

FY19 Autism Eligibility Report

February 2019

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 (DDS) has been working diligently to implement the expanded eligibility requirements the Autism Omnibus Law of 2014. DDS is using the most recent edition of the Diagnostic and Statistical Manual to verify the presence of Autism Spectrum Disorder (ASD), 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. DDS has revised its application and processes to support the expansion programming. 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.

DDS 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. DDS is also working closely with the Autism Commission and participates in all of the of the Commission's Sub-Committees and on-going work and collaborations among state agencies.

In FY 18 DDS received funding for the Turning 22 class which included the Autism Spectrum population. In FY19, the appropriation for the implementation of this legislation at DDS is $18,083,764

**Eligibility Update**

Between November 2014 and December 2018, DDS determined that 1,887 individuals met the criteria as a person with ASD and 9 met the criteria as a person with Prader-Willi Syndrome. Of those individuals, 1072 were over the age of 22 and 815 were between the ages of 18 and 21. In addition, DDS determined that 5 individuals over the age of 22 met the criteria for Prader-Willi Syndrome without an intellectual disability and 4 were between 18 and 21. In FY19, 266 individuals (representing 22% of the Turning 22 class) were individuals who met the criteria for ASD. 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 the 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 Disabilities and all have at least an average IQ – making this population significantly different from the traditional population served by DDS.

**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,

the Agency with Choice model 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 Day Activities;
* Family Supports (for individuals living with families) including companions, respite and flexible funding;
* Individual Supports (for individuals living independently) including in-home support/assistance; and
* Vocational and Social Skills Coaching.

Of the 1072 individuals over the age of 22, 685 are receiving a total of 1702 DDS services, and 387 individuals are currently not receiving any DDS-funded services. Of the 815 individuals between the ages of 18 and 21, 363 are currently enrolled in a combination of 791 services, and 452 individuals are currently not receiving any DDS funded services.

Although the eligibility for adult services occurs at age 22, DDS 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 of them have not yet requested services. For those young adults who have finished school DDS 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, but 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.

Coaching is a newer service that has been offered by DDS since FY17, which has been frequently requested by the newly eligible population. DDS is currently piloting a pre-coaching program for a small number of individuals for whom the challenge of engagement is an impediment to acceptance of DDS services. The pilot will end June 30, 2019, at which time DDS in collaboration with DMH will be in the position to analyze the results. DDS is frequently asked for assistance in seeking mental health treatments for 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 supports for newly eligible individuals including those with severe behavioral health challenges and significant mental health issues 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. In FY19, the Turning 22 account (5920-5000) has supported DDS’s ability to meet the needs of its autism only transitioning class.

**Staffing**

DDS has expanded and strengthened its infrastructure to support this new service population. 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, DDS has hired 39 full-time equivalents (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 with ASD. This includes 6.5 FTES being added to the Autism Support Centers and 4.5 FTES to select Family Support Centers. In FY19, DDS will begin collecting standardized data from the Autism Support Centers to determine the scope of their activities and whether they have been able to reach the expansion population through their programming.

**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 this new population. While the establishment of IT infrastructure in the consumer registry system (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 the Department of Mental Health (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 December 2015. DDS and DMH meet regularly to learn about how each agency functions and 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 joint trainings and facilitated local and regional meetings throughout the state to build a collaborative working relationship, service design and mutual consultation model.

DDS recognizes that additional clinical support from DMH is needed to improve support services needed by these individuals. Through the ISA DDS has purchased a) 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 Clinic. The fellowship at Boston Medical Center began in January 2018. Each hospital program has identified a specific contact person to facilitate the referrals. To date approximately 50 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 web-based module is now available on line and is being implemented to medical residents and other health professionals in the hospital. The fellowship programs in collaboration with DMH and DDS have now begun offering bi-monthly training and shared opportunities to learn from each other.

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. DMH and DDS are in the early stages of developing a Request for Information to help identify interesting new ideas for services in the provider community. The agencies on a case-by-case base have implemented creative solutions to meet the needs of individuals with ASD and co­morbid 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 FY19.

**Future Developments**

As DDS continues to implement the statute, it is clear that the needs of the Autism population are very diverse and 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 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.

DDS 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; however, there is still a stigma associated with applying for DDS services among the ASD population. The ability to serve the Turning 22 Class has helped to address the needs of the ASD population; however, as the population of post T-22 increases, the resource level for that portion of the population has not kept pace with the demand. DDS is not able to offer services to all of the newly eligible individuals. The dichotomy between the transition age youth and those post turning 22 remains difficult for DDS to address. DDS will continue to explore the types of services needed to support adults with ASD and looks forward to working with the all of the interested stakeholders in continuing to implement the mandates outlined in the statute.