Where Are We Now?
The State of Disability Services for Adults with Autism in Massachusetts

Caroline Budney Zimmerman

Over the past six years, the number of students diagnosed with autism in Massachusetts has doubled. Many of these individuals will be looking for some level of supportive services once they leave the educational system. Massachusetts currently lacks the resources and infrastructure needed to meet the demands of this growing population. To address these issues, Massachusetts needs to take a two-pronged approach to prepare for the increasing adult population with Autism Spectrum Disorder (ASD). By combining short- and long-term approaches, the Commonwealth can transition to a more effective service model while ensuring that those currently in the system are supported. This includes: (1) moving to electronic record-keeping, (2) allowing an individual’s case files to follow them to each referral and (3) developing a research commission to gather and analyze data around the needs of adults with autism. Through research and analysis, Massachusetts can re-frame the way they approach disability services for adults with ASD and become a leader for other states as they experience similar challenges in managing their population of aging individuals with ASD.

Over the past six years, the number of primary and secondary students diagnosed with autism in Massachusetts has doubled, according to data from the Massachusetts Department of Elementary and Secondary Education. 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 (CDC, 2009; APA, 2009). Many of these individuals will be looking for some level of supportive services once they leave the educational system.
Context

Autism Prevalence in Massachusetts

The prevalence of adults with autistic disorder in Massachusetts 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) (Kritz, 2009). There is no single department charged with serving and tracking all adults with this condition, so each agency is responsible for its own data. DDS currently does not categorize the type of disability or diagnosed condition among its adult clients, so it is not known how many of their clients have autism. MRC currently tracks autism in its vocational rehabilitation (VR) program due to reporting requirements from its federal funding agency. MRC may provide services to adults with autism through its other programs, such as community living or home care assistance, but there is no data available at this time to show demographic detail on who they serve. So, even though their VR program is adding to the knowledge around how adults are being served, the agency as a whole still has room for improvement.

Adult prevalence can be estimated by looking at data that are available on children, which is gathered due to regulations surrounding the Individuals with Disabilities Education Act (IDEA) legislation. There are two parts to the act, IDEA Part B and Part C; each addresses a different set of distinct needs which children of all ages face. IDEA Part B targets children and youth ages 3-21, and gives students access to special education and other support services for students in K-12 and preschool programs. One provision of the IDEA legislation, Title 1, part B, section 618 describes the reporting procedures that each state is responsible for. It includes the number of students with disabilities and includes those who are at risk for developmental delay and those who use early intervention services (U.S. Department of Education, 2009b).

Massachusetts has kept individual data on the number of children with a diagnosis of autism since 2001. In a 2005 report, the Massachusetts Department of Public Health determined that the Department of Education had the best data on autism in Massachusetts (Massachusetts Department of Public Health, 2005).
Table 1

*IDEA Part B: Children with Autism in Massachusetts*

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

*Note.* From Data Accountability Center, IDEA, 2009.

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

By looking at the oldest cohort, 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 ages 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, 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 has risen since 2004. Although MRC does not have data on consumers in community living programs, data from the vocational rehabilitation program clearly demonstrate that there is an increasing need for vocational programs for individuals with autism.

It is important to note that there has been much debate nationally over whether there is an increase in the number of people with autism or whether it is being diagnosed more often (Frombonne, 2003; Blaxill, 2004). For the purposes of this article, this issue will not be discussed in depth. Regardless of the reasons for the increased number of adults with autism, as a provider of adult services, Massachusetts must focus on the increase in the number of autism cases, and prepare to serve a larger cohort than in the past. Currently, Massachusetts doesn’t know how this cohort is faring in the adult service system and there is great concern that the state is unprepared for the influx, over the coming decade, of adults with autism who will seek services.

Table 2

|MRC Consumers with Autism as a Primary or Secondary Disability|
|-----------------------------|-----------------------------|-----------------------------|-----------------------------|-----------------------------|
|                            | Primary disability | Secondary disability | Total | % of MRC consumers |
| Current active consumers   | 552               | 103                 | 655   | 2.19            |
| Served FY 2008             | 386               | 85                  | 471   | 1.89            |
| Served FY 2007             | 296               | 56                  | 352   | 1.34            |
| Served FY 2006             | 268               | 43                  | 311   | 1.27            |
| Served FY 2005             | 224               | 40                  | 264   | 1.07            |
| Served FY 2004             | 172               | 27                  | 199   | 1.02            |

Note. Served is defined as the period from eligibility to case closure. From MRC, 2009.
Current Service Models in Massachusetts

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

For day services there are two typical models of service: Day Habilitation Services and Vocational Services. Day Habilitation Services focus on the habilitative or clinical needs of the individual. Habilitation, as defined by DDS, means “the process by which an individual is assisted to acquire and maintain those life skills necessary to cope more effectively with personal and environmental demands or to improve physical, mental, and social competencies” (DDS, 2009a). Services focus on such skill and habilitation needs can include: Occupational Therapy, Physical Therapy, Speech and Language Therapy, or Behavioral Treatment. These programs are funded by the Division of Medical Assistance (DMA).

Vocational Services encompass a broad range of opportunities, but focus on paid employment. These types of programs can range from a sheltered workshop, where the individual works in a group on piecework, to supported employment in the community with or without a job coach. However, only some adults with autism are able to work in the community. Recent national estimates suggest 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 (Ganz, 2007).

In terms of residential services, there are two options that families and individuals in Massachusetts can take advantage of, based on availability: campus-based or community-based programs. 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. In community living programs, there is a specific focus around community integration and socialization, since these living arrangements are located throughout many towns and cities. Campus-based programs, such as the New England Village, provide residential services on-site (New England Village, 2009). The campus models offer a variety of supportive and recreational services on site, but also provide opportunities for community involvement. They are often in rural areas and a good option for individuals who have a heightened sensitivity to noises common to
metropolitan areas. Currently, community-based residential programs are more commonly used than campus-based programs.

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.

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 would be useful in helping Massachusetts plan for an increase in need. Lastly, although it is not formally tracked, there are many individuals who end up on waiting lists especially for residential services due to a lack of capacity. In 2006, over 64,000 people with developmental disabilities were reported to be on waiting lists nationally for placements into residential services; research studies have estimated that the figure could be as high as 84,500 (Braddock et al., 2008). This is likely to become a more significant problem as individuals with disabilities in the baby boom generation age and more adults need out-of-home services. The availability of research evidence on appropriate adult services will help the state provide services for the current disabled population, as well as plan for future needs.

**Related Legislation: Chapter 688**

Massachusetts enacted Chapter 688 in 1983 to create a transition into the adult services system for students with disabilities (Horace Mann, 2009). It is also known as the “Turning 22 Law” because in Massachusetts, individuals with disabilities exit the educational system when they graduate or when they turn 22 years of age. Administered by the Executive Office of Health and Human Services (EOHHS), this law connects individuals leaving the educational system with adult services through a two-year planning process and the development of a transition plan. This law is not an entitlement; it does not guarantee services but it does help to plan for the future needs of the individual (DDS, 2009b). Students are eligible if they are receiving special education services,
need continuing services, and are only able to work 20 hours per week or less in non-supported employment (Commonwealth of Massachusetts, EOHHS, 2009). Depending on their needs, cases are referred to the Department of Developmental Services (DDS), the Massachusetts Rehabilitation Commission, the Massachusetts Commission for the Blind or the Massachusetts Commission for the Deaf and Hard of Hearing.

**Current Challenges in Service Provision**

There are a few gaps in knowledge that Massachusetts needs to address before attempting to change the way they provide services to individuals with disabilities. First, Massachusetts does not know the size of its current adult autism population, let alone how they are being served or by which programs. Secondly, due to the fragmentation of disability services and lack of data, Massachusetts is unable to compare across programs or agencies and determine the effectiveness of current programming or placements for adults. Lastly, there is little state or national data to indicate what best practices in adult services look like for adults with autism.

**(Lack of) Information Sharing**

Upon leaving the educational system between ages 18 and 22, the Department of Developmental Services (DDS) and the Massachusetts Rehabilitation Commission (MRC) refer individuals with disabilities to adult services and programs. Massachusetts does not currently have a unified tracking mechanism for adults with disabilities; each agency is responsible for tracking its own clients and referring them to the appropriate services. Currently DDS does not keep track of diagnoses other than the primary one, so when an individual is placed through their agency, additional disabilities or conditions are not taken into account. This is problematic because individuals with autism commonly experience multiple conditions including seizures, impulsive behavior, mood instability, anxiety and depression (Charles et al 2008). If these conditions are not taken into account when planning placements, adults with autism may end up in a program that does not effectively suit their needs.

Additionally, since autism is on a spectrum, it requires scaled treatment as the diagnosis can affect people with differing severity.
For example, three typical scenarios on the autism spectrum include: (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. Each of these individuals will need vastly different levels of support, and therefore individualized referrals are needed to meet the specific needs of each client. DDS's current approach may be due to the high volume of individuals that they manage and the large case loads that their employees carry.

By sharing information across programs, some of this challenge could be alleviated. Under the Individuals with Disabilities Education Act (IDEA) legislation, school districts must keep track of the number of students enrolled in special education with autism. So, the Massachusetts Department of 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 this information could follow the child into the adult system, agencies like DDS would be able to better place these individuals.

(Lack of) Available Research

The dearth of evidence available surrounding best practices for serving and caring for individuals with autism creates many challenges for service providers and states. It limits the ability to plan future services, make decisions on the expansion of services, focus on the use of effective services, and estimate the efficiency or lack thereof of different service delivery models.

The possible causes of autism are still unknown, so much of the research focuses on finding the cause and the effects of autism on young, developing children. For example, the National Institutes of Health (NIH) supports two major research networks for autism: the Collaborative Programs of Excellence in Autism (CPEA) and Studies to Advance Autism Research and Treatment (STAART). CPEA's research focuses on determining the possible causes of autism by looking at a variety of factors including genes, immunology, and the environment. They also look at the ways that autism is diagnosed and treated (NIH, 2009). The STAART Network focuses on
“causes, diagnosis, early detection, prevention, and treatment of autism” (NIH STAART, 2009).

It is critical, however, to fund research at different stages of life, including adulthood, to better understand how the disability progresses or changes over time. Individuals with autism can live well into their 40’s and beyond, although their mortality rate is higher than in the general population (Mouridsen et al., 2008). So, expanding research to include all stages of life could help inform needs for learning and skill development for those who are past school-age and in the adult system.

Inherent in the question of aging is the fact that some of these individuals may outlive their parents or outgrow the age at which their parents can effectively care for them. Therefore, adult care and programming is a significant and growing issue for many families with autism. By supporting research that looks at treatment and programming geared towards adults, we can better serve current and future generations of adults with disabilities.

Leaders of Change

Consumers and families are the main supporters and advocates of improvements to disability services. The Arc of the United States (formerly known as the Association for Retarded Citizens), Autism Speaks, and the National Autism Association (NAA) are just some of the special interest groups that would voice support for improving service delivery in Massachusetts. Especially given Massachusetts’ progressive approach to healthcare, national advocacy groups would support efforts to improve disability services in the hopes that Massachusetts would be used as a model for other states.

In the Massachusetts legislature, there are a number of strong supporters interested in investing in disability services. Representative Barbara L’Italien (D-Andover), Representative Tom Sannicandro (D-Ashland), and Senator Karen Spilka (D-Ashland) are among the key supporters for statewide efforts to improve disability services in Massachusetts. In 2009-2010, Rep. Sannicandro is sponsoring 6 disability-specific bills, Rep. L’Italien is sponsoring 10 disability-specific bills, and Sen. Spilka is sponsoring 2 disability-specific bills (Commonwealth of
While it is difficult to get a broad base of support for new spending in this economic climate, the short term expenditures associated with the following policy alternatives could create long-term cost-savings. New policy options need to be considered to develop a long-term strategy to avoid the inefficient use of state resources.

Scopes for Improved Services

Massachusetts is not prepared to meet the needs of an increase in the number of individuals with autism. The Executive Office of Health and Human Services (EOHHS) needs to plan for the increasing cohort of adults with autism over the next 10 years and dramatically improve the current knowledge and information systems used in disability services. There are two options that should be considered, each with a specific time horizon.

*Short –Term Options (1-4 years): Information Gathering, Dissemination and Sharing*

One major issue that can be addressed over the next 1-4 years is improved information dissemination and data management regarding individuals with disabilities. For example, information regarding diagnoses, prior therapies that have been tried, prior work placements, secondary conditions, and behavioral conditions would all be useful for an agency to have to make a successful placement. Logistically, agencies have their own data collection methods based on their eligibility criteria and the data they feel is critical to have. Targeted information gathering is necessary for agencies; intake would require an incredible amount of time if each agency tried to get a complete personal history. However, having a complete and accurate personal history available could ensure that appropriate services are provided for individuals with disabilities in Massachusetts. Therefore, there are a few ways that information management could be improved and made more useful to the state and inform both providers and clients in their decision making. First, there could be improvement in terms of information sharing across agencies. Secondly, there could be improvement in the way that data are collected and managed for each individual case, as
evidenced by efforts begun by the Massachusetts Rehabilitation Commission (MRC).

**Information sharing across agencies.** Disability services are fragmented, with multiple agencies and programs providing supports to individuals with autism. Currently, when an individual is deemed eligible for adult services and leaves the educational system, a new case file is opened at the transition or referral agency. Each agency has its own standard operating procedures when it comes to intake of new clients. For example, DDS does not track dual or multiple diagnoses; they focus on intellectual quotient to ensure that the client is eligible for services. When an individual is placed through DDS, other disabilities or conditions are not taken into account. As stated earlier, this is problematic because individuals with autism commonly experience seizures, impulsive behavior, mood instability, anxiety and depression in addition to cognitive impairments (Charles et al., 2008). If these conditions are not taken into account when planning their placement, they may end up in programs that do not effectively suit their needs.

One solution to this is having case files follow each individual from the Department of Education to DDS or the individual’s specific referral agency. Given that the IDEA legislation already mandates certain reporting procedures that states are required to follow, specifically around keeping track of students with disabilities, it is a duplication of effort for the transition agency to open an entirely new case for an individual who already has a history with the Department of Education (U.S. Department of Education, 2009c). That would help alleviate any information falling through the cracks, and give the referring agency much more background to work with to make a successful and efficient placement.

Some challenges in moving forward with this option might relate to privacy issues around the sharing of personal information. One way to alleviate concerns around the release of information is to include other family members in planning and releasing information. For example, there could be an option for individuals to sign release forms to allow their information to travel with them across agencies. Additionally, if even only a basic treatment history or primary diagnostic information could be shared between agencies, it would vastly improve the ability of DDS and MRC to make effective referrals.
**Data management.** Another way that information dissemination and utilization can be improved is through changes in the way that agencies manage their consumer data. Currently, the Massachusetts Rehabilitation Commission’s Vocational Rehabilitation program collects information on primary and secondary disabilities for all consumers. At the point of application, the counselor collects this information and enters it into MRC’s case management database. This reporting procedure is mandated by their federal funder, the Rehabilitation Services Association (RSA), which influences the way that they collect and manage their client information. Other agencies, such as DDS, are not funded by RSA, and thus do not have to conform to the same reporting regulations or eligibility requirements. However, if data systems can facilitate information sharing across agencies, then the DOE, MRC and DDS could coordinate the information they have on an individual to create a more complete picture of each individual without having to change their eligibility requirements or other agency-specific functions.

There are three main steps that can be taken to improve data management. First, the move to electronic recordkeeping is critical for improved operations. Most agencies are moving this way, but there are still some areas in which paper documents are being used. Another approach is to utilize an agency-wide cross-database comparison tool. This is a type of software tool that is able to look at multiple databases, such as Oracle and SQL Server, and compare fields in each database against each other. Instead of trying to implement a single database across multiple agencies, this tool allows the database administrator to compare fields, such as service areas, and compare utilization rates or financing across an entire agency or even between agencies. If an agency cannot take a snapshot of itself and understand how its money is being spent, where people are being placed and if any service duplication is occurring, then their standard operating procedures are not efficient. Lastly, DDS should consider ensuring that its database is compatible with other agencies serving the adult disabled population. This recommendation seeks to consolidate and make uniform information on individuals being served by the Commonwealth.

Before establishing an effective system of data management, several challenges need to be addressed. First, there is variation across programs within the same agencies for how data are
managed. For example, two programs within the MRC, the Home Care program and the Vocational Rehabilitation program, use different disability categories. They are, however, working on a key to enable cross-program comparisons. So even within agencies, it is acknowledged that it will be a challenge to coordinate; however the benefits of transparency and referral coordination could potentially save money in the long run by eliminating the duplication of services.

Secondly, DDS will have concerns that uniform reporting for all of their disability services will create extra paperwork for them, considering they already don’t have enough time or resources to serve the current need. However, if coordinated reporting is developed to align with the federal reporting requirements DSS already has, this would not create extra work. DDS can select a database that has the capability to select out fields for various types of reporting, so in the long-run it can make things easier. Also, instituting uniform tracking across the agency can make all of DDS’s disability services more efficient, not just programs for individuals with autism.

DDS should take note of MRC’s management of their Vocational Rehabilitation program, as well as their attempt at agency-wide coordination. DDS should consider how MRC’s model can be adapted for its case management and referral needs. If DDS can improve its ability to coordinate with MRC, then its improved data management could increase information sharing and facilitate comparisons across agencies, providing consistent disability service tracking.

**Long-Term Option (one to 10 years): Need for Research**

As evidenced in this paper, there is a significant lack of information around services for adults with autism. Considering the youth prevalence of autism in Massachusetts, there will be more adults with autism with service needs over the next ten years. Effective policy decisions require accurate information on which to base future recommendations.

*Research commission.* Massachusetts should consider forming a commission to gather data surrounding the status and future needs of adults with autism as well as formulate policy and service recommendations for the Commonwealth. This commission could report to EOHHS and involve a number of local stakeholders.
including state agencies, service providers, and universities. The work of a research commission would enhance the current knowledge base and assist in developing policy recommendations for improving the delivery of disability services for adults with autism and other developmental disabilities.

Policymakers and practitioners need accurate state-level data for a clear understanding of the current state of autism services in Massachusetts. The following areas are understudied and need more attention to formulate effective and efficient future policies:

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

By compiling these data, Massachusetts will better understand the current state of its disability services. It could also enable EOHHS to begin looking at specific areas in which overlap and inefficiencies may occur.

Information is also needed to facilitate effective program design and future policy planning. By gathering the following data, this commission could better inform policymakers and practitioners in terms of priority setting and policy development:

- Evidence around **best practices** for serving adults with autism
- Research on *implementation, effectiveness and efficiency* of various behavioral therapies
- Research on *training and retaining* front line workers and primary caregivers.

First, this research commission could assist in disseminating findings around best practices for serving adults with autism, especially around behavior therapies. Most of the current research is around children, and it is entirely possible that adults will have different needs and reactions to therapy. There also needs to be research on various kinds of behavioral therapies. Only applied behavior analysis (ABA) has been tested over time, and only with
children. Lastly, there needs to be research around training front line workers and primary caregivers as well as more analysis on how to retain them in their positions for longer periods of time. Included in this is determining the distinct needs of adults with autism, and 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 tax-payers, and weigh alternative service options with confidence.

While this research agenda covers a broad range of focus areas, it speaks to the lack of understanding that remains around autism especially for adults. This research commission could also build on work that is currently being done. For example, the Waisman Center at the University of Wisconsin-Madison along with a researcher at Boston University are doing a research project called Adolescents and Adults with Autism (Seltzer et al, 2009), looking at how autism affects adolescents, adults, and their families over a 12 year period. They currently are investigating 405 families and are funded by the NIH (Waisman Center, 2009). Over the course of this study, other Massachusetts institutions, including Brandeis University, have been involved as well.

**IT investment.** Massachusetts needs to consider investing in research around using IT solutions to streamline service delivery and daily operations. While there are a number of software packages that exist, there are two in particular that have a national presence. The first example is the AWARE case management system which integrates case management and fiscal information for vocational rehabilitation programs as well as programs for the blind. It is currently used by organizations in 17 states, including Maryland, California, Michigan and Florida (Alliance Enterprises, 2009). MRC has considered a program like this for their vocational rehabilitation program, but has been limited by the capital that is needed to purchase and switch over to this program. Another example is a software solution called Therap Services. Therap Services offers, “an integrated suite of cost effective applications for the developmental disability community” (Therap Services, 2008). This software suite is currently used by providers in 28 states, including California, Florida, Massachusetts, and New York. Therap Services is a web-based application, so one benefit is that there are
no costs to the agency in terms of software purchasing, installation or upgrades.

It is important to look at evaluations of these software programs and investigate whether they can be used for a variety of disabilities and program types. With the retirement of the baby boom generation, IT systems are a good way to ensure that knowledge gets passed along to new case workers. While these systems may not be a complete solution for all agencies and services, IT solutions can be used to facilitate information sharing. There is much research that can be done around a new IT infrastructure that could facilitate coordination across a number of agencies.

Improving communication between agencies and even intra-agency can facilitate more effective service delivery and improved coordination. In the long run, an improved and streamlined IT system facilitates information sharing and improves the accuracy of referrals for all individuals with disabilities in Massachusetts. The impact of moving forward with this option would be felt far beyond the autism community.

The cost of investing in an IT infrastructure shift is significant; especially upfront. So while this is an ideal solution to service coordination and information management, it may be difficult to fund. However, one opportunity for financing some of these IT options is through the American Recovery and Reinvestment Act of 2009. There is a significant amount of funding going towards green jobs, and perhaps the move away from paper documents to an all-online system could fit within the purview of one of the many greening projects (Pelosi, 2009).

**Recommendations**

Massachusetts needs to take a two-pronged approach to prepare for the increasing adult population with ASD. As can be seen in Table 3, both short- and long-term strategies need to be utilized to improve service delivery and streamline daily operations.

*Phase 1: Short-Term Investment: Improved Data Management*

EOHHS should consider taking action on two short-term recommendations. First, all agencies in EOHHS handling disability
services should move to electronic record keeping. This includes DDS, MRC and any other agency that manages and makes referrals for individuals with disabilities. IT systems can streamline data collection and ensure that knowledge gets passed along to case workers. While there are some up-front costs in moving to electronic databases and case management systems, the long-run benefits of improved communication within agencies, transparency of information across case workers and potential for improved referrals outweigh the short-term costs.

Second, individuals eligible for adult services need to have their own treatment files follow them to each agency to which they are referred for services. It is understandable that agencies have certain operating procedures that can make it difficult to spend a lot of time with each client getting his or her personal history. By allowing the individual’s case file to stay with him or her, it saves time for both the agency and individual, and opens up the opportunity to make referrals that target the strengths of the individual; since that information would now be available. It also gives the opportunity for the agency to make placement choices that build on the individual’s past experiences. This can make the transition into adult services more appropriate and seamless because the individual may end up in a situation similar to one they have experienced in the past.

Table 3

Policy Recommendations

Phase 1: Short-Term Investments

1. Agencies move to electronic record keeping

2. Individuals have personal files follow them to each referral agency

Phase 2: Long-Term Investments

1. Develop research commission to gather and disseminate information
These short-term recommendations will have immediate impact on disability services and would require the least disruption to the current system.

**Phase 2: Long-Term Investment: Research Commission**

EOHHS should formulate and support a research commission focusing on research and policy solutions for adult disability services, with a specific focus on autism. This research commission could initiate statewide data gathering, become a clearinghouse for current research and partner with state or federal organizations in furthering areas in which there are gaps in the literature.

Through research and analysis, Massachusetts and the EOHHS have the opportunity to re-frame the way that they approach disability services for adults with ASD. With more information surrounding best practices, effective interventions and the specific needs of adults with autism, Massachusetts can effectively manage the incoming cohort of adults with autism and ensure appropriate referrals and placement. This recommendation could also set up Massachusetts to be a leader for other states to model as they experience similar challenges in managing their population of aging individuals with ASD.

**Conclusion**

As evidenced through this analysis, EOHHS is not prepared for an increase in the autism population. Massachusetts lacks accurate information on the numbers of adults with autism that are currently being served. Due to the fragmentation of the system and lack of data, EOHHS is unable to compare across programs or agencies and determine the effectiveness of current programming or placements for adults. Because of the lack of research available, Massachusetts is not able to develop its disability services around best practices in adult services.

To effectively plan for an increasing cohort of adults with autism into the Massachusetts adult disability system over the next 10 years, the EOHHS needs to ensure that agencies improve their information dissemination by moving to electronic databases across the board, and allowing individual case files to follow the individual to all referral agencies so that personal needs don’t fall through the cracks. Long-term investments such as an autism research
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commission will enable EOHHS and Massachusetts to serve its adult population with autism more effectively and efficiently.

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Notes

1. Note on use of language in this article. 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. So for the purposes of this article, ‘autism’ will be used synonymously with ‘ASDs’; however it is understood that high functioning individuals will be less likely to need state supported services as adults.

References


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