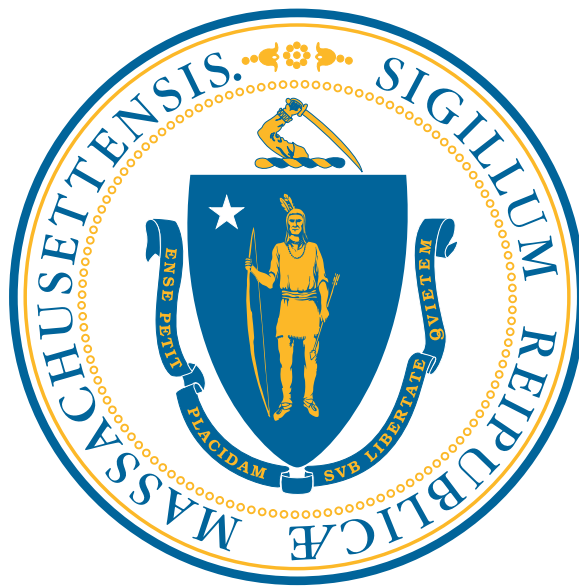


THE MASSACHUSETTS AUTISM COMMISSION REPORT

MARCH 2013



OUR VISION

The Autism Commission envisions a Commonwealth in which all individuals with autism have full access, throughout their lifetimes, to all the supports and services they require to be contributing, productive, and fulfilled members of our community, to the fullest extent of their desire and capability.

TABLE OF CONTENTS

I. Letter from the Chair	2
II. List of Commission Members	4-5
III. Executive Summary	6-8
IV. Autism in Massachusetts	9-10
V. Priorities, Findings, and Recommendations.....	11-32
VI. Implementation Chart.....	33-48
VII. Appendices	49
<i>Appendix A. Legislative Resolve</i>	<i>50</i>
<i>Appendix B. Overview of Commission Process</i>	<i>51-52</i>
<i>Appendix C. Reports from State Agencies on the Delivery of Services</i> <i>and Supports for Individuals with Autism Spectrum Disorder.....</i>	<i>53</i>
1. Department of Public Health – Early Intervention.....	55-57
2. Department of Developmental Services	58-68
3. Massachusetts Rehabilitation Commission	69-72
4. Executive Office of Elder Affairs-Mass Health Office of Long Term Services and Supports.....	73-74
5. Department of Mental Health	75-82
6. Department of Early Education and Care.....	84-87
7. Department of Elementary & Secondary Education	88-90
8. Department of Higher Education	91-94
9. Department of Housing and Community Development	95-97
<i>Appendix D. Introduction to Subcommittee Reports and the</i> <i>Subcommittee Reports in their Entirety.....</i>	<i>98-164</i>
1. Birth to Five Subcommittee	100-121
2. Schoolage Subcommittee	122-137
3. Transition Subcommittee	138-152
4. Adult Subcommittee	153-164
<i>Appendix E. Glossary</i>	<i>165-171</i>

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

TABLE OF CONTENTS

I. Letter from the Chair	2
II. List of Commission Members	4-5
III. Executive Summary	6-8
IV. Autism in Massachusetts	9-10
V. Priorities, Findings, and Recommendations	11-32
VI. Implementation Chart	33-48
VII. Appendices	49
<i>Appendix A. Legislative Resolve</i>	50
<i>Appendix B. Overview of Commission Process</i>	51-52
<i>Appendix C. Glossary</i>	53-58

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,

A handwritten signature in blue ink, reading "Barbara L'Italien". The signature is fluid and cursive, with the first name "Barbara" written in a larger, more prominent script than the last name "L'Italien".

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, Founder of the LADDERS Program

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.

¹State 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 Massachusetts⁵

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 6,646,144⁷ 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 Education¹⁰ 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.

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*

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

- 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*

**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.

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.cdc.gov/nbddd/autism/http-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

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*

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

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 to 12/31/16
	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 recommendations 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 endorsed³⁷ 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: 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 and Secondary 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 to 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.

•
The Massachusetts Developmental Disabilities Council (MDDC) for providing staff support to the Commission.

•
Faith Behum, MDDC Policy Specialist, for her exceptional support and commitment to the Commission, the subcommittees and writing groups.

•
Advocates for Autism of Massachusetts, The Flutie Foundation, Autism Speaks, and the Massachusetts Developmental Disabilities Council for their contributions to print this report.

•
Susan Sutherland for her fine work in completing the layout and design of the report.