



Report on Interdisciplinary Memory Assessment Clinics (Item 332)

December 1, 2016

***DARS Vision: Supporting Virginians' efforts to secure independence
and employment***

Report on Interdisciplinary Memory Assessment Clinics

Preface

Item 332 of the 2016 Appropriations Act requires the Department for Aging and Rehabilitative Services to report on its progress towards implementing the “Interdisciplinary Memory Assessment Clinics with Dementia Care Management” as described in the Dementia State Plan.

P. The Department for Aging and Rehabilitative Services shall report on its progress toward implementing the “Interdisciplinary Memory Assessment Clinics with Dementia Care Management” (IMACDCM) as described in the Dementia State Plan. The report shall include the outcomes of the federal “Family Access to Memory Impairment and Loss Information, Engagement and Supports” (ADSSP grant), the “Dementia Specialized Supportive Services Project” (ADI-SSS grant) and any other relevant data with recommendations for further implementation of IMACDCM. The department shall consult with relevant stakeholders in preparing the report. The department shall provide the report to the Chairmen of the House Appropriations and Senate Finance Committees on December 1, 2016.

Report on Interdisciplinary Memory Assessment Clinics

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Executive Summary

The Department for Aging and Rehabilitative Services has been awarded \$1.68 million in federal funding to implement three programs (counseling, care coordination, and education). Collectively the three programs form the core specialized services of an interdisciplinary Memory Assessment Clinic, which can diagnose and treat dementia while offering care coordination and specialized services for both the patient and their caregiver. Grant funding has provided the opportunity to pilot and adapt these programs, and ultimately lay the foundation for establishing regional Memory Assessment Clinics.

Current estimates indicate 140,000 individuals aged 65 and older are living with Alzheimer's disease in Virginia and 455,000 caregivers provide assistance to a loved one with dementia. According to national averages older adults with dementia require 171 hours of care per month in comparison to the 77 needed by older adults with other chronic conditions. Often caregivers feel overwhelmed by the responsibility and desperately need support. Regional Memory Assessment Centers can provide this support and assist persons with dementia to age in their environment of choice. Current federal funding will be exhausted by the end of February 2018.

Over the last two years, 130 caregivers of persons with dementia have been enrolled in the counseling program, which includes meeting with a counselor for six sessions. Of the six sessions, four of them include family members and friends. These sessions are important to establish a support system for the caregiver and find ways to distribute the caregiving responsibilities. Caregivers also discuss issues and challenges they are encountering and receive guidance. *The caregivers have experienced fewer symptoms of depression, feel less burdened, visit their physician less often, and feel they have been able to keep their loved one at home longer.*

Since the spring of 2016, 47 persons newly diagnosed with dementia enrolled in the care coordination program. A Dementia Care Manager helps the participant to understand their condition and know what to expect. Depending upon the unique needs of the participant or their caregiver the manager may help them apply for Medicaid, arrange for the participant to attend an adult day center, or assist them in joining support groups. Additionally, seven residents with dementia residing in an independent living community have participated in a 10-week educational program. Sessions are devoted to teaching the participants effective strategies for coping with their condition. Topics include memory strategies, financial resources, planning for the future, fall prevention, medication management, exercise, managing health, assistive devices, social engagement, talking to people about dementia, and home safety.

Outcomes for the care coordination and education programs are not available at this time. However, *anticipated outcomes include fewer symptoms of depression, a decrease in the use of unplanned or emergency healthcare, an increase in steps taken to prepare for the dementia, and an increased understanding of strategies to cope with changes in memory.*

The three programs described in this report have served a collective total of 187 participants and are designed to support persons with dementia to live in the community longer and to decrease the burden felt by their caregivers. *If the care recipients of the participating caregivers and the*

participants with dementia were delayed from residing in a nursing facility for only 2 months, it would save approximately \$2.5 million. The Alzheimer's Disease and Related Disorders Commission recommend the 2017 General Assembly support the development and funding of interdisciplinary Memory Assessment Clinics with Dementia Care Managers.

Introduction

Since September of 2014 the Department for Aging and Rehabilitative Services (DARS) has been awarded \$1.68 million in federal funding from the Administration for Community Living to support persons with **dementia** and their caregivers through the implementation of innovative programs. Collectively the three programs described in this report (counseling, care coordination, and education) form the core specialized services of an **interdisciplinary** Memory Assessment Clinic. A Memory Assessment Clinic can properly diagnose and treat dementia while offering care coordination and specialized services for both the patient and their caregiver. To date, seven Memory Assessment Clinics have been identified in Virginia, which are already diagnosing and treating persons with dementia and with additional resources could offer specialized services.

Grant funding has provided the opportunity to pilot and adapt these programs, and ultimately lay the foundation for establishing regional Memory Assessment Clinics in the future. Appendix A includes a complete list of participating organizations and acknowledges stakeholder contributions to the report. Virginia's Dementia State Plan¹ sets the goal of providing access to quality coordinated care for individuals with dementia in the most integrated setting. This goal calls for the creation of *statewide interdisciplinary memory assessment centers* with specialized services for individuals with dementia and their caregivers from assessment and diagnosis through end-of-life. For a visual representation of this goal visit Appendix B.

¹2015-2019 Dementia State Plan: Virginia's Response to the Needs of Individuals with Dementia and their Caregivers

<http://leg2.state.va.us/DLS/h&sdocs.nsf/5c7ff392dd0ce64d85256ec400674ecb/038b0d48417df2de85257ed1004a427f?OpenDocument&Highlight=0.dementia>

Why does Virginia need Memory Assessment Centers?^{2,3}

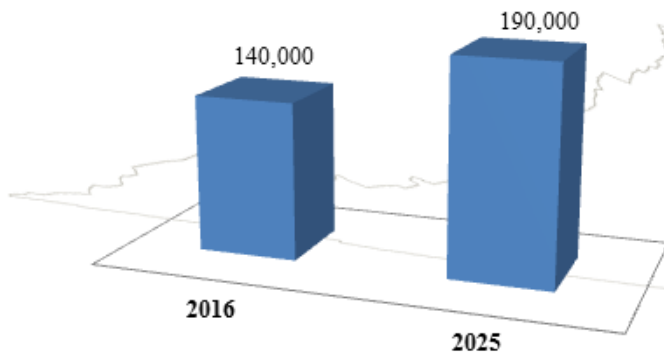


1 in 9 adults aged 45 and older are experiencing worsening memory loss or confusion

140,000

Older adults aged 65 and older currently living with Alzheimer's disease

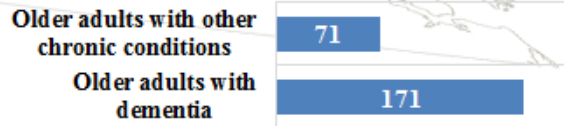
Projection of older adults aged 65 and older living with Alzheimer's disease



455,000

Number of caregivers providing care for a loved one with dementia

Hours of care per month (national estimate)



519,000,000

Hours of unpaid care provided by caregivers in 2015 with an estimated economic value of \$220 billion

The number of individuals and families affected by dementia in Virginia is immense and will only continue to grow. Caring for a person with dementia is very time intensive. Often caregivers feel overwhelmed by the responsibility and desperately need support as they try to keep their loved one living in the community. Regional Memory Assessment Centers can provide this support and assist persons with dementia to age in their environment of choice for as long as possible. Current federal funding will be exhausted by the end of February 2018.

Bolded words are defined in Appendix C.

² 2013 Behavioral Risk Factor Surveillance System, Virginia Department of Health

³ 2016 Alzheimer's Disease Facts and Figures, Alzheimer's Association

Program Overviews

Counseling Program (FAMILIES)

FAMILIES: Family Access to Memory Impairment and Loss Information, Engagement and Supports

Caregivers of persons with dementia have the opportunity to meet with a trained counselor for a total of six, one to one and a half hour sessions. During these sessions the caregivers discuss issues and challenges they are encountering and receive guidance from a professional. For example, caregivers often need help understanding behavior changes and knowing how to react. Behavior changes might include repeating questions, **wandering**, sadness, agitation, confusion, suspicion, and aggression. Out of the six sessions, four of them include family members and friends.

These sessions are important to establish a support system for the caregiver and find ways to distribute the caregiving responsibilities onto a small network of people rather than the role being fulfilled by only one person. Outside of the counseling sessions the caregivers have the opportunity to contact the counselor if they encounter a crisis or if the individual who they are caring for experiences sudden changes. Caregivers also attend weekly or monthly support groups in their community. In addition, caregivers attend a follow-up visit six months after their last counseling session. **Respite care** is arranged for caregivers through partnerships with home care agencies or **adult day centers**, when needed, so they are able to participate in the program.

Care Coordination Program

Individuals who have received a diagnosis of dementia within the last six months are assigned to one of two Dementia Care Managers upon enrolling in the program. The participant is asked to identify their primary caregiver and they are also enrolled (the absence of a caregiver does not prohibit enrollment). After enrollment the Dementia Care Manager visits the participant's home to perform an assessment and identify areas where support is needed. Subsequent encounters are devoted to providing the participant and their caregiver with information and connecting them to resources.

The Dementia Care Managers help the participant to understand their condition and know what to expect, including personality or behavior changes that may occur and planning for the future. Participants are encouraged to designate a Power of Attorney and create a living will. Depending upon the unique needs of the participant or caregiver the Dementia Care Manager may help them apply for Medicaid, arrange for the participant to attend an adult day center, or assist them in joining support groups.

Participants are called by their Dementia Care Manager once a month and communication also occurs in between depending on the needs of the participant and their caregiver. The Dementia

Care Managers may also accompany the participants and their caregivers during visits with their healthcare providers. Participants will enroll in the program for a minimum of one-year. At the end of one-year they will participate in an assessment to determine the impact of the program and then offered the opportunity to continue receiving support from their Dementia Care Manager.

Education Program (ESP)

ESP: Effective Strategies Program.

Residents of independent living communities with dementia are invited to participate in a 10-week educational program. Caregivers are also encouraged to participate. Participants attend two one and a half hour sessions per week (total of 20 sessions) held on-site at the community. Each session is devoted to teaching the participants effective strategies for coping with and managing their condition. Session topics include memory strategies, financial resources, planning for the future, fall prevention, medication management, exercise, managing health, assistive devices, social engagement, talking to people about dementia, and home safety. Professionals, including Neuropsychologists, Physical Therapists, Occupational Therapists, Neurologists, Art Therapists, Nurses, Social Workers, and Speech Therapists, deliver a one-hour interactive, educational session and then spend an additional 30 minutes with the participants. Food is provided to allow time for socializing and bonding.

Progress and Preliminary Outcomes

Counseling Program (FAMILIES)

Over the last two years (September 2014 – August 2016), 130 caregivers living in the Charlottesville and Williamsburg areas have been enrolled in FAMILIES. Of these 130 caregivers, 66 have completed all six counseling sessions. Counselors have delivered 668 hours of counseling.

Preliminary outcomes include:

Caregivers exhibited fewer symptoms associated with clinical depression after the sixth session. Symptoms of clinical depression continued to decline at the six-month follow-up. Symptoms of caregiver burden decreased and continued to decrease from the end of the sixth session to the six-month follow-up. Caregivers experienced an improvement in their reactions to challenging behaviors (e.g., difficulty concentrating, repeating the same question, losing or misplacing objects, threatening self-harm, appearing sad or depressed). Also, caregivers visited their physician less often during participation in the program and at the six-month follow-up.

The majority of caregivers reported satisfaction and multiple positive benefits from participation in the program. These include:

- Plan on using the information provided.
- Able to keep the person with dementia in the home.
- Able to access new services for the person with dementia.
- Able to access new services for themselves.
- Learned coping skills.
- Experienced improved mood.
- Experienced improved health.
- Have more support.
- Program had a positive impact on them.
- Would recommend the program to someone else.

Quotes from FAMILIES participants:

“... [it gave me] the opportunity to discuss ‘feelings’ about my situation that I would not normally do.”

“Made me understand that I was not in this thing alone.”

“This program has been a blessing. Nothing I would change.”

“Good advice and friendship. A safe, supportive space.”

Care Coordination Program

From September 2015 – August 2016, 47 persons newly diagnosed with dementia were enrolled in the program and reside in various locations across the Commonwealth. All 47 participants identified a primary caregiver who was also enrolled. The Dementia Care Managers have noted that the monthly calls seem to reduce the number of crisis or emergency situations the participants encounter. Participants have been frequently interested in support groups, adult day centers, and in-home care. The following case study provides an example of the immense impact having access to a Dementia Care Manager can have for a participant and their caregiver.

Case study:

The participant is a 67-year-old woman with younger onset Alzheimer’s disease (diagnosed before the age of 65) who is cared for by her husband, a 69-year-old man who continues to work full-time from home. The participant has declined rapidly and is quite impaired with a complex medical history including diabetes, thyroid issues, and depression. She needs help with activities such as eating, bathing, dressing, and walking. Her husband provides care full-time and when they enrolled in the Care Coordination Program only had sporadic assistance from in-home aides.

Through their participation in the Care Coordination Program the Dementia Care Manager was able to help them obtain a wheelchair at no charge and to refer the participant to an adult day center where respite care is also provided at no charge. Due to the participant’s level of impairment, without the care of her husband and community-based supports, the alternative would be placement in a nursing facility. However, as a result of the program the husband has been able to obtain the assistance he needs to provide care to the participant safely at home, which is their environment of choice. To date, the program has been able to help avoid unnecessary emergency room visits, fulfilled medical needs, and supported the caregiver in his ability to continue working and provide full-time care by coordinating outside supports, as needed.

Education Program (ESP)

From September 2015 – August 2016, seven persons with a diagnosis of dementia, residing in an independent living facility in the Charlottesville area, were enrolled in the program. Six out of the seven participants live alone, so the program has been able to reach a vulnerable population at risk for social isolation and lack of support, which can lead to poor health outcomes. Participants are forming new relationships with the other residents and enjoy the opportunity to discuss what they are experiencing with individuals who will understand.

At this time, there are no preliminary outcomes available for the care coordination and education programs. Preliminary outcomes for the Care Coordination Program will be available beginning in the summer or fall of 2017 when the initial group of participants completes their one-year assessment, which will be compared to the assessment conducted at their enrollment. Outcomes for the Effective Strategies Program will be available in 2018 when the target of 60 to 80 participants has been reached. Participants complete a pre and post assessment, which will be

used to determine outcomes. A larger sample size is required before analysis of the outcomes can occur. *Anticipated outcomes for the Care Coordination and Effective Strategies programs include fewer symptoms of depression, a decrease in the use of unplanned or emergency healthcare, an increase in steps taken to prepare for the dementia, and an increased understanding of strategies to cope with changes in memory.*

Conclusion

The three programs described in this report have served a collective total of 187 participants. They are designed and intended to support persons with dementia to live in the community longer and to decrease the burden felt by their caregivers. If the care recipients of the participating caregivers and the participants with dementia were delayed from residing in a nursing facility for only 2 months, it would save approximately \$2.5 million. This estimate is based on the median annual rate for a semi-private room in a nursing facility in Virginia (\$80,483 annually or \$6,707 per month) as reported by the 2015 Genworth Cost of Care Survey. The Alzheimer's Disease and Related Disorders Commission recommend the 2017 General Assembly support the development and funding of interdisciplinary Memory Assessment Clinics with Dementia Care Managers.

Appendices

A. Participating Organizations and Acknowledgements

Counseling Program (FAMILIES)

Charlottesville Area:

University of Virginia, Memory and Aging Care Clinic
Central and Western Virginia Chapter, Alzheimer's Association
Jefferson Area Board for Aging (*local Area Agency on Aging*)

Williamsburg Area:

Riverside Center for Excellence in Aging and Lifelong Health
Southeastern Virginia Chapter, Alzheimer's Association
Peninsula Agency on Aging (*local Area Agency on Aging*)

Care Coordination and Education Programs

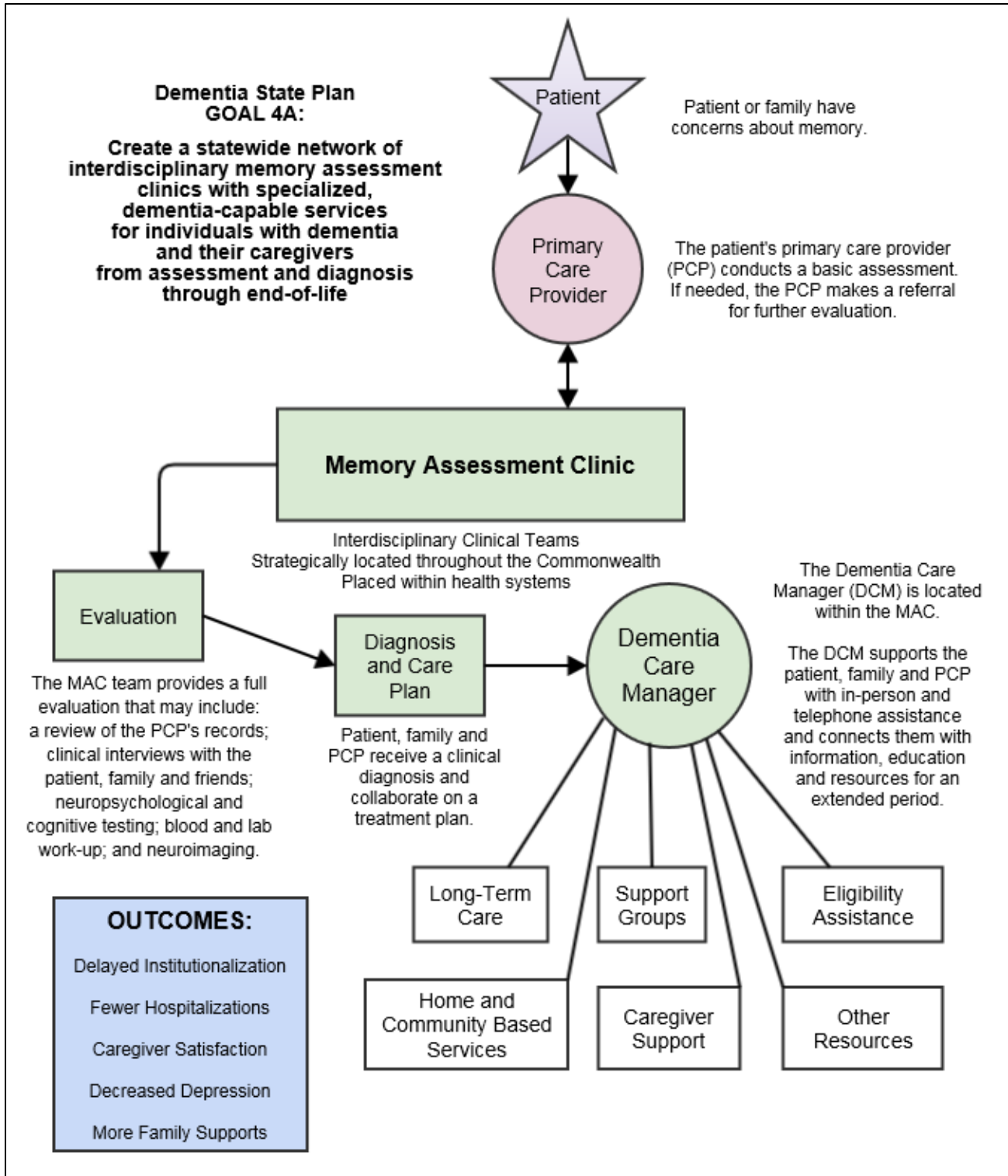
University of Virginia, Memory and Aging Care Clinic
Jefferson Area Board for Aging

Acknowledgements

Information and input for the report was collected from the participating organizations listed above and the Alzheimer's Disease and Related Disorders Commission, including the Coordinated Care Work Group.

DARS staff for the report included Devin Bowers, Dementia Services Coordinator.

B. Regional Memory Assessment Clinic Model



C. Definitions

Adult Day Center

Adult Day Centers are a community-based, non-residential service that supports the health, nutritional, social, emotional, cognitive, recreational and daily living needs of adults in a professionally staffed, protective group setting for individuals who cannot be left alone during the day.⁴

Dementia

Dementia is a term used to refer to a collection of neurodegenerative diseases, which affect cognitive abilities and memory. These neurodegenerative diseases include Alzheimer’s disease, frontotemporal dementia, vascular dementia, and Lewy body dementia. Over time individuals with a form of dementia experience changes in memory, thought, navigation, language, behavior, mood and personality. Due to the debilitating nature of these diseases, care from family members and friends and/or paid care is required to assist with activities such as meal preparation, taking medications, housework, money management and eventually eating, toileting, and bathing.

Interdisciplinary

The patient is cared for by an interdisciplinary team consisting of Neurologists, Neuropsychologists, Nurse Practitioners, Social Workers, Occupational Therapists, Physical Therapists, and Care Managers.

Respite Care

Respite care is the provision of short-term, intermittent, temporary relief to those who are caring for family members who might otherwise require permanent placement in a facility outside the home. Respite programs provide planned short-term and time-limited breaks for families and other unpaid care givers.⁵

Wandering

Wandering is meandering, aimless, or repetitive locomotion and can be goal-directed or non-goal directed. During goal-directed wandering the person appears to be searching for someone or something. Non-goal directed wandering is aimless with no apparent objective. Persons who wander are at risk for elopement, meaning they may try and succeed in leaving their place of residence without supervision and go unaccounted for an extended period of time. Elopement can be extremely dangerous due to exposure to weather (including extreme heat and cold), dehydration, starvation, lack of medication, and risks posed by streets or highways.⁶

⁴ 2015 – 2019 Dementia State Plan: Virginia’s Response to the Needs of Individuals with Dementia and their Caregivers

⁵ 2015 – 2019 Dementia State Plan: Virginia’s Response to the Needs of Individuals with Dementia and their Caregivers

⁶ National Council of Certified Dementia Practitioners, Wandering and Elopement Resources, <https://www.nccdp.org/wandering.htm>