

FY22 Autism Eligibility Report

February, 2022

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) continues to work 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 shared training opportunities to support the ASD population, to clarify eligibility criteria between the agencies, and to determine how to support those individuals who have an Autism Spectrum Disorder and significant mental health needs. DDS works closely with the Autism Commission and participates all but one 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.

For FY2023, the Governor’s H2 budget seeks an appropriation of $36,607,970 for the implementation of this legislation.

**Eligibility Update**

Since January 1, 2021, DDS determined that 485 new individuals met the criteria of ASD eligibility without an intellectual disability for a total of 3,325 ASD individuals as of December 31, 2021. This is a 17.2% increase from last year. Of the 3,325 individuals, 14 met the criteria of Prader-Willi Syndrome. One additional individual is eligible as both ASD and Prader-Willi. Of the total ASD individuals eligible for DDS, 2,156 over the age of 22 and 1,169 are between the ages of 18 and 21. In addition, DDS determined that 11 individuals over the age of 22 met the criteria for Prader-Willi Syndrome with an intellectual disability and 4 were between 18 and 21. Eighty percent (80%) of the ASD individuals are males and twenty (20%) are females.

In the FY2022 Turning 22 class, 343 individuals meet the criteria for ASD eligibility, representing 28% of the Turning 22 class. There are also 257 individuals with ASD and ID within the FY2022 T22 class which is an additional 21% of the FY2022 Turning 22 class. These numbers do not reflect the total work effort of the eligibility teams as the numbers exclude all children’s applications processed and as well as all Intellectual Disability adult applications.

The majority of individuals are presumed 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 companion, respite, and flexible funding,
* Individual Supports (for individuals living independently) including in-home support/assistance,
* Vocational and Social Skills Coaching,
* Pre-Engagement/Coaching, and
* College Navigation.

Of the 1,169 individuals ages 18-21, 497 are currently enrolled in a combination of 927 DDS services. Of the individuals ages 22+, 1478 are receiving a total of 3399 DDS 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. 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. The availability of services has been impacted by the need of providers to respond to COVID-19 in 2021. While there has been some return to site-based day and employment supports, many of these services continue to be provided remotely through technology or at lower program capacity during COVID surges and challenges providers are facing addressing the workforce crisis.

In FY2022, the Turning 22 account (5920-5000) has supported DDS’s ability to meet the needs of its autism only transitioning class

**New Services**

Coaching has been offered by DDS to individuals with ASD since FY2017 through a pilot program. As part of the original coaching pilot service, DDS added a pre-engagement program for a small number of individuals who were slow to engage DDS services. DDS also piloted a college navigation program for individuals attending community colleges and state universities. Given the success of both pilots, in August 2020, DDS posted a combined procurement to add Pre-Engagement/Coaching, and College Navigation to services available statewide for individuals with Autism. At the end of the procurement, 19 providers were qualified in total, 14 were qualified for both services, 3 were approved for Pre-engagement/Coaching only and 2 were approved for College Navigation only. There are at least 6 qualified providers for these new services as of July 1, 2021 in each of the four DDS regions. Since the start of the FY2020, 10 of the qualified providers have been awarded contracts. As of December 31, 2021, there are 205 individuals enrolled in Pre-Engagement/Coaching and College Navigation has an enrollment of 75 students.

Two new supportive technology services, Assistive Technology (AT) Services and Remote Support and Monitoring Services became available to individuals served by DDS through the Department’s “Technology Forward Initiative” in December 2021. These new services are aimed at promoting and developing the use of supportive technology as opportunities for individuals to lead more inclusive and independent lives.

Assistive Technology (AT) Services consists of three services, AT consultation/ evaluation services to determine the assistive technology needs of an individual, AT equipment to cover costs of equipment per the assessment and Assistive technology support which includes set-up, training for the individual and support network that aids an individual in the use of assistive technology equipment There are 9 AT provider agencies that contracted with DDS and began receiving referrals in available December of 2021

Remote Supports and Monitoring Services combines technology and direct care staff to support people with developmental disabilities.  Remote Supports and Monitoring Services (RSM) provide for an off-site direct service provider that monitors and responds to an individual’s health, safety, and other needs using live two-way communication system(s) and other technologies, while offering individuals more independence in their life.  The are 6 RSM provider agencies that contracted with DDS and began receiving referrals in available December of 2021

**Challenges**

Typically, 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 thoughtfully and conscientiously 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. Throughout the COVID pandemic, Autism Service Coordinators along with all DDS Service Coordinators were given cell phones and laptops to maintain communication and support to individuals served by the department. Autism Service Coordinators returned to a hybrid working environment in 2021 and were able to participate in some face-to-face interactions with individuals on their caseload. Use of text messaging, videoconferencing, and social media continues to be an effective venue for maintaining contact and communication.

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.

**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.

In the absence of a Statewide Autism Supports Manager, the Deputy Assistant Commissioner has been leading the Regional Autism Coordinators to align the Department’s statewide efforts. Regional Autism Supports Coordinators work within their respective regions to identify and map resources, implement departmental and local initiatives, act as liaison’s to providers, other state and local community groups and support the ASD Service Coordinators within their region. Each of the twenty-three DDS Area Offices has at least one full time Autism Service Coordinator, and as of January 2022, DDS has added an additional 10 Adult ASD Service Coordinators to the 35.5 FTE’s in 2021 for a total of 45.5 FTEs. The current average caseload is 65 individuals. These Service Coordinators are responsible for the targeted case management of adults with Autism Spectrum Disorders.

**Community Infrastructure**

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 held a statewide procurement of its network of Autism Support and Family Support Centers. To improve outreach with the adult ASD population, the procurement process included revisiting the scope of services offered. Awards were effective January 1, 2021 with some allowances for a transition period where a change in providers occurred. Given the difficulty of engaging individuals with ASD, DDS contracted for three different models for information and referral and outreach. There are two Autism Support Centers which serve both children and adults located in the Central West region; there are two ASD adult only Autism Support Centers located in the Northeast and the Metro area as well as Children’s Autism Support Centers. In the Southeast region there is one Children’s Autism Support Center and there are nine (9) Family Support Centers in which an Autism Support Specialist was added. DDS will analyze which of these designs is most effective in reaching the adult Autism population.

**Collaboration with the Department of Mental Health**

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 used this resource. 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. 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. For the 2020-2021 academic year (July to June): Combined, the sites recorded 23 evaluations of DDS/DMH clients resulting in diagnostic clarification, service needs and treatment planning suggestions for individuals with ASD and mental health issues. Nine evaluations were conducted with the Massachusetts General Hospital Autism Spectrum Disorder Fellowship site and 14 at the UMMHC Neuropsychiatry Clinic, Center for Autism and Neurodevelopmental Disorders (CANDO) site.   
  
The Fellows are located at very active clinics and participate in additional evaluations and follow-up along with clinic staff. In addition, they have opportunities to participate in conferences, various publications, book chapters and presentations with other senior staff members, giving them significant clinical and research experience as part of the Fellowship.

DDS/DMH have collaborated on two joint proof of concept proposals that have been included in the EOHHS American Recovery Act Plan (ARPA) submission. The “**Transitional Residential Services for Persons with ASD and Behavioral Health Diagnosis**” proposal seeks to develop specialized five 4-person group living residences and 2 respite homes (one adolescent and one adult respite) for individuals with ASD and co-occurring mental health disorder. Individuals will have access to needed services and supports from DDS and DMH in one setting.

“**Expanding In-Home Services for Individuals 18 to 25 with ASD and Behavioral Health Diagnosis**” will provide intensive supports in the individuals home to allow them to remain in their homes and actively participate in their communities rather than being placed in institutional settings in hospitals, boarding in the ER, or homeless.

As in previous years, DDS was able to offer a number of ASD trainings in 2021, with funding from SEIU Local (509), to DDS, DMH and provider staff.

**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 a 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. Responding to the COVID-19 health crisis, has fast tracked the deployment of technology to staff and staff use of virtual tools to engage and provide supports. DDS intends to capitalize and embrace the lessons learned to identify new venues for providing supports and services. 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.