

Commonwealth of Massachusetts

Department of Developmental Services

Autism Waiver Program

2015 Legislative Report

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All information contained in this report is current as of November 15, 2015.

#### I. Executive Summary

The Department of Developmental Services' (DDS) Autism Division respectfully submits this report in response to language contained in the FY15 budget. Line-item 5920-3010 mandates the submission of this report as follows:

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 joint committees on education and health care financing on the status of the waiver application and on the operation of the waiver, once obtained. The report 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 the effectiveness of the waiver.

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, 2015 through November 15, 2015.

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 designated 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 provided 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 built 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. The 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 point in time and 325 over the course of the Federal waiver year. These "enrollment caps" mean that at any given point in time, there cannot be more than 220 participants enrolled; however, in order to maximize enrollment, the Department has determined that up to 325 participants are allowed to participate during a given Waiver Year that runs from October 1 to September 30.

In September 2015 the Department submitted a renewal application to the Centers for Medicare and Medicaid (CMS). Currently CMS has approved an extension through December 2015. Additionally as part of the FY 16 budget the Autism Division received an increase in funding in the amount of \$500,000. These funds will allow the Waiver program to expand to 260 children point in time and 370 participants during the course of the Waiver year which runs from October 1 to September 30<sup>th</sup>. The program has expanded its reserved capacity for three years olds from ten children to twenty children. The Autism Division is currently enrolling additional children.

To date the Autism Division has held six Open Request Periods since the Autism Waiver Program began in 2008: October 2008, October 2010,

April 2012, October 2013, November 2014 and October 2105 which concluded recently. These Open Request Periods have consistently resulted in high numbers of interested families. The most recent open request period that ended October 30<sup>th</sup>, 2015 yielded 749 applications. The Autism Division has established that on an annual basis going forward, the last two weeks of October every year will be the open request period.

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 Autism Waiver Programs for children in the nation. The Waiver provides Expanded Habilitation, Education services (positive behavioral supports, social- and communication-based interventions) and related support services such as community integration activities and respite.

Each Autism Waiver Program participant works with a staff of one 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 communication, socialization, basic skill development and adaptive behavior. 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 each 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 \$7500 of the annual budget is available for ancillary services. After the 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 with support from both a Behavioral Consultant and Direct Support staff to continue to assist the family. This Step-Down Program is available up until the child's ninth birthday.

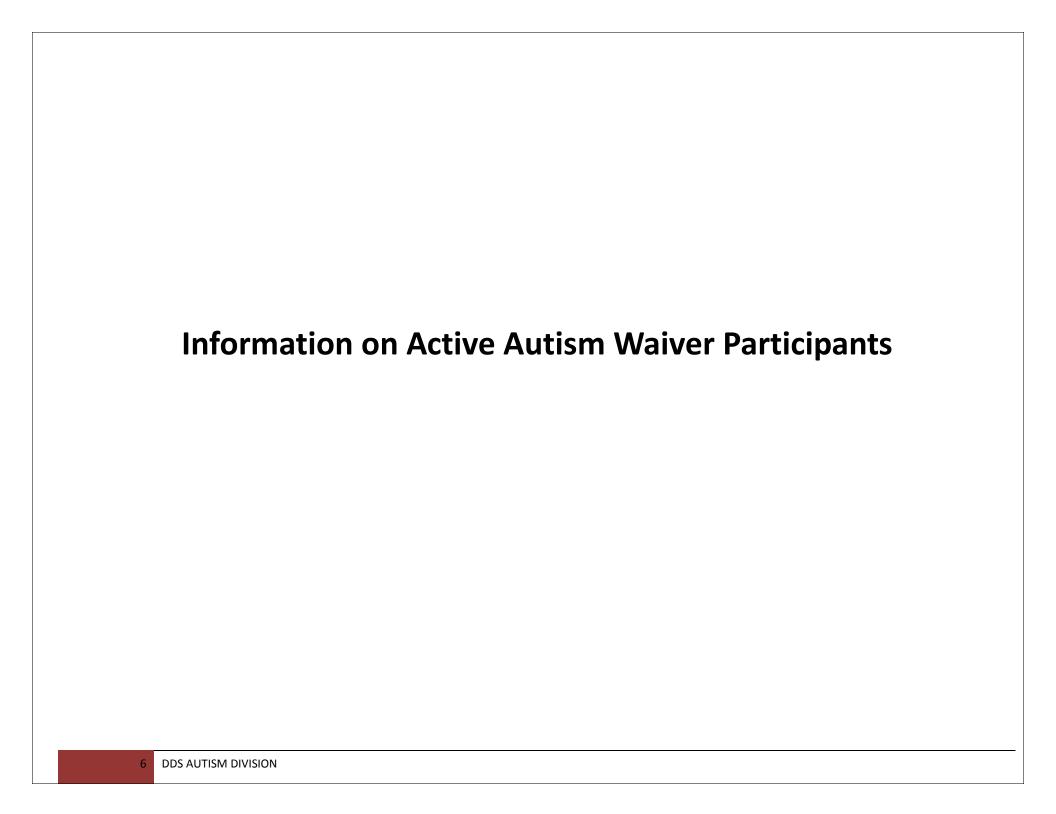
#### **II. Background on the Autism Waiver Program**

The Autism Division (the Division) of the Department of Developmental Services (DDS) 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 and who meet all the eligibility criteria required for entrance into the Waiver. For the first three years that the child is enrolled in the Program, the Waiver provides social, communication based interventions through a service called 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 communication, socialization, and to provide opportunities for basic skill acquisition. The service consists of in-home and community-based one-to-one interventions developed and monitored by trained clinicians. 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. The Waiver also provides related support services such as community integration activities and respite.

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. Five thousand five hundred dollars (\$5,500) can be allocated toward these ancillary supports in 2015.

After three years of intensive services, the family transitions into the Step-Down Program. The Step-Down Program supports are up to \$5,500 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.

In the event that 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.



#### III. Information on Active Autism Waiver Participants in Calendar 2015

As this report is based on a calendar year cycle (per line-item 5920-3010), information to follow is based on participation within the Autism Waiver Program starting in January 2015 and ending as of November 15, 2015.

## **Enrollment Updates for the Autism Waiver**

Since January 1, 2015, 77 new children were determined eligible for services and a total of 278 children participated in the Waiver Program from January 1, 2015 through November 15, 2015. As of November 15, 2015, there are 240 children currently enrolled in the Autism Waiver Program. All budget details are based on the 278 children served across the calendar year.

#### **Autism Waiver Program Eligibility Data (Calendar Year 2015)**

Since January of 2015, the Division processed 204 Waiver applications. The processing of applications includes finding children on the list that are over the age of nine, are not on MassHealth Standard and are not eligible to enroll in MassHealth Standard, and identifying families who elect to not participate in the eligibility process despite repeated attempts to connect by phone and mail.

The process for clinical eligibility involves either 1) collecting records to verify the child's DDS eligibility or 2) determining DDS eligibility by going through the DDS children's eligibility process. The Division performs two clinical assessments that measure the child's deficits in the areas of socialization, communication and behavior. If the child does not meet these criteria, (in CY 2015, 10 children did not) families are sent a letter notifying them that their child cannot participate in the Waiver Program. If a child is found to meet this clinical eligibility (as is the case for 77 in CY 2015), the family is approved for enrollment into the Program.

| Waiver Applicants Processed Within CY 2015                       | <u>Total</u> |
|--|--------------|
| Determined Eligible for the Program                              | 77           |
| Age ineligible   | 22           |
| MassHealth Ineligible  | 22           |
| Voluntary Withdrawals (Family withdrew or DDS could not contact) | 32           |
| Determined Clinically Ineligible                                 | 10           |
| Moved out of state   | 3            |
| Eligibility in Process   | 35           |
| TOTAL-   | 204          |

#### Active Participants in the Autism Waiver Program-January 1, 2015- November 15, 2015.

#### **Male/Female Distribution Information**

In Calendar Year 2015, approximately 77% of participants were males and 23% were females and this follows the national trend that indicates boys are much more likely to receive an autism diagnosis than girls.

| Gender of Participants Served in CY 2015 | <u>Total</u> |
|--|--------------|
| Male                                     | 214          |
| Female                                   | 64           |
| Total                                    | 278          |

#### **Diagnostic Information**

Approximately 5% of the children served in the Waiver have diagnosed co-morbid conditions that are identified in the child's medical record. These conditions include metabolic, genetic, and physical 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. In 2015 the references in the medical records to the presence of a co-morbid psychiatric condition meeting diagnostic criteria was small.

| Diagnostic Information for Participants Served Calendar Year 2015        | <u>Totals</u> |
|--|---------------|
| Autism & PDD (Pervasive Developmental Disorder)                          | 263           |
| RETTS Syndrome   | 1             |
| Autism & Other Co-Morbid Conditions-both Health and Developmental Issues | 14            |
| Total  | 278           |

#### **Cultural and Linguistic Information**

The 278 children served in the Waiver Program in CY 15 represent a wide range of linguistic and cultural backgrounds as identified by the Autism Clinical Managers and Parents/Guardians. If a family requires the use of an interpreter, the Division provides interpreters and translations.

| Cultural Information for Participants |                   |  |  |
|---------------------------------------|-------------------|--|--|
| <b>Ethnicity</b>                      | # of Participants |  |  |
| -                                     |                   |  |  |
| Caucasian                             | 103               |  |  |
| Latino/Hispanic                       | 78                |  |  |
| African American                      | 30                |  |  |
| Portuguese                            | 27                |  |  |
| Dominican                             | 8                 |  |  |
| Haitian                               | 6                 |  |  |
| Middle Eastern                        | 6                 |  |  |
| Chinese                               | 4                 |  |  |
| Vietnamese                            | 3                 |  |  |
| Greek                                 | 2                 |  |  |
| Moroccan                              | 2                 |  |  |
| Cape Verdean                          | 2                 |  |  |
| Russian                               | 2                 |  |  |
| Nigerian                              | 1                 |  |  |
| Egyptian                              | 1                 |  |  |
| Ghana                                 | 1                 |  |  |
| Indian                                | 1                 |  |  |
| Puerto Rican                          | 1                 |  |  |
| TOTAL                                 | 278               |  |  |

| Language Information for      | Participants  |
|-------------------------------|---|
| <u>Language</u>               | # of Participants   |
| English                       | 185   |
| Spanish                       | 63 (28 Require Interpreter)                                     |
| Portuguese                    | 15 (1 Require Interpreter)                                      |
| Haitian Creole                | 2 (0 Require Interpreter)                                       |
| Vietnamese                    | 3 (0 Require Interpreter)                                       |
| Mandarin                      | 1 (0 Require Interpreter)                                       |
| Russian                       | 1 (0 Require Interpreter)                                       |
| Cape Verde Creole             | 1 ( 1 Require Interpreter)                                      |
| Cantonese                     | 3 (3 Require Interpreter)                                       |
| Egyptian Arabic               | 4 (1 Require Interpreter)                                       |
| Total Non-English Primary     | 93  |
| Total                         | 278 (34 Require Interpreter)                                    |
| Total Requiring Interpreters: | 34/278= 15% of Participants<br>or<br>35/93 = 37% of Non-English |

# Breakdown of Age of Participants - Age as of November 15, 2015

The Program serves a wide range of ages of children between two and until the child turns 9 years of age.

| Age of | 278 Participants as of 11/15/15 |          |
|--------|---------------------------------|----------|
| Age 2  | 0                               | Age 6 47 |
| Age 3  | 13                              | Age 7 57 |
| Age 4  | 26                              | Age 8 46 |
| Age 5  | 54                              | Age 9 30 |

## **Sibling Data of Participants:**

January through November 15, 2015

| Sibling Information for Participants        |   |  |
|---|---|--|
| Siblings:                                   | Breakdown Totals (status of other children) |  |
| Number Siblings Pairs Enrolled: (non-twins) | families: 14                                |  |
|   | 6 sets of brothers                          |  |
|   | 5 brother/sister pairing                    |  |
|   | 3 three children, 3 boys                    |  |
| Number of Sibling Pairs Enrolled: (twins)   | families: 14                                |  |
|   | 7 sets of twin boys                         |  |
|   | 5 set of twins boy/girl                     |  |
|   | 1 set of twin girls                         |  |
|   | 1 set of twin boys plus a non-twin sister   |  |
| TOTAL (non-duplicative count):              | Families: 28                                |  |

# **City and Town Distribution of the 278 Participants**

The Waiver Program enrollment is heavily weighted with children from major cities like Worcester, Boston and Springfield.

| Town       | # | Town             | #  | Town            | #  | Town         | #  | Town             | #   |
|------------|---|------------------|----|-----------------|----|--------------|----|------------------|-----|
| Adams      | 1 | Dorchester       | 16 | Leicester       | 1  | Norwood      | 1  | Wareham          | 1   |
| Agawam     | 1 | Dudley           | 2  | Leominster      | 3  | Palmer       | 1  | Watertown        | 1   |
| Allston    | 1 | East Bridgewater | 2  | Littleton       | 3  | Peabody      | 3  | Webster          | 1   |
| Amherst    | 1 | East Boston      | 2  | Lowell          | 5  | Plymouth     | 2  | West Bridgewater | 1   |
| Arlington  | 1 | East Taunton     | 1  | Ludlow          | 3  | Quincy       | 2  | West Roxbury     | 4   |
| Attleboro  | 1 | East Walpole     | 1  | Lynn            | 7  | Reading      | 1  | West Yarmouth    | 1   |
| Auburn     | 2 | Everett          | 8  | Malden          | 4  | Revere       | 2  | Westborough      | 1   |
| Barre      | 2 | Fall River       | 7  | Mansfield       | 2  | Roslindale   | 1  | Westfield        | 2   |
| Bellingham | 1 | Fitchburg        | 1  | Marlborough     | 1  | Roxbury      | 1  | Weymouth         | 1   |
| Beverly    | 3 | Florence         | 1  | Mashpee         | 1  | Salem        | 1  | Wilbraham        | 1   |
| Billerica  | 1 | Framingham       | 6  | Mattapan        | 4  | Sharon       | 1  | Winchendon       | 1   |
| Boston     | 3 | Franklin         | 1  | Mattapoisett    | 1  | Shrewsbury   | 1  | Woburn           | 3   |
| Bourne     | 1 | Gloucester       | 2  | Medford         | 2  | Somerville   | 1  | Worcester        | 22  |
| Brighton   | 1 | Greenfield       | 1  | Methuen         | 3  | South Boston | 1  | Total:           | 278 |
| Brimfield  | 1 | Hampden          | 1  | Milford         | 5  | South Easton | 1  |                  |     |
| Brockton   | 5 | Haverhill        | 3  | Millville       | 1  | Southbridge  | 5  |                  |     |
| Burlington | 2 | Holyoke          | 8  | Natick          | 1  | Springfield  | 22 |                  |     |
| Cambridge  | 4 | Hopedale         | 1  | New Bedford     | 18 | Stoughton    | 2  |                  |     |
| Chelsea    | 1 | Hyde Park        | 1  | Newtonville     | 1  | Taunton      | 2  |                  |     |
| Chicopee   | 6 | Indian Orchard   | 2  | North Adams     | 1  | Wakefield    | 1  |                  |     |
| Clinton    | 1 | Jamaica Plain    | 2  | North Dartmouth | 1  | Waltham      | 1  |                  |     |
| Dedham     | 1 | Lawrence         | 5  | Northborough    | 1  | Ware         | 1  |                  |     |

### **Disenrollment Information**

Between January 2015 through November 15, 2015, 51 children dis-enrolled from the Autism Program. Twenty-eight (28) children left the Program as scheduled on their ninth birthday; one (1) child left due to ineligibility for continued MassHealth Standard coverage.

| Disenrollment Information for Participants |               |  |
|--|---------------|--|
| Reason for Disenrollment                   | <u>Number</u> |  |
| Turned Nine                                | 28            |  |
| Moved Out of State                         | 5             |  |
| Residential Placement                      | 1             |  |
| Lost MassHealth Standard                   | 1             |  |
| Not Utilizing Services                     | 6             |  |
| Voluntary Withdrawal                       | 9             |  |
| Lost Diagnosis                             | 1             |  |
| TOTAL                                      | 51            |  |

#### **Open Request Period Demographics - October 2015**

#### **Male/Female Distribution Information**

About 78% of participants were males and 22% were females and this follows the national trend that indicates boys are much more prone to an autism diagnosis than girls.

| Gender of Open Enrollment Applications CY 2015 | <u>Total</u> |
|--|--------------|
| Male   | 587          |
| Female   | 162          |
| Total  | 749          |

#### **Cultural and Linguistic Information**

The 749 applicants for the Waiver Program in CY 15 represent a wide range of linguistic backgrounds as identified by the and Parents/Guardians. If a family requires the use of an interpreter, the Division provides interpreters and translations.

| Language Information for | Applicants        |                             |                   |
|--------------------------|-------------------|-----------------------------|-------------------|
| <u>Language</u>          | # of Participants | <u>Language</u>             | # of Participants |
|                          |                   |                             |                   |
| English                  | 592               | Amharic                     | 2                 |
| Spanish                  | 92                | Creole                      | 2                 |
| Portuguese               | 26                | Grujrati                    | 1                 |
| Chinese                  | 10                | French                      | 1                 |
| Vietnamese               | 8                 | Russian                     | 1                 |
| Arabic                   | 4                 | Turkish                     | 1                 |
| Cantonese                | 3                 | Did not identify a language | 3                 |
| Mandarin                 | 3                 | Total                       | 749               |

# **Breakdown of Age of Open Enrollment Applicants**

| Ages of | f Applicants |                    |
|---------|--------------|--------------------|
| Age 1   | 9            | Age 6 99           |
| Age 2   | 80           | Age 7 88           |
| Age 3   | 152          | Age 8 42           |
| Age 4   | 139          | Age 9 and older 15 |
| Age 5   | 125          |                    |

# Sibling Data of Open Enrollment Applicants:

| Sibling Information for Applicants          |   |
|---|---|
| Siblings:                                   | Breakdown Totals (status of other children) |
| Number Siblings Pairs Enrolled: (non-twins) | families: 24                                |
|   | 10 sets of brothers                         |
|   | 8 brother/sister pairing                    |
|   | 3 sister/sister pairings                    |
|   | 3 three children, 2 boys and 1 girl         |
| Number of Sibling Pairs Enrolled: (twins)   | families: 7                                 |
|   | 3 sets of twin boys                         |
|   | 2 sets of boy/girl twins                    |
|   | 2 sets of twin girls                        |
| TOTAL (non-duplicative count):              | Families: 31                                |

# **City and Town Distribution of the Open Enrollment Applicants 2015**

The applicants are heavily weighted with children from major cities like Worcester, Boston and Springfield.

| Town          | #  | Town            | #  | Town           | #  | Town             | #  | Town             | #  | Town         | #   |
|---------------|----|-----------------|----|----------------|----|------------------|----|------------------|----|--------------|-----|
| Adams         | 1  | Clinton         | 2  | Hanscom        | 2  | Milford          | 1  | Salem            | 8  | Westfield    | 10  |
| Agawam        | 4  | Concord         | 1  | Harvard        | 1  | Millbury         | 2  | Saugus           | 3  | Westford     | 3   |
| Allston       | 4  | Danvers         | 1  | Haverhill      | 6  | Millville        | 1  | Seekonk          | 1  | Weymouth     | 4   |
| Arlington     | 2  | Dedham          | 2  | Hingham        | 1  | Milton           | 2  | Sheffield        | 1  | Whitinsville | 3   |
| Ashburnham    | 1  | Deerfield       | 1  | Holden         | 3  | Monson           | 1  | Shirley          | 1  | Wilbraham    | 1   |
| Ashland       | 2  | Dighton         | 1  | Holliston      | 2  | North Brookfield | 1  | Shrewsbury       | 1  | Winchendon   | 1   |
| Assonet       | 1  | Dorchester      | 36 | Holyoke        | 17 | North Weymouth   | 1  | Somerset         | 1  | Winchester   | 1   |
| Athol         | 1  | Douglas         | 2  | Hopkinton      | 2  | New Bedford      | 26 | Somerville       | 15 | Winthrop     | 2   |
| Attleboro     | 4  | Dracut          | 1  | Hudson         | 1  | Newburyport      | 2  | South Boston     | 2  | Woburn       | 3   |
| Auburn        | 1  | Dudley          | 1  | Hull           | 1  | Newton           | 1  | South Dennis     | 1  | Worcester    | 46  |
| Bedford       | 1  | Duxbury         | 1  | Hyannis        | 3  | North Adams      | 2  | south Easton     | 1  | Total:       | 749 |
| Belchertown   | 2  | East Boston     | 11 | Hyannisport    | 1  | North Andover    | 2  | South Hadley     | 2  |              |     |
| Bellingham    | 2  | East Brookfield | 2  | Hyde Park      | 12 | North Attleboro  | 3  | Southwick        | 1  |              |     |
| Berkley       | 1  | East Longmeadow | 1  | Indian Orchard | 4  | North Easton     | 1  | Spencer          | 2  |              |     |
| Beverly       | 2  | East Wareham    | 1  | Jamaica Plain  | 4  | Northampton      | 2  | Springfield      | 57 |              |     |
| Billerica     | 2  | Eastham         | 1  | Lanesboro      | 1  | Norton           | 1  | Stoneham         | 1  |              |     |
| Blackstone    | 1  | Easthampton     | 5  | Lawrence       | 15 | Norwood          | 3  | Stoughton        | 3  |              |     |
| Boston        | 25 | Essex           | 1  | Lenox          | 1  | Orange           | 3  | Sunderland       | 1  |              |     |
| Boxborough    | 2  | Everett         | 9  | Leominster     | 6  | Oxford           | 2  | Swampscott       | 2  |              |     |
| Bradford      | 2  | Fairhaven       | 3  | Lexington      | 1  | Palmer           | 2  | Taunton          | 13 |              |     |
| Braintree     | 2  | Fall River      | 6  | Lowell         | 29 | Peabody          | 3  | Tewksbury        | 2  |              |     |
| Brewster      | 1  | Fitchburg       | 11 | Ludlow         | 1  | Pittsfield       | 4  | Townsend         | 1  |              |     |
| Brighton      | 4  | Forestdale      | 1  | Lunenburg      | 1  | Plymouth         | 3  | Tyngsboro        | 2  |              |     |
| Brockton      | 13 | Foxboro         | 4  | Lynn           | 11 | Princeton        | 1  | Uxbridge         | 3  |              |     |
| Brookline     | 2  | Framingham      | 11 | Malden         | 5  | Quincy           | 14 | West Boylston    | 1  |              |     |
| Buzzard's Bay | 1  | Franklin        | 1  | Mansfield      | 2  | Randolph         | 6  | West Springfield | 5  |              |     |
| Cambridge     | 7  | Gardner         | 1  | Marblehead     | 1  | Raynham          | 2  | Wakefield        | 1  |              |     |
| Centerville   | 1  | Gloucester      | 2  | Marlborough    | 1  | Reading          | 1  | Watertown        | 1  |              |     |
| Charlestown   | 2  | Grafton         | 1  | Mattapan       | 3  | Revere           | 11 | Ware             | 1  |              |     |
| Chelmsford    | 1  | Granby          | 2  | Medfield       | 1  | Rockland         | 1  | Wareham          | 1  |              |     |
| Chelsea       | 8  | Greenfield      | 1  | Medford        | 8  | Roslindale       | 8  | Webster          | 5  |              |     |
| Cheshire      | 1  | Groton          | 2  | Melrose        | 3  | Roxbury          | 9  | Wellfleet        | 5  |              |     |
| Chestnut Hill | 4  | Hadley          | 1  | Methuen        | 2  | Russell          | 2  | West Roxbury     | 1  |              |     |
| Chicopee      | 12 | Halifax         | 1  | Middleboro     | 1  | South Yarmouth   | 1  | Westborough      | 3  |              |     |

#### IV. Autism Waiver Program Provider Information

In CY 2015, the Autism Waiver Program allocation is approximately \$4.8 million. This appropriation includes approximately \$1.3 million necessary to cover the administrative costs of the Program. It also includes the Financial Management Service's monthly fees-per-participant which is an additional cost of approximately \$320,000 as of November 2015.

The administrative budget is broken down as follows:

- @\$900,000 Personnel Costs: 18 Autism Support Brokers
- @\$310,000 Personnel/Operational Costs: 1 Program Director and 5 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 the Fiscal Intermediary fees is broken down as follows:

• @\$28,000 per month (Approximately \$346,000 per year) – 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 schools 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 October 31, 2015, the list of unique providers totaled 660 an increase over the previous year. Many providers deliver more than one service listed in the chart below. 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.

# Provider Totals (As of November 15, 2015):

| Service Type   | Description of Provider Duties  | Total # |
|--|---|---------|
| <b>Expanded Habilitation, Education:</b> Senior Level Therapists | Responsible for the creation and oversight of the in-home support plan  | 248     |
| Step Down Program (after 3 years): Behavioral Consultants        | Responsible for providing technical assistance for the continuation of the in-home support plan   | 41      |
| Expanded Habilitation, Education: Therapists                     | Responsible for carrying-out the in-home plan with the child on a one-to-one basis  | 328     |
| Expanded Habilitation, Education: Direct Supports                | Responsible for carrying-out the in-home plan with the child on a one-to-one basis  | 451     |
| Habilitation, Community Integration                              | Responsible for helping the child to participate in activities and other programs provided in community settings  | 255     |
| 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 | 155     |
| 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  | 456     |
| Total Unique Providers Services                                  |   |         |

#### **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.

| Point-in time number captures budget totals as of November 15, 2015 |                        |  |  |  |
|---|------------------------|--|--|--|
| Service   | Amounts                |  |  |  |
| (total budgeted for 278 participants)                               | (rounded in thousands) |  |  |  |
| Expanded Habilitation, Education                                    | \$ 4,318,635           |  |  |  |
| Behavioral Consultation (Step Down)                                 | \$ 140,866             |  |  |  |
| Habilitation, Community   | \$ 103,362             |  |  |  |
| Family Training   | \$ 7,075               |  |  |  |
| Respite (includes related workers comp costs                        | \$ 246,642             |  |  |  |
| Home/Vehicle and Adaptive   | \$ 49,516              |  |  |  |
| Goods and Services/Homemaker  | \$ 99,727              |  |  |  |
| TOTAL Budgeted Service Dollars:                                     | \$ 4,967.622           |  |  |  |

#### Service Amounts per Participant: Covers budget information for participants from January 2015- November 15, 2015

Of the 278 Waiver Program participants, 171 children received over \$20,000 worth of services and supports, while another 50 received services and supports between \$10,000 and \$20,000. There were 5 participants with budgets under \$10,000 and the majority of these participants turned 9 during CY 15 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 CY 15, 52 children were enrolled in the Step Down program, receiving \$5,500 of supports.

| Number of Participants in various Budget Categories |                        |   |  |  |  |
|---|------------------------|---|--|--|--|
| Service   | Number of Participants | Amounts (rounded into dollar bands)         |  |  |  |
| Overall Budgeted Amount                             | 171                    | \$20,000 - \$25,000 (Max is \$25K)          |  |  |  |
| Overall Budgeted Amount                             | 50                     | \$10,001 - \$19,999                         |  |  |  |
| Overall Budgeted Amount                             | 5                      | \$10,000 or below-includes prorated budgets |  |  |  |
| Step Down Budgeted Amount                           | 52                     | \$5,500 or below                            |  |  |  |
| Total   | 278                    |   |  |  |  |
| Service   | # of Participants      | Amounts (rounded dollar bands)              |  |  |  |
| Expanded Habilitation, Ed                           | 143                    | \$20,000 - \$25,000 (Max is \$25K)          |  |  |  |
| Expanded Habilitation, Ed                           | 49                     | \$15,001 - \$19,999                         |  |  |  |
| Expanded Habilitation, Ed                           | 22                     | \$10,001 - \$15,000                         |  |  |  |
| Expanded Habilitation, Ed                           | 12                     | \$10,000 or below-includes prorated budgets |  |  |  |
| Behavioral Consultation (Step Down)                 | 52                     | \$5,500 or below                            |  |  |  |
| Overall Total                                       | 278                    | Exp. Hab, Ed & Behavioral Consultation      |  |  |  |
| Service   | # of Participants      | Amounts (rounded dollar bands)              |  |  |  |
| Total Ancillary Services                            | 136                    | Under \$2,500                               |  |  |  |
| Total Ancillary Services                            | 72                     | \$2,501 - \$5,500 (Max is \$5,500)          |  |  |  |
|   | 70                     | No Ancillary Services/Or in Step Down       |  |  |  |
| Total   | 278                    |   |  |  |  |

#### **VI.** Measuring Programmatic Outcomes

The Federal CMS review of the Autism Waiver Program requires internal oversight and program monitoring on at least a quarterly basis. CMS reviewed the program and it met all of the waiver assurances.

#### VII. Next Steps

The program closely tracks the birthdates of participants in order to better predict known turnover. Each Clinical Manager works an eligibility caseload in addition to their full waiver caseload to ensure the pool of applicants is deep enough to fill the predicted open slots.

The program is now exploring additional methods to insure that families from diverse backgrounds can effectively participate in the program.

This will involve using interpreters at initial contact and developing a pilot to create a pool of family partners to assist new families in the program.

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 less 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.

#### VIII: 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.