

**Commonwealth of Massachusetts**

**Department of Developmental Services**

**Autism Waiver Program**

**2021 Legislative Report**

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 *All information contained in this report was current as of November 10, 2021.*

1. **Executive Summary**

The Department of Developmental Services’ (DDS) Autism Division respectfully submits this report in response to language contained in the Fiscal Year 2022 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, 2021; 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 covers the Administration’s activities related to the Autism Waiver Program from January 1, 2021 through November 10, 2021.

The Massachusetts Autism Waiver Program is an entirely self-directed program, meaning that families play a key role in hiring staff and identifying 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 is a program for children under the age of nine with an autism spectrum disorder who meet all eligibility criteria required for entrance into the Waiver. 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 oversight and assistance to families and an Autism Support Broker that 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 $28,000/year. This cap was increased during CY20 and will continue into CY22. 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 $8,500 per year, beginning CY20 (increased from$7,500 previously).

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 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.

This waiver year has been impacted dramatically by Covid-19 and has required a number of programmatic adjustments. MassHealth and DDS sought and received permission for additional flexibilities, Appendix K, from The Centers for Medicare and Medicaid Services (CMS), including the addition of a home delivered meal service, the delivery of Education Habilitation and Behavioral Consultation services via telehealth, increases in the prospective budget caps, the elimination of in person meetings, an allowance for electronic signatures across program documents, and permission to allow children over the age of 9 to remain in the program until their 10th birthday throughout the Appendix K flexibility period. Covid-19 has also impacted the open request period as well as enrollment as many families were concerned about outside contacts in their family home.

The Autism Waiver was successfully renewed for a period of five years effective October 1, 2020, although we continue to operate under the Appendix K flexibility.

The current Appendix K flexibilities will remain in effect until the Public Health Emergency has been terminated; the Center for Medicare and Medicaid will then provide a 6- month wind down of the Appendix K flexibilities at which time DDS will operate the waiver program with the approved changes which were effective on October 1, 2020. An amendment was filed to request the permanent addition of the Home Delivered Meal service to the available ancillary service options effective 7/1/21.

Finally, MassHealth and DDS have requested to use funds under the American Rescue and Recovery Act (ARPA) to expand capacity under the waiver. DDS and MassHealth are waiting for Federal approval.

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| --- | --- |
|  | **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 |
| 2020 | 603 |
| 2021 | 665 |
|  |  |

**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, 2021 and ending November 10, 2021.

**Enrollment Updates for the Autism Waiver**

Since January 1, 2021, 49 new children were determined eligible for services and a total of 320 children participated in the Waiver Program. As of November 10, 2021, there are 242 children currently enrolled in the Autism Waiver Program. All budget details are based on the 320 children served across the 2021 calendar year.

**Autism Waiver Program Eligibility Data (Calendar Year 2021)**

The Division processed 295 Waiver applications in CY21. 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.

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| **Waiver Applicants Processed Within CY 2021** | **Total** |
| Determined Eligible for the Program | 49 |
| Age Ineligible | 14 |
| MassHealth Ineligible | 126 |
| Voluntary Withdrawals (Family withdrew or DDS could not contact) | 89 |
| No Autism Diagnosis | 3 |
| Eligibility in Process | 14 |
| **TOTAL** | **295** |

**Active Participants in the Autism Waiver Program-January 1, 2021- November 10, 2021**

**Male/Female Distribution Information**

In Calendar Year 2021, 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.

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| **Gender of Participants Served in CY 2021** | **Total** |
| Male  | 254 |
| Female  | 66 |
| **Total** | **320** |

**Diagnostic Information**

Approximately 15% 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 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.

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| --- | --- |
| **Diagnostic Information for Participants Served Calendar Year 2021** | **Totals** |
| Autism & PDD (Pervasive Developmental Disorder) | 272 |
| RETT Syndrome | 0 |
| Autism & Other Co-Morbid Conditions – Both Health and Developmental Issues | 48 |
| **Total** | **320** |

**Cultural and Linguistic Information**

|  |  |
| --- | --- |
| **Language Information for**  | **Participants**  |
| **Language** | **# of Participants** |
| English  | 225 |
| Spanish | 53 (33 require interpreter) |
| Portuguese | 19 (7 require interpreter) |
| Arabic | 9 (3 requires interpreter) |
| Vietnamese | 3 (2 requires interpreter) |
| Korean | 3 (0 requires interpreter) |
| Cantonese | 2 (0 require interpreter) |
| Polish | 1 (0 requires interpreter) |
| Cape Verdean Creole | 1 (0 require interpreter) |
| Amharic | 1 (1 require interpreter) |
| Greek | 1 (0 requires interpreter) |
| Mandarin | 1 (1 requires interpreter) |
| Haitian Creole | 1 (0 requires interpreter) |
| **Total** | **320 (47 requiring interpreters)** |

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| **Cultural Information for Participants** |
| **Ethnicity** | **# of Participants** |
|  |  |
| Caucasian | 122 |
| Latino/Hispanic | 87 |
| African American | 47 |
| Portuguese | 16 |
| Brazilian | 8 |
| Middle Eastern | 7 |
| Vietnamese | 5 |
| Arabic | 3 |
| Asian-American | 3 |
| Chinese | 3 |
| Haitian | 3 |
| Korean | 3 |
| Caucasian-Hispanic | 2 |
| Dominican | 2 |
| Cape Verdean  | 1 |
| Egyptian | 1 |
| Greek | 1 |
| Kenyan | 1 |
| Moroccan | 1 |
| Nigerian | 1 |
| Polish | 1 |
| Puerto Rican | 1 |
| Ugandan | 1 |
| **Total** | **320** |

The 320 children served in the Waiver Program in CY21 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 10, 2021

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

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| --- | --- |
| **Age of 320 Participants as of 11/10/21** |  |
| Age 2: 0 |  Age 6: 35 |
| Age 3: 5 |  Age 7: 50 |
| Age 4: 20 |  Age 8: 60 |
| Age 5: 37 |  Age 9+: 113 |

**Sibling Data of Participants**

January 1 through November 10, 2021

|  |  |
| --- | --- |
| **Sibling Information for Participants**  |  |
| **Siblings:** | **Breakdown Totals (status of other children)** |
| Number Siblings Pairs Enrolled: (non-twins) | Families: 22 |
| Number of Sibling Pairs Enrolled: (twins)  | Families: 9 |
| Number of Sibling Pairs Enrolled: (twins + non-twin sibling) | Families: 1 |
| Number of Sibling Pairs Enrolled: (triplets) | Families: 1 |
| Number of Siblings Pairs Enrolled: (non-twins+sibling, non-triplets) | Families: 1 |
| **TOTAL (non-duplicative count):** | **Families: 34** |

**City and Town Distribution of the 320 Participants**

The Waiver Program enrollment includes many children coming from major cities like Boston and its neighborhoods (37), Springfield and its neighborhoods (31) and Worcester (44).

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| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Town** | **#** | **Town** | **#** | **Town** | **#** | **Town** | **#** | **Town**  | # |
| Agawam  | 2 | Dudley | 1 | Lowell | 12 | Quincy | 1 | Webster | 3 |
| Amherst | 2 | East Boston | 3 | Ludlow | 1 | Randolph | 1 | Westfield | 3 |
| Ashland | 1 | Easthampton | 1 | Lynn  | 10 | Revere  | 3 | Westport | 1 |
| Athol | 1 | Everett | 6 | Lynnfield | 1 | Roslindale  | 1 | Westwood | 1 |
| Attleboro | 3 | Fall River  | 5 | Malden | 1 | Rowley | 1 | Winchendon | 1 |
| Auburn | 1 | Fiskdale | 2 | Marlborough | 2 | Roxbury | 2 | Woburn | 1 |
| Bedford | 1 | Fitchburg  | 2 | Medford  | 1 | Sharon  | 2 | Worcester | 44 |
| Billerica | 1 | Framingham  | 9 | Medway  | 2 | Somerville | 2 |   |   |
| Boston | 4 | Franklin | 1 | Melrose | 2 | South Grafton | 1 | **Total:** | **320** |
| Braintree | 2 | Gloucester  | 1 | Methuen | 4 | South Hadley | 3 |  |  |
| Brighton | 2 | Granby  | 2 | Middleborough | 1 | South Hamilton | 3 |  |  |
| Brockton  | 4 | Haverhill | 3 | Millbury | 1 | South Yarmouth | 1 |  |  |
| Burlington | 1 | Hingham  | 2 | New Bedford | 11 | Southbridge  | 3 |  |  |
| Cambridge  | 4 | Holyoke | 9 | North Andover | 1 | Springfield | 31 |  |  |
| Canton | 1 | Hudson | 1 | North Attleboro | 1 | Stoughton | 1 |  |  |
| Charlestown | 2 | Hyannis  | 3 | Northborough | 3 | Sunderland | 2 |  |  |
| Chelsea | 2 | Hyde Park | 4 | Norton | 1 | Sutton | 3 |  |  |
| Chicopee | 10 | Jamaica Plain | 2 | Norwood | 2 | Swansea | 2 |  |  |
| Clinton | 2 | Lawrence  | 2 | Oxford | 2 | Taunton | 2 |  |  |
| Danvers  | 1 | Leicester | 2 | Pittsfield | 3 | Uxbridge | 2 |  |  |
| Dorchester | 17 | Leominster | 3 | Plainville | 2 | Ware | 2 |  |  |
| Dracut | 1 | Leverett | 1 | Plymouth | 1 | Wareham | 2 |  |  |

**Disenrollment Information**

Between January 1, 2021 through November 10, 2021,78 children disenrolled from the Autism Program: 72 children left the Program due to their age.

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| --- | --- |
| **Disenrollment Information for Participants**  |  |
| **Reason for Disenrollment** | **Number** |
| Turned Nine | 72 |
| Moved Out of State | 3 |
| Lost Autism Diagnosis | 1 |
| Voluntary Withdrawal | 4 |
| Placed in Residential Placement  | 1 |
| **TOTAL** | **81** |

**Open Request Period**

**Male/Female Distribution Information**

In Calendar Year 2021, 76% of applicants were males and 24% were females. This follows the national trend that indicates boys are much more prone to receiving an autism diagnosis than girls.

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| **Gender of Open Enrollment Applicants CY21** | **Total** |
| Male  | 505 |
| Female  | 160 |
| **Total** | **665** |

**Cultural and Linguistic Information**

The 665 applicants for the Waiver Program in CY21 represent a wide range of linguistic backgrounds as identified by the Parents/Guardians. Twenty four percent (24%) of the applicants noted the need for interpretation or translation in other languages on their applications. The most frequently spoken languages other than English are Spanish (13.68%), Chinese (3.30%), Portuguese (3.0%), Vietnamese (1.2%) and Haitian Creole (1.05%).

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

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| Language Information for CY21 Applicants |
| Language | # of Applicants | Language | # of Applicants |
| English | 506 | ASL | 2 |
| Spanish | 91 | Cape Verdean Creole | 2 |
| Chinese (Mandarin & Cantonese) | 22 | Russian | 1 |
| Portuguese  | 20 | French | 1 |
| Vietnamese | 8 | Somali | 1 |
| Haitian Creole  | 7 |  |  |
| Arabic | 4 | **Total** | **665** |

**Breakdown of Age of Open Enrollment Applicants**

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| --- |
| **Ages of Applicants** |
| Age 1< 7 | Age 6 105 |
| Age 2 50 | Age 7 85 |
| Age 3 138 | Age 8 27  |
| Age 4 107 | Age 9+ 13 |
| Age 5 133 |  |
|  | **Total 665** |

**Sibling Data of Open Enrollment Applicants**

|  |  |
| --- | --- |
| **Siblings** | **Breakdown Totals (status of siblings enrolled)** |
| **Number Sibling Pairs: (non-twins**) | **Families: 38** |
| 21 brother/brother pairings |
| 10 brother/sister pairings |
| 4 sister/sister pairings2 brother/brother/sister pairing1 brother/brother/brother pairing |
| **Number of Sibling Pairs: (twins)**  | **Families: 11**  |
|  | 5 sets of twin boys3 sets of twin girls3 sets twin boy/girl pairings |
| **Total (non-duplicative count)** | **Families: 49** |

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

Applicants are from 159 communities with many coming from major cities like Springfield, Worcester, Lowell, Lawrence, New Bedford and Dorchester.

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| Springfield | 58 | Framingham | 5 | Brookline   | 2 | North Adams | 2 | Hyannis | 1 |
| Worcester | 31 | Woburn | 5 | Templeton | 2 | Williamstown | 2 | Grafton | 1 |
| Lowell | 31 | Chelsea          | 5 | Burlington | 2 | Northborough | 2 | Boxford | 1 |
| New Bedford | 29 | Brockton | 5 | Huntington | 2 | Easthampton | 2 | Scituate | 1 |
| Lawrence | 26 | Taunton | 4 | Mashpee | 2 | Billerica | 2 | Dudley | 1 |
| Dorchester         | 25 | Ludlow | 4 | Dighton | 2 | West Roxbury | 1 | Seekonk | 1 |
| Boston | 21 | East Boston | 4 | Mattapan      | 2 | Greenfield | 1 | Dunstable | 1 |
| Chicopee | 19 | Peabody | 4 | Sudbury | 2 | Lincoln | 1 | Sharon           | 1 |
| Holyoke | 17 | Shrewsbury | 4 | Granby | 2 | Windsor | 1 | Newburyport | 1 |
| Cambridge | 15 | Amherst | 4 | Tyngsboro | 2 | Easton | 1 | Adams | 1 |
| Roxbury | 10 | Turner’s Falls | 4 | Centerville | 2 | Natick | 1 | Gardner | 1 |
| Pittsfield | 9 | Attleboro | 4 | Bridgewater | 2 | Hingham | 1 | Dedham          | 1 |
| Methuen | 9 | Arlington | 4 | Charlestown | 2 | Warren | 1 | Wareham | 1 |
| Fall River | 8 | Norwood       | 4 | Feeding Hills | 2 | Palmer | 1 | Somerset | 1 |
| Quincy | 8 | Marlboro | 4 | Milton | 2 | North Reading | 1 | Watertown | 1 |
| Hyde Park               | 8 | Norton | 3 | Sheffield | 2 | Agawam | 1 | Mattapoisett | 1 |
| Lynn | 8 | Salem | 3 | Hatfield | 2 | Sturbridge | 1 | West Boylston | 1 |
| Everett | 7 | Allston     | 3 | South Boston | 2 | Clinton | 1 | Hudson | 1 |
| Malden | 7 | Beverly | 3 | Westford | 2 | Nantucket | 1 | Bellingham | 1 |
| Haverhill | 7 | Ware | 3 | Stowe | 2 | Dalton | 1 | Medway | 1 |
| Braintree | 7 | Florence | 3 | Whitinsville | 2 | Charlton | 1 | North Grafton | 1 |
| Newton          | 7 | Oxford | 3 | Bedford | 2 | Georgetown | 1 | Southbridge | 1 |
| Indian Orchard | 6 | Andover | 3 | Holbrook | 2 | North Andover | 1 | Northampton | 1 |
| Medford | 6 | Dartmouth | 3 | Three Rivers | 2 | Raynham | 1 | Barre | 1 |
| Westboro | 6 | Brighton    | 3 | Winthrop | 2 | Wayland | 1 | Brewster | 1 |
| Tewksbury | 6 | South Hadley | 3 | E Longmeadow | 2 | Danvers | 1 | Stoneham | 1 |
| Leominster | 5 | Ashland | 3 | Holden | 2 | North Attleboro | 1 | Blackstone | 1 |
| Revere      | 5 | Westfield | 3 | Waltham | 2 | Roslindale | 1 | Stoughton | 1 |
| Dracut | 5 | Chelmsford | 3 | Holliston | 2 | Wilbraham | 1 | Assonet | 1 |
| Somerville | 5 | Wakefield | 2 | Gloucester | 2 | Swansea | 1 | Belmont | 1 |
| W Springfield | 5 | Jamaica Plain | 2 | Randolph | 2 | Franklin | 1 | Onset | 1 |
| Middleboro | 5 | Saugus | 2 | Weymouth | 2 | Acton | 1 | ***Total*** | ***665*** |

**III. Autism Waiver Program Provider Information**

In CY21, 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 10, 2021.

The CY21administrative 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 CY21) – 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 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 10, 2021, the list of unique providers totaled 1,432. 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 10, 2021):  |
| **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 | 163 |
| **Step Down Program** *(after 3 years)***:**Behavioral Consultants | Responsible for providing technical assistance for the continuation of the in-home support plan | 116 |
| **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 | 385 |
| **Expanded Habilitation, Education:**Therapists  | Responsible for carrying-out the in-home plan with the child on a one-to-one basis | 305 |
| **Expanded Habilitation, Education:**Direct Supports | Responsible for carrying-out the in-home plan with the child on a one-to-one basis | 398 |
| **Habilitation, Community Integration** | Responsible for helping the child to participate in activities and other programs provided in community settings | 241 |
| **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  | 268 |
| **Total Number of Providers Credentialed by Service Type**  |  | 2028 |
| **Total Unique Number of Credentialed Providers**  |  | 1432 |

**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, safety purchases, and home delivered meals.

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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 | $3,816,075 |
| Behavioral Consultation (Step Down) | $ 236,730 |
| Behavioral Consultation Direct Support (new Step Down service for 2019) | $ 165,201 |
| Habilitation, Community Integration | $ 6,427 |
| Family Training | $3200 |
| Respite (includes related workers comp costs) | $ 130,008 |
| Home/Vehicle Adaptations and Adaptive Aids | $ 154,867 |
| Goods and Services/Homemaker | $ 122,354.45 |
| Home Delivered Meals | $ 93,075 |
| **TOTAL Budgeted Service Dollars:** | $ 4,743,005 |

**Service Amounts per Participant:** Covers budget information for participants from January 1, 2021 - November 10, 2021

Of 320 Waiver Program participants, 116 children received over $20,000 worth of services and supports, while another 78 received services and supports between $10,000 and $20,000. There were 30 participants with budgets under $10,000 and the majority of these participants turned 9 and were not yet 10 (Appendix K flexibility) during CY21 and therefore had prorated budgets to reflect their shortened time in the program. Most participants in the Program were also receiving ancillary services such as goods and services to purchase safety equipment, home/vehicle adaptations and home delivered meals due to food insufficiency. Most families also received a respite service, providing critical relief to families. In CY21, 96 children were enrolled in the Step- Down program, receiving up to $8,500 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 | 116 | $20,000 - $28,000 (Max is $28K) |
| Overall Budgeted Amount | 78 | $10,001 - $19,999 |
| Overall Budgeted Amount | 30 | $10,000 or below- includes prorated budgets |
| Step Down Budgeted Amount | 96 | $8,500 or below |
| **Total** | **320** |  |
| **Service** | **# of Participants** | **Amounts (rounded dollar bands)** |
| Expanded Habilitation, Ed |  106 | $20,000 - $28,000 (Max is $28K) |
| Expanded Habilitation, Ed |  47 | $15,001 - $19,999 |
| Expanded Habilitation, Ed |  35 | $10,001 - $15,000 |
| Expanded Habilitation, Ed |  36 | $10,000 or below-includes prorated budgets |
| Behavioral Consultation (Step Down) |  96 | $8,500 or below |
| **Overall Total**  |  **320/320** | **Expanded Habilitation Education & Behavioral Consultation** |
| **Service** | **# of Participants** | **Amounts (rounded dollar bands)** |
| Total Ancillary Services | 133 | Under $2,500 |
| Total Ancillary Services | 59 | $2,501 - $5,500 (Max is $5,500) |
|  | 128 | No Ancillary Services/Or in Step Down |
| **Total**  | **320** |  |

**IV. 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 FY21.

 **V. 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 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 opening slots. The Department has also established an internal process to receive files of currently eligible children from 23 DDS Area Offices who have applied during the open request period.

The Autism Division has also implemented a transition process post-termination of waiver services to increase knowledge of the family and the child’s needs when the case is turned over to 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 ensure 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 children transition out of the waiver program. Based on the number of new requests during the October 2021 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 rates for services increase and demands for skilled professionals are needed.

**VI**: **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.*