

Vermont Choices for Care: Personal and Systemic Factors Leading to Nursing Facility Readmission

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Executive Summary

The Choices for Care (CFC) program was established by the Vermont Department of Disabilities, Aging and Independent Living (DAIL) in order to “provide Vermonters with individual choice and equal access to long-term care options in the community and nursing facilities . . .(and) prevent unnecessary use of nursing facility care by elders and adults with disabilities who have functional impairments” (Vermont Department of Aging and Independent Living, 2010).

In this study, UMass evaluators conducted qualitative in-person interviews with 23 CFC participants who had left a nursing home to live in the community and were then readmitted to a nursing facility for a long-term stay (≥ 90 days). The evaluators also conducted telephone interviews with 13 family caregivers and 12 case managers, including 10 from the Area Agencies on Aging (AAAs) and 2 from home health agencies (HHAs) to understand their perspectives on the reasons that some people who left nursing facilities returned to the facilities for long-term stays. In addition, the evaluators reviewed the Independent Living Assessment (ILA) and the care plan documents for each individual who was interviewed or whose family caregiver was interviewed.

The informants reported that the reasons that these CFC participants returned to a nursing facility included predisposing person factors such as falls and accidents, mental health, cognitive impairment and related issues, obesity and longstanding disability with an onset in youth or young adulthood. Individual preferences were also a factor. Although some CFC participants expressed a preference for the community setting from whence they came, in a few instances, CFC participants stated that they preferred the nursing home and so decided to return.

Additionally, a wide array of enabling environmental characteristics prompted the move back to a nursing facility when difficulties were encountered in the community. These ranged from challenges related to transition coordination and communication to limitations in the current assessment and care planning process, such as inadequate information regarding the caregiver’s perspective on the CFC participant’s needs and the caregiver’s ability to provide for them.

Informants also reported their perception that there was a need for better service integration and enhanced support for individuals who require more hours of care, particularly at night. They reported challenges in obtaining sufficient and appropriate support in community settings for those who may require assistance with lifting from more than one person or who may require the use of assistive technology, such as Hoyer lifts.

To better identify address these factors, we make recommendations in four areas: 1) improve the CFC assessment, care planning and case management processes; 2) enhance information and referral; 3) ensure appropriateness and sufficiency of services, and 4) enhance capacity of settings. The CFC assessment and care planning process does not conform to current knowledge about promising practices in the field and should be updated to incorporate an emphasis on the CFC participant's strengths, goals and preferences. Additionally, it should more comprehensively address issues such as mental health, cognitive impairment, risk for falls, caregiver support and other items. In addition, input from caregivers about the strengths and needs of the CFC participant and their own capacity and needs as caregivers should be sought. In performing the assessment and creating and implementing the care plan, it may be worthwhile to adopt a care team approach, such as that the approach utilized by Vermont's Community Health Teams, the Services and Supports at Home (SASH) program and that which was proposed in the planning process for Vermont's Dual Eligible application.

A team approach has been used successfully in other states to serve older individuals and people with disabilities (Meyer, 2011; Komisar & Feder, 2011; Palsbo, Mastal & O'Donnell, 2006). To ensure that this improved assessment and care planning process is implemented as intended, revisions to the case management standards and training for case managers and others involved is key. We recommend a multistakeholder advisory workgroup led by an independent contractor as a useful strategy for obtaining input into the development of a new process.

In addition, using the ADRC and other mechanisms to perform additional outreach and marketing regarding community options and available supports to individuals, family caregivers and physicians is an existing strategy that should continue to be supported going forward. Efforts to provide opportunities for education and counseling for family caregivers should take into consideration the demands on their time and incorporate strategies such as online education and phone counseling.

Our study of a relatively small sample of individuals who had returned to nursing facilities for a long-term stay suggested that efforts to address the appropriateness and sufficiency of services should begin with improved transition coordination and communication to ensure the smoothest possible transition from nursing facility to the community. As noted in a previous UMass policy brief, strategies to assist individuals who require more hours of care could include the use of non-medical providers, who could be trained and certified according to a standardized process (Cumings and Bruner-Canhoto, 2012). Training for family members and other direct care workers may also enhance their ability to support CFC participants in the

community through behavior management, the use of assistive technology such as Hoyer lifts and other strategies.

Although the rural nature of Vermont can pose significant logistical challenges for providing care, efforts to address the need for more nighttime care could include the approval of a minimum number of hours for such care. It could also include providing more support and education for family caregivers in managing the challenges of nighttime care through the use of behavioral consultants or consultation with physicians. Additionally, raising awareness of the availability of care in the ERCs and Adult Family Care for individuals needing 24-hour assistance who may prefer these settings and enhancing the capacity of these settings to serve a broader array of CFC participants is yet another strategy to provide support to those with the greatest need. By adopting these recommendations, DAIL has the opportunity to further position the CFC program to more fully meet the needs of its participants and to continue its progress towards achieving its mission.

Introduction

The mission of Vermont's Department of Disabilities, Aging and Independent Living (DAIL) is to "make Vermont the best state in which to grow old or to live with a disability - with dignity, respect and independence" (Vermont Department of Disabilities, Aging, and Independent Living, 2014). In 2005, Vermont secured a Medicaid 1115 waiver to establish the Choices for Care (CFC) program in order to "provide Vermonters with individual choice and equal access to long-term care options in the community and nursing facilities . . . (and) prevent unnecessary use of nursing facility care by elders and adults with disabilities who have functional impairments" (Vermont Department of Aging and Independent Living, 2010). This purpose is consistent with the Supreme Court's decision in *Olmstead v. L.C.* in which the Court found that the integration mandate of the Americans with Disabilities Act requires states to eliminate unnecessary segregation of persons with disabilities and to ensure that persons with disabilities receive services in the most integrated setting appropriate to their needs, as long as this does not require a fundamental alteration in state services (*Olmstead v. L.C.*, 1999). To implement these policies, CFC expanded opportunities for individuals to receive long-term services and supports in settings of their choice whenever feasible across the continuum of care, including their own (or family members') homes, enhanced residential care (ERC) settings, and nursing facilities.

CFC established three levels of need for long-term services – Highest Need; High Need; and Moderate Need – which is assessed using an independent living assessment. Individuals in both the Highest Need and High Need groups must meet Vermont's traditional nursing facility clinical and financial eligibility criteria; these individuals may choose to receive services in

community-based settings or in a nursing facility. Although some individuals in the Moderate Need group may meet these same clinical or financial criteria, they are not required to do so in order to participate in the MNG program (Cumings & Bruner, 2013).

Individuals identified as Highest Need are guaranteed services. Services are available to individuals in the High Need group as funds become available. Notably, Vermont has been fully able to provide service to individuals in the High Need group since February 2011 (the last time there was a waiting list for High Need individuals). Services are available to individuals in the Moderate Need group as funds allow. MNG funds are distributed to community agencies, which then manage access to services. In some areas of the state, this involves the use of waiting lists; Waiting lists have existed since the inception of the MNG program and given the large number of potentially eligible individuals, this is not anticipated to change in the foreseeable future.

CFC offers a range of community-based long-term services to individuals in the Highest Need and High Need groups. Depending on the setting (i.e. home vs. ERC), services may include case management, personal care, adult day care, respite care, companion services, medication management, social and recreational activities, 24-hour supervision, laundry and housekeeping services, personal emergency response systems, home modifications and assistive devices.

Home-based services can be delivered through consumer-directed care, surrogate-directed care, agency-directed care, and Flexible Choices (aka “cash and counseling”) models. A more limited set of services – case management, adult day care, homemaker services, and flexible funding – are available to those in the Moderate Need group.

With the establishment of the CFC program, Vermont strove to build on previous efforts to rebalance its system of long-term services and supports by “serving a lower percentage of people in nursing homes and a higher percentage in alternative settings” (Vermont Department of Disabilities, Aging and Independent Living, 2014). The program has grown considerably over the past nine years, from serving 3,447 individuals in October 2005 (Cumings & Trafton, 2014), to serving 5,294 individuals as of January 2015 (Personal Communication, Bard Hill, February 27, 2015). Moreover, beginning in 2013 and continuing to the present, a greater percentage of CFC participants have been receiving services in community settings (home and ERCs) than in nursing facilities (Choices for Care Data Report, 2014), pointing to the success of the program in reducing the use of institutional care and increasing the use of community-based services. Among CFC participants receiving home and community-based services, overall satisfaction with the program and program services is high (Cumings & Trafton, 2014).

Similar to other states, Vermont has used a variety of programs to support the transition of elderly people and people with disabilities from nursing facilities to community settings. Despite these efforts and the apparent success of the CFC program, the Vermont Department of Disabilities, Aging and Independent Living (DAIL) has observed that some CFC program participants have been readmitted to a nursing facility after having previously been discharged to the community. The reasons for this are unclear. Vermont DAIL contracted with the University of Massachusetts Medical School's Center for Health Policy and Research to conduct a qualitative evaluation of the CFC program to identify and explicate personal and/or systems factors that may impede a CFC participant's ability to remain in the community and contribute to undesired readmission to a nursing facility.

This policy brief presents findings from interviews conducted with CFC participants who experienced nursing facility readmission, as well as participants' family members and case managers in an effort to shed light on this phenomenon, and offers a set of recommendations that may help to address the issues and concerns raised by these informants and further help to promote community tenure for some CFC participants.

Literature Review

Although an extensive literature exists documenting the reasons that individuals enter a nursing facility, the literature that documents the specific experiences of those who are readmitted to a nursing facility after having been previously transitioned to the community is limited (Howell, 2007; Silberberg, Quinn & Lucas, 2007; Liu, McBride, & Coughlin, 1994; Miller & Weissert, 2000; Gaugler, Duval, Anderson & Kane, 2007). One factor that the literature clearly identifies as predicting future nursing facility admission is previous nursing facility admission (Gaugler, et al., 2007; Howell, et al. 2007; Coughlin, McBride, & Liu, 1990; Jette, Branch, Sleeper, Feldman, & Sullivan, 1992; Pearlman & Crown, 1992; Wolinsky, Callahan, Fitzgerald, & Johnson, 1992). Thus, the CFC participants who were of interest in this policy brief were already at significant risk of readmission to a nursing facility based upon their previous history of nursing facility use.

Studies of nursing facility admission have tended to use the Andersen Behavioral Model of Health Service Use as a framework for analyzing predictors of nursing facility admission; a few of the studies examining nursing facility readmission have done the same (Chen, Thompson-Adams, Berkowitz, Young & Ward, 2011; Howell, 2007; Andersen, 1995; Andersen & Newman, 1973). Although there is some overlap between the model components, the Andersen model organizes factors that may predict nursing facility admission into three categories: 1) predisposing factors which can include person variables such as sociodemographic characteristics and health status; 2) enabling factors, which can include

factors that facilitate or impede use of services such as the person's social environment and influences, and availability of informal care; and 3) the individual's perceived need for services as determined by measures such as the number of self-reported limitations in activities of daily living (ADLs) (Chen, et al. 2011; Andersen, 1995; Andersen & Newman, 1973). The small body of literature on readmission to a nursing facility following previous discharge to the community supports the notion that predisposing characteristics play an important role, but provides only limited insight into the role of enabling factors and/or need (as perceived by individuals, their family members and/or the professional caregivers serving them) in nursing facility readmissions.

An important source of literature on this subject can be found in evaluations of specific initiatives designed to assist individuals to transition to the community, such as the Money Follows the Person (MFP) Rebalancing Demonstration. Enacted originally by Congress in 2006 as part of the Deficit Reduction Act and expanded by the Affordable Care Act in 2010, the MFP program was designed to enhance opportunities for individuals who wish to transition to the community to do so and to assist states in rebalancing their systems in favor of providing community long-term services and supports (LTSS) (Orshan, Denny-Brown, Morris, Peebles, Kehn, Williams & Schoenfeldt, 2013).

The national evaluation of the MFP program is being conducted by Mathematica Policy Research, which has issued a series of reports on the program. In the Mathematica report on Grantee Progress as of June 2013 (Lim & Irvin, 2013), national data showed that of 35,050 total individuals, 6% of those transitioned as part of the MFP program were readmitted for a period of 30 days or more to a nursing facility, hospital or other long-term care institution between June 2009 and June 2013. Nationally, elderly individuals age 65 and older experienced the highest rate of readmission in the period from January to June, 2013 with a rate of 8%, followed by individuals with physical disabilities under 65, with a readmission rate of 5%. Rates of readmission varied widely by state. Vermont experienced a relatively low rate of readmission with only 1-4% of participants readmitted during that period (Lim & Irvin, 2013).

As reported by states, the most common reason for readmission was deterioration in an individual's physical or mental health status, followed by events such as falls or accidents that led to a hospitalization, the existence of a complex or chronic condition, and inadequate community or family member support either at baseline or at some time during the individual's residence in the community. Four states reported that readmission occurred at the request of either the family or the participant (Orshan, 2013). An earlier study conducted by Mathematica showed that MFP participants with lower levels of care need as assessed in the nursing facility

were significantly less likely to be readmitted than those with higher levels of assessed need (Lim & Irvin, 2013).

A study of one of the earliest and largest transition programs to precede MFP, implemented in New Jersey in 2000, found that the factors predicting readmission to a nursing facility included being male, single, and dissatisfied with one's living situation; not living alone; and experiencing a fall during the first 8 to 10 weeks post discharge (Howell, et al, 2007). A study of individuals enrolled in 12 Program of All-Inclusive Care for the Elderly (PACE) initiatives, found that admission to PACE directly from a nursing facility predicted subsequent nursing facility use. Among individuals originally admitted to PACE from the community, the only significant predictor of subsequent admission to a nursing facility was visual impairment (Friedman, Steinwachs, Rathouz, Burton & Mukamel, 2005).

In addition to studies examining specific transition initiatives, Chen and colleagues used national data to examine various patterns of transitions between the community and nursing facilities between 1994 and 2000. Their results showed that repeated nursing facility use and long-term admission were predicted by increased age and a lack of private insurance coverage. Income, on the other hand was not a significant predictor. Additionally, this pattern of repeated or long-term nursing facility use was predicted by high utilization of varied "discretionary services", including senior centers, Meals On Wheels, homemaker/companion services and personal care services (PCS), as well as high utilization of varied "nondiscretionary services", i.e. those prescribed and delivered by clinicians (and typically required by people with higher service needs) such as skilled nursing services, allied health therapies, oxygen and hospice care. Income, among other factors, was not a significant predictor (Chen, et al., 2011).

Another study examining the question at hand is one conducted by Chapin and colleagues (2009) which focused on individuals who had applied for nursing facility admission and received a pre-admission screening assessment, but were then "diverted" to the community. Individuals who were significantly more likely to be residing in the community rather than a nursing home five years later tended to be living alone and to have a lower level of impairment. There were no significant differences in age, gender, and availability of full-time informal support between those living in the community and those residing in a nursing facility at the end of the study period.

Method

In order to gain a multi-stakeholder perspective on the personal and systemic factors which can impede a participant's ability to remain in the community after discharge from a nursing facility, in-depth interviews were conducted with three types of informants – CFC participants currently residing in a nursing facility; participants' caregivers; and participants' case managers. Interview questions for the three informant types were developed by the UMMS evaluators in collaboration with Vermont DAIL staff.

Using the SAMS database, Vermont DAIL staff initially identified 73 living CFC participants who, since the beginning of the program, had been readmitted to a nursing facility after having been discharged to a community setting; such settings included participants' (or family members') homes, assisted living facilities, residential care facilities and, more recently, adult family care. To be included in the interview sample, CFC participants had to have been readmitted to and currently residing in a nursing facility for 90 or more consecutive days, and had to be able to consent to and participate in an interview of approximately 20-30 minutes in length. In addition, priority was given to CFC participants who had returned to the nursing facility in 2012 or later to maximize the likelihood that participants and caregivers would be able to recall circumstances that may have led to the readmission. Three additional individuals who were identified as having met eligibility criteria by nursing facility staff were added to the sample.

The majority of the CFC participants meeting eligibility criteria were concentrated in nursing facilities in the Burlington, Rutland, Springfield, White River Junction and Vernon areas. A Vermont DAIL staff member contacted the nurse managers or administrators of the nursing facilities in these areas to inform them of the project, to notify them that a member of the UMMS evaluation team would be in contact with them, and to seek their assistance in identifying CFC participants capable of participating in an interview.

With the assistance of nursing facility staff, the UMMS evaluators identified and recruited 23 CFC participants to participate in the interviews. The purpose of the evaluation was explained to participants and all signed a consent letter agreeing to be interviewed. Individual in-person interviews were conducted with the 23 CFC participants by a member of the UMMS evaluation team. Interviews lasted from 20 to 60 minutes; all interviews were audio-recorded and detailed notes were taken. Additionally, the evaluators interviewed 6 caregivers for CFC participants whose cognitive status rendered them unable to participate meaningfully in an interview. Characteristics of the 29 CFC participants who either participated themselves or for whom a caregiver was interviewed are shown in Table 1, below.

Table 1: Characteristics of CFC Participants (N=29)

Characteristics	N
Gender	
Male	12
Female	17
Age	
50-64	4
65-74	11
75-84	5
85+	9
Geographic Region (City/County)	
Barton/Orleans	1
Bennington/Bennington	3
Brattleboro/Windham	2
Burlington/Chittenden	6
Derby/Orleans	2
Ludlow/Windsor	1
Newport/Orleans	1
Rutland/Rutland	5
St. Albans/Franklin	1
St. Johnsbury/Caledonia	3
Vernon/Windham	1
White River Junction/Windsor	3
Community Setting	
Home	19
Extended Residential Care (ERC)	10
Community Tenure Between Nursing Facility Stays	
< 1 year	8
1-3 years	11
3+ years	10

Interviews with CFC participants were conducted by a member of the UMMS evaluation team and included a set of open-ended questions covered the following domains:

- Participant's reasons for returning to the nursing facility
- Participant's overall experience while previously living in the community
- Services received while living in the community
- Involvement of family members, friends and other caregivers, when available
- Any challenges to getting services and satisfaction with services in the community
- Any needed services that were not available/provided in the community
- Actions that can be taken to assist more CFC participants to remain in the community

At the completion of the interview, participants were asked for permission to contact a caregiver (i.e. family members and/or guardians) to obtain their perspectives on the circumstances associated with participants' readmission to the nursing facility. Although a few declined to give permission, the majority of CFC participants agreed and either provided the interviewer with the caregiver's name and contact information or gave permission to the nursing facility staff to do so. In many instances, nursing facility staff made the initial contact with the caregiver to inform them that a member of the UMMS evaluation team would be contacting them to arrange an interview.

Individuals providing case management services to the 29 CFC participants in the community were identified by Vermont DAIL staff using the SAMS database; DAIL staff provided this information to the UMMS evaluation team. A member of the UMMS evaluation team contacted the Area Agency on Aging (AAA) and other community-based organizations (CBOs) to introduce the project and to arrange interviews with case managers. A total of 12 case managers were ultimately interviewed; 10 (83% of the sample) were employed by the AAA and two (17%) were employed by home health agencies (HHAs). This ratio of AAA case managers to those employed at HHAs does not fully reflect the actual distribution of case managers in the community where approximately 50% of case managers work in AAAs and the other 50% work in HHAs and the findings should be interpreted accordingly. Two case AAA case managers and three HHA case managers that had been identified were no longer working with the organization identified in the SAMS database and could not be located.

Telephone interviews were conducted with 13 caregivers, including the 6 mentioned above, and with 12 case managers. Interviews with caregivers and case managers covered the same domains as the interviews with CFC participants. Caregiver and case manager interviews were not generally audio-recorded; rather detailed notes were taken by the UMMS evaluator conducting the interviews.

In addition to formal interviews with CFC participants, caregivers and case managers, the UMMS evaluation team obtained basic background information from nursing home staff regarding residents. The UMMS evaluation team also reviewed relevant CFC program documents, including written program descriptions, past CFC evaluation reports and policy briefs, and the program's Independent Living Assessment form, which is used by case managers in a face-to-face interview to identify a potential CFC participant's needs for Home and Community Based Services (HCBS). Once the information from the participant has been entered into the form, a computer program generates an estimate of the number of hours of assistance that the individual requires.

The interview audio-recordings and detailed notes were reviewed by two members of the UMMS evaluation team. The evaluation team members worked together to review the initial set of interviews, conducting a thematic analysis to identify emerging themes regarding events and circumstances related to participants' readmission to a nursing facility. The evaluators continued the thematic analysis of subsequent interviews, using a constant-comparative approach to identify and confirm major themes. The analysis of program documents and review of relevant literature helped to augment the interview findings.

Findings

Informants uniformly expressed appreciation for the services provided by Vermont's CFC program. This appreciation is reflected in comments from caregivers, such as *"My dad couldn't have stayed home with my mom without them"* and *"the state did well by us."* CFC participants also shared their appreciation of the program commenting, *"People who came in were very good with me. I got what I needed."*

Nevertheless, several challenges to successfully maintaining CFC participants in the community were raised during the interviews, along with recommendations for ways to enhance the current system of services. Recommendations for service enhancements to the CFC program and improved access to services provided by other programs or entities are provided later in this brief (see pages 24-34). The Andersen model provides a useful framework for organizing the major themes that arose from the interviews of CFC participants currently residing in nursing facilities, their family caregivers and the case managers who worked with the participants while they lived in the community.

Predisposing Person Factors

History of Falls and Accidents

Falls and accidents were reported by all three types of informants (CFC participants, caregivers and case managers) as an important reason for readmission to a nursing facility. Falls occur in all settings, including nursing facilities and certainly our interviews revealed that they were a precipitant to nursing facility admission among the CFC participants we interviewed. This finding is consistent with the literature. (Cameron, Murray, Gillespie, Robertson, Hill, Cumming, & Kerse; Gill, Murphy, Gahbauer, & Allore, 2013; Kiel, O'Sullivan, Teno & Mor, 1991; Tinetti & Williams 1997). One woman who lived in her own home commented, *"I fell and then someone had to come and pick me up. This led to the reason for deciding to come to a nursing home."* Falls occurred both among people who were living at home and among those who were living in residential care facilities. One woman described frequently falling at her residential care facility and when asked, said that none of the staff there had ever worked with her on fall prevention and that it was her sister, not staff, who got her a walker that improved her stability. This same resident commented that her fall at the residential care facility precipitated a "temporary" nursing facility stay which then became permanent saying, *"I came to the nursing home because I fell at the _____ House; the doctor wanted me to stay [here]."*

One circumstance associated with falls and accidents that came to light during the interviews – and that is not well documented in the literature -- was being injured while using a power wheelchair. Four CFC participants who used power wheelchairs were interviewed. Three CFC participants stated that they had either fallen or otherwise been injured while using a power wheelchair and that this incident had led directly to their readmission to a nursing facility. One woman explained that she fell while transferring into her power wheelchair and that it *"dragged me around the living room and ran over me . . .until it hit the desk"* causing injury. Another participant described breaking his shoulder and his arm when *"I was heading for the bathroom [in the wheelchair] and I collided with the toilet. It took about 3 hours to get up. I didn't have my portable phone with me and had to get the phone so that I could call rescue."* Yet another power wheelchair user reported getting his sleeve caught on his wheelchair's joy stick and slamming his legs into a dresser, causing the injury that led to his nursing facility readmission.

Mental Health and Substance Abuse Concerns

Informants identified several CFC participants as having a history of mental illness or substance abuse. One woman described having made two suicide attempts during her lifetime, saying, *"My father committed suicide and I guess I thought I should do the same."* In several cases, this history was identified as a contributing factor to a nursing facility readmission. For example, one caregiver described her mother as having *"an altered state of mental health"*

which led to her mother feeling “*overwhelmed*” when she was discharged home and prompting her mother’s decision to request readmission to a nursing facility.

Similarly, a number of case managers raised concerns about a lack of coordination and communication between the LTSS and mental health service provider organizations, which may result in inadequate mental health services for some CFC participants. Case managers suggested that that this lack of coordination may be due, in part, to the structure of the CFC program and the assessment process, noting that the assessment process does not adequately address mental health and related concerns. Some of them felt that, even when identified, these needs are not always addressed adequately. One case manager described a particular nursing facility readmission that she felt could have been prevented “*if there had been greater involvement with the mental health agency.*” Yet another noted:

We need to look at CFC. The program was built to deal with clients with physical needs and now we are seeing people with mental health needs and cognitive impairment. There has to be an agreement to come together to work with people with mental health [needs]. There is not a lot of collaboration.

Case managers were clear that they felt that problems related to mental health needs were not due to shortcomings in the CFC program alone. Although they felt that a substantial number of CFC participants had significant mental health needs, they perceived that serving individuals over the age of 60 was not a priority among mental health providers and felt that this was a broader issue that needed to be addressed to improve access to mental health services for CFC participants.

Behavioral and Cognitive Concerns

Additional issues related to challenging behaviors were raised in the interviews. Caregivers found managing behaviors related to cognitive impairment very difficult. One caregiver whose mother had dementia stated, “*When it was just physical needs we could have taken care of her; but when it came to the mental part of it, it just became impossible.*” Both caregivers and case managers described incidents of possible self-neglect among a few CFC participants as contributing to a nursing facility readmission. For example, caregivers and case managers described behaviors such as the accumulation of possessions to a point that bordered on hoarding, a lack of attention to personal hygiene and not following through on prescribed medical care among some CFC participants.

Obesity

Several CFC participants interviewed were significantly overweight. In some cases, individuals may even have been considered morbidly obese, but we did not have sufficiently complete information on all individuals to make this determination. As one CFC participant stated, *"I'm a big woman."* Another noted that, *"I like to eat . . . and you can tell."* There is evidence in the literature that obesity is a predictor of nursing facility admission (Elkins, Whitmer, Sidney, Yaffe & Johnston, 2006; Valiyeva, Russell, Miller & Safford, 2006). Nursing facility staff and, in some cases, the CFC participants, described how their weight created challenges to obtaining care in the community and led to their readmission to a nursing facility.

Longstanding Disability

A number of the CFC participants had longstanding disabilities stemming from childhood or early adulthood, ranging from polio and cerebral palsy to intellectual disability, brain injury, mental illness or substance abuse and, in some cases, combinations of these disabling conditions. These individuals generally tended to be among the younger participants, with their ages usually falling in the 50-64 or 65-74 age ranges.

Enabling Environmental Factors

Transition Communication and Coordination

Case managers raised concerns about coordination and communication during the transition process. One case manager commented that, *"Nursing home discharge for a number of reasons is not a smooth process and can set people up for failure."* There appeared to be a lack of clarity regarding the roles and responsibilities of the case managers and other professionals involved in the transition process. For example, more than one case manager noted that equipment such as wheelchairs and shower benches that should have been provided in the person's home were frequently not there when the individual arrived or were not appropriately tailored to the individual's needs. In addition, case managers noted that there was frequently a gap in a CFC participant's access to medications because the pharmacies need confirmation that the participant was living at home in order to fill a prescription.

The Influence of Physicians in Nursing Facility Admissions

During several interviews, CFC participants and family caregivers mentioned that the participant's physician helped them to decide that the nursing facility was the best option. This finding is consistent with the literature pointing to the significant influence that physicians have on older adults, individuals with disabilities and their caregivers' regarding nursing facility decisions (Kemper & Murtaugh 2006; McAuley & Travis, 1997). A frequent comment by family caregivers was that the CFC participant was admitted because *"the doctor thought it was best for her to be in the nursing home."* Another caregiver said that while caring for her parent who

was diagnosed with dementia, the family reached out to the doctor for guidance but did not get a response until...

...one day we showed up at the doctor's office with her and said we are at the end of this and then the doctor contacted the nursing home to start the process of getting her back into the nursing home.

A CFC participant mentioned that when her service providers changed, her physician suggested that she consider a nursing facility because there she would receive needed assistance with medication management and the other care. More than one person noted that their nursing facility admission was originally intended to be temporary, but that once admitted the “*doctor wanted me to stay there*”, and they did so based upon this advice. Neither CFC participants nor family caregivers described instances where physicians referred them to community services.

It is a fundamental tenet of CFC to allow participants to choose the setting in which to receive services. Although there were a few CFC participants who stated that they would prefer to be at home or in another setting, some commented that the nursing facility was the right place for them and that it was their choice to remain there. One participant who is contending with memory loss stated, “*The nursing home is good. I would prefer to be here.*” Another participant stated, “*I like this better. It's more like home here.*” When asked for her reasons for choosing to be readmitted to a nursing home, yet another CFC participant said,

I came to the nursing home to be evaluated and then decided to stay. I found the staff to be nice. The food is not bad for institutional food. The place is nice. They do try hard and they do a lot of nice things.

Enhanced Residential Care Options

CFC participants were frequently confused about their options for assisted living and residential care facilities. They did not appear to have accurate information about the differences between these two settings and the costs and services associated with each setting. Several individuals stated that they did not consider assisted living because they “*could not afford it*” and seemed to be unaware that assisted living may provide a limited number of slots for Medicaid-eligible individuals or that there are other residential care settings in addition to assisted living or nursing facilities. It appeared that several participants believed that the care options available as one's care needs increased were home, assisted living and nursing facility.

Some CFC participants who were familiar with residential care facilities raised concerns about these settings, specifically about the physical structure of the buildings. More than one

described the rooms available in the residential care facilities as “*small and dark.*” Individuals who used wheelchairs described feeling very cramped in these settings, particularly in the bathrooms, with comments such as “*I couldn’t move.*” These characteristics made the residential care facilities less attractive as options for care for some participants. On the other hand, those participants who did live in residential care facilities before reentering the nursing facility, tended to describe them in very positive terms. A typical comment was, “*I loved living in _____ House.*” Some residents described being sorry to leave these settings, making comments such as “*I would have liked to have stayed there, but I couldn’t.*”

Perceived Service Needs

The CFC Eligibility and Assessment Process

Family caregivers and case managers noted that the current complexity of the CFC program can impede a participant’s use of services. One family caregiver described completing the annual financial redetermination forms sent by the state as “*painstaking.*” Another family caregiver commented, “*When they send the redetermination form, I would do it for my parents, because it’s a lot of information.*” A case manager noted that, “*the paperwork for Vermont Medicaid is pretty overwhelming . . . there are many people who would have difficulty with the paperwork.*” And another described how the complexity of the application paperwork discouraged one participant from signing up for the Flexible Choices program.

In addition to concerns about the complexity of the paperwork, other concerns were raised about the assessment process. An examination of recent versions of the Independent Living Assessment (ILA) form revealed a brief set of questions about a program participant’s emotional and mental wellbeing. However, we reviewed 28 ILA forms for the CFC participants that we interviewed and found that in 8 of these assessments at least one portion of the mental health assessment – usually the section on emotional wellbeing -- had not been completed. Some case managers felt that the form should ask additional questions related to mental health needs. One case manager noted that it is important to document, “*why the person needs the assistance. Is it a psychiatric diagnosis that stands in the way of completing the task or is it a physical limitation? The form doesn’t give an opportunity to identify that and that makes a difference in service needs.*”

Examination of the assessment form also revealed a deficit-based focus and a paucity of questions related to a CFC participant’s strengths, goals and preferences. The approach to assessment currently reflected in the ILA is not consistent with the state’s commitment to a person-centered system. The absence of an emphasis on strengths, goals and preferences may undermine the effectiveness of care planning.

Several family caregivers commented that they felt that there should be greater opportunity for their perspectives and needs to be included in the assessment process, thereby indicating another possible shortcoming of the assessment process. One daughter of a participant who was her parent's primary caregiver described sitting in on the assessment with a social worker and her parent, and feeling that her parent was inflating the capacity of the available family support network and the parent's own ability to complete tasks. She stated that, *"There should be a real assessment of whether somebody can handle living independently and whether the other person is equipped to help take care of their needs."* Another caregiver described feeling ignored and not able to share his ideas for his spouse's care. Caregivers also described feeling overwhelmed by the demands of caregiving for their loved ones and CFC participants noted that they moved into the nursing facility because their family caregivers *"just couldn't do it any more"*.

Although Vermont's Independent Living Assessment Manual states that "in order to obtain accurate and complete information, it is sometimes necessary to gather information from other sources, including family and caregivers", it leaves such inquiries to the discretion of the person completing the assessment. The assessment form itself includes a brief section on "Supportive Assistance", but does not direct the case manager to ask these questions directly of a caregiver. In fact, only one question is clearly intended to be asked directly of a caregiver – "In your role as a caregiver do you need assistance in any of the following areas?" A review of the ILA forms for the CFC participants included in this study revealed that, in most instances, this question was left blank by case managers.

Sufficiency and Appropriateness of Services

Need for Additional Service Hours. Although many CFC participants and caregivers had high praise for the individuals who provided their care while in the community, most of the family caregivers made statements to the effect that *"just a few more hours"* were needed to enable their loved one to remain in the community. Some caregivers described the CFC participant as needing more hours of care overall, while others were more specific in describing how extra hours of care would be helpful. Assistance with toileting or catheter care was a common concern, both during the day, and particularly at night. Nighttime is particularly difficult for caregivers due to the need to assist with these tasks along with transferring and positioning the individual in bed. In the words of one public guardian of a woman with combined physical and mental health conditions, *"nighttime is a deal breaker."* This same guardian cited the woman's incontinence overnight as a major contributing factor to her readmission to a nursing facility after a very brief stay in the community. Another family caregiver talked about her mother soiling herself at night and having to wait until someone came the next morning to be cleaned up. Similarly, a caretaker whose mother had dementia

mentioned that, *“it would have been helpful to have someone available who could keep watch overnight so that I could get some sleep.”* She said that as the dementia progressed, her mother would get up at night and wander around the house crying and that this was difficult for her to manage.

The concerns about sufficient service hours were echoed by the case managers. There appeared to be a general perception among case managers that fewer hours were being approved than had been authorized when the CFC program began in 2005. Additionally, several case managers felt that Long-term Care Clinical Coordinators (LTCCCs) routinely approve fewer hours than calculated by the case managers through the ILA. One case manager noted, *“I answer the questions correctly and the system calculates the hours, but then I send it on to the LTCCCs and they cut the service plan hours.”* There is a variance process that would permit case managers to request additional hours, but as one case manager described it *“the process of getting a variance is too long and too difficult. You are often left wondering if you are going to get [an approval] or not.”* In addition, as suggested in a previous policy brief by UMMS evaluators, not all case managers appear to be aware of the variance process (Bruner-Canhoto, et al., 2012).

There are additional challenges with ensuring that CFC participants receive the hours of care that they need. Case managers noted that *“home health agencies cannot fill the hours”* even when they are approved by the LTCCC’s. Transportation and the time and distance necessary for direct care workers to travel to provide care were also described as barriers. As one case manager noted, *“it is easier to serve people when they are in a city.”* Lastly, case managers and caregivers felt that relatively low wages reduced the availability of workers to provide direct care.

Such reports, particularly of a need for nighttime care, are consistent with the literature, which shows that such difficulties predict and, at times, hasten nursing facility admission (O’Donnell, 1992; Pollack, 1990). It is a problem posing unique challenges due to the practical issues of staffing nighttime hours, particularly in a rural state with long distances to travel. One caregiver stated,

The basic thing is that the doctor said that my husband needs 24 hour care and we can’t afford the extra money to pay people to take care of him and the VNA did not have enough people who could come in to do something like that. I don’t think they do that for anybody.

One case manager reported that some CFC participants were *“able to use their 720 hours of companion care for overnight care in the consumer-directed or surrogate program, but*

they use those hours up quickly.” Although many acknowledged the logistical challenges it would involve, a number of case managers and family caregivers felt that in some cases, CFC participants needed 24-hours of care in order to be maintained in the home. One case manager commented that *“[even though] it may be expensive for the state, the state should explore the provision of 24-hour care in a participant’s home.”*

Adult Family Care is another alternative for providing nighttime or 24-hour care, but case managers reported that the process of getting Adult Family Care was inefficient because,

“there is no existing list of approved and available homes which can be reviewed to determine whether a site meets the needs of a participant. You have to call the authorizing agency and tell them that someone is interested and then they will look for someone.”

Case managers reported that this process can create delays in obtaining this service. Another concern raised about Adult Family Care was the trustworthiness of the individuals willing to assume this responsibility. One CFC participant reported having been mistreated by his caregiver in Adult Family Care and returned to a nursing facility as a result.

Need for Two-Person Assist. When describing the CFC participants who were significantly overweight or perhaps morbidly obese, nursing facility staff in some of the facilities we visited indicated that, at least in part, the individual was readmitted to the nursing facility because they required *“a two-person assist.”* Although interviews revealed that some CFC participants may have had assistive devices such as Hoyer lifts in their homes, for the most part family caregivers did not utilize these devices to assist them in providing care to their family members. One family caregiver, a small elderly woman caring for a husband who was over six feet in height, when asked about a Hoyer lift said that, *“I simply couldn’t do it.”* At least one family caregiver interviewed mentioned that getting paid staff to use the Hoyer lift was also difficult. She mentioned that they eventually found male personal care assistants (PCAs), but that they all were smaller than her husband and one male PCA *“would not even try the Hoyer lift.”*

Challenges in serving CFC participants whose size made them difficult for one person to lift and transfer was encountered not only in the home, but in other settings as well. A CFC participant who had resided in a residential care facility commented that she moved from that setting to a nursing home because, *“I needed help from two people and they weren’t set up for that.”* When asked about whether residential care facility staff had ever tried using a Hoyer lift, she stated that, *“They don’t have those things. They’re not equipped like a nursing home.”* One

case manager commented that she was unable to find a home for a client through the Adult Family Care program because the adult family homes,

“could not take the participant because she requires too much help – a Hoyer lift transfer or a 2-person lift. I couldn’t find anybody who could provide that level of care with the budget that would be given to the participant.”

Need for Worker Training. Most participants were very pleased with and appreciative of the services they had received in the community, generally describing them as *“very helpful.”* One family caregiver commented that, *“We were quite happy with the agency we had and we had choices of 3 different agencies. Any time you called with a question or something, somebody got back to you.”*

Even so, a couple of family caregivers mentioned that some of the workers could have used more training. One family caregiver stated,

“Some of the people who came in were very poorly trained. One time while with my Mom, a girl came in and asked what she can do now. I told her to clean the bathroom. She went into the bathroom for less than 3 minutes with a paper towel and came out and said it was cleaned.”

As noted previously, there were difficulties in getting direct care workers to use equipment like Hoyer lifts, also suggesting a need for training.

Case Management Needs. Although case management services were generally viewed as helpful, one family caregiver voiced frustration with the case management services received. She stated,

In the last 6 months we had her at home, there wasn’t anyone who contacted us and said, do you need more help, do you need more outside people coming in. We were just given this amount of hours and told this was it. I think that she needed to be reevaluated more often. There didn’t seem to be anything in place to do that.

Case managers raised concerns about the adequacy of hours allotted for case management, particularly for CFC participants with mental health needs. They felt that these individuals in particular needed more case management hours. One case manager also commented that it would be useful to adopt more of a care team approach to service planning and delivery, but this would also require more hours of time for coordination by the case manager.

Medication Management Needs. The need for additional support for medication management was a theme raised by CFC program participants, family caregivers and case

managers alike. Medication management can be particularly challenging for elderly persons and persons with disabilities for a variety of reasons, including their frequent need for multiple prescriptions and underlying physical and cognitive limitations. One CFC participant identified the difficulties that he had in managing his medication as the primary reason he had returned to a nursing facility, saying *“I kept forgetting them . . . and so I figured I had better get back here [the nursing facility].”* Another participant explained that he found it difficult to take his medications regularly, even with assistance, stating, *“A nurse did all of the medications. She organized them in a seven day planner but it was still tough to take them all.”* One of the case managers described how a CFC participant’s need for narcotics for pain relief contributed to her readmission to a nursing facility, stating that,

“the client was prescribed some strong narcotics and had problems managing the medication when living in the community. With PACE (adult day programs) closing, the physician wasn’t sure the client could manage the medication herself at home, so he suggested she go to the nursing home.”

Availability of Family Caregiver Education and Support. Family caregivers tended to minimize their own needs as illustrated by the words of one family member who stated, *“I didn’t ask for anything for myself.”* Even so, during the interviews it became apparent that there were supports and education that would have enhanced family caregivers’ ability to continue providing care and may have helped to prolong the CFC participant’s ability to stay in the community. One support need identified by family members was counseling. The daughter of one CFC participant noted, *“A lot of people don’t ask the caregiver how they are doing. Some type of caregiver support system would be wonderful - person to person, a group counselor, via phone would be great.”* Yet another family member commented, *“I think it would be good to offer a social worker who could work as counselor or therapist for the patient and for the caregiver (emphasis added).”*

Interviews with family caregivers suggested that they could also benefit from information about their loved one’s medical conditions and future prognosis and other aspects of care. One woman described how she was *“learning on the job about dementia care”* as she cared for her aging mother and would have appreciated more information in advance. Another caregiver commented on the need for more information, saying *“there just needs to be more support to help people taking care of elders. This is the first time for them. They don’t know the ropes. They don’t know what they are up against.”* In addition, one spouse of a CFC participant stated that she would appreciate social opportunities that caregivers and their loved ones could attend together. Even as family caregivers recognized the possible benefits of support for

themselves, they felt keenly the lack of time for getting such support, even if they were aware of the available services. One family member commented,

“I work and have to take care of my mother. I could never attend the workshops. I just didn’t want to take any more time away from life to attend the workshop. I just didn’t have any more time to give.”

Discussion and Recommendations

In interpreting the findings from the qualitative interviews, it is important to bear in mind that the events described took place during a period of substantial system redesign. Vermont has long been a leader in health system reform, instituting many innovative initiatives as part of its Blueprint for Health such as Primary Care Medical Home (PCMH), Vermont Information Technology Leaders (VITL) and Services and Supports at Home (SASH) along with new programs approved as part of an 1115 waiver and many others. The pace of reform was accelerated with the passage of the Affordable Care Act and together these efforts have prompted significant change in the health care system in Vermont. The services and supports made possible under Vermont’s health reform efforts and the ACA may not have been available during the period when many of the respondents were living in the community. Although we prioritized interviewing those respondents who had been readmitted in 2012 or later, individuals who had been in a nursing facility for longer periods were included in the study sample. Approximately a third of respondents had been living in a nursing facility for three years or more and another third had been living in a nursing facility for 1-3 years. Therefore, many of these participants may not have been able to avail themselves of some of the services and supports available as a result of health reform.

Additionally, it is helpful to consider that, generally, the CFC participants and family caregivers interviewed for this study talked about their personal experiences while case managers were more abstract and generalized to their perceptions of the program as a whole. Our questions invited the informants to point to challenges in their experiences with the CFC programs because this evaluation focused on people who returned to the nursing facility and thus were not able to remain in the community. It is also useful to bear in mind that qualitative interviews such as these are useful for identifying and elaborating on emergent concerns related to issues under investigation, but are not generalizable to an entire population. The findings should be considered in this light.

Based upon our findings, we make recommendations in four key areas: 1) improve the assessment, care planning and case management processes; 2) enhance marketing and outreach; 3) ensure the sufficiency and appropriateness of services; and, 4) enhance the capacity of settings.

Revise the CFC Assessment, Care Planning and Case Management Processes

The findings suggest a need for enhancements to the CFC assessment, care planning and case management processes to better address the needs of CFC participants and their caregivers. In addition, they suggest the need for a multidisciplinary team approach.

Revise the CFC Independent Living Assessment

Our review of the existing Independent Living Assessment (ILA) forms revealed a deficit-focused approach which left little room for an examination of the CFC participant's strengths, needs and preferences. The final rules issued pursuant to the Affordable Care Act and governing all HCBS 1915(c) waiver programs enhance those provisions of the Medicaid program that require person-centered-planning to include assessments not only of the program participants' needs, but also their strengths, goals, and preferences (Medicaid Program, 2014). Although these provisions do not apply directly to the Choices for Care program, which is instead authorized under the 1115 waiver, they do represent the most current thinking about promising practices for assessment and, as a result of being required under the 1915(c) waiver, will likely be widely adopted among HCBS programs offering services similar to those offered in Choices for Care. Therefore, to conform to prevailing practice, we would recommend that this approach be incorporated into the ILA conducted by the CFC program as well.

The findings also suggest a need for more comprehensive assessment of mental health and other conditions that may have an impact on an individual's long term care needs, such as brain injury. Similarly, it may be that the current questions regarding falls could be enhanced to better assess risks for falls and other accidents, including for participants who use wheelchairs, particularly power wheelchairs. The tool used by the state of Washington includes a fairly detailed set of questions about falling, although even this set of questions does not contain questions about falling specific to wheelchair users. Washington's tool also has an in-depth assessment of the care recipient's mental health needs with questions about a variety of behaviors such as hoarding and verbal abusiveness.

Although it is important that any assessment be person-centered and respectful of the needs and perspectives of the CFC participant, caregivers stated that they would like an opportunity to provide input into the assessment of the CFC participant's needs and also to have a chance to describe their own capacity and needs with regard to caregiving. Efforts to enhance assessment to address issues such as these are currently underway in other states, such as Minnesota and Washington (Minnesota, 2014; Washington, 2003). There is a growing consensus among policymakers that assessments for home and community based services should be not only person-centered, but also family-centered and include a full caregiver assessment (Kako, 2011; Kelly, Wolfe, Gibson & Feinberg, 2013; Commission on Long-Term

Care, 2013). This effort is in response to the voices of families and also to growing evidence that improving caregiver support can delay nursing facility admission (Mittelman, 2006). According to the AARP Public Policy Institute, as of December 2013, fifteen states included a full caregiver assessment and three additional states were in the process of developing such an assessment for the Home and Community Based Services programs (Kelly, et al., 2013). Minnesota and Washington are among those states on the forefront of caregiver assessment and have tools worth examining (Minnesota, 2014; Washington, 2003). They include questions regarding the impact of caregiving on the caregiver's health, stress level and other aspects of their wellbeing, and ask about the use of caregiver support services. The inclusion of a caregiver assessment is an important first step in providing better support for caregivers. It would help to identify the information and services they need to maintain their loved one in the community.

The Affordable Care Act also amended provisions governing Medicaid Home and Community-Based services to require a caregiver assessment for the 1915(i) state plan option. Again, although, these rules do not govern Vermont's CFC program, which is operated pursuant to an 1115 waiver, they do reflect current trends in the field of assessment and so should be included in any effort to revise Vermont's ILA.

Revise the CFC Care Planning Process

Concomitant with the process of reviewing and potentially revising Vermont's ILA, attention should be paid to the content of the care plan document. The current version of the care plan document is relatively bare bones, listing little more than those services for which the CFC participant is authorized, beginning and end dates for service, the number of units of service allocated, the total cost and in some instances, whether services are self-directed or agency directed. It does not constitute a person-centered document that truly provides a picture of the individual as someone with strengths, preferences, goals and needs. In addition to amending requirements for assessment in the HCBS program, the ACA also amended requirements for service plans and required that they include individually identified goals and preferences, e.g. community participation, employment, income and savings, health care and wellness, education and others. It also required that the plan describe both paid and unpaid services and supports, identify the service providers and other items. As noted above, these regulations are not binding on the CFC program; however, these new standards should be carefully considered in any effort to update the care plan document.

Revise the CFC Case Management Standards

The revision of the CFC assessment and care planning processes would also necessitate a revision of the existing case management standards as it would have significant implications for the performance of this role. Such a revision would also present an opportunity to enhance

the existing standards, which are approximately 20 years old and, for the most part, contain relatively broad statements about the role of case managers with relatively little detail about the activities to be performed as part of this role on a day to day basis.

Incorporate a Multidisciplinary Care Team

Our findings suggest that an interdisciplinary team approach might be a more effective way of addressing the assessment, care planning and care management needs of individuals with such varied and complex physical and mental health/substance abuse issues such as those found among CFC participants. A care team approach is utilized by Vermont's Community Health Teams which support the 124 primary care practices operating as patient-centered medical homes (PCMHs), an approach which has been shown to be cost-effective. These care teams can include professionals ranging from physicians and nurses to nutritionists, pharmacists, physical and occupational therapists and social workers. The care team approach is also used in the SASH program, Medicare and Medicaid Accountable Care Organizations (ACOs) and was included in the planning for Vermont's Dual Eligibles Demonstration (Vermont Agency of Human Services, 2013; Vermont Department of Health Care Access, 2015).

A care team approach has been used successfully in other states to serve older individuals and people with disabilities by organizations such as the Commonwealth Care Alliance (CCA). In addition to performing well on measures of quality, CCA has also shown that its team-based model can reduce hospitalizations and nursing facility stays and slow the growth of medical costs for older people and people with disabilities (Meyer, 2011). Care team approaches have been used successfully in other programs across the country as well (Komisar & Feder, 2011; Palsbo, Mastal & O'Donnell, 2006).

A multidisciplinary care team would facilitate the integration of medical and mental health/substance abuse services and the needs of those with longstanding disabilities such as brain injury. Another area in which a care team approach might be helpful is in the area of fall assessment. When falls are identified as a concern during the initial assessment, the care plan could include a follow-up home safety evaluation, for example, by an occupational therapist as the next step. These efforts could be supplemented by providing CFC participants and family caregivers with checklists and other information that would help them to raise their own awareness of environmental or other factors that may present a falling hazard and providing them with information about programs and resources to address these problems (Rubinstein, 2006).

For those individuals who use wheelchairs, the care plan could also include the services of a physical or occupational therapist who is skilled in wheelchair evaluation, perhaps in

conjunction with a durable medical equipment professional, to determine whether an individual's wheelchair is appropriately tailored to the individual's needs. It may also be necessary to provide additional training for individuals and caregivers in skills necessary for the safe operation of the wheelchair, including how to make safe transfers from wheelchair to bed, chair and toilet.

This substantial reform of the assessment, care planning and case management standards should be accompanied by training of the case managers and others involved in care so that the new processes and tools are understood and the expectations for assessment, such as the need for annual reassessment, care planning and case management are clear.

In summary, the ILA, the care plan and case management standards are merely tools to be used as part of a larger process of determining how to best serve a CFC participant. As the CFC program is integrated into the Global Commitment 1115 waiver, we recommend that DAIL take this opportunity to review, revise and/or supplement the existing assessment, care planning and case management processes, including these tools, to better address the needs of the individuals it serves. In so doing, we recommend that Vermont strongly consider incorporating an interdisciplinary team approach into those processes. We would recommend that Vermont DAIL update assessment, care planning and case management training accordingly to ensure effective implementation.

We further recommend that Vermont DAIL consider hiring an outside contractor with relevant expertise to convene an advisory workgroup for this purpose, including Vermont DAIL staff, case managers and other service providers, CFC participants and their caregivers, nursing facility representatives and other stakeholders to review existing processes, tools and standards, compare them to those utilized in other states and develop recommendations for new tools, processes and standards going forward. As part of this effort, the advisory workgroup could identify areas where coordination and communication could be enhanced to ensure effective implementation of the results of the assessment, related care plan and case management.

Enhance Outreach and Marketing

Enhanced outreach and marketing to individuals, family caregivers and health care providers could address several of the challenges identified in the findings, such as the need to raise awareness about community LTSS alternatives to nursing facilities among participants, family caregivers, physicians and other health professionals. In addition, caregivers could benefit from information and resources to support their own health and wellbeing. Fall

prevention is yet another area where enhanced outreach and information might prove beneficial for CFC participants, caregivers and healthcare providers.

The Vermont Aging and Disability Resource Connection (ADRC) has taken on an increasing role in educating individuals and family caregivers about the availability of care in different settings through the use of Options Counseling and other mechanisms. The ADRC is also a central player in efforts to educate physicians and health care professionals about the needs of and resources for people with disabilities and elders. It has piloted the ADRC Care Transitions Pilot Project which involves forging connections and sharing information about individuals served among the ADRC partner agencies, hospitals and community health teams in southwestern Vermont. This project will eventually incorporate the Universal Transfer Protocol Process which will involve the development of an initial set of standardized data elements to be exchanged among providers and recipients of services. This purpose of this effort is to facilitate the sharing of information among providers in a timely way in order to improve outcomes during and after care transition. An additional potential benefit of this arrangement may be to increase medical providers' awareness of the availability of home and community-based services as an alternative to nursing facility care and develop their relationships with these providers, thereby strengthening their ability to present a full array of choices to their patients.

In addition, through the use of Options Counseling and other mechanisms, the ADRC has taken on an increasing role in educating individuals and family caregivers statewide about the availability of care in different settings. Vermont DAIL should continue to support the ability of the ADRC partner agencies to perform outreach and marketing to inform potential CFC participants of their community living options and to educate family caregivers regarding programs providing support to them. There is an opportunity for both public and private entities, such as the Family Caregiver Support Network, the Area Agencies on Aging (AAAs), the AARP and the ADRCs to cooperate and to do further outreach and marketing to promote efforts to reach out to families such as the Senior Help Line.

Existing efforts could be enhanced by providing opportunities for families to obtain support and information with a minimal time commitment from the family member, such as the suggestion of one family caregiver that counseling be provided by phone. In addition, there has been some success in using online opportunities for family caregiver education and support. In addition to minimizing the demands on family caregivers' time, these strategies may address the logistical challenges inherent in providing supports to individuals living in the rural areas or Vermont (Blusi, Asplund & Jong, 2013; Clark & Leipert, 2012).

Outreach and marketing could also be an important component of efforts to reduce the incidence of falls among CFC participants. Currently, a wide range of organizations including hospitals, primary care practices, along with more broad-based entities such as Vermont's Department of Health and the Fall Prevention Coalition pursue a variety of initiatives to reduce the incidence of falls. There is an opportunity to encourage greater collaboration among these various entities and reenergize efforts to disseminate information and training about fall prevention. There is evidence to show that efforts to educate primary care clinicians and other staff in home care, outpatient rehabilitation, and senior centers about how to perform effective risk assessment and implement strategies for the prevention of falls can be effective (Tinetti, Baker, King, Gottschalk, Murphy, Acompora, Carlin, Leo-Summers & Allore, 2008). As noted previously, there is also evidence that providing information regarding fall prevention directly to individuals and family caregivers is also beneficial (Rubinstein, 2006). Given the risk of falls identified for wheelchair users in this evaluation, efforts to prevent falls and accidents should include information and strategies for prevention specifically tailored to these participants, particularly those using power wheelchairs.

Ensure Appropriateness and Sufficiency of Services

Enhance Service Integration and Communication

Our interviews with CFC participants, family caregivers and case managers suggest a need for greater integration and communication among different types of service providers, including LTSS and mental health service providers, along with providers serving individuals with other conditions, such as head injury or developmental disabilities, particularly for aging individuals with these conditions. As previously mentioned, a more in-depth assessment of certain aspects of a CFC participant's health and wellbeing, such as mental health, would be an important first step toward this goal as would a more detailed care plan. Our recommendation regarding an interdisciplinary care team approach such as those being utilized by the CHTs, SASH and other programs would also be an important step toward enhancing service integration. The use of a person-centered integrated care team would provide the CFC participant and case manager with more ready access to necessary expertise in mental health, brain injury and other needs specific to the individual which would facilitate the incorporation of such expertise into all aspects of assessment, planning and provision of services.

On a systemic level, DAIL has formed an LTSS Health Integration Team which represents the agency in the work of the Vermont Health Care Innovation Project (VHCIP) funded by Vermont's State Innovation Model Grant (SIM), a federal initiative designed to effectuate payment and service delivery reform. The SIM/VHCIP initiative presents an additional opportunity to address how LTSS, mental health and substance abuse services may be better integrated at the systemic level both for CFC participants and for all Vermonters.

Lastly, Vermont DAIL has recently launched an initiative to address self-neglect which holds promise for enhancing efforts to promote recognition and improved services for individuals who engage in behavior that may constitute self-neglect. This is a concern that would also potentially benefit from an interdisciplinary care team approach (Vermont Department of Disabilities, Aging and Independent Living, 2014).

Enhance Transition Coordination and Communication

In keeping with the theme of service integration, our findings underscored the importance of a smooth transition from the nursing home to the community and indicated that, at times, the coordination and communication between the nursing facilities, case managers, community service providers, individuals and their family members could be more effective. Federal regulations and guidelines require that individuals and families be fully informed about how to access services in the community as part of the transition process; however, ensuring that services are accessed as intended is challenging. (Requirements for Long-Term Care Facilities, 2010 and Centers for Medicare and Medicaid Services State Operations Manual, 2014) Vermont DAIL may want to examine this issue more closely to obtain more information about how and why breakdowns in communication and coordination occur so that steps to improve the transition process can be identified. This issue is yet another example of the need for modification of the current assessment, care plan and case management processes and underscores the likely advantages of utilizing a multidisciplinary team. It also illustrates the potential benefits of using the Uniform Transfer Protocol to enhance the timely sharing of information among providers.

Address Need for Two-Person Assist

Although it would not be an effective strategy in all situations, family caregiver education on how to use Hoyer lifts and other strategies for transferring people who would otherwise require a two-person assist may be an important step in preserving the ability of many families to care for their loved one at home. This topic could be first addressed at the individual level as part of the assessment and care planning processes and then case management could be used to ensure that training and assistance are provided as appropriate. It can be addressed at the systemic level by incorporating it into the broader caregiver education efforts described above. Our findings also suggest that additional training for personal care assistants and other direct care workers, both in the individual's home and in residential care facilities and adult family care homes, may be a useful strategy.

Additionally, given that Adult Family Care may be a useful approach for providing care to individuals with substantial care needs, Vermont DAIL may want to offer education on these

strategies to Adult Family Care providers and perhaps even increase reimbursement for Adult Family Care providers who are willing to offer this level of assistance. Requiring all Adult Family Care providers to provide this service could also be an option, but considering the relatively small size of the program and the challenges involved in recruiting providers, other approaches might prove more fruitful.

Licensure for residential care facilities does not permit them to care for people who require a two-person assist without a waiver, and there are currently few incentives to go through the waiver process. Vermont DAIL may want to consider whether the scope of services provided by residential care facilities could be expanded to meet this need, thereby accommodating the preferences of those CFC participants who prefer this setting.

Enhance Access to Medication Management Services

Medication management can be particularly challenging for elderly persons and persons with disabilities for a variety of reasons, including their frequent need for multiple prescriptions and any physical and cognitive limitations individuals may have. An important step in addressing medication management among community-dwelling individuals is proper assessment of medication needs and the support required to ensure adherence to a prescribed medication regimen (Marek, 2008). The ILA form does include questions about medication management, but perhaps additional questions on this topic could be included. Some examples would be questions regarding whether the individual understands the frequency and dosage of the medications prescribed, whether he or she is actually able to complete the tasks needed to take the medications, e.g. open the pill bottle. Additionally a request for a list of the medications prescribed could be included as part of a larger revision of the assessment, helping to fully identify participants' medication management needs. This information could then contribute to a strategy for meeting this need in the care plan.

There is evidence in the literature for several strategies to support appropriate medication management ranging from simplifying medication regimens and pill packaging to phone reminders from nurses and telehealth interventions (including using televideo) to monitor medication adherence (Marek, 2008; Campbell, Boustani, Skopelja, Gao, Unverzagt & Murray, 2012; Smith, 2007). For elderly individuals with mild cognitive impairment, strategies that involve human communication, including telehealth interventions, have been demonstrated to have greater effectiveness than strategies that do not involve human communication (Campbell, et al., 2012; Smith, Lunde, Hathaway & Vickers, 2007). A recent study of a telehealth approach to integrating care for chronic illness and depression in elders involving the use of tele-monitoring of symptoms and medication use, a depression problem solving program, and enhanced communication between physicians and other providers, found

lower levels of depression, improved self-management and few emergency room admissions among participants in the treatment group compared to controls (Gellis, Kenaley, McGinty, Bardelli, Davitt, & Ten Have, 2012).

Hospitals, home health care agencies and others seeking to reduce readmissions for Medicare beneficiaries and generally improve patient care have been exploring the use of telehealth strategies, as have Medicaid programs in 13 states (Broderick & Lindeman, 2013; Center for Connected Health Policy, 2015). As part of the revision of the case management standards, a requirement regarding identifying and referring CFC participants to telehealth programs when appropriate could be included. Vermont DAIL may also find it useful to monitor this trend as implemented by other entities and, at an appropriate point in the future, consider whether it would be worthwhile to explore incorporating telehealth strategies into Choices for Care. Additionally, it would be worthwhile to undertake an examination of other practices currently utilized for supporting medication adherence among CFC participants to identify opportunities for improving this aspect of care.

Address Needs for Service Hours

A recurring theme in our interviews was the need for “just a few more hours” of care. Addressing this need is perhaps one of the most challenging issues confronting Vermont DAIL in its efforts to maintain CFC participants in the community, for reasons that have to do with both financing and logistics. In a previous UMMS policy brief on the potential role of non-medical providers in the CFC program, we recommended that Vermont engage in a 2-year phase-in process that would result in a system that would allow non-medical providers to offer their services to CFC participants (Cumings & Bruner-Canhoto, 2012). Although it is possible that these providers could displace current personal care and similar low cost services, it is equally and perhaps more likely that this strategy has the potential to substitute lower cost services for higher cost home health services. This strategy would also expand the available pool of workers, thereby helping to address some of the logistical barriers to providing more hours of care, in addition to the financial barriers. Concerns about the skill level of non-medical providers could be addressed through a training and certification process and the inclusion of these providers would increase the capacity of the CFC program to meet participants’ needs (Cumings & Bruner-Canhoto, 2012). One potential resource for such training may be the Massachusetts Direct Care Workforce Training Program sponsored by the Massachusetts Area Health Education Centers. This program offers online resources and a Train-the-Trainer curriculum for its ABCs for Direct Care Workers to states. (Massachusetts Area Health Education Centers, 2015).

In part, the desire for more hours was motivated by the need for additional support during the night. Some other states, such as Massachusetts, address the issue of nighttime care by approving a minimum number of hours, e.g. 2 hours, to address nighttime needs, but it is difficult to know whether such a solution would work in Vermont, due to the logistical challenges associated with travel and staff availability that might need to be addressed. Nevertheless, Vermont DAIL may find it worthwhile to examine this approach more closely to see whether it could feasibly be part of a solution to the problem of providing nighttime care, at least in some instances.

In addition to examining policy approaches for providing nighttime care, Vermont DAIL may want to pursue efforts to help caregivers manage some of the symptoms of dementia, such as nighttime awakening. In at least one study of such techniques, caregivers were successful in using behavioral interventions to improve the sleep hygiene of their loved one with dementia (McCurry, 2003). As suggested in a previous policy brief, Vermont DAIL may find it useful to provide access to behavioral consultants in the home to assess the behavior of the CFC participant and educate family caregivers about strategies for managing it (Cumings, et al., 2012). When the assessment reveals the need for such a service, it could readily be incorporated into the care plan and a behavioral consultant could even be an ongoing member of the care team. Additionally, the care plan could include a consult with the family physician about medical interventions that may help to address these symptoms. Such strategies may help to address the need for 24-hour care as well.

A revised assessment process and coordination of a care team's efforts might have implications for the number of hours of case management. To make this change in the most effective way possible, it may be useful to address the manner in which case management is currently reimbursed, which currently consists of fee for service payments for service in 15 minute increments. The workgroup could address this issue as part of their charge.

Lastly, the process of revising the assessment, care planning and case management processes is a potential opportunity for reassessing how the number of hours of service is determined. The additional information yielded by an interdisciplinary care team approach may provide for a more individually tailored approach to making this determination. The task force charged with the duty of revising the assessment, care planning and care management processes should examine this question carefully as part of its efforts.

Enhance Capacity of Settings

Many of the individuals who had experience living in the residential care facilities had positive comments about those settings and some expressed the wish that they could have

stayed there. Therefore, it may be worthwhile to pursue strategies for enhancing the capacity of the residential care facilities to serve the broadest possible population. In addition to addressing the issues raised in the previous recommendation regarding individuals who require a two-person assist, it may be useful to address the concerns regarding accessibility raised by those CFC participants who did not find the residential care facilities appealing, due to factors such as the relative inaccessibility of some. Given the level of functional impairment among CFC participants, addressing such concerns would enhance the ability of these settings to serve those who would most benefit from the significant support level of support they can provide.

Adult Family Care is a fairly new program and is an important alternative for providing nighttime or 24-hour care. To promote greater utilization of the program, Vermont DAIL may want to consider the concerns that were raised in the interviews about the length of time that it takes to obtain a placement, even though the current process may be a best practice for creating an individualized, person-centered match between the adult family care provider and the CFC participant. Other states pursue a variety of approaches for recruiting families (Mollica, Simms-Kastelein, Cheek, Baldwin & Farnham, 2009) *Building Adult Foster Care: What Can State Do?* Washington, DC: American Association of Retired Persons, 2009). In addition, as noted above, additional outreach to family caregivers through the Options Counseling available through the ADRC or other means would be an important way to ensure that this alternative is more widely available.

Conclusion

DAIL offers a wide variety of LTSS to support the transition of CFC participants from nursing facilities to community settings, and program participants, their family caregivers and case managers all value the services it provides. Despite DAIL's efforts to support participants in the community, a variety of personal and systemic factors prompt some CFC participants to return to nursing facilities for long-term care. To better identify address these personal and systemic factors, we make recommendations in four areas: 1) improve the CFC assessment, care planning and case management processes; 2) enhance information and referral; 3) ensure appropriateness and sufficiency of services, and 4) enhance capacity of settings.

The CFC assessment and care planning process does not align with current principles for person-centered planning and promising practices in the field and should be updated to incorporate an emphasis on the CFC participant's strengths, goals and preferences. In addition, it should more comprehensively address issues such as mental health, cognitive impairment, risk for falls and other issues. Revising the assessment and care planning processes would inevitably require a revision of the case management standards as well. In performing the assessment and creating and implementing the care plan and case management, we recommend a care team approach, such as is used the Community Health Teams, SASH and other programs. In addition, input from caregivers about the strengths and needs of the CFC

participant and their own capacity and needs as caregivers should be sought. To ensure that this improved process is implemented as intended, training for case managers and others involved is key.

We also identified a need for more information about community living options among individuals and family caregivers and health care providers. To address this issue, we recommend supporting the efforts of the ADRC and other mechanisms to disseminate information and provide referrals regarding community options and available supports to individuals, family caregivers and physicians is an existing strategy that should be enhanced going forward. Efforts to provide opportunities for education and counseling for family should take into consideration the demands on their time and incorporate strategies such as online education and phone counseling.

Our third recommendation would be to enhance the appropriateness and sufficiency of services. These efforts should begin with improving transition coordination and communication to ensure the smoothest possible transition from nursing facility to the community. Strategies to assist individuals who require more hours of care could include the use of non-medical providers, who could be trained and certified according to a standardized process. Efforts to address the need for more nighttime care could include the approval of a minimum number of hours for such care or more support and education for family caregivers in managing the challenges of nighttime care through the use of behavioral consultants or consultation with physicians. Our fourth recommendation is to raise awareness of the availability of care in the ERCs and Adult Family Care and enhance the capacity of these settings to provide the widest variety of options to individuals with the greatest need. By adopting these recommendations, DAIL has the opportunity to further position the CFC program to more fully meet the needs of its participants and to continue its progress towards achieving its mission.

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