



The Commonwealth of Massachusetts
Executive Office of Health & Human Services
Department of Developmental Services
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February 11, 2016

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The Honorable Karen E. Spilka, Chair
Senate Committee on Ways and Means
State House, Room 212
Boston, MA 02133

The Honorable Brian S. Dempsey, Chair
House Committee on Ways and Means
State House, Room 243
Boston, MA 02133

Dear Chairs:

In accordance with the provisions of HB4047 of Chapter 226 of the Acts of 2014, I am submitting the enclosed Progress Report on Autism Omnibus Bill.

Please feel free to contact me should you need additional information.

Sincerely,

A handwritten signature in blue ink that reads "Elin M. Howe".

Elin M. Howe
Commissioner

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Karyn Polito
Lieutenant Governor

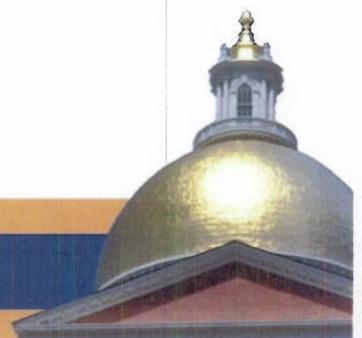


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FY16 Autism Omnibus Bill Report

February 2016



As required by HB4047 of Chapter 226 of 2014 Act Relative to Assisting Individuals with Autism and Other Intellectual or Developmental Disabilities.

“The Department of Developmental Services shall file an annual report reviewing its progress in the implementation of this act on or before the first business day of February, and shall file the first such report not later than February 3, 2015. The report shall include, but not be limited to: (1) the number of new clients with autism or Prader-Willi syndrome; (2) the number of individuals, if any, on a waitlist for the services provided under this act and the reasons for and the expected duration of the waitlist; (3) the number of additional staff hired to assess and evaluate the clients and services; (4) the number of staff hired to deliver, manage and administer the services; (5) challenges encountered and met in serving new clients; (6) challenges that continue and those that are foreseen in the near future; (7) additional costs incurred in serving these clients; and (8) savings if any realized.”

Implementation

The Department of Developmental Services has been working diligently to implement the expanded eligibility requirements which were signed into Law by Governor Patrick in August 2014. The Department is using the most recent edition of the Diagnostic and Statistical Manual to verify the presence of Autism Spectrum Disorder. The Department is in the process of adopting the developmental disability definition as the criteria for functional impairments. DDS will use standardized assessment tools, records, and clinical interviews to establish whether an applicant has three areas of substantial functional limitations. The Department has designed a number of new materials including new applications, fact sheets, and assessment processes to support the expansion. Materials can be found on the DDS website. To support the eligibility changes DDS has designed and trained its Regional Eligibility Teams in these new activities. Most importantly, the Department of Developmental Services has written new regulations to provide the administrative framework for the statute. DDS conducted two Public Hearings on the regulations. Since November 2014, DDS has been accepting applications for Autism Spectrum Disorders, Prader-Willi Syndrome and Smith-Magenis Syndrome. The Department has worked closely with Department of Mental Health to establish a shared training agenda to support the ASD population, to clarify eligibility between the agencies and determine how to support those individuals who have both an Autism Spectrum Disorder as well as significant mental health needs. In FY16, the appropriation for the implementation of this legislation is \$12,667,000.

Eligibility Update

Between November 2014 and January 2016, DDS has determined that 469 individuals met the criteria as a person with autism spectrum disorder. Two hundred twelve (212) individuals were over the age of 22 and 253 were between the ages of 18-21. In addition DDS determined that one (1) individual over the age of 22 met the criteria for Prader-Willi without intellectual disability and three (3) were between the ages of 18-21. These numbers do not reflect the total work effort of the eligibility teams because they exclude all children’s applications processed as well as all Intellectual Disability adult applications. The Department has developed new applications to reflect the Department’s expanded eligibility and fact sheets to explain the requirements.

Eighty percent (80%) of the individuals are males. The majority of individuals currently reside with their families or live independently. Many of the individuals have significant mental health issues ranging from anxiety disorders, depression and major mental illness. None of these individuals are persons with intellectual disability. All of these individuals have at least an average IQ with some substantially higher.

Services:

In the initial year DDS has used its existing service delivery system and the array of services that are offered to the rest of the Department's adult population to provide services for the newly eligible population. Individuals can choose their service delivery method: traditional provider contracted system, agency with choice or full self-direction. Nineteen percent (19%) of the of the individuals have chosen self-direction. Once the choice of service delivery method has been selected the individual selects services from the Department's current array of services. DDS provides the following services: Service Coordination, a variety of Employment Supports and Activities during the day, a variety of Family Supports for Individuals Residing in Family Home including companions, respite, flexible funding and a variety of Individual Supports for Individuals who live independently, a variety of short term services related to vocational and avocational interests and social skills.

Of the two hundred thirteen (213) individuals over the age of 22, one hundred two (102) individuals are receiving a total of 245 DDS services. DDS staff continues to work with the remaining ninety-three (93) individuals who are not yet enrolled in services. There is currently no waiting list for services.

Many of the DDS services currently offered can meet the individuals' needs; the Department's Autism Service Coordinators are quite skillful in identifying services and making adjustments as permitted; however, some services need modifications in terms of staff experience while others are not currently available within the DDS menu of services. The average cost of services is \$14,886.

Engaging individuals has been challenging for the Autism Service Coordinators. Many of these individuals have had no experience with state agency services and have been without services since leaving school. The DDS staff worked diligently to engage each individual and their family to identify appropriate services. This takes time to build a relationship so that service planning can begin.

Requests for peer mentoring, coaching, specialized therapies and alternative housing supports are examples of services that are being requested.

DDS has provided a limited array of housing options for individuals with severe challenges.

Although the eligibility for adult services occurs at age 22, the Department has been offering family supports to individuals between the ages of 18-21 and their families. Most of these young adults are living with family and attending school and the vast majority have not requested services at this time. For those young adults who have finished school the Department has been offering services such as employment and day supports.

Staffing

The Department has strengthened its infrastructure to support the new populations. DDS has established an Autism Implementation Working Group to ensure the highest level of attention to this initiative. The Deputy Commissioner chairs the group which meets monthly; it is designed to gather feedback from the field, review clinical needs, monitor expenditures, identify service needs and gaps identify risk factors and identify training needs.

DDS has added one (1) Autism Service Coordinator to each of the twenty-three DDS Area Offices. These individuals have the targeted case management responsibility for Adults with Autism Spectrum Disorders and have been trained to support the expansion population. Service Coordinators deliver and manage the service delivery at the local level. DDS has added four (4) Eligibility Specialists, one (1) to

each of the Regional Eligibility Teams and is in the process of increasing Psychologist capacity as well. To date DDS has added one (1) FTE psychologist and is in the process of adding two (2) additional psychologists to assess and evaluate potential applications. Additionally, the Department has hired one (1) additional legal counsel to support both the eligibility process and service delivery concerns as they arise. The Department has hired two Contract Specialists and intends to hire two (2) more. Two (2) Program Coordinators have been hired and two (2) more will be added shortly. The Department is using its existing Area, Regional and Central Office managers to provide overall supervision for these activities. In total, the Department intends to hire thirty-eight full and half full-time equivalents (39 FTES) FTES to support the new population.

Community Infrastructure:

DDS has expanded the capacity of its seven (7) Autism Support Centers by adding dedicated staff to address the needs of Adults on the Spectrum. DDS has also expanded a limited number of Family Support Centers to address the needs of Adults on the Spectrum:

Below is the Department's progress to date:

Six and one-half (6.5) FTES have been added to the Autism Support Centers

Four and one-half (4.5) FTES have been added to select Family Support Centers

Data Tracking and Internal Controls

DDS has developed a Data Management System that tracks eligible individuals on a monthly basis as well as individuals served and individuals in the planning phases. A fiscal monitoring system has been put in place to monitor the 12.6 M appropriation dedicated to the Adult Autism account. DDS is continuing to update business processes in its consumer record system and health information system to support the IT changes needed to support the new populations. The IT in Meditech (consumer registry system) has been completed; work in the HCSIS (Health Care Information System) which is the quality management system for DDS is in the development phase.

Collaboration with DMH

DDS and DMH have entered into an Interagency Service Agreement (ISA) to collaborate in the development and funding of supports and services to individuals who are eligible for services in both systems. The ISA has been shared with the Legislature in late December 2015. The agencies meet regularly to learn about how each agency functions, the services it offers and has developed a broad based agenda to increase the working knowledge and relationships through regular meetings at the local, regional and central offices. The agencies have committed to joint trainings, service design and mutual consultation based on the respective knowledge of the two agencies. DDS has determined that it needs added clinical support from DMH. Through the ISA DDS has committed to purchasing two (2) psychiatric fellowships (one at Mass General, the other at UMass Medical), short term psychiatric consultations, forensic risk consultations. Additionally DDS and DMH are developing a joint training plan for all levels of the agencies. To date there have been three days of joint training with a more to follow.

Future Developments

The Department of Developmental Services is in the early phases of implementation and therefore it is premature to provide some of the detail requested for inclusion in this legislative report. Future reports will highlight challenges encountered in serving new clients as we gain more experience, additional costs incurred in serving these clients and savings realized.

It has been both challenging and exciting to design and try to implement the new eligibility activities and deliver services to a new population simultaneously. DDS has identified the need to continue to educate its workforce in developing a greater understanding of the needs of the new population and how they differ from the current adult population with particular emphasis on the mental needs of the population. Access to psychiatric care in the community and inpatient care has been challenging. In this first year of service delivery the Department has learned a great deal about how to engage adults with ASD, what types of services are needed and the challenges associated with implementing them. As the population increases DDS anticipates that there may be a waiting list for services.