**Commonwealth of Massachusetts**

**Department of Developmental Services**

**Autism Waiver Program**

**2019 Legislative Report**

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**All information contained in this report was current as of November 15, 2019.**

1. **Executive Summary**

The Department of Developmental Services’ (DDS) Autism Division respectfully submits this report in response to language contained in the Fiscal Year 2020 budget. Line-item [5920-3010](http://www.mass.gov/bb/gaa/fy2016/app_16/act_16/h59203010.htm) , which mandates the submission of this report as follows:

*“...that the department shall report to the house and senate committees on ways and means, the joint committee on education and the joint committee on children, families and persons with disabilities on the number of contracted support services provided for families with autistic children under this item and the costs associated with such services not later than January 10, 2020; provided further, that such report shall include, but not be limited to, the services provided by the children’s autism spectrum disorder waiver, with information regarding the number of children enrolled in the waiver and receiving services, linguistic and cultural diversity, age, gender and geographic representation of the applicants and the children enrolled in the program and department plans to continue to assess the demand for waiver services, any executive office of health and human services plans to expand the waiver for children on the autism spectrum of all ages in the future and any other information determined relevant by the department…”*

The information in this calendar year report was collected by the Autism Division and covers the Administration’s activities related to the Autism Waiver Program from January 1, 2019 through November 15, 2019.

As a result of Chapter 107 of the Acts of 2005, the Department’s Autism Division submitted an application to the Centers for Medicare and Medicaid Services (CMS) proposing a Federal Medicaid Waiver Program to serve young children on the autism spectrum. DDS received approval from CMS on October 1, 2007, allowing the Division to administer a three-year pilot Autism Waiver Program. In June 2010, DDS submitted a renewal application to CMS, receiving approval on October 1, 2010. This Renewal Autism Waiver Program allowed the Division to continue the Autism Waiver Program for an additional five years. Additionally, the Renewal Autism Waiver Program designates ten slots for three-year-olds transitioning out of Early Intervention - a statewide service available to families of children between birth and three years of age through the Department of Public Health (DPH). This provides the opportunity for families with younger children to access the program and to continue with an in-home support program model. The renewal Waiver also builds in a Step-Down Program after three years of intensive in-home supports that allows families to receive behavioral consultation services and other ancillary supports until the child reaches his/her ninth birthday.

CMS approved a waiver amendment in January 2013, increasing the program capacity to 157 participants and up to 205 unique children over the Waiver Year due to an increase in funding for the Autism Waiver Program at Legislative Mid-Year. CMS approved another waiver amendment in late November 2013 to increase capacity based on an increase in funding for the Autism Waiver Program. This amendment increased the capacity for waiver year 3 retroactive to July 1, 2013 and increased capacity in years 4 and 5. The capacity for waiver years 4 and 5 is 220 at any point in time and 325 over the course of the Federal waiver year.

In September 2015, the Department submitted another renewal application to CMS. As part of the FY16 Budget, the Autism Division received an increase in funding in the amount of approximately $500,000. These funds allowed the Waiver Program to expand to 260 children at any point in time and 370 participants during the course of the waiver year, which runs from October 1 to September 30. The program has expanded its reserved capacity for three-year-olds from ten children to twenty children. As part of the FY19 Budget, the Autism Division received an increase in funding in the amount of $500,000. These funds will allow the Waiver program to serve additional children and increase rates for direct support workers in agencies and employees of families. The current Autism Waiver program is in its 5th year and submission of a new five-year waiver is currently underway.

To date, the Autism Division has held nine Open Request Periods since the Autism Waiver Program began in 2008: October 2008, October 2010, April 2012, October 2013, November 2014, October 2015, October 2016, October 2017, October 2018, and October 2019. These Open Request Periods have consistently resulted in high numbers of interested families as reflected in the table below.

|  |  |
| --- | --- |
| **Year** | **Number of Families Interested in Autism Waiver Program** |
| 2008 | 1,200 |
| 2010 | 600 |
| 2012 | 800 |
| 2013 | 800 |
| 2014 | 750 |
| 2015 | 734 |
| 2016 | 817 |
| 2017 | 907 |
| 2018 | 869 |
| 2019 | 742 |
|  |  |

The Massachusetts Autism Waiver Program is distinguished from many other national programs in that it is an entirely self-directed program, meaning that families play the key role in hiring staff and identifying the services and supports they wish to have in place for their child. There are no other completely self-directed waiver programs for children in the nation. The Waiver provides Expanded Habilitation, Education services (one-to-one behavioral, social and communication-based interventions) and related support services such as community integration activities and respite.

Each Autism Waiver Program participant works with a DDS Autism Clinical Manager (or “Targeted Case Manager”) that provides overall oversight and assistance to families and one Autism Support Broker who helps families design and maintain their services and expenditures. The staff works with families to develop an in-home support plan with the goal of addressing the individual child’s needs in the areas of behavior, communication, or socialization. Additionally, the family is offered other ancillary services (safety equipment, respite, and community integration activities) and related supports.

During the first three years of participation (the “intensive phase” of the Program), families are given access to a budget of up to $25,000/year. The majority of these funds are directed toward the positive behavior support program in the home and in the natural environments of the participant. Up to $5,500 of the annual budget is available for ancillary services. After three years of intensive services, the family transitions into the Waiver’s Step-Down Program, which is intended to allow the parent to take over the in-home strategies learned during the intensive phase along with support from a Behavioral Consultant and Direct Support staff to continue to assist the family. This Step-Down Program is available until the child’s ninth birthday at a maximum amount of $7,500 per year.

1. **Background on the Autism Waiver Program**

The DDS Autism Division currently administers an Autism Spectrum Disorder Home and Community Based Waiver Program for Children (the Waiver). The Waiver is a program for children under the age of nine with an autism spectrum disorder who meet all the eligibility criteria required for entrance into the Waiver.

For participants, the major service for the first three years of the Waiver Program is Expanded Habilitation Education. The goal of this service is to help support children with autism by addressing the significant deficits they face in the areas of behavioral, social, and communication skills. The service consists of in-home and community-based one-to-one interventions developed and monitored by trained clinicians. Expanded Habilitation includes, but is not limited to, behavioral approaches such as Applied Behavioral Analysis (ABA), developmental and relational models such as Floor Time and communication models. The goal of the Expanded Habilitation Education Service is to help children develop basic adaptive skills, elementary verbal skills, and appropriate interactive and play skills. Most children receive some form of ABA.

The Waiver Program uses a service delivery model called Participant Direction, in which the parent takes the lead in designing the program and selecting service providers based on the child’s assessed level of need. The parent works closely with the Autism Waiver Program staff to develop a support plan that outlines the goals and objectives for the child, while also looking at the child’s strengths and areas of concern. Each family receives day-to-day support from an Autism Support Broker at one of the seven DDS funded Autism Support Centers, and programmatic oversight and problem-solving assistance from a Targeted Case Manager at the Autism Division. This support plan translates into a coordinated set of in-home services with a budget that relates to the costs of the services.

During the “intensive portion” (the first three years of the Program) each family has an available annual allocation of $25,000. The budget for those within the intensive portion of the Waiver also includes the availability of ancillary supports such as safety equipment, respite, and community integration activities. Up to $5,500 can be allocated toward these ancillary supports. After three years of intensive services, the family transitions into the Step-Down Program. The Step-Down Program supports are up to $7,500 per family and include Behavioral Consultation along with all ancillary services to help the family continue the in-home program on their own. This portion of the Autism Waiver Program is parent-driven with help from a Behavioral Consultant and can continue up until the child’s ninth birthday.

If a child is turning nine within the service year, the Waiver staff prorates the $25,000 budget to reflect the number of months that the child is eligible for the Program. In these cases, the staff prorates the in-home services portion of the budget. The family may access the entire $5,500 allocation for ancillary supports to help meet the health and safety needs of the child. These needs often include installing locks, alarms, and home adaptations such as fences.

**Information on Active Autism Waiver Participants**

1. **Information on Active Autism Waiver Participants**

As this report is based on a calendar year (CY) cycle (per line-item 5920-3010), information to follow is based on participation within the Autism Waiver Program starting January 1, 2019 and ending November 15, 2019.

**Enrollment Updates for the Autism Waiver**

Since January 1, 2019, 74 new children were determined eligible for services and a total of 330 children participated in the Waiver Program. As of November 15, 2019, there are 240 children currently enrolled in the Autism Waiver Program. All budget details are based on the 330 children served across the 2019 calendar year.

**Autism Waiver Program Eligibility Data (Calendar Year 2019)**

The Division processed 343 Waiver applications in CY19. The processing of applications includes determining which children on the list are over the age of nine, are not covered by MassHealth Standard and/or are not eligible for MassHealth Standard (making them ineligible) as well as making repeated attempts to connect with eligible families (by phone, email, and mail) who have been unresponsive.

The processing of applications also includes a review of clinical eligibility either by collecting records to verify the child’s existing DDS eligibility or by finding the child to be DDS eligible at the conclusion of the DDS children’s eligibility process. Following the DDS eligibility confirmation or determination, the Division performs two clinical assessments that measure the child’s deficits in the areas of socialization, communication, and behavior. If the child was not found to meet the criteria for clinical eligibility (in CY19, 3 children did not meet eligibility), families are sent a letter notifying them that their child cannot participate in the Waiver Program. If a child is found to meet the clinical eligibility criteria (74 children in CY19), the family is approved for enrollment into the Program. The following table references the 343 Waiver applications processed.

|  |  |
| --- | --- |
| **Waiver Applicants Processed Within CY 2019** | **Total** |
| Determined Eligible for the Program | 74 |
| Age Ineligible | 33 |
| MassHealth Ineligible | 114 |
| Voluntary Withdrawals (Family withdrew or DDS could not contact) | 96 |
| Determined Clinically Ineligible | 3 |
| Eligibility in Process | 23 |
| **TOTAL** | **343** |

**Active Participants in the Autism Waiver Program-January 1, 2019- November 15, 2019**

**Male/Female Distribution Information**

In Calendar Year 2019, approximately 79% of participants were males and 21% were females. This follows the national trend that indicates boys are much more prone to an autism diagnosis than girls.

|  |  |
| --- | --- |
| **Gender of Participants Served in CY 2019** | **Total** |
| Male  | 261 |
| Female  | 69 |
| **Total** | **330** |

**Diagnostic Information**

Approximately 10% of the children served in the Waiver have diagnosed co-morbid conditions. These conditions include metabolic, genetic, physical, and psychiatric disorders. In some cases, other conditions are more salient than the autism, requiring multiple hospitalizations and intensive nursing. Scheduling of in-home services can be more challenging when dealing with these conditions compared to cases where autism is the sole diagnosis. Sometimes the co-morbid diagnoses occurs post enrollment.

|  |  |
| --- | --- |
| **Diagnostic Information for Participants Served Calendar Year 2019** | **Totals** |
| Autism & PDD (Pervasive Developmental Disorder) | 297 |
| RETT Syndrome | 0 |
| Autism & Other Co-Morbid Conditions – Both Health and Developmental Issues | 33 |
| **Total** | **330** |

**Cultural and Linguistic Information**

|  |  |
| --- | --- |
| **Language Information for**  | **Participants**  |
| **Language** | **# of Participants** |
| English  | 214 |
| Spanish | 62 (36 require interpreter) |
| Portuguese | 20 (6 require interpreter) |
| Haitian Creole | 6 (0 require interpreter) |
| Vietnamese | 3 (1 requires interpreter) |
| Yoruba | 5 (0 require interpreter) |
| Arabic | 8 (1 requires interpreter) |
| Korean | 3 (0 requires interpreter) |
| Egyptian Arabic | 2 (1 requires interpreter) |
| Cantonese | 1 (0 require interpreter) |
| Russian | 2 (0 requires interpreter) |
| Bengali | 1 (0 require interpreter) |
| Nepali | 1 (0 require interpreter) |
| Greek | 1 (0 requires interpreter) |
| Mandarin | 1 (1 requires interpreter) |
| **Total** | **330 (46 requiring interpreters)** |

|  |
| --- |
| **Cultural Information for Participants** |
| **Ethnicity** | **# of Participants** |
|  |  |
| Caucasian | 111 |
| Latino/Hispanic | 110 |
| African American | 35 |
| Nigerian | 5 |
| Portuguese | 17 |
| Puerto Rican | 7 |
| Haitian | 6 |
| Dominican | 4 |
| Brazilian | 3 |
| Middle Eastern | 11 |
| Vietnamese | 2 |
| Moroccan | 2 |
| Chinese | 2 |
| Egyptian | 4 |
| Cape Verdean  | 1 |
| Russian | 2 |
| Nepalese | 1 |
| Korean | 3 |
| Asian –American  | 2 |
| Greek | 1 |
| Ugandan | 1 |
| **Total** | **330** |

The 330 children served in the Waiver Program in CY19 represent a wide range of linguistic and cultural backgrounds as identified by the Autism Clinical Managers and Parents and Guardians. If a family requires the use of an interpreter, the Division provides interpreters and translations at no charge to the family.

**Breakdown of Age of Participants** – Age as of November 15, 2019

The Program serves a wide range of ages of children between two and nine.

|  |  |
| --- | --- |
| **Age of 327 Participants as of 11/15/19** |  |
| Age 2: 0 |  Age 6: 45 |
| Age 3: 12 |  Age 7: 81 |
| Age 4: 15 |  Age 8: 65 |
| Age 5: 33 |  Age 9: 79 |

**Sibling Data of Participants**

January 1 through November 15, 2019

|  |  |
| --- | --- |
| **Sibling Information for Participants**  |  |
| **Siblings:** | **Breakdown Totals (status of other children)** |
| **Number Siblings Pairs Enrolled: (non-twins**) | Families: 23 |
| **Number of Sibling Pairs Enrolled: (twins)**  | Families: 6 |
| **Number of Sibling Pairs Enrolled: (twins + non twin sibling)** | Families: 1 |
| **Number of Sibling Pairs Enrolled: (triplets)** | Families: 1 |
| **TOTAL (non-duplicative count):** | Families: 31 |

**City and Town Distribution of the 330 Participants**

The Waiver Program enrollment is heavily weighted with children coming from major cities like Boston and its neighborhoods (40), Springfield and its neighborhoods (31) and Worcester (39).

|  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Town** | **#** | **Town** | **#** | **Town** | **#** | **Town** | **#** | **Town**  | # |
| Adams | 1 | Dudley | 1 | Leominster | 2 | Norton  | 1 | Spencer | 1 |
| Agawam  | 1 | Duxbury | 1 | Littleton | 1 | Norwood  | 2 | Springfield | 28 |
| Arlington | 2 | East Boston | 3 | Lowell  | 9 | Oxford  | 1 | Stoughton | 1 |
| Ashland | 1 | Everett | 9 | Ludlow | 1 | Pittsfield | 3 | Sutton | 1 |
| Athol | 1 | Fall River  | 7 | Lynn  | 5 | Plainville | 1 | Taunton | 4 |
| Attleboro | 5 | Fiskdale | 2 | Lynnfield | 2 | Plymouth | 1 | Uxbridge | 3 |
| Auburn | 1 | Fitchburg  | 3 | Malden | 5 | Quincy  | 2 | Ware  | 1 |
| Barre | 1 | Framingham  | 8 | Marlborough | 1 | Randolph | 1 | Wareham | 2 |
| Beverly | 1 | Franklin | 1 | Marshfield | 1 | Revere  | 6 | Webster | 2 |
| Boston | 8 | Gloucester  | 1 | Mattapoisett | 1 | Roslindale  | 2 | West Roxbury | 2 |
| Braintree | 1 | Granby  | 2 | Medford  | 3 | Roxbury | 3 | Westborough | 1 |
| Brighton | 1 | Greenfield | 1 | Medway  | 2 | Salem | 1 | Westfield | 5 |
| Brockton  | 4 | Haverhill | 2 | Melrose | 3 | Salisbury  | 1 | Westport | 1 |
| Burlington | 2 | Holliston  | 1 | Methuen | 5 | Sharon  | 1 | Woburn | 1 |
| Cambridge  | 3 | Holyoke | 3 | Middleborough | 2 | Shirley | 1 | Worcester | 39 |
| Canton | 2 | Hopkinton | 1 | Milford | 1 | Somerville | 2 |   |   |
| Charlestown | 2 | Hudson | 1 | New Bedford | 15 | South Boston  | 1 | **Total:** | **330** |
| Chicopee | 14 | Hyannis  | 3 | Newton | 2 | South Grafton | 1 |  |  |
| Clinton | 4 | Hyde Park | 4 | North Adams | 1 | South Hadley | 1 |  |  |
| Danvers  | 1 | Indian Orchard | 3 | North Andover | 1 | South Hamilton | 3 |  |  |
| Dorchester | 14 | Jamaica Plain | 1 | North Attleboro | 1 | South Yarmouth | 1 |  |  |
| Dracut | 1 | Lawrence  | 3 | Northborough | 1 | Southbridge  | 5 |  |  |

**Disenrollment Information**

Between January 1, 2019 through November 15, 2019,109 children disenrolled from the Autism Program - 77 of whom left the Program as scheduled on their ninth birthday; however, 15 children left due to ineligibility for continued MassHealth Standard coverage.

|  |  |
| --- | --- |
| **Disenrollment Information for Participants**  |  |
| **Reason for Disenrollment** | **Number** |
| Turned Nine | 77 |
| Moved Out of State | 4 |
| Lost MassHealth Standard | 15 |
| Voluntary Withdrawal | 10 |
| Placed in Residential Placement  | 3 |
| **TOTAL** | **109** |

**Open Enrollment**

**Male/Female Distribution Information**

In Calendar Year 2019, approximately 79% of applicants were males and 21% were females. This follows the national trend that indicates boys are much more prone to receiving an autism diagnosis than girls.

|  |  |
| --- | --- |
| **Gender of Open Enrollment Applicants CY19** | **Total** |
| Male  | 584 |
| Female  | 158 |
| **Total** | **742** |

**Cultural and Linguistic Information**

The 742 applicants for the Waiver Program in CY19 represent a wide range of linguistic backgrounds as identified by the Parents/Guardians. The most frequently spoken languages other than English are Spanish (12%), Chinese (3%) and Portuguese (1%).

The number of applicants speaking a language other than English decreased as compared to CY18 (162 in CY19 vs. 222 in CY18) and the number of languages spoken among the pool of applicants decreased slightly (11 languages in CY19 vs. 16 languages in CY18).

If a family requires the use of an interpreter, the Division provides interpreters and translations at no charge.

|  |  |  |  |
| --- | --- | --- | --- |
| Language Information for  | CY19 Applicants |   |   |
| Language | # of Applicants | Language |  # of Applicants |
| English | 580 | Khmer | 5 |
| Spanish | 91 | Guajarati | 1 |
| Chinese  | 20 | Somali | 1 |
| Portuguese  | 18 |  |  |
| Vietnamese | 8 |  |  |
| Haitian Creole | 5 |  |  |
| Arabic | 9 |  |  |
| Nepali | 4 |  |  |
| Burmese | 2 | **Total** | **742** |

**Breakdown of Age of Open Enrollment Applicants**

|  |  |
| --- | --- |
| **Ages of Applicants** |  |
| Age 1 11 | Age 6 112  |
| Age 2 107 | Age 7 69  |
| Age 3 145 | Age 8 38  |
| Age 4 138 | Age 9 and older 9 |
| Age 5 111 |  |
|  | **Total 742** |

**Sibling Data of Open Enrollment Applicants**

|  |  |
| --- | --- |
| **Siblings:** | **Breakdown Totals (status of siblings enrolled)** |
| **Number Sibling Pairs Enrolled: (non-twins**) | **Families: 28** |
| 11 sets of brothers |
| 14 brother/sister pairings |
| 1 sister/sister pairings |
| **Number of Sibling Pairs Enrolled: (twins)** **Number of Twins/Siblings Enrolled:****Total (non-duplicative count)** | **Families: 12** |
| 8 sets of twin boys |
| 1 set of twin girls3 sets twin boy/girl pairings**Families: 1**1 set twin boy/girl pairing plus 1 brother **Families: 41** |

**City and Town Distribution of the Open Enrollment Applicants**

Applicants are from 236 communities with a heavy weighting coming from major cities like Boston, Springfield, Worcester, New Bedford, Holyoke, Lowell and Quincy.

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| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Springfield | 73 | Granby | 5 | Milford | 3 | Florence | 2 | Blackstone | 1 | Marion | 1 | South Boston | 1 |
| Worcester | 49 | Plymouth | 5 | Natick | 3 | Gloucester | 2 | Boxford | 1 | Marlborough | 1 | South Dennis | 1 |
| New Bedford | 43 | Webster | 5 | North Adams | 3 | Holbrook | 2 | Brewster | 1 | Mattapoisett | 1 | South Hamilton | 1 |
| Holyoke | 41 | Whittinsville | 5 | North Andover | 3 | Holliston | 2 | Buzzards Bay | 1 | Medfield | 1 | South Waltham | 1 |
| Lowell | 21 | Indian Orchard | 4 | North Attleboro | 3 | Leominster | 2 | Charlton | 1 | Melrose | 1 | South Weymouth | 1 |
| Fall River | 19 | Middleboro | 4 | Norton | 3 | Mansfield | 2 | Chelmsford | 1 | Milbury | 1 | Southbridge | 1 |
| Chicopee | 18 | Peabody | 4 | Pittsfield | 3 | Mashpee | 2 | Cherry Valley | 1 | Millers Falls | 1 | Stoughton | 1 |
| Lynn | 18 | Revere | 4 | Rowley | 3 | North Hampton | 2 | Chestnut Hill | 1 | Millis | 1 | Swampscott | 1 |
| Quincy | 18 | Somerville | 4 | Roxbury | 3 | Norwood | 2 | Danvers | 1 | Nantucket | 1 | Tyngsboro | 1 |
| Dorchester | 17 | South Hadley | 4 | Salem | 3 | Palmer | 2 | Dennisport | 1 | Needham | 1 | Wakefield | 1 |
| Boston | 15 | Tewksbury | 4 | Sudbury | 3 | Shrewsbury | 2 | East Walpole | 1 | Newton | 1 | Waltham | 1 |
| Brockton | 15 | Walpole | 4 | Sutton | 3 | Somerset | 2 | East Wareham | 1 | North Dartmouth | 1 | Wareham | 1 |
| Cambridge | 10 | Wareham | 4 | Taunton | 3 | Spencer | 2 | Easton | 1 | North Grafton | 1 | West Hatfield | 1 |
| Framingham | 10 | Adams | 3 | West Springfield | 3 | Stoneham | 2 | Gardner | 1 | North Reading | 1 | West Yarmouth | 1 |
| East Boston | 7 | Amherst | 3 | Westborough | 3 | Watertown | 2 | Greenfield | 1 | Northborough | 1 | Westford | 1 |
| Everett | 7 | Burlington | 3 | Westfield | 3 | Weymouth | 2 | Hanover | 1 | Onset | 1 | Westminster | 1 |
| Ludlow | 7 | Canton | 3 | Woburn | 3 | Acton | 1 | Harvard | 1 | Orleans | 1 | Westport | 1 |
| Attleboro | 6 | Dracut | 3 | Ashland | 2 | Acushnet | 1 | Huntington | 1 | Oxford | 1 | Whitman | 1 |
| Haverhill | 6 | East Longmeadow | 3 | Billerica | 2 | Agawam | 1 | Hopkinton | 1 | Plainville | 1 | Wilbraham | 1 |
| Lawerence | 6 | Easthampton | 3 | Bridgewater | 2 | Andover | 1 | Jamaica Plain | 1 | Randolph | 1 | Woronoco | 1 |
| Mattapan | 6 | Hadley | 3 | Brighton | 2 | Arlington | 1 | Lancaster | 1 | Reading | 1 |   |   |
| Medford | 6 | Hingham | 3 | Dartmouth | 2 | Ashland | 1 | Lee | 1 | Rehoboth | 1 | **TOTAL 742** |   |
| Beverly | 5 | Hudson | 3 | Dedham | 2 | Athol | 1 | Leicester | 1 | Rochdale | 1 |   |   |
| Braintree | 5 | Hyannis | 3 | Dighton | 2 | Auburndale | 1 | Leverett | 1 | Russell | 1 |   |   |
| Chelsea | 5 | Malden | 3 | East Taunton | 2 | Bedford | 1 | Lynnfield | 1 | Saugus | 1 |   |   |
| Fitchburg | 5 | Metheun | 3 | Fairhaven | 2 | Bellingham | 1 | Marblehead | 1 | Seekonk | 1 |   |   |

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**IV. Autism Waiver Program Provider Information**

In CY19, the Autism Waiver Program allocation is approximately $6.9 million. This appropriation includes approximately $1.5 million necessary to cover the administrative costs of the Program. It also includes the Financial Management Service’s (FMS) monthly fees-per-participant which is an additional cost of approximately $280,000 as of November, 15, 2019.

The CY19 administrative budget is broken down as follows:

* $850,000 – Personnel Costs: 18 Autism Support Brokers
* $310,000 – Personnel/Operational Costs: 1 Division Director and 7 supporting DDS Autism Clinical Managers
* $100,000 – Other Personnel Costs: Necessary Central Office Unit personnel to administer, provide quality assurance and support billing and claiming activities

The budget for FMS fees is broken down as follows:

* $26,000- $28,000 per month (Approximately $280,000 for CY19) – Fiscal Management Service (FMS) monthly per participant fee: Covers staff time related to processing timesheets, payments, and provider credentials.

At the outset of the Autism Waiver Program, a major outreach effort took place to locate and qualify potential providers of services offered through the Program. This outreach included: all Early Intervention providers in the Commonwealth, all Special Education Departments in school districts across the state, all major providers of autism and related services and Colleges/Universities with majors/minors in the disability education field. The Autism Support Brokers do a concerted outreach effort to try and obtain new providers about every 12-18 months or as needed to meet an individual family’s needs.

All identified potential providers were added to a Master Provider List (MPL) that consists of Agencies, Independent Contractors, and Employees. As of November 15, 2019, the list of unique providers totaled 1,244. The MPL, which is an online web-based listing, is available to families in their geographic region and is utilized by the Autism Support Brokers at initial meetings with every new family.**Providers by Service Information**

Due to the flexibility of the Waiver Program’s service design, many of these providers are new to DDS.

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| --- |
| Provider Totals (As of November 15, 2019):  |
| **Service Type**  | **Description of Provider Duties** | **Total #**  |
| **Expanded Habilitation, Education:**Senior Level Therapists | Responsible for the creation and oversight of the in-home support plan | 289 |
| **Step Down Program** *(after 3 years)***:**Behavioral Consultants | Responsible for providing technical assistance for the continuation of the in-home support plan | 96 |
| **Step Down Program** *(after 3 years)***:**Behavioral Consultants – Direct support | Responsible for carrying-out the in-home plan with the child on a one-to-one basis | 398 |
| **Expanded Habilitation, Education:**Therapists  | Responsible for carrying-out the in-home plan with the child on a one-to-one basis | 340 |
| **Expanded Habilitation, Education:**Direct Supports | Responsible for carrying-out the in-home plan with the child on a one-to-one basis | 482 |
| **Habilitation, Community Integration** | Responsible for helping the child to participate in activities and other programs provided in community settings | 285 |
| **Family Training** | Responsible for teaching families about a variety of topics based on needs, such as autism in general, working on safety or reinforcing the work of the in-home service providers | 150 |
| **Respite** | Responsible to provide respite care of the child, allowing the parent or guardian to get out of the house for a short period of time  | 538 |
| **Total Number of Providers Credentialed by Service Type**  |  | 1,846 |
| **Total Unique Number of Credentialed Providers**  |  | 1,244 |

**Participant Budgets by Service Type**

The majority of service provision funding is spent on the Waiver’s intensive in-home support program, Expanded Habilitation Education. Children receive an average of between 6 to 10 hours a week of intensive in-home support services provided by a variety of therapists and based on a set of goals developed with input from the parent/guardian. Families also prioritize respite and community integration as important services.

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| **Participant Budget Data by Service Type*****Point-in time number captures budget totals as of November 15, 2019*** |
| **Service** ***(total budgeted for 330 participants)*** | **Amounts**  |
| Expanded Habilitation Education | $3,226,687 |
| Behavioral Consultation (Step Down) | $483,553 |
| Behavioral Consultation Direct Support (new Step Down service for 2019) | $166,386 |
| Habilitation, Community Integration | $35,919 |
| Family Training | $1,880 |
| Respite (includes related workers comp costs) | $171,708 |
| Home/Vehicle Adaptations and Adaptive Aids | $88,868 |
| Goods and Services/Homemaker | $102,605  |
| **TOTAL Budgeted Service Dollars:** | $4,277,607 |

**Service Amounts per Participant:** Covers budget information for participants from January 1, 2019 - November 15, 2019

Of the 330 Waiver Program participants, 102 children received over $20,000 worth of services and supports, while another 61 receive services and supports between $10,000 and $20,000. There were 27 participants with budgets under $10,000 and the majority of these participants turned 9 during CY19 and therefore had prorated budgets to reflect their shortened time in the program. Most participants in the Program are also receiving ancillary services such as goods and services to purchase safety equipment, home/vehicle adaptations and community integration services in order to increase the child’s ability to participate in community activities. Most families are also receiving a respite service, providing critical relief to families. In CY19, 140 children were enrolled in the Step Down program, receiving up to $7,500 of supports that includes Behavioral Consultation.

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| **Number of Participants in various Budget Categories** |
| **Service** | **Number of Participants** | **Amounts (rounded into dollar bands)** |
| Overall Budgeted Amount | 102 | $20,000 - $25,000 (Max is $25K) |
| Overall Budgeted Amount | 61 | $10,001 - $19,999 |
| Overall Budgeted Amount | 27 | $10,000 or below- includes prorated budgets |
| Step Down Budgeted Amount | 140 | $7,500 or below |
| **Total** | **330** |  |
| **Service** | **# of Participants** | **Amounts (rounded dollar bands)** |
| Expanded Habilitation, Ed | 88 | $20,000 - $25,000 (Max is $25K) |
| Expanded Habilitation, Ed | 45 | $15,001 - $19,999 |
| Expanded Habilitation, Ed | 28 | $10,001 - $15,000 |
| Expanded Habilitation, Ed | 29 | $10,000 or below-includes prorated budgets |
| Behavioral Consultation (Step Down) | 140 | $7,500 or below |
| **Overall Total**  | **330/330** | **Expanded Habilitation Education & Behavioral Consultation** |
| **Service** | **# of Participants** | **Amounts (rounded dollar bands)** |
| Total Ancillary Services | 112 | Under $2,500 |
| Total Ancillary Services | 54 | $2,501 - $5,500 (Max is $5,500) |
|  | 164 | No Ancillary Services/Or in Step Down |
| **Total**  | **330** |  |

**V. Measuring Programmatic Outcomes**

The Federal CMS review of the Autism Waiver Program requires internal oversight and program monitoring on at least a quarterly basis. The Autism Division has completed the required Quality Assurance reports to CMS and conducted provider performance reviews in FY19.

**VI. Next Steps**

The DDS Autism Division adopted a new approach with the Autism Waiver eligibility process following the April 2013 Open Request period. An open request period occurs on an annual basis the last two weeks of October. This has assisted the community in anticipating the open request period in a more predicable manner. There is now a pool of eligible applicants waiting to fill the spots that become available as other participants age out or leave the program for unplanned reasons. This process helps to keep enrollment more consistent. Each Clinical Manager works a caseload of eligibility requests on an ongoing basis to fill the opening slots. The Department has also established an internal process to receive files of currently eligible children from the 23 DDS Area Offices who have applied during the open request period.

The Autism Division has also implemented a transition process post-termination of the waiver services to increase the knowledge of the family and the child’s needs when the case is turned over to the DDS field offices. DDS Area staff are invited to a transition meeting to insure a smooth hand-off for the family. The DDS Autism Division provides each Region with a list of eligible participating children so that they can also anticipate planned terminations.

The Autism Division works to insure that children also receive the state plan ABA service if the family is interested in receiving this service in addition to waiver services. The addition of state plan ABA services is helpful when the children transition out of the waiver program. Based on the number of new requests during the October 2019 open request period, there is strong continued interest in the waiver program. More importantly, it is clear that the benefits of the comprehensive waiver services are highly desirable. There are also increased costs associated with providing services as the rates for services increase and demands for skilled professionals are needed.

The Division remains encouraged and driven by the many children in the Program who have surpassed their goals and continue to thrive in their In-Home Programs. Several children now have language skills that had none when they first started in the Autism Waiver Program. Others are demonstrating fewer behavioral issues due to the intensive in-home behavioral programs provided by in-home staff. Still others have mastered basic skills like eating at the table and using the bathroom consistently, improving the lives of not only the child, but also the caregivers and siblings. The demand for the Program remains high and it is clear that it addresses an important need for young children with autism spectrum disorders – a demand the Division is committed to meet.

**VII**: **Legislation**

**Chapter 107 of the Acts of 2005, An Act relative to federal reimbursement for services for children with Autism, Approved by the Governor, October 5, 2005**

*Be it enacted by the Senate and House of Representatives in General Court assembled, and by the authority of the same, as follows:*

*The secretary of health and human services shall, within 3 months of the effective date of this act, apply to the federal Centers for Medicare & Medicaid Services for a home and community-based services waiver under section 1915(c) of the federal Social Security Act, 42 U.S.C. section 1396(n), to allow eligible children with autism spectrum disorder to receive waiver services to support the children in their homes and communities.*

*The waiver application shall provide services for children with autism spectrum disorder who are institutionalized or at risk of institutionalization. Autism spectrum disorder includes the following disorders as defined in the Diagnostic and Statistical Manual of Mental Disorders, fourth edition (DSM-IV-TR, 2000): autistic disorder, Asperger's disorder, pervasive developmental disorder not otherwise specified, childhood disintegrative disorder, and Rett's disorder.*

*The waiver application shall include intensive in-home intervention services for children with autism spectrum disorder, and any other services determined appropriate to support children with autism spectrum disorder in their homes and communities.*

*The waiver application shall specify the required credentials for the providers of services covered by the waiver, including credentials required for supervisors of direct care providers and credentials required for direct care providers.*

*The waiver application shall ensure that the process and procedures for applying for waiver services are fully accessible to families of children with autism spectrum disorder who are from linguistically and culturally diverse communities.*

*Services under the waiver shall be coordinated with services provided by school committees under chapters 71B and 111G of the General Laws. This section shall not affect or limit a school district's ability to obtain Medicaid reimbursement for school-related health services, or affect or limit a school district's responsibility to provide all services, including home-based services, required pursuant to said chapter 71B, 20 U.S.C. section 1400 to 1487, inclusive, and 29 U.S.C. section 794.*

*On January 15, 2006, and every year thereafter, the secretary of health and human services shall file a report with the clerk of the house of representatives who shall forward the same to the joint committees on education and health care financing on the status of the waiver application and on the operation of waiver, once obtained. The report on the operation of the waiver shall include, but not be limited to, a description of the number of children receiving services under the waiver, the race and primary language of the children served and their families, the types of services provided, and any available information pertaining to impact and effectiveness of the waiver.*