

FY20 Autism Eligibility Report

February 2020

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 of 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 revised its application and processes to support the expansion programming.

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 many of the Commission's Sub-Committees and ongoing work and collaborations with state agencies. DDS also created an internal Autism Services work group to support the development of new service models.

In FY2020, the appropriation for the implementation of this legislation at DDS is $30,752,968.

**Eligibility Update**

Between November 2014 and December 2019, DDS determined that 2,341 individuals met the criteria of ASD and 9 met the criteria of Prader-Willi Syndrome. One additional individual was found eligible as both ASD and Prader-Willi. Of those individuals, 1,408 were over the age of 22 and 933 were between the ages of 18 and 21. In addition, DDS determined that 7 individuals over the age of 22 met the criteria for Prader-Willi Syndrome without an intellectual disability and 4 were between 18 and 21. Additionally, one individual under age 22 was found eligible as both ASD and Prader-Willi.

In FY2020, 316 individuals (representing 23% 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 and as all Intellectual Disability adult applications. Eighty percent (80%) of the individuals are males and twenty (20%) are females.

The majority of individuals are competent and reside either with families or live independently. Many of them have significant mental health issues ranging from anxiety disorders and 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 this population. Individuals can choose their service delivery method, including the traditional contracted system, Agency with Choice model, or full self-direction. Once the choice of service delivery method has been selected, the individual selects services from the Department's current array of services, including:

* 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 **1,408 individuals over the age of 22**, 963 are receiving a total of 2,429 DDS services, and 452 individuals are currently not receiving any DDS-funded services. Of the **933 individuals between the ages of 18 and 21**, 447 are currently enrolled in a combination of 954 services, and 489 individuals are currently not receiving any DDS funded 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. DDS staff work diligently to engage each individual and their family to identify appropriate services and establish a rapport with these individuals and families. Peer mentoring, coaching, specialized therapies and alternative housing supports are examples of services that are being requested.

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 services requested can meet the individuals' needs; however, some require modifications, while others are not currently available within the DDS menu of services.

Coaching is a newer service that has been offered by DDS since FY2017. Coaching has been frequently requested by the newly eligible population. As part of the original coaching pilot service, DDS added a pre-coaching program for a small number of individuals who were slow to engage DDS services. After the pilot’s end on June 30, 2019, DDS has worked in collaboration with DMH to review the results and is now incorporating that learning into the upcoming coaching procurement. DDS also piloted a college navigation program for individuals attending community colleges and state universities. This service will also be incorporated into the upcoming coaching procurement.

DDS is frequently asked for assistance in seeking mental health treatment for the newly eligible population. DDS entered into an agreement with DMH to make the DMH Clubhouse services available to interested adults; however, individuals have not been using this resource.

Parents of adults of those about to turn 22 often express interest in residential services. DDS' ability to provide housing supports for newly eligible individuals, including those with severe behavioral health challenges and significant mental health issues, is extremely limited as these individuals present with very different needs compared to individuals with intellectual disabilities who reside in traditional DDS group homes. In limited instances, DDS has provided shared living options or more intensive individual supports. In FY2020, the Turning 22 account (5920-5000) has supported DDS’s ability to meet the needs of its autism only transitioning class.

**Staffing**

DDS has strengthened its infrastructure to support the ASD adult 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. Each DDS Area Office has at least one full time Autism Service Coordinator, and as of January 2020, DDS has 30 Adult Service Coordinators statewide. These individuals are responsible for targeted case management for Adults with Autism Spectrum Disorders and average caseload for ASD service coordinators is approximately 65 individuals who are 18 years or older.

**Community Infrastructure**

DDS added dedicated staff to its 7 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 FY2019, DDS began 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 programming. Outreach to the ASD adult population from the Autism Support Centers and Family Support Centers has been challenging because individuals who are competent do not perceive they have a disability and do not want to be associated with disability services. In FY2020, DDS will procure its network of Autism Support and Family Support Centers and is revisiting the scope of services and expectations for the adult ASD population to improve these connections.

**Collaboration with the Department of Mental Health**

DDS and DMH were required to develop a plan to provide services to individuals who have both a mental illness and a developmental disability. DDS and DMH entered into an Inter-Agency Agreement to collaborate in the development and funding of supports and services to individuals who are eligible for services from both agencies. The agencies meet regularly and host joint trainings for staff. DDS and DMH also have an Inter-Agency Agreement that expanded clinical expertise through the addition of 3 Fellowships, one at UMass Medical, one at Mass General Hospital and one at Boston Medical Center. The Fellows have provided 81 consultations since they began in 2016, resulting in diagnostic clarification and service needs and treatment planning suggestions for individuals with ASD and behavioral health issues.

DDS has also been able to offer a number of ASD trainings, with funding from SEIU Local (509), to DMH staff and provider staff throughout FY2019 and 2020.

DDS and DMH developed a joint Request for Information to help identify service gaps and innovative ideas for future service development (31 responses were received). The agencies are currently reviewing responses. Additionally, on a case-by-case basis, the agencies have implemented creative solutions to meet the needs of individuals with ASD and co­morbid mental health issues.

**Future Developments**

As DDS continues to implement the statute, it is clear that the needs of the ASD population are diverse. Challenges that have emerged since the start of this newly eligible population include:

* The mental health needs of individuals with ASD and the difficulty of accessing appropriate services,
* The supportive housing needs for a subset of the population, and
* Engagement with individuals with ASD.

Most of the individuals are competent adults which require an individualized approach. DDS does not anticipate that there will savings associated with the provision of these services. DDS recognizes the need to further educate its workforce in developing a greater understanding of the needs of the ASD 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 individuals. One barrier to behavioral health treatment for ASD individuals has been limited access to psychiatric care.

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 continues to be stigma associated with applying for DDS services among the ASD population. The ability to serve the Turning 22 class has helped to address their needs. DDS will continue to explore the types of services needed to support adults with ASD and looks forward to working with all interested stakeholders, including the Autism Commission, in continuing to implement the mandates outlined in the statute.