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Governor

Karyn Polito
Lieutenant Governor



Marylou Sudders
Secretary

Elin M. Howe
Commissioner

DDS Respite Services and Intensive Family Supports

December 2016





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Department of Developmental Services
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January 6, 2017

Senate Chair
Joint Committee on Ways and Means
State House, Room 519
Boston, MA 02133

House Chair
Joint Committee on Ways and Means
State House, Room 243
Boston, MA 02133

Senate Chair
Joint Committee on Elder Affairs
State House, Room 424
Boston, MA 02133

House Chair
Joint Committee on Elder Affairs
State House, Room 167
Boston, MA 02133

Dear Chairs:

Line item 5920-3000 of Chapter 133 of the Acts of 2016 requires the Department of Developmental Services (DDS) shall submit a report to the Joint Committee on Ways and Means and the Joint Committee on Elder Affairs on respite services and intensive family supports for individuals over 40 years of age.

Sincerely,


Elin M. Howe

Line Item 5920-3000 of the Fiscal year (FY) 2017 General Appropriation Act requires:

“For respite services and intensive family supports; that the department shall expend not less than \$1000,000 to provide respite services and intensive family supports for individuals over 40 years of age; and provided further that the department shall submit a report to the house and senate chairs of the joint committee on ways and means and house and senates chairs of the joint committee on elder affairs on respite services and intensive family supports for individuals over 40 years of age no later than December 31, 2016 and shall include, but not be limited to, the following: (a) the current number of individuals over 40 years of age who are eligible for respite services and intensive family supports; (b) the number of individuals over 40 years of age who are currently receiving respite services and intensive family supports; and (c) the amount of respite services and intensive family supports that each individual over 40 years of age receives.”

Background:

The Department of Developmental Services (DDS) has been providing flexible family support services since 1995 to children and adults eligible for services from DDS who are living at home with their families. The primary goal of family support is to provide a variety of options to individuals with disabilities and their families that enable them to stay together and to be welcomed, contributing members in their home communities. The DDS Family Support system is based on the principle that individuals and families know their own needs and best understand what resources will be most helpful to support their family member at home. Services and programs are designed to be responsive to the dynamic and changing needs of the individual with a disability and his/her developmental stages throughout life within the family unit.

These *Guiding Principles for Family Support* serve as the foundation for the delivery of services: Family support strives to achieve the goal of helping families stay together through:

- ❖ Developing families’ natural capacities to meet the needs of family members;
- ❖ Offering additional supports such as staff resources, goods and services, and financial assistance; and
- ❖ Enhancing the capacity of communities to value and support people with disabilities and their families.

The FY 2017 budget appropriation in the respite and Family Support Appropriation Account was \$62,846,395 million, an increase of \$5 million dollars in expansion funding from FY ‘16. There are a variety of different ways that family support services, including respite, are offered to families. These approaches include:

- Services provided by Family Support and Cultural/Linguistic-Specific Family Support Centers, Autism Support Centers and other family support programs such as the Medically Complex Programs. Services include information and referral, individualized service navigation, trainings, support groups, and social, recreational and community events.
- Services delivered by qualified Support Service providers with whom DDS contracts to provide an array of in-home and community support services, such as adult companion, respite, etc.
- Individualized flexible funding allocations, primarily in the form of stipends. This flexible funding is available to individuals and their families for the intermittent purchase of allowable supports and/or goods and services, including respite.. This funding is designed to supplement assistance available to the individual or family through generic funding sources, including other state or federal assistance available to the family.

Allowable services and goods are defined in the Department's Addendum to the Family Support Guidelines and Procedures (2011).

- Self-directed service options that can make available more intensive in-home and community support services that are individualized and offer more control and management by the individual and family in the choice of services and the hiring and management of workers.

(A) The current number of individuals over 40 years of age who are eligible for respite services and intensive family supports

There are 37,112 individuals eligible for DDS services living in the community, which includes approximately 20,000 children and adults are living at home with their families.

Currently there are 3,092 individuals over 40 years of age who are reported as living with family members. This information is based on data recorded in the DDS Meditech system as of 12/28/16.

(B) The number of individuals over 40 years of age who are currently receiving respite services and intensive family supports; and (C) the amount of respite services and intensive family supports that each individual over 40 years of age receives."

The majority of individuals over the age of 40 living with their family who are receiving respite and/or other related in-home and community support services are receiving this through individual flexible funding allocations administered by the 43 DDS funded Family Support Centers. These Centers also provide individualized support and service navigation to family members/caregivers as well as an array of other supportive services including a variety of trainings, support groups, and a diversity of social and recreational opportunities.

- Based on the most recent data collected through 6/30/16, approximately 1,600 individuals over the age of 40 and their families received flexible funding allocations/stipends, which represents about \$1.6 million dollars in funding. The most common use of this funding is for respite, but it can also be used for a variety of other in-home and community supports, and for other allowable goods and services that help families meet their caregiving needs that are not covered by other funding resources, e.g., adaptive equipment.

In addition, some individuals over 40 years of age who living with their family receive respite services, in the family home or in a site based setting, and other in-home and community support services delivered by qualified Support Service provider agencies with whom DDS contracts. These services offer assistance and support to both the individual with a disability and their family member/caregivers and include: respite, individualized home supports, adult companion, peer support, and behavioral supports and consultation.

- Approximately 400 individuals over 40 years of age and their families are currently receiving one or more of these services.

Individuals and families can also receive more intensive family support services through two self-directed service options available through DDS. This includes a Participant-Directed Program model that utilizes a fiscal management service, and Agency With Choice, which is a co-employment service model between the individual/family and a

qualified provider agency. These options afford individual and families more control in service design, hiring of staff, and management of their budget

- Currently there are about 90 individuals over the age of 40 and their families who are currently using these services for respite and other in-home and community supports.

Future Directions:

With the \$5 million dollars in expansion funding for family support services in the FY '17 budget, \$1.2 million has been designated to specifically provide new or enhanced supports to individuals 60 years of age and over who are living with family members. This funding is intended to provide a more robust package of in-home and community support services and resources to older family members committed to continuing to care for their family member at home.

As of August 2016, 656 individuals over the age of 60 were identified as living with family members. Activities will include outreach to all of these families by DDS Area Office staff to identify what supports families may already be receiving and determine their needs for additional supports. This can include both service needs for the older caregiver(s) as well as supports for the individual with a disability. Based on the needs of families, individual funding allocations will be made available to offer respite and other in-home and community supports either through flexible funding/stipend allocations or through provider-delivered support services. Families who are not connected to their local Family Support Center will be encouraged and assisted to make this connection, and they will be able to access service navigation assistance and support, as well as other supportive services and social opportunities for themselves and/or their family member. The Family Support Centers will also strategically develop new specialized support for older caregivers that may incorporate transportation, support groups, trainings, social events, and assistance with future planning.

It is anticipated that with expansion funding in future years DDS would look strategically at the needs of family members/caregivers of individuals between the ages of 50 to 60, and then between the ages of 40 to 50 in order to be pro-active in our outreach and support efforts to provide important and necessary respite and other assistance to older individuals and their families.