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FY17 Autism Omnibus Bill Report

February 2017



In accordance with the provisions of Section 28 of 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 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.”

the Department of Developmental Services (“DDS” of “Department”) submits the following report:

Implementation

DDS has been working diligently to implement the expanded eligibility criteria and services that were required under the Autism Omnibus Law of 2014. The Department is using the most recent edition of the Diagnostic and Statistical Manual’s criteria to verify the presence of Autism Spectrum Disorder (ASD). DDS has adopted the developmental disability definition as the criteria for functional impairments and is using standardized assessment tools, records, and clinical interviews to establish whether an applicant has the required three areas of substantial functional limitations. DDS has revised its application and processes to support the expansion of eligibility and services. The Department has established regular meetings with the four DDS Regional Eligibility Teams and Eligibility Psychologists to ensure the consistent implementation of its regulations and processes. DDS is working closely with the Department of Mental Health (DMH) to develop a shared training agenda to, clarify eligibility criteria between the agencies, and determine how to support those individuals who have co-occurring Autism Spectrum Disorder and significant mental health needs. In Fiscal Year 2017, the appropriation to address the supports and services for these “newly eligible” individuals at the Department 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 2016, DDS determined that one thousand ten (1,010) individuals have met the criteria as a person with ASD. Five hundred nineteen (519) of these individuals are over the age of 22 and four hundred ninety-one (491) are between the ages of 18 to 21. DDS also determined that four (4) individuals over the age of 22 and three (3) individuals between the ages of 18 to 21 met the criteria for Prader-Willi Syndrome without an intellectual

disability. In addition to these newly eligible individuals, DDS eligibility Teams also process all applications for children, and applications for adults with an intellectual disability. Seventy-nine percent (79%) of these new applicants are male and twenty-one (21%) are female. The majority currently reside with their families or live independently. Many of these individuals have significant mental health issues ranging from anxiety disorders, depression to a major mental illness. None of these individuals have an intellectual disability. All of them have at least an average IQ. Most of these individuals are legally competent, which varies greatly from those who have an intellectual disability and have traditionally been served by the Department.

Services

DDS is using its existing service delivery system and the array of services that are offered to the rest of the Department's adult clients to provide services for this 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 service delivery method has been selected, the individual chooses 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, and flexible funding;
- Individual Supports for Individuals who live independently; and
- Short term services related to vocational and avocational interests and social skills.

Presently, there are over 1,040 individuals who have been determined eligible for autism services:

- 450 are currently receiving DDS supports including day and employment services, residential options (including 24/7 placements in emergency situations) Family Support Services and Service Coordination;
- 350 individuals are pending service enrollment;
- The other 200 are still in school, are exploring DDS services or are not requesting DDS services at this time.

Many of the services currently offered by DDS can meet the needs of these individuals. DDS Autism Service Coordinators work directly with the individual and make adjustments to services based on their individual needs wherever possible. The average cost of services is less than \$25,000.

DDS's Autism Service Coordinators have reported that it can be difficult to engage these newly eligible individuals because most do not have any previous experience with state agencies and have been out of high school for a number of years. DDS staff work diligently and creatively to engage each individual, and to work with their family to identify appropriate services. Establishing a rapport with these individuals can be a time consuming process.

Examples of services being requested are; peer mentoring, coaching, specialized therapies and alternative housing supports. . Coaching is a new service that has been offered by DDS in FY 17

and it is a highly requested service by these newly eligible individuals. DDS has also entered into an agreement with DMH to make the DMH Club House services available to interested adults.

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, chaired by the Deputy Commissioner 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 ("ASC") to each of its twenty-three (23) Area Offices. These individuals have received training to support this new population and have case management responsibility these individuals. ASCs manage the delivery of services . DDS has added four (4) Eligibility Specialists, one to each of its Regional Eligibility Teams. To date, DDS has added two (2.) FTE psychologists, and is in the process of adding one (1) additional psychologists to assess and evaluate potential applications. The Department has hired one (1) additional legal counsel to support both the eligibility process and any service delivery concerns that may arise. The Department has also 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. Overall, the Department has hired thirty-eight full time equivalents (38) and anticipates adding one additional position for thirty-nine equivalents(39 FTES) FTES to support the new population.

Community Infrastructure:

DDS has added dedicated staff to its seven Autism Support Centers also expanded a limited number of its 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.

Data Tracking and Internal Controls

DDS has developed a Data Management System that; 1) tracks the number of eligible individuals on a monthly basis; 2) the number of individuals currently being served; and 3) eligible individuals in planning phase for services. A fiscal monitoring system has been put in place to monitor the fiscal 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 this new population. While the establishment of IT infrastructure in the consumer registry system, called Meditech, has been

completed, work in the Health Care Information System (HCIS), which serves as the quality management system for DDS, is still 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 for individuals who are eligible for services from both agencies. . 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 state-wide through regular meetings at the local, regional and central office levels. The agencies have conducted a joint training hosted by their Central Offices and have facilitated local and regional meetings. The purpose of these meetings has been to build a collaborative working relationship, service design models, and mutual consultation models based on the collective knowledge of both agencies. DDS recognizes that additional clinical expertise from DMH is needed to further support services needed by these individual. Through the ISA DDS has purchased a) two psychiatric fellowships (one at Mass General, the other at UMass Medical); 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. Each hospital program has identified a specific contact person to facilitate the referrals. Additionally, DDS and DMH are in the process of developing a joint training plan for all levels of their agencies. DDS is currently piloting a training program for direct support workers to increase their working knowledge about ASD\,DDS will make a decision shortly about whether to expand this further. DDS has been able to offer a number of ASD trainings, with funding from SEIU 509, to DMH and provider staff.. DDS anticipates that it will be able to continue this training series into this spring.

Future Developments

As the Department continues to implement the requirements of 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 newly eligible ASD population; (2) the supportive housing needs for a small subset of the population; (3) the ongoing challenge of engaging 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 gains additional experience and expertise, 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 for DDS 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 different needs of the new population compared to the adult population it has traditionally served. In particular, there needs to be a 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 these services. While the number of individuals requesting services has increased, the resources allocated has remained level, resulting in a waiting list for services. DDS will continue to explore the types of services needed to support adults with ASD and looks forward to working with the Autism Commission and all of the interested stakeholders to fully implement the objectives under Chapter 226 of the Acts of 2014.