

February 2013

Vermont Choices for Care: Alzheimer's Disease and Related Disorders

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Executive Summary

Alzheimer's disease and related disorders (ADRD) currently affect over 11,000 Vermont residents (Alzheimer's Association- Vermont chapter, 2011). In Vermont, ADRD is ranked seventh as the leading cause of death (Stevens, 2009). Vermont's population of individuals aged 65 years and older is expected to increase (Stevens, 2009) and the proportion of 85+ will increase dramatically as well (Houser, Fox-Grage & Ujvari, 2012). The number of individuals diagnosed and living with ADRD is expected to increase together with the aging of the population. With this demographic imperative coupled with Vermont's evolving health care system's reform efforts and the Blueprint for Health, Vermont Department of Disabilities, Aging and Independent Living (DAIL) asked the University of Massachusetts Medical School (UMMS) Evaluation Team to analyze the effectiveness of Vermont's Choices for Care (CFC) Program in providing services that meet the needs and preferences of eligible individuals with ADRD in all CFC settings (nursing facilities, Enhanced Residential Care [ERCs] and Home and Community-Based Services [HCBS]). Specifically, DAIL is focused on the following areas of interest related to individuals with ADRD and the services and settings provided by CFC:

- a) Service design
- b) Service planning
- c) Service delivery
- d) Use of psychotropic medications
- e) Use of behavioral supports
- f) Worker training and support
- g) Informal caregiver training and support

To conduct the analysis, the Evaluation Team interviewed over eighty stakeholders using an interview guide based on the above areas of interest, performed literature scans and reviews of relevant Vermont documents, and reviewed policies and programs from other states and agencies. From this information, the Evaluation Team summarized the benefits and challenges that CFC and the state of Vermont face when working with individuals with ADRD and their families. Many of these benefits and challenges relate specifically to CFC; others, including the training, supports and medication areas, are more global in scope and should be understood as the responsibility of other stakeholders (providers, facilities, Alzheimer's Association, Governor's Commission, and so on) with the support of DAIL and CFC. This information also shows the commitment and interests of stakeholders, agencies and providers to work towards a system which better meets the needs of Vermonters with ADRD and their families. It is important to understand that many of the challenges noted below are not specific to Vermont, but represent challenges to other states and the nation.

Some of the CFC-specific benefits include choice and options; availability of 24 hour care options in facility settings; and the expected implementation of Adult Family Care, an HCBS option, allowing CFC to meet the challenge of providing "close to" 24 hour care in HCBS settings (supporting informal caregivers who provide the majority of care). Other benefits involve the regular assessment of care needs and the integrated role of individuals and family members in care planning across the continuum of care. CFC also has specific benefits for individuals with ADRD related to behavioral supports which include the 1:1 care individuals can receive in Adult Day Programs and HCBS as well as the fact that case managers can act as information resources. CFC is effective in the current continuum of care for individuals with ADRD in certain 24 hour care settings such as ERCs and nursing facilities with a specific focus on ADRD. Overall, the quality of CFC services was reported as good to excellent.

However, there are challenges for CFC in providing services for individuals with ADRD. CFC's current HCBS options, which are typically unable to provide 24 hour care, are limited in their effectiveness and must rely on family/informal caregiver support to provide the majority of the care (a concern for Vermont and nationally, especially when an increased burden on informal caregivers necessitates facility placement). So, while choice is an asset for participants, when "close to" 24 hour care was needed by individuals with ADRD, there was a winnowing of choice to only facility options. This situation may change with the anticipated full implementation of Adult Family Care. Other challenges specific to CFC include the fact that the cognitive assessments in the Independent Living Assessment are not robust for service planning and that the process for requesting a variance in service plan hours is unclear. Additional CFC challenges are maintaining continuity of care when transitioning from non-medical providers, limited transportation and a reluctance to accept services due to fear, denial and stigma.

As a state, Vermont has several benefits along with specific challenges for individuals with ADRD. Prime among the benefits are coordination and collaboration across the provider networks including Aging and Disability Resource Connection and 211, and the community-mindedness of rural culture. Psychotropic medications are seen as a last resort for some Vermont facility and HCBS respondents, with *OASIS* training curriculum being implemented in nursing facilities as a way to promote cultural change and to train staff regarding alternatives to and the proper use of medications. Training was noted as both a benefit and a challenge. All provider organizations provide some ADRD training; these organizations are interested in working together to share best practices. Information and supports are available from many provider organizations for informal caregivers. Psychotropic medications may not be a last resort for all facilities, a challenge both Vermont and the nation face. There is a lack of training for HCBS staff and families on the use of these medications. Additionally, there is insufficient information about non-medication supports for HCBS staff and families. Providers seem challenged by several aspects of training such as a lack of mandated training, no standard or common training and a fragmented awareness of training. Families are often not aware of appropriate trainings or are not able to access the trainings.

The Evaluation Team was struck by the breadth and depth of programs related to ADRD currently being offered across Vermont and of benefit to CFC participants with ADRD; this finding highlights a critical mass of interested organizations and individuals in Vermont primed for next steps related to ADRD. One area identified for improvement was training. While the Evaluation Team found evidence of a wide range of training being conducted in many venues and modalities, there was unevenness and a lack of consistency across these venues and modalities for paid staff and family caregivers, representing an opportunity for improvement.

Given the findings, Choices for Care and DAIL have some specific opportunities to increase the effectiveness of its services for eligible individuals with ADRD and their families. There are also several specific strategies the state of Vermont can implement, with the support of stakeholders, to assist Vermonters with ADRD, whether or not eligible for CFC. This multiple pronged approach will leverage each stakeholder's expertise to address the myriad of challenges presented by ADRD for all settings, providers and payers. To assist with strengthening ADRD services, the UMMS Evaluation Team is recommending the following for CFC and DAIL specifically and for Vermont in general (chart on next two pages for ease of distribution).

ADRD Recommendations

Focus Area	CFC-specific recommendations	Vermont recommendations
Service Design and Delivery	<ul style="list-style-type: none"> • Complete the launch of Adult Family Care. • Explore ways to assess and to allocate hours for services which include validated tools and pilot tests. • Investigate residential habilitation and supportive living options, and technological approaches to allow the creation of “closer to” 24 hour care in the community for CFC. • Review and modify instructions and guidance for requesting variances. • Allow non-medical providers to perform reimbursable services as a policy change (see Cumings & Bruner-Canhoto, 2012) for ongoing continuity of care and to assist in the filling of service hours. • Explore the provision of additional and flexible services by Area Agencies on Aging (AAAs) for Moderate Needs individuals with ADRD and their families. • Consider reinvestment of CFC funds across all care settings. 	<ul style="list-style-type: none"> • Create best practice forums for providers and stakeholders (Alzheimer’s Association, Governor’s Commission among others) to work together and with CFC around the following issues: <ul style="list-style-type: none"> ○ innovative service delivery options, include dementia care management and other evidence-based practices (see findings) ○ strategies for filling service plan hours (such as creating dedicated schedulers) ○ screening, assessment and eligibility determination processes ○ technological approaches ○ support group organization ○ training (see below recommendations). • Expand Adult Day Programs throughout the state.
Service Planning	<ul style="list-style-type: none"> • Encourage case management agencies and other stakeholders (such as AAAs and the Alzheimer’s Association) to develop toolkits and materials to facilitate contingency, financial and advanced care directive planning for individuals with ADRD and their families. 	<ul style="list-style-type: none"> • Create toolkits and materials to encourage contingency, financial and advanced care directive planning for individuals with ADRD and their families.
Use of Psychotropic Medications	<ul style="list-style-type: none"> • Support and encourage the dissemination of <i>OASIS</i> and medication management training to a variety of settings. • Work with the HHAs and other stakeholders to review the role of nurses to assist individuals with ADRD and family members with medication management in HCBS settings. 	<ul style="list-style-type: none"> • Continue the dissemination of <i>OASIS</i>. • Explore medication management training for other settings, including ERCs and Assisted Living facilities. • Use best practice forums to offer training regarding cause and effect of psychotropic medications including Train the Trainer models for HCBS nurses to build confidence related to psychotropic medications in HCBS settings. • Create specific training materials and modalities for primary care physicians and medical professionals on psychotropic medications and ADRD and other topics.

Focus Area	CFC-specific recommendations	Vermont recommendations
Use of Behavioral Supports	<ul style="list-style-type: none"> Participate in a workgroup with providers and stakeholders (including DMH, VDH, DDS and DVHA) to identify strategies to better meet the needs of the ADRD population in Vermont by shifting the culture away from behavior management toward person centered planning. 	<ul style="list-style-type: none"> Initiate and participate in workgroup to identify strategies to better meet needs for individuals with ADRD by shifting the culture away from behavior management to person centered planning for ADRD population in Vermont. Workgroup to include AAAs, HHAs, other providers/facilities, Governor's Commission, DAIL, DDS, DMH, VDH and DVHA. Use best practice forums to disseminate specific programs and trainings that are working on small scales (including providing information about resources for adaptive equipment and evidence-based practices as noted in the findings). Offer more 1:1 caregiver support for behavioral issues through care management, caregiver specialists and/or behavioral consultants in the home.
Worker Training and Support	<ul style="list-style-type: none"> Participate in the development of training as appropriate as a part of the workgroup (see recommendations in next column). 	<ul style="list-style-type: none"> Establish a statewide ADRD training workgroup (with AAAs, HHAs, other providers/facilities, Governor's Commission, DAIL, DDS, DMH, VDH and DVHA), perhaps facilitated by the Alzheimer's Association, to: <ul style="list-style-type: none"> Manage best practice forums (noted above) Establish basic expectations around ADRD knowledge for all staff Explore the creation of an annual statewide ADRD conference for staff Create regular telephonic ADRD informational/learning sessions for paid staff, potentially using the Evaluation Team's recruitment strategy of placing a notice for such calls in paychecks.
Informal Caregiver Training and Support	<ul style="list-style-type: none"> Provide CFC-specific materials as requested by providers and stakeholders developing public awareness vehicles around ADRD (see recommendations in next column). 	<ul style="list-style-type: none"> Work to develop various types of public awareness vehicles around ADRD including brochures, newspaper articles, public service announcements, internet materials, public access television programs and face to face workshops (see Vermont State Plan on Dementia). Work with the Blueprint's Community Health Teams to increase awareness of ADRD.

Introduction

The purpose of this Policy Brief is to analyze the effectiveness of Vermont's Choices for Care (CFC) Program in providing services that meet the needs and preferences of individuals with Alzheimer's disease and related disorders (ADRD) in all CFC settings (nursing facilities, Enhanced Residential Care [ERCs] and Home and Community-Based Services [HCBS]). Specifically, the Vermont Department of Disabilities, Aging and Independent Living (DAIL) is focused on the following areas of interest related to individuals with ADRD and the services and settings provided by CFC:

- a) Service design
- b) Service planning
- c) Service delivery
- d) Use of psychotropic medications
- e) Use of behavioral supports
- f) Worker training and support
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Although the primary focus is CFC, there is recognition that the provision of services to individuals with ADRD and their families encompasses a wide range of state and community-based providers beyond those which are available through CFC; therefore throughout this report, this reality will be reflected in the comments shared by respondents and the recommendations. Additionally, Vermont's overall health care reform, including its efforts to establish a single payer system and its on-going implementation of the Vermont's Blueprint for Health, also contributes to the context of this report. As a result, the policy recommendations will identify actions which can be taken by CFC and also by the state of Vermont (in general) and other state and community-based organizations.

As the population ages, the prevalence of Alzheimer's disease and related disorders has increased and is expected to increase drastically (Tilly, Wiener, Gould & O'Keeffe, 2011). Even though ADRD is not a "normal" stage of aging, advancing age is a risk factor for Alzheimer's disease; as the elder population increases, so will the numbers of individuals affected by ADRD (Tilly et al., 2011). Currently, at least 5.4 million Americans of all ages have Alzheimer's disease, the most common type of dementia (Tilly et al., 2011). By 2025, it is anticipated that 6.7 million people 65 years and older will have Alzheimer's disease (Alzheimer's Association, 2012).

Recognizing the current and future impact of ADRD, the federal government has taken several actions. Two such actions are: 1) in 2011, Medicare made available a new benefit of an annual cognitive evaluation for beneficiaries (Andrews, 2010), and 2) President Obama signed the National Alzheimer's Project Act into law on January 4, 2011 (US Department of Health and Human Services, 2012). The law requires the Secretary of Health and Human Services to establish the Advisory Council on Alzheimer's Research, Care and Services to develop a national plan on Alzheimer's disease and to monitor its implementation (US Department of Health and Human Services, 2012). Although these actions shape policy, for individuals with ADRD and their families, it is access to local services which determines their quality of life.

Today in Vermont, over 11,000 residents are diagnosed with ADRD (Alzheimer's Association- Vermont chapter, 2011). In Vermont, ADRD is ranked seventh as the leading cause of death (Stevens, 2009). An additional piece of the demographic picture is Vermont's population of oldest old, 85+, who are most at risk for ADRD. Currently, Vermont is ranked 10th in the United States for the proportion of 85+ individuals (2.3%), which is already higher than

the national average of 2.0%. This proportion is projected to more than double by 2050 to 5.8% (Houser, Fox-Grage & Ujvari, 2012). Given that age is a primary risk factor for ADRD, the number of individuals diagnosed and living with ADRD in Vermont is expected to increase together with the aging of the population.¹

Vermont is also implementing the Blueprint for Health (<http://hcr.vermont.gov/blueprint>), which includes chronic disease management initiatives that may have the potential to impact ADRD services and treatment. "Vermont's Blueprint for Health was initiated in 2003 and endorsed by the 2006 health care reform legislation. Not only a chronic care program, the Blueprint is a statewide system mandated as the standard for care across all payers and providers" (Jarris, 2008 cited in Jones, 2009, p. 10). "The Blueprint revolves around six core system competencies: public policy, community, self-management, information systems, health care practice, and health systems. Vermont's holistic approach to chronic disease management has been rolled out in increments, targeting a few communities at a time for specific interventions" (Jarris, 2008 cited in Jones, 2009, p. 10). By April 2012, the Blueprint model had been implemented statewide with at least two primary care practices in each health service area and involves hospitals, insurers, medical health centers, independent primary care practices, electronic medical records, chronic disease management workshops and the multidisciplinary Community Health Teams throughout Vermont. Thus, it is imperative, and in line with the demographic challenges, the national agenda and state efforts, for Vermont and DAHL to explore the current state of CFC as it serves eligible individuals with ADRD, and to identify potential opportunities for Vermont and organizations to better serve individuals with ADRD regardless of setting or payer.

Throughout this report, the term, Alzheimer's disease and related disorders (ADRD), describes "a wide range of symptoms associated with a decline in memory or other thinking skills severe enough to reduce a person's ability to perform everyday activities. Alzheimer's disease accounts for 60 to 80 percent of cases" (Alzheimer's Association. n.d.c). There is currently no cure for ADRD; it is progressive and fatal. The progression usually begins with an early stage of mild cognitive impairment with some memory loss impeding daily functioning, followed by a moderate stage and then a severe stage during which individuals need help with all aspects of daily life through round the clock care and supervision (Tilly et al., 2011).

Methods

The main purpose of this report is to examine Vermont's long-term support service system, specifically CFC, as it responds to the service needs of individuals diagnosed with Alzheimer's disease and related disorders and their family members. With this examination, the UMMS Evaluation Team will then present recommendations for Vermont related to CFC-eligible individuals with ADRD and their family members. As noted, the UMass Evaluation Team recognizes that individuals with ADRD and their family members access services beyond those provided by CFC and as a result, some recommendations will reflect this reality.

The UMMS Evaluation Team relied on three different strategies to gather data and reach conclusions:

1. Literature reviews and environmental scans

- To obtain a general overview of ADRD and long-term support services. The UMMS Evaluation Team studied the Vermont State Plan on Dementia (Stevens, 2009). Additional materials such as the National Plan to Address Alzheimer's Disease (US Department of Health and Human Services, 2012) and policy

¹ Although this report does not focus on individuals with developmental/intellectual disabilities (DD/ID), as individuals with DD/ID live longer, ADRD is increasingly affecting this population. As CFC and DAHL explore next steps, outreach to Developmental Disabilities Services would aid with establishing an inclusive ADRD policy.

analyses on long-term services and dementia (Tilly et al., 2011) were reviewed for a national scope. Journal articles were also reviewed.

2. Twenty-five telephone interviews

- With over eighty key informants/stakeholders. Stakeholders included unpaid family caregivers, paid caregivers, Home Health Agency (HHA) staff, Area Agency on Aging (AAA) staff, PACE staff², Nursing Facility and ERC staff, Adult Day Program staff, Governor's Commission on ADRD, Vermont Alzheimer's Association, Long Term Care Clinical Coordinators, and other health care professionals (i.e., physicians). See Resource list for additional information.

3. A review of documents from other select states and programs

- That may be useful as resources for Vermont. States and programs were chosen, in collaboration with DAIL and stakeholders during the interviews, as representative of population size, region of the country and/or rural/urban mix similar to Vermont, or as particularly innovative.

As noted above, the following topic areas guided the reviews and interviews: service design; service planning; service delivery; use of psychotropic medications; use of behavioral supports; worker training and support; and informal caregiver training and support. The UMMS Evaluation Team also asked interview respondents specific questions about recommendations to improve CFC services and access to information and support for individuals with ADRD and their families, as well as a question related to CFC and the state of Vermont reinvesting funds to improve outcomes for CFC-eligible individuals with ADRD. The responses to these questions are reported in the findings sections and, given the Team's assessment of the appropriateness, actionability and viability of specific recommendations, may also be included in the policy recommendations section as part of the Team's final recommendations for DAIL and Vermont.

Using the semi-structured interview guide with targeted questions for each of the areas of interest, the UMMS Evaluation Team conducted telephone interviews with individuals and groups that have involvement with CFC services for individuals with ADRD. Potential respondents were initially identified through discussions with DAIL. Then, during each interview, the Team asked for additional individuals who should be contacted for an interview. Through these processes, the Evaluation Team interviewed over eighty respondents, representing a diverse array of providers, facilities, agencies, medical professionals, paid caregivers, family caregivers and other stakeholders. These interviews lasted between 35 minutes and an hour and 15 minutes.

UMMS recorded and summarized all interviews. The Team then conducted a thematic analysis of the summarized interview data and the literature to identify strengths, challenges and opportunities for improvement related to the effectiveness of CFC services for individuals with ADRD, any opportunities for the reinvestment of CFC savings or for other long-term improvements, and any recommendations for Vermont in general.

This Brief is organized as follows:

- Background of Choices for Care and ADRD.
- Findings of all data collection by area of interest.
- Discussion and summary table to consolidate the findings associated with ADRD for CFC.
- Recommendations based on objective analysis of these findings.

² While finalizing the writing of this policy brief, the Evaluation Team learned that PACE was set to close in March 2013. Because PACE staff participated in this process, the Team decided to keep their feedback in the report.

Background

Vermont's commitment to serving its citizens diagnosed with ADRD and their family members has been long-standing. In 2004, a three year Administration on Aging demonstration grant and state dollars were used to provide supportive, educational and direct service interventions to caregivers of individuals with ADRD with the aim of allowing the individual with ADRD to remain in the community (Stevens, 2007). The implementation of the Choices for Care waiver soon after the Alzheimer's demonstration grant began was hailed as an additional avenue for improving service options for eligible individuals with ADRD and their caregivers.

In October 2005, Vermont implemented Choices for Care, an 1115 Waiver Demonstration program. The purpose of the program is to ensure that older adults and people with disabilities have access to long-term support services in a setting of their choice. To achieve this goal, CFC encompasses the entire continuum of long-term support services. Today, CFC includes Home and Community-Based Services (HCBS) delivered through consumer-directed care, surrogate-directed care and a "cash and counseling" model (Flexible Choices); Enhanced Residential Care (ERC); and nursing facilities.

To fully support the provision of CFC services, a three-tiered system was established in which individuals with long-term care needs are identified as: Highest Needs, High Needs or Moderate Needs. Individuals identified as Highest Needs are guaranteed services. Individuals who are identified as High Needs may face a delay in access to services depending on the availability of funding, and may be placed on an applicant (waiting) list. Highest and High Needs individuals meet "Vermont's 'traditional' nursing home clinical and financial eligibility criteria" (see Choices for Care, Data Report, April 2012, p. 6) and can choose the setting in which to receive services (i.e., home, ERC, nursing facility). Those individuals who are identified as Moderate Needs are below the level of care that would require nursing facility placement, may not meet the financial criteria for Medicaid long-term support services, and can receive limited homemaker services, adult day services and case management. Similar to the High Needs group, Moderate Needs individuals may also be placed on an applicant (waiting) list (Cumings & Bruner-Canhoto, 2011).

Although individuals with ADRD seeking long-term services and supports may be assessed to need and receive services at any of the three tiers, based on the interviews, it appears that many individuals, especially those in the early stages of a dementia, first access the CFC service system through the Moderate Needs tier. As noted above, through this designation, the individual can receive homemaker services, Adult Day Program and case management services. Miller, Rosenheck and Schneider (2011) recommended that caregiver support and interventions be offered to those caring for individuals with less advanced ADRD because otherwise healthy individuals with ADRD may be at increased risk for institutionalization when caregivers experience a high level of burden. Yet, at the same time, literature also suggests that family caregivers sometimes either put off seeking services because of a reluctance to have an outsider provide care, or wait until there are challenging behaviors (Cherry, 2012). Caregivers seeking services may encounter eligibility criteria which make it difficult for someone with ADRD to qualify for services, and/or paid care workers who lack the skills needed to provide services to an individual with ADRD (Cherry, 2012). As ADRD progresses, individuals with ADRD are more likely to meet the criteria for High and Highest Needs and meet the nursing facility level of care requirement. Given all of these competing realities, the challenge then is determining how best to use CFC's capacity to meet the evolving needs and preferences of individuals with ADRD and their family members as the disease progresses.

Findings

To explore how well CFC is currently meeting the challenge of evolving needs and preferences of individuals with ADRD, to provide a foundation for recommendations to improve CFC and to describe findings related to more global, non-CFC improvements, this section presents the information gained from the data collection. Findings include the summarized responses of the interviewed stakeholders, literature reviews, and reviews of state policies, programs and related documents. Each section begins with de-identified quotes of interview respondents.

Service Design

- *“CFC relies heavily on family to provide support to [the] person with dementia, this is a huge responsibility both emotionally and physically.” - Advocate*
- *“Some people can't take advantage of [CFC] because they don't have family that would provide care outside the hours provided by the program.” – HCBS staff*
- *“Because of the nature of Alzheimer's Disease, people need more hours of coverage on a day to day basis.” – HCBS staff*
- *“The process for getting a variance is too long and too difficult. You are often left wondering if you are going to get [an approval] or not.” –HCBS staff*

CFC services encompass both home and facility settings that serve individuals with ADRD. Among respondents, the choice of care setting and the menu of options for care delivery were highlighted as positive aspects of CFC services in relation to ADRD. Home and Community-Based Services such as Adult Day Centers and personal care services were reported as beneficial and effective options for many individuals with ADRD and their families. Active case management was noted as a beneficial aspect of CFC as it helps to educate individuals and their family members about their CFC options and to adjust services as needed. However, similar to experiences across the country, as the care needs for individuals with ADRD increase, services under home and community-based options often become insufficient in terms of hours of coverage and staff resources. The result of this is often a placement of individuals with ADRD in settings able to accommodate higher levels of care (such as nursing facilities), which may not have been the preferred choice of the CFC client. Certainly, there is evidence that people with Alzheimer's disease receiving long-term services and supports are more likely to be in a nursing home or facility than served by HCBS (Borrayo, Salmon, Polivka & Dunlop, 2002). Vermont is not alone in this challenge; other states are also hard-pressed to provide larger numbers of service hours in a community-based setting. This challenge has rarely been met. However, Massachusetts has Adult Foster Care and Residential Habilitation (four person homes) and Montana and Texas have supported living options. These programs serve only a small number of individuals and seem to be the exception rather than the rule. The state of Vermont is creating community-based 24 hour care options through an Adult Family Care (AFC) program that is currently being piloted and considered for inclusion in the CFC menu of services. Inclusion of an AFC service option would broaden CFC consumers' options and may provide individuals whose care needs increase, who under the current model often transition into institutional settings, the opportunity to remain in the community longer.

Overall, it was reported that there are not enough CFC services designed to meet the needs of individuals with ADRD. There are several ERCs, nursing facilities and Adult Day Centers that do specialize with specific memory care units and programs. However, a majority of interviewees reported that CFC home and community-based service options (from consumer-directed care to Home Health Agency services) do not seem to meet the needs of individuals

with ADRD sufficiently. Respondents perceived that CFC services for individuals with ADRD fell short of meeting needs due, in large part, to inadequate service allotments for cueing and supervision, insufficient caregiver training on ADRD, a lack of availability of services during evening and night hours, limited opportunities for respite and caregiver support, and limited access to assistive technology. Many of these issues are not unique to Vermont and are challenges faced by aging and disability agencies nationwide.

It was noted that many of these types of services and additional hours may be obtained through requests for variances³. However, the variance process, as explained by respondents, did not completely ameliorate these gaps. Under CFC regulations, variances are granted under specific conditions⁴ and must be submitted in writing by the case managers involved in the coordination of the individual's care. Case managers involved in requesting a variance described the process as opaque and confusing. Several respondents noted that criteria used in granting a variance under CFC are unclear. Additional formal guidance about variances would be useful.

Even with current variances, respondents noted that the robust network of services necessary for individuals with ADRD to successfully live in the community was not always available through home and community-based service options under CFC, again similar to the rest of the country. One respondent commented that it could be that there is such a commitment to having someone live in the community (certainly a positive outcome of CFC) that service providers and caregivers are reluctant to acknowledge that there are times when other options are more beneficial for the individual with ADRD, the caregiver and the service system. Many individuals with ADRD may need close to a 24 hour a day option and respondents agreed that currently CFC does not typically have such a community option. The 24 hour community-based care option called Adult Family Care currently being piloted under CFC may provide the service option for individuals who need near 24 hour care and who wish to remain in a community setting (see Combined Bi-annual Report for April 2012-September 2012).

Respondents commented that the lengthy eligibility process for CFC services and the high threshold for assistance with physical care needs such as Activities of Daily Living (ADLs) also inhibit CFC from meeting the needs of individuals with ADRD. The current Independent Living Assessment (ILA), which is used to determine an individual's level of care needs for CFC, is administered in an interview format and is comprised of several assessment topics relating to an individual's status including questions regarding the individual's emotional/behavioral/cognitive status.⁵ However, several respondents noted the ILA is a tool which determines service hours based primarily on the physical functional needs of the individual, not cognitive status. As a result, in spite of the fact that Vermont has very inclusive nursing facility eligibility criteria, individuals with early stage ADRD are not likely to be considered High or Highest Needs unless they experience a co-morbidity that limits their ability to perform ADLs. Current CFC regulations for the Moderate Needs group limit individuals' access to services that may benefit them and reduce caregiver burden during the early stages of ADRD which, in turn, could delay institutionalization and/or higher costs as the disease progresses (Gaugler, Kane, Kane & Newcomer, 2005). Several respondents emphasized that individuals with ADRD and their caregivers typically access a continuum of services (including services for those eligible for CFC as well as

³ "Variance" means an exception to or exemption from these regulations granted by the Department as allowed under applicable statute and regulation. <http://dail.vermont.gov/dail-statutes/statutes-ddas-cfc-documents/cfc-regulations>.

⁴ Choices for Care 1115 Long-term Care Medicaid Waiver Regulations: "XI. Variances - 1. The variance will otherwise meet the goals of the Choices for Care waiver; and 2. The variance is necessary to protect or maintain the health, safety or welfare of the individual. The need for a variance must be documented and the documentation presented at the time of the variance request." <http://dail.vermont.gov/dail-statutes/statutes-ddas-cfc-documents/cfc-regulations>.

⁵ Vermont Department of Disabilities, Aging and Independent Living. 2009. "Vermont Independent Living Assessment (ILA) Manual, Version 4.0" <http://www.ddas.vermont.gov/ddas-publications/manuals-guides/ila-manual-full-version>.

those not eligible for CFC), during a 'crisis' phase. They noted that if these individuals were able to access services earlier, they may not reach a crisis mode and may in fact stay at a lower level of care for a longer period of time, requiring fewer intensive and expensive services. This idea is supported by research on caregiver support and other early intervention services which have been proved effective at delaying entry into nursing facilities (Weimer & Sage, 2009; Miller, Rosenheck & Schneider, 2011).

Both community-based services staff and facility representatives expressed concern with the calculation of the service hour needs and, in turn, the reimbursement received for the provision of services for individuals with ADRD as well as the volume of service hours needed to provide adequate care. While individuals with ADRD may have the physical capability to perform certain activities of daily living (ADLs), they may require significant and extensive cueing and/or supervision to carry out the activities. For example, one respondent spoke of the time it takes for an individual with ADRD to shower as being much longer than a person with functional limitations because of the cueing, supervision and frequent redirection that must occur⁶; other respondents spoke of the need for 1:1 supervision in facilities. Respondents thought that the ILA does not appear to lead to an allotment of enough service hours in an individual's care plan to cover this type of extensive and time-consuming cueing or supervision and may limit the capability of providers, across all HCBS settings, to adequately staff the care plan to provide services for individuals with ADRD as their condition progresses. A similar issue appears to occur with the Minimum Data Set (MDS) and Residential Assessments (RA), tools used to determine service needs and therefore reimbursements for nursing facilities and ERCs. This again may accelerate the rate in which individuals with ADRD experience transitions to higher care settings (like individuals from ERCs transferring to nursing facilities). In addition to working on variances as noted above, it is important that CFC continues its exploration of assessment and service allocation methodologies which have been validated and pilot tested.

Awareness of CFC services also appears to vary greatly. Several interviewees highlighted the role of case managers and Long Term Care Clinical Coordinators (LTCCCs) in providing options counseling services for CFC-eligible individuals. However, respondents also noted that many individuals, family members and caregivers are not aware of the full scope of services available to them due to several reasons. These reasons include the complexity of the service system, the overwhelmed state of the individuals navigating the system, the knowledge and experience of the case manager or LTCCC, and the potential bias of the case manager who may advocate or promote their agency as the primary CFC service option. The complexity of the care setting and delivery options and the coordination of multiple services, though significantly eased by case managers, may still be daunting to family members and caregivers who are likely balancing other personal stressors in their life. Additionally, while the knowledge base and experience level of case managers and LTCCCs varies, for case managers, their position as an employee of a potential care provider may represent a conflict of interest.

Service Planning

- *"Consumer and family members are pivotal in the care planning process." - HCBS staff*
- *"We have constant communication with families and caregivers." - HCBS provider*
- *"It is not infrequent that a family member requests a meeting to discuss an issue which may trigger a change in care plan." - Facility provider*
- *"I do all the planning and that is my preference." - Family caregiver*

⁶ See <http://www.alz.org/care/alzheimers-dementia-bathing.asp>.

- *“What is best for the person with dementia may not necessarily be best for the family. [We] have to look at what’s best for that family as well – Alzheimer’s is a family disease.” – Advocate*

The care needs of CFC participants with ADRD are assessed at regular intervals depending on the setting of care and the policies of the agency/facility providing services. In home and community-based settings, case managers take an active role in both care planning and adjustments to the care plan. Case managers conduct annual onsite, face-to-face assessments and have regular contact every month with CFC clients. Adult Day Programs and PACE providers reported making regular adjustments in the provision of care to their clients, as needed, to address any changes. Likewise, ERCs and nursing facilities have procedures in place to assess and reassess individuals on a regular basis.

In the event of a significant change to a care plan (i.e., as a result of a hospitalization, drastic change in behavior, or an overall increase of care needs), a change in care setting may be needed to provide the care for the CFC participant. The threshold for such a transition varies by setting and by agency and is likely influenced by the level of support available to and from caregivers, both formal and informal, who provide care for the individuals with ADRD. The level of support given by informal caregivers, in turn, is affected by their own changing capacity due to stress, physical ability and aging. Transitions from one care setting to another, especially transitions from community-based settings to facility settings such as nursing facilities, inevitably require a change in both staff and environment that can be especially stressful for individuals with ADRD. Several respondents noted the importance of having consistent staff when providing services to individuals with ADRD. The literature supports that staff changes (for CFC and other services and payers) can increase disorientation among individuals with ADRD and lead to disruptions in care (Freeman, 2003). A similar experience was described by non-medical providers who often provide assistance to individuals with ADRD prior to their eligibility for CFC. Non-medical providers are not eligible for reimbursement under CFC; therefore once individuals qualify for CFC, they may no longer receive services from the non-medical providers. In this case, the relationships with staff from these providers may then be stopped abruptly. Care transitions, both during initial CFC eligibility onset and between care settings, may require additional service planning assistance for individuals and their families in order to be successful.

Opportunity for consumer and family member input in the care planning process is embedded in the full spectrum of CFC services. While care teams vary in size and make-up across settings, consumer and family representation is common in each service option. CFC case managers are active participants and leaders in care planning for home and community-based settings. Facility settings, PACE and some Home Health Agencies reported the use of an integrated care team in planning and providing services for individuals under CFC, including those with ADRD. An integrated care team includes the individual, family members, case managers, medical providers, frontline workers, and other staff such as activities staff and social workers. These respondents noted the value and benefit of having many disciplines and individuals involved in the care planning to ensure that all needs are addressed appropriately and timely. This collaborative team approach, which incorporates family caregivers, is also an added benefit for those CFC-eligible individuals with ADRD who have behavioral issues.

While consumers and their family often have an opportunity to engage in care planning under CFC, the issue of consumer preference in planning is complex in regards to individuals with ADRD. As ADRD progresses, it is often the family member who must be the voice for the individual, as the individual may no longer be able to communicate or participate in the process. Overall, respondents thought that CFC participants were in the setting of their or their family members' choice. However, it was often a resigned choice, made after other choices were no longer viable.

While care options such as Adult Day Centers provide care during day time hours in the community and may alleviate caregiver burden, other home and community-based options may not be adequate for individuals with advanced ADRD.⁷ As noted above, a care setting with 24 hour care may be required and this level of care is not typically available through HCBS under CFC (or in any program) without ongoing and robust informal/family support.

Even among 24 hour care settings like ERCs, there are some discharges; most ERC discharges (85%-93% during 2006-2012, representing between 43 and 95 people each year) are to nursing facilities.⁸ While the cognitive status of the individuals who were discharged from ERCs to nursing facilities is unknown, several respondents spoke of individuals with ADRD being transitioned from ERCs. Individuals also leave ERCs by dying with between 29 and 73 deaths per year from 2006 to 2012. Thus, individuals in ERCs are typically discharged to nursing facilities or age in place in the ERC until death.

The progressive limiting of options for CFC-eligible individuals with ADRD appears to occur in two ways. As noted above, the individual's care setting may eventually become limited to those CFC service options that provide 24 hour care. In the absence of informal caregivers with capacity and capability (including when informal caregivers burn out or are sick themselves), these settings (like ERCs and nursing facilities) are possibly not the first choice, but may be the only viable choice. While this is an issue shared by all states, as noted above, some states have partially met the challenge, at least on small scales, with Adult Foster Care or Supportive Living residences which provide 24 hour care in a community setting.⁹ Vermont's current pilot Adult Family Care program may offer a solution to the expressed need for access to 24 hour care in community settings. The individual's and family member's care setting and geographic location preference is also, at times, limited as a result of facility waitlists, as certain facilities may reach capacity more quickly than others. The need and timeframe of a discharge/transition does not always allow for individuals to wait for a specific bed to open up on a waitlist, thus leading to a resigned, limited choice of care setting and/or location.

Service Delivery

- *"Excellent- That's what our consumers tell us through assessments and the satisfaction survey." – HCBS provider*
- *"Good. I think we need to do more work on fulfilling the plan of care." – HCBS provider*
- *"Good to excellent in facilities based on resident and family satisfaction surveys." – Facility*
- *"[Quality of services] is good – could be better. Sometimes goes to poor when a provider can't staff the service plan the way it should be staffed."- HCBS provider*
- *"Some receive good services and some not. In general, not adequate. It depends on the person and the situation." – HCBS provider*

This domain involved questions related to the quality of services and access to those services. Overall, respondents reported that the quality of the services used by CFC participants with ADRD was good to excellent, mirroring past

⁷ Although PACE in Vermont is closing, literature suggests that individuals in PACE are less likely to have a nursing facility admission than others, regardless of cognitive impairment (Freidman, Steinwachs, Rathouz, Burton & Mukamel, 2005). The evidence is less clear in terms of Adult Day Centers where McCann et al. (2005) found a higher risk of nursing facility placement for Adult Day program participants with Alzheimer's disease, in contrast to anecdotal reports and other randomized trials.

⁸ Data provided by DAIL.

⁹ See <http://www.mass.gov/elders/housing/supportive-housing/supportive-housing-initiative-program-overview.html>.

consumer survey data (see Cumings & Bruner-Canhoto, 2012). In fact, only one respondent felt that the quality was not good specifically for individuals with ADRD. The most common quality issue concerned the adequacy of services. Respondents felt that while the quality of the services was good, there were not enough services or there were some gaps in the services. Specifically, gaps were noted in terms of coordination of services, service continuity when moving from non-CFC services to CFC services, and filling hours in the service plan. One agency proudly reported that they filled almost all of their hours by having two dedicated schedulers on staff to ensure that coverage. However, many other provider respondents commented that filling service plan hours can be extremely challenging; across the nation, states are confronted with this challenge (including the need for back-up workers) (Seavey & Salter, 2006).

While CFC services can be received at all times of the day and night and can be received for cueing and supervision, respondents felt that more evening and night hours are needed as are more hours for supervision and cueing. This feeling was present for respondents despite the fact that CFC service hours appear to be high compared with other states. Again, the importance of variances should be noted. Respondents felt that more variances should be approved and that CFC should consider a possible change to the overall service system to eliminate the need for variances in certain situations. As noted above, the variance process and exactly what to write to request the variance were unclear to many respondents.

In terms of what helps CFC participants with ADRD access the service delivery system, case management services, the provider network and choices of services were all discussed. Case management services were recognized for their help in accessing services, with both AAAs and HHAs being noted as a source of information, by many of the respondents. One respondent noted that in certain parts of the state, the HHA and Council on Aging are close collaborators, again a strength to provide access. Indeed, the provider network, including AAAs, HHAs, Adult Day Centers and facilities, is tightly connected in Vermont, allowing for many entry points into the system. This network, along with the Aging and Disability Resource Connection (ADRC) and the statewide information number (211), was important to respondents as a facilitator of access to services by providing information to people. Another facilitator of access is in the name, "Choices for Care", namely—choice. Having a choice of services on the long-term supports and services continuum was seen as allowing people access to the wide range of services they need. Finally, the rural nature of Vermont was seen as a potential asset by some respondents to access as there is a community-mindedness and neighborliness within a rural population that can provide support to individuals in times of need.

However, the rural contours of Vermont also hindered access to services in several distinct ways. First, there is the distance between individuals living in their own homes. This necessitates travel or transportation. Transportation was mentioned as a hindrance by respondents in several ways. Transportation to services is an issue. A lack of transportation can lead to isolation. Also, individuals with ADRD may not want to be transported because of the cognitive changes occurring and a general resistance to care. Rural individuals participating in CFC may face "a limited range of services [provided] to a limited number" (Li, 2006, p. 116).¹⁰ Rural culture also hinders access in that individuals in Vermont may be unwilling to accept services in their home due to pride, stigma, denial or fear.

Several other significant issues hinder access including the lack of education and information about ADRD; lack of enhanced reimbursement for facilities to provide specialized care to individuals with ADRD; lack of collaborative relationships; not enough dementia-related programs for participants or their caregivers; and the difficulty individuals

¹⁰ This challenge to access was contradicted by at least one respondent who felt that the rural nature of Vermont meant that there was not as much competition (population-wise) for the limited services.

with ADRD have with the financial eligibility process, despite case manager assistance. Although, as noted above, there is information provided by multiple entities, some respondents felt that certain segments of the population could benefit from more information about ADRD in general and how CFC may be helpful to eligible individuals with ADRD specifically. These segments include primary care physicians, who are often the first professionals individuals contact for assistance; caregivers who are not in crisis, who may be able to take advantage proactively of information; and individuals in rural areas, to combat the difficulties of isolation, stigma and denial.

Another challenge to access, existing collaborations notwithstanding, was the lack of continuity between providers due to disjointed relationships and a lack of meaningful involvement by all providers. Certainly, anecdotal information from non-medical providers highlighted the fact that these providers were not collaborated with during CFC's processes, even though they may have been the provider of choice prior to CFC involvement. By not allowing reimbursement of non-medical providers through CFC, relationships between specific staff and individuals are broken upon receipt of CFC, a problem noted above.

While there are services and programs available for individuals with ADRD who are on CFC, respondents noted the need for more dementia-related services including additional respite care (e.g., more Adult Day programs) and support groups. In terms of eligibility, a very specific concern was noted related to financial eligibility requirements. Even with the assistance of a case manager, it can be very challenging for an individual with ADRD to access the information necessary for the financial application process. A respondent explained that if the individual with ADRD lived alone or had been out of state for a time (with unknown financial transactions), the current caregiver assisting the individual with ADRD may not know where financial records are kept or how to get the information and the individual with ADRD may no longer have the capacity to assist with gathering the records. For a person or a family dealing with ADRD, the five year 'look back' or review of finances may represent a significant hurdle that impedes access to CFC. While this is a federal and state requirement for Medicaid eligibility and is not amenable to action, it is noteworthy and factors into contingency planning findings and recommendations below (see informal caregiver training and support).

Use of Psychotropic Medications

- *"Medication is not the first step in PACE. It is important to work with the family and the patient." –PACE Staff*
- *"Nursing oversight is a gap for everyone in CFC. Those that are in a nursing facility are receiving intense nursing oversight but if a person chooses to receive care at home, nursing oversight is largely absent." -AAA Staff*
- *"If the client has no family, medication management and administration does not happen in a proper way." –AAA Case Management Staff*

The use of psychotropic medications for individuals with ADRD in the CFC program varies across care settings. Interview respondents agreed that in the home and community-based programs, the use of such medications is a solution of last resort and is rarely used. In this setting, the medication is either requested by the caregiving family member or recommended by the client's doctor. Although the individuals with ADRD who are prescribed psychotropic medication are monitored by their doctor, interview respondents expressed concern regarding the lack of nursing oversight in the home (a concern potentially affecting any CFC individual on medication requiring close monitoring).¹¹

¹¹ Some of the issues of medication management may be mitigated for individuals who also receive Medicare. In October of 2012, a settlement was announced in a class-action lawsuit which will require Medicare to pay for in-home skilled care for

The perception among AAA and HHA case managers is that unless the client has another debilitating condition that requires a licensed nurse to manage that client's medication, the HCBS CFC services the person with ADRD receives rarely includes regular skilled nursing medication monitoring. Interview respondents also expressed concern with the fact that even if a nurse is present in the home, that nurse feels liable for the information he/she is providing regarding medication management and administration. This concern may be an outcome of the nurse delegation policy Vermont follows that allows nurses to delegate relatively few tasks to non-licensed personnel (Reinhard, Kassner, Houser & Mollica, 2011). Automatic medication dispensers with a reminder feature are sometimes an option for persons with ADRD. One case manager spoke about not being able to get a medication dispenser with the reminder feature for one of her clients who had ADRD because the extra feature of the reminders was above the cost that CFC allocates for assistive technology. The respondent did not speak about the possibility of requesting a variance. The respondent also did not speak about other potential device options, which may not involve a monthly fee and may be below the \$750 limit posed by CFC.

A further review of assistive technologies showed that today there are several options which can aid individuals and their families with medication management and other activities. *Intelligent Assistive Technology Applications to Dementia Care: Current Capabilities, Limitations, and Future Challenges* identifies "58 total technologies, both basic and advanced, with potential applications to dementia care" (Bharucha et al., 2009, p. 3). Technologies including cognitive aids, environmental sensors, video/audio technologies and monitoring systems have the potential to improve the quality of life of individuals with ADRD and their family caregivers, while delaying the need for institutional care. For example, assistive technology is often used for prompting and reminding (Carswell et al., 2009). Bharucha et al. (2009, p.3) identified six prospective memory aid devices (Memory Glasses, Visually Enhanced Recipe Application (VERA), Cook's Collage, Intelligent Mobility Platform, Opportunity Knocks and Activity Compass) that may "address any of the other progressive cognitive and functional impairments associated with dementia such as aphasia, agnosia, apraxia, visuospatial, or executive dysfunction."

In order to enhance safety for individuals in the more advanced stages of the disease, technology can be used for monitoring the day-to-day activities such as medication management as well as monitoring those with a wandering tendency or locating a person who may be lost. Examples of such physiological sensors and environmental detectors include electronic fall detectors, motion detectors, force/pressure/contact sensors, and proximity detectors as well as vital signs and metabolic parameters testing devices like the Medical Mood Ring and Tadiran's MDKeeper (Bharucha et al., 2009).

As another example, to support elders living in their homes for as long as possible, Dr. Allan Teel has developed a program that relies on technology with staff supports. The approach utilizes small computer cameras connected to motion sensors in the client's home to virtually monitor their activity. Dr. Teel's *Maine Approach* also takes advantage of new technological tools to engage elders through video calling, recording and conferencing (<http://www.fullcircleamerica.com/qu.html>). Both Bharucha and Teel offer approaches that use technology to supplement and complement existing support, examples that Vermont and CFC may wish to explore further.

In Adult Day Centers, medication administration is handled by the nurse on duty. Interviewees agreed that the current system is working and they have no concerns. Some Adult Day Center interviewees reported that the nurse who manages the medication administration talks to the staff that work directly with the clients and tells them what

individuals with chronic conditions like Multiple Sclerosis and Parkinson's disease---conditions which are unlikely to improve (Kennedy, 2012).

behaviors they can expect from each individual taking medication. In some instances, the staff and the nurse were able to work together to identify the environmental triggers for the individual's outbursts and develop a non-medication plan to anticipate those triggers.

While some Vermont facilities may have different experiences, our facility respondents reported that for individuals with ADRD receiving care in these facilities, the use of psychotropic medications is also considered a solution of last resort. In these facilities, care teams are required to show documentation proving that all other non-medication options were used unsuccessfully prior to the administration of psychotropic medications. In response to the CMS initiative "Partnership to Improve Dementia Care in Nursing Homes"¹² with the goal of reducing the use of antipsychotic drugs in nursing homes by 15% nationally by the end of 2012, Vermont introduced the *OASIS* program and is seeking funding for its full implementation. Interview respondents spoke highly of the *OASIS* program and recommended that more programs like it be implemented in Vermont, not only in nursing facilities but in all settings (with appropriate modifications).

With the introduction of *OASIS*, Vermont is striving to change the way nursing facilities operate. *OASIS* was developed by Dr. Susan Wehry, DAIL Commissioner. Initially implemented in Massachusetts, *OASIS*' goals are to foster culture change¹³ and to provide nursing facility staff members with tools which help to effectively deal with the everyday needs and challenges of people receiving services in long-term care settings and reduce the inappropriate use of psychotropic medications. Understanding the needs of each individual and developing behavioral strategies led to fewer resident incidents, decreased restraints and fewer falls, while improving quality of life and giving a greater sense of security and safety. Staff in the participating *OASIS* nursing facilities found the training advantageous because it helped staff understand the psychology of talking with residents with cognitive impairments, and also shifted the focus to the prevention of challenging behaviors.

The Alzheimer's Association has provided trainings on this topic as well. The trainings were well-attended, according to respondents and the topic was found to be interesting and relevant. In spite of this, there was general consensus among respondents regarding the need for additional training about psychotropic medications. If more training was available in this area, staff, medical professionals and families could all learn that the first step is to identify the cause for the behaviors such as anxiety or depression; and to try least invasive methods before turning to medication as a solution. Respondents suggested that the Alzheimer's Association hold trainings on a more regular schedule in different geographic areas of Vermont and with different audiences of providers, medical professionals, and families, thereby increasing knowledge of medications and behavioral alternatives among all of these groups.

As Vermont is a mostly rural state and accessibility was found to be a hurdle for family caregivers, the recommendations were to explore different mediums of dispersing the information and to consider individual home visits, online face-to-face meetings and trainings similar to REACH OUT (see below). Medication was found to be useful in managing pain and suffering when used judiciously. However, there were instances described when just taking a deeper look at the environment surrounding the individual helped decipher the challenging behavior.

¹² See Center for Medicare and Medicaid Services Press Release, "CMS Announces Partnership to Improve Dementia Care in Nursing Homes", May 30, 2012.

¹³ "The terms "cultural change", "person-centered care" and "person-directed care" are often used interchangeably" (California Healthcare Foundation, 2008, p. 1) to represent the recent shift in the nursing homes are run. This change can involve streamlining the staff, empowering frontline workers and "creating a more flexible and responsive service delivery system to meet the needs and preferences of individual residents" (p. 4).

Education into these types of strategies was noted as beneficial for caregivers, both formal and informal, including medical professionals.

Use of Behavioral Supports

- *“Families have no one to turn [to] when they encounter behavioral changes.” – HCBS provider*
- *“We have more staff in late afternoon and early evening than during the day due to sun downing.” – Facility*
- *“The skill set is not available for behavior based interventions [in home and community-based settings]” – HCBS Provider*
- *“REACH OUT has made a difference as far as getting information and resources to those that live at a distance” – HCBS provider*

As part of the National Alzheimer’s Project Act (NAPA), signed by President Obama in January 2012, a “review of the state of the art evidence-based interventions that can be delivered by community-based organizations” was requested (U.S. Department of Health and Human Services, 2012, p. 24). The review revealed “more than forty non-pharmacological treatments and care practices [that] have positive effects for some people with ADRD who live in the community and some family caregivers” (Maslow, 2012, p. 4). These treatments and care practices are geared to helping people with ADRD and their families manage and cope with the difficult situations brought on by the disease. “Despite the substantial number of interventions found in the review, most are only well known to the researchers, clinicians and service providers who developed and implemented them” and to the small sample which it directly impacted (Maslow, 2012, p. 8). For example, one of the programs evaluated was the Minnesota Family Workshop (MFW). The evaluation showed that family caregivers who participated in the MFW group meetings said they “reacted less to the person’s behavioral symptoms and had reduced feelings of depression and burden” (Maslow, 2012, p. 13). Analysis showed that “these positive outcomes were associated with the new knowledge, skills and beliefs about caregiving obtained by the caregivers through participation in the MFW” (Maslow, 2012, p. 13).

In contrast to *OASIS* training in nursing facilities, some respondents reported that there is very little information available regarding non-medication alternatives for individuals with ADRD who chose to receive services at home. Due to this lack of information, the skill set for non-pharmacological interventions is limited. Family caregivers indicated that they often learn as they go, as no formal training or resources had been provided. Some family caregivers rely on the individual’s doctor for information on dealing with difficult behaviors, while others said they have used the care plan meeting to discuss alternative interventions with the case manager. There was not much discussion about specific dementia support from case managers themselves. As noted by Cherry (2012), dementia care management and consultation can be a critical element to help individuals with dementia remain at home with HCBS. In interviews with family caregivers, we found no evidence of this type of service. However, we did find a wide array of training resources on the national Alzheimer’s Association website including free e-learning workshops, DVDs on caregiving, a list of books on caregiving and even an online care training and certification program.

Although there is no cure for Alzheimer’s disease, a number of treatments (like the MFW) have shown promise in terms of enhancing quality of life for individuals with ADRD. Some other treatments are as complicated as receiving acupuncture or sensory therapy; while some involve life changes such as diet and exercise (www.alz.org). The Alzheimer’s Association of Vermont was identified as a key resource for people with dementia and their families. The Association offers a variety of courses such as “Living with Alzheimer’s for Caregivers (early, mid and late stages) and for People with Alzheimer’s”, “Know the 10 Signs: Early Detection Matters”, and “The Basics: Memory Loss,

Dementia, and Alzheimer's". The Alzheimer's Association resources are useful for formal and informal caregivers who have access to a computer with internet and know how to navigate the internet to get the correct information. Respondents suggested a higher degree of collaboration with the Alzheimer's Association is needed to disseminate the resources on their website through different and more traditional media. While the Evaluation Team is not aware of any collaborative initiatives taking place, the Governor's Commission could be one such forum for collaboration.

Music is also known to have great power when it comes to individuals with ADRD. "Most people associate music with important events and a wide array of emotions. The connection can be so strong that hearing a tune long after the occurrence evokes a memory of it" (Alzheimer's Foundation of America, n.d). Based on this finding, programs such as Dan Cohen's "Music and Memory" were created with the goal of improving the quality of life for elders with ADRD through the use of personalized music. Cohen brought iPods loaded with individuals' favorite music to long-term care facilities. The idea was successful and the iPod Project was initiated to continue to bring personalized music programs to individuals with ADRD regardless of their physical location (i.e. at home, in a nursing facility, assisted living facility, hospital or hospice). A few Vermont nursing facilities (including the Vermont Veterans' Home) are using Music and Memory.

Adult Day Program staff seemed to have the opportunity to participate in trainings regarding ADRD and difficult to manage behaviors on a regular basis. Given those opportunities, staff feels obligated to pay closer attention to the individuals' behaviors and, with the support from the nursing staff, can come up with alternatives to medication. Individuals with ADRD who attend an Adult Day Program also have the opportunity to receive 1:1 care.

Given the slow progression of ADRD, a person may live with dementia for years before exhibiting difficult to handle behaviors. There was a consensus regarding the fact that family caregivers often don't ask for help and don't explore resources until those difficult to handle behaviors interfere with their everyday life. Some respondents recommended that Validation training (see below) and redirection training be offered to all caregivers, while some recommended that a curriculum should be made mandatory for those caring for CFC-eligible individuals with ADRD.

Respondents noted that it was challenging to engage Department of Mental Health services and resources to assist with behaviors exhibited by individuals with ADRD because ADRD is not seen as a specific purview of DMH in Vermont.¹⁴ However, with the passage and implementation of Act 79¹⁵, there may be a timely opportunity to engage DMH as it works towards designing a mental health system which meets the current and future needs of Vermonters. In addition to collaborating with DMH, DAIL could take advantage of the behavioral expertise found in Developmental Disabilities Services (DDS) staff to help people with ADRD and their caregivers deal with difficult behavioral issues. Perhaps, DAIL, DMH, DDS, Vermont Department of Health and Department of Vermont Health Access (DVHA) can work together to identify strategies to better meet the behavioral and more "mental health-type" needs of the ADRD population in Vermont.

¹⁴ This is the case in other states as well, including California (Cherry, 2012).

¹⁵ "Act 79, "An Act Relating to Reforming Vermont's Mental Health System," was passed by the State Legislature on March 27, 2012 and signed by Governor Shumlin on April 4, 2012. "The Act intends to both strengthen the mental health system by offering a wide variety of traditional and alternative services and ensure that mental health care is on par with other health care initiatives" (Hutchings, Cohen, Huckshorn, Schwalbe, and Cobb, 2012, p. 13).

Across the board, interview respondents want to see more individual behavioral support given to family caregivers. Funds are available to AAAs to support different elder care needs including behavioral support needs, however nothing specific was mentioned in the interviews. The evaluation of the Administration on Aging (AoA) grant from 2004 in Vermont found the program to be useful and “the level of its flexibility was seen as a strength of the current program in addressing the needs of a broad group of caregivers” (Stevens, 2007, p. 26). The evaluating team also suggested that the program coordinators “increase outreach and education strategies to bring caregivers into respite care services during early stages of ADRD” (Stevens, 2007, p. 26). Dementia care management and counseling have also been shown to provide positive outcomes related to keeping individuals in the community with HCBS (Cherry, 2012).

Programs such as the ones mentioned above as well as REACH OUT, the Collaborative Care Model for Alzheimer’s Disease and Related Dementias (Maslow, 2012), and Partners in Dementia Care (Maslow, 2012) have effectively offered family caregivers additional education and support they need to keep their loved ones at home. REACH OUT is a home-based support program for adults caring for a loved one with dementia available through Central Vermont Council on Aging (<http://www.cvcoa.org/support-groups.html>). The program lasts 6 months; during this time, the caregiver receives home visits and phone calls from a case manager with the focus on educating about dementia, the stress of caregiving, safety, health, relaxation, coping with dementia behaviors and enhancing social support. Another program promoted by the AoA is the Savvy Caregiver Program, providing education on challenging behaviors of individuals with dementia (Cherry, 2012).

In addition to the technology noted above, when caring for someone with ADRD, caregivers must look very closely at the living environment and learn to adapt it as the disease progresses. Making a home safe for those experiencing a steady decline in both cognitive and physical functioning is extremely important. Interviewees raised concerns regarding the perceived lack of resources from CFC to purchase items like door alarms, tracking bracelets, or door covers that look like book cases (without variances). As the disease progresses, depth perception and the ability to distinguish colors are often affected. Respondents noted that using color contrasts when it comes to flooring, bedding, and window coverings may help a patient feel safer, thus reducing agitation and anxiety. Such small details about the living environment may not cross a family caregiver’s mind; however, with training, more family caregivers would have the appropriate tools to care for their loved ones in a safer manner.

Worker Training and Support

- *“[I] find that using a train the trainer model helps to instill the philosophy and ideas of the training throughout the organization.” -Facility director*
- *“As part of a training, I received a one-pager on ADRD, which I still pull out and reread.” -HCBS staff*
- *“Someone getting paid as a caregiver should be trained.” -HCBS staff*

In this section respondents were asked whether paid caregivers receive training. If training was not provided, respondents were then asked to share their ideas on the type of training which should be provided. Almost all respondents identified training as an important factor in delivering services to CFC participants with ADRD and their families. Based on the information shared, all organizations across the continuum of care provide some training opportunities to staff. Respondents identified trainings such as Validation Method and OASIS.

Variability emerges as respondents described the type of training and the frequency which that training is offered. In some instances, organizations use their monthly staff meetings to provide training on a variety of topics including dementia. One respondent noted that within an agency, paid caregivers receive dementia training as part of orientation training, quarterly and on an as-needed basis. A few other respondents talked about an as-needed request for assistance with specific consumers and spoke of a team training approach that included the case manager, the nurse, the physician and the paid caregiver. Facilities of all types also ensure that their staff is aware of and knowledgeable of dementia by providing trainings.

Many of the interviewees noted the positive impact of receiving training on the Validation Method developed by Naomi Feil. Validation is a method of communication, built on an empathetic attitude and a holistic view of individuals. By using validation techniques caregivers aim to decrease disorientation and to support the individual in the expression of his/her feelings (Davis, n.d.). In November 2012, there was a state-wide Validation Method training that many respondents mentioned attending and spoke of excitedly. Some facilities have already adopted *OASIS*, mentioned above, and have found it to be instrumental in successfully changing the interactions between their direct service workers and individuals with ADRD.¹⁶

However, there appears to be a sense of unevenness in the content and frequency of the trainings. According to respondents, the provision of trainings within an agency and statewide is further complicated by the fact that there is no standard ADRD training for paid caregivers. Research has shown that informed (i.e., trained) paid and unpaid caregivers impact the quality of life of an individual with ADRD (Alzheimer's Association Campaign for Quality Care, 2009). In Massachusetts, the Executive Office of Elder Affairs, the Alzheimer's Association and the Aging Services Access Points are working to enhance the provision of HCBS to individuals with ADRD and their families. One component of this project is the provision of ADRD habilitation training for direct service workers.

Most respondents commented that more consistent training available statewide on ADRD would be beneficial for paid caregivers who work in the community and in facilities. It was also suggested that CFC explore the possibility of making ADRD training mandatory for all caregivers who work with individuals with ADRD. If the state required that all paid caregivers working with individuals with ADRD go through some basic training, situations like the paid agency caregiver leaving the home when the participant asks them to leave (because of cognitive issues such as the participant not remembering that the caregiver is there to help them) would happen less often. The state can work with the Alzheimer's Association, home care providers and other stakeholders to recommend or establish training guidelines which can be implemented across the care continuum. In this way, individuals with ADRD and their families will know that someone working with them in the home or a facility possesses baseline knowledge of ADRD. One way of determining the viability of this idea could be that CFC and DAIL partner with the Alzheimer's Association, home care providers, paid and unpaid caregivers, and other stakeholders to review the current types of ADRD trainings and the structures for delivering those trainings. Respondents noted that efforts should also be made to ensure that training materials are available in a variety of platforms (in-person, on-line, etc.) and at a variety of times. According to respondents, statewide training could include specific topics such as the progression of ADRD, redirection/validation, communication skills, how to create a safe environment and use of behavioral supports.

¹⁶ In addition to *OASIS* noted above, another training program for staff (specifically in Assisted Living), STAR- Staff Training in Assisted Living Residences, was evaluated [not in Vermont] as well-received and as helpful in reducing distress of residents (Teri, Huda, Gibbons, Young & van Leynseele, 2005).

Respondents noted that due to time constraints and funding concerns, some paid caregivers who are not associated with an agency (i.e., a family member or a friend) may not access the trainings which are available. While paid agency staff/caregivers are able to access trainings easily in or at their agency, the cost and time needed to attend outside trainings often prevents them from taking advantage of these opportunities. Respondents from organizations across the spectrum of care suggested that through partnerships among agencies, facilities, the state and advocacy organizations, training availability and access can be improved. Even though there are several opportunities for training, the information provided suggests that there is a need to develop a baseline of core competencies about ADRD across the care continuum which should be available to all. Because of its long-standing commitment to the provision of quality services, DAIL and CFC may be able to facilitate the discussion.

Informal Caregiver Training and Support

- *"Families need information about ADRD, medical equipment and medicines, behavioral supports, safety in the home and self-care." -LTCCC*
- *"Families need to know how to deal with other medical issues which accompany ADRD." -Family caregiver*
- *"Care is hard work. There isn't always enough left to take part in trainings and supports." -Family caregiver*
- *"Giving someone a booklet and a pep talk doesn't feel like it's enough to let them know how to take care of their mother." -HCBS provider*
- *"Families need assistance with planning: contingency planning, financial planning, advanced care directive planning." - HCBS provider*

More than 80% of dementia care is provided by the family in the community (Cherry, 2012). For these caregivers, there are risks; Miller et al. (2011, p. 382) wrote, "family members and other unpaid caregivers experience considerable psychological and physical co-morbidity". Across the spectrum of care, providers have a variety of roles related to providing training and support for individuals with ADRD and their informal/family caregivers. Cherry (2012) argues that HCBS can keep people with dementia at home through programs that highlight caregiver education and support. The majority of agencies provide information to family caregivers. Depending on the specific type of provider, that information may include the assessment of eligibility for services, a referral to additional services or the oversight of services as a case manager.

Due in part to stigma or a sense of "I know how to care for my loved one", few family caregivers appear to access trainings on ADRD. Literature on caregiving acknowledges that caregivers for individuals with ADRD are often stressed and overwhelmed (Tilly et al., 2011). However, in order to assist a loved one with ADRD and to maintain one's own health, respondents noted that it is imperative that family caregivers take full advantage of the information and services which are available. Those family caregivers who do not often burn out faster, resulting in the individual with ADRD being placed even sooner in a care facility (Miller et al., 2011). Caregivers also are at a high risk of jeopardizing their own health (Alzheimer's Association Campaign for Quality Care, 2009). Because ADRD is a disease which affects the entire family, some suggest that assessments for services should include the caregiver's understanding of the conditions and support needs (Cherry, 2012). There are several tested and validated assessment tools which CFC may want to consider adding to its service assessment process (Schwartz, Darlak, & Whitlatch, 2012).

Some of the specific types of information which respondents stated would aid families included basic knowledge about ADRD, progression of the disease, medical and non-medical changes, communication skills, creating a safe

environment, providing ADLs and available resources across the spectrum of care. Just as important was the need for family caregivers to avail themselves of respite services. Several respondents, including current and former caregivers, acknowledged that caring for a family member with ADRD is emotionally and physically demanding; additional information, above and beyond what is currently given, would be helpful.

Although some family caregivers do participate in support groups, many others do not. Some respondents noted that the best support groups are the ones which allow the caregiver to bring the person for whom they are caring to the meeting. Research also shows that support groups which involve the individual with ADRD and the caregiver together for an hour and then in separate support groups for the second hour are effective (Maslow, 2012). These suggestions present an opportunity for organizations, including the Alzheimer's Association and AAAs, to determine whether they can adopt these best practices in their activities.

Family caregivers noted case managers, Councils on Aging, facility staff and AAAs were all avenues they used for support. Respondents suggested that other avenues for providing information could be physician offices, a live online chat, use of local television shows and additional 1:1 conversations between the caregiver and case manager (see Cherry, 2012). Other respondents suggested that in addition to these resources, it is important that family caregivers are aware of and actively involved in planning for the future. Planning should include developing contingency plans in case of an emergency, completing advanced care directives and financial planning. Recognizing that family caregivers often times are overwhelmed, some participants suggested that the annual reassessment meeting could be used to aid with any needed contingency planning. Based on the interviews, this practice does not seem to be common across all case management agencies. As noted by Cherry (2012), financial and legal planning can be a benefit of and should be part of the continuum of HCBS services. Additionally, more upfront planning could address issues related to representative payees and to ensuring that individuals are not exploited financially, a potential concern for DAIL and for Vermont in general.

Also important is the need for the family caregivers to be able to maintain their own health. Although many family caregivers had not accessed training on how to take care of their health, over time they had been persuaded to take advantage of respite services. Through their own experiences, respondents stated they learned that it is important to find time for themselves. One family caregiver talked about an initial reluctance to use respite services and what a support it was when the caregiver finally used the service because it allowed for a long-needed vacation. Some respondents talked about the previously-mentioned REACH OUT program and the Powerful Tools for Caregivers training, a 6-week program geared toward family caregivers.¹⁷ In Montana, the evaluation of trainings for caregivers involved in the Powerful Tools program found that "70% have used positive self-talk taught in the class" and "63% are very confident that they can cope with the stress of caregiving".¹⁸

Ideas to improve services

In addition to specific ideas noted above as to how areas could be improved, we asked respondents for their recommendations on two fronts: 1) what CFC should do to meet the increase in the need for services for CFC-eligible individuals with ADRD and 2) how CFC should reinvest any savings to improve outcomes and control costs for individuals with ADRD. These ideas are presented here to provide a sense of potential strategies CFC and DAIL may wish to consider, not as formal recommendations for action. Obviously, some of the ideas are more actionable

¹⁷ See <http://www.cvcoa.org/support-groups.html>.

¹⁸ See http://www.montanafamilies.info/FCS_report%20_008final.pdf. P. 4

than others. Respondents were also asked how their organization could assist CFC and Vermont with the increasing need for ADRD services as the population ages.

Recommendations for CFC revolved around five areas:

- increase the capacity of existing services;
- create new services within CFC;
- change CFC regulations related to eligibility, categories of need and/or provider networks;
- provide education; and
- increase financing for existing services.

While some of these suggestions reflected misunderstanding or misinformation about CFC and its policies (for example, CFC does not actually provide training or education), others are evidence of thoughtful and meaningful engagement in the topic area for all care settings, which should encourage DAHL to consider reinvestments across the continuum of care settings. Respondents recommended increasing provider capacity in Adult Day Programs and nursing facilities in certain locations (especially for individuals in ERCs who need to move into nursing facilities). Some respondents suggested certifying non-medical providers for CFC services, and providing and regulating overnight care (Adult Day Programs at night). Across the board, respondents advocated for increased funding, although Vermont's rates for many services (including Adult Day Programs) are among the highest in the United States. Additionally, respondents suggested allowing for more flexibility in respite dollars especially to address emergent (non-planned) situations. CFC also has the opportunity to explore increasing the role of AAAs in providing services to Moderate Needs individuals diagnosed with ADRD.

The agencies, facilities and organizations also felt that there was an active role for them to help Vermont prepare for and meet the increasing need for ADRD services. Facilities spoke about growing their capacity to meet the need and sharing their knowledge through best practice forums (though nothing is actually preventing them from doing that now). HCBS providers recognized their responsibility to market their services. These HCBS providers also spoke of advocating and working together with the state to create additional service models, including, but not limited to the Adult Family Care model about to be launched. In the findings, there are other potential service models (Massachusetts, Montana) that may be adapted for Vermont; in addition, state staff may have possible innovations that could be further discussed and vetted to determine the viability of ideas. Other groups talked about helping by providing training on ADRD topics and assisting families to advocate.

Summary /Discussion

Within this section, we provide a summary of the benefits and challenges to CFC for ADRD. Most of these challenges represent challenges for all states and should be seen in that national context. Some of these challenges and benefits relate specifically to CFC; others, including training, supports and medication areas, are more global in scope and should be understood as the responsibility of other stakeholders (providers, facilities, Alzheimer's Association, Governor's Commission, and so on) with support from DAHL and CFC.

Area	Benefits of CFC for ADRD	Challenges of CFC for ADRD
Service Design including assessment and eligibility	<ul style="list-style-type: none"> • Choice of care setting • Options for care delivery • Availability of 24-hour care options in some settings • Counseling/Information and referral by case managers and LTCCCs • Adult Family Care close to implementation 	<ul style="list-style-type: none"> • Few specialized ADRD services in HCBS • Need for 24 hour care in home settings • Complexity of service system • Potential bias of case manager for services from own agencies • Cognitive assessment in Independent Living Assessment (ILA)- not robust for service planning
Service Planning	<ul style="list-style-type: none"> • Care needs assessed regularly • Role of individual and family member embedded across continuum of care • Use of integrated care team for planning in facilities 	<ul style="list-style-type: none"> • Care transitions/discharges • Care setting selected because only viable option (often facility is the 24 hour option)
Service Delivery	<ul style="list-style-type: none"> • Quality of services good to excellent • Case Managers aiding access • Coordination and collaboration across the provider networks including ADRC and 211, allowing for multiple entry points • Community-mindedness of rural culture 	<ul style="list-style-type: none"> • Adequacy of HCBS for ADRD • Unclear variance process • Maintaining continuity of care when transitioning from non-medical providers • Limited transportation • Reluctance to accept services due to fear, stigma • Need for 5 years of financial records (though cannot be changed)
Use of Psychotropic Medications	<ul style="list-style-type: none"> • Noted as last resort by respondents • Supervised at facilities and Adult Day Programs • OASIS program 	<ul style="list-style-type: none"> • May not be last resort for all facilities • Lack of direct medical oversight for CFC participants in home setting • Lack of trainings for some staff and families on psychotropic medications
Use of Behavioral Supports	<ul style="list-style-type: none"> • Evidence-based training and support programs • Families turn to doctor and case managers for information • People in Adult Day Programs and HCBS have the opportunity to receive 1:1 care 	<ul style="list-style-type: none"> • Insufficient information about non-medication supports for HCBS staff and families • Perception of limited CFC resources to purchase home modification equipment and personal assistive technologies
Worker Training and Support	<ul style="list-style-type: none"> • All organizations provide some ADRD training to staff • Some effective training models • Organizations interested in working together to share best practices 	<ul style="list-style-type: none"> • No standard training • Little mandated training • Awareness of available trainings fragmented
Informal Caregiver Training and Support	<ul style="list-style-type: none"> • Information and supports are available from many organizations • Some Adult Day Centers hold trainings for informal supports regarding behaviors and the cause of it, using individual cases as example 	<ul style="list-style-type: none"> • Families not aware of the trainings • Families unable to access trainings

The major findings indicate that CFC can be quite effective for individuals with ADRD and their families in certain 24 hour care facility settings. CFC's HCBS options, which are typically unable to provide 24 hour care, are more limited in their effectiveness and must rely on family/informal caregiver support to provide the majority of the care (a concern for Vermont and nationally, especially when an increased burden on informal caregivers necessitates facility placement). Adult Day Centers are a beneficial option for CFC participants with ADRD and their families. ERCs and nursing facilities are effective service options for CFC and ADRD. Given these choices, the Evaluation Team found that CFC was effective in providing choice to individuals and families and they were able to participate in care planning around these choices. However, often, when 24 hour care was needed, there was a winnowing of choice to only facility options, much like the rest of the country which is struggling with the challenges and barriers to providing "close to" 24 hour care in the community setting. Again, as noted, Adult Family Care is being piloted, which is expected to address the gap.

Another major finding from the interviews and literature reviews was around training. Additional training is needed for every group involved with CFC and individuals with ADRD. The Evaluation Team found evidence of a wide range of training being conducted in many venues and modalities. However, there was an unevenness and a lack of consistency across these venues and modalities. Little training was mandatory and often ADRD as a topic received only brief mention. Family and informal caregivers as well as caregivers not associated with an agency lacked training and could certainly benefit from specific training. While some of the training may have a CFC focus, it is recognized that training about ADRD has a broader context than CFC and will need to be addressed on many levels.

Finally, the Evaluation Team was struck by the breadth and depth of programs currently being offered across Vermont related to ADRD and of potential benefit to CFC participants with ADRD. This includes *OASIS*, but also other smaller-scale interventions. In specific facilities or through specific agencies, "pockets" of programs for ADRD have developed including Music and Memory and Validation Method. While these programs are of varying sizes, they highlight the critical mass of interested individuals needed to take some types of programming or training statewide.

Policy Recommendations

The recommendations on the next two pages are separated into two main sections: recommendations for CFC and DAIL specifically and recommendations for Vermont and stakeholders in general. The separation is necessary to 1) focus CFC recommendations on actionable and relevant changes for CFC and CFC-eligible individuals with ADRD and 2) to include additional recommendations that have merit, but over which CFC does not have authority to enact. We see DAIL with a supporting role in many of the below efforts, with AAAs, Home Health Agencies, the Alzheimer's Association, the Governor's Commission, consumer organizations, caregivers and individuals with ADRD each providing necessary resources for these recommendations.

Focus Area	CFC-specific recommendations	Vermont recommendations
Service Design and Delivery	<ul style="list-style-type: none"> • Complete the launch of Adult Family Care. • Explore ways to assess and to allocate hours for services which include validated tools and pilot tests. • Investigate residential habilitation and supportive living options, and technological approaches to allow the creation of “closer to” 24 hour care in the community for CFC. • Review and modify instructions and guidance for requesting variances. • Allow non-medical providers to perform reimbursable services as a policy change (see Cumings & Bruner-Canhoto, 2012) for ongoing continuity of care and to assist in the filling of service hours. • Explore the provision of additional and flexible services by Area Agencies on Aging (AAAs) for Moderate Needs individuals with ADRD and their families. • Consider reinvestment of CFC funds across all care settings. 	<ul style="list-style-type: none"> • Create best practice forums for providers and stakeholders (Alzheimer’s Association, Governor’s Commission among others) to work together and with CFC around the following issues: <ul style="list-style-type: none"> ○ innovative service delivery options, include dementia care management and other evidence-based practices (see findings) ○ strategies for filling service plan hours (such as creating dedicated schedulers) ○ screening, assessment and eligibility determination processes ○ technological approaches ○ support group organization ○ training (see below recommendations). • Expand Adult Day Programs throughout the state.
Service Planning	<ul style="list-style-type: none"> • Encourage case management agencies and other stakeholders (such as AAAs and the Alzheimer’s Association) to develop toolkits and materials to facilitate contingency, financial and advanced care directive planning for individuals with ADRD and their families. 	<ul style="list-style-type: none"> • Create toolkits and materials to encourage contingency, financial and advanced care directive planning for individuals with ADRD and their families.
Use of Psychotropic Medications	<ul style="list-style-type: none"> • Support and encourage the dissemination of <i>OASIS</i> and medication management training to a variety of settings. • Work with the HHAs and other stakeholders to review the role of nurses to assist individuals with ADRD and family members with medication management in HCBS settings. 	<ul style="list-style-type: none"> • Continue the dissemination of <i>OASIS</i>. • Explore medication management training for other settings, including ERCs and Assisted Living facilities. • Use best practice forums to offer training regarding cause and effect of psychotropic medications including Train the Trainer models for HCBS nurses to build confidence related to psychotropic medications in HCBS settings. • Create specific training materials and modalities for primary care physicians and medical professionals on psychotropic medications and ADRD and other topics.

Focus Area	CFC-specific recommendations	Vermont recommendations
Use of Behavioral Supports	<ul style="list-style-type: none"> Participate in a workgroup with providers and stakeholders (including DMH, VDH, DDS and DVHA) to identify strategies to better meet the needs of the ADRD population in Vermont by shifting the culture away from behavior management toward person centered planning. 	<ul style="list-style-type: none"> Initiate and participate in workgroup to identify strategies to better meet needs for individuals with ADRD by shifting the culture away from behavior management to person centered planning for ADRD population in Vermont. Workgroup to include AAAs, HHAs, other providers/facilities, Governor's Commission, DAIL, DDS, DMH, VDH and DVHA. Use best practice forums to disseminate specific programs and trainings that are working on small scales (including providing information about resources for adaptive equipment and evidence-based practices as noted in the findings). Offer more 1:1 caregiver support for behavioral issues through care management, caregiver specialists and/or behavioral consultants in the home.
Worker Training and Support	<ul style="list-style-type: none"> Participate in the development of training as appropriate as a part of the workgroup (see recommendations in next column). 	<ul style="list-style-type: none"> Establish a statewide ADRD training workgroup (with AAAs, HHAs, other providers/facilities, Governor's Commission, DAIL, DDS, DMH, VDH and DVHA), perhaps facilitated by the Alzheimer's Association, to: <ul style="list-style-type: none"> Manage best practice forums (noted above) Establish basic expectations around ADRD knowledge for all staff Explore the creation of an annual statewide ADRD conference for staff Create regular telephonic ADRD informational/learning sessions for paid staff, potentially using the Evaluation Team's recruitment strategy of placing a notice for such calls in paychecks.
Informal Caregiver Training and Support	<ul style="list-style-type: none"> Provide CFC-specific materials as requested by providers and stakeholders developing public awareness vehicles around ADRD (see recommendations in next column). 	<ul style="list-style-type: none"> Work to develop various types of public awareness vehicles around ADRD including brochures, newspaper articles, public service announcements, internet materials, public access television programs and face to face workshops (see Vermont State Plan on Dementia). Work with the Blueprint's Community Health Teams to increase awareness of ADRD.

Conclusion

Choices for Care and DAIL have some specific opportunities to increase the effectiveness of services for CFC-eligible individuals with ADRD and their families. Specific recommendations focus on extending Adult Family Care from the pilot stages, exploring other options to create more potential “closer to” 24 hour care settings in the community, clarifying the variance process, and adding non-medical providers as a service option. Additional recommendations for Vermont in general, rather than CFC specifically, include providers and stakeholders working together to ensure that consistent, standard and valuable training is disseminated to all staff and caregivers who work with individuals with ADRD (including the continuation of *OASIS* in nursing facilities). An ongoing best practice forum program/training workgroup can be a vehicle for many of the recommendations. Implementing these recommendations will allow CFC and DAIL and also Vermont in general to continue providing high-quality services to individuals with ADRD across all settings and continuums of care.

Resources

UMass Medical School's Disability and Community Services conducted interviews with over eighty key informants during preparation of this policy brief. The Team recruited from the following pool of identified stakeholders:

Stakeholder types	Recruitment Strategies
1. Home Health Agency (HHA) Staff	Worked with DAIL to draft a letter of introduction which the UMass evaluators sent to CEOs, Directors and/or Managers.
2. Area Agency on Aging (AAA) Staff	
3. Adult Day Program Staff	
4. Long Term Care Clinical Coordinators (LTCCC)	
5. Nursing Facility Staff/ERC Staff	
6. PACE Staff	
7. Non-medical providers	
8. Advocates and stakeholders (DAIL staff, state staff, researchers, Alzheimer's Association, Governor's Commission of Alzheimer's disease, professional trade associations)	
9. Paid Caregivers	Placed notice in paychecks. Set up 2 dates and times for a toll-free group interview.
10. Family/(unpaid caregivers)	Worked with Nursing facilities, ERCs, HHAs, AAAs and the Vermont Alzheimer's Association.
11. Health Care Professionals	Part of interviews as appropriate.

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