

**Report on Aging with Developmental Disability Initiatives**

**April, 2022**

**Massachusetts Department of Developmental Services**

**Report on Aging with Developmental Disability Initiatives**

**Line Item 5920-3025 of the Fiscal Year (FY) 2022 General Appropriation Act** requires *the department of developmental services shall report 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: (a) the number of participants served by each initiative; (b) the participant outcomes, including impacts on the physical and cognitive health of participants; (c) the cost of each initiative and the cost per participant; (d) the implementation plans for these initiatives in fiscal years 2023 and 2024; and (e) 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 to address the above listed areas of concern. In addition, new initiatives were started. Please see previous reports for past initiatives. In CY2020, a new focus area was identified: older caregivers. Given these focus areas, CY2021 initiatives included:

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| 1. Clinical Consultations including the addition of a nurse practitioner to provider follow up to Dr. Julie Moran’s age-related diagnostic clinic |
| 1. Webinar development, release, and ongoing distribution |
| 1. Flexible funding for older caregiver needs |

Please note: Some past initiatives including DDS End of Life policy education and collaboration, 5 Wishes decision tool and National Task Group (NTG) on ID and Dementia Care Practices Training were limited by the COVID-19 public health emergency. However, importantly, DDS and its clinical and service resources were able to take advantage of flexibilities in Medicare and Medicaid and virtual technology made available to the Department by EOHHS to allow virtual clinical and service visits.

1. *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.
* 12 consultations provided in CY 2021
* Dr. Karen Shedlack, a psychiatrist, is contracted to provide clinical consultations to individuals who may be experiencing psychiatric issues related to aging.
  + 33 consultations provided in CY 2021
* Kathy Service, nurse practitioner (NP), to provide follow up contact for individuals seen in Dr. Julie Moran’s age-related diagnostic clinic. The NP assesses how caregivers are accessing community resources that provide support services for caregivers for individuals with Alzheimer’s Disease or Related Dementias (ADRD) and provides additional information and recommendations for caregivers and individualized training for family or provider caregivers with particular concerns or challenges.
  + 13 follow up visits provided in CY 2021
  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 -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):

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| --- | --- |
|  | **2021** |
|  | **# of YouTube Clicks** |
| **Total General Aging** | **3,445** |
|  |  |
| **Total Dementia** | **2,133** |
|  |  |
| **Launching a Memory Café** | **60** |
|  |  |
| **Total Adaptation** | **215** |
|  |  |
| **Aging and Disability Resource Consortia (ADRC)** | **40** |
|  |  |
| **End of Life Training** | **1,984** |
|  |  |
| **Grand total of clicks/views** | **7,877** |

* 1. Flexible funding for older caregivers
* In FY21, DDS allocated $60,000 to the four regions ($15,000 per region) to be distributed through the Family Support Centers to fund goods, services, and supports for elder caregivers.
* The funding was distributed beginning in February 2021.
* The funding was used by Family Support Centers to provide Short-Term Emergency Needs, Respite/Respite Support, Adaptive Equipment & Supplies, Recreational & Social Inclusion Activities and Home Management Support Services, along with other needs. Respite/Respite Support were the categories that were funded for the most people and represented more of the funding followed by Short-Term Emergency Needs and Other Needs.

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

As an overall outcome to this work, many of the initiatives, activities and outcomes of DDS’ work related to aging and I/DD have been presented at state and national conferences. DDS has been contacted by other states for more information about aging-related work.

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. Flexible funding for older caregivers
   * Through this funding, 72 individuals with IDD and their families received funds. 54 caregivers (75%) were over the age of 75 and most caregivers were parents (81%). The average age of the individual with IDD was 45.7 years old. Over 25% of the funding was used for short-term emergency needs. See Attachment #2 for additional information.
2. *The cost of each initiative and cost per participant*

CY21 Aging Funding Breakdown:

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| --- | --- |
| Clinical Consultations | $ 40,000 |
| Flexible Funding | $ 60,000 |

Calendar year 2021 Special Funding Initiative Participants

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

|  |  |
| --- | --- |
| Clinical Consultation | 58 |
| Webinar development and release (YouTube views) | 7,877 |
| Flexible funding for older caregivers | 72 |

1. *The implementation plans for these initiatives in fiscal year 2023 and 2023*

**FY23/FY24 Planned Activities**

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

* Continue clinical consultation resources of Dr. Moran; Dr. Shedlack; and Dr. Williams.
* Continue 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.
* Conduct an in-depth needs assessment on older caregivers supported through DDS to identify best practices, opportunities, and gaps.
* Create a concrete plan and road map of deliverables including but not limited to trainings, facilitation guides, program development tools (i.e., best practices replication guides) and other needed materials for older caregivers. Create training webinars for caregivers based on outcomes from DDS participation ACL grant on ADRD Caregiver Support needs.
* Offer a flexible funding resource for older DDS participants and their older family caregivers.
* Provide regional and/or area trainings on Dementia Friendly Care for people aging with ID by newly trained NTG State Master trainers with possible collaboration with the Alzheimer’s Association.
* Seek ways to use technological solutions to provide training, consultation and support to individuals, family members and staff of individuals with ID/ADRD and/or aging issues. Ideas include the creation of “online” support/consultation hours on a regular basis, so caregivers can call in to or video chat with experts on aging topics as well as ask specific questions. Additional research into other strategies to enhance care with technology (i.e., assistive technology, tele-medicine, and remote support) should be conducted as part of DDS’ “Technology Forward” initiative.
* Explore the possibility of funding Care Consultations by Clinicians from the Alzheimer’s Association of MA/NH for individuals living with their family or in community settings. The consultation would be done post diagnosis of Alzheimer’s disease or related dementia in order to assess what the ongoing environmental, emotional and support needs of the individual are and provide individualized training and guidance to family members or staff on how to meet those needs.

1. *Recommendations for enhancing the care of individuals with developmental disabilities who are aging*
   1. Continued implementation and support of activities noted above, specifically:
      * Funding Nurse Practitioner for follow up to Dr. Julie Moran’s age-related diagnostic clinic
      * Funding Clinical Resources, including a psychiatrist, for individuals aging with I/DD.
      * Funding older caregiver flexible supports
   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
      * Collaboration with Alzheimer’s association to provide Clinical Consultation Care Plans for individuals with ID recently diagnosed with ADRD
2. Build capacity to implement technological solutions and strategies to support aging with I/DD initiatives

Attachment #1

**Aging & IDD Training Webinars and Materials**

**Number of YouTube Clicks for CY2020\***

|  | **2021** |
| --- | --- |
|  | **# of YouTube Clicks** |
| **Aging with Intellectual & Developmental Disability Trainings** **(Main Landing Page)** | **N/A** |
| **http://shriver.umassmed.edu/cdder/aging\_idd\_education** |  |
| **General Aging (Landing Page)** | **853** |
| Understanding Age Related Changes | 202 |
| The Role of Polypharmacy | 134 |
| Identifying and Assessing Pain | 134 |
| Behavior Related Changes and Aging in Adults with IDD | 100 |
| Health Promotion and Aging in Adults with IDD | 165 |
| Mobility and Aging in Adults with IDD | 84 |
| Aging with Down Syndrome | 384 |
| Aging and Cerebral Palsy | 1,389 |
| **Total General Aging** | **3,445** |
|  |  |
| **Dementia and IDD (Landing Page)** | **294** |
| Resources for Individual's with IDD and Alzheimer's Disease and Related Dementias | N/A |
| Early Evaluation of Dementia and Alzheimer’s Disease | 190 |
| Stages of Alzheimer’s Disease | 1,478 |
| Applying the Knowledge to Dementia Caregiving and Caregiver Support | 87 |
| Caregiving in Action: Case Studies and Practical Tips | 84 |
| **Total Dementia** | **2,133** |
|  |  |
| **Launching a Memory Café** | **60** |
|  |  |
| **Adapting the Residence, Day Program and Community (Landing Page)** | **N/A** |
| Adapting the Residence for Aging Adults with IDD | 49 |
| Adapting the Day Program for Aging Adults with IDD | 86 |
| Honoring Cultural Practices and Individual Preferences | 18 |
| Community Inclusion and Solutions | 62 |
| **Total Adaptation** | **215** |
|  |  |
| **Aging and Disability Resource Consortia (ADRC)** | **40** |
|  |  |
| **End of Life Training** | **N/A** |
| Life Sustaining Treatment Policy | 60 |
| Guardianship and Aging in Intellectual Disability, Part I | 58 |
| Guardianship and Aging in Intellectual Disability, Case Studies, Part II | 77 |
| Medical Orders for Life Sustaining Treatment (MOLST) | 52 |
| End-of-Life Definitions | N/A |
| Five Wishes | 1,737 |
| **Total End of Life** | **1,984** |
|  |  |

Attachment #2

**Flexible Funding for Older Caregivers**

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| --- | --- | --- |
| **Type of Support** | **Number of individuals** | **Amount of Money** |
| **Home Management Support Services** | 9 | $4,350.00 |
| **Short-Term Emergency Needs** | 17 | $14,975.00 |
| **Adaptive Equipment & Supplies** | 5 | $5,090.85 |
| **Recreational & Social Inclusion Activities** | 9 | $5,800.00 |
| **Respite/Respite Support** | 21 | $12,211.75 |
| **Personal Growth** | 1 | $280.00 |
| **Specialized nutrition/clothing** | 3 | $1,257.83 |
| **Other Approved Use (Specify)** | 17 | $13,926.56 |

Other approved uses included utility bill, grocery store gift card, garden items for caregiver, electric/massage recliner for caregiver/family (delivery and set up), house cleaning, foot massager for caregiver, kitchen table (+ shipping), small refrigerator (+ shipping) and television for caregiver.