational assessment, training in interviewing, benefits counseling, travel training, several On the Job Training (OJT) opportunities, assistance in targeting a specific type of job and skills training in that job, job placement services that included interview practice, resume review, job leads and placement advocacy. It was not until his interaction with MRC that the promise of true success in his chosen field became a realistic goal for him. The counselor was able to consult with experts in the field, and was then able to target the services from within the range of possible services to meet AG's specific needs and support him to the point that he is now successfully, competitively employed."*

Through continued training and collaboration with those knowledgeable about the needs of individuals with ASD (consumers, providers and others), and information-sharing, MRC will continue to build on its ability to serve those on the spectrum who can benefit from the agency's services.

EXECUTIVE OFFICE OF ELDER AFFAIRS
MASSHEALTH OFFICE OF LONG TERM SERVICES and SUPPORTS

Brief Description of Office of Long Term Services & Supports

The Office of Long Term Services and Supports (OLTSS) is a Division of both the Executive Office of Elder Affairs and MassHealth (Medicaid). It is comprised of four Departments: Clinical Services, Community Service, Coordinated Care (Program for All Inclusive Care to the Elderly and Senior Care Options, which are both programs for elders) and Institutional, Day and Residential programs, which are Day Habilitation, Adult Day Health, Adult Foster Care, Group Adult Foster Care, Chronic Disease and Rehabilitation Hospitals and Nursing Facilities.

The mission of OLTSS is to partner with enrolled providers to provide MassHealth state plan services to individuals with disabilities and the elders who qualify for these services in order to assist these individuals to remain in their community. For those who need other options, Nursing Facility and Long Term Hospital programs are also available on the continuum of care spectrum. The only service provided by OLTSS for children is the Community Case Management program. This program services children who require more than two hours per day of continuous skilled nursing services at home or in a community placement.

Data, Statistics and Incidence Related to the ASD Population

OLTSS programs that support individuals currently served by the Department of Developmental Services are Day Habilitation with approximately 8,000 and Adult Day Health with approximately 2,500 individuals. There is no data on how many of the DDS eligible individuals served in these programs have a diagnosis of ASD. In addition, there is currently no reliable data that identifies the number of individuals with ASD receiving the other services overseen by the Office.

Services and Programs Serving Individuals with Autism Spectrum Disorder

The OLTSS Services and Programs that may be supporting Adults with ASD are primarily Group Adult Foster Care, Adult Foster Care, Day Habilitation, and Adult Day Health. The eligibility requirements for each of these programs are as follows.

- *Group Adult Foster Care (GAFC):* Individuals must be 22 years of age or older; must require daily assistance with at least one Activity of Daily Living (ADL); and must receive clinical approval from the designated Aging Services Access Point (ASAP). For a "community setting", the individual must be determined financially eligible for MassHealth Standard and live in appropriate subsidized housing; for an "assisted living setting", the individual must be determined financially eligible for the SSI-G living arrangement through Social Security and this triggers MassHealth eligibility.

- *Day Habilitation:* Individuals must be age 18 or older, unless still enrolled in a special education program through the Local Education Authority; must have a diagnosis of intellectually disability or developmental disability; and a physician must order the service and affirm that the individual must need and be expected to benefit from Day Hab services which are designed to improve his/her level of independent functioning. If the individual is residing in a Nursing Facility, he/she must be recommended for Specialized Services per the Pre-Admission Screen and Annual Resident Review (PASARR). This is the tool

- mandated by a 1987 federal law that screens for the appropriateness of nursing facility admission.

- *Adult Foster Care (AFC):* Individuals must be age 16 or older and receive clinical approval from the designated ASAP. To be eligible for Level I AFC, the individual must require daily, physical assistance or cueing and supervision during the entire task with at least one Activity of Daily Living (ADL); for Level II, the individual must require physical assistance with 3 ADLs or physical assistance with 2 ADLs and management of behaviors that require caregiver intervention.

- *Adult Day Health (ADH):* The individual must be age 18 or older and receive clinical approval from the designated ASAP. In order to be eligible for the Basic Level, the individual must require assistance with one or more ADLs or at least one skilled service; for the Complex Level, the individual must meet nursing facility eligibility criteria; and for Health Promotion Prevention level, the individual must have met clinical eligibility criteria upon admission but no longer meets that criteria.

Case Management and Training

OLTSS does not employ Case Managers, only Program Managers who are responsible for working with their specific program's providers to ensure that the program services are delivered in accordance with MassHealth regulations and to ensure that all quality and regulatory requirements are met in order to be paid for services provided to the MassHealth individual.

Funding

OLTSS programs are funded as Medicaid programs. The appropriation is not a line item by program; rather an overall MassHealth amount that is then allocated by each MassHealth division. OLTSS is given a set amount to operate all OLTSS programs from this overall account.

Future Goals and Initiatives

Future goals and initiatives for serving adults in this population are to continue working with the stakeholder and provider communities and the EOHHS Office of Disabilities to design specialty programs for adults on the spectrum within the Day Habilitation, Adult Day Health and Group Adult Foster Care programs as needs are identified. One example of the work that is being done is the development of specialized Day Habilitation programs that are designed to support adult individuals with ASD with specialized programming and staff trained in behavioral support approaches that meet the unique needs of this population. Similarly, a Group Adult Foster Care program could be designed for adults with ASD that provided skills training, behavioral supports and specially trained staff.

DEPARTMENT OF MENTAL HEALTH

Brief Description of the Department of Mental Health

Vision and Mission

The vision of the Department of Mental Health (DMH) is "Community First." DMH, as the State Mental Health Authority, provides access to and ensures that, services and supports meet the mental health needs of individuals of all ages, enabling them to live, work and participate in their communities. The Department establishes standards to ensure effective and culturally competent care to promote recovery. The Department sets policy, promotes self-determination, protects human rights and supports mental health training and research. This critical mission is accomplished by working in partnership with other state agencies, individuals, families, providers and communities.

DMH operates pursuant to Massachusetts state statute, M.G.L. Ch. 19 and DMH regulations. DMH's primary mission is to provide for services to citizens with long-term or serious mental illness, early and ongoing treatment for mental illness, and research into the causes of mental illness. In fulfilling its primary mission, DMH:

- Ensures that individuals authorized for services have access to services and supports to enable them to live, work, attend school, and live and participate as independently as possible in their communities;
- Provides or arranges for DMH services for adults and children for whom services authorized;
- Establishes standards and policies to ensure effective and culturally competent care that promotes recovery and self-determination and protects human rights; and
- Supports mental health training and research.

Organizational Structure

Since July, 2010, DMH has been organized into 3 geographic regions: Central-West, Northeast-Suburban and Metro-Southeast. Each of the three areas operates Area and Site Offices. The Commissioner's office is located in Boston and statewide senior and executive staff is located in either Boston or Westborough.

DMH Services and Functions

DMH operates or contracts for the operation of community-based services and operates two state psychiatric continuing care hospitals, (Taunton and Worcester State Hospitals), psychiatric inpatient services in units in two public health hospitals (Tewksbury Hospital and The Lemuel Shattuck Hospital) as well as four mental health centers which also have small acute psychiatric inpatient units (Mass Mental Health Center, Solomon Carter Fuller Mental Health Center and Pocasset and Corrigan Mental Health Centers). DMH also contracts for psychiatric inpatient services at Kindred Hospital Parkview. DMH is in the process of opening the new, state-of-the-art psychiatric facility, Worcester Recovery Center and Hospital, that will promote recovery and resilience for adults and adolescents with mental illness across the Commonwealth.

DMH licenses community based residential sites for individuals with mental illness and all private acute psychiatric inpatient facilities and units (approximately 2,407 beds in 65 private psychiatric facilities). DMH ensures that licensed private hospitals are in compliance with regulatory requirements based on accreditation standards, licensing surveys conducted every two years and in response to complaints or incident-driven investigations.

The list of DMH operated or contracted community based services and other DMH functions follows:

DMH Community-based Services include:

- Community Based Flexible Supports (CBFS)
- Program of Assertive Community Treatment (PACT)
- Clubhouses
- Case Management
- Recovery Learning Communities
- Forensic - Court Clinic and Jail Diversion services
- Respite Services
- Homeless Support Services
- Child and Adolescent Residential Services
- Child and Adolescent Flexible Supports

Other DMH functions/services include:

- Performance Management/and Contract/Services monitoring
- Facility Licensure
- Investigations
- Training e.g. trauma-informed care, restraint reduction, wellness promotion
- Mental Health Services Research: DMH contracts with two academic Centers for Excellence - the University of Massachusetts Medical School Department of Psychiatry Center for Mental Health Services Research and the Beth Israel Deaconess Medical Center Commonwealth Research Center for clinical neuroscience and psychopharmacological research
- Collaboration with MassHealth Office of Behavioral regarding:
    - management of managed behavioral health services and
    - implementation of Children's Behavioral Health Initiative

Service Authorization

Individuals must apply for authorization to receive DMH services. The determination of whether to authorize DMH services for an individual depends on an assessment of whether:

- Individual meets the clinical criteria for DMH services;
- Individual requires DMH services and has no other means for obtaining them;
- DMH has available capacity.

To meet clinical criteria for DMH services an applicant must:

- Have a qualifying mental disorder as the primary disorder requiring treatment, and
- Meet functional impairment and illness duration criteria

For Adults: an applicant must have a serious and long term mental illness resulting in functional impairment that substantially interferes with or limits one or more major life activities. Serious and long term mental illness is defined as disorder of thought, mood, perception, orientation, or memory that grossly impairs judgment, behavior, capacity to recognize reality, or results in inability to meet ordinary demands of life.

For Youth: an applicant must be 18.75 years of age or younger at the time of application and have a qualifying mental, behavioral or emotional disorder. DMH utilizes the Substance Abuse and Mental Health Services Administration definition for Serious Emotional Disturbance, i.e. one that substantially interferes with or limits his/her role or functioning in family, school, or community activities.

Additional clinical criteria include that an applicant diagnosed with one or more of following disorders/conditions must also have a qualifying mental, behavioral or emotional disorder to meet clinical criteria for DMH services:

- Disorders usually first diagnosed in infancy, childhood or adolescence
- Conditions considered delirium, dementia and amnestic and other cognitive disorders
- Conditions considered mental disorders due to general medical condition not elsewhere classified e.g., traumatic brain injury
- Conditions considered substance-related disorders.
- Conditions under the category of attention deficit/disruptive behavior disorders: conduct disorder, oppositional-defiant disorder, and disruptive behavior disorder not otherwise specified.

Overview of Data on Individuals DMH Serves

DMH provides services for approximately 22,000 individuals (~2,400 youth and 19,000 adults). The following table depicts utilization by children/adolescents and adults by service. It should be noted that this is not an unduplicated count of individuals as some individuals may use more than one service at a time and/or in different time periods.

Individuals* Utilizing Department of Mental Health Services in FY11 **(* This is a duplicated count)**	**Total**	**Child/Adolescent (age 0-21)**	**Adults (age 21+)**
Inpatient Continuing Care	**1,572**	158	1,414
Community Based Flexible Supports (CBFS)	**13,501**	536	12,965
Program of Assertive Community Treatment (PACT)	**955**	33	922
Clubhouse Services	**3,603**	37	3,566
Adult Case Management	**5,495**	437	5,058
Recovery Learning Communities	**0**	0	0
Forensic - Court Clinic and Jail Diversion services	**724**	51	673
Adult Respite Services	**842**	87	755
Homeless Support Services	**523**	20	503
Child and Adolescent Case Management	**1,066**	1,059	7
Child and Adolescent Residential Services	**776**	764	12
Child and Adolescent Flexible Supports	**1,279**	1,174	105
Child and Adolescent Respite Services	**199**	199	0

Description of DMH Services for Adults and for Children and Adolescents

Continuing Care Inpatient Services

Inpatient continuing care consists of person-centered services provided in hospitals for the ongoing stabilization and treatment of an individual with a psychiatric condition to facilitate their rehabilitation and recovery under one or more of the following circumstances: 1) in which the individual continues to pose a danger to him/herself or others or the condition has resulted in marked psychosocial dysfunction or grave mental disability; 2) the condition requires intense multidisciplinary specialized treatment in a secure setting; and/or, 3) current psychopharmacological regimens have not be successful in restoring the patient to either baseline or an improved level of functioning and ongoing medication adjustments are necessary to help the patient achieve greater stability and functioning with the goal of returning to the community.

Community Based Services for Adults

Community Based Flexible Supports (CBFS): CBFS is the cornerstone of DMH's redesigned community-based system. CBFS enhanced and transformed service components by combining into one service type the delivery of residential and community rehabilitative services that were previously provided via separate funding and through a more fragmented system. CBFS was implemented beginning in July 2009. There are 19 contracted CBFS providers and six state-operated CBFS programs. The network of CBFS contractors works with individuals, their families and other natural supports to develop an array of rehabilitative interventions and supports that meet their needs and promote and facilitate recovery. These interventions and supports are designed to promote and provide safe and stable housing options; support individuals' ability to fully participate in their communities including seeking and retaining gainful, independent employment; facilitate self-management of psychiatric symptoms and distress; and promote self-determination, empowerment, wellness and improved physical health. CBFS encompasses four key service components: Rehabilitation, Supervision, Support, and Housing/Room and Board. In addition, CBFS contractors are responsible for: client screenings and enrollment; assessments and integrated, person-centered treatment planning; quality and utilization management; data collection and reporting; service documentation and discharge planning. CBFS was implemented in July 2009 via a competitive procurement process.

Program of Assertive Community Treatment (PACT): PACT is an intensive multidisciplinary team approach providing acute- and long-term support, community based psychiatric treatment, assertive outreach, and rehabilitation services to persons served. The PACT Team provides assistance that promotes recovery and community integration, ensures person-centered goal setting, and assists persons in gaining hope and a sense of empowerment. The program provides services to persons served who often have co-occurring disorders such as substance abuse, homelessness or involvement with the judicial system. The team is the single point of clinical responsibility and assumes accountability for assisting persons served to meet needs and achieve goals for recovery. Most of the services are provided directly by PACT team members in the natural environment of the person and are available on a 24 hour, 7 day a week basis. Services are comprehensive, highly individualized and are modified as needed, through an ongoing assessment and treatment planning process.

Clubhouse Services: Clubhouse Services is a psychosocial rehabilitation service that provides supports through a membership-based community center. Clubhouse Services assist people served to recognize their strengths, develop goals, and enhance the skills people determine are needed to live, work, learn, and participate fully in their communities. Components of Clubhouse Services includes: linkage to community resources, housing supports, employment services, education services, health and wellness services, social and recreational services, transportation services and empowerment and advocacy.

Case Management: DMH case management is a service designed to assist individuals gain access to continuing care and other community services, and to coordinate the provision of those services among various providers. To provide case management, DMH case managers must assess the

person's service needs, create a service needs plan, and help to coordinate those services among providers in accordance with the plan.

Recovery Learning Communities (RLCs): The RLC provides peer-to-peer support to individuals with serious mental illness. It is expected to serve as a "hub" in its respective DMH Area. The RLC Program is a resource and referral center that provides general information on topics of concern to peers. The information focuses on community resources and programs. Services may be offered in a variety of settings; at the RLC Program site, community mental health centers, inpatient hospitals, generic community settings, town hall, fairs, shopping mall, etc. Services include: providing and/or referring to a wide range of peer to peer support services; supporting the providers of peer-to-peer support through training, continuing education, and consultation; and linking together peer-operated services and supports for the purpose of creating a network. This network improves communication, facilitates the delivery of services, coordinates advocacy, and assists in responding to a person's needs, aspirations and goals as they evolve over time. The main goal of every RLC Program is to help persons achieve full community integration. Participation is not an end unto itself, but an additional step toward recovery. The services of a RLC Program are delivered primarily by peers.

Respite Services: Respite Services provide temporary Short-term, community-based clinical and rehabilitative services that enable a person to live in the community as fully and independently as possible. Respite Services provide supports that assist persons to maintain, enter or return to permanent living situations. Respite Services are Site-Based and/or Mobile. Site-Based Respite Services provide temporary supportive services and Short-term, community based living arrangements in a distinct location. Mobile Respite Services are mobile services, accessible to persons in variety of community settings such as: their current living situation, inpatient facilities, skilled nursing homes, and homeless shelters.

Homeless Support Services: Comprehensive screening, engagement, stabilization, needs assessment and referral services for adults residing in shelters.

Community Based Services for Children/Adolescents

Child and Adolescent Residential Services: There are a wide range of therapeutic services provided in supervised community-based residential settings, as well as in the family home. Residential services are often provided in conjunction with treatment and rehabilitative services. DMH currently provides out-of-home care in a wide variety of settings, the most intensive of which are provided in locked settings, on state hospital grounds, called Intensive Residential Treatment Programs ("IRTPs"); as well as a single Clinical Intensive Residential Treatment Program ("CIRT") unit that is staff secure and designed to meet the needs of the highly disrupted latency aged children. Community-based residential is provided in staff secure group homes settings for children and adolescents across the Commonwealth. Under the aegis of residential services, the Department also provides intensive, in-home support and outreach to youth, as well as intensive foster care services. DMH is in the process of re-procuring these services jointly with the Department of Children and Families (DCF).

Child and Adolescent Flexible Supports: Individual *and Family Flexible Support Services (IFFS*S) provide an individualized and targeted set of interventions and services intended to prevent out-of-home placement, sustain the youth with his/her family and community, and assist the youth to successfully function in the community. Through this service, a youth and his/her family develop the skills, strategies and supports needed to live successfully in the community and to support the youth's ongoing development of age-appropriate social, emotional, academic and pre-vocational competencies. The IFFSS is designed to be highly flexible to meet the varying needs of youth with serious emotional disturbance and their families. The most intensive service under flexible support services is Family Systems Intervention (FSI), which provides ongoing support, outreach, engagement, skill development, and care coordination to an identified youth and his or her family in the home and community through a team model that is available 24 hours a day, seven days a week to assist families and youth to develop skills and support that promote family cohesion and successful community living. Individual Youth Support (IYS) provides fee-for-service non-school hour mentoring to an identified youth to assist the youth in developing self-management abilities; social, communication, and pre-vocational skills, and self-confidence. Flexible Supports also includes Youth Support Groups (YSG) which provide a structured small therapeutic group setting to provide social and emotional skill building, community integration, therapeutic recreation, and educational and vocational preparation for identified youth and their families, and Collateral Contact/Case Consultation, which allows the Department to fund collateral contacts and consultations for identified youth to ensure that services are integrated and clinically coherent. IFFSS flexible supports also includes flexible pool dollars, which allows providers to purchase on behalf of identified youth and families service and goods to maximize the benefit from other DMH services.

Child and Adolescent After-School Services: These are voluntary, highly structured, therapeutic milieus for children and/or adolescents, designed to provide services that enable the clients to learn and practice behavior and symptom management techniques as well as provide supervision and support around problem solving, communication and relationship building for clients whose stabilization is fragile, and whose symptoms interfere with their ability to be integrated into family, school and community activities. These settings also provide a bridge between acute or long- term care settings and other community based programs or help to maintain the child/adolescent in the community. After-school may include full day, partial day, after-school, early evening, weekend or vacation programming.

Child and Adolescent Family Supports: DMH funds a *statewide network of Family support* Specialists who provide a range of services to parents/caregivers of youth with emotional or behavioral health needs, service providers, school systems, hospitals, and other entities involved in the care of youth with SED. These Family Support staff members assist parents/caregivers to navigate the system, access entitlements, and develop the skills that allow them to effectively advocate for the services and supports they and their child need. In addition to this individualized, one-on-one support, parent coordinators also facilitate parent support groups that are open to all parents or caregivers of a child with emotional or behavioral health needs, across payer groups. Each coordinator also works closely with organizations in the local community, such as school systems, mental health providers, and hospitals, to provide information and education about the needs of youth with emotional/behavioral health needs and their families, and to advocate for appropriate services and interventions to meet these needs. In addition, DMH provides funding to the Parent Professional Advocacy League (PAL), the statewide organization that supports and advocates on behalf of parents and families of children with behavioral health needs. This organization works to promote parent participation in policy and program development so that behavioral health services are family-driven, and reflect family voice and choice.

State Agency Consultation: The Department provides consultation to other child-serving agencies on specific children and adolescents around issues of serious emotional disturbance and mental health though our six locally-based Area Child/Adolescent Psychiatrists as well as the central office clinical staff. Training related to trauma informed care is offered to staff of other agencies and providers.

Forensic – Court Clinic and Jail Diversion

Court Clinic services include court-based forensic mental health assessments and consultations for persons who are facing criminal or delinquency charges and civil commitment proceedings. These court-based services involve the provision of individual statutory and non-statutory evaluations regarding persons with mental health and substance abuse difficulties as well as the provision of mental health liaisons to adult and juvenile justice court personnel.

DMH Forensic Transition Teams provide reentry services for DMH clients who are transitioning from prisons, jails and other places of detention to the community.

Jail Diversion: DMH operates police-based and court-based jail diversion activities in partnership with other agencies as well as through federally-funded projects aimed at minimizing or preventing the involvement of persons with mental health histories in the criminal justice system. There are currently 18 police-based jail diversion programs in communities across the state, as well as two DMH funded Mental Health Courts and additional re-entry and court diversion services.

DMH Services Related to Individuals with ASD

In accordance with its statutory mission, DMH services are designed to meet the needs of individual's serious and persistent mental illness/serious emotional disturbance. The majority of DMH clients are diagnosed with schizophrenia and other psychotic disorders. Approximately a third of DMH clients are diagnosed with bipolar disorder or psychotic depression. In order to be authorized for services, DMH clients must exhibit significant functional impairments as a result of their mental illness. DMH services are specifically designed to meet the rehabilitative needs of individuals with serious mental illness or serious emotional disturbance.

Although individuals with Autism Spectrum Disorders (ASD) may exhibit certain functional impairments similar to those of individuals with serious and persistent mental illness or serious emotional disturbance, DMH services are not designed to address the behavioral support needs of this population.

Ideas for Improving EOHHS services for persons with ASD and DMH's role

DMH believes that an opportunity exists for EOHHS agencies to collaborate to create services, including residential supports for individuals with ASD, which are specifically tailored to better address the mental health needs of these individuals, and to provide consultation supports for acute medical service to increase the understanding of the unique needs and best practices for serving persons with ASD. In its role as the state's mental health authority, DMH does and will continue to provide expert consultation to other agency staff and health care providers to help ensure that the EOHHS delivery systems, including any services designed for persons with ASD, also meet the behavioral health needs of individuals served.

EXECUTIVE OFFICE OF EDUCATION

DEPARTMENT OF EARLY EDUCATION AND CARE

Brief Description of the Department of Early Education & Care

The Department of Early Education and Care (EEC), part of the Massachusetts Executive Office of Education, was created in 2005 with the combination of the Office of Child Care Services (previously under the Executive Office of Human Services) and the Early Learning Services Division (previously under the former Department of Education, (now known as the Department of Elementary and Secondary Education). The enabling statute that establishes the Department of Early Education and Care is MGL CH. 51D. The agency was created with the purpose to build a first-in-the-nation coordinated, comprehensive system of early education and care in Massachusetts.

EEC employs approximately 160 employees who work in six different offices throughout the Commonwealth. The Central Office is in Boston, the Metro-Boston office is in Quincy, the Northeast office is in Lawrence, the Central Massachusetts office is in Worcester, the Southeast and Islands office is in Taunton and the Western Massachusetts office is in Springfield. EEC's primary responsibility is the licensing of over 12,000 providers who care for over 250,000 children on any given day. EEC licenses early education and care, out-of-school time programs, group care and temporary shelter facilities, as well as adoption and foster care agencies serving children and youth throughout Massachusetts.

EEC's other primary responsibility is the administration of a statewide financial assistance program for low-income families with children up to age 13, through the dispersal of the Massachusetts portion of the Federal Child Care Block grant. The federal Child Care Block Grant provides subsidized child care to 6,000 eligible children in Massachusetts. EEC also provides support for information and referral services, inclusive programming for children with special needs and parenting and family support for families throughout the Commonwealth.

The mission statement of the agency is to "provide the foundation that supports all children in their development as lifelong learners and contributing members of the community, and supports families in their essential work as parents and caregivers."
The following values guide the agency in its efforts to serve the Commonwealth:

- Learning starts at birth.
- We value all children and all families.
- All children can succeed and we have the responsibility to help them do that.
- Families and caregivers are integral to the healthy development of children and must be engaged as partners.
- Our workforce is the backbone of our services; we value and support their skill development, diversity, and fair compensation.
- Families live within communities and must be reached and supported in ways that maximize accessibility.
- We believe in and practice equity and therefore children with the greatest educational and care needs and multiple risk factors come first.
- Providing culturally appropriate services is critical to being effective in the lives of children and families.
- We support the continuum and continuity of every child's education and care.
- A strong, nimble current system exists upon whose assets we will grow services.
- Accountability at all levels is important and we will work together to measure, recognize needs and develop the assets of the field.

Data, Statistics and Incidence Information Related to the ASD Population

The Department licenses early childhood education programs that serve approximately 250,000 children. EEC does not have data specifically identifying the number of children within that number who are on the autism spectrum. The EEC regulations at 102 CMR 7.04 (13) pursuant to children with disabilities states that the licensee must accept applications and make reasonable accommodations to welcome or continue to serve any child with a disability. In determining whether accommodations are reasonable and necessary, the licensee must, with parental consent, and as appropriate, request information about the child from the Local Education Agency (LEA), Early Intervention Program or other health or service providers. Through this regulation EEC ensures that children with disabilities, including those on the autism spectrum have access to early education opportunities.

EEC also provides subsidies to early education providers to serve approximately 6,000 children who meet specific eligibility criteria. Although EEC does not have data at present on the number of children on the autism spectrum who receive subsidized child care, the regulations for eligibility under 102 CMR 606 (10.4) (1) states that families with an incapacitated parent or a child with special needs are financially eligible for the Income Eligible Child Care Program provided that their gross monthly income is at or below 85% of the State Median Income as determined by EEC at the time of enrollment. Financial eligibility will continue until the family's income reaches 100% of the State Median Income as determined by EEC.

EEC also licenses approximately 450 residential programs for children that have a capacity to serve 8,000 children. Although EEC does not have the exact number of programs since the population of clients served is fluid, a large number of these programs provide out-of-home placement for children on the autism spectrum.

EEC also provides other funding to agencies and LEAs providing Inclusive Preschool Programs for Children age 3-5 with disabilities. EEC oversees professional development opportunities designed to build capacity of educators to support children with disabilities and requires that one third of all professional development provided to educators must address diverse learners. EEC also funds state wide mental health consultation and behavioral specialists' consultation related to early intervention services for children with special needs and developmental delays.

Services and Programs Serving Children with ASD

Children with special needs who cannot attend child care without specific program accommodations may be eligible for funding from the Income Eligible flex pool. Such funding may be used to support training for program staff, consultation to identify necessary supports for the child, technical assistance in meeting the individual needs of the child, enhanced staffing to maintain the child in the program, or specialized equipment. Children served through this funding must have documented physical, mental, or behavioral disabilities that have prohibited or will prohibit the child from participating in the program. Contracted programs seeking funding to serve such children must submit their requests with appropriate documentation to their Regional Policy and Training Advisor for

approval. Non-contracted programs seeking to serve children with voucher funding must submit their requests, along with appropriate documentation, to their Resource & Referral Agency for approval.

Children in early educational environments who are over three years of age with documented special needs may be eligible for early intervention services through the Department of Public Health. EEC has entered into an Interagency Service Agreement with the Department of Public Health to utilize area Regional Consultation Programs to assess children with special needs, including those on the autism spectrum, and make referrals to early intervention services.

Children with special needs over three years of age who have an individual education plan or a 504 plan are eligible for funding from the local school district for additional supports in their early education and after school classroom as well.

Case Management and Training

The Department of Early Education and Care does not provide case management services for children, including children on the autism spectrum.

EEC contracts with six Regional Educator and Provider Support (EPS) Grantees to provide training opportunities through coaching and mentoring, competency development and intentional professional development for all educators in the mixed delivery system. According to 102 CMR 606 7.09 (3), one third of all required professional development must address diverse learners. EEC also has agreements with six Regional Readiness Centers, coordinated by the Executive Office of Education (EOE), to provide coordination between early education and care, elementary and secondary education and higher education to provide a continuum of services for all children including those on the autism spectrum.

EEC also funds Early Childhood Mental Health Consultation Grants in each region to provide training opportunities and resources to early education and care providers. A grantee is available in each EEC region to provide early childhood mental health consultation services to programs in the mixed delivery system (Head Start, private center-based, independent and system-affiliated family child care, private and public schools) and out-of-school time programs. Through direct consultation between the programs and the grantees, programs, families and children will be able to training or consultation services.

Gaps and Challenges

The gaps and systemic challenges for children in early education environments relates directly to the early identification of children on the autism spectrum and targeting services at an early age to ensure successful education experiences. At the present time, some early educators and other professionals in early education programs lack the ability to adequately identify indicators in children with autism spectrum disorder.

Future Goals and Initiatives for Children with ASD

The Department was one of nine states recently awarded the federal *Race to the Top* early learning challenge grant. One of the goals under this grant is the creation of the Massachusetts Early Childhood Information System (ECIS). The goal of the ECIS is to create a multi-agency data base of individualized child information. This would include child-level demographic and program participation information and child-level data on development. The ECIS database would allow different agencies in the Executive Office of Education and the Executive Office of Health and Human Services to link child level data across educational and other systems with a unique child identifier. The creation of this would allow for the ability to identify behavior linked to ASD at an early age and target appropriate resources earlier.

Another aspect in the *Race to the Top* grant for Massachusetts is the *Kindergarten Entry Assessment* project. This is an ambitious undertaking to have every child entering kindergarten in Massachusetts undergo a formative assessment by 2015. Assessing children's school readiness at kindergarten entry is essential to identifying the learning needs of children and targeting instructional and programmatic support. This is particularly important for high needs children, who often enter school behind in foundational developmental skills and knowledge, putting them at risk for future academic struggles. The *Massachusetts Kindergarten Entry Assessment* (MKEA) will play a necessary role in describing children's early learning and developmental trajectories while also arming state and local educators with new tools for addressing achievement gaps at one of the earliest points in children's public school careers. MKEA will use formative assessment to establish children's level of school readiness and monitor learning progress in kindergarten across all essential domains of school readiness, e.g. language and literacy development, cognition and general knowledge, including early mathematics and early scientific development, approaches toward learning, physical well-being and motor development, and social and emotional development. Part of this important initiative would be identifying developmental delays at kindergarten entry and making referrals for services. This would be particularly useful in identifying children with potential ASD at kindergarten age and providing early age treatment.

DEPARTMENT OF ELEMENTARY and SECONDARY EDUCATION

Brief Description of the Department of Elementary & Secondary Education's Programs related to ASD

The Department of Elementary and Secondary Education (ESE), part of the Massachusetts Executive Office of Education, is the lead state education agency under the Individuals with Disabilities Education Act. ESE is charged with providing general oversight to the approximately 400 public school districts in the state that provide direct services to students with disabilities, including students on the autism spectrum. ESE is not a direct service agency, but does monitor, respond to complaints from consumers of education services, and administer several grant or funding programs that have an effect, at least in part, on students on the autism spectrum.

Data, Statistics and Incidence Related to the ASD Population

In FY2010-2011, a total of 9,886 children ages 6-21 were found eligible for special education due to disability on the autism spectrum. Their educational placements included:

Full inclusion	35.9%
Partial Inclusion	15.6%
Substantially separate programs	31.3%
Out-of-district programs/schools	17.2%

These data represent a significant increase in the numbers of students categorized as having ASD in Massachusetts and reflect a 59% increase over the last five years when considering students from ages 3 – 21. This increase is greater than any other disability category during the same period.

Eligibility

The Commonwealth uses the federal definition (34 CFR 300.8(c) (1) (i)) to describe its autism disability category.

(i) Autism means a developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age 3 that adversely affects a child's educational performance. Other characteristics often associated with autism are engagement in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences. The term does not apply if a child's educational performance is adversely affected primarily because the child has an emotional disturbance, as defined in paragraph (b)(4) of this section.
(ii) A child who manifests the characteristics of "autism" after age 3 could be diagnosed as having "autism" if the criteria in paragraph (c)(1)(i) of this section are satisfied.

The ESE is committed to ensuring that school districts have the most current, evidenced-based information regarding academic and non-academic services and supports for students with autism and their families, and has issued several technical assistance and administrative advisories to assist districts in these efforts.

Case Management and Training

The ESE does not case manage, however, ESE engages in a variety of activities that support the local districts in their management of supports and services for students with ASD in their districts, including professional development for teachers, administrators, related service providers and paraprofessional personnel, as well as advisories issued to district managers.

Professional development has been made available through a virtual coursework platform for professionals. Coursework in the area of autism spectrum disorders is both specific and general and is focused on understanding the characteristics of students with ASD, including their language, sensory, and behavior needs: *Meeting the Academic and Non-Academic Needs of Students with Asperger Syndrome*, *Strategies for Students with Sensory Dysfunction*, *Managing Behaviors in Inclusive Settings*, *Differentiated Instruction*, *Universal Design for Learning*. These are three-credit, graduate level courses.

Advisories specifically addressing the needs of students with ASD include:
(1) *Technical Assistance Advisory SPED 2007-1: Autism Spectrum Disorder*. It requires the Individualized Education Program (IEP) Team to discuss students' needs that are consistent with best practices for addressing the needs of students diagnosed with ASD and describes the specific seven areas the Team must consider when developing the IEP.
(2) *Technical Assistance Advisory SPED 2011-2: Addressing the Needs of Students with Disabilities in the IEP and in School Bullying Prevention and Intervention Efforts*. This advisory provides further clarification to the Bullying and Intervention Law (May 2010) enacted for all students. The advisory is especially designed to address the needs of students with ASD who may be the target of, or unknowingly the perpetrator of, bullying. It states that whenever the IEP Team evaluation indicates that a student's disability affects social skills development, or when the student's disability makes him or her vulnerable to bullying, harassment, or teasing, the IEP must address the skills and proficiencies needed to avoid and respond to bullying, harassment; and, for students identified with a disability on the autism spectrum, the IEP Team must consider and specifically address the skills and proficiencies needed to avoid and respond to bullying, harassment, or teasing.
(3) *Administrative Advisory SPED 2012-1*: *The Autism Insurance Law.* The law is to enable families to obtain additional services, from designated private health insurance providers, for children with ASD.

Funding

ESE has had both periodic focused and general grant programs used by some districts to support autism services. A sample of the types of grants includes:
(1) The use of ARRA funds in the development, expansion, and improvement of programs for students with ASD. Many districts used these funds to start new, in-district programs for students previously in out-of-district placements.
(2) Fund code #274 professional development for educators in public schools.
(3) Fund code #249 professional development for educators in approved private special education schools.
(4) Special Education Enhancement grants to 21st Century Community Learning Centers to enable them to include students with more significant disabilities, including ASD, in their after-school programming.

Additionally, for many years ESE and the Department of Developmental Services (DDS) have cooperated to fund and manage a "Community Education Program" to provide wrap-around home

and community services for students with developmental disabilities, including autism, and their families in order to prevent the development of a need for out-of-home or -district services. Funds are allocated through an interagency service agreement and transferred from ESE to DDS from the "circuit breaker" line item. In FY12, this program is funded at $6.5 million.

Gaps and Systemic Challenges

In recognition of the complexity of the characteristics of ASD and the extent to which it affects many aspects of life function, the ESE advocates for and participates in collaboration with other state agencies and professional organizations to both identify gaps in systems and services and design supports and intervention to address these. Partnering agencies include the Federation of Children with Special Needs; the Departments of Public Health, Early Education and Care, and Developmental Services; the MA Act Early Campaign (a federally supported CDC initiative to identify warning signs of autism as early as possible), and UMASS-Boston among others. Although the transition from early intervention to school-based services has seen much improvement, the transition from school to work/career/college remains a systemic challenge.

Within ESE, the Special Education Planning and Policy Development office has collaborated with other units regarding the development of policies and procedures for the education of students with ASD. Two noteworthy initiatives are:
(1) adding new competencies for the license of teachers of students with moderate disability – a minimum of ten hours of instruction in the use of Augmentative and Alternative Communication and Other Assistive Technologies, and
(2) collaboration on the development of the educator evaluation for teachers of students with disabilities – both moderate and severe.

Future Goals and Initiatives for Children with ASD

ESE has discussed some concerns raised during the work of the Autism Commission and agreed to the following activities:

1. ESE will incorporate the requirements of evaluations as outlined in the autism advisory into the Web-based Monitoring System self-assessment for monitoring use starting in the 2012-2013 school year.

2. ESE will review the data on students with autism and language spoken in the home and consider actions to develop state capacity to serve students with ASD from different language backgrounds.

3. ESE will consider developing additional online virtual coursework addressing augmentative and alternative communication to assist in building capacity in the Commonwealth for schools to work with non-verbal students with ASD.

4. ESE is in the process of developing the concept and practice of using "endorsements" to show additional content knowledge for professional teaching license-holders and is including the concept of an "autism" endorsement in this consideration.

5. Consistent with our current course on Positive Behavioral Interventions and Supports (PBIS), ESE will look into unique autism intersections with PBIS work.

DEPARTMENT OF HIGHER EDUCATION

Brief Description of Department of Higher Education

The Massachusetts Department of Higher Education, part of the Massachusetts Executive Office of Education, is responsible for executing the Board of Higher Education's policies as well as coordinating programs and initiatives central to public higher education in the Commonwealth.

The 13-member Board of Higher Education is the statutorily created agency in Massachusetts responsible for defining the mission of and coordinating the Commonwealth's system of public higher education, including its institutions. The Board of Higher Education works to create and maintain a system of public higher education that provides Massachusetts citizens with the opportunity to participate in academic and educational programs for their personal betterment and growth; to contribute to the region's existing base of research and knowledge; and to further the Commonwealth's future economic growth and development.

The Board's core responsibilities are in the following functional areas: Academic Policy and Program Approval, Financial Aid, Fiscal and Capital Planning, Research and Performance Measurement, Workforce Development, and overseeing the Commonwealth's Optional Retirement Program. The Board of Higher Education is also increasingly engaged in PreK-16 efforts, College and Career Readiness initiatives, and general advocacy on behalf of the system.

The Board of Higher Education coordinates its activities within a framework of an integrated public education system extending from early childhood through the university level. The Board of Higher Education also encourages collaboration between educational institutions, business, and industry to promote employment opportunities, educational improvements, and economic growth.

Data, Statistics and Incidence Related to the ASD Population

Because the Department of Higher Education does not collect data on the incidence of disability, including autism, from each of the public higher education campuses in its central database (HEIRS), the Department released a questionnaire to the campuses in Spring 2011 to investigate the incidence of disability including autism. Apart from student enrollment figures, the data presented in Tables 1 and 2 are reported individually by each campus and should be considered anecdotal.

Table 1: Incidence of Disability & Autism at Massachusetts Public Institutions: Academic Year 2009-2010

Segment	Responding Institutions	Total Enrollment	Students who Requested Services	Students who Received Disability Services	Incidence of Autism
Community College	15	137,509	9,520	7,374	450
State University	7	48,048	1,711	1,512	63
University of Massachusetts	4	60,691	2,047	1,354	69
Total	**26**	**246,248**	**13,278**	**10,240**	**582**

Data sources: Total enrollment, Massachusetts Department of Higher Education, HEIRS database.

All other data was collected via online questionnaires which were completed by each responding institution's disability services director or similar position in spring 2011. 26 public institutions responded.

Table 2: Incidence of Autism & Disability at Public Higher Education Institutions, Academic Year 2009-2010

	Yes	No	Unable to Determine	Missing
Enrollment of students with autism spectrum disorders has increased in the last five years.	25	NA	NA	1
Enrollment of students with disabilities has increased in the last five years.	24	0	1	1
Student disability is underreported.	18	5	3	0

Data was collected via online questionnaires which were completed by each responding institution's disability services director or similar position in spring 2011. 26 public institutions responded.

Summary: Incidence of Autism

There are an estimated 10,240 students with disabilities attending the public higher education institutions in Massachusetts (herein referred to as the “campuses”). The majority of these students, approximately 70%, are enrolled at the community colleges. The campuses report that of the total number of students with disabilities, 582 have autism spectrum disorders and that 450 of those students are enrolled at community colleges. Therefore, it is clear that the community college segment is enrolling the vast majority of students with autism.

The campuses report that both the enrollment of students with disabilities and the enrollment of students with ASD have increased since the 2004-2005 academic year. The majority also believes that students often do not report their disability; this leads to the assumption that the incidence may be larger than what is currently documented. Consequently, the full impact of autism spectrum disorders in higher education may not be fully realized.

In addition to a noted increase in enrollment of students with disabilities including autism, campuses make the following observations:

- Autism spectrum disorders require a different kind and level of services as opposed to other disabilities. Available accommodations may not address social and communication challenges reflective of autism. Students with autism may not require academic support, but their academic performance and well-being could be further supported by classes covering such

- skill areas such as communication, socialization, etc. which are not traditionally provided by campuses.

- Increased incidence of autism permeates all aspects of campus life, including faculty development and residence life. For example, faculty and staff would benefit from receiving professional development in disability awareness, including autism spectrum disorders, and in universal design techniques.

- There is a need for greater outreach to high schools and other agencies to prepare students for transition to higher education. Students with disabilities and their families are often not informed of what level of services to expect in college, the differences between the K-12 system and higher education in terms of required services that institutions must provide to students with disabilities, the importance of student self-advocacy in higher education and the expectations of college. As a result, the transition to college can be very difficult. Greater communication with and outreach to the K-12 system is needed in order to promote students' success in higher education.

Campuses report the increase in students with disabilities demands greater services to students, faculty and staff; however, available resources are limited.

DEPARTMENT OF HOUSING AND COMMUNITY DEVELOPMENT

DEPARTMENT OF HOUSING AND COMMUNITY DEVELOPMENT

Brief Description of the Department of Housing and Community Development

The mission of the Department of Housing and Community Development (DHCD) is to strengthen cities, towns and neighborhoods to enhance the quality of life of Massachusetts residents. To accomplish our mission, we will provide leadership, professional assistance and financial resources to promote safe, decent affordable housing opportunities, economic vitality of communities and sound municipal management. We will forge partnerships with regional and local governments, public agencies, community-based organizations and the business community to achieve our common goals and objectives. In all of these efforts, we will recognize and respect the diverse needs, circumstances and characteristics of individuals and communities.

Divisions of DHCD

There are four divisions within DHCD that carry out this mission:

- *Housing Development Division*: This Division manages the state resources available to support the production and preservation of privately-owned affordable housing. The programs provide funding opportunities to for-profit and non-profit developers for affordable housing projects that serve both families and individuals with annual incomes at or below 80% of area median income.

- *Public Housing and Rental Assistance Division*: The Public Housing and Rental Assistance Division provides funding for approximately 45,000 public housing units that are managed by the state's 242 independent Local Housing Authorities. In addition, this Division has the responsibility for regulatory and administrative oversight of all state-aided public housing programs that address the needs of low-income families, elderly, and persons with disabilities.

- *Housing Stabilization Division*: The Division of Housing Stabilization (DHS), DHCD's newest unit, is charged with the mission of preventing homelessness, sheltering those for whom homelessness is unavoidable, and rapidly re-housing the homeless in stable, permanent housing. DHS's work is guided by the Massachusetts Commission to End Homelessness' Plan to End Homelessness and the Patrick-Murray Administration's Interagency Council on Housing and Homelessness. This division also oversees the Tenancy Preservation Program that serves persons with disabilities who are facing eviction.

- *Community Services Division*: This Division builds the capacity of individuals and strengthens communities through a comprehensive and integrated service delivery approach. The Office of Sustainable Communities supports local community development and capacity building activities, providing assistance, workshops and training, and resources. The Division also administers the federal CSBG, LIHEAP, and CDBG programs.

Brief Overview of Funding

DHCD does not provide any services designed specifically for Persons with Autism Spectrum Disorder, nor does it collect data on how many persons it serves with a diagnosis of ASD. Several of its housing programs serve Persons with Disabilities, and there are three supportive housing loan programs funded through state bonds that fall under DHCD's umbrella. The quasi-public Community Economic Development Assistance Corporation (CEDAC) acts as the underwriting agent for these programs, which provide deferred-payment, subordinated permanent mortgage financing to help meet the costs of producing affordable housing. Loans to community-based projects are made through:

- *Facilities Consolidation Fund*, which finances community residences for clients of the Department of Mental Health and the Department of Developmental Disabilities, and permanent housing for the mentally ill. This program provides funding for the production and acquisition of special needs housing for clients of DMH and DDS who are being de-institutionalized, living in inappropriate or unsafe housing, or are homeless. FY2012 funding available was $7,500,000, which supported 140 units of housing.

- *Housing Innovations Fund,* which supports limited equity cooperatives, single-room occupancy housing, housing for special needs populations, and other innovative projects. FY2012 funding available was $8,000,000, supporting 400 units.

- *Community Based Housing (CBH),* which provides funding for the development of integrated housing for people with disabilities, including elders, with priority for individuals who are in institutions or nursing facilities, or are at risk of institutionalization. FY2012 funding available was $5,000,000, supporting 36 units.

The Division of Public Housing and Rental Assistance manages several rental assistance programs for which low-income persons with disabilities are eligible:

- Chapter 667: elderly and persons with disabilities (FY2012 funding included in Public Housing Administration budget; 4,500 units households)
- Chapter 707: clients of the DMH (FY2012: $6,000,000; 1,200 households)
- Chapters 689, 167: clients of DMH and DDS (FY2012 funding is included in the PHRA Administration budget)
- Alternative Housing Voucher Program: very low income persons with disabilities, under age 60. (FY2112: $3,450,000; 400 households)

Section 8 Rental Assistance Special Vouchers: persons with disabilities are eligible under several of the Special Voucher programs. (FY2012: $230,000,000 in federal funds for all the Section 8 voucher programs; 19,954 households)

Appendix F:Introduction to Sub-committee Reports and the Sub-committee Reports in their Entirety

Introduction to Sub-committee Reports

The four sub-committees were created to analyze the specific needs of individuals with autism in four age groups. The sub-committees included Birth to Five, School age, Transition, and Adult. Members of the sub-committees included professionals, parents and other family members, as well as self-advocates. The membership of each sub-committee was composed of individuals who had both designated interest and expertise in the issues facing individuals with autism in each age group. Each sub-committee had two chairs that were responsible for directing the group's work.

The sub-committees met between January 2011 and August 2011. They were charged with identifying the most prevalent issues facing their respective age group and designing methods for improving services and supports for this population. The Sub-committees drafted reports and made presentations to the full Commission on their findings. The Commission used the information the sub-committees reported to assist in determining its own priorities and recommendations.

Each sub-committee was given the same template to draft a report detailing the group's findings. The four sub-committee reports are displayed in their entirety below.

BIRTH TO FIVE SUB-COMMITTEE

FINAL REPORT

Birth to Five Sub-committee Report

Members: Autism Commission Sub-committee - Birth to Five

Louann Larson-Co-Chair
Division Director
Family Support Division, Northeast Arc
Linda Schaeffer-Co-Chair
Director
Thom-Pentucket Early Intervention Program
Massachusetts Early Intervention Consortium, Representative
Kathleen Carley
Executive Director
Project CHILLD
Therapeutic Center for Holistic Integration of Listening Learning and Development
Cariann Harsh
Director
Autism Division - Massachusetts Department of Developmental Services
Crystal Hebert
Parent
Coordinator: Act Early Outreach Task Force
Susan McCarthy
Assistant Division Director
Family Support Division, Northeast Arc
Kristy Murphy
Director
Building Blocks Program, Northeast Arc
Margaret Nelson
Education Specialist
Special Education Planning and Policy Development Office
Massachusetts Department of Elementary and Secondary Education
Tracy Osbahr
Director of Specialty Services
Massachusetts Department of Public Health
Marisa Petruccelli
Director
Autism Spectrum Disorders Clinic, National Autism Center
Joan Toussaint
Educational Advocate

Overview of the Group Process

There have been 8 meetings of the Birth to Five Sub-committee starting in January 2011 and continuing until August 2011. Please see attached minutes for details of these meetings.

The overall focus of the group meetings were to identify the current services /supports available to children birth to five with an ASD diagnosis, the existing gaps and barriers and to recommend strategies to close these gaps. Services/supports that were evaluated included: screening, diagnosis, information and referral, family support, personnel preparation, therapeutic and habilitative services, school based services and transition. In the interest of not "reinventing the wheel", we identified key partners whose efforts are already focusing on closing some of the gaps we identified: early identification of children from all parts of the state and early connection of families to regional support centers. Below are the partners we researched:

- The Act Early state campaign has already involved all of the key stakeholders in the field of community based early childhood services in its planning process, out of which has come a comprehensive plan to reach out to community health centers, pediatricians and day care providers, including underserved communities. We see their (unfunded) awareness campaign as essential to ensuring that ALL children are getting the proper screening and follow up in a timely way. As a national campaign of the CDC, they have a wealth of very high quality materials on line available to use for this purpose.
    - In **July**- Elaine Gabovitch, MA Act Early Ambassador and State Team Leader, discussed the Act Early efforts in MA including the establishment of Outreach, Training and Early Identification task forces. The partnership with the CDC was reviewed and the available resources distributed to members of the sub-committee.

- The Autism Consortium was formed as a partnership between the major teaching hospitals in Massachusetts who are also the primary providers of diagnostic services in the Commonwealth. The Consortium represents a model we would like to replicate on a larger scale, one that systematically and timely connects families to supports such as information and referral, support groups and counseling. The Consortium is an important link to ensure that families are not only connected to the supports within the Consortium, but to their local (regional) Autism Support Centers, which provide them with long term support. The Consortium also has excellent on-line resources that can be of use to families and professionals across the state.
    - In **April**-Sheri King, Resource Specialist at The Autism Consortium, provided an overview of the services offered to families, the research that is being done and the impressive range of informational resources available on the Consortium website, including a resource database. A follow up meeting was held between Shari, Deirdre Phillips, Executive Director of the Consortium, Cariann Harsh (director of Autism Division at DDS and Sub-committee member), and Sub-committee co-chairs, Louann Larson and Linda Schaeffer. We met to explore the possibility of developing a partnership consisting of two components: (1) possibly sharing a database between the Consortium and DDS funded regional Autism Support Centers and (2) creating a more formalized two-way referral process

In addition to the monthly meetings, members researched the following questions and information:

- What are the existing Autism Related Options of Study: Degrees, Certifications and Educational Programs in Massachusetts?[38]

- Is it feasible for a partnership to be formed between The Autism Consortium and The Autism Support Centers? Can the resource databases be combined?

- How easy is it for families to access, understand and navigate web-based resources? A review of 7 web sites was completed in order to determine which features were family friendly and easily understood. These sites were chosen because (1) they were managed by authoritative organizations and (2) members of the sub-committee had found at least one aspect of their site to be very useful to families and/or professionals:

    - Autism Speaks
        - http://www.autismspeaks.org

    - Autism Consortium
        - http://www.autismconsortium.org

    - Centers for Disease Control
        - http://www.cdc.gov/ncbddd/actearly/index.html

    - American Academy of Pediatrics
        - http://www.aap.org/healthtopics/autism.cfm

    - New England INDEX
        - http://www.disabilityinfo.org

    - Mass Advocates for Children
        - http://www.massadvocates.org/autism-center.php

    - Asperger's Association of New England
        - http://www.aane.org

Overall the group actively discussed each agenda item and jointly determined steps needed. The following report reflects the consensus of the sub-committee members.

[38] Charts are included after the conclusion of the Birth to Five Sub-committee Report

CURRENT BEST PRACTICES

The following are components of the current Massachusetts autism service system that can be built upon:

- American Academy of Pediatrics (AAP), and its Massachusetts Chapter, supports and promotes early and frequent screening.
    - AMERICAN ACADEMY OF PEDIATRICS (AAP): "Identification and Evaluation of Children With Autism Spectrum Disorders" by Chris Plauch Johnson, MD, MEd, Scott M. Myers, MD, and the Council on Children With Disabilities, published in AAP's journal, Pediatrics.[39]
    - MASSACHUSETTS CHAPTER OF AAP scheduled a conference in November 2011 entitled: "*The 2011 Summit on Early Childhood: Investment in our Future"* its primary focus was finding ways to improve coordination among pediatricians and other professionals to address early childhood developmental and behavioral health needs.[40]

- Act Early's Campaign of the Centers for Disease Control (CDC) provides tools and strategies to educate parents, health professionals and early childhood educators about early signs of developmental 'red flags'.

    - ACT EARLY GOALS AND TOOLS FOR PROFESSIONALS can be easily accessed at their website:[41]
    - MASSACHUSETTS STATE TEAM PLAN for the Act Early Campaign has developed a plan to implement the goals of the campaign at the state level, including action steps to increase public awareness, to implement training for professionals, and develop and disseminate culturally sensitive screening kits and protocols.

- Under the provisions of the Children's Behavioral Health Initiative, behavioral health screening, (and when indicated, diagnosis and treatment) is the right of all children on MassHealth:
    - CHILDREN'S BEHAVIORAL HEALTH INITIATIVE (CBHI) includes provisions requiring primary care providers to offer standardized behavioral health screenings at well child visits, and requires mental health clinicians to use a standardized behavioral health assessment tool.[42]

- Early Intervention Programs serve and screen children who have not yet been diagnosed. EARLY INTERVENTION (EI) SERVICES through the Department of Public Health (DPH) may be available to a child under the age of three, and his/her family, if the child is not reaching developmental milestones in one or more areas of development; or, has a diagnosed condition that may result in a developmental delay; or, is at risk for developmental delay due to a combination of certain biological and/or environmental factors. A multi-disciplinary team provides therapeutic services to the child in 'natural settings' to facilitate the developmental progress of the

[39] www.pediatrics.org/cgi/doi/10.1542/peds.2007-2361

[40] http://mcaap.org/assets/Summit-on-Early-Childhood-10-4-2011.doc

[41] http://www.cdc.gov/ncbddd/actearly/index.html

[42] http://www.masspartnership.com/provider/index.aspx?lnkID=CBHI.ascx

child.[43] If the early intervention clinicians observe 'red flags' consistent with ASD, they will refer the family to a diagnostician who can determine if the child is on the spectrum.

- Intensive Autism Specialty Services are provided for children under the age of three with a diagnosis of Autism Spectrum Disorder (ASD)
    - INTENSIVE AUTISM SPECIALTY SERVICES through Department of Public Health (DPH) are designed to offer intensive intervention to children with a diagnosis on the autism spectrum. Specialty Service Providers (SSPs) work in conjunction with Early Intervention Programs to address the needs of the family related to enhancing the child's development using a range of techniques (applied behavioral analysis, discrete trial training, floor time, incidental teaching) to address the core characteristics of autism in highly individualized treatment programs settings' to facilitate the developmental progress of the child.[44]

- Autism Waiver Services are available to a limited number of families of children with intensive needs, providing home-based therapeutic services and other supports
    - CHILDREN'S AUTISM WAIVER administered through the Department of Developmental Services' Autism Division provides intensive in-home services (such as ABA and DIR/Floor Time) for children from low-income families with autism spectrum disorder and other services to support children in their homes and communities. Children must be between the ages of 0-8, be Medicaid eligible, and be at risk of institutionalization.[45]

- The Family Preservation Project helps to keep children in their local home, school, and community by providing intensive home-based services to the child, and a variety of supports to the family.
    - The DESE/DDS FAMILY PRESERVATION PROJECT is the result of an interagency agreement between the Department of Elementary and Secondary Education (DESE), which pays for the services, and the Department of Developmental Services (DDS), which administers the services.

- There are seven Autism Support Centers located in all geographic regions of the state
    - AUTISM SUPPORT CENTERS, funded by the Autism Division of DDS, provide information and referral services to approximately 7000 parents and professionals annually.
    - AUTISM SUPPORT CENTERS also provide social skills, sensory and support groups, family activities, and trainings to approximately 1500 families annually.

    - Consensus has been reached in defining what constitutes "best practice" in the transition of children from early intervention to educational services
        - "BEST PRACTICES IN EARLY CHILDHOOD TRANSITION" was a report produced collaboratively in 2010 by the Department of Public Health (DPH), Department of Early Education and Care (DEEC), and the Department of Elementary and Secondary Education (DESE). It includes important recommendations for parents and EI service coordinators to follow, including starting early (at least 6 months before the child's 3rd birthday) to plan for the next stage, and to gather and organize the documents and information that will facilitate future meetings with educators, clinicians, medical personnel, or insurers, who may be involved in shaping the child's IEP and plan of care and treatment.[46]
        - A MEMORANDUM OF UNDERSTANDING (MOU) between DPH, DESE, DEEC, and AYC (Department of Children and Families – HeadStart/Migrant HeadStart) has been drafted.

- Clear guidelines have been provided to educators regarding the elements of appropriate educational services for students with ASD

    - SECTION 1. CHAPTER 71B, SECTION 3 OF THE GENERAL LAWS, passed in 2006, changed expectations regarding the standards for the education of students on the autism spectrum[47]

    - DESE ADVISORY: SPED 2007-1: AUTISM SPECTRUM DISORDERS: Technical Assistance ("Best Practice") Advisory from the Department of Elementary and Secondary Education (DESE) was issued in 2006 to provide guidance to educators about proper implementation of the changes to Chapter 71B[48]

    - The Act Relative to Insurance Coverage for Autism (ARICA) has opened up access to therapeutic services for some children by requiring private health insurers in Massachusetts to provide coverage for the diagnosis and treatment of Autism Spectrum Disorder

    - The AUTISM INSURANCE RESOURCE CENTER at The Shriver Center provides information to and gathers feedback from the public regarding insurance coverage[49]

[43] http://www.eiplp.org/documents/earlyintervention_brochure_2008.pdf

[44] http://www.mass.gov/eohhs/docs/dph/com-health/early-childhood/puzzling-behavior.pdf

[45] http://www.massadvocates.org/major-initiatives-autism.php#Waiver

[46] http://www.mass.gov/Eeoe/docs/EEC/programs_licensing/special_needs/transition_guide.pdf

[47] http://www.malegislature.gov/Laws/GeneralLaws/PartI/TitleXII/Chapter71b/Section3

[48] http://www.doe.mass.edu/sped/advisories/07_1ta.html

[49] http://www.disabilityinfo.org/arica/

THE GAPS:

A) Some groups of children, especially those with young mothers, mothers who have a primary language other than English, and mothers who were foreign born, have lower rates of early ASD diagnoses and do not have the benefit of intensive specialty services at an early age. These findings are published in the May 16, 2011 issue of the journal, Pediatrics: Early Diagnoses of Autism Spectrum Disorders in Massachusetts Birth Cohorts, 2001-2005, by Susan E. Manning, Carol A. Davin, Wanda D. Barfield, Milton Kotelchuck, KarenClements, Hafsatou Diop, Tracy Osbahr and Lauren A. Smith[50].

B)There is a shortage of diagnosticians, resulting in long wait times for appointments, and consequently, long delays between time of screening and time of diagnosis.

C) Families of children who are diagnosed feel confused about where to turn for information, and often not aware of resources right in their own communities.

D) The transition from one service system to another is difficult for many parents and children.

E) Some school personnel and parents are unaware of children's rights under Chapter 71B[51], resulting in educational plans that are not adequate to meet students' individual needs.

F) The Autism Waiver serves only 130 children and their families with intensive home based supports, while close to 600 families had applied for the supports in 2011.

G) Families need a break from round the clock care, but respite services and flexible funding are severely limited.

H) Insurance coverage under ARICA is a "limited covered benefit" that does not apply to those covered by MassHealth or by self-insured plans, and is subject to insurance carrier interpretation.

I) there is a shortage of qualified professionals available to provide the therapies required by children who are currently eligible for these services.

[50] http://pediatrics.aappublications.org/content/early/2011/05/12/peds.2010-2943

[51] For a description of Chapter 71 B please follow this link: http://www.malegislature.gov/Laws/GeneralLaws/PartI/TitleXII/Chapter71b/Section3

BIRTH TO FIVE SUB-COMMITTEE RECOMMENDATIONS

RECOMMENDATION #1
SUPPORT THE "LEARN THE SIGNS, ACT EARLY CAMPAIGN" BY ADOPTING THE STATE PLAN: TO BE IMPLEMENTED IMMEDIATELY[52]

Act Early is a CDC initiative with an impressive web presence, complete with high quality downloadable materials, but it is only useful if the material is distributed by key partners and accessed by providers and parents.

The Act Early Campaign's State Team members have been working diligently on a volunteer basis to promote the dissemination of these CDC-generated materials about red flags and the importance of early screening to childcare and pediatric healthcare providers in Massachusetts.

A. As a short term goal, the dissemination of these CDC materials could become part of a systematic, statewide effort, potentially coordinated by the Autism Support Centers. State funding for printing and distribution of materials would need to be allocated to the Centers specifically for this purpose.
B. The MA Act Early State Team is involved in two efforts aimed at fostering culturally appropriate screening protocols: one is a pilot with 3 health centers, and a second involves the development of a screening protocols and kits for CHC's and pediatric practices in three languages other than English. We recommend that the state assist in these efforts, applying the findings of the pilot project to other centers, and funding the production and distribution of the screening kits throughout the state.
C. A long term goal of the MA Act Early Campaign is to increase the availability of clinicians who are trained to provide comprehensive evaluations of children at risk for ASD. We recommend that there be a coordinated plan, developed in partnership with the AAP, Mass Psychological Association and MA medical schools, to address the need for training of physicians and psychologists

[52] Unless specified otherwise

RECOMMENDATION #2:
CREATE A SINGLE POINT OF ENTRY: MEDIUM TO LONGTERM IMPLEMENTATION (3 TO 5 YEARS)

A. DESIGN: We recommend that the use of a Hub (Autism Division) and Spoke (Regional Autism Centers) intake system, where someone entering the "wheel" (through early intervention, or a specialty service provider) will be directed to their local Autism Center. And if someone at a Center receives a call from a family who lives outside of their area, the intake still be conducted, automatically connecting them with the Autism Division, and the referral made to the Autism Center in their own area, all with one phone call.
B. RATIONALE:
    a. When a child is diagnosed with ASD, many families struggle to find information and support, not realizing that there is a Center located in their own community, staffed with professionals well-prepared to guide them. A protocol that shortens the span of time between diagnosis and connection with a Center will reduce stress for the family and facilitate access to appropriate benefits, services and supports for the child.
    b. Allows unduplicated demographic data to be collected in a systematic way to facilitate future planning, evaluate effectiveness, identify underserved regions and populations.
    c. Even minimal information gathered about families, such as email, town and birth date of child/individual with ASD would allow for targeted dissemination of information about pertinent trainings and workshops, age appropriate events and opportunities, and reminders of steps to take with the approach of important transitional planning targets (i.e., 3 years, 5 years, 14 years, etc.)
    d. Credible and sustained research into etiology and treatment of ASDs will ultimately benefit all children and families; therefore we recommend that information about opportunities to participate in locally conducted research should be routinely shared with interested families by the Autism Division.

RECOMMENDATION #2: (cont'd)
CREATE A SINGLE POINT OF ENTRY

C. COMPONENTS:

a. **Intake and Referral to local Autism Centers:** All diagnosticians in the state would be expected to refer the family of a child with an ASD diagnosis to their local Center, (or alternately, to the Autism Division, where they would be referred to the local Center). The family would be asked to sign a consent to be referred directly by the diagnostician. If the family declines, the diagnostician would provide the easy-to-remember toll-free phone number (for instance: 1-888-4-AUTISM) and/or website (for instance: www.Autism.ma.state.us) where they would be directed to the appropriate contact. Families not wanting to be identified beyond contact information could access basic information, training and referral through the Centers. Those wishing to access more substantial supports such as flexible funding, case management, social skills or support groups would go through a more thorough (but uncomplicated) intake process. Additional resources would be required by the Centers for increased staffing to respond to the increased volume of calls and requests for service that the 'single-point-of-entry' protocol would generate.

b. **Centralized resource database managed cooperatively by local Centers:** Currently Centers each maintain their own databases and have rich information about services and supports in their local areas, sometimes including feedback from families who have accessed them. Ideally, such information could be fed into a centrally maintained database that could be accessed directly by families from a central Website.

c. **Website:** The Website would have a straight forward title so that it could easily be located in a web search. It would be designed explicitly for parents (who likely have limited time available to spend on the computer, and who may be experiencing a high degree of stress as they absorb the implications of their child's diagnosis): It should provide information in an easy to read format, in small doses, with options for visitors to "learn more" about a particular topic, as they are ready. It should encourage them to connect with their local Center where they can access supports in their own community.

RECOMMENDATION #3:
EDUCATE IEP TEAM MEMBERS ABOUT THE CONTENTS OF THE 2007 DESE ADVISORY: TO BE IMPLEMENTED IMMEDIATELY

A. The Advisory[53] represents best practice guidance from the DESE related to the change in special education law enacted in the spring of 2006 that affects special education programming for students with disabilities on the autism spectrum. Its purpose is to assist school districts and other interested parties in understanding the requirements set forth in the changes in the special education law and in implementing best practices for meeting the needs of these students. As such, all districts should provide training to their staff regarding the content of the Advisory and incorporate it as standard practice in all schools.
B. Routinely offer training about the "Advisory" to all parents through the regional Autism Resource Centers

[53] web link provided under Best Practices above

RECOMMENDATION #4:
IMPLEMENT POLICIES THAT WILL INCREASE THE AVAILABILITY OF QUALIFIED AUTISM PROFESSIONALS: TO BE IMPLEMENTED IN THE NEXT 3 TO 5 YEARS; SHARING OF INFORMATION ABOUT COURSES CAN BE IMPLEMENTED IMMEDIATELY

A) Establish and maintain a database of institutions offering courses, certifications and degree programs in autism and autism related fields, and provide public access via a centralized (Autism Division)) website.[54]

B) Develop an autism specialization within the state university and community college system, with loan forgiveness or other incentives to attract students.

[54] See charts after conclusion of Birth to Five Sub-committee report

RECOMMENDATION #5:
INTRODUCE LEGISLATION TO CLOSE GAPS IN THE ARICA LAW:TO BE IMPLEMENTED IN THE NEXT THREE YEARS

- The article MANAGEMENT OF CHILDREN WITH AUTISM SPECTRUM DISORDERS, published in AAP's journal, Pediatrics "reviews the educational strategies and associated therapies that are the primary treatments for children with autism spectrum disorders".[55] While this review does not identify the full range of therapies available, it illustrates that there is a variety of effective strategies, in addition to ABA, which have been shown to be effective, and which are well-accepted by the medical community. Recognizing that research on the efficacy of various approaches is still in its infancy, and that new interventions will continue to emerge as potentially effective and legitimate treatments, it may be necessary to broaden the scope of covered services, and/or to broaden the interpretation of the language of the current law.

- Coverage mandates should be extended to all children with ASDs, including those insured by MassHealth and self-funded plans.

[55] MANAGEMENT OF CHILDREN WITH AUTISM SPECTRUM DISORDERS , by Scott M. Myers, MD, Chris Plauche Johnson, MD, MEd, and the Council of Children with Disabilities http://pediatrics.aappublications.org/content/120/5/1162.full

CONCLUSION

As the Birth-to-Five Sub-committee crafted its recommendations, its members were cognizant that autism services in early childhood are relatively robust when compared to supports available at other points in the lifespan. By implementing these recommendations, we believe that policy-makers and providers will be able to strengthen the existing early childhood 'scaffolding'; coordinating and building on exemplary efforts already underway, for little cost, and with little bureaucratic maneuvering.

These efforts will yield benefits that reach far beyond age five. The earlier young children are screened, diagnosed, and appropriately treated by qualified personnel, and the sooner their *families* are connected to local support networks, the better prepared these future school children, teens and adults will be for the challenges ahead.

Autism Related Certificate Options

Affiliation	Certificate Program	Available to:	Website	Location
Antioch University New England	Autism Spectrum Disorders Certificate	Working professionals and parents	http://www.antiochne.edu/ap/asd/asd.cfm	Keene,NH
Antioch University New England	Applied Behavior Analysis Certificate	Students who hold a master's or bachelor's degree	http://www.antiochne.edu/ap/aba/	Keene,NH
Cambridge College	Behavior Analyst Certificate	Students who hold a master's degree and have met other general requirements	http://www.cambridgecollege.edu/lawrence/programs.cfm	Lawrence, MA
Elms College	Certificate of Advanced Graduate Study in Autism Spectrum Disorders	Students who hold a master's or bachelor's degree	http://elms.edu/-Academics-/Graduate_Programs/Autism_Spectrum_Disorders.xml	Chicopee, MA
Endicott College: Institue of Behavioral Studies	BCBA Certificate	Professionals who hold a graduate or undergraduate degree in Special Education, Psychology, or highly related fields	http://endicott.edu/GradProf/InstBehavStudiesCertification.aspx	Beverly, MA
Endicott College: Institue of Behavioral Studies	Certified Applied Behavior Analyst Technician	Special Education paraprofessionals. Training is provided to classroom assistants who assist teachers in the implementation of evidence-based Applied Behavior Analysis teaching techniques for students diagnosed with Autism Spectrum learning disorders.	http://endicott.edu/GradProf/InstBehavStudiesCertification.aspx	Beverly, MA

Affiliation	Certificate Program	Available to:	Website	Location
The ICDL (Interdisciplinary Council on Developmental and Learning Disorders) DIR Institute	DIR (Developmental, Individual difference, Relationship-based Model) Certificate	The program is designed for *licensed and credentialed* professionals from different disciplines who apply DIR® principles and practices in their existing areas of expertise and specialization in their work with children and adolescents with developmental, learning and infant mental health challenges	http://www.icdl.com/dirInstitute/competency/index.shtml	Bethesda, MD (Distance Learning options)
Lesley University	Autism Spectrum Disorders Advanced Professional Certificate	Students who hold a master's or bachelor's degree	http://www.lesley.edu/online_learning/autism_apc_pos.html	Cambridge, MA
New Hampshire Technical Institute	Autism Early Invervention Specialist Certificate	Students, working professionals and parents	http://www.nhti.edu/academics/academicprograms/certautism.html	Concord, NH
Salem State College	Advanced Graduate Study in Autism Spectrum Disorders	Students who hold a master's or bachelor's degree in education or a related field	http://www.salemstate.edu/academics/schools/9076.php	Salem, MA
University of Massachusetts	Graduate Certificate Program in Behavioral Intervention in Autism	Students who hold a master's or bachelor's degree	http://www.umassonline.net/degrees/Online-Certificate-Autism.cfm	Various Locations in MA
University of New Hampshire	Graduate Certificate in Autism Spectrum Disorders	Students who hold a bachelor's degree in a related field	http://www.iod.unh.edu/Academics/graduate-certificate-autism-spectrum-disorders.aspx	Durham, MA
University of Southern Maine	Certificate in Applied Behavior Analysis	Students who hold a master's degree	http://www.usm.maine.edu/catalogs/graduate/certificates.htm	Portland, ME
Westfield State University	Graduate Certificate in Applied Behavior Analysis	Students who hold a bachelor's degree in a related field	http://www.wsc.ma.edu/prospective-students/academics/psychology/psychology-graduate/	Westfield, MA

Autism Related Degree Options

Affiliation	Degree Program	Available to:	Website	Location
Becker College	Bachelor or Arts in Psychology-Applied Behavior Analysis	Students have a high school diploma or GED	http://www.becker.edu/pages/262.asp	Worcester, MA
Elms College	Master of Science in Autism Spectrum Disorders	Students who hold a bachelor's degree in a related field	http://elms.edu/-Academics-/Graduate_Programs/Autism_Spectrum_Disorders.xml	Chicopee, MA
Endicott College: Institute of Behavioral Studies	Master of Education in Special Needs and Behavioral Studies	Students who hold a bachelor's degree in a related field	http://endicott.edu/GradProf/InstBehavStudiesDegrees.aspx	Beverly, MA
Simmons College	Master of Science in Behavioral Analysis	Students who hold a bachelor's degree in a related field	http://www.simmons.edu/gradstudies/programs/behavior-analysis/ms.php	Boston, MA
Simmons College	Doctorate in Applied Behavior Analysis	Students who have a master's degree or higher in Behavior Analysis, Applied Behavior Analysis, or a related field, including psychology, education, or special education, and must be a Board Certified Behavior Analyst™	http://www.simmons.edu/gradstudies/programs/behavior-analysis/phd.php	Boston, MA
University of Massachusetts	Masters Degree in Curriculum & Instruction: Autism Studies Option	Students who hold a bachelor's degree in a related field	http://www.umass.edu/education/licensure/programs.shtml	Amherst, MA

Affiliation	Degree Program	Available to:	Website	Location
University of Massachusetts, Dartmouth	Masters Degree in Psychology-Applied Behavior Analysis	Bachelor's degree in Psychology or a closely related field	http://www1.umassd.edu/graduate/prospects/programs.cfm	Dartmouth, MA
University of Southern Maine	Master of Science in Educational Psychology-Applied Behavior Analysis	Students who hold a bachelor's degree in a related field	http://usm.maine.edu/sehd/Educational-Psychology/progreqs.htm	Portland, ME
Western New England College	Master of Science in Applied Behavior Analysis	Students who hold a bachelor's degree in a related field	http://www1.wnec.edu/artsandsciences/index.cfm?selection=doc.8393	Springfield, MA
Western New England College	Doctorate in Behavior Analysis	Students who have earned a master's degree in behavior analysis or are certified as a master's-level behavior analyst by the Behavior Analysis Certification Board	http://www1.wnec.edu/artsandsciences/index.cfm?selection=doc.6317	Springfield, MA
Westfield State University	Master of Arts in Applied Behavior Analysis	Students who hold a bachelor's degree in a related field	http://www.wsc.ma.edu/prospective-students/academics/psychology/psychology-graduate/	Westfield, MA

Autism Related Educational Options

Affiliation	Program	Format	Website	Location
Advances Learning Center	Consultation Services	Consultation	http://www.advancesonline.com/Consultation.shtml	Watertown, MA
Advances Learning Center	Parent Workshops	Workshop	http://www.advancesonline.com/Workshops.shtml	Watertown, MA
Aspergers Association of New England	Cinical Supervision and Educator Consultations	Consultation	http://www.aane.org/aane_services/consultation_training.html	Watertown, MA
Aspergers Association of New England	Consultation for Families, Adults and Professionals	Consultation	http://www.aane.org/aane_services/consultation_training.html	Watertown, MA
The Astra Foundation	DIR/ Floortime Classes for Parents and Professionals	Course	http://www.astrafoundation.org/	Acton, MA
Autism Projects, MA Advocates for Children	Education and Training for Parents and Professionals	Course/Training	http://www.massadvocates.org/trainings.php	Boston, MA
The Autism Resource Center of Central MA	IEP Clinics	Clinic	http://www.autismresourcecentral.org/education.html	West Boylston, MA
The Autism Resource Center of Central MA	Activities of Daily Living Clinics	Clinic	http://www.autismresourcecentral.org/education.html	West Boylston, MA
The Autism Resource Center of Central MA	Visual Clinics	Clinic	http://www.autismresourcecentral.org/education.html	West Boylston, MA
The Autism Resource Center of Central MA	Floortime for Parents	Course	http://www.autismresourcecentral.org/education.html	West Boylston, MA
The Autism Resource Center of Central MA	Empowering Families with Brain Gym-Parent Course	Course	http://www.autismresourcecentral.org/education.html	West Boylston, MA
The Autism Resource Center of Central MA	Autism 101	Course	http://www.autismresourcecentral.org/education.html	West Boylston, MA
The Autism Resource Center of Central MA	Parent/Professional Workshops	Workshop	http://www.autismresourcecentral.org/education.html	West Boylston, MA
Affiliation	**Program**	**Format**	**Website**	**Location**

Autism Related Educational Options				
Affiliation	**Program**	**Format**	**Website**	**Location**
The Autism Resource Center of Central Mass.	Tea with MD's	Workshop	http://www.autismresourcecentral.org/education.html	West Boylston, MA
The Autism Resource Center of Central Mass.	Conference Grants for Families	Conference	http://www.autismresourcecentral.org/education.html	West Boylston, MA
The Autism Resource Center of Central Mass.	ABA for Parents	Training	http://www.autismresourcecentral.org/education.html	West Boylston, MA
Community Autism Resources	Inclusion of Students with Autism: What Every Classroom Teacher Should Know!	Course	http://www.community-autism-resources.com/services/courses/index.html	Swansea, MA
Community Autism Resources	Paraprofessional Training: Working with Individuals with ASD	Course	http://www.community-autism-resources.com/services/courses/index.html	Swansea, MA
Community Autism Resources	Finding Local, State, and Federal Resources for ASD	Course	http://www.community-autism-resources.com/services/courses/index.html	Swansea, MA
Community Autism Resources	Review of Best Practice in the Education and Support of Persons with Autism Spectrum Disorder	Course	http://www.community-autism-resources.com/services/courses/index.html	Swansea, MA
Community Autism Resources	Learning Styles of Individuals with Autism Spectrum Disorders	Course	http://www.community-autism-resources.com/services/courses/index.html	Swansea, MA
ICDL (The Interdisciplinary Council on Developmental and Learning Disorders)	Introduction to the DIR/Floortime Model for parents and professionals	Online Video Lecture	http://www.icdl.com/distance/basic/index.shtml	Bethesda, MD (Distance Learning Options Available)
ICDL (The Interdisciplinary Council on Developmental and Learning Disorders)	Look into my Eyes Parent's Floortime Project	Online Video Lecture	http://www.icdl.com/distance/basic/index.shtml	Bethesda, MD (Distance Learning Options Available)

Affiliation	Program	Format	Website	Location
ICDL (The Interdisciplinary Council on Developmental and Learning Disorders)	Autism Spectrum or Not?	Online Audio Lecture	http://www.icdl.com/distance/webRadio/index.shtml	Bethesda, MD (Distance Learning Options Available)
ICDL (The Interdisciplinary Council on Developmental and Learning Disorders)	Peer Play	Online Audio Lecture	http://www.icdl.com/distance/webRadio/index.shtml	Bethesda, MD (Distance Learning Options Available)
ICDL (The Interdisciplinary Council on Developmental and Learning Disorders)	Case Study of ADHD	Online Audio Lecture	http://www.icdl.com/distance/webRadio/index.shtml	Bethesda, MD (Distance Learning Options Available)
ICDL (The Interdisciplinary Council on Developmental and Learning Disorders)	Coping with Stress The New Road Map to Guide Early Child Developmental Policies	Online Audio Lecture	http://www.icdl.com/distance/webRadio/index.shtml	Bethesda, MD (Distance Learning Options Available)
ICDL (The Interdisciplinary Council on Developmental and Learning Disorders)	Integrating Developmental and ABA Approaches	Online Audio Lecture	http://www.icdl.com/distance/webRadio/index.shtml	Bethesda, MD (Distance Learning Options Available)
The Kindle Center	Workshops and Training for Parents and Professionals	Training/Workshop	http://www.kindlebehavior.com/workshops.php	Burlington, MA
The New England Center for Children	Parent Training	Training	http://www.necc.org/consulting_training/training.asp	Southborough, MA
The New England Center for Children	ABA Workshops	Workshop	http://www.necc.org/consulting_training/workshops.asp	Southborough, MA

SCHOOLAGE SUB-COMMITTEE FINAL REPORT

School Age Sub-committee

Co-Chairpersons

Judith Ursitti, Autism Speaks, Parent
Richard Martin, NECC

Member

Joan Anderson, Special Education Administrator
Lisa Attenazio
Kevin Barrett
Lydia Brown, Self Advocate
Michelle Brown, Special Educator, OT
Carol Coleman, Parent
Shawn Connelly, Agency Representative
Elizabeth Carona, MD Behavioral Pediatrician
Ann Gaston, Grandparent
Rebecca Girard, Program Representative
Robin Huer
Elizabeth Keefe, Special Education College Instruction
Madeline Levine, Agency Representative
Cariann Harsh, Agency Representative
Ann Neumeyer, MD, Pediatric Neurologist
Lisa Puccia, Parent
Christopher, Supple, Esq. Attorney, Parent
Caroline vanBruinswaardt, Parent
Timothy Walsh, Parent, Advocate

Sub-committee Meetings:

January 26, 2011 (MDDC – Quincy)
February 9, 2011 (State House)
March 9, 2011 (State House)
April 6, 2011 (State House)
May 11, 2011 (State House)
June 8, 2011 (Lurie Autism Center)
July 15, 2011 (Lurie Autism Center)
August 20, 2011 (Lurie Autism Center)

Background of Target Population:

The target population included individuals age 6-17 who had been diagnosed with one of the pervasive developmental disorders according to the DSM-IV. This includes Autistic Disorder, Asperger's Syndrome, PDD-NOS, Rhett's Syndrome and Childhood Disintegrative Disorder

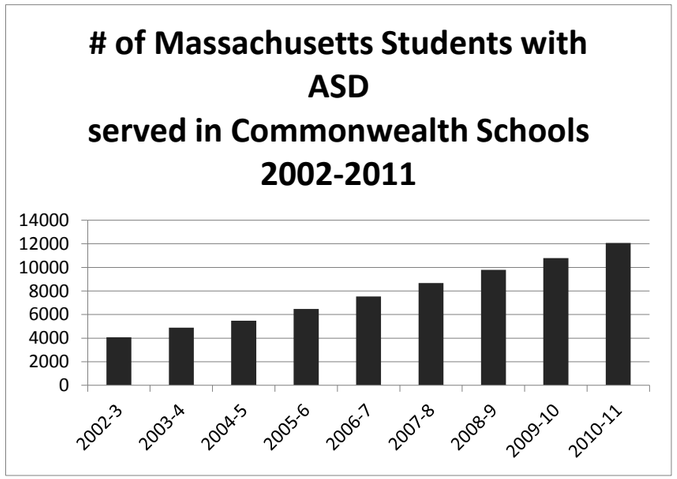
Other demographics included those who might *no*t have received an official diagnosis, but who would likely fall under the PDD umbrella if/when appropriately identified. CDC autism surveillance indicates the average age of diagnosis in the U.S. is 5.6 years. The Asperger's diagnosis generally occurs much later: 7.2 years.[56]

All services and supports were considered, including those provided by the state, local and federal governments as well as those funded privately.

The full range of needs was considered to the best of the Sub-committee's ability, including considerations for range of diagnosis (i.e. autistic disorder and Asperger's Syndrome can require different supports), age, as well as geographic and cultural disparities.

Additional information was analyzed regarding trends in the number of Massachusetts Students with Autism Served in Commonwealth Schools over the past decade:

Figure 1. Number of Massachusetts Students with Autism Served in Commonwealth Schools, 2002-2011.[57]



[56] Paul T. Shattuck, PhD, et al. Timing of Identification Among Children with an Autism Spectrum Disorder*J. Am. Acad. Child Adolescent. Psychiatry 2009; 48(5): 474-483*

[57] Source:Massachusetts Student Information Management System

The increase is staggering, calculated at almost 200% according to information obtained from DOE:

Table 1. Percent Increase of Students with ASD in the Commonwealth, 2002-2011

Category	2002-3	2010-11	% increase (decrease)
Total number of students served in Commonwealth	983,313	966, 395	(1.7%)
Total number of students with disabilities	155,204	164,711	6.1%
Total number of students with ASD	***4,080***	***12, 058***	***195%***

Source: Massachusetts Student Information Management System

Existing Services and Supports:

The sub-committee analyzed existing supports and services, identifying general themes and then expanding the analysis to include the three focus areas: family supports, healthcare and education.

General Themes

The identified general themes were as follows:

- Need for interagency collaboration.
- Consolidation of sources of information. The need for a stream of consistent information was deemed critical.
- Development of better definitions of behavior support, taking into account range of skills.
- Building professional capacity.
- Need for development of transition support.
- Awareness and enforcement of anti-bullying statutes.

Family Supports

Autism impacts not only the person diagnosed, but also parents, siblings, grandparents and others. The following is an analysis of the existing supports and services for families:

- Availability of home support services and trained personnel is inconsistent.
- Respite capacity is limited.
- Information and training about best practices is inconsistent.
- Mental health services are lacking.
- Cultural barriers complicate the ability to access services.

- Community awareness and understanding of the range of behaviors and skills across the spectrum has improved.
- Capacity for range of service needs is limited for both properly trained professionals as well as community non-professionals.

Healthcare

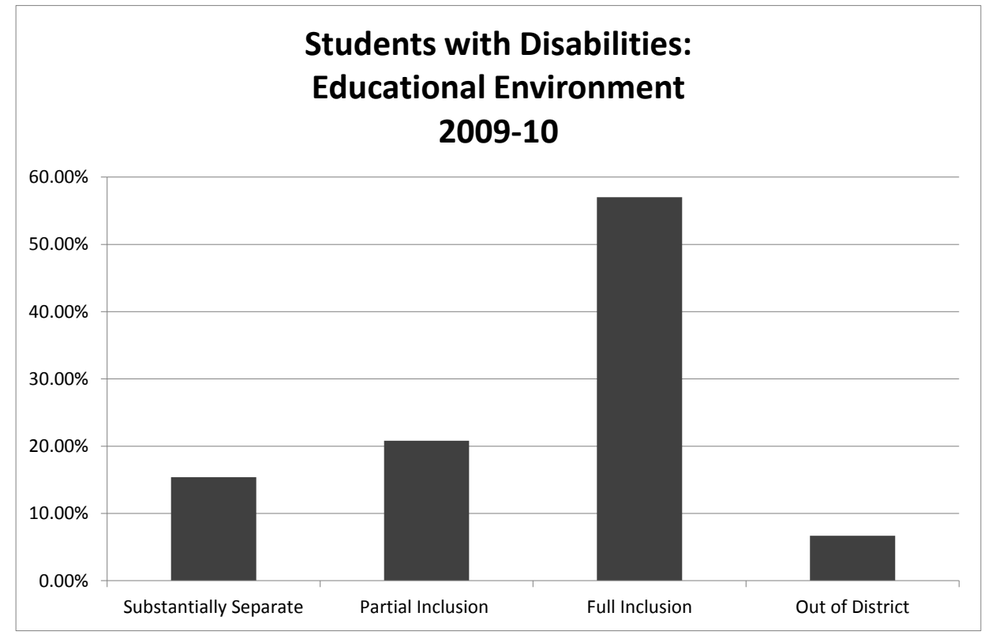
Access to timely screening, diagnosis and treatment of ASD is critical yet currently:

- The number of providers in Massachusetts is not meeting the demand for diagnosing individuals in a timely manner.
- Medical professionals lack training to accurately recognize the signs of all types of ASD. (For example, there is no screening tool for Asperger's Syndrome.)
- Massachusetts has the strongest autism insurance reform law in the nation.
- Massachusetts has one of the most limited Autism Waivers in the nation.
- Stakeholders need assistance pursuing health insurance benefits under ARICA, the state autism insurance law and also the Medicaid Autism Waiver as well as MassHealth.
- Mental health supports are virtually non-existent.
- The American Academy of Pediatrics encourages the medical home model, but funding remains an issue. Interagency collaboration is required for the medical home model to be successful.

Education

Massachusetts has the reputation of being one of the strongest educational systems in the nation, with the majority of students being educated alongside their peers in a full inclusion setting.

Figure 2. Students with Disabilities Educational Environment, AY 2009-10.



Source: ***Report to the Legislature: Annual Report on Students with Disabilities 2009-2010.***

Definitions:

Full Inclusion – at least 80 percent of the time in general education classroom

Partial Inclusion – 40 percent to 79 percent of the time in general education classroom

Substantially Separate – less than 40 percent in general education classroom

Out of District Placements – separate schools or residential facilities

Provision of *appropriate* education to students on the autism spectrum is inconsistent.

- There is currently limited access to information regarding the range of services within the educational domain and also services outside of the public schools.
- Consistency and availability of services across communities and school districts does not exist. For example, the Boston Globe recently reported that families have been relegated to moving to other towns, pursuing "real estate therapy" in order to live in school systems that provides appropriate educational services.
- Behavior supports sensitive to the range of skills across the spectrum are limited.
- Special education instructors as well as regular education teachers lack autism specific training.
- Since a majority of students diagnosed with an ASD are included in a full inclusion setting, training is critical or the student will not be able to access the curriculum in any sort of meaningful way.

Identified Needs and Related Recommendations:
The needs of the school-age autism population across the Commonwealth are many. When you consider the diversity of the population, prioritizing needs presents a formidable challenge. For example, the needs of a non-verbal teenager might be quite different than those of a kindergartner diagnosed with Asperger's Syndrome. Resources available in suburban communities can be starkly different than those found in rural areas. Different communities have different cultural points of reference. Access to quality education, transportation and basic healthcare can be a challenge.

Certain general themes were encountered throughout the sub-committee's analysis:

- While a number of services exist, there are not enough and these are widely dispersed making availability and access difficult.
- It can be challenging for families to find programs; there is an increasing amount of information available, but there is not sufficient centralization of information sources to make it easy to access
- Funding is inadequate to provide the range and adequacy of service needs

The sub-committee, as referenced previously, determined the most effective course of action would be to focus on three key focus areas: family supports, healthcare and education. The focus area groups worked over the course of several months to identify needs and to make recommendations that would be both meaningful and achievable.

These are included in the tables below:

Medical Focus Group Identified Needs and Related Recommendations

Medical Issues	Needs	General Recommendations	Action Steps
Access to diagnosis	1) Education of pediatric providers to identify signs/symptoms of high functioning ASD and Asperger Syndrome	Work with stakeholders and agencies in the field to create a viable and validated mechanism for screening and surveillance of high functioning ASD and AS in school aged children	1) Support collaboration between stakeholders and researchers 2) Insure that screening materials are appropriate for diverse populations and languages
Access to diagnosis	2) Access to adequately trained providers who accept insurance	Educate families with insurance not covered under ARICA about other options for insurance coverage (for example, for families with MassHealth, use CommonHealth subsidy of secondary commercial insurance policies subject to ARICA)	1) Provide State funding for a contact person within MassHealth to support families when they are applying for supplementary insurance 2) Provide State funding for the newly created Autism Insurance Resource Center to increase awareness of Autism Insurance Resource Center and other autism insurance advocates.

Medical Focus Group (continued)

Medical Issues	Needs	General Recommendations	Action Steps
Access to ongoing medical treatment	Lack of expertise/resources in most pediatric settings to address complex medical, social, and mental health needs of children with ASD	Create incentives and supports for pediatric providers to create a "medical home"	1) Provide supplemental reimbursements to pediatric providers who create a medical home with care coordination for patients with ASD 2) Fund care coordinators (possibly through Autism Waiver mechanism) through DPH to support pediatric practices throughout the state by creating centralized sources of information (e.g. databases) and telephone support/consultation (in model of MCPAP) to pediatric providers and families 3) Provide supplemental reimbursements to other medical providers (specialists/dentists) who provide services for children with ASD to offset additional time/resources devoted to patient visits.

Medical Focus Group (continued)

Medical Issues	Needs	General Recommendations	Action Steps
ARICA	1) Education of pediatricians about the law and their role	Increase awareness and knowledge	1) Collaborate with Massachusetts Chapter of AAP, Mass Medical Society, and other stakeholders to provide information about the program and how to help families access services (e.g. writing prescriptions and referrals that are accepted by insurance) 2) Disseminate information to pediatricians and educators about the distinctions between educational and medical services (e.g. upcoming Technical Bulletin from the AG's office and DOE regarding this issue)
ARICA	2) Ongoing education of parents about the law	Increase awareness and knowledge	Fund Autism Resource Centers to provide guidance and information to parents about ARICA
MENTAL HEALTH	Access to adequately trained providers who accept insurance	Increase access through primary care providers, and increase access to providers with expertise in the field	1) Expand funding of MCPAP to augment autism expertise within the program 2) Provide financial incentives/supplemental reimbursement for psychiatric providers (both psych pharmacologists and therapists) who care for complex patients with ASD

Education Focus Group Identified Needs and Related Recommendations

Educational Issue	Current Issue	Recommendation
Students	• Precipitous rise in number of students with ASD served by Commonwealth schools\	• Total number of students with disabilities in Massachusetts has remained static; configuration has changed. Investigate implementation of services and supports across districts in Commonwealth • Survey districts across the state for a look at implementation of services for consistency/equity
Practice	• Use of evidence based practice in school may limit the number of methodologies used	• Support districts through grant funds in engaging in action-based research to identify services and practices that improve access to the curriculum for students with ASD • Support ongoing University and other research on interventions • Seek grant funding to support these initiatives • Establish an Autism Advisory Council that reports to the state Board of Education by adding to the list of current advisory councils, "Autism Spectrum Disorders" following the line "There shall be established advisory councils to the board in the following areas" in M.G.L. Chapter 15, Section 1G. • Require an appropriately trained professional with experience/expertise with ASD on IEP team (see defining training, experience, below)

Education Focus Group (continued):

Educational Issue	Current Issue	Recommendation
Teacher Preparation	• Number of students with disabilities in MA	• Creation of a competency-based endorsement for licensed teachers working with students with ASD in MA • Invitation of members of Autism community/university representation to join DESE to develop endorsement for ASD • Establish an ongoing Autism Advisory Board to work with state agencies including DESE • Creation of university and community organization sponsored professional development series (low cost, fundraiser to organizations that serve families) - Offer PDPs for teachers (would minimize cost of training for Commonwealth, invite participation of MA IHE's) • Identify University and Agency point persons to ensure previous • Establish a best practices web site as resource for those who work with ASD population, including regulations such as c. 71b • Establish definitions of "appropriately trained" and specific competencies

Family Supports Focus Group Identified Needs and Related Recommendations:

Family Supports Issue	**Needs**	**General Recommendations**
Availability of home supports and personnel	Substantial need for a range of services as documented by wait lists in various agencies (e.g. DDS, ARCs, MGHY).	Quantify, consolidate, and distribute data about available providers. Expand home support services.
Availability of home supports and personnel	Access to ABA providers.	Rely on evidence-based practice when developing support services. Consolidate and make available lists of ABA providers.
Availability of home supports and personnel	Physical activity (especially in winter) and wellness programs for children with autism need to be focuses of support services.	Develop after school programs that emphasize physical activity. Expand the availability of facilities where families can bring their children. Develop and disseminate information about wellness practices related to ASDs. Increase recreational programs designed to serve children with ASDs.

Family Supports (continued)

Family Supports Issue	Needs	General Recommendations
Availability of home supports and personnel	Providers of services to children with ASDs often overlook emotional support for families.	Increase awareness by various service providers of the need to include this as a component of services. Broaden programs to include overall wellbeing of parents/caregivers of children with ASDs
Building respite capacity	Lack of trained providers.	Specify competencies for individuals providing care to include level of education, experience, and strategies to work with children across the spectrum. Investigate and expand the network of possible providers (e.g. church groups, college students in related fields) with incentives (e.g. college credit). Develop/expand upon a model of "drop in" respite programs.
BUILDING RESPITE CAPACITY	Parents may have insufficient knowledge to evaluate the adequacy of respite providers.	Create a list of characteristics/skills parents can use as an evaluation tool.

Family Supports (continued)

Family Supports Issue	Needs	General Recommendations
Safety and Community Awareness	Non-professional caregivers may be at risk of injury when working with children/adolescents with ASDs who have challenging behavior.	Include behavior management strategies as part of training.
Safety and Community Awareness	Wandering can be a significant problem.	Disseminate information to families and physicians that wandering now has a code and parents can get help with this behavior. Develop parent awareness of need to notify public safety officials if their child/adolescent exhibits this behavior.
Safety and Community Awareness	Social media can be a resource for socialization but can also pose risks especially for children/adolescents with more advanced social skills.	Examine the impact of social media on children/adolescents and develop guidelines for families on how to navigate social media safely.
Safety and Community Awareness	General awareness and availability of safety-related programs are not equitably available across all communities.	Evaluate the availability of safety-related programs and develop a system to insure all communities have access. Build upon currently available programs to improve effectiveness of community awareness.

Family Supports (continued)

Family Supports Issue	Needs	General Recommendations
Safety and Community Awareness	There are key people in the community who need to know about the range of behaviors presented by children/adolescents across the spectrum to avoid misunderstanding and victimization.	Identify and advise communities about 'who needs to know' (e.g. first responders, public safety personnel, teachers, transportation workers, clergy, judicial system).
Cultural Barriers	Some cultures may be reluctant to access services due to cultural belief systems.	Expand outreach services that examine and sensitively respond to encourage families to explore services.
Cultural Barriers	Language can be a significant impediment to access.	Make ELL specialists available in all government services.

TRANSITION SUB-COMMITTEE
FINAL REPORT

Members of the Transition Sub-Committee Workgroup

CHAIR	
Gloria Ricardi Castillo	-Co-Director, NEARC/ Autism Support Center -Mother of a young adult son with autism
MEMBERS	
Marty Martini	-Executive Director of Minute Man Arc - Board of Directors Doug Flutie Jr. Foundation - Father of an adult young man with autism.
Elaine Gabovitch	- Family & Community Partnerships Director & LEND faculty, UMass Medical School/E.K. Shriver Center - State Ambassador & Team Leader, MA Learn the Signs/Act Early Campaign - Member, Mayor Menino's Autism Task Force - Mother of a teenage son with autism
Paula Jacobson, MEd	-Past President of the Board of Directors at NEARC -Parent Advocate -Parent to young man with ASD
Janine A. Solomon	-Senior Staff Attorney Disability Law Center -Primary practice area special education; litigated in the *Dracut Public Schools* case -Mother of a pre-teen with autism
Stacey Cruwys	-Outreach Coordinator of the Spotlight Program (Social Skills) at Northeast Arc
Kathy McNamara Ohman, LICSW	Parent of two young men with Autism
Kathleen Kelly	-Director of the Transition Program at the Northeast Arc
Maureen Durkin O'Connell, M.A.	-Mother of a young adult daughter with autism -Ipswich Public Schools Teacher
Marisa L. Petruccelli, Psy.D.	-Clinic Director, Autism Spectrum Disorders Diagnostic Clinic- a joint program of The National Autism Center and May Institute
Linda Tarmy	-MA Department of Elementary and Secondary Education
Carolyn Langer MD	-MassHealth, Chief Medical Officer -Co-founder of cub scout 222 for boys with special needs. -Parent of a teenager with ASD

Vision Statement for Transition Services:
Transition planning is the route to adulthood and should begin early, at least by age 14, but possibly earlier. Transition should be a purposeful, organized and outcome-oriented process designed to help students with disabilities move from school to employment or post-secondary education. In other words, transition builds the bridge to an enriching adult life.

Parents and student should begin to consider what the student wants to do after leaving public education, in a way that is meaningful to him or her. Family involvement and personal goals should be addressed in the transition plan. The student's educational team should use a "person centered approach" or similar planning tool to develop a Transition Plan and appropriate and measurable post-secondary goals and objectives on the student's Individual Education Plan. Special attention should be given to non-English speaking families by providing translations to all documents in their native language and by having qualified interpreters attend meetings.

Strengths and needs of students on the autism spectrum vary greatly. Strategies and tools are available so that students of various abilities can take part in the transition planning process. The student's participation and self-determination needs to be continuously cultivated.

The student should have an effective communication system that works for him or her whether the student is verbal and uses speech and language fully or nonverbal and accesses communication via an assistive technology device; such communication will allow the student to participate in the process and increase his or her chances of success during the transition process and beyond.

There should be interagency collaboration among adult service providers, employers and post-secondary institutions early on, as well as other local and state agencies. Duplication of efforts can be reduced by improving interagency coordination and collaboration. **It is recommended to utilize a common transition planning process and standard documents; acceptance of other agencies' services (i.e., assessments) and selection of a single transition service coordinator.**

Planning for transition well before leaving school will help the student sort out the maze of resources, determine eligibility for these resources overcome the gaps in services, and get him or her started on a productive path to independence in adulthood.

Brief Overview: Transition Sub-committee Process
The group's major objective was to ascertain how services are currently delivered to individuals across the Autism spectrum, including Asperger's Syndrome (now referred to as Autism Spectrum Disorders or ASD) during the transitional age of 14-22. Throughout the 7 months and 8 meetings the sub-committee reevaluated the process as a whole and continually discussed the development of the entire group's plan, remaining cohesive, on task, and consistent as possible.

Based on extensive professional and personal experiences, the group quickly identified the foundation of our age group as „Building the Bridge" to adult services. Serious gaps and inconsistencies in services exist for adults as they transition from an entitlement system under special education law which focuses on a school district's obligation to provide transition services to adult services with strict eligibility requirements to a non-entitlement system with services based on budgetary constraints.

Background on the Target Population
This group extensively examined the needs of 14-22 year olds but throughout the process the group considered individuals of all ages across the entire autism spectrum. ***It is our consensus that all children and adults with ASD need a single point of entry in order to effectively navigate the services and opportunities in our Commonwealth, thus enabling individuals to maximize their life potentials.*** All public and private sector agencies were examined in the process of our review. Our work group of advocates, parents, state agency representatives and educators respectfully considered the needs of all individuals on the spectrum, from those with Asperger's Syndrome to those with limited or non-verbal functioning. The group agreed that special attention should be given to the non-English speaking population. Due to language and/or cultural barriers the non-English speaking population is a very difficult group to perform effective outreach to and consequently serve. The group discussed how to perform better outreach to this population in order to make sure that these families and children receive needed services and supports.

Existing Services and Supports
Our group first examined best practices related to transition for 14-22 year old students with ASD both offered within and outside Massachusetts; in public and private schools. The group also analyzed how public and private agencies deliver services to the autism population focusing on the services offered to transition age youth living with autism. . Upon researching the current practices in place in Massachusetts our work group developed a working checklist for best practices to explore further. The committee interviewed 14 public and private schools as well as services provided by DDS, MRC, DESE, DMH, HES, CBHI[58], and outpatient clinics that serve mental health patients in emergencies, and a wide range of not-for-profit agencies (including ARCs, etc.). The group also benefited from an important and extensive study done by Ms. Eve Wilder of the UMMS/Shriver Center LEND Fellowship Program dated June 14, 2011. Her report, "The Turning 22 Puzzle," reviewed best practices, systems and policy change activities in other states, and made important policy recommendations for serving adults on the autism spectrum. The group found Ms. Wilder's policy recommendations particularly helpful in regards to her suggestion to "Create an Autism Registry to Track the Prevalence of ASD in both Children and Adults".

Our group encountered many models of best practices throughout the Commonwealth including exceptional educational transition plans and transition coordinators at a non-profit. The sub-

[58] DDS-Department of Developmental Services; MRC-Massachusetts Rehabilitation Commission; DESE-Department of Elementary and Secondary Education; DMH-Department of Mental Health; HES-Health and Education Services; CBHI- Children Behavioral Health Initiative

committee discussed what the guiding principles of transition should be and decided on these principles by dividing the areas of need into four sub-categories: self-determination, vocational training; life skills; and post-secondary education. Below we describe the findings and concerns, gaps in services, and recommendations for each of the four areas.

Self-determination

Findings/Concerns:

Self-determination is a concept that crosses over all transition areas: post-secondary education, vocational training, health care and activities of daily living. It is also an essential skill that all individuals living with ASD can use in their daily lives. Many students with severe disabilities will not be able to learn all the skills and knowledge needed to solve difficult problems. However, this is equally true for most areas in which students with severe disabilities receive instruction, a situation that has been dealt with by the principle of partial participation (Baumgart et al., 1982).[59] This principle states that even if a student cannot do all steps in a task or activity, he or she can likely learn at least one step and maximize his or her participation. The four guiding principles of self-determination are: 1) services should be designed to help individuals and families so that they can be integrated in the community; 2) supports should be designed to help individuals and their families recognize the individual's true abilities and potential; 3) supports should be individual/family-friendly in that they are understandable, easy to access, culturally-sensitive; and 4) the system should be transparent: those receiving services should have easy access to information to aid in the decision-making process.

Self-determination is an essential component for transition. It includes feeling a sense of empowerment and the ability to take action in one's life, voice concerns when problems occur, communicate needs effectively, assert legal and personal rights, and the ability to recognize and stand up for oneself when at risk of being taken advantage of or victimized. This skill is pertinent when adolescents are transitioning between providers in the health care system. During this time, adolescents take increased responsibility for their own health care while these individuals and their families begin to transfer care from their pediatrician to an adult provider.[60] As this example portrays, without secure self-advocacy skills, students may not be able to navigate their world independently.

In Massachusetts transition planning services are required to begin at age 14. Self-determination is a major component of the transition planning process. The state's Transition Planning Form (TPF) requires an action plan outlining "how the student can develop self-determination skills and be prepared both academically and functionally to transition to post-school activities in order to achieve his/her post-secondary vision." There are multiple methods to assess the level of self-determination used during the transition process. In developing self-determination goals and objectives, you need to know what skills comprise self-determination, decide what skills to teach to individual students, and know where to find instructional materials to provide instruction (i.e., self-determination curricula). These methods will be used to determine the strengths and weaknesses present in the current system of transition supports in reference to self-determination.

[59] Baumgart et al., (1982). Principle of Partial Participation and Individualized Adaptations in Educational Programs for Severely Handicapped Students. *Journal of the Association for the Severely Handicapped* , 7, 17-27.

[60] In the event that the disability is significant enough to interfere with the ability to make financial and medical decisions, parents need to file a petition to maintain guardianship or initiate conservatorship when the adolescent turns 18.

Gaps in Services:

- DDS articulates the principles of self-determination but the realities of the budget often limit individuals" options as it relates to their free choice.
- Many families transitioning their sons and daughters into the adult system go through a period of "sticker shock" and feel overwhelmed by the system. For many years parents only interact with their child's school. During transition they have to look into a future for their child that will be full of interactions with many agencies, for some this will be their first time dealing with DDS, DMH or MRC. At this time, families feel very vulnerable and in many cases are facing for the first time the harsh reality of their son or daughter's future. For many kids on the spectrum if their families have not been connected with an agency until the time of transition this can be daunting. Collaboration among agencies is essential.
- Primary care providers are often not trained in how to share information with adolescents with autism about a variety of important health topics. This makes it difficult for adolescents with autism to be knowledgeable about their health.
- Lack of trained adult specialists[61] exist to work with this population.
- Schools do not always provide self-determination curriculum and training for students so that they can identify their own strengths and needs and be able to communicate them to others as independently as possible.

Recommendations:

1. Ensure that the 688 and or any referral process for adult services takes into consideration all providers, what the students' needs are and will be and if eligibility for services will be an issue.

2. Teach students about their IEP and transition plan and require them to be active members of their team throughout the transition process.

3. Schools should ensure that their students have goals to improve their self-advocacy and provide the resources and training to reach these goals

4.Utilize person-centered planning and individual choice to drive outcomes for programmatic and placement needs for individuals with developmental disabilities.

5. Allow for more input from families in the transition process; possibly the development of a Family Advisory Council.

6. Re-open and expand the services provided through the DESE/DDS prevention program (funded by DESE and administered by DDS). These funds are used to provide supports to families who receive funding for in home supports & therapies which help their children with disabilities stay enrolled in their home school.

Life Skills Summary

Findings/Concerns

Comprehensive life skills training for people on the autism spectrum enables individuals to reach their maximum potential for living independent lives. This preparation relies upon comprehensive and

[61] Trained adult specialists are professionals with experience in the field of autism

standardized curricula - across all ages of the autism spectrum - and must be accessible to all regardless of socio-economic background, race, or ethnicity.
Critical components of quality life skills programs include:

1. **Personal Care and Independent Living Skills**- grooming, dressing, eating, food preparation, money management, home maintenance, etc.
2. **Transportation**- travel training, including pedestrian safety, using public transportation, reserving The Ride or other services
3. **Recreation and Leisure –** seamless inclusion in and access to community resources
4. **Post School living/ Housing**- a range of options must be available in the individual's community, including group living, adult foster care, and in-home supports.
5. **Medical Needs** – including self-advocacy, making all medical appointments and daily medicine routines.
6. **Peer and Social Relationships**, social skills, personal safety, and accessing social time in the community must be affordable, accessible, and appropriate for the entire spectrum.
7. **Navigating the Adult World** – understanding adult benefits, guardianship issues, banking, grocery shopping, using a pharmacy, communication assessments.
8. **Health Care Transition**- assistance with adult benefits, including applying for Social Security, government funded medical programs, and locating physicians who serve adults on the spectrum.
9. **Life Coach –** assistance with job-coaching, life-coaching, social pragmatics, social- emotional health.
10. **Puberty & Sexual Education**- basic fundamentals of teaching should be included based on each student level; this should be collaboration between schools and parents.

Gaps in Services
Currently life skills are covered to some degree, but their content and depth varies greatly from one school district to another. A personal skills inventory including the above elements should guide the areas of greatest need as the individual ages and aid in the design of a comprehensive, lifelong, person centered approach.

Recommendations:
1. A single point of entry or intake to assist individuals with acquiring life skills. This process would allow referrals to be made to various public and private agencies depending on the age and needs of the consumer.

2. Eligibility for services based upon functional assessments rather than IQ measures, due to the inherent characteristics of autism and the autism spectrum

3. Parents register at entry point to receive regular information and critical updates about services and application requirements at important transitional service points. Service coordinators and life coaches assist families and individuals, particularly those who may not have access to the internet or for whom English is not their native language.

Vocational Supports
Findings/Concerns:
Young adults with ASD need to be involved in a consumer friendly, person centered employment training system. Appropriate training opportunities for people on the spectrum are limited and less available to those who live outside of urban catchment areas. This information was based on personal and professional experience of the members working in this particular group.

Vocationally, young adults with ASD may regularly experience difficulties understanding the routine subtleties of interaction with co-workers and the concept of team work to accomplish tasks. Generalizing information from one work experience to the next often requires more practice or training than for neurotypical employees. Individuals with ASD are often more successful with sequential singular tasks with clear cut directions, expectations, and anticipated results.

Gaps in Services:

- There is a need for specialized employment training targeted at a range of function levels that consider the unique profile and needs of young adults with ASD, while providing ongoing coaching, support with job search and job maintenance.
- There is a need for investment in long term job development that match the skill set specific to this population, employment that adults with ASD are able to maintain over time and achieve success in. Coaching supports would facilitate this goal.
- There is a need for meaningful collaboration to provide integrated vocational services between schools and state and private agencies. There should be incentives for schools to develop employment connections in the community that transition to paid jobs at age 22.

Recommendations:
Life coaching and Assessments - should begin early at the onset of transition planning, (age 14). Multiple types of assessments should inform instructional planning and vocational training. These include but are not limited to intelligence testing, safety skills assessment, vocational/functional assessments, adaptive behavior assessments, personal interests" inventories or preference assessments, employability tests and self- determination. A comprehensive array of assessments should be administered and repeated throughout the transition process and thereafter to provide a framework to adjust training and monitor progress.

Schools- Should be trained in transition "best practices" for individuals with ASD; their role and responsibilities. Schools should make use of the Department of Elementary and Secondary Education's Work Based Learning Plan.[62]

1. **Job Training Coordinated with #3** –should include instruction to fluency on the skill to be performed at the work site, but also adaptive skills identified in assessment results that will have a direct impact on successful employment. These might include: vocational advocacy, (asking for help, procedures specific to the jobsite, e.g., when to take lunch, how to express concerns with supervisor, etc.), personal grooming and hygiene, money management and transportation. There should also be instruction on coping with unexpected situations, (sick days, public transportation delays, inclement weather, etc.) and resources.

2. **Job Development with Flexible Coaching Supports** – Coaching supports should be made available to all individuals with ASD. An effort should be made to create incentives for employers offering employment to individuals with ASD. Appropriate supports should be provided to employers to understand how to manage, coach, evaluate and problem solve with individuals with ASD. There should be a state-wide directory of employers willing to engage

[62] http:/www.skillslibrary.com/wbl.htm

individuals with ASD in internships or jobs. We recommend the development of a state-wide interagency collaboration model that will provide individuals with ASD access to vocational training and employment opportunities, that will include funds for the training, coaching and support needs of individuals with ASD, to become successful employees and contributors to their communities. An effort should be made to explore private and non-profit funding sources to support employment initiatives for individuals with ASD.

3. **Transportation** – for training and employment should be accessible to individuals with ASD.

Short Term Goals:

- Training for schools based on transition „best practices" for student with Autism roles and responsibilities
- Training for vocational personnel transition „best practices" for students with Autism – roles and responsibilities

Long Term Goals:

- Development of a state-wide interagency collaboration model that will provide students with Autism access to educational and vocational opportunities

- Development of a state-wide cadre of employers willing to engage student with Autism as interns and/or employees

- Allocation of additional State funds for the training, coaching, and support needs of students with Autism to be successful employees.

- Finding additional funding sources across the state to help support the employment initiatives for students with Autism - private and non-profit

Transition to Post-Secondary Education
Findings/Concerns:
Transition from school to post-secondary education for students with ASD must be well planned. There are many inconsistencies and misunderstandings when it comes to transition planning for these students. For example, students need more than academic preparedness to experience success in a post-secondary educational institution. Whether it is a community college, four year school, technical training, or a certificate program, all students will need to have the ability to understand and correctly interpret the social skills[63], abstract language, and perspective of others in order to navigate their world. They will also need executive functioning skills6 to make decisions and solve problems for themselves. Also, it is critical that students play an active role in this process. They must learn to be their own self advocate and be ready to identify their needs so that they can communicate them to others.

Gaps in Services:
Many of the gaps in services for students interested in continued education are due largely to poor communication between service providers. It is critical that during the transition process all agencies including but not exclusive to the Department of Developmental Services, the Department of Mental Health and Massachusetts Rehabilitation Commission discuss the best possible approach for the transition in a person centered format. The team can be a critical link to ensuring that services are effective and not duplicated.

The presumption that DDS eligible students will not pursue higher education is unfounded. We have anecdotal information of students with mild mental retardation during the transition process that have never been given the opportunity to explore options like technical or vocational schools.

An essential component to planning for post-secondary educational goals is assessments. Not only are academics assessments necessary to make placement decisions, but also evaluations on social skills, pragmatic language skills, and executive functioning abilities. A thorough understanding of the student's abilities is critical in order to begin the planning process. Once there is an understanding, the student should be actively involved by researching and visiting all possible opportunities in order to make an informed decision. This includes but is not limited to: researching careers, discovering and exploring interests, interviewing people in the profession, internships, enrolling in a college class, college/school tours, and assistance with the application process. It is also essential that those who are guiding the student understand who they are working with. Lastly, because a post-secondary education vision can change over time, the team must regularly check-in and evaluate the goals to make sure everything is on track.

Recommendations:
1. Immediately: Begin planning for post-secondary education early (age 14). Assemble the team and review checklists annually in a Transition meeting. This is required but according to reports from parents it does not seem to be taking place in every school across Massachusetts. Parents have the right to reject the IEP if the Transition Planning Form is not on the IEP but many parents are not aware of this

2. Conduct interest inventories and assessments in all suggested areas to determine thoughtful placement decisions.

3. Set goals in the Transition Planning Form (TPF) and review them regularly with the team. Make adjustments/changes as necessary.

4. The student MUST be part of the process and be able to communicate his/her needs. The law instructs the Team to include the student at the meetings as an active participant. As members of the Team, the student and parent have a voice in all discussions and the student should play an active role from the start and learn to be their own self-advocate.

[63] Executive Function-The term executive function describes a set of cognitive abilities that control and regulate other abilities and behaviors. Executive functions are necessary for goal-directed behavior. They include the ability to initiate and stop actions, to monitor and change behavior as needed, and to plan future behavior when faced with novel tasks and situations. Executive functions allow us to anticipate outcomes and adapt to changing situations. The ability to form concepts and think abstractly are often considered components of executive function

Conclusion: Closing Letter from the Transition Sub-committee Chair Gloria Ricardi-Castillo

To Whom It May Concern:

The majority of the sub-committee members are parents of children with ASD; people who know firsthand the needs of this population.

We have worked diligently to come up with our report that hopefully will provide the Commissioners with the proper information that when implemented will allow students with ASD in Massachusetts to get the support and tools they need to go through the transition process. So that they can be ready when they graduate out of school to ensure a productive life whether they are going to a day program, to work, or to higher education.

Due to my position at the Autism Support Center, throughout the years I have had the opportunity to talk to hundreds of families looking for help, support and information. Regardless of where the calls are from, every single parent longs for the best services for their child. The process is not easy, never mind the fact that parents are stressed out, vulnerable, confused and in many cases feeling that they are running out of time-because as we all know the earlier that services are provided the best chances for a good outcome!

Commonly we can see that the more affluent communities tend to have more services and support while the less privileged communities have an arduous struggle to receive much needed services. What we hope for is change, we hope that in the future students with autism will attain the tools they need to succeed no matter where they are. We hope that from Springfield to Newton every single student with ASD has a comprehensive program that meets their needs.

I would like to thank everyone involved in this group; it has truly been a pleasure working with such a remarkable group of people! Throughout this process we put aside our differences and biases (if there were any) for a greater purpose. It has undoubtedly been an honor.

Sincerely,
Gloria Ricardi Castillo

Transition Best Practices Checklist
Parents and student have begun to consider what the student wants to do after leaving public education in a way that is meaningful to him or her. Family involvement and goals are addressed in the plan.
The student's team uses a "person centered approach" or similar program to develop a transition plan.
The transition plan starts at 14 (by Law in MA). It could start earlier.
Focusing in skills for life; real work experience (paid or volunteer) is included in the student's transition plan, while the student is still in school.
The student has a formal communication system that works for him or her.
Financial/income needs are addressed in the transition plan.
Establishing interagency collaboration with adult service providers, employers and post-secondary institutions early on as well as other local and state agencies-possibly included them in the transition plan.
Fostering family involvement in the transition planning process.
Continuously cultivate student's participation and self-determination
Collaboration with post-secondary institutions: High School to College: "What Every parent needs to know"

The following areas are addressed, as appropriate:
_Transportation

_Recreation and leisure

_Post School leaving arrangements

_Advocacy

_Medical needs (medications, insurance)

_Peer and social relationships

_Employment

_Post-Secondary education

_Job training

_Employer Training

_College Application/transition

_Housing

_Health Care transition to adult providers

_Independence Living Skills (ADL"s)

Example: Self Determination Self-Assessment Is designed to help students discover how much self-determination they have in their lives

____ I decide whether to live alone or with someone else.

_____I control who can and can't come into my home.

_____I can choose where I live.

_____I choose my own friends.

_____I decide whether or not to have a boyfriend or girlfriend.

_____I have people in my life who respect my values and choices.

_____I decide how to be part of my community.

_____If I want to go somewhere, transportation isn't a problem

_____I'm able to stand up for myself to get what I need.

_____I can deal with abuse, whether it's verbal, sexual or physical.

_____My basic human rights are respected.

_____I'm free to choose the kinds of goals I want to pursue.

_____I'm able to choose my medical doctor.

_____I freely choose what kinds of medical treatment I get.

_____I decide how involved I want to be in my medical treatment.

_____I have the money I need to live the kind of life I want.

_____I have the final say over how I spend my money.

_____I'm able to avoid people who show prejudice toward me.

14 Massachusetts Private/Public Schools
Interviewed by Sub-Committee members

1. Melmark New England
2. New England Academy
3. Newton Public Schools
4. Westfield Public Schools
5. Riverview School
6. Lower Cape regional Tech.
7. Chatham High School
8. Salem High School
9. Worcester Public Schools
10. Cotting School
11. Nashoba Learning Group
12. LABBB Program
13. Minute Men Program
14. New England Academy

ADULT SUB-COMMITTE FINAL REPORT

Massachusetts Autism Commission
Adult Services Sub-committee Report
Submitted July 16, 2012

Adult Services Sub-committee Members:

Martha Ziegler,	ARC of Mass.
David Specht,	Guardian
Dusya Lyubovskaya	Self-advocate
Eric Olson	Parent
Setha Olson	Parent
Kevin Barrett	Self-advocate
Lydia M.X.Z.Brown	Self-advocate
Tom Erhard	Parent
Edward Smith, Esq.	Attorney, Lobbyist, and Parent
Phil Schwarz	Asperger Association of New England ("AANE") Board VP, Parent, Autism National Committee Board Member
Rosalie Konjoian	Parent
Judith G. Doherty, M.Ed,	Parent, and Current Board Member for Autism Support Center and Executive Committee Member for Advocates for Autism of Massachusetts ("AFAM")
Nan Leonard	Attorney, Parent
Joyce Kohn	Self-advocate
Irving Sacks	Parent
Susan Senator	Parent and Author
Henry Milorin	Parent
Sara Willig	Self-advocate
Catherine Boyle	President of Autism Housing Pathways, Parent
Ann Guay	Attorney, Board Member of Mass Advocates for Children, Past AFAM Government Affairs Chair, and Parent
David Harmon	Financial Advisor, Current AANE Board Member, Executive Committee Member for AFAM, and Parent

Adult Services Sub-committee Presenters:

Catherine Boyle	President of Autism Housing Pathways, Parent
Alana Murphy	Massachusetts Department of Housing and Community Development
Martin Robb	Massachusetts Department of Housing and Community Development
Joanne McKenna	Massachusetts Department of Housing and Community Development
Rita Gardner	Executive Director of Melmark New England, Inc.
Jeff Kielson	Executive Director of Advocates, Inc.
Nannette Ohman	Executive Director, Autism Alliance of Metro-West

Autism Commissioners in Attendance:

Dania Jekel	Executive Director, Asperger's Association of New England ("AANE")
Michael Wilcox	AANE Board Member, Self-Advocate
Amy Weinstock	Director Autism Insurance Resource Center, Chair of the AFAM Health Insurance Committee
Janet George, PhD	Asst.Commissioner of Policy, Massachusetts Department of Developmental Services

Adult Services Sub-committee Contributors:

Michael Borr	Chairman AFAM
Christine Hubbard	Chair of AFAM Adult Services Sub-committee

Adult Services Sub-committee Meeting Dates:

January 31, 2011	February 9, 2011	March 9, 2011
May 11, 2011	June 1, 2011	July 6, 2011
July 13, 2011	July 27, 2011	August 3, 2011

Overview of Group Process

- Led discussions with Adult Sub-committee members regarding perceived strengths and shortfalls of current services for adults with autism in Massachusetts.
- Encouraged stakeholders to come and share their experiences with the Adult Services Sub-committee. We asked them to let us know what was working and what were the gaps in services, as they saw them.
- Considered Recommendations Regarding Services for Adults on the Autism Spectrum submitted by Advocates for Autism of Massachusetts. Invited individuals with experience in housing, employment and services for adults with Autism to come and present to the Sub-committee
- Developed proposed recommendations and arranged for a facilitator to assist the group as it developed final recommendations.

Background on the Target Population

- We focused our efforts on individuals with autism over the age of 18 and included the entire spectrum, including those with High Functioning Autism and Asperger's Syndrome.
- For the most part, we limited our research to adult services and examined services being offered in Massachusetts and other states including New Jersey, Connecticut and Pennsylvania.
- We did not limit our sub-committee's research to state services and gave considerable consideration to private supports available to adults with Autism.
- We were fortunate to have a strong presence of self advocates on the sub-committee who shared their own experiences and suggestions.

- The Adult Services Sub-committee's Recommendations took into account the full range of individuals with autism, including those with High Functioning Autism and Asperger's Syndrome.

Existing Services and Supports

- Reviewed Executive Office of Health & Human Services ("EEOHS") presentation on Adult Services to Autism Commission on 12/20/10.
- Reviewed presentations given by the Department of Developmental Disabilities ("DDS"), the Department of Mental Health ("DMH") Massachusetts Rehabilitation Commission ("MRC"), and the Office of Long Term Care concerning adult services made to the Autism Commission on January 24, 2011.
- Submitted written request to EEOHS for existing data regarding Adults with Autism.
- Reviewed Autism Commission Reports issued by other states, including New Jersey, Texas, Oregon, Colorado, Illinois and the Interagency Autism Coordinating Committee
- Spoke to Pennsylvania Bureau of Autism Services regarding Keystone Program and reached out to experts in Connecticut to compare and contrast its services with Massachusetts.
- Invited experts in housing, employment, and adult services to come and present to the Adult Services Sub-committee.

Identified Needs:

- Identified strengths and gaps in adult services provided in Massachusetts.
- Examined specialized housing/living support, employment and day habilitation supports, healthcare and mental health services, family support, data collection, higher education, community training, a public awareness campaign and loan forgiveness programs.
- Despite being eligible for services, we knew that adults who were eligible for services were not having all of their needs met. We spoke to family members and service providers about the gaps in services and asked for their suggestions on how to improve services. Particular attention paid to health care, employment and housing.
- Examined the challenges faced by adults with autism who do not qualify for services due to their IQ score yet have considerable needs.
- Special consideration given to eligibility issue and role of IQ in determination of who will receive services. Reviewed practices of states who considered functional ability when making determinations about eligibility for service
- The largest barrier to meeting the needs of adults with autism is a lack of understanding about the challenges of autism and inadequate funding. Programs need to be expanded and developed to meet the growing number of adults with Autism but there is not enough funding to pay for these programs.

Recommendations of the Adult Services Sub-committee
Originally Submitted to the Autism Commission
August 8, 2011

Each Executive Office of Health and Human Services ("EOHHS") agency shall develop a strategic plan, in consultation with their stakeholders, to support the needs of adults with Autism Spectrum Disorder ("ASD").

Recommendations for Immediate Action

a) It shall be the responsibility of each agency that serves adults with autism to develop the skills and expertise to meet the needs of individuals with autism and their families and not to limit any services to short term services. This will require that all servicing state agencies provide their staff with specialized training to meet more effectively the multiple service delivery needs of individuals with autism and their families.

b) Review all MassHealth programs, including Adult Foster Care ("AFC") and Day Habilitation to see what modifications can be made to make them more accessible to individuals with autism.

c) Provide budget language to ensure funding for students transitioning into the Turning 22 Program including annualization language.

d) Ch. 257 rate setting shall take into account the behavioral management needs of individuals with autism, staff qualification issues, staffing levels, and training needs.

e) EOHHS shall promote more inter-agency agreements and the coordination of services, similar to DESE/DDS, a program which provides funding to families whose children are at risk of a residential placement. Many of the students enrolled in this program have autism.

Recommendations for Long Term Implementation

f) Promote self-direction and individual/family directed services. Allocations should be individualized, linked to the person, and follow the individual through the system, across agency and service delivery systems.

g) Develop programs tailored to meet the needs of adults with autism, across the spectrum; including clinically intensive programs for adults requiring such levels of support. Seek new funding for programs for adults with autism across the spectrum through the use of additional federal waiver programs and/or Medicaid state plan services.

h) Funding for transportation services is a critical component in developing housing, employment, and day programming options. Budget line items for transportation need to be increased to meet these growing needs.

i) EOHHS shall appoint a task force to consider programmatic access and sensory accommodations for adults with autism under the Americans with Disabilities Act ("ADA") to improve community access.

Eligibility Issues

Revise the eligibility criteria for services for individuals with autism through the Department of Developmental Services ("DDS"). One agency will be primarily responsible for case management to ensure no adult with autism who is eligible for services falls between the cracks.

Recommendations for Immediate Action

a) Develop a single point of entry for adults with autism, ages 18 and older.

b) This entity will make an assessment of the individual and determine eligibility for services.

c) Eligibility should now be solely based on the level of impairment of functional adaptive skills, and not IQ. Adopt specifically designed functional assessment tools and criteria for autism.

d) Better to reflect the complex nature of the communication/sensory/functional and related deficits that are associated with persons with autism and other developmental disabilities, and their varied service needs, we think it is important to consider the eligibility definitions as defined in Missouri and Vermont.

e) Once eligibility is established, case management will be assigned to either the Department of Developmental Services, the Massachusetts Rehabilitation Commission or the Department of Mental Health based on the primary need of the individual with autism.

f) Case management services to adults with autism will be provided by one lead case manager who will receive specialized training in autism and the appropriate supports. Self-direction (individual and family) tailored to meet individual needs will be emphasized.

g) A diagnosis of autism will no longer be considered grounds for exclusion from DMH eligibility for services provided to individuals and/or families.

Specialized Housing/Living Supports

Every individual with autism found eligible for supported living services, shall have access to a safe, affordable and supportive place to live, appropriate to his or her needs.

Recommendations for Immediate Action

a) Provide current information through a clearinghouse on available housing for adults with autism, including state-run and local options.

b) Improve community access to meaningful and improved information and supportive services to individuals with autism and their families.

c) Develop emergency housing and supports for those with autism, at risk for homelessness or domestic violence, including emotional abuse.

d) Revise MassHealth regulations to broaden Adult Foster Care and Person Care Assistant ("PCA") services to better meet the needs of individuals with autism.

e) Planning for anyone receiving residential supports and services needs to be individualized and /or family-centered.

f) Establish criteria and best practices for life skills training.

Recommendations for Long Term Implementation

g) Develop a formal, statewide housing policy to establish priorities for individuals with autism.

h) Broaden access to low interest housing financing to individuals with autism, and their families.

i) Create innovative mechanisms for savings development for individuals with autism and their families such as Individual Development Accounts, PASS Plans, tax free savings plans (similar to 529 plans) and special needs trusts including third party, self-settled and pooled special needs trusts.

j) Require appropriate staffing levels and staff with specialized training, in residential settings, in order to meet the safety, behavioral and health needs of individuals with autism. Families need to be able to consider placement options outside their area office's catchment.

k) The amount of funds allocated for an individual will be based on current determined needs and will be regularly evaluated and adjusted throughout the individual's lifespan.

Employment/Day Habilitation Supports

All individuals with autism shall have meaningful access to daily activities and/or employment, appropriate to their needs and abilities.

Recommendations for Immediate Action

a) State and federal employment funding grants need to be expanded to include <u>all</u> eligible individuals diagnosed with autism.

b) Employment programs need to be developed to meet the specialized needs of individuals with autism. These programs can be funded through a combination of additional Federal 1915 waiver programs, other government funding and private resources.

c) Create and strengthen employment supports that maximize the abilities of individuals with ASD, including intermittent supports when needed for individuals with autism working in the private sector.

d) Sponsor roundtable discussions that include community partners such as (businesses, community organizations, autism service providers and adults with autism) to brainstorm ways to engage adults with autism in all aspects of employment, in collaboration with the Division of Workforce Development, unions, recognized business and trade organizations and employers.

e) Revise MassHealth regulations to broaden Day Habilitation services to meet more systematically the developmental needs of individuals with autism.

Recommendations for Long Term Implementation

f) Massachusetts will create a comprehensive range of training, employment, and support options to meet the varied needs of all individuals with autism.

g) Develop continuous job coaching, job development and work cooperatives with an emphasis on long-term employment retention and support.

h) Enhanced business incentives, including state tax credits, need to be developed for employers who hire and retain individuals with autism for meaningful employment commensurate with the individual's skills and abilities.

i) Improve access to public and specialized transportation.

j) Increase efforts to educate private and public employers about the potential advantages of hiring adults with autism as employees, and their strengths and potential contributions to the workplace.

Healthcare /Mental Health Services

All individuals with ASD should have access to appropriate health care and mental health services.

Recommendations for Immediate Action

a) Crisis intervention services should be available to individuals with autism.

b) Request differential rate reimbursement by MassHealth for behavioral management services to health care providers.

Recommendations for Long Term Implementation

c) Provide appropriate psychiatric, behavioral and mental health services for those individuals with autism who require them.

d) Offer incentives to increase the number of primary care physicians, neurologists, psychiatrists, dentists, emergency room personnel and other medical specialists with an expertise in autism such as medical school loan forgiveness, mentorship training and additional specialized training.

e) Integrate behavioral and physical health services for individuals with autism.

f) Autism services need to be included in the Essential Benefits Package of the Affordable Care Act.

Family Support

Family support services need to be re-prioritized and be viewed to be just as equally important as residential services.

Recommendations for Immediate Action

a) Revised MassHealth regulations to broaden Adult Foster Care services in order to better meet the needs of individuals with autism.

Data Collection

Establish integrated data systems among state agencies and stakeholders, to track diagnosis, treatment, services and outcomes of individuals with autism in order to improve coordination of care and to disseminate information.

Recommendations for Long Term Implementation

a) Develop, manage, and utilize a data system that will provide time sensitive information about individuals with autism for the public, consumers and policy makers.

b) Produce a detailed annual report on the population served, with particular attention to gaps in service delivery, and any differences between plans for services and the actual services provided.

c) Some individuals with autism have aggressive and or destructive behaviors. Study the prevalence and severity of domestic violence in families of an individual with autism. In addition to treating the cause of the aggressive/destructive behaviors, support should be provided to siblings and other family members who are subjected to aggressive/destructive behavior.

d) Post Traumatic Stress Disorder has been reported in the siblings and parents of an individual with autism who has aggressive and or destructive behavior, as well as in individuals with autism. The scope and prevalence of PTSD among individuals with autism and their family members should be measured and supports made available to treat PTSD.

Role of Autism Support Centers to Serve Adults with ASD

Expand the mission of the Autism Support Centers to provide information and referral services to adults with ASD and their families.

Recommendations for Immediate Action

a) Assist individuals with autism and their families to understand the range of available services across the lifespan and across agencies.

b) Ensure new funding to cover this expansion of staff and services.

Higher Education Recommendations

Develop pathways to include special programming through which student with autism can reach their postsecondary educational and professional goals.

Recommendations for Long Term Implementation

a) Special Educators and Guidance Counselors advising students with autism who are interested in pursuing higher education shall assist students with autism and their families as they consider appropriate college options, including attendance at community colleges.

b) Provide training to reach college students with autism and to help educators understand both their strengths and weaknesses in the academic setting.

Community Training

Develop and expand community training for professionals who interact regularly with adults with autism.

Recommendations for Immediate Action

Community training shall be developed where it does not exist and expanded where it does, with assistance from organizations such as bar associations, and offered to professionals who have frequent interaction with adults with autism, including but not limited to:

a) First Responders, such as law enforcement, emergency medical technicians and firefighters;

b) Judicial officials, such as judges, district attorneys, victim advocates, Rogers' monitors, court security officers and probate personnel;

c) Registry of Motor Vehicle personnel; and

d) Case managers, vendor agencies, social workers, intake workers, and other service-providing agency personnel.

Create an Autism Public Awareness Campaign

Develop an Autism Public Awareness Campaign

Recommendations for Immediate Action

a) Create a public awareness campaign highlights the strengths and contributions to society of adults with autism while educating the public about the nature of the challenges and disability that these individuals have.

b) This campaign should promote *understanding* of individuals with autism.

Create and Expand Loan forgiveness programs

Develop loan forgiveness programs for professionals who work with individuals with autism

Recommendations for Long Term Implementation

a)Create and expand loan forgiveness programs for primary care physicians with an autism specialty, special education teachers and direct service providers who work with individuals with autism .

Concluding Remarks:

As the number of adults with autism continues to climb, these recommendations attempt to address the complex needs of all adults with autism. Many adults with autism who are eligible for services cannot access the services they need to lead meaningful lives. Moreover, those adults with High Functioning Autism and Asperger's Syndrome who would benefit from supports are not typically eligible for services.

Government agencies understand that the needs of adults with autism are complex and not being entirely met. While demand for services continues to rise, the bad economy has led to across the board budget cuts for existing programs and thwarted development of any new programming. Without more money, these recommendations cannot be implemented.

Despite these challenges, the Adult Services Sub-committee welcomed the opportunity to develop these recommendations and submit them to the Autism Commission which it believes will improve the lives of adults with autism in Massachusetts.

Publications Reviewed

Unlocking the Door to Community Living: A Guide for Families of People with Disabilities, Jewish Family & Children's Services, June 2011.

Report of State Services to Individuals with Autism Spectrum Disorders (ASD), Centers for Medicare & Medicaid Services (CMS) ASD Services Project, April 2011.

Fact Sheet on Autism Employment, National Conference on Autism & Employment, Stadifer, September 2011.

2001 Strategic Plan for Autism Spectrum Disorder Research, Interagency Autism Coordinating Committee, 2011.

Report to the Governor, Oregon Commission on Autism Spectrum Disorders, December 2010.

Expanding Employment and Career Options for Individuals on the Autism Spectrum in 21st Century Digital Media and Communications Technology, Bergman, Alan September 2010.

Study on the Costs and Benefits of Initiating a Pilot Project to Provide Services to Adults with Autism Spectrum Disorders and Related Disabilities, State of Texas Department of Aging and Disability Services, August 2010.

Addressing the Needs of Adults with Autism Spectrum Disorder: Recommendations for a Plan of Action for the State of New Jersey, Adults with Autism Task Force, October 2009.

Report of the Colorado Autism Commission For Senate Bill 08-163, October 1, 2009.

Report of the Minnesota Senate Autism Task Force, March 2009.

The Current State of Services for Adults with Autism, Peter f. Gerhardt, Ed.D., Organization for Autism Research January 2009.

Report to the Vermont Legislature to Address Services for Individuals with Autism Spectrum Disorders, January 2008.

Supporting Individuals with Autism Spectrum Disorders: Quality Employment Practices, The Institute Brief, Kurtz and Jordan, December 2008

Life Journey Through Autism: A Guide for Transition to Adulthood, Danya International, Inc., Organization for Autism Research and Southwest Autism Research & Resource Center, 2006.

APPENDIX E: GLOSSARY

Adult Foster Care ("AFC")
Services provided in a home setting by a caregiver who resides with the individual with a disability age 16 and older. Services provided include assistance with adult daily living skills and personal care. Individuals who participate in Adult Foster Care must meet MassHealth financial and clinical eligibility requirements.

Adult Service Coordinators
Arrange, coordinate, and monitor the services and supports that Department of Developmental Services ("DDS") provides, purchases or arranges for an individual. The Service Coordinator will chair and develop an **Individual Support Plan** (ISP) which helps the DDS team work with the individual to plan his or her life. The ISP addresses areas of life which are important to the individual. Portions of the services provided by the Service Coordinators are reimbursed through the Medicaid State Plan through CMS.

Applied Behavior Analysis ("ABA")
An evidence- based treatment for individuals with autism that utilizes positive reinforcement to encourage positive behavior while at the same time reducing interfering behaviors. ABA can also help children and adults with autism learn new skills.

An Act Relative to Insurance Coverage for Autism ("ARICA")
2010 Law in Massachusetts requiring private insurers to cover medically necessary treatment for autism.

Asperger Syndrome
One of the autism spectrum disorders (see definition below) characterized by normal intelligence.

Augmentative and Alternative Communication
Individuals unable to communicate orally can utilize other methods of communication to express themselves. Augmentative and Alternative communication can be achieved with assistive technology devices, including computers and iPads or through the exchange of pictures and symbols.

Autism Case Management Services
Intensive case management supports are provided to assist families whose children are enrolled in the Autism Waiver Program. Each family is assigned to work with a **Department of Developmental Services ("DDS") Autism Clinical Manager** who oversees the development of the individual plan of services, provides on-going support and technical assistance around the in-home behavioral supports and provides oversight and assistance to the **Autism Support Brokers** who are employed through the Autism Support Centers. These Brokers work directly with families to provide assistance with staffing, budgeting, paperwork and day-to-day guidance around program rules and regulations.

Autism IEP Act
This Massachusetts law requires the Individualized Education Plan ("IEP") Team to consider and specifically address the full range of a child's complex communication, social, behavioral, and academic needs resulting from ASD to help ensure provision of appropriate supports and services.

Autism Spectrum Disorder
A developmental disability significantly impacting verbal and nonverbal communication and social interaction. Autism Spectrum Disorders, as defined by the DSM-IV, include Autism, Pervasive Developmental Disorder-Not Otherwise Specified, Asperger Syndrome, Rett Syndrome and Childhood Disintegrative Disorder.

Autism Support Centers
There are seven autism support centers in Massachusetts offering assistance to families of children with autism. Their staff have expertise in autism and offer programming for parents and children with autism, including support groups, February Vacation camps, and after school programming. Autism support brokers who assist with Waiver services are also housed in the autism support centers. Many of the autism support center staff are parents of children with autism.

Board Certified Behavior Analyst ("BCBA")
A national certification process for providers of ABA services overseen by the Behavior Analyst Certification Board (BACB). A law in Massachusetts requires ABA providers to be licensed , and meet specific education, experience, and examination requirements. This will be effective sometime in 2014.

Bureau of Special Education Appeals ("BSEA")
The BSEA conducts mediations, advisory opinions and hearings to resolve disputes among parents, school districts, private schools and state agencies concerning eligibility, evaluation, placement, individualized education plans (IEPs), special education services and procedural protections for students with disabilities.

Children's Autism Medicaid Waiver
The Children's Autism Waiver Program is a Medicaid Home & Community Based Wavier program that provides intensive in-home and community based services to MassHealth eligible children under age 9 who have an autism diagnosis and are at risk for institutionalization. The Waiver Program is administered by the Department of Developmental Services' Autism Division, and up to 157 children may participate in the Waiver program at any given time. Over the course of the Waiver year, 205 children may be served. The federal government reimburses Massachusetts at 50% of the cost of the Waiver Program. Children chosen to participate in the Waiver program are eligible for up to $25,000 a year of services for a three year period up until their 9th birthday. All staff working with the waiver have extensive experience working with children with autism.

Co-Morbid Disorder
The appearance of two more illnesses at the same time, such as the co-occurrence of autism and schizophrenia.

Co-Occurring Mental Illness
An individual diagnosed with two or more mental health disorders.

The Department of Elementary Secoand ndary Education/Department of Developmental Services Residential Placement Prevention Program ("DESE/DDS" Program)
The DESE/DDS program provides supports to families to keep children at home and reduce the risk for residential placement of students who are in school and DDS eligible. It also provides supports to families who opt to bring their children home from a residential placement. Children must be 6-17 years of age at the time of enrollment in the Program. The DESE/DDS Program is funded by the state through funds allocated to Department of Elementary and Secondary Education and administered by the Department of Developmental Services. There are currently 485 students receiving services through the DESE/DDS program, 75% of whom have an autism diagnosis.

Day Hab Program
Serves individuals with intellectual disabilities or other developmental disabilities providing a structured day program designed to build skill development, improve level of functioning, and facilitate independent living and self-management skills. The services available are nursing services and oversight such as; administration of medications and treatments and monitoring each member's health status, developmental skills training, therapy services, and assistance with Activities of Daily Living (ADLs). Day Hab supports individuals over 22. Consumers must meet both financial and clinical eligibility requirements.

Early Intervention ("EI")
EI in Massachusetts is a statewide, integrated, developmental service available to families of children between birth and three years of age. Children may be eligible for EI if they have developmental difficulties due to identified disabilities, or if typical development is at risk due to certain birth or environmental circumstances. Children with autism are automatically eligible for Early Intervention services. EI provides family-centered services that facilitate the developmental progress of eligible children. EI helps children acquire the skills they will need to continue to grow into happy and healthy members of the community.

Early Intervention Specialty Services
Any child enrolled in early intervention with a diagnosis on the autism spectrum confirmed by a physician or licensed psychologist is eligible for Specialty Service Programs for children with autism spectrum disorder ("ASD"). These intensive, individualized treatment programs promote social skills and communication and manage behavior that interferes with learning. As active participants in these programs, parents learn strategies that can help their children progress. Specialty Service Programs for children with ASD work in conjunction with community Early Intervention Programs to deliver comprehensive, coordinated service to children on the spectrum and their families.

Inclusive Concurrent Enrollment Program ("ICE")
The state-funded Inclusive Concurrent Enrollment Discretionary Grant Pilot Program develops new partnerships between high schools and public institutions of higher education to offer students with severe disabilities, ages 18-22, who have not passed Massachusetts Comprehensive Assessment ("MCAS") the opportunity to participate in inclusive college courses (credit or noncredit) with necessary services and supports, as determined through the school district's special education process.

Individualized Education Plan ("IEP")
The IEP is a written statement signed by the parent that lists services designed to meet the unique needs of eligible children. It can also contain "related services" to help the child access the general curriculum. Review all the potential services listed on an IEP grid. An IEP is legally enforceable.

Interagency Council on Housing and Homelessness
The Council works to implement the recommendations from the Massachusetts Commission to End Homelessness and uses a "housing-first" approach to ending homelessness.

Intensive Family Flexible Support Services ("IFFS") Program
These are time limited services and involve additional supports, problem solving with families and a greater level of Case Management than what is offered through the Family Support Centers. The goal is to get the family/child stabilized and then gradually decrease supports typically over a period of six months.

Least Restrictive Environment
The **Individuals with Disabilities Education Act** ("IDEA") is a federal law governing special education. It was originally enacted in 1975 and was most recently revised in 2004. The key goal of the IDEA is to ensure that eligible children with disabilities receive an education that will support their educational advancement, post-secondary education and/or employment, and personal independence Students with disabilities must be educated in the **Least Restrictive Environment** ("LRE"). To the maximum extent feasible, students should be educated among their typical peers and according the statewide curriculum framework. The IDEA's preference for the LRE means that students must receive their special education services within a general education classroom whenever possible. Special or separate classes and schooling should only occur when supplementary aids and services, such as resource room or pull-out services, are insufficient to satisfy the child's needs.

1-800-AGE-INFO
An elder services web site and 800 number created by Massachusetts Executive Office of Elder Affairs and the Massachusetts Healthcare Association. It provides information on programs for the elderly and assistance in locating services throughout Massachusetts.

MassAccess
A housing registry that helps people to find affordable housing in Massachusetts. A key feature of the Registry is to highlight homes for people with disabilities who need accessible or barrier-free housing.

Massachusetts Act Early Program
This state program aims to educate parents and health care, early childhood and educational professionals about healthy childhood development, early warning signs of developmental disorders including autism spectrum disorder, the importance of routine developmental screening, and timely early intervention whenever there is a concern. It is an affiliate of the CDC "Learn the Signs, Act Early" program to promote early, periodic developmental screening of all children.
www.maactearly.org

Massachusetts Child Psychiatric Access Program ("MCPAP")
This program provides psychiatric expertise to help primary care physicians recognize the signs of mental illness in children and help them provide care to children with mental health issues in their practices.

MassHealth
MassHealth is a public health insurance program offered by the state to low- to medium-income residents of Massachusetts, including individuals with disabilities. The Commonwealth is reimbursed approximately 50% of the cost of the MassHealth program by the federal government.

Mass Rehabilitation Commission's Assistive Technology Program
The Assistive Technology Program was created by the Mass Rehabilitation Commission ("MRC") to enable individuals with severe disabilities to access assistive technology devices and training. MRC contracts with three organizations for the provision of AT assessments, purchase and set-up of equipment, training and follow-up. These providers provide services on a regional basis and have on-site AT devices to be used for evaluation and training.

Operation House Call
A medical education program started at the Boston University School of Medicine which is offered to third year medical students at several Boston area medical schools during their pediatric rotation. The goal of the program is to help medical students better understand the challenges faced by families of children with intellectual and developmental disabilities and increase interest in caring for individuals with disabilities. The Arc of Massachusetts collaborates with the program. Students who participate visit families in their homes and learn about the medical needs of their children.

Personal Care Attendant Program
The Personal Care Attendant Program provides MassHealth funds for individuals with chronic disabilities to hire staff to provide physical assistance with personal care.

Respite Care
Temporary help provided by a professional to caregivers to allow them a break in caring for a family member with an illness or a disability.

Schizophrenia
A chronic, severe brain disorder that often manifests itself in an individual in their late teens and early twenties. Individuals with schizophrenia may experience paranoia and hear voices.

Section 8 Housing
A federal program that helps low-income Massachusetts residents, including those with disabilities, to pay for their housing. **Tenant-Based vouchers** enable individuals to choose their own apartments and limit rental payments to 30% of income. **Project-based vouchers** require an individual to live in a particular housing unit.

Self-Funded Insurance Plans
Pursuant to the federal Employee Retirement Income Security Act ("ERISA"), certain "self-funded" or "self-insured" insurance plans are subject only to federal law and exempt from state insurance regulations, including mandates. In those instances where employers bear the entire risk for employee insurance claims, such plans are exempt from state regulation. As a result of ERISA, many employees are unable to access benefits required by An Act Relative to Insurance Coverage for Autism "ARICA" unless their employer volunteers to comply.

Transition Coordinators
The primary link to information and assistance from DDS during the transition from special education to adult life. They help individuals and the families understand what DDS can offer and assist with identifying and securing requested supports. The Transition Service Coordinator will also chair the Individual Transition Plan (ITP) meeting. From this meeting, they will develop a document that specifies what kinds of support the student/family is requesting upon leaving special education. Soon after graduation or when an individual leaves school and transitions into adult supports, an individual's case will be transferred to an adult service coordinator within the area office.

Transition Planning
Helping an individual with disabilities move from the school setting into adult services. Areas to be considered include: post-secondary education options, housing, employment, public benefits, recreation and social interests.

Vocational Rehabilitation Division
A division within Mass Rehabilitation Commission ("MRC"), it provides counseling, assessment, training and job placement support as well as assistance with adaptations and accommodations that will ultimately result in competitive employment for the individual with a disability

ACKNOWLEDGEMENTS

The Massachusetts Autism Commission Report
is the result of the combined effort of legislators, state agency representatives, and citizens of the Commonwealth. Specifically, the Autism Commission gratefully acknowledges and thanks:

The families and self-advocates who attended Commission and subcommittee meetings and were involved in any capacity with moving this project forward. Your insights ensured that the findings and recommendations reflected as much as possible the experiences of the Autism community in the Commonwealth.

The parents, individuals with autism, and the professionals who submitted vignettes to be included in the final report. Your vignettes both educated members of the Autism Commission about specific experiences of the Autism community in Massachusetts and illustrated issues and triumphs of your community in ways no amount of research could reflect.

Members of the Autism Commission writing group including Chair Barbara L'Italien, Ann Guay, Amy Weinstock, Michael Wilcox, Julia Landau, Margaret McPhee, and Rita Gardner who each contributed a tremendous amount of time and effort to the development of this document.

Jennifer Barrelle for her early guidance and organizing of the Autism Commission.

Members of state agencies who provided information and support during the Commission process specifically Rosalie Edes, Elin Howe, and Janet George.

Advocates for Autism of Massachusetts, The Flutie Foundation, Autism Speaks, and the Massachusetts Developmental Disabilities Council who each contributed funds to print this report. And Susan Sutherland who is responsible for the layout and design of the report.