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# Report on Aging with Intellectual Disability Initiatives

September 2016

Massachusetts Department of Developmental Services



September 12, 2016

The Honorable Karen E. Spilka, Chair  
Senate Committee on Ways and Means  
State House, Room 212  
Boston, MA 02133

The Honorable Brian S. Dempsey, Chair  
House Committee on Ways and Means  
State House, Room 243  
Boston, MA 02133

Kristen Lepore, Secretary  
Executive Office for Administration & Finance  
State House, Room 373  
Boston MA, 02133

Dear Chairs:

The Department of Developmental Services respectfully submits this report in response to language contained in the FY17 budget. Line-item 5920-3025 mandates the submission of this report to the Executive Office for Administration and Finance and the House and Senate Committee on Ways and Means on "initiatives to address the needs of individuals with developmental disabilities who are aging including, but not limited to, individuals with Down syndrome and Alzheimer's disease, through the identification of best practices for services for such individuals, including: (a) medical care coordination models that address conditions common to individuals with developmental disabilities who are aging; (b) the provision of training for direct care and other staff in the identification of dementia or other age-related conditions; and (c) the collection of data regarding the effectiveness of the initiatives included in this item."

Legislative language required that the report include "the status of these initiatives including, but not be 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 cost per participant; (iv) the implementation plans for these initiatives in fiscal year 2017 and fiscal year 2018; and (v) recommendations for enhancing the care of individuals with developmental disabilities who are aging."

Per the reporting mandate, the information requested is provided below for your review.

### *Overview of initiatives*

Beginning in the spring of 2015, DDS convened a workgroup to develop recommendations to address the needs of individuals with intellectual/developmental disabilities who are aging.

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 in FY2015 to address the above listed areas of concern. These initiatives were:

a. Consultants (Shedlack and Williams)
b. National Task Group on ID and Dementia Care Practices Training
c. Webinar development
d. DDS End of Life policy
e. 5 wishes
f. Memory Café informational training and Memory Café RFR Q&A
g. Memory Café RFR implementation

#### *I. The total number of participants served by each initiative*

##### *a. Clinical Consultation*

- Ronda Williams, RPH, PhD, a clinical psycho-pharmacologist who consults with DDS, now also provides consultations with Area Office nurses on specific cases in which medications may be impacting individuals with age-related issues.
  - 1 consultation provided in the final 4 mos. of FY16
- Dr. Karen Shedlack, a psychiatrist, is now contracted to provide clinical consultations to individuals who may be experiencing psychiatric issues related to aging.
  - 9 consultations provided in the last 4 mos. of FY16

##### *b. National Task Group on ID and Dementia Care Practices Training*

- 3 day training conducted by National Task Group (NTG) on Intellectual Disabilities and Dementia Care Practices to prepare provider and DDS Clinicians to care for and support individuals with ID who are dealing with dementia and their caretakers in order to provide in-state Trainers as an ongoing resource to providers and other clinicians.
  - 69 overall attendees
  - 26 attendees completed Train-the-Trainer to become Master Trainers

##### *c. Webinar development*

- Creation of an "Aging with ID" link prominently displayed on DDS homepage. (<http://www.mass.gov/eohhs/gov/departments/dds/aging-with-id.html>)
- Creation of 10 educational webinars in process or awaiting final approval. Webinars will be posted on the DDS homepage.

- 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- to be renamed "End of Life Policy".
  - What is a MOLST form? Informational and instructional webinar on the purpose of a MOLST form 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
  - ADRC (Aging & Disability Resource Consortium): 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 are pending completion of webinars
- d. DDS End of Life Policy
- Revised
    - Distribution is pending
- e. 5 Wishes Documents
- Booklets purchased and distributed to Area Offices for use in end of life planning with individuals
    - 2000 booklets
- f. Memory Café informational training and Memory Café RFR Q&A
- 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. DDS provided an overview training in advance of the RFR release
    - 5 trainings provided statewide
    - 115 people attended
- g. Memory Café RFR implementation
- The RFR provided for initial funding for Memory Cafes, specifically the development of integrated Memory Cafes that include individuals served by DDS and its providers as well as the broader community.
    - 31 proposals received
    - 13 Memory Cafes funded (See Attachment #1)

- Since April 1, 2016, at least 337 guests have attended a memory café funded by DDS. Guests included individuals aging with I/DD and others from the general public with memory issues and their care partners

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

a. Clinical Consultation

- The consultation with pharmacologist Ronda Williams clarified which medication was most likely causing a significant side effect in one individual, which resulted in the prescribing practitioner reducing and then discontinuing the medication.
- The clinical reviews by Dr. Karen Shedlack resulted in confirmation or clarification of diagnosis for presenting problems, and identification of appropriate medication regimens, including medication reduction and discontinuation of medications that present side effects as the person ages. Feedback was provided to the prescribing practitioners. The consults provided insight into rationale for changes in behavior, level of function or cognition and guidance in creation of a treatment plan. Referrals to specialists to address particular concerns were also initiated and standing diagnoses were confirmed or questioned. Final outcomes for these interventions are still pending.

b. National Task Group on ID and Dementia Care Practices Training

- Evaluation is pending.
- Planning is underway for FY17 Statewide trainings for provider staff on Dementia Friendly Care for people aging with ID by new NTG State Master trainers

c. Webinar development

- Evaluation is pending.

d. DDS End of Life Policy

- Distribution is pending.

e. 5 Wishes Documents

- Area Office Nurses 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. While this document has just recently been provided to the Area Offices, it is our hope that the results of their use will clarify and strengthen the understanding between the person and their health care agent about what medical interventions and care they may want in their final days.

f. Memory Café informational training and Memory Café RFR Q&A

- Memory Café training evaluations showed that they were very effective and well-received. 99% of attendees agreed they had learned key elements of a memory café. 94% agreed that the training had provided relevant information for the creation of an inclusive memory café under the RFR and 94% agreed that they had made progress in planning the café.

g. 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)

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

FY16 Special Funding Breakdown:

Consultants (Shedlack and Williams)	\$15,187.50
National Task Group on ID and Dementia Care Practices 3 day Training Scholarships	\$17,551.00
Webinar development (University of Massachusetts Medical School)	\$50,000.00
End of Life policy revisions	N/A
5 wishes	N/A
Memory Café informational training and Memory Café RFR Q&A (Jewish Family and Children's Service)	\$3,373.62
Memory Café RFR implementation (13 funded)	\$151,239.18
<b>Total</b>	<b>\$237,351.30</b>

FY16 Special Funding Initiative Participants

Note: Numbers include individuals who had a consultation, were trained, or were guests at a memory café; this does not include webinar views. Given that DDS and provider staff were trained related to dementia and ID as well as Memory Café activities, many more individuals will be reached by initiatives, but the exact number is unknown.

Consultants (Shedlack and Williams)	10
National Task Group on ID and Dementia Care Practices 3 day Training Scholarships	95
Webinar development (University of Massachusetts Medical School)	pending
End of Life policy revisions	N/A
5 wishes	2000 booklets
Memory Café informational training and Memory Café RFR Q&A (Jewish Family and Children's Service)	115
Memory Café RFR implementation (13 funded)	337

*IV. The implementation plans for these initiatives in fiscal year 2017 and fiscal year 2018*

**FY17 Planned Activities**

Building on the activities and successes of FY2016, DDS will be implementing the following:

- Continuation of clinical consultation resources
- Additional, maintenance funding for 13 memory cafes
- Fund pilot for community-based day services innovation for aging population
- Release revised End of Life policy
- Statewide trainings for provider staff on Dementia Friendly Care for people aging with ID by new NTG State Master trainers

- Seek funds to support services of Gerontology and DD Nurse Practitioner to provide follow up support and services for providers and staff for individuals seen in Dr. Julie Moran's age related diagnostic clinic at Tewksbury Hospital
- Seek funds to support additional start up memory cafés

#### **FY17 Planned Funding Breakdown**

Dr. Karen Shedlack (psychiatrist consultant)	\$43,000
Ronda Williams (clinical psycho-pharmacologist consultant)	\$4,500
Memory Cafes Maintenance funding for existing cafes: \$4,000 per café (x 13 cafes)	\$52,000
Community-based activities project (RFR in the fall):	\$50,000
<b>Total</b>	<b>\$149,500</b>

#### **V. *Recommendations for enhancing the care of individuals with developmental disabilities who are aging***

1. Recommendations involve implementing all FY17 Planned activities noted above.
2. Of particular note, DDS has already moved forward on the pilot for community-based day services innovation for aging population
  - RFI released- 22 responses with recommendations to enhance community-based supports
  - Currently under review
  - RFR being prepared for pilot program in FY17
3. 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.
  - Plans to present ID specific aging issues to ADRC and Elder services staff and providers
  - Memory Café funding awarded to Elder Services agencies and Councils on Aging. Collaboration between councils on aging and other memory café awardees also encouraged.
  - Creation of educational webinar with ADRC to explain services available through ADRC and areas where collaboration between agencies could enhance services for ID population.

Sincerely,



Elin M. Howe  
Commissioner

Attachment #1

Organizations Awarded Startup Funding for Integrated Memory Café through RFR

1. Berkshire Family & Individual Resources
2. Cambridge Family and Children's Service
3. Conch Shell Counseling
4. Division of Andover Elder Services
5. Martha's Vineyard Center for Living
6. MaryMac Missions
7. Middleborough Council on Aging-Town of Middleborough
8. New England Village
9. People, Incorporated
10. Road To Responsibility
11. Sunshine Village
12. The Arc of Bristol County
13. United Cerebral Palsy Association of Metro Boston

## Attachment #2

### Memory Café Evaluation

#### Online Survey and Focus Group with Memory Café Directors

- Between 1 and 6 staff members helped organize and run the Memory Cafés.
- Almost all Cafés had volunteers to help with the Memory Café.
- Music and art activities were hosted by Memory Cafés. Other activities included accessible gardens, flower arranging, magician, photo booth/scrapbooking, pet therapy, chair yoga, and gift of a letter (engaging individuals in handwriting letters to loved ones).
- Memory Cafés advertise primarily via flyers and newsletters.
- Important aspects of the Memory Cafés for individuals (based on staff observation):
  - Guests treated with respect
  - Focuses on abilities, not on disabilities or diagnosis
  - Has welcoming volunteers/staff
  - Is accessible
- Challenges:
  - The culture of elder services and disability services are different.
  - Funding is necessary to continue to hold inclusive cafés.
  - It can be hard to find DDS staff resources to bring individuals to café and stay with them.
- What worked:
  - Offered lunch
  - Provided transportation
  - Signed guest book (as a way to capture feedback)
  - Held disability awareness training to break down barriers between elder services and disability services
  - Facilitation to help with integration

#### Some testimonials:

- A spontaneous email from one of the participants stated: "Memory Cafe was a hit!"
- A volunteer quote: "The presenter was so interesting!"
- The person who schedules the space said this about the Cafe: "It is really great that this is being provided for people in the community."
- "I want to let you know about an amazing weekly event funded by DDS, that being the 'memory cafe' for folks with special needs, dementia etc. [It] is doing a really great job with this every week and I am volunteering by playing music as part of this weekly event with 6-7 great people including two retired docs, a nurse and other caretakers. I really think this would be a real "feel good" moment... to see the changes you have made in people's lives. People come alive when they hear us play their favorites and they follow along and sing with us on all the old standards (which aren't so old as many are songs we grew up with)."