

**Report on Aging with Developmental Disability Initiatives**

**March 2019**

**Massachusetts Department of Developmental Services**

**Report on Aging with Developmental Disability Initiatives**

**March, 2019**

**Line Item 5920-3025 of the Fiscal Year (FY) 2019 General Appropriation Act** requires that *the department shall issue a report, not later than March 1, 2019, to the executive office for administration and finance and the house and senate committees on ways and means on the status of these initiatives including, but not limited to: (i) the number of participants served by each initiative; (ii) the participant outcomes, including impacts on the physical and cognitive health of participants; (iii) the cost of each initiative and the cost per participant; (iv) the implementation plans for these initiatives in fiscal years 2020 and 2021; and (v) recommendations for enhancing the care of individuals with developmental disabilities who are aging…*

**Overview of initiatives**

Beginning in the spring of 2015, DDS convened the Aging with Intellectual Disabilities (ID) workgroup to develop recommendations to address the needs of individuals with intellectual/Developmental disabilities who are aging. The workgroup was chaired by the Assistant Commissioner of Quality Management and DDS Director of Health Services. It included internal DDS members, EOHHS members and interested stakeholders (family member, Alzheimer’s Association, UMMS). Based on identified needs, DDS focused their attention on three main areas:

1. Healthy Aging and Clinical Resources

2. End of Life Care, Support and Planning

3. Community and Work/Retirement Activities

Based on recommendations from the Aging with ID Workgroup members, several initiatives were implemented or were continued in calendar year 2018 to address the above listed areas of concern. In addition, new initiatives were started. These initiatives were:

|  |
| --- |
| 1. Clinical Consultations |
| 1. Webinar development, release and ongoing distribution |
| 1. Memory Café continuation |
| 1. Alterative Aging Focused Day Supports pilot |
| 1. DDS End of Life policy |
| 1. 5 Wishes decision tool |
| 1. National Task Group on ID and Dementia Care Practices Training |
| 1. Partnership with Massachusetts Councils on Aging |

1. *The total number of participants served by each initiative*
   1. Clinical Consultation

* Ronda Williams, RPH, PhD, a clinical psycho-pharmacologist who consults with DDS, provides consultations with Area Office nurses on specific cases in which medications may be impacting individuals with age-related issues.
* 3 consultations provided in CY 2018
* Dr. Karen Shedlack, a psychiatrist, is contracted to provide clinical consultations to individuals who may be experiencing psychiatric issues related to aging.
* 26 consultations provided in CY 2018
  1. Webinar development, release and ongoing distribution (See detail in Attachment #1)
* Ongoing distribution of educational webinars linked on the DDS webpage.
* Aging and I/DD: General physical and psychological age related changes in IDD: Health, Behavior, Support needs as person ages
* Memory Café: What is it and how do I get one started?
* DDS Policy-End of Life Policy: Introduction to the revised Life Sustaining Treatment Policy
* Informational and instructional webinar on the purpose of a Medical Orders for Life Sustaining Treatment (MOLST) form, which includes medical orders for a person facing a life-threatening condition or very serious life limiting illness, and the process to be followed to complete one for an individual with ID.
* 5 Wishes: Introduction to and instructions on how to use the 5 Wishes document for end of life planning.
* Guardianship: Legal rights, authority and responsibilities of guardianship as it relates to end of life planning
* End of Life Planning: FAQs; definitions (DNR, DNI, Health care Agent, etc.), types of guardianship
* Accessing/providing community services as individuals with ID age: Things to consider
* Aging & Disability Resource Consortium (ADRC): Overview of services provided by ADRC and how to access
* End of Life: Cultural & Religious concerns: How to prepare for the care of individuals with ID at the end of life as it relates to their heritage or religious beliefs.
* Webinar views (for more detail, see Attachment #1): In CY2018, there were over 4000 views of the webpages and almost 4000 YouTube views.

|  |  |  |
| --- | --- | --- |
| **2018** | **# of Clicks** | |
| **Webinars/webpages** | **Web Page** | **YouTube** |
| Aging with Intellectual & Developmental Disability Trainings (Main Landing Page) | 923 | N/A |
| General Aging (Landing Page) | 301 | N/A |
| Total General Aging | 710 | 1,101 |
|  |  |  |
| Dementia and IDD (Landing Page) | 455 | N/A |
| Total Dementia | 719 | 917 |
|  |  |  |
| Launching a Memory Café | 166 | 736 |
|  |  |  |
| Adapting the Residence, Day Program and Community (Landing Page) | 95 | N/A |
| Total Adaptation | 294 | 156 |
|  |  |  |
| Aging and Disability Resource Consortia (ADRC) | 110 | 227 |
|  |  |  |
| End of Life Training | 615 | 817 |
| Grand total of clicks | 4,388 | 3,954 |

* 1. Memory Café Continuation (see detail in Attachment #2)
* A Memory Café is a regularly-scheduled time and place for individuals with memory issues AND their care partners (both informal and formal caregivers) to meet together for socialization, fellowship, community-building and information.
* 10 Memory Cafes are currently funded.
* In calendar year 2018, a range of 10 to over 100 individuals attended each of the 10 Memory Cafés funded by DDS. Memory Cafes met monthly, weekly or every other month with I/DD and others from the general public with memory issues and their care partners.
  1. Alterative Aging Focused Day Supports (see detail in Attachment #3)
* In CY18, DDS continued a contract with Cooperative for Human Services to provide day supports to individuals who are aging. Cooperative for Human Services implemented a program that includes site and community activities in shorter time increments than a traditional day program; and a mobile “pop-up” approach for individuals who can’t get to the program.
* This program, in CY2018, served an average of 17 participants each month.
* Day supports are offered to individuals daily 6 days per week either at a designated location or served individually in the person’s home.
  1. DDS Life Sustaining Treatment Policy (End of Life Policy)
* Spring 2018 Training provided to DDS attorneys and Area Office Nurses by DDS legal office and Health Services on DDS End of Life Policy and how Medical Orders for Life Sustaining Treatment (MOLST) forms are managed in DDS. Fall 2018 training provided by legal office to AO nurses on guardianship language and how it relates to end of life planning at DDS.
  1. 5 Wishes Documents
* 750 (500 in English, 250 in Spanish) more Booklets purchased and distributed to Area Offices for use in end of life planning with individuals (the first round of 2500, that had been purchased in 2016 and second round of 1000 purchased in 2017, have been distributed)
  1. National Task Group (NTG) on ID and Dementia Care Practices Training
  + Participation by DDS in a grant with the ACL (Administration of Community Living) managed by Massachusetts Councils on Aging (MCOA) on Alzheimer’s Disease and Related Dementias (ADRD) caregiver support and training changed the focus of the training to the creation of a training for caregivers from outside DDS like VNAs, adult day programs, hospice, home health aides. A resource manual was created and raining needs were identified as a result of feedback from caregivers gathered by NP conducting post ADRD diagnosis interviews with caregivers.
  + Trainings for caregivers scheduled for April 26, 2019. NTG Master Trainers will assist with trainings.

1. *The participant outcomes, including impacts on the physical and cognitive health of participants*

1. Clinical Consultation Outcomes
   * Clarification of medication interactions and likely cause of problematic side effects, resulting in medication reduction and discontinuation.
   * Confirmation or clarification of diagnosis for presenting problems, and identification of appropriate medication regimens. Improvement in behaviors or reduction in side effects in multiple cases.
   * Feedback was provided to the prescribing practitioners.
   * Insight was provided into rationale for changes in behavior, level of function or cognition.
   * Guidance was given in creation of treatment plans.
   * Facilitation of referrals to specialists to address particular concerns and confirmation of standing diagnoses.
   * Follow up support and guidance provided for individual and caregivers as planning for ongoing support for individuals diagnosed with ADRD goes forward.
2. Webinar development

* See Attachment #1.

1. Memory Café RFR implementation
   * Most cafés hold sessions on a monthly basis.
   * One café holds weekly sessions.
   * Additional evaluation activities are ongoing (see Attachment #2).
2. Alternative Aging Focused Day Supports

* Cooperative for Human Services formalized the day program in January 2018 by creating the Co-op Café at its Dartmouth Street location in Malden, MA. Participants meet and socialize with people of all ages from both residential and Individual Support Services in a true coffee house setting during day hours. In addition, CHS has become a CBDS provider and plans to become prequalified in July 2019 under the new procurement.
* The program offerings have remained high in number and complexity and have become much more customized as individuals continue to specify their unique interests.
* There were many positive outcomes noted in survey evaluations and in anecdotes. Participants were satisfied with services, with meaningful activities, with choices and with learning.
* Activities include the following:
  + In Wellness, Farm to Table – produce distribution and healthy lunches, Cooking Groups & Meal Planning, Healthful Snacks, Hosted Sports Activities, Group Games & Yoga, Modified Exercise Training Curriculum and Nursing Support & Health Training.
  + In Community Partnerships, YMCA Diabetes Prevention, GMVNA, UMASS Lowell Assistive Technology, MASS Families, Our Farm – Jackson Farm, and

Squash Connection (weighted blankets).

* + In Volunteerism, On the Rise, Malden Community Garden, Greater Boston Stage Company (Stoneham Theater), Somerville Veteran’s Shelter, and CHS Giving Back Traditions.
  + In Community Connections, Coop Café, Trinity Evangelical Church, CHS Cultural Connections, Reading Club and Harvest Program (healthy food share & distribution.
* Outcomes seen for individual participants include decrease in medications, more activity, new strategies to decrease falls, decreases in anxiety and the ability to leave home more often.
* CHS staff have noted that there have been increased participation, increased willingness to explore, higher levels of Engagement, increased spontaneous interactions, expanded social networks and higher levels of personal pride for program attendees.

1. DDS End of Life Policy

* Training provided to DDS legal staff and Area Office nurses on EOL policy and MOLST forms
* Training provided to Area Office nurses on guardianship limitations and responsibilities as they are related to EOL planning and MOLST forms

1. 5 Wishes Documents

* Area Office Nurses continue utilize and encourage use of the 5 Wishes document with individuals to guide discussions regarding their end of life wishes with their guardians or health care agents so there is a clear understanding of what their wishes and desires may be.

1. National Task Group (NTG) on ID and Dementia Care Practices Trainings

* Trainings developed for caregivers as part of DDS participation in ADRD grant from ACL managed by MCOA. First trainings to occur 4/26/19. NTG Master trainers will participate in trainings.

1. *The cost of each initiative and cost per participant*

CY18 Aging Funding Breakdown:

|  |  |
| --- | --- |
| Clinical Consultation | $31,500 |
| Webinar development and release | 0 |
| Memory Café continuation  (budgeted: $44,000 for FY2018, $40,000 for FY2019) | $51,492.62 |
| Alterative Aging Focused Day Supports pilot | $106,000 |
| DDS End of Life policy | 0 |
| 5 Wishes decision tool | $1,100 |
| National Task Group on ID and Dementia Care Practices Training | 0 |

Calendar year 2018 Special Funding Initiative Participants

Note: Numbers include individuals who had a consultation, were trained, or were guests at a memory café.

|  |  |
| --- | --- |
| Clinical Consultation | 29 |
| Webinar development and release | 8342 |
| Memory Café continuation | Range 10- over 100 individuals for the year for each cafe |
| Alterative Aging Focused Day Supports pilot | Average 17 a month |
| DDS End of Life policy | N/A |
| 5 Wishes decision tool | 1000 |

1. *The implementation plans for these initiatives in fiscal year 2020 and 2021*

**FY20/FY21 Planned Activities**

Building on the activities and successes of previous years, DDS will be implementing the following over the next two calendar years:

* Continue clinical consultation resources
* Maintain funding for 10 memory cafes
* Continue and potentially expand community-based day services innovation for aging population; fund pilot alternative aging-focused day supports through CBDS service.
* Provide regional and/or area trainings on Dementia Friendly Care for people aging with ID by newly trained NTG State Master trainers
* Work to sustain the services of the Gerontology DD Nurse Practitioner in providing follow up contact to assure adequate access to support services for caregivers for individuals seen in Dr. Julie Moran’s age related diagnostic clinic.
* Provide trainings based on the needs identified by the Gerontology DD Nurse Practitioner for all caregivers including other community providers of care like home health aides and ASAPs on Dementia Friendly Care for people aging with ID and provide the training.
* Create training webinar for caregivers based on outcomes from DDS participation ACL grant on ADRD Caregiver Support needs.

1. *Recommendations for enhancing the care of individuals with developmental disabilities who are aging*
   1. Continued implementation and support of all activities noted above.
      * Funding Memory Cafes
      * Funding Nurse Practitioner for follow up to Dr. Julie Moran’s age related diagnostic clinic
   2. In addition, DDS and the Executive Office of Elder Affairs have created opportunities for enhanced inter-agency coordination
      * DDS is now on the Advisory Board for Dementia Friendly Massachusetts Initiative/ADSSP grant.
      * DDS plans to present ID specific aging issues to ADRC and Elder services staff and providers
      * Collaboration between Councils on Aging and other memory café awardees also encouraged
      * Ongoing discussion with the Councils on Aging to build partnerships, including presenting information about individuals with developmental disabilities to their membership agencies.

Attachment #1

Webinar Counts- Detail

|  | **2018** | |
| --- | --- | --- |
|  | **# of Clicks** | |
| NP=Web Page or You Tube Video Not Posted in 2016 | **Web Page** | **YouTube** |
|  |  |  |
| **Aging with Intellectual & Developmental Disability Trainings** **(Main Landing Page)** | **923** | **N/A** |
| **http://shriver.umas­­­­­smed.edu/cdder/aging\_idd\_education** |  |  |
| **General Aging (Landing Page)** | **301** | **N/A** |
| Understanding Age Related Changes | 52 | 171 |
| The Role of Polypharmacy | 39 | 39 |
| Identifying and Assessing Pain | 32 | 43 |
| Behavior Related Changes and Aging in Adults with IDD | 33 | 62 |
| Health Promotion and Aging in Adults with IDD | 40 | 22 |
| Mobility and Aging in Adults with IDD | 40 | 58 |
| Aging with Down Syndrome | 72 | 226 |
| Aging and Cerebral Palsy | 101 | 480 |
| **Total General Aging** | **710** | **1,101** |
|  |  |  |
| **Dementia and IDD (Landing Page)** | **455** | **N/A** |
| Early Evaluation of Dementia and Alzheimer’s Disease | 76 | 56 |
| Stages of Alzheimer’s Disease | 81 | 793 |
| Applying the Knowledge to Dementia Caregiving and Caregiver Support | 50 | 38 |
| Caregiving in Action: Case Studies and Practical Tips | 57 | 30 |
| **Total Dementia** | **719** | **917** |
|  |  |  |
| **Launching a Memory Café** | **166** | **736** |
|  |  |  |
| **Adapting the Residence, Day Program and Community (Landing Page)** | **95** | **N/A** |
| Adapting the Residence for Aging Adults with IDD | 70 | 39 |
| Adapting the Day Program for Aging Adults with IDD | 71 | 74 |
| Honoring Cultural Practices and Individual Preferences | 21 | 14 |
| Community Inclusion and Solutions | 37 | 29 |
| **Total Adaptation** | **294** | **156** |
|  |  |  |
| **Aging and Disability Resource Consortia (ADRC)** | **110** | **227** |
|  |  |  |
| **End of Life Training** |  |  |
| Life Sustaining Treatment Policy | 98 | 39 |
| Guardianship and Aging in Intellectual Disability, Part I | 71 | 50 |
| Guardianship and Aging in Intellectual Disability, Case Studies, Part II | 36 | 62 |
| Medical Orders for Life Sustaining Treatment (MOLST) | 155 | 69 |
| End of Life Definitions | 66 | N/A |
| Five Wishes | 189 | 597 |
| **Total End of Life** | **615** | **817** |
|  |  |  |
| **QINA Aging Brief** | 28 | N/A |

Attachment #2

Memory Café Evaluation

Organizations Awarded Continued Funding for Integrated Memory Café through RFR

Conch Shell Counseling, Falmouth

Division of Andover Elder Services, Andover/Lawrence

Martha's Vineyard Center for Living, Martha's Vineyard

MaryMac Missions, Topsfield

Middleborough COA, Middleborough

New England Village, Pembroke

People, Inc., Fall River

RTR (Express Yourself), Marshfield

The Arc of Bristol County, Attleboro

UCP of Metro Boston, Watertown

Evaluation of 10 Memory Cafes

All 10 memory cafes responded and their answers to the questions are noted below. Respondents were associated with the organizations sponsoring and implementing the memory café and were asked to respond in that role.

**Respondents Role:**

|  |  |
| --- | --- |
| Executive Directory | 4 |
| Memory Café Coordinator | 4 |
| Family Support Center Director | 1 |
| Vice President | 1 |

**Respondents Primarily Work with:**

|  |  |
| --- | --- |
| People with disabilities | 4 |
| Older adults | 4 |
| Both | 2 |

**Frequency and Location**

**How often held café:**

|  |  |
| --- | --- |
| Once a month | 5 |
| Twice a month | 1 |
| Once a week | 1 |
| Every other month | 1 |
| 5 times per year | 1 |
| 4, but not quarterly | 1 |

**Was there a change in how often you held café from 2016?**

|  |  |
| --- | --- |
| Same number | 5 |
| Increase | 3 |
| Decrease | 2 |

**Where are you holding café?**

|  |  |
| --- | --- |
| Senior Centers | 3 |
| Public Library | 2 |
| Community Organizations | 1 |
| Day Program | 1 |
| Agency Space (public event space, store) | 2 |
| Garden | 1 |

**Participants & Guests**

**Number of Guests: Average number of guests at each café (including care partners)**

|  |  |
| --- | --- |
| 20+ | 4 |
| 6-10 | 3 |
| 16-20 | 2 |
| 11-15 | 1 |

**Number of Guests: Total number of guests in 2018, (including care partners)**

|  |  |
| --- | --- |
| 76-100 | 3 |
| 1-10 | 2 |
| 51-75 | 2 |
| 100+ | 2 |
| 26-50 | 1 |

**Number of Events Attended by People eligible for DDS Services:**

|  |  |
| --- | --- |
| 5 or more | 7 |
| 3 - 4 | 1 |
| All | 2 |

**Staff & Volunteers**

**How many staff/volunteers organize or work at the café?**

|  |  |  |  |
| --- | --- | --- | --- |
|  | 1-3 People | 4-6 People | None |
| Number of Staff that Organize Café: | 9 | 1 | N/A |
| Number of Staff that Work the Café | 8 | 2 | N/A |
| Number of Volunteers that assist | 8 | N/A | 2 |

Respondents indicated that staff supervise the café, welcome guests, run activities, socialize with guests, help serve food, set up/clean up, and often perform. Volunteers perform tasks similar to staff in addition to performing (artists, musician, guides, docents).

**Costs**

**Costs associated with café: Per month**

|  |  |
| --- | --- |
|  | Range |
| Administrative (CORI, etc.) | $0-450 |
| Other Miscellaneous Costs | $25-575 |
| Artists Stipends | $25-200 |
| Supplies (i.e., art materials, books, etc.) | $20-80 |
| Rent | $25-110 |

Attachment #3

Alternative Aging-Focus Day Supports

**Number of Regular Participants by Month**: 17

**Average weekly participation:** 13 hours-57.7 hours

**Cost per participant**: $6235/year