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# **FY 18 Autism Omnibus Bill Report**

**February 2018**



Pursuant to Chapter 226 of the Acts of 2014, An Act Relative to Assisting Individuals with Autism and other Intellectual or Developmental Disabilities, the Department of Developmental Services (DDS) submits the following report:

*“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 the Autism Omnibus Law of 2014. The Department is using the most recent edition of the Diagnostic and Statistical Manual to verify the presence of Autism Spectrum Disorder (ASD). The Department has adopted the developmental disability definition as the criteria for functional impairments and uses standardized assessment tools, records, and clinical interviews to establish whether an applicant has three areas of substantial functional limitations. The Department has revised its application and processes to support the expansion. To support the eligibility changes there are regular meetings with the four DDS Regional Eligibility Teams and separate meetings with the Eligibility Psychologists to ensure the consistent application of the regulations and processes. The Department worked closely with the Department of Mental Health (DMH) to establish a shared training agenda to support the ASD population, to clarify eligibility criteria between the agencies and determine how to support those individuals who have an Autism Spectrum Disorder and significant mental health needs. In Fiscal Year 2018, the appropriation for the implementation of this legislation at DDS is \$12,672,283.

The Department is also working closely with the Executive Director of the Autism Commission. Two of the Autism Commission's Sub-Committees are chaired by DDS staff, and other staff from DDS are members of the subcommittees and contribute to their on-going work and collaboration among state agencies.

### **Eligibility Update**

Between November 2014 and December 31<sup>st</sup>, 2017, DDS determined that one thousand four hundred sixty-three (1463) individuals met the criteria as a person with autism spectrum disorder. Seven hundred eighty-one (781) were over the age of 22 and six hundred eighty-two (682) were between the ages of 18 to 21. In addition, DDS determined that six (6) individuals over the age of 22 met the criteria for Prader-Willi Syndrome without intellectual disability and three (3) were between the ages of 18 to 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.

Seventy-nine percent (79%) of the individuals are males and twenty-one (21%) are females.

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 to major mental illness. None of these individuals are persons with Intellectual Disability and all of these individuals have at least an average IQ, with some substantially higher. Most of these individuals are competent which is a significant difference from the population of individuals with varies greatly from those with Intellectual Disability and have traditionally been served by the Department.

### **Services**

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, including traditional contracted system, agency with choice or full self-direction. Twenty-one percent (21%) 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;
- Employment Supports and Activities during the day;
- Family Supports for Individuals Residing in a Family Home including companions, respite, flexible funding;
- Individual Supports for Individuals who live independently; and
- Short term services related to vocational and avocational interests and social skills.

Of the seven hundred eighty-one (781) individuals over the age of 22, four hundred forty-four (444) individuals are receiving a total of one thousand one hundred (1100) DDS services. Three hundred forty-three (343) individuals are currently not receiving any DDS funded services.

Of the six hundred eighty-two individuals age 18 to 21, two hundred-eighty (280) are currently enrolled in a combination of six hundred thirty-three (633) services. Four hundred two (402) individuals are currently not receiving any DDS funded services. Although the eligibility for adult services occurs at age 22, the Department has been offering family supports to individuals between the ages of 18 to 21 and their families. Most of these young adults are living with family and attending school and the vast majority has not yet requested services. For those young adults who have finished school the Department offers services such as employment and day supports.

Many of the DDS services currently offered can meet the individuals' needs and the Department's Autism Service Coordinators identify services and make adjustments as permitted. Some services require modifications in terms of staff experience while others are not currently available within the DDS menu of services.

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 works diligently to engage each individual and their family to identify appropriate services. Establishing a rapport with these individuals can be a time consuming process.

Requests for peer mentoring, coaching, specialized therapies and alternative housing supports are examples of services that are being requested. Parents of adult children or those about to turn 22 often express interest in residential services. Coaching is a new services that has been offered by DDS since FY17, which became and has been frequently requested by the newly eligible population. DDS also entered into an agreement with DMH to make the DMH Club House services available to interested adults. This has not yet proven to be a desired service by the adult ASD population.

Parents of adults or those about to turn 22 often express an interest in residential services. DDS's ability to provide housing for newly eligible individuals with severe behavioral health challenges is very limited. These individuals present with very different needs compared to individuals with intellectual impairments who currently reside in DDS homes. In limited instances, DDS has provided shared living options or more intensive individual supports.

### **Staffing**

The Department has expanded and strengthened its infrastructure to support the new populations. An Autism Implementation Working Group has been established to gather feedback from the field, review clinical needs, monitor expenditures and identify service needs and gaps, risk factors and training needs.

DDS has added one (1) Autism Service Coordinator to each of the twenty-three (23) 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 to (1) each of the Regional Eligibility Teams, and has increased Psychologist capacity. 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 four (4) Contract Specialists and four (4) regional Program Coordinators. The Department is using its existing Area, Regional and Central Office managers to provide overall supervision for these activities. In total, the Department has hired thirty-nine full time equivalents (39 FTES) to support the new population. Based on the current number of newly eligible individuals the caseloads for the Autism Service Coordinators in some area offices is now in excess of 70 individuals.

### **Community Infrastructure:**

DDS has added dedicated staff to its seven Autism Support Centers and also expanded a limited number of Family Support Centers to address the needs of Adults on the Spectrum. This includes:

- 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.

DDS has designed and will implement a data collection process in FY 18 to provide information about utilization and the impact of the additional FTES added to the 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 planning phases. A fiscal monitoring system has been put in place to monitor the appropriation dedicated to the Adult Autism account. DDS is able

to capture eligibility data, types of services received, services requested, delayed or funding unavailable. 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. While the establishment of IT infrastructure in the consumer registry system, called Meditech, has been completed, work in the Health Care Information System (HCSIS), which serves as the quality management system for DDS, is still in the development phase.

### **Collaboration with DMH**

DDS and DMH 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 was shared with the Legislature in late December 2015. DDS and DMH meet regularly to learn about how each agency functions and the agencies have developed a broad based agenda to increase the working knowledge and relationships through regular meetings at the local, regional and central office levels. The agencies have conducted a joint training hosted by the Central Offices of the two agencies and have facilitated local and regional meetings. The purpose of these meetings has been to build a collaborative working relationship, service design and mutual consultation model based on the collective knowledge of both agencies.

DDS recognizes that additional clinical support from DMH is needed to further support services needed by these individuals. Through the ISA DDS has purchased a) three (3) psychiatric fellowships (one at Mass General, one at UMass Medical and one at Boston Medical Center); b) short term psychiatric consultations; and c) forensic risk consultations. These consultations have provided diagnostic clarity for the agencies and a treatment plan for a specific individual. The fellowships at Mass General occur either at the Lurie Center or the Bressler Center. The UMass Consultations occur at the Developmental Disability Clinic or at the Neuro Psychiatric Clinical. The fellowship at Boston Medical Center is slated to begin in January 2018. Each hospital program has identified a specific contact person to facilitate the referrals. To date approximately 30 consultations have been provided. Additionally, Boston Medical Center has developed a web-based module training system for hospital personnel focused on the Transition Age youth. The plan is for the training to be rolled out to residents, other medical staff and made available at Boston Medical School. Based on the outcome, the modules will be shared with the other teaching hospitals in the state.

DDS and DMH have developed a joint training plan and now share the training calendars from the respective agencies for all staff. DDS and DMH have engaged in multiple individual case consultations for shared individuals and have begun to identify service gaps. The agencies on a case by case base have implemented creative solutions to meet the needs of individuals with ASD and co-morbid mental health issues. DDS has participated in many working groups to flesh out the clinical competencies necessary for a specialty ASD/IDD unit and has been part of a team with DMH, MassHealth and DESE to explore state of the art options for inpatient care for children and youth on the spectrum. DDS has been able to offer a number of ASD trainings, with funding from SEIU Union (509), to DMH staff and as provider staff throughout FY 18.

### **Future Developments**

As the Department continues to implement the legislation, it is clear that the needs of the Autism population are very diverse and that additional services, resources, and more education are needed.

There are a number of major challenges that have emerged: (1) the complex mental health needs of the ASD population and the difficulty of accessing appropriate services; (2) the supportive housing needs for a subset of the population; (3) the ongoing challenge around engagement of individuals with ASD; and (4) the need for additional resources. Most of the individuals are competent adults which requires a more individualized and time-consuming approach. As the Department continues to gain experience, it will be better able to provide some of the details requested for inclusion in the report. Based on current experience, DDS does not anticipate that there will be savings associated with the provision of these services.

It has been both challenging and exciting to design and implement the necessary new eligibility process and concurrently deliver services to this new population. DDS recognizes the need to further educate its workforce in developing a greater understanding of the needs of the new population compared to the adult population it has traditionally served. In particular, there needs to be greater emphasis on the mental health needs of these new individuals. Access to psychiatric care in the community and inpatient care has been challenging. In this second 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 has increased and the resource level has remained level, DDS is not able to offer services to all newly eligible individuals. DDS will continue to explore the types of services needed to support adults with ASD and looks forward to working with all of the interested stakeholders in continuing to implement Chapter 226 of the Acts of 2014.