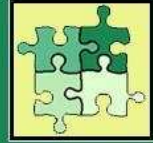




**ADVOCATES FOR AUTISM  
OF MASSACHUSETTS**



## **Awash in Autism**

### **Why We Must Begin to Address the Critical Need for Services for Adults with Autism in Massachusetts**

**February 2010**

**Advocates for Autism of Massachusetts**

<http://www.afamaction.org>

A Unified Voice for Children and Adults with  
Autism Spectrum Disorder  
and Their Families

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## Introduction

“My daughter has a mix of autism and medical issues that make it hard to fit into existing programs.”

In the past two decades the number of children diagnosed with autism spectrum disorders has grown exponentially. Autism was once viewed as a rare childhood disorder. The most recent prevalence estimates from the Centers for Disease Control and Prevention (CDC) are that 1 in 110 children in the United States have an autism spectrum disorder (ASD).

<http://www.cdc.gov/ncbddd/autism/index.html>

It is now more common than Down syndrome, cerebral palsy, hearing loss and visual impairment. **Many experts in the field believe it is a public health crisis.**

“Our main concern is that the organization running the day hab has not addressed the increasing needs of autism at all. Because of the overall lack of autism training there, our son is not getting services that would help him to continually progress in his daily living skills, and to increase his community involvement. He does receive family support and PCA hours...If these funds get reduced, we would not be able to work in our full time jobs, and we have no clue how we could continue to live anywhere near the way we do now. Bills could not be paid...”

The prevalence of ASD is also an emerging crisis for state human services. While there is much we do not know about why these numbers have increased so dramatically, we do know that these children are now aging into adulthood.

And we know that the supports necessary to enable adults with ASDs to live fulfilling lives, safe from harm and crisis, just do not exist in forms or to the extent adequate to their needs or their growing numbers.

A tsunami is on the horizon. **Indeed the beginning of the wave is hitting the classes of individuals now turning 22 in Massachusetts.** This is evident from data presented in the prevalence study that the Massachusetts Department of Public Health published in 2005: **between 2002 and 2007 the number of children in Massachusetts aged 18-21 with autism enrolled in special education in Massachusetts more than doubled.**<sup>1</sup>

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<sup>1</sup> **Services for Adults with Autism in Massachusetts: An Overview** Prepared for Advocates for Autism of Massachusetts by Caroline V. Budney, M.P.P., and Marji Erickson Warfield, Ph.D., Lurie Institute for Disability Policy, Heller School for Social Policy and Management, Brandeis University. July, 2009, p. 2.

“My daughter is 25 and has tried two adult day programs and one work program. Not only were the autistic needs not met but the programs provided little or no sign language support which is her communications system. She did not have a chance of succeeding in these day programs.”

Parents and others in the community are sounding the siren. Their deep concern about **the level of preparation and planning in Massachusetts – even for individuals with ASDs who fit current eligibility criteria for services from the state’s Department of Developmental Services (DDS)** – is reflected in the comments we have received in the AFAM Needs Survey.<sup>2</sup>

Note: Quotations in boxes are taken directly from the Needs Survey. Names used in quotes have been changed.

“Transition from 22 to adult services is critical! When I transferred to a failed adult placement I ended up in Hogan Center for over a year to correct meds and behavior support plan.”

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<sup>2</sup> This survey was targeted to that segment of the population diagnosed with ASDs in Massachusetts who are 14 years and older and who have needs or will have needs for intensive and specialized day, employment, and residential supports when they reach the age of 22. It will be referred to in this report as the “Needs Survey.”

## **EXECUTIVE SUMMARY**

This report focuses on people who meet current eligibility requirements for service from the Massachusetts Department of Developmental Services (DDS). Consequently, the first Needs Survey was not designed to survey individuals with ASDs who typically have not been served by DDS, such as those diagnosed with Asperger's Syndrome and high functioning autism. Because autism is a spectrum disorder, the nature and degree of supports that may be required for an individual to have meaningful access to housing, a job and community life will vary. However, the needs of this underserved population are real, and growing, and thus, the Needs Survey and this report are just the beginning of our work. We hope that it will open a dialogue about the lack of resources and the myriad of issues that adults with ASDs in Massachusetts face no matter where they fall along the spectrum.

### **What is autism?**

The *Diagnostic and Statistical Manual of Mental Disorders, 4<sup>th</sup> Edition, Text Revision* (2000) (*DSM-IV-TR*) is a manual published by the American Psychiatric Association that includes all currently recognized mental health disorders. According to the *DSM-IV-TR*, autistic disorder is a disorder of neurodevelopment characterized by impaired social interaction and communication and by restricted and repetitive behaviors. The *DSM-IV-TR* groups autistic disorder with other related disorders under the umbrella term "autism spectrum disorders" (ASDs). ASD is a general term describing this group of complex neurobiological disorders that inhibit a person's ability to communicate, respond to surroundings and form relationships. ASDs are associated with rigid routines and repetitive behaviors.<sup>3</sup> Symptoms can range from very mild to quite severe. This variation and the challenges it presents for caregivers and staff is often captured in the saying "If you've seen one person with autism, you've seen one person with autism."

Autism is four times more likely to strike boys than girls, but it occurs in all racial, ethnic and social economic groups.

Some of the characteristics that a person with autism may exhibit include: difficulty understanding verbal language, gestures and/or social cues; literal or nonfunctional speech and/or echolalia; difficulty relating to others or participating in conversational exchange; difficulties in generalizing and maintaining skills across a variety of settings; over or under arousal to light, sound, smell, taste or touch than is typical; anxiety, abnormal fears or lack

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<sup>3</sup> ASD is a term that includes a spectrum of diagnoses (*i.e.*, autistic disorder, PDDNOS, Asperger's Syndrome, Rett's Disorder and Childhood Disintegrative Disorder). For the purposes of this report "autism" and adults with autism" are used to refer to ASDs and adults with ASDs.

of appreciation of real danger; difficulty with transitions or changes in routine manifest in stress and frustration; strong visual skills and rote and long-term memory skills; intense focus, especially on preferred activities, concrete thinking and, in some cases, heightened musical, mathematical, technological or artistic abilities and interests.<sup>4</sup>

These characteristics may present as challenges at some times and as strengths at others. In supporting a person with autism, a caregiver must get to know the person well and take these complex characteristics into account in customizing supports that work for the particular individual.

“Hope that some of the best practices that are in place at my son's school will be extended into adult services; I worry about having him in the care of people who have minimal training re: autism.”

In contrast to many with the diagnosis of intellectual disabilities who more often present with a more even level of functioning across all settings of daily living (employment site, day program, community and residence), a person with autism may exhibit a more splintered set of skills and may have difficulties functioning in some settings or on some occasions due to communication and sensory and other environmental challenges. These difficulties can result in the need for behavior support and creative solutions. While social skills are often strengths in the traditional populations served by DDS, people with autism may lack social skills or

motivation, increasing the complexity of structuring appropriate behavior supports.

The CDC estimated in 2002 that the proportion of children (then aged 8) with ASD who also had “cognitive impairment” (defined as having intelligence quotient [IQ] scores of 70 or below) ranged from 33.1% to 58.5% in a set of 14 surveillance sites within 14 states being monitored by the CDC.<sup>5</sup> Unfortunately, Massachusetts is not one of these sites and the Mass. DPH 2005 Prevalence Study did not include such an estimate for Massachusetts.

Anecdotally we know that increasing percentages of the members of the Turning 22 classes who have been found eligible for services from DDS (and therefore have been found to have cognitive impairment) in recent years consist of individuals with an ASD diagnosis. It should be stressed that IQ

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<sup>4</sup> National Town Hall Advancing Futures for Adults with Autism. Shaping Policies, Services, and Resources. A Participant's Guide. Nov. 13, 2009, page 7.

<sup>5</sup>Centers for Disease Control. Prevalence of Autism Spectrum Disorders – Autism and Developmental Disabilities Monitoring Network, 14 Sites, United States 2002, page 10.

testing is not a good measure of determining the true functioning level of a person with autism, due to the fact many people with autism have splinter skills and difficulties in assessment.<sup>6</sup>

## What is AFAM?

Advocates for Autism of Massachusetts (AFAM) was formed in 2004 to address the need for public advocacy on behalf of individuals, families and professionals who have or deal with people with autism spectrum disorders (ASDs). The organization provides an important arena for mobilizing people who deal with ASDs in their day-to-day lives.

“Special needs individuals over 22 who are not mentally retarded have access to pitifully few resources and supports.”

AFAM strives to assure the human and civil rights of individuals of all ages across the entire Autism Spectrum and promote the availability of essential supports so that they may live fully and enjoy the same opportunities as other citizens of the Commonwealth.

In 2008, recognizing the dramatic growth in the numbers of children with ASDs and the aging of these children into adulthood, AFAM formed an Adult Services Committee. The committee’s charge:

**Encourage the Commonwealth of Massachusetts to adopt a proactive strategy for developing community, residential and employment supports geared for adults with ASDs – those who are adults currently in need of such services and the hundreds of children with ASDs who will soon be reaching adulthood.**

The committee consists of volunteers who are members of the AFAM Executive Committee and other parents and professionals from across the state who are advocates for and providers of services to people with ASDs.

The committee began its work by conducting a survey targeted to one segment of the population of individuals with ASDs – those aged 14 years and older who have or will have needs for intensive and specialized day, employment and residential supports when they reach the age of 22.

Over the past year the committee has also worked with the Lurie Institute for Disability Policy at the Heller School of Brandeis University to produce a white paper that provides an overview of the current state of services in Massachusetts for adults with ASDs. **Services for Adults with Autism in**

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<sup>6</sup> Dawson M, Mottron L, Gernsbacher MA (2008). "[Learning in autism](#)," in Byrne JH (ed.-in-chief), Roediger HL III (vol. ed.). *Learning and Memory: A Comprehensive Reference*. 2. Academic Press. pp. 759–72.

**Massachusetts: An Overview** was prepared for AFAM by Caroline V. Budney, M.P.P., and Marji Erickson Warfield, Ph.D., of the Lurie Institute, and begins on page 20 of this report.

## MASSACHUSETTS IS FACING A CRISIS

Massachusetts is now at a critical stage. As is true across this country, an entire generation of school children with ASDs is becoming adults and is in need of specialized day programs, employment supports, family supports and residential services.

For years it has been assumed that adults with autism could be served by programs and supports created for people with intellectual disabilities, without taking into account the unique communication, sensory, environmental, social and behavioral factors that distinguish autism from other intellectual disabilities.<sup>7</sup>

“My son has severe behavioral challenges and needs a very structured ABA program with 1:1 care.

Thus far my son has had a great transition to his day program at the Arc. However we are now left up in the air with no family funding and he has had behavioral issues lately.”

The needs of people with ASDs are often more staff-intensive than those of the traditional population served by DDS throughout its history. The staff ratios and specialized training needed to keep individuals with autism safe, for example, is often greater than staff ratios and training for the current population DDS serves. Implications for the cost of programs and their design are significant.

**These difficulties are compounded by the fact that this wave of individuals with autism is reaching adulthood at a time when the service system for individuals with disabilities is severely underfunded and overwhelmed. To grapple with this challenge in the midst of the worst fiscal and financial crisis since the Great Depression is extraordinarily difficult. But we cannot wait to begin to address this challenge because the number of people with ASDs turning 22 each year is increasing and increasing.**

“We fall in the cracks of the system that is under budget and relies on IQ of 70 - But does not consider functional IQ which is at a 12 year level - Where does one go for services that cost 20-30K a year when they fall between agencies?”

<sup>7</sup> The New Jersey Center for Outreach and Services for the Autism Community. Meeting the Needs of Adults with Autism: A Blueprint for the Future. October 2006, page 6.



Parents of those many teenagers with ASDs who do not meet the criteria of eligibility for services from DDS but who have on-going and intensive needs that will not disappear when they turn 22 also expressed grave concerns as to how eligibility for services is determined in responding to the Needs Survey:

“Frank is our son and will be 22 in 8 mos. He will leave his day school of 6 years at that time. With DDS denying him services, we are beside ourselves as to his future, as he is unable to function on his own. We have no close relatives and Frank is an only child.”

“Dan is a friendly, well-behaved eager to please young man with a diagnosis of autism who turned 22 a year ago. He left his school program with some good job skills and had a part-time job, procured by his mother, that used those skills. Dan’s parents chose an agency to be Dan’s provider that they thought could build upon those skills, but that did not happen. The provider was supposed to provide a job coach for Dan’s part-time job, but on some days that did not happen. On those days Dan’s parents would have to scramble to provide the job coach services, or have Dan stay at home. There was no provision for transportation in Dan’s program so on the days that he was at the agency his parents would be driving him a total of 57 miles round trip. On those days, Dan sat around and was not engaged in any meaningful vocational activity. After trying for seven months to resolve the problems, Dan’s parents decided to administer his program themselves through a different agency funded by DDS. Although this option seems to serve Dan’s needs better, it has involved a tremendous amount of work for Dan’s parents, including finding and interviewing job coaches, accompanying Dan to volunteer activities, and trying to fill Dan’s time in a meaningful way. Both of his parents work from home, but this alternative is unsustainable in the long run. One of Dan’s parents is a cancer patient in remission; his parents are not wealthy. There is neither the energy nor the resources to continue to create his program without assistance. There seem to be no meaningful options.”

## **Recommendation: Establish a Fast Track Task Force to Begin Immediately to Tackle this Challenge**

To spur the Commonwealth to adopt a proactive strategy for meeting the needs of the ever-increasing number of adults with autism in Massachusetts, we ask that a fast track task force be established immediately to identify effective solutions to this challenge.

As detailed in the White Paper, such a task force should be charged with developing a more complete understanding of the current status and future needs of adults with autism in the state and with proposing policy and service options to meet their needs.

This task force should gather information about adults with autism and their needs to facilitate the design of effective supports and policies focused on:

- Identifying innovative and positive approaches that are working for adults with autism currently receiving services in Massachusetts and elsewhere,
- Developing best practices for serving adults with autism,
- Implementing the use of various kinds of therapies, including behavioral therapies and adaptations to existing service models, and
- Training for direct care workers and primary caregivers that is comprehensive and cost effective.

There have been a large number of expert panels and government task forces that have suggested guidelines for the delivery of educational services for children with autism.<sup>8</sup> What is important to note is that education continues to be the primary treatment option for autism spectrum disorders. Although this report concerns adults with autism in Massachusetts, the lessons learned around treatment of children with ASDs are highly relevant to adults. While the supports needed for adults may not be considered “education” in the sense of a legal entitlement, they are comparable types and qualities of instructional support and long-term care many adults with ASDs need for a reasonable quality of life in a Massachusetts community.

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<sup>8</sup> National Research Council (2001). Educating Children with Autism. Committee on Educational Interventions for Children with Autism. Division of Behavioral and Social Sciences and Education. Washington, D.C.: National Academy Press.

It is important that the recommendations of the Maine Administrators of Services for Children with Disabilities (MADSEC) be reviewed.<sup>9</sup> A key focus of the MADSEC Autism Task Force is the evidence-based approach to assessing interventions for autism. The MADSEC report notes that an intervention for individuals with autism can be characterized in four ways:

- It may be objectively substantiated as effective based upon the scope and quality of scientific research.
- It may anecdotally show promise, but is not yet objectively substantiated as effective using controlled studies and subject to the rigors of good science.
- It may have been repeatedly subjected to the rigors of science, which leads numerous researchers to conclude that the intervention is not effective, may be harmful or may lead to unintended consequences.
- It may be without scientific evaluation of any kind.<sup>10</sup>

MADSEC includes among their recommendations that those who determine or provide autism interventions "...ensure services for children with autism are based upon scientifically validated procedures; ensure that services to children with autism include systemic instruction procedures focusing on both the acquisition of skills and the decrease/elimination of interfering behaviors;" and "require ongoing evaluation of autism interventions using controlled studies and subject to the rigors of good science. Ongoing evaluation should minimally include a credible method of evaluation, and criteria for determining whether to terminate or continue the intervention."<sup>11</sup>

Areas of focus of the recommended fast track task force should also include:

- Identifying best practices in coordinating transition from schooling to adult services,
- Identifying issues around determinations of eligibility for services, including issues relating to the inadequacy of IQ testing for assessing functional ability, and proposing solutions for the same,
- Formulating policies that encourage the development and expansion of day and residential programs, employment supports and family

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<sup>9</sup> Maine Administrators of Services for Children with Disabilities (MADSEC). (2000) . *Report of the MADSEC Autism Task Force*. From <http://www.madsec.org/docs/ATFReport.pdf>.

<sup>10</sup> Ibid, p.3.

<sup>11</sup> Ibid, p.7.

supports that offer options which are flexible and person-centered and build on the person's strengths, talents and interests to better meet their needs,

- Formulating a pilot program that could demonstrate a clinical and service structure that addresses co-morbid health, psychiatric and severe behavioral disorders,
- Consideration of the ways health is monitored, medical and dental services are delivered and medication is administered, and the development of policies to improve the same, and
- Identifying funding sources that are flexible, diversified (public and private; state and federal) and sustainable and can be used in a variety of ways to meet the person's unique and evolving needs.

Stakeholders at the task force table should include the various state agencies involved in delivering services to people with autism (e.g., DDS, the Massachusetts Rehabilitation Commission, the Department of Elementary and Secondary Education, MassHealth), agencies and institutions which might play a role in increasing the number of trained workers who deliver the services (e.g., Department of Higher Education, universities or colleges), representatives from adult service providers of day and residential programs and employment supports, experts in delivering health and dental services to people with autism, experts in educational programs for teens with autism, and parents and self-advocates.

By initially focusing on how services currently are being provided to adults with autism who meet DDS eligibility criteria, we can begin to identify the systemic and structural changes that will allow those services to be delivered more effectively from both a quality and cost perspective. Resources that could be consulted for best practices include the autism guidelines of the Association for Behavioral Analysis's Autism Special Interest Group<sup>12</sup>, the National Research Council's *Educating Children with Autism*<sup>13</sup>, the Report of the MADSEC Autism Task Force<sup>14</sup>, the Clinical Practice Guideline from the New York State Department of Health<sup>15</sup>, and the *National Standards Report* published by the National Autism Center in 2009 and containing a comprehensive review of interventions. Work undertaken by task forces in

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<sup>12</sup> Autism Special Interest Group (SIG). Association for Behavior Analysis, Revision Adopted September 15, 2004. From [http://www.abainternational.org/SpecialInterests/autism\\_guidelines.asp](http://www.abainternational.org/SpecialInterests/autism_guidelines.asp).

<sup>13</sup> National Research Council. (2001). *Educating Children with Autism*. Washington, D.C.: National Academy Press.

<sup>14</sup> Maine Administrators of Services for Children with Disabilities (MADSEC). (2000). Report of the MADSEC Autism Task Force. From <http://www.madsec.org/docs/ATFReport.pdf>.

<sup>15</sup> New York State Department of Health. (1999). Clinical Practice Guideline: The Guideline Technical Report. Autism/Pervasive Development Disorders, Assessment and Intervention for Young Children (Age 0-3 Years). Publication No. 4217.

other states, pilot programs underway elsewhere and success stories within our own state could all be examined to develop creative, innovative and effective policy proposals.

This undertaking on behalf of adults with autism could also benefit other nontraditional populations served by DDS that have needs for similar specialized services and staff trained in providing behavior supports, such as individuals impacted by brain injury and other conditions.

**Given the numbers of adults with autism soon reaching adulthood and the intensity and nature of their needs, this is an imperative that cannot be ignored or delayed.**

## Report of Results of AFAM Needs Survey

### Purpose of Survey and Targeted Population

As described above, AFAM conducted a Needs Survey of people with ASDs and their families. The Needs Survey was targeted to people in Massachusetts with a diagnosis of an autism spectrum disorder (ASD) from age 14<sup>16</sup> and up and **specifically targets those individuals who have already been or are likely to be deemed eligible for services as adults through the Commonwealth's Department of Developmental Services (DDS)**. That is, many will have a diagnosis of mental retardation in addition to an ASD.

The purpose of the Needs Survey is to provide DDS and others within the administration, the General Court, and the broader community with an overview of the individuals who likely meet present criteria for eligibility for services in the near future and the intensity of their needs.

Again, we wish to emphasize that ASD is a spectrum disability and the needs of individuals diagnosed with ASDs vary along that spectrum. This report focuses on one segment of the spectrum. It constitutes a first step in research on and data collection about the needs of adolescents and adults with ASDs in Massachusetts.

### Methodology

The AFAM Needs Survey is based on a template previously developed by The Arc of Massachusetts for its June 2009 report "The Unmet Needs of People with Intellectual and Developmental Disabilities in Massachusetts." The AFAM Adult Services Committee adapted the template to its target population and sought input on the survey questions from providers of services to the autism community. A number of families with members on the targeted end of the autism spectrum completed a draft form of the survey.

The survey in its final form was made available as of April 14, 2009 and was widely publicized on websites and by emails, newsletters and announcements by AFAM and its member organizations and various schools. The primary collection point of the survey was the Survey Monkey website,

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<sup>16</sup> We chose the age of 14 as a criterion because transition planning in Massachusetts begins at age 14, and it is significant if adolescents in this age range need assistance with activities of daily living (whereas that would not be the case with younger children).

but paper copies were also made available by downloading and at various events through the year. (23 paper copies were received.)

### Overview of Results

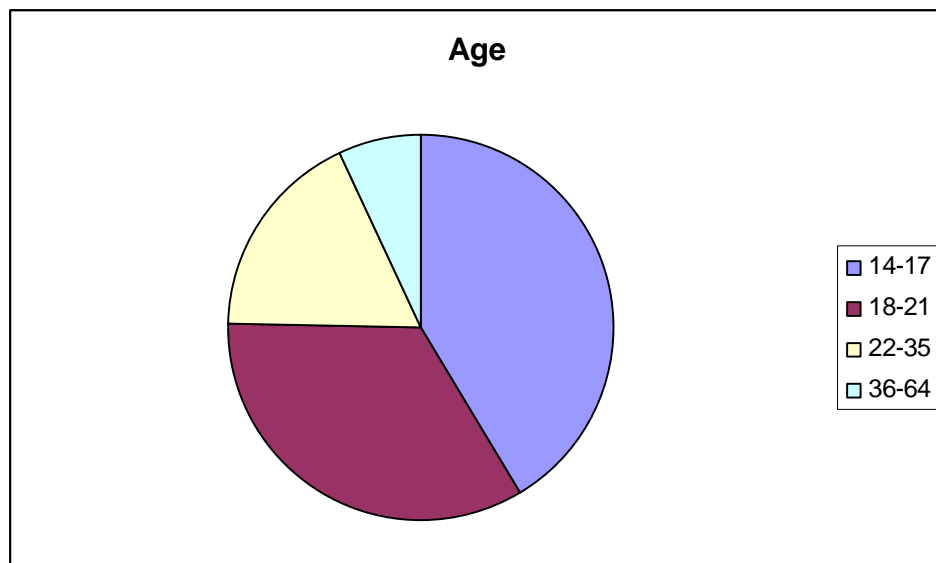
Survey results are based on 262 unique survey responses received by AFAM as of February 5, 2010.<sup>17</sup>

### General Background Information (Demographics; Age; Diagnosis)

Responses were received from respondents living in 90 different cities and towns in Massachusetts located in all geographic regions of the state.

The age of the respondents included people over the age of 22, but we are focusing on those aged 14-21 for the first two bulleted points below, as that age cohort relates to planning.

- Age of people turning 22 in the near term: the percentage of total responses for the ages 14-21 combined was 76%.
- These numbers combined were 198 people. Of those, 89 were in the 18-21 group so are in the most immediate need.



- 96% of all respondents have a primary Diagnosis of Autism Spectrum Disorder, with 77% having Autism/PDDNOS as their primary diagnosis.

<sup>17</sup> Respondent refers to the person with a disability whose needs are the subject of the completed survey. In most cases a caretaker (parent or other family member, guardian or staff worker) filled out the survey with this person's help or on their behalf.

- 98% have this diagnosis available from a qualified professional in writing.
- 44% of all respondents have Mental Retardation as a secondary diagnosis. (The survey question did not ask if the person had mental retardation; there were questions asking what the primary diagnosis is and what the secondary diagnosis is. These data should not be interpreted to indicate that only 44% has mental retardation. (An additional 15% reported having a secondary diagnosis of "intellectual limitations.")
- 68% live at home with family, 21% live in a residential school and 6% live in a 24/7 group home (adult placement).

### **Activities of Daily Living<sup>18</sup>**

- 54% need assistance with four or more self care types of activities of daily living (such as bathing, dressing, etc...).
- 45% of the respondents need physical prompts and 46% need greater assistance to complete self-care types of activities of daily living.
- With respect to household chores or instrumental activities of daily living<sup>19</sup>, 96% need assistance with four or more such chores or activities.
- 34% of the respondents need physical prompts and 82% need greater assistance with such chores and activities.
- In terms of transportation and safety issues, 59% (133 people) need a monitor in the van all the time (42%) or sometimes (17%). 84% need help walking in the neighborhood and crossing streets. And 59% (136 people) need to be prevented from bolting.

### **Eligibility for Services**

- 85% of the respondents have been found eligible for DDS services as a child.
- 80% have been found eligible or told they will be eligible for DDS services as an adult, and 23% have been found eligible for services from the Massachusetts Rehabilitation Commission (MRC).

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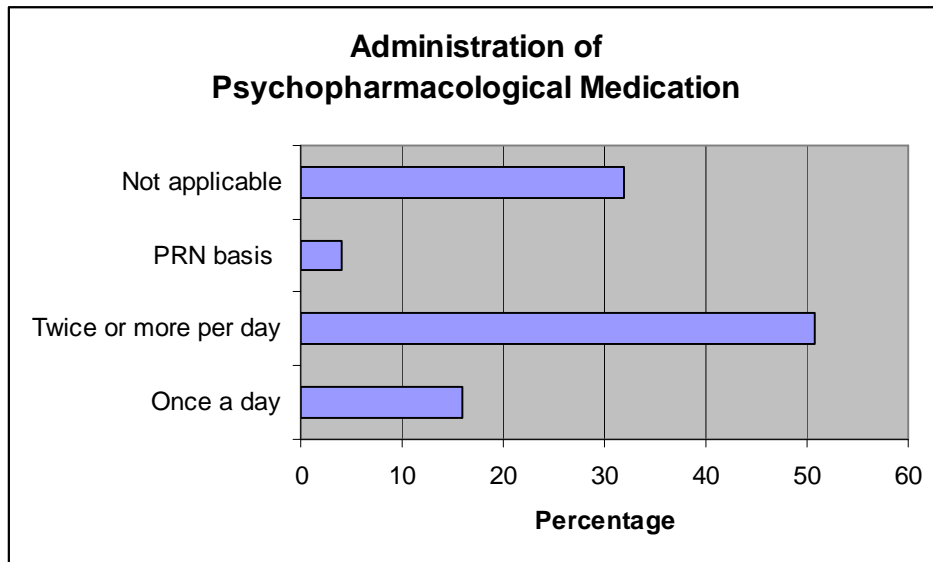
<sup>18</sup> Activities of Daily Living or ADLs were described as Dressing, Toileting, Bathing, Other personal hygiene, Eating, and Scheduling/arranging personal activities.

<sup>19</sup> Instrumental activities of daily living or IADLs were described as Laundry, Cleaning, Shopping, Meal prep and cleanup, Transportation and Basic finance and paperwork.



## Health/Dental Care

- 82% need help taking medications; 69% need help with health care needs on a daily basis.
- 71% require psychopharmacological medications<sup>20</sup> once or more per day or on a prescribed as needed basis.



## Employment/Day Activities

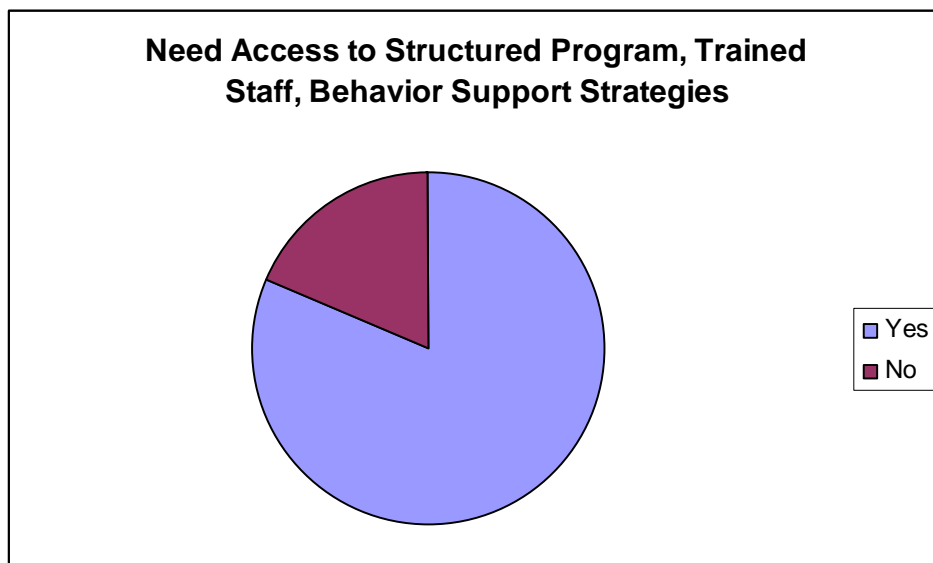
The respondents spend their days in a variety of settings, in part a function of age:

- 28% attend a public school.
- 13% attend a collaborative program.
- 42% attend a private c. 766 school.
- 10% attend a day habilitation program (*i.e.*, day programs funded and licensed by MassHealth, typically structured around social and recreational activities, with ancillary supports such as occupational therapy, physical therapy, speech and language services and other assistance).
- 6% work in a supported work environment (sometimes referred to as enclaves or sheltered workplaces; generally in a group with staff supervision).
- 15% work in the community with a job coach.

<sup>20</sup> These medications are often prescribed for anxiety, seizures, obsessive compulsive symptoms, depression, etc....

Significant findings of the survey with respect to these settings include:

- 36% get 1:1 staffing in their present program. 29% get 1:2 staffing in their present program.
- 73% state that they need a highly structured setting.
- 81% need specially trained staff to implement their program.



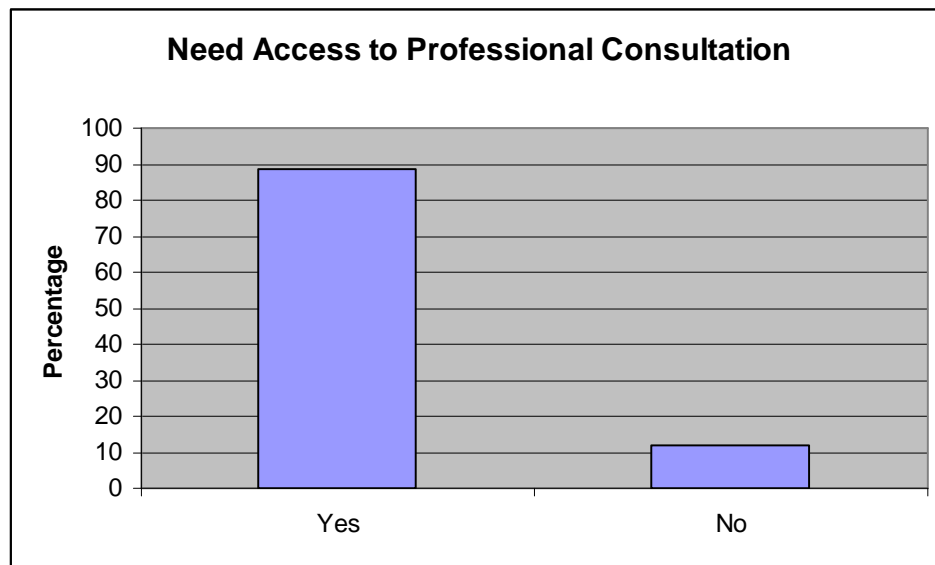
- Among the components needed in the adult program for these respondents are: functional communication training (73%); adaptive skill development (69%); social skill development (94%); opportunities for independent employment in the community (32%); opportunities for employment in the community with a job coach (72%); opportunities for employment in a supported work environment (51%); strategies to address sensory challenges (61%); opportunities for volunteer work in the community (54%); opportunities for social and recreational activities (93%); and therapeutic ancillary supports (such as occupational therapy, physical therapy, speech and language services and other assistance) (62%).

### **Behavior Support**

- 76% need a behavior support plan in their current residential, day and or educational program to assist with strategies for increasing desirable behaviors. 71% reported needing such a plan to assist with functional communication training; 74% reported needing such a plan to assist with adaptive skill development to replace challenging behaviors; 64% reported needing such a plan to assist with environmental

modifications and other antecedent management strategies (e.g., picture schedules); and 61% reported needing such a plan to assist with strategies to address sensory issues.

- 89% reported needing access to professional consultation from an expert on autism experienced in comprehensive, positive approaches to write the behavior support plan, monitor its implementation and/or provide consultation.



- Respondents also reported needing access to the following types of specialists within the residential, day and/or educational programs: speech pathologist (69%); occupational therapist (64%); physical therapist (33%); behavior psychologist (61%); developmental psychologist (37%); and board certified behavior analyst (54%).
- 49% need ongoing behavioral support at least weekly.
- 63% need 1:1 staffing at sometime during the day due to behavior support needs.
- 53% need environmental modifications of the places where they live and work due to behavior support needs.
- 20% need protective equipment to be safe, including helmets, mitts, etc.
- 70% reported a secondary diagnosis requiring psycho pharmacological treatment, including depression (12%), anxiety (48%), OCD (26%), bipolar disorder (13%) and seizure disorder (26%).

The implications for day, employment and residential programs are significant in several ways. When looking at day habilitation programs, for

example, the Medicaid regulations state that an individual must be able to function in a 1:4 staff to participant ratio. It is the current practice of DDS to enhance this ratio through additional funding when needed.

For vocational programs the average staff to participant ratio is much greater than 1:4.

The average community residential placement budget for a person served through DDS has been well under \$100,000, with a ratio of 1:3 or 1:2 throughout the program hours, with one overnight staff who may be awake or asleep depending on the needs of the residents. Two thirds of the individuals with an ASD are currently receiving 1:1 or 1:2 staffing, and this must be maintained for safety.

Specially trained staff that can support behavior and implement programs which may involve physical restraint are more frequently needed for people with ASDs.

DDS already contracts with private providers to operate some community residential programs such as those described above. There are, however, a limited number of agencies that provide these services well.

**The big changes are in the number of individuals becoming eligible for adult services who will require these programs and the intensity of their needs, and the resulting increases in costs of service.**

**What is needed is a thoughtful planning process to encourage the creation of well-structured programs and supports with appropriately trained staff and other supportive resources.**

A copy of the survey and the complete results are available for viewing and downloading at AFAM's website: [www.afamaction.org](http://www.afamaction.org).

## **Services for Adults with Autism in Massachusetts: An Overview**

Prepared for Advocates for Autism of Massachusetts  
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### **Executive Summary**

Over the past six years, the number of students diagnosed with autism in Massachusetts has doubled. In the near future, many of these individuals will be looking for services and supports as adults.

Currently, adults with disabilities in Massachusetts are served primarily by the Department of Developmental Services (DDS)<sup>21</sup> through three general categories; day services, residential services and home-based services. With costs for these services ranging anywhere from \$33,000 to \$150,000 annually per individual, the introduction of increasing numbers of adults with ASD into the adult service system raises many concerns.

There is relatively little literature available surrounding adults with autism nationally or in Massachusetts. Studies have shown mixed results in outcomes for adults with autism, but there have been few extensive studies exploring outcomes across the entire spectrum.<sup>22</sup> Regardless, many individuals continue through adulthood needing support from outside sources. In Massachusetts challenges to meeting these needs include insufficient funding for transition services from the education system to the adult system, retaining trained front line workers who support and care for adults with disabilities, a lack of service coordination, and a lack of adequate physical and oral health care.

This report suggests that Massachusetts could benefit from the appointment of a research commission or task force charged with conducting a

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<sup>21</sup> On July 1, 2009, the Department of Mental Retardation became the Department of Developmental Services (DDS) in Massachusetts.

[http://www.mass.gov/?pageID=eohhs2terminal&L=4&L0=Home&L1=Government&L2=Departments+and+Divisions&L3=Department+of+Mental+Retardation&sid=Eeohhs2&b=terminalcontent&f=dmr\\_g\\_name\\_change&csid=Eeohhs2](http://www.mass.gov/?pageID=eohhs2terminal&L=4&L0=Home&L1=Government&L2=Departments+and+Divisions&L3=Department+of+Mental+Retardation&sid=Eeohhs2&b=terminalcontent&f=dmr_g_name_change&csid=Eeohhs2)  
> 5/5/09.

<sup>22</sup> Howlin, Goode, Hutton, Rutter. Adult outcomes for children with autism. *Journal of Child Psychology and Psychiatry*. 2004. 45(2): 212-229.

comprehensive examination of the literature around best practices for serving adults with autism, determining the distinct characteristics and needs of adults with autism, compiling an inventory of the services adults with autism currently receive in Massachusetts, and examining ways to make services cost-effective for agencies and organizations. If this is pursued, Massachusetts could provide data and policy recommendations to other states as they experience similar challenges in managing their growing population of adults with autism.

## **1. Autism Prevalence in Massachusetts**

### **Autism<sup>23</sup> Prevalence in Massachusetts**

Individuals identified as having Autistic Disorder are characterized as demonstrating a combination of the following characteristics: impairment in social interactions, challenges in verbal and nonverbal communication, repetitive and patterned behaviors and having delays in these areas before the age of 3.<sup>24,25</sup> Prevalence is defined as the total number of cases of a disease or condition in a given population at a specific time. The prevalence of adults with autistic disorder in Massachusetts in 2009, however, is difficult to determine with accuracy because adults with disabilities interact with a number of agencies, most commonly the Department of Developmental Services (DDS) and the Massachusetts Rehabilitation Commission (MRC). There is no single department charged with serving and tracking all adults with this condition, so each agency is responsible for its own data, and DDS currently does not track its clients with autism as a separate group.

Adult prevalence can be estimated from data available on children, which is gathered due to regulations surrounding the Individuals with Disabilities Education Act (IDEA) legislation. Massachusetts has kept individual level data on the number of children with autism since 2001; prior to that, they used a flat percentage to estimate autism in special education classes. In a 2005 report, the Massachusetts Department of Public Health determined that

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<sup>23</sup> Note on use of language in this paper. There is scattered consistency in the use of “autism” and “autism spectrum disorder (ASD)” in the literature. According to the DSM-IV, ASDs include Autistic Disorder, Asperger’s Disorder, Pervasive Developmental Disorder-not otherwise specified (PDD-NOS), Rhett’s Disorder and Childhood Disintegrative Disorder. Also, across agencies there may be variation in the categorization of ASDs, since there are no biological markers, only behavioral indicators. For the purposes of this paper, ‘autism’ will be used synonymously with ‘ASDs’; however it is understood that high functioning individuals with ASD may be less likely to need as extensive supported services as adults.

<sup>24</sup> Centers for Disease Control. Autism Information Center.

<sup>24</sup> <[http://www.cdc.gov/ncbddd/autism/overview\\_changes\\_diagnostic.htm](http://www.cdc.gov/ncbddd/autism/overview_changes_diagnostic.htm)> 2/2/09

<sup>25</sup> Diagnostic and Statistical Manual of Mental Disorders, text revision. <<http://www.dsmivtr.org/>> 2/2/09.

the Department of Elementary and Secondary Education had the best data on autism in Massachusetts.<sup>26</sup>

In 2002-2003 there were 4,080 students aged 3-21 with autism, and by 2007-2008 this had increased 2.1 times to 8,699 students with autism enrolled in special education in Massachusetts public schools (see Table 1).

**Table 1. IDEA Part B: Children with Autism in Massachusetts by Age Group<sup>27</sup>**

	<b>Ages 3-21</b>	<b>Ages 18-21</b>
<b>2002-2003</b>	4,080	205
<b>2003-2004</b>	5,087	263
<b>2004-2005</b>	5,706	304
<b>2005-2006</b>	6,494	321
<b>2006-2007</b>	7,545	390
<b>2007-2008</b>	8,699	460

By looking at the oldest cohort (ages 18 to 21), it is possible to estimate the number of individuals who may be in need of adult services in the next few years. In 2007-2008, there were 460 students with autism in Massachusetts aged 18-21. This is 2.2 times the number in 2002-2003. These figures represent students who participate in special education programs in the Massachusetts public schools, but it does not necessarily include all individuals with autism in the state. For example, students who are out of school would not be included in this count; however, it is a good starting point. Most of these students will be in need of some form of adult services once they turn 22.

In terms of program utilization, the Massachusetts Rehabilitation Commission (MRC) has data on the number of individuals with autism as a primary or secondary disability in their Vocational Rehabilitation program. As seen in Table 2, MRC currently serves 655 individuals with autism in its Vocational Rehabilitation program. While this is a small percentage of its entire client base, the numbers of individuals with autism have been rising steadily since 2004. Although they do not have data on their community living program, data from the Vocational Rehabilitation program suggests that there is an increasing need for vocational programs for individuals with autism.

<sup>26</sup> Center for Environmental Health, Environmental Epidemiology Program, Massachusetts Department of Public Health. *Prevalence Estimates of Autism and Autism Spectrum Disorder in Massachusetts*. December, 2005.

<sup>27</sup> Adapted from: IDEA Data Accountability Center. *Part B Child Count*.

<<https://www.ideadata.org/PartBChildCount.asp>> 2/26/2009.

**Table 2. MRC Consumers with Autism as a Primary or Secondary Disability<sup>28</sup>**

	<b>Primary Disability</b>	<b>Secondary Disability</b>	<b>Total</b>	<b>% of MRC Consumers</b>
Current Active Consumers (open)	552	103	655	2.19%
Served Federal Fiscal Year 2008	386	85	471	1.89%
Served Federal Fiscal Year 2007	296	56	352	1.34%
Served Federal Fiscal Year 2006	268	43	311	1.27%
Served Federal Fiscal Year 2005	224	40	264	1.07%
Served Federal Fiscal Year 2004	172	27	199	1.02%
*Served is defined as the period from eligibility to case closure.				

There has been much debate over whether there is an increase in the number of people with autism or whether it is being diagnosed more often.<sup>29,30</sup> Regardless, as a provider of adult services, Massachusetts must deal with the increase in the number of autism cases, and prepare to serve a larger cohort than in the past.

## **2. Current Service Models Used in Massachusetts**

In Massachusetts, there are a number of different service models used to support adults with autism. Most services fall under three general categories, day services, residential services and home-based services.

### **Day Services**

For day services there are 2 typical models of service, Day Habilitation Services and Vocational Services. Day Habilitation Services focus on the habilitative or clinical needs of the individual. These needs can include: Occupational Therapy, Physical Therapy, Speech and Language Therapy, or Behavioral Treatment; and are focused on skill development and rehabilitation. These programs are funded by the Division of Medical Assistance (DMA). There is a broad range in terms of the cost of these services as some individuals receive additional funding by the Department of Developmental Services (DDS). The range is approximately \$15,000 to \$30,000 annually per person.

Vocational Services include a wide variety of services, but focus on paid employment. Individuals can be employed in a diversity of programs ranging

<sup>28</sup> Massachusetts Rehabilitation Commission. From MRC Research, Development & Evaluation department. 2/26/2009.

<sup>29</sup> Frombonne, Eric. The Prevalence of Autism. *JAMA*. 2003;289(1):87-89 (doi:10.1001/jama.289.1.87)



from a sheltered workshop, where the individual works in a group on piecework tasks, to supported employment in the community where the individual may or may not have a job coach. Only some adults with autism are able to work in the community. One study reported that 35% of high functioning adults with autism work, while only 10% of adults with moderate to severe autism are able to work in a supported employment environment.<sup>30</sup> The cost of these services varies according to the needs of the individual and can range from \$10,000 to approximately \$30,000 annually per person.<sup>31</sup>

### **Residential Services**

In terms of residential services, there are two main options that families and individuals in Massachusetts pursue based on availability: campus-based or community based programs. In general, for adult residential services programs, community-based programs are more commonly used. Residential community-based arrangements can be individual houses, apartments or group homes located within a general community. Residential services provide assistance with daily routines and behavioral therapies. Services are generally customized to meet each individual's needs, and programs provide support ranging from intensive 24-hour supervision to drop-in case management.<sup>32</sup> Some campus-model programs have living facilities that are dormitory-style as opposed to a group home. In addition, some facilities like New England Village have ranch-style homes and townhouses for its residents<sup>33</sup>. Campus programs provide opportunities for community involvement as well as a variety of on-site vocational, educational, and recreational opportunities.<sup>33</sup>

Community-based programs seek to integrate the individuals into the local community. Organizations such as the May Institute provide this kind of opportunity for adults with autism and provide training around community integration and socialization as part of their service.

### **Home-based Services**

Lastly, there are home-based service models, which allow for treatment and assistance to take place in the individual's own home. In this service model, support service workers provide all services on site. The advantage to this kind of service model is that it allows for individuals with autism to learn therapeutic techniques in their everyday environment, which can help in the development of routines or in learning new behaviors.

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<sup>30</sup> Ganz, Michael L. "The Lifetime Distribution of the Incremental Societal Costs of Autism." *Arch Pediatr Adolesc Med*/Vol. 161, April 2007. Pg. 344.

<sup>31</sup> Jim Sperry, May Institute. Informal discussion. 12/17/08.

<sup>32</sup> May Institute. *Adult Services*.

<sup>33</sup> [http://www.mayinstitute.org/adult\\_services/mr\\_autism\\_and\\_dd/community\\_living.asp](http://www.mayinstitute.org/adult_services/mr_autism_and_dd/community_living.asp) 1/5/2009.

<sup>33</sup> New England Village. <http://www.newenglandvillage.org> 1/7/2009.

While these are the most commonly used services, individualization and flexibility according to the needs of an individual with autism are critical. Research surrounding the effectiveness and appropriateness of each service model would be helpful in enabling Massachusetts to plan for an increase in adults with autism seeking services. Lastly, although it is not formally tracked, there are many adults who end up on waiting lists especially for residential services due to a lack of capacity. This information is critical in understanding how well the state is able to provide services for the current and future population of adults with disabilities.

### **3. Variations in Service Cost**

There is a dearth of data or academic literature around the costs of providing services to adults with ASD. There are some studies that look at the economic impact of ASD on families, but those pertain mostly to families with young children and the economic impact felt by the family unit.<sup>34</sup> There are also some studies that look at health care expenditures, but again, these focus primarily on children's health care needs.<sup>35,36</sup>

There are some challenges when it comes to estimating the cost of providing services to adults with ASD. First, ASD is a spectrum disorder, so the range in need and thus services can vary dramatically. Secondly, the research tends to focus on children, so little is known about the costs of adult services or the potential economic benefits of these services. Lastly, studies have traditionally looked at the family impact, so the ability to disaggregate costs by different perspectives (e.g., provider, taxpayer, etc.) is very difficult. One study attempted to combine data and understand average lifetime costs through the use of average per capita costs. However, looking at numbers under these generalized circumstances limits the ability of states to use these data in decision making since mean estimates mask tremendous variability across individuals.<sup>37</sup>

Given the lack of data, we gathered Massachusetts-specific information to generate a range of costs associated with providing services to three "model" individuals on the autism spectrum. The creation of these three "model" individuals was based on conversations with several providers of services to adults with autism and other developmental disabilities. The cost estimates come from provider experiences in serving individuals with these characteristics.<sup>38</sup>

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<sup>34</sup> Montes G, Halterman JS. "Association of Childhood Autism Spectrum Disorder and Loss of Family Income." *Pediatrics*. 121(4). April 2008.

<sup>35</sup> Liptak G, Stuart T, Auinger P. "Health Care Utilization and Expenditures for Children with Autism: Data from U.S. National Samples." *J Autism Dev Disord*. 36. 2006.

<sup>36</sup> Kogan, M. et al. "A National Profile of the Health Care Experiences and Family Impact of Autism Spectrum Disorder Among Children in the United States: 2005-2006." *Pediatrics* 122(6). 2008.

<sup>37</sup> Ganz, Michael L. "The Lifetime Distribution of the Incremental Societal Costs of Autism." *Arch Pediatr Adolesc Med*/Vol. 161, April 2007. Pp. 343-349.

<sup>38</sup> Deb Wood, South Norfolk County Arc.

These three individuals are:

- (1) An adult requiring 24/7 supervision;
- (2) An adult going to a day habilitation program who is heavily supervised and requires transportation; and
- (3) An adult who works in the community with support from a job coach and is living at home.

(1) First, for an individual requiring close and constant (*i.e.*, 24/7) supervision, the estimates are as follows: An average Group Home placement is about \$75,000 per year, with intensified staffing (*e.g.*, 1 to 1) that could go up to \$150,000. The costs can be extensive in this case due to an individual's staffing needs and the extent to which they have behavioral or medical conditions that require monitoring.

The low end of the cost estimate, \$75,000, was drawn from the settlement on the Boulet lawsuit. The Boulet lawsuit was filed in 2000 in Massachusetts on behalf of individuals who had been on the waiting list for DDS residential services for an extended amount of time without being placed.<sup>39,40</sup> Additional costs for higher staffing are added on top of the Boulet figures to get the higher end of the estimates, \$150,000, since many individuals with autism require higher staffing ratios.

(2) Secondly, for an individual who attends a day habilitation program, the average cost is \$8,000-\$10,000 a year. That estimate assumes the individual can function in a 1 staff to 4 participant ratio. If the person requires more staffing, they could be charged extra depending on the type of staffing and whether the person requires a 1:2 or a 1:1 staff to participant ratio.

These day habilitation figures were based on the current Medicaid billing rates. The base rates illustrate the cost for individuals who are assessed as having a high need, which ends up being a 1:4 staff to client ratio. However, many individuals with autism need more support, so the costs go up as the staffing ratios increase.

(3) Finally, for an individual who works in the community, the average cost of a vocational training program is \$15,000 per year. The staff to participant ratio for this type of program is usually 1:9. Most people with autism would need some extra support. In order to obtain more staffing, they might incur an additional \$18,000 per year charge. Thus, even for an individual who is

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<sup>39</sup> The Arc of Massachusetts. *The History of The Arc of Massachusetts: Lawsuits*.

<<http://www.arcmass.org/Home/WhoWeAre/lawsuits/tabid/615/Default.aspx>> 7/27/09.

<sup>40</sup> The Commonwealth of Massachusetts. Health and Human Services: FY2009 Budget Summary.

<[http://www.mass.gov/bb/gaa/fy2009/app\\_09/act\\_09/h59202020.htm](http://www.mass.gov/bb/gaa/fy2009/app_09/act_09/h59202020.htm)> 7/27/09.

able to work in the community, their annual vocational costs are around \$33,000 per year.

Transportation could also be needed by these individuals. The average cost of transportation (in a group van) without a monitor is \$28 per day. But, as with the other services, to add a monitor would require an additional cost. Further, if a specially trained monitor is required to control behavior, the cost would be dependent on their hourly rate. In general, people with severe behaviors are often transported by their group homes for approximately \$200 per day.<sup>41</sup>

Transportation and vocational training estimates are from Lifeworks Inc. Lifeworks has a variety of vocational and supportive services for adults with developmental disabilities in Massachusetts. They serve individuals in both the greater Boston and Norwood areas, totaling 214 people.

#### **4. Unmet Needs**

Many individuals with ASD continue through adulthood needing support from outside sources.<sup>42</sup> Therefore, it is critical to not only assess adult services to ensure that they are providing adequate supports to adults with autism and contributing to positive outcomes but it is also important to delineate areas of unmet need. Four areas that require attention are: (1) funding for transition services, (2) lack of disability-specific training for direct care givers and supervisors, (3) insufficient service coordination and (4) lack of adequate access to experienced primary health care providers and oral health care providers.

#### **Transition Services: Funding**

The first issue of unmet need is funding for transition services. In Massachusetts, there are two laws that deal with transitioning youth with disabilities into the adult human services system: the Individuals with Disabilities Education Act (IDEA) and Chapter 688. IDEA is federal legislation that requires schools to provide appropriate education for children with disabilities, including specialized support services to ensure that each child is given the opportunity to reach his/her fullest potential in both education and life skills. This planning is done via an individual education plan (IEP), through which students can include additional skills that will help them with employment and independent living. Also included in the IEP is transition planning, for when the child turns 22 or graduates from high school. Although transition planning is required by law, there are no quality assurance measures currently in place to ensure that all of the students' needs are being met. Further, even though transitioning from the entitlement-based special education system to a non-entitlement based

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<sup>41</sup> Cost estimates from Deb Wood, South Norfolk County Arc. 3/24/09.

<sup>42</sup> Howlin, Goode, Hutton, Rutter. Adult outcome for children with autism. *Journal of Child Psychology and Psychiatry*. 2004. 45(2): 212-229.

adult services system is complex, classroom teachers are given the responsibility for developing IEPs and transition plans for their students. Teachers could benefit from further support and professional development in this area, but additional training would require both time away from their many other responsibilities and extra funding.

Another law that supports young people transitioning out of the education system is Chapter 688. This is a law that provides young people with a two year planning process and provides a single point of entry into the adult human services system.<sup>43</sup> The Eligibility requirements for Chapter 688 are that a student:

- (1) Be receiving special education paid for by the Commonwealth of Massachusetts
- (2) Need continuing habilitative services at the time of turning 22 or graduating from special education, and
- (3) Be unable to work competitively (without specialized supports) for more than 20 hours per week at the time of leaving school<sup>44</sup>

Also, students are automatically eligible for transition services if they are currently receiving Supplemental Security Income (SSI), Social Security Disability Insurance (SSDI), or are registered with the Massachusetts Commission for the Blind.

So, although individuals with autism only make up a portion of the Turning 22 class each year, with the growing numbers of children with autism appearing in Massachusetts special education classrooms, there will be an increase in the number of individuals with autism who are eligible to apply for Turning 22 services.

Through the Turning 22 process, most individuals with ASD who are deemed eligible for services are assigned to the Department of Developmental Services (DDS), or the Massachusetts Rehabilitation Commission (MRC). Individuals deemed eligible for the Turning 22 program have a number of options. They can utilize community based residential services, day services or supported employment, transportation services and/or family support services.

But under the Massachusetts Department of Developmental Services rule, 115 CMR 6.00, regarding eligibility and prioritization guidelines, "all supports, including assessments, planning and the development and implementation of Individual Service Plans, are subject to the availability of resources." So, once funding runs out, DDS is not obligated to provide

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<sup>43</sup> Massachusetts Department of Mental Retardation. *The Road Forward: DMR Guide for Transition Planning*. March, 2008.

<sup>44</sup> Massachusetts Department of Mental Retardation. *The Road Forward: DMR Guide for Transition Planning*. March, 2008.

services. Also, the Department bases its prioritization on an assessment of the individual's, "functional limitation(s), cognitive impairment, medical needs and behavioral needs as well as generic resources and natural supports available to meet the individual's needs."<sup>45</sup> Thus, the funding of services for adults with disabilities is prioritized as follows: (1) Community, 24-hour residential supports (2) Community living supports and (3) supportive services.<sup>46</sup>

Approximately 2/3 of the total Turning 22 funding goes to individuals with high needs (24/7 care). Less than 1/3 of the funding goes to day rehabilitation, employment support or family support services for adults. DDS has discretion in its funding priorities after it meets the needs of the priority individuals. However, there is not much funding leftover. Although there is some annualized funding, it is not sufficient to provide supports for those who need day rehabilitation, employment support or other support services. When funding runs out, the Department is not obliged to pay for support services.<sup>47</sup>

However, as can be seen in Table 3, the proposed funding level for 2010 is the lowest it's been in many years due to the latest round of budget cuts; and could have dire effects on the individuals served by this program. The Arc of Massachusetts voiced its concern over the budget cuts, which include but are not limited to the Turning 22 funding, "The budget cuts do not take into account students graduating from high school for which full year funding is not allocated. These cuts may impact more than 500 of the 608-plus graduating."<sup>48</sup> Although funding can vary based on severity of disability; the average funds per student is a useful proxy to gauge the change in funding levels.

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<sup>45</sup> Department of Mental Retardation. 115 CMR 6.00. "Eligibility, Individual Support Planning and Appeals." <[http://www.mass.gov/Eeohhs2/docs/dmr/regs/reg\\_115cmr006.pdf](http://www.mass.gov/Eeohhs2/docs/dmr/regs/reg_115cmr006.pdf) > 4/14/2009.

<sup>46</sup> Department of Mental Retardation. 115 CMR 6.00. "Eligibility, Individual Support Planning and Appeals." <[http://www.mass.gov/Eeohhs2/docs/dmr/regs/reg\\_115cmr006.pdf](http://www.mass.gov/Eeohhs2/docs/dmr/regs/reg_115cmr006.pdf) > 4/14/2009.

<sup>47</sup> Leo Sarkissian. Executive Director, ARC of Massachusetts. 3/31/2009.

<sup>48</sup> The Arc of Massachusetts. *FY2010 Budget: Governor's Vetoes/Final Report*. As of June 29, 2009. <<http://www.arcmass.org/StateHousePolicy/MainBudgetPage/StateBudgetInformationFY2010/FY10GovernorVetoesFinalBudget/tabid/865/Default.aspx> > 7/28/09.

**Table 3. Turning 22 Appropriations, 2003-2010<sup>49,50,51</sup>**

<b>Fiscal Year</b>	<b>Appropriation</b>	<b>Class Size</b>	<b>Average Funds per Student</b>
<b>2003</b>	6,468,000	453	14,278
<b>2004</b>	6,468,000	502	12,884
<b>2005</b>	6,468,000	513	12,608
<b>2006</b>	6,468,000	597	10,834
<b>2007</b>	8,500,000	571	14,886
<b>2008</b>	7,700,000	608	12,664
<b>2009</b>	7,700,000	609	12,644
<b>2010</b>	5,000,000 <sup>52</sup>		

If the levels of funding remain as they are proposed, there will be little if any funds left to address critical or timely needs. According to The Arc of Massachusetts, these include:

- Lack of emergency preparedness; no funding set aside for crisis situations
- No flexibility to increase areas such as family support or employment and transportation
- Newly eligible individuals end up on a waiting list due to a lack of funding<sup>53,54</sup>

### **Training of Frontline Workers**

While DDS does require basic training for its workers in CPR, First Aid, and Human Rights, ensuring that front line workers have sufficient behavioral

<sup>49</sup> The Arc of Massachusetts. *Summary of the Governor's Budget for 2009*.

<<http://www.arcmass.org/StateHousePolicy/StateBudget/Governors2009Budget/tabid/779/Default.aspx>> 2/11/2009.

<sup>50</sup> Department of Mental Retardation. *Historical Budget Levels*.

<[http://www.mass.gov/bb/h1/fy2009h1/brec2\\_09/dpt09/hhdmr.htm](http://www.mass.gov/bb/h1/fy2009h1/brec2_09/dpt09/hhdmr.htm)> 2/11/2009.

<sup>51</sup> The Arc of Massachusetts. *FY2010 Budget: Governor's Vetoes/Final Report*. As of June 29, 2009.

<<http://www.arcmass.org/StateHousePolicy/MainBudgetPage/StateBudgetInformationFY2010/FY10GovernorVetoesFinalBudget/tabid/865/Default.aspx>> 7/28/09.

<sup>52</sup> This figure comes from the FY 10 budget as of June 29, 2009. The allocation was originally 7,700,000 but with the budget cuts it became \$5,000,000. The Turning 22 class size was not available yet, so it has been left blank; but it is still important to note the decrease in allocation for FY 10 and the potential impact that it can have on young adults with disabilities.

<sup>53</sup> The Arc of Massachusetts. *The Turning 22 Dilemma: Line Item 5920-5000 (amendment 991 in the House)*.

<sup>54</sup> On the fact sheet from the ARC of MA cited in footnote 21, it is noted that no funds were allocated for 2009 to support individuals on waiting lists.

training has been a challenge for many service agencies. Many do not have the time or resources to invest to certify their workers in areas of therapeutic specialization such as applied behavior analysis (ABA). While there are a variety of treatments available for individuals with autism, ABA has been the most rigorously tested, and shown effective in studies involving children.<sup>55</sup> Another challenge that many organizations have experienced is that reimbursement rates do not include money for training; so it is entirely up to the organization to foot the bill for training. Considering that many organizations face problems with high staff turnover in the social services sector, the cost of continually training new workers can be burdensome.

Currently there is no requirement for the professional credentialing of workers who interact on a daily basis with individuals with disabilities. The social, communicative and behavioral symptoms of autism may make it difficult for an untrained worker to help facilitate the completion of program related tasks or other activities. Whether it's supported employment, education, or residential services, working with individuals with autism requires some understanding of the disability, how it influences individual behavior and the methods and techniques that will best serve each client's needs. A lack of training is also problematic because individuals with autism commonly experience seizures, impulsive behavior, mood instability, anxiety and depression.<sup>56</sup> If front line workers are not familiar with how to handle certain situations, it can be dangerous to both the individual with autism as well as their support worker.

Thus, the programs serving individuals with autism may not be running as efficiently as they could. Some organizations do a good job of training internally, but at this point training is an agency-level function. It would be ideal to have certification at the state-level for more uniform standards of care in working with the ASD community. These recommendations have been echoed in other issue briefs from groups such as the Autism Society of America.

### **Service Coordination**

Massachusetts needs to revisit its current practices around linkage and referral services for young adults with ASD. Currently, upon eligibility for the Turning 22 class, individuals with disabilities are often screened first by DDS to determine their service needs. However, at this time DDS does not track co-morbid conditions such as ASD. While individual diagnostic information of ASD may come out when the case worker gathers the personal histories, transition planning is done on a case-by-case basis. So, there is no way to look across data gathered by DDS and see how the individuals with autism

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<sup>55</sup> Charles J, Carpenter L, Jenner W, Nicholas J. Recent Advances in Autism Spectrum Disorders. *Psychiatry in Medicine*. 2008; 38(2): 133-140.

<sup>56</sup> Charles J, Carpenter L, Jenner W, Nicholas J. Recent Advances in Autism Spectrum Disorders. *Psychiatry in Medicine*. 2008; 38(2): 133-140



are faring. Due to this lack of uniformity, the agency does not take into account the needs of the cohort of young adults with autism or look at the implications of transition services for this group.

Also, due to the Turning 22 funding mechanism, DDS waits to hear from the legislative appropriations committee as to how much money they will have to spend before making transition plans. This process does not encourage long-range planning, since the department does not want to make plans that it cannot carry out. Therefore it encourages case workers to make transition plans only one year in advance.<sup>57</sup>

Since individuals with autism are a heterogeneous group, individualized referrals are required to meet the specific needs of each client. This is challenging given the high volume of individuals that DDS has to manage and the large case loads their employees carry. However, by sharing information across programs, some of this challenge could be alleviated. Due to the IDEA legislation, school districts must keep track of the number of students with autism enrolled in special education (see Table 1). So, the Massachusetts Department of Elementary and Secondary Education has a lengthy history on the progress of each child in special education, including developmental disability status, severity of need and types of interventions that have been tried while they have been in school.

If those case files could be shared with DDS, their employees would have the information necessary to be able to make more appropriate referrals for services that target the strengths of the individual. Currently, there is inconsistency as to how this information sharing is carried out. For example, even when DDS gets files ahead of time, they are not necessarily shared with the potential service providers.<sup>58</sup> So the providers who are working with the clients with ASD may lack pertinent data that could help them serve their clients better.

A report from the Autism Society of America states "In autism, service needs are often intense, therefore a knowledgeable, accessible case manager is critical to helping clients and their families with appropriate service provision."<sup>59</sup> There could be some privacy issues around the sharing of personal information, but even sharing diagnostic information between agencies would improve the ability of DDS, and MRC in turn, to make effective referrals.

### **Lack of adequate physical and oral health care**

There is much evidence illustrating the challenges that individuals with developmental disabilities face in obtaining quality health care services,

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<sup>57</sup> Rita Gardner, Executive Director, Melmark New England. Conversation, 5/20/2009.

<sup>58</sup> Rita Gardner, Executive Director, Melmark New England. Conversation, 5/20/2009.

<sup>59</sup> Sullivan, Ruth Christ. Autism Society of America. Position Paper on The National Crisis in Adult Services for Individuals with Autism. *Updated May 2007*. Pg. 9.

especially as they grow into adulthood.<sup>60</sup> For example, physicians receive little training around working with individuals with developmental disabilities. Many individuals actually end up staying with their pediatricians into adulthood due to the difficulty in obtaining a primary care physician who has experience working with adults with ASD or other developmental disabilities.<sup>61</sup> However, this arrangement doesn't serve individuals with ASD well, because adults have different age-related health needs than children. Therefore, pediatricians are not able to provide appropriate care for their adult clients with ASD.

While evidence has focused on the importance of oral health care for children, this need continues into adulthood. One source described the greater oral health needs of people with disabilities by reporting that these individuals exhibit "a higher percentage of malocclusions than the normal population. This is related to more frequent occurrences of craniofacial deformities, abnormal growth and development, and a higher incidence of abnormal tongue posture and orofacial muscular disturbances."<sup>62</sup>

This report also noted that a number of the medications that individuals take can have adverse affects on oral health. "Seizure medications can cause gingival hyperplasia. Psychotropic and cardiovascular medications can cause dry mouth. The high sugar content in medications for children can contribute to dental decay."<sup>63</sup> In addition to the greater level of dental problems, there is a significant need for dentists and orthodontists who are willing to treat individuals with autism and other developmental disabilities. There is a disincentive to provide dental services to individuals with developmental disabilities because many dentists have not had experience or training in working with these individuals and because the Medicaid reimbursement rates that they receive for this work are low.<sup>64</sup> The low rates are especially problematic since office visits can take longer for individuals with special needs than others.

## 5. Recommendations

Only a moderate amount of evidence exists regarding the treatment and well-being of adults with autism in Massachusetts. The breadth of this paper is not sufficient to make any broad-based policy recommendations due to the lack of information in many areas of adult services. Therefore, a

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<sup>60</sup> Krahn G, Hammond L, Turner A. *Cascade of Disparities: Health and Health Care Access for People with Intellectual Disabilities*. Mental Retardation and Developmental Disabilities Research Reviews. 12: 70-82 (2006).

<sup>61</sup> Nichols A.D., Ward R.L., Freedman R.I. and Sarkissian L.V. *Left Out in the Cold: Health Care Experiences of Adults with Intellectual and Developmental Disabilities in Massachusetts*. December, 2008. The Arc of Massachusetts. Pg. 20-23.

<sup>62</sup> Waldman B, Perlman SP, Swerdloff M. "Orthodontics and the population with special needs." *American Journal of Orthodontics and Dentofacial Orthopedics*. 118(1). 2000.

<sup>63</sup> Waldman B, Perlman SP, Swerdloff M. "Orthodontics and the population with special needs." *American Journal of Orthodontics and Dentofacial Orthopedics*. 118(1). 2000.

<sup>64</sup> Parish S, Moss K, Richman E L. "Perspectives on Health Care of Adults with Developmental Disabilities." *Intellectual and Developmental Disabilities*. 46(6).

commission tasked with developing a more complete understanding of the status and future needs of adults with autism that can assist in the development of policy and service options is recommended.

### **Research Commission**

Massachusetts should consider creating a commission to gather data surrounding the status and future needs of adults with autism and to formulate policy and service recommendations for the state regarding this population. The following areas remain understudied and need more attention in order to formulate effective and efficient policies going forward:

- **Number of adults with autism** who are *served* in Massachusetts
- Number of adults with autism currently on **waiting lists** for services
- **Intensity and type of services used** by adults with autism
- Unmet services needs
- Longitudinal **cost estimates**, both to the individual and to the state

These data will make it possible for people in Massachusetts to better understand the current state of their disability services and overall service system. It could also enable them to begin looking at areas in which overlap and inefficiencies may occur. Information focused on adults with autism is also needed to facilitate effective program design and future planning for policies focused on:

- **Best practices** for serving adults with autism,
- The implementation, use, and utility of various kinds of **behavioral therapies**, and
- **Training** for front line workers and primary caregivers.

First, a research commission could contribute to the literature around **best practices** for serving adults with autism, especially in determining which behavior therapies work well with adults. Most of the behavior therapy research is around children, and it is possible that adults will have different needs and reactions to therapy. There also needs to be research on a broader array of **behavioral strategies**. Only applied behavior analysis (ABA) has been tested over time, and only with children. Lastly, there needs to be research around **training and retaining front-line workers** and primary caregivers and around how to make training **cost-effective** for agencies and organizations. This might include looking at ways to include training in Medicaid reimbursement formulas. In the future, Massachusetts will be able to look at the costs to individuals, communities and taxpayers; and weigh accurately alternative service options.

While this covers a broad range of focus areas, it speaks to the lack of understanding that remains around autism especially for adults. As can be inferred by looking at the youth prevalence of autism in Massachusetts, there will be an increase of adults with autism who have service needs over the next ten years. The challenges that exist in the current system of adult services for individuals with autism are likely to be exacerbated if they are not addressed effectively over the next few years. Therefore, the Commonwealth needs to invest in research and analysis so that effective policies and practices can be developed and implemented for the next generation of adults with autism.

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## **AFAM Member Organizations**

Autism Support Center – Danvers

Autism Resource Center of Central Massachusetts- W. Boylston

Community Autism Resources – Swansea

Autism Society of America, Massachusetts Chapter – Wellesley

Community Resources for People with Autism – Easthampton

Asperger’s Association of New England – Watertown

Family Autism Center – Westwood

Till/BFA Autism Services – Greater Boston

Autism Alliance of Metrowest – Natick

Doug Flutie, Jr. Foundation for Autism – Framingham

The Arc of Massachusetts – Waltham

Massachusetts Advocates for Children – Boston

Autism Speaks New England Chapter - Dedham

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