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Governor

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Lieutenant Governor



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Secretary

Jane F. Ryder
Commissioner

Report on Aging with Intellectual Disability Initiatives

March 2018

Massachusetts Department of Developmental Services



March 15, 2018

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

The Honorable Jeffrey Sanchez, Chair
House Committee on Ways and Means
State House, Room 243
Boston, MA 02133

Michael Heffernan, 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 FY18 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: (i) medical care coordination models that address conditions common to individuals with developmental disabilities who are aging; (ii) training for direct care and other staff in the identification of dementia or other age-related conditions; and (iii) the collection of data regarding the effectiveness of the initiatives."

Legislative language required that the report include "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 cost per participant; (d) the implementation plans for these initiatives in fiscal year 2019 and fiscal year 2020; and (e) recommendations for enhancing the care of individuals with developmental disabilities who are aging"

Please feel free to contact Steve Tringale (Steven.J.Tringale@MassMail.State.MA.US) with any questions.



Jane Ryder
Commissioner

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. 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 2017 to address the above listed areas of concern. These initiatives were:

a. Clinical Consultations
b. Webinar development and release
c. Memory Café continuation
d. Alternative Aging Focused Day Supports pilot
e. DDS End of Life policy
f. 5 Wishes decision tool
g. National Task Group on ID and Dementia Care Practices Training

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.
 - 3 consultations provided in CY 2017
 - Dr. Karen Shedlack, a psychiatrist, is now contracted to provide clinical consultations to individuals who may be experiencing psychiatric issues related to aging.
 - 20 consultations provided in CY 2017
- b. Webinar development (See detail in Attachment #1)
 - Creation of educational webinars 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
 - 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.
- Creation of an "Aging with ID" link prominently displayed on DDS homepage. (<http://www.mass.gov/eohhs/gov/departments/dds/aging-with-id.html>)
- Webinar views: In CY2017, there were over 8,000 views of the webpages.

	2016		2017	
	# of Clicks		# of Clicks	
NP=Web Page or You Tube Video Not Posted in 2016	Web Page	YouTube	Web Page	YouTube
Aging with Intellectual & Developmental Disability Trainings (Main Landing Page)	387	N/A	2,386	N/A
General Aging (Landing Page)	26	N/A	485	N/A
Total General Aging	211	118	1146	629
Dementia and IDD (Landing Page)	33	N/A	513	N/A
Total Dementia	33	14	932	744
Launching a Memory Café	146	8	354	289
Adapting the Residence, Day Program and Community (Landing Page)	NP	N/A	160	N/A
Total Adaptation			353	154
Aging and Disability Resource Consortia (ADRC)	26	19	136	74
End of Life Training	119	36	1581	638
Grand total of clicks	981	195	8046	2528

- c. 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.
 - 11 Memory Cafes are currently funded
 - In calendar year 2017, an average of 18 individuals (range from 5-50) attended a memory café funded by DDS. Memory cafes met monthly, weekly or every other month, meaning memory cafes served over 480 guests in CY2017. Guests included individuals aging with I/DD and others from the general public with memory issues and their care partners.
- d. Alternative Aging Focused Day Supports (see detail in Attachment #3)
 - In calendar year 2017, DDS awarded a contract to 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, from April through December 2017, served an average of almost 16 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.
- e. DDS Life Sustaining Treatment Policy (End of Life Policy)
 - Revised and distributed new policy DDS POLICY #:2017-1 (<https://www.mass.gov/lists/dds-policies>) in calendar year 2017 to Area Offices.
- f. 5 Wishes Documents
 - 1000 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, have been distributed)
- g. National Task Group on ID and Dementia Care Practices Training
 - Planning is underway for FY18 Statewide trainings for provider staff on Dementia Friendly Care for people aging with ID by NTG State Master trainers who were trained in FY 17.

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

- a. Clinical Consultation Outcomes
 - Clarification of medication interactions and likely cause of problematic side effects, resulting in medication reduction and discontinuation. The clinical reviews

- Confirmation or clarification of diagnosis for presenting problems and identification of appropriate medication regimens
 - 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.
- b. Webinar development
- Evaluation is pending.
- c. 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)
- d. Alternative Aging Focused Day Supports
- The program offerings have increased in number and complexity and become much more customized as individuals continue to specify their unique interests.
 - Outings to the MFA, Peabody Essex Museum and the Museum of Science were some of the highlighted events. Activities include volunteerism and giving back projects to the community, crafting including soap-making and group gatherings for music and baking. 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.
 - Evening venues include live entertainment, travel presentations, stand-up comedians, book readings and wild animal education.
 - The program has been extremely well received and attended.
- e. DDS End of Life Policy
- Updated and distributed.
 - Training webinar provided
- f. 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.
- g. National Task Group on ID and Dementia Care Practices Trainings

- Trainings to be scheduled for provider staff on a Regional or Area level by nurses trained as Master trainers by the NTG in FY 2017.

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

CY17 Aging Funding Breakdown:

Clinical Consultation	\$47,500
Webinar development and release	0
Memory Café continuation	\$40,600
Alternative Aging Focused Day Supports pilot (9 months of CY17)	\$74,997
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 2017 Special Funding Initiative Participants

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

Clinical Consultation	23
Webinar development and release	8046
Memory Café continuation	337
Alternative Aging Focused Day Supports pilot (9 months of CY17)	16 a month/9 months
DDS End of Life policy	N/A
5 Wishes decision tool	1000

IV. *The implementation plans for these initiatives in fiscal year 2019 and 2020*

FY18/FY19/FY20 Planned Activities

Building on the activities and successes of calendar year 2017, DDS will be implementing the following over the next three calendar years:

- Continuation of clinical consultation resources
- Additional maintenance funding for 11 memory cafes
- Continuation and possible expansion for community-based day services innovation for aging population
- Provide statewide training re: revised End of Life policy for Area Office nurses and DDS attorneys.
- Provide regional and/or area trainings on Dementia Friendly Care for people aging with ID by newly trained NTG State Master trainers

- DDS procured funds through participation in an Administration for Community Living (ACL) Grant to support services of 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 Grant covers 9/2017-8/20. Will also identify training needs for other community providers of care like home health aides and ASAPs on Dementia Friendly Care for people aging with ID and provide the training.

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

1. Continued implementation of all activities noted above.
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
 - Memory Café funding awarded to Elder Services agencies and Councils on Aging. 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.
3. Evaluate the Alternative Aging Focused Day Supports pilot to determine feasibility and cost effectiveness of the addition of such a model past the pilot period.
4. Evaluate the geriatric nurse practitioner aspect of the ACL grant to determine the feasibility and cost effectiveness of the addition of such a model past the grant period.

Attachment #1

Webinar Counts- Detail

	2016		2017	
	# of Clicks		# of Clicks	
NP=Web Page or You Tube Video Not Posted in 2016	Web Page	YouTube	Web Page	YouTube
Aging with Intellectual & Developmental Disability Trainings (Main Landing Page)	387	N/A	2,386	N/A
http://shriner.umasmed.edu/cdder/aging_idd_education				
General Aging (Landing Page)	26	N/A	485	N/A
Understanding Age Related Changes	63	NP	114	63
The Role of Polypharmacy	43	41	67	30
Identifying and Assessing Pain	30	NP	64	34
Behavior Related Changes and Aging in Adults with IDD	NP	NP	80	118
Health Promotion and Aging in Adults with IDD	NP	17	78	49
Mobility and Aging in Adults with IDD	NP	NP	55	64
Aging with Down Syndrome	31	32	102	131
Aging and Cerebral Palsy	18	28	101	140
Total General Aging	211	118	1146	629
Dementia and IDD (Landing Page)	33	N/A	513	N/A
Early Evaluation of Dementia and Alzheimer's Disease	NP	NP	117	135
Stages of Alzheimer's Disease	NP	3	103	467
Applying the Knowledge to Dementia Caregiving and Caregiver Support	NP	6	116	64
Caregiving in Action: Case Studies and Practical Tips	NP	5	83	78
Total Dementia	33	14	932	744
Launching a Memory Café	146	8	354	289
Adapting the Residence, Day Program and Community (Landing Page)	NP	N/A	160	N/A

Adapting the Residence for Aging Adults with IDD	NP	NP	87	59
Adapting the Day Program for Aging Adults with IDD	NP	NP	46	37
Honoring Cultural Practices and Individual Preferences	NP	NP	32	19
Community Inclusion and Solutions	NP	NP	28	39
Total Adaptation			353	154
Aging and Disability Resource Consortia (ADRC)	26	19	136	74
End of Life Training				
<u>Life Sustaining Treatment Policy</u>	NP	NP	408	125
<u>Guardianship and Aging in Intellectual Disability, Part I</u>	NP	NP	258	74
<u>Guardianship and Aging in Intellectual Disability, Case Studies, Part II</u>	NP	NP	134	52
<u>Medical Orders for Life Sustaining Treatment (MOLST)</u>	NP	NP	349	175
<u>End of Life Definitions</u>	NP	NP	155	N/A
<u>Five Wishes</u>	119	36	277	212
Total End of Life	119	36	1581	638
QINA Aging Brief	NP	N/A	21	N/A

Attachment #2

Memory Café Evaluation

Organizations Awarded Continued Funding for Integrated Memory Café through RFR

1. Cambridge Family and Children's Service, Cambridge
2. Conch Shell Counseling, Falmouth
3. Division of Andover Elder Services, Andover/Lawrence
4. Martha's Vineyard Center for Living, Martha's Vineyard
5. MaryMac Missions, Topsfield
6. Middleborough COA, Middleborough
7. New England Village, Pembroke
8. People, Inc., Fall River
9. RTR (Express Yourself), Marshfield
10. The Arc of Bristol County, Attleboro
11. UCP of Metro Boston, Watertown

Evaluation of 11 Memory Cafes

All 11 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 Director	3
Memory Café Coordinator	3
Program Director	3
Vice President	2

Respondents Primarily Work with:

People with disabilities	5
Older adults	4
Both	2

Frequency and Location

How often respondents held café:

Once a month	7
Once a week	1
Every other month	1
9 times per year	1
Weekly for 7 months of year	1

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

Same number	6
Increase	4
Decrease	1

Where are you holding café?

Senior Centers	3
Public Library	2
Community Organizations	2
Human Services Agency	2
Social enterprise space & travel to assisted living facilities	1
Garden	1

Participants & Guests

Number of Guests:

Average number of guests each cafe (including care partners)	Reported Range 5-50 guests (Mean: 17.2/median: 13)
Total number of guests for 2017 (including care partners)	Reported Range 10-85 guests (Mean: 43.7/median: 40)

Number of Events Attended by People eligible for DDS Services:

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

How many people who are DDS eligible attended the memory cafe with care partners that were Staff, Family, or Friends?

	Number of Respondents	Number of Participants
Staff	11	89
Family	8	14
Friends	6	7

Integrated Participants

How did you integrated the two groups of participants (DDS eligible and not) (check all that apply)

Activities that brought group together (i.e., drum circle)	9
Outreach to both groups	9

Holding the café in a “neutral location”	6
Ice breakers	5
Force movement around the room (i.e., supplies at different tables)	4
People search out activity they enjoy (no matter who is in group)	4
Other: Have difficulty reaching typical elder community, all attendees DDS, Do not identify the separate groups	2
Serve lunch before café	1

Activities:

Types of activities hosted: (check all that apply)

Music	11
Art	10
Movement (i.e., dance, yoga)	9
Open Discussion (i.e., physicians, museum docents)	6
Animal Programs	6
Lecture	4
Other: relaxation exercises, holiday event with Santa, visit community venues (farm), day at the circus, tea party, make thank you cards	4
Outdoor Activities (i.e., garden)	2

Least effective activities:	Reason
Lectures	Not as participatory
Some art activities	People feel they don't have “skills”
Animal programs	
Community site visit	Not as many participants
May depend on the participants for the day	Participants not feeling well, some don't like noise

Most successful activities:	Reason
Music, sing along, movement, art	Activities that are hands on, move from language to sensory
Santa visit, circus event, animal visits, some site visits (involve activity)	
Four respondents reported that all activities they tried were successful.	

Feedback and Outcomes

How collecting feedback (check all that apply):

Interviews	5
Paper Surveys	4
Other: through group discussion, observation, open door policy	3
Do not currently collect feedback	2
Guest Book (attendees add comments)	1
Poster (attendees write comments/attach stickies' on Poster)	1
Email Surveys	0
Phone Surveys	0

What is Important:

	Extremely Important	Very Important	Important	Somewhat Important	Not Important
Guests treated with respect	11	0	0	0	0
Has welcoming volunteers/staff	10	1	0	0	0
Is accessible	10	1	0	0	0
Focuses on abilities, not on disabilities or diagnosis	9	2	0	0	0
Decreases social isolation	8	2	1	0	0
Has creative activities	6	5	0	0	0
Offers something for family members or friends to do together	5	4	2	0	0
Respite for care givers	5	2	3	0	1

One respondent indicated that the café created a sense of community. Another respondent indicated that even though most people attended with staff and respite was not a priority, they staff still appreciated the relaxed atmosphere.

Successes & Challenges

What worked for the inclusive memory cafe:

Universal topics such as music, making something together (art), museum conversations, talk on brain functions
Having plans for each cafe is helpful, guest artists that have an understanding of our purpose and that have worked with people who are experiencing memory loss, being flexible also key.
It has been a great experience and opportunity for individuals with I/DD and their caregivers to interact with others who are in similar situations.
The participants have enjoyed the opportunity to come out to an event designed to accommodate their needs.

Families and caregivers definitely appreciate program
Having Cafe guests be part of choosing activities
We have a large space so that works well because we can meet as a group in a circle and still break out into small groups
Support from the area DDS office
Listening to guest desires, The 10' long wheelchair-accessible picnic table, which was purchased with 2016 Memory Cafe funding, and the new Pear Tree Patio (which we funded) was a huge success. Outdoor Portable Bathroom was renewed based on 2017 Memory Cafe funding

Challenges for the inclusive memory cafe:

Advertising for more members of the community to attend
Staff challenges: Staff changes without agency explaining philosophy to all staff, standing at back of room and not participating, shift change during Cafe or arriving over 1/2 hour late to Cafe. Sometimes if a "program" attends, they do not send enough staff so we have learned to provide additional staff to help. For example, a local rest home
Having to use someone else's space, set up and break down each week, carry supplies back and forth.
Attracting diverse group: Building attendance, participation by typical elders from the community, we have been successful in attracting individuals with DD and have one gentleman from the community who attends with his wife; our challenge continues to be attracting individuals supported by DDS who are experiencing memory issues; learning from our experience hosting mixed population garden parties ~ our experience has tended to be that groups stay with their group, and families stay with their family
Challenges have been specific to individuals such as one participant has not participated for a while due to medical issues or at times a participant may refuse to leave their home even though when at the cafe has a great time
Timing of the cafe, have not found the perfect time yet

Attachment #3

Alternative Aging-Focus Day Supports

Number of Regular Participants by Month:

Apr	14	Sept	16
May	15	Oct	16
Jun	15	Nov	17
Jul	16	Dec	17
Aug	17		

Average monthly participation: 15.88 participants

Cost per participant: \$4,723 (9-month period)

At launch, the program offerings were still in the early stages of development. Once established, the Aging Day Supports program attracted more participants through peer word-of-mouth and encouragement from staff. The program also served seniors who were home from day programs on various Monday holidays; their participation was excluded from the group of regular participants above.

There does not appear to be a correlation between number of annual incidents reported and the level of daily engagement of the participant group. In reviewing the incident reports, nearly all reports were due to individuals in need of emergency medical treatment. Given the age of the participant group, an increase in medical complications is to be expected. Note: one participant began participation in April as a hospice patient and passed away in June. However, his frequency of engagement increased during that brief time period.