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Flexibility for the Moderate Needs Group in Choices for Care

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Background

In October 2005, Vermont implemented Choices for Care (CFC), a 1115 research and demonstration waiver, to further its efforts to make long-term services and supports as available in the community as they are in facility settings. CFC encompasses the entire continuum of long-term services and supports. Today, CFC includes Home and Community-Based Services (HCBS) delivered through consumer-directed care, surrogate-directed care, agency-directed care and a "cash and counseling" model (Flexible Choices); Enhanced Residential Care (ERC) settings; and nursing facilities.

To fully support the provision of CFC services, a three-tiered system has been established in which individuals with long-term service needs are identified as: Highest Needs, High Needs or Moderate Needs. Highest and High Needs individuals meet Vermont's 'traditional' nursing home clinical and financial eligibility criteria and can choose the setting in which to receive services (i.e., home, ERC, nursing facility). Those individuals who are identified as Moderate Needs are below the level of care that would require nursing facility placement and may not meet the financial criteria for Medicaid long-term support services. DAIL established the Moderate Needs Group program to expand long-term services and supports to individuals "as a preventative method of delaying institutionalization, the use of more expensive services and maintaining quality of life" within the community (CFC Year 2 Quarterly Report, 2007). Similar to the High Needs Group, Moderate Needs individuals may also be placed on an applicant (waiting) list.

Choices for Care provides limited case management, homemaker and adult day services to individuals in the Moderate Needs Group (MNG); in September 2013, there were 1,238 MNG participants. In the past, Moderate Needs Group participants responding to the Long-Term Services Consumer Survey have indicated that the services sometimes do not meet their needs. This feedback coupled with the fact that there are waiting lists[1] while some providers still have allocated funds to support Moderate Needs participants at the end of the year[2] led the Department of Disabilities, Aging and Independent Living (DAIL) to reevaluate the services which are currently provided and the system which is used to deliver those services.

DAIL would like to better meet the needs of participants within the Moderate Needs Group. With the goals of fully maximizing the use of Moderate Needs funds, serving more people, creating more flexibility for the people using services, and improving satisfaction, DAIL proposes allocating a pre-determined amount of Choices for Care reinvestment money into a new Moderate Needs Flexible Funds service.

Methodology

The Choices for Care Evaluation team from the University of Massachusetts Medical School supported this project with research and policy activities including:

[1] As of September 2013, there were 338 people waiting for homemaker (122 Medicaid eligible) and 24 people waiting for adult day (4 Medicaid eligible). Vermont Assembly of Home Health & Hospice Agencies in its 2013 testimony to the Health Access Oversight Committee noted that Medicaid eligible MNG participants can remain on waiting lists from 3 to 36 months (Comments on the CFC Program, 2013).

[2] In SFY2012, 26% of Homemaker funds were not spent and 18% of Adult Day funds were not spent. In SFY2013, 17% of funds allocated to Homemaker providers were not spent and 6% of Moderate Needs funds allocated to Adult Day providers were not spent.

1. Conduct research on similar flexible service options. Information was collected on CFC's Flexible Choices and the Flexible Family Funding program in Developmental Disabilities Services in Vermont. State programs which served populations similar to Vermont's Moderate Need Group and use state funding to support the program were also examined. These included Wisconsin Community Option Program (Regular), Oregon Project Independence, Ohio Alzheimer's Respite Program and New Jersey Assistance for Community Caregiving along with Cash and Counseling Programs.

2. Gather and analyze secondary data to provide context and further research to inform practice and policy recommendations and actions related to the CFC Moderate Needs Group. Data included calls to the 211 service, Senior Health Line data and ADRC information that provided information about what types of services are being requested and discussed currently.

3. Interview stakeholders in Vermont related to the specific topics noted above (assessment, flexible funding service options and outcomes). The UMass team developed an interview guide consistent with the goals of the project. More than fifty stakeholders including three consumers (1 Flexible Choices consumer and 2 Moderate Needs Group consumers) were interviewed. These stakeholders included:

    - Area Agency on Aging staff including leadership and case management
    - Homemaker staff including leadership and case management
    - Adult Day staff including leadership and management
    - Long Term Care Clinical Coordinators
    - DAIL Advisory Board members
    - Non-medical providers
    - Alzheimer's Association
    - DAIL staff
    - COVE
    - Current Moderate Needs Group members and/or caregivers
    - Transition II
    - Flexible Choices members

In order to define the specifics of possible modifications to the Moderate Needs program, DAIL has established a Work Group. The UMass Evaluation team is contributing data to the Work Group. The Work Group is comprised of DAIL staff, providers, consumer advocacy organization (2 representatives from the AAA, HHA, ADC, VCIL) and content experts as topics arise. The Work Group is meeting at least four times through December 2013 to develop program models incorporating flexible options in the MNG program.

Interview Findings

The majority of respondents stated that the current system helps participants in the Moderate Needs Group to remain in the community. At the same time, almost everyone acknowledges that there are challenges, which mean that the current system does not always work for all Moderate Needs Group participants. The availability of services emerged as a significant challenge. The Assessment process, using the Independent Living Assessment, was also mentioned as a challenge to participants (this issue was deemed outside the scope of this report, but perhaps actionable in another

forum).[3] Most importantly for the topic of flexible funding, the limitations to the services in terms of the amounts of services available to a participant as well as the number of participants able to be served were considered quite challenging to the program. In addition, transportation was specifically mentioned as a barrier for some MNG participants wanting to access adult day services and for those wanting to do an errand.

The Moderate Needs Group program was seen by many people as person-centered because participants could choose between and among the two main services provided (Homemaker and Adult Day). For those who responded that the program was not person-centered, they often mentioned the fact that there were only Homemaker and Adult Day services from which to choose and that the participant could only get services from the designated agency. One specific potential change was noted that could improve MNG person-centeredness: creation of a flexible funding option (similar to Flexible Choices available to Highest/High Needs participants, for some respondents).

Respondents were asked about flexible options, including the ability for participants to self- or surrogate-direct services and/or to have an individual budget from which to buy goods and services. Almost all respondents commented that "Choice is good". For those who supported self-direction and individual budgets for Moderate Needs Group participants or considered the options in spite of their reservations (see below), the major benefit would be that providing flexible options gives the participant control of his/her life, facilitates autonomy and allows the participant the capacity to meet his/her needs. They noted that flexible options should become one choice available to Moderate Need Group participants and not mandated as the only option, again highlighting the value of flexibility for individuals needing long-term services and supports. These respondents also saw the potential need for the case manager and substantial oversight in a flexible option.

A majority of the stakeholder respondents (mostly current MNG providers) were not supportive of self-direction and Individual budgets for Moderate Needs Group participants. This majority responded:

- Providing flexible options will negatively impact the financial sustainability of the long-term support service system and providers will have to close their businesses. This perhaps hyperbolic comment seems right in line with Doty, Mahoney & Sciegaj (2010) who found that there could be resistance to self-directed models from traditional providers of services because of perceived competition. However, no research or evidence was found to support this statement.

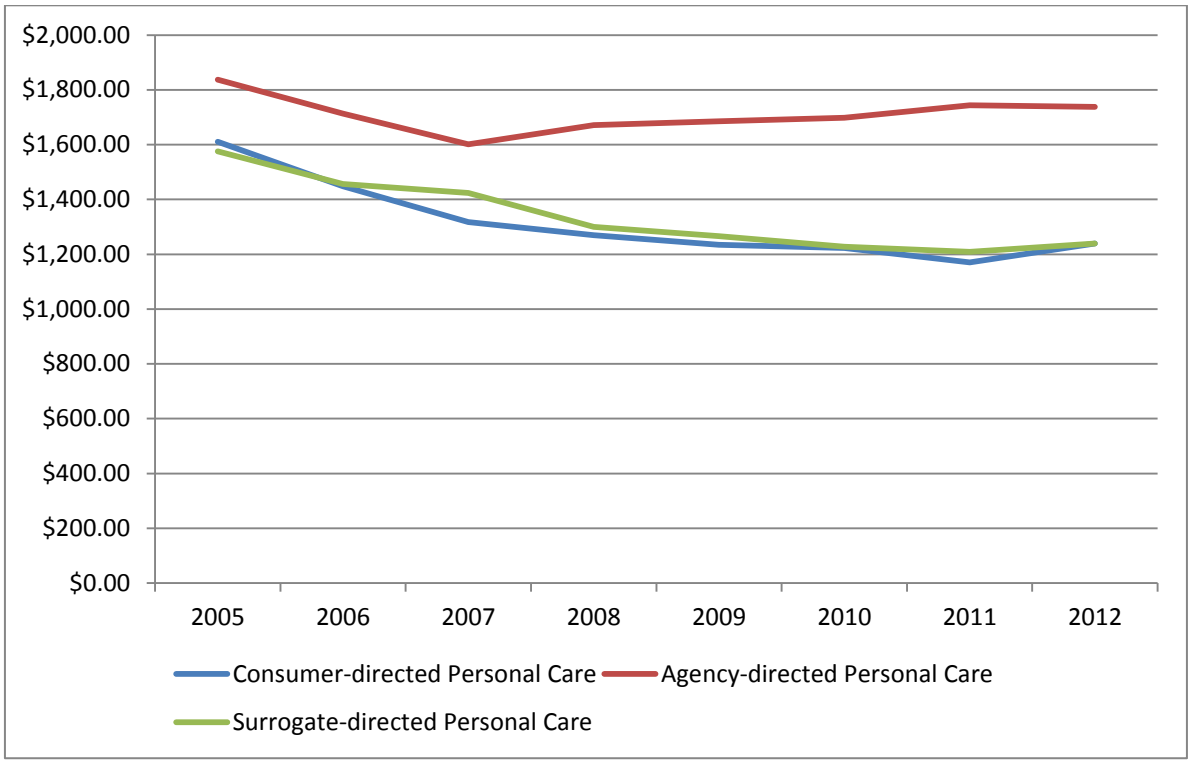
- Providing flexible options is something participants are unable to manage and will ultimately endanger the health of the participant and end up costing the state more money. This response seems contradicted by Vermont's own experience with Flexible Choices and the high and highest needs groups, which have not shown these problems.

In a 2012 report by the Providers' Council in Massachusetts, it was acknowledged that the provision of a self-directed option does create challenges for providers such as meeting customer expectation, providing services with efficiency, and demonstrating performance, value, affordability and quality control. The report also acknowledges that there are opportunities for provider agencies to educate consumers about their services (Public Consulting Group, 2012).

[3] Although most respondents commented that the assessment process worked well, there were some who also stated that it did not work well. Some respondents thought that the assessment helped create a holistic view of the participant. However, others felt that the ILA was too cumbersome and did not address the cognitive area or current LTSS adequately. Another issue was that for Adult Day, participants may be assessed with both a short-form and a long-form ILA due to service requirements.

"Officials … are increasingly turning to consumer-directed budgets as the most cost-effective way to reduce and eventually eliminate waiting lists and assure access to services by allowing the use of nontraditional providers. In this respect, state officials (especially those in other poor, rural states) find Arkansas's Cash and Counseling experience useful and encouraging. The lesson: People entitled to personal care in Arkansas can enroll immediately in Independent Choices and use their budgets flexibly to obtain nontraditional services—yet the availability of this form of assistance has not increased demand" (Doty, Mahoney, & Sciegaj, 2010, p. 52). As seen in Chart 1, in Vermont, from 2005 to 2013, the average yearly per-person cost for both Personal Care options was in fact lower than Agency-directed Person Care (DAIL Provided Information, 2013).

Chart 1. Average Yearly Per-Person Cost for Choices for Care (Personal Care)



Self-direction Information

Research shows that some of the concerns identified above by respondents do not reflect the full reality based on the experiences of other states' programs. Several of the programs were designed specifically for elders and give the participant the option to self-direct. For example, the New Jersey Assistance for Community Caregiving Program is a program designed for individuals 60 years or older, who are assessed as clinically eligible for nursing facility care. In this program, an individual can purchase services from traditional waiver providers and nontraditional qualified entities. The participant with the care manager can decide to directly purchase services. In a study conducted with Massachusetts agency-directed home care recipients age 60 years and older, 18% said that they would like to take more responsibility for managing their services (Tilly & Wiener, 2001). Researchers found that although some elders are able to do the administrative work, many were not interested in doing the administrative work. However, with clear and easy to understand information about the program, participation in a self-directed option can be increased (Ottmann, Allen, & Feldman 2013). Although the majority of Vermont Flexible Choices participants are younger than 65 years old, participants' ages range from 21 years old to 103 years old (Interview, October 2013). This information, along with the

research, would suggest that individuals of any age can participate and take advantage of a self-direction option. The number of CFC participants who have chosen Flexible Choices rose from 4 in 2006 to 120 by June 30, 2013 (CFC Data Report, 2013).

Additionally, very few respondents acknowledged that a self-direction option can allow a participant to use a representative or a surrogate. Even though the term "self-direct" may suggest that the management of services is done by the program participant alone, the actual implementation of the concept does allow for surrogates/representatives to work with the participant. Indeed, in many Cash and Counseling Programs, a surrogate works with the participant. In these instances, the surrogate role is unpaid and the surrogate cannot become the person who provides services to the participant. Vermont's experience with Consumer-directed/Surrogate-directed services shows that these options could be viable for Moderate Need Group participants. Specifically, numbers for Self-directed and Surrogate directed Personal Care have risen and showed stability over the last few years, with Surrogate-directed Personal Care being greater; Surrogate-directed represents about a third of all Personal Care and Self-directed is about one-fifth. Agency-directed Personal Care remains about half of all CFC Personal Care (DAIL provided information, 2013).[4]

Table 1. Percent of CFC Participants Receiving Personal Care Through Self-direction, Surrogate-direction and Agency-direction.

	Jul-05	Jul-06	Jul-07	Jul-08	Jul-09	Jul-10	Jul-11	Jul-12	Jul-13
Self-directed Personal Care	14%	16%	18%	21%	23%	22%	22%	23%	21%
Surrogate-directed Personal Care	37%	37%	37%	35%	36%	36%	34%	34%	31%
Agency-directed Personal Care	49%	47%	46%	44%	41%	42%	43%	43%	48%
Total number of people	1061	1145	1367	1428	1362	1348	1339	1297	1415

Even as respondents voiced their concerns and objections to Moderate Needs Group participants having the option to self-direct, many respondents shared their ideas on the type of assistance someone would need in order to self-direct. Nearly all of the respondents stated that the Case Manager would be crucial to assisting a participant to self-direct.[5] Respondents noted that the Case Manager's role would include the education of the participant about the option to self-direct, approval of the participant to self-direct, oversight of the participant's use of services, and assistance to the participant to set up services. Respondents stated that the case manager could provide the same type of oversight assistance as is done for participants in the High and Highest Needs Groups through Flexible Choices.

Respondents also identified other types of assistance which would allow participants to take advantage of a self-direction option. Respondents commented that participants should receive options counseling, need to know who to contact if have a question and/or there's a problem, and be able to obtain assistance with fiscal management and with hiring and

[4] Similarly, Surrogate-directed Companion has greater numbers than Self-directed Companion with Surrogate-directed Companions representing almost half of all Companion and Self-directed almost a third (DAIL provided information, 2013).
[5] Doty, Mahoney & Sciegaj (2010) named case managers as another stakeholder who is often resistant to self-direction. They stress the importance of training for the new roles and responsibilities of case managers and structures that don't create disincentives.

firing workers and their responsibilities. Some respondents thought that the Area Agency on Aging Case Manager could aid a participant to self-direct by educating, advocating, and guiding the participant. As a respondent noted, "AAA Case Managers are trained to provide this type of assistance."

The literature suggests that counseling and fiscal management are important. The earlier states which participated in Cash and Counseling Programs found that they had to work with case managers to ensure they understood their new role as Counselor, Support Broker, or Care Manager (Schore, Foster & Phillips 2007). In the New Jersey Assistance for Community Caregiving and Oregon Project Independence, a professional works with the participant. Vermont is fortunate in that it has experienced case managers and coordinators who have aided participants on the Flexible Choices program and the Veterans Independence Program[6] which they can apply to working with MNG participants.

Individual budget Information

Despite the objections of a majority of respondents to the option of an individual budget, many respondents shared ideas on assistance, information and issues to be considered for setting up a system which allows an individual budget. Many of these issues are also issues for Flexible Choices; it is unknown to what extent respondents were commenting on how similar or different these issues would be for a flexible option for MNG.

Respondents observed that if an individual budget becomes an option, a participant would need to know that the option is available. Additionally respondents stated that education on how it is used, assistance to set up an individual budget, awareness of personal accountability, guidelines on items which can be purchased, reporting requirements, and information about additional community resources (so as not to use the budget to purchase goods and services which can be obtained through other resources) are essential to aiding a participant to use an individual budget.

Respondents further identified issues which DAIL should consider such as:

- establishing a process to resolve any disagreements which may arise between the case manager and the participant about how the budget is being used,
- preventing fraud and abuse of participants,
- instituting looser guidelines to allow participants and families to more easily meet needs,
- providing periodic classes on-line and in-person for participants to learn how to self-direct/manage an individual budget, and
- ensuring that program management is done by an organization which views flexible options as an opportunity for flexibility and as a way for the participant to enhance control, dignity, autonomy and his/her outlook on life.

The majority of the respondents noted that the case manager is crucial to assisting a participant with an individual budget. Respondents identified several tasks which should be done by the case manager: assist with paperwork; assist with advertising the position for an in-home worker; provide oversight; assist the participant to identify and access services beyond the scope of the program; work with participant to look at needs and to determine how to spend budget; advocate and negotiate with the participant; and be the person a participant can call with a problem.

[6] In this program, AAA staff act as "care advisors" for participating veterans, who develop and manage their own service plan or have a surrogate to help them develop and manage the plan. "The program is open to veterans of all ages. There are no income requirements, but individuals must need nursing home level care." (http://svcoa.org/news.php?id=123)

It should be noted that within the lists are tasks which within Vermont's Flexible Choices program are performed by case managers or by Transition II workers. DAIL will need to decide to use the same tasks delineations currently used in Flexible choices or to use another model. To that point, some respondents did not believe that the state should set up a mini Flexible Choices for MNG participants. There were a couple of reasons for this opinion. A respondent commented that information about flexible options would have to come from entities not interested in giving the participant that type of autonomy; other respondents stated that by introducing the flexible option, there was increased risk of participant exploitation, fragmentation of the current program, the introduction of unnecessary complexity into a very simple program and the participant was being given too many choices. However, importantly, many stated that if the state did want to allow flexible options for the MNG participant, the state should use the tools and system which exists to aid Flexible Choices participants.

A major part of an individual budget option is *what* participants can buy with the budget. Respondents mentioned specific items (See List 1).

List 1. Possible Purchases Suggested by Interviewees

Adult day services	Washing machine	Socialization
Personal Care Services	Lifeline	Exercise classes
Housekeeping	Medication alert	Personal grooming (haircuts)
Transportation	Ramps	Computer
Pickup/delivery of medications	Foot care	Non-medical adaptive devices for home
Intensive house cleaning	Air conditioners	Environmental modifications
Nutrition	Assistive devices	Bathroom accommodations
Services for safety at home	Companionship	Widening doorways
Respite	Meal prep	Cushions for the wheelchair
Shovel snow	Home repairs	Fans, Dehumidifiers, humidifiers

Some respondents noted that establishing a list of specific items which can be purchased would undermine the program's ability to meet individual needs. One person noted that each person is different and needs are different, so there may be very few absolutely prohibited items, rather permissible items should be based on how an item or service can meet a person's need within the overall care plan. Although some respondents answered that no parameters and guidelines should be established, many more respondents identified the need for some parameters. Even though ideas differed as to what should be permitted, the respondents offered a range of parameters which can be summarized as follows:

- Range of permissible items should be as wide as possible
- Goods and services should only be purchased if they aid with the realization of the mission of the Moderate Needs Group program
- Participants cannot purchase anything which is illegal
- Use the list which is established for participants on the Flexible Choices program
- Establish a list which identifies items which absolutely cannot be purchased.

In order to have a context for examining the goods and services which were suggested by respondents, information was gathered about the types of goods and services purchased by participants in Cash and Counseling Programs and Vermont's Flexible Choices.[7] An assessment of New Jersey's Cash and Counseling Program examined 500 records of individual who stayed in the program almost fifteen months. Records showed that "46% of individuals purchased transportation; 37% purchased laundry service and 36% purchased insurance to protect against liability for in-home workers; although in some cases, it may have been insuring automobiles or computers" (Simon-Rusinowitz, Loughlin, & Mahoney, 2011). An analysis of Arkansas' experience found that initially dollars were primarily spent in the cash and counseling option for personal care assistance and that this amount exceeded the amount spent by agency providers. Further review led researchers to conclude that this happened because individuals used their dollars to fully meet their authorized personal assistance needs (Doty, Mahoney, & Sciegaj, 2009).

In Vermont's Flexible Choices, personal care assistance is the largest and most common purchase (Interview, October 2013). For example, about 75% of Flexible Choices payments (January-November, 2013) were for personnel costs, accounting for approximately $2.3 million that ARIS paid (ARIS provided data, 2013). Other goods and services include assistive technology, equipment, and social/education/therapeutic lessons (see List 2).

List 2. Examples of Goods and Services Purchased through Flexible Choices

Personal Care Services	Generators
Backup batteries for wheelchair	Diabetic shoes
Protein drinks/ Supplements	Accessible vehicle parts
Exercise equipment	Scooters
Backup wheelchair	Extra bandages, antibiotic pads
Therapeutic riding lessons	Adult diapers (brand is better)
Mattresses	Lotions (doctor-recommended)
Gym membership	High-tech stand-able wheelchair

Measures to evaluate outcomes and quality of life

Many respondents provided specific measures and outcomes to assess the impact of changes on the individual participant, the caregiver and the Moderate Needs group program. For the individual participant, respondents identified: physical and mental health of the individual, length of stay in the MNG program, medication management, participant assessment of well-being, participant satisfaction with the program and participant involvement in the community. Concerning individuals with dementia, respondents stated it may also be important to measure a family's preparation for safety and future changes as the disease progresses. In 2000, Benjamin et al, based on a group of over 500 Medicaid recipients in California, found that recipients in the consumer directed model reported more positive outcomes than those in the agency model. There were statistically significant differences in terms of recipients' safety, unmet needs and service satisfaction. Benjamin concluded that although both models have strengths and weaknesses, the consumer directed model is associated with more positive outcomes (Benjamin, Matthias, & Franke 2000). In Vermont, Flexible Choices, Self-directed and Surrogate-directed Personal Care participants strongly agreed or agreed with the statement "My services help me to maintain or improve my health" at over 90% and strongly agreed or agreed with the statement

[7] In addition, 211 information requests by individuals 60+ and individuals with disabilities highlighted that many individuals calling 211 was requesting monetary assistance (homeless motel vouchers/housing subsidies, utility assistance and food stamps) and less direct home and community-based services.

"My services help me to achieve my personal goals" at over 85 to 90% (Robertson, Maurice & Madden, 2013). Quality scores were also in the high 90%'s for all three as well.

For family caregivers, respondents stated that it is important to assess whether the use of flexible options alleviated stress, impacted the health status of the caregiver and provided respite. Respondents stated for the individual hired, the program should ensure a livable wage, provide opportunities for on-going trainings and establish a way to let workers know that their work is valued and important.

To measure the overall Moderate Needs Group program, respondents suggested that the consumer satisfaction survey is used, an assessment of the outcomes for participants using the flexible option and participants using the agency directed option is conducted, and that a retrospective study looking at MNG participants who ultimately transition in nursing facilities is considered. The literature shows that programs have used various combinations of all of these ideas to assess the outcomes and quality of life of individuals who choose to self-direct.

Fraud and Abuse/Oversight

Many of the respondents commented that by providing flexible options, the incidents of fraud and abuse would increase. Although fraud and abuse are cited as a significant concern, there are several steps which are being taken by states currently to deal with this issue. Such steps involve the use of a fiscal intermediary, use of audits and education of consumers and workers about the rules and regulations of the program (Fraud Presentation Detection in Participant Direction program, presentation at 2013 HCBS Conference). Anecdotal evidence from Flexible Choices suggests that fraud and abuse are not widespread problems; however, in the interest of solid fiscal and social responsibility, DAIL should consider oversight activities carefully. Respondents noted that activities could include the following: apply the same oversight and monitoring requirements as in Flexible Choices and Adult Foster Care, have the case managers check in more often (at least monthly) with the participant, monitor the individuals providing services to the participant, use the quality assurance processes which already exist and conduct regular audits of the program.

Recommendations

The majority of respondents (mostly, providers) are against providing a self-direction option and/or an individual budget for Moderate Needs Group participants because they are concerned that it will (1) negatively impact the financial viability of current providers and (2) over time hurt the health and well-being of the MNG participant. Research and Vermont's own experiences with Flexible Choices has shown that these particular concerns are not borne out. No research UMMS found has indicated that self-direction endangers current providers. Vermont's own surveys have not uncovered any harm in self-direction. Indeed for other respondents, the provision of flexible options will increase choice and allow MNG participants to get those services which best meet their needs. To date, research literature and the experience of participants in the Vermont Flexible Choices support this observation.

The UMMS Evaluation Team believes that offering some kind of flexible funding for MNG is the right action for DAIL and the state of Vermont to take. This action is in line with many of the CFC core objectives including: to support individual choice, to serve more people, to expand the range of service options, to eliminate or reduce waiting lists, to manage spending to available funding, and to ensure that services are of high quality and support individual outcomes (CFC Data Report, 2013). In order to ensure that the flexible funding for MNG meet these objectives, DAIL should carefully consider the following recommendations.

Functioning of the program

- Determine whether DAIL will use existing Flexible Choices system to aid MNG participants with flexible options
    - UMMS recommends basing the new option on Flexible Choices to take full advantage of the successful system already in place. For example, ARIS can be used for the financial/payroll management activities.
- Develop mechanisms to allow potential MNG participants to learn about the flexible option irrespective of how they are enrolled in the MNG program
    - Actions can include developing website and brochure materials for case managers, advocates and potential participants; holding webinars and telephone information sessions to explain the option as it is rolled out and coordinating with advocacy organizations to ensure that they have information about the flexible option. States found that multiple trainings and the identification of early supporters who championed the option to colleagues further aided with positive implementation (Doty, Mahoney & Sciegaj, 2009).

Structure of the program

- Determine whether the option to self-direct and to manage an individual budget will be an alternative to agency-directed services
    - UMMS encourages DAIL to offer the option as an alternative to fully allow for person-centered flexibility to obtain the goods and services they need. Some participants will choose agency-directed, while others will choose self-directed services. Most of the programs UMMS examined provided the self-direction or budget option as an alternative to receiving traditional (agency-directed) services.
- Determine whether the role of a case manager will be part of a flexible option or whether the individual will have to purchase the service
    - UMMS recommends that some type of professional be involved in the assessment, planning and provision of flexible funding; again, Flexible Choices can serve as a model.
    - If case managers are engaged in flexible funding, DAIL should work with case managers to define their role within a flexible option for MNG participants. Because LTCCCs encounter potential MNG participants, it is important that they are also trained on the flexible option and the role of the case manager. DAIL should also ensure that other stakeholders in the long-term support service system understand the flexible option and the role of the case manager. In so doing, DAIL will aid all of the organizations to work together.
- Determine whether participation in the pilot is open to current MNG participants or whether it is for any new and/or wait listed MNG participants
    - To allow for additional participants, the pilot should be open to both current, wait listed and new participants. In this way, the MNG program will be able to serve more individuals through either avenue.

Financing

- Identify financing for the flexible options pilot and beyond (Oregon's Project Independence is funded on a 2-year cycle).
    - UMMS recommends a two-year pilot funded through the reinvestment monies.
- Determine how many dollars can be provided to an individual to ensure that the use of flexible options meets needs.
    - Some states establish an upper limit for an individual's budget. In New Jersey Assistance for Community Caregiving, the amount is $600 a month. UMMS recommends that DAIL consider the number of individuals expected to be served in the pilot and divide the amount of funding for this new option by that number and the number of months (up to 24 for the two year pilot) to determine an upper limit. This upper limit should not be more than the current monthly amount available for MNG participants in traditional services. Since the Homemaker and Adult Day amounts are so different, the average amount could be used ($675/month at the new rates). As with other areas of CFC, a variance process could be implemented.
- Establish a set list or guidelines for purchases with an individual budget.
    - UMMS recommends that DAIL applies the Flexible Choices guidelines for determining which goods and services can be purchased. In this way, DAIL will continue to implement person-centered principles as participants are able to purchase the services and the goods which meet their needs.

Oversight and Monitoring

- Establish mechanism to ensure that services are being provided
    - UMMS suggest that DAIL can use the expertise that already exists and use Flexible Choices systems/case managers to ensure that services are being provided.
- Ensure that MNG participants are aware of their rights and responsibilities
    - UMMS encourages the development of materials similar to the materials available in Flexible Choices.
- Ensure that the perspectives of consumers are heard through oversight and monitoring activities
    - UMMS also recommends the addition of Choices for Care participants who select Flexible Choices and who select MNG flexible funding on the DAIL Advisory Board to ensure that their perspectives, issues and concerns are fully included in discussions and further DAIL activities.

Evaluation

- Identify the individual consumer goals and outcomes
    - The existing consumer survey should be used to measure individual outcomes for MNG participants in the flexible funding option by ensuring that the survey adequately samples these participants.

- Determine program performance and outcomes
    - UMMS recommends monitoring the number of people served in each option and on the waiting list.
    - UMMS recommends analyzing and monitoring participants using flexible funding and participants using agency services in terms of costs and services/goods purchased as well as in terms of length of stay as MNG and/or in the community. These analyses are not randomized control trials and as such the data will only be suggestive.

Conclusion

The UMass Medical School Evaluation Team interviewed over 50 stakeholders, participated in a DAIL-led workgroup, and researched flexible options across the country. Based on these activities, UMMS strongly encourages DAIL and the state of Vermont to build on its successes and implement a flexible funding option pilot for the Moderate Needs Group based on CFC's Flexible Choices.

APPENDIX: ADDITIONAL INFORMATION FROM INTERVIEWS

Current program

The majority of respondents stated that the current system helps participants in the Moderate Needs Group to remain in the community. At the same time, almost everyone acknowledges that there are challenges, which mean that the current system does not always work for all Moderate Needs Group participants.

- **Current program works well**
  - Services allow people to continue with independent living
  - Non-medical care that allows someone to stay home
  - Supports someone not to deteriorate
  - Provides relief to families and avoids placing someone in a nursing home
  - Keeps someone safe and healthy in the community

- **Challenges**
  - Eligibility process
    - To open, no verification of the financial information that is submitted
    - Eligibility and prioritization processes, allowing MNG people with lesser needs to access before others with more significant MNG needs
    - Perceived gap between Moderate Needs and High/Highest Needs for individuals with dementia and others; should be a mechanism for agencies to do something
  - Availability of services
    - Services limited
    - Insufficient home makers
    - Allocation of funding for Adult Day and Homemaker Services not enough
    - Participants need more than light housekeeping so agency putting in a lot of non-billable hours
    - Families don't know what is available
    - Waiting lists
    - Case managers don't understand that if there's a waiting list at the HHA doesn't mean there is a waiting list at the Adult day
    - Transportation barrier for getting people to Adult Day services

- **Person-centeredness**
  - MNG is person-centered
    - By definition, the program is person-centered
    - The program is person-centered once the participant accesses adult day services
    - The participant expresses needs and the home health agency is responsive
    - Agency works within the constraints of the regulations
    - Work with the case manager to meet any needs beyond what is provided by the Moderate Needs Group program
    - Use the individual plans of care to meet the participant's needs
    - Participants can use case management, home maker or adult day services
  - MNG is not person-centered
    - Unable to look at services people really need such as transportation
    - Not able to get the hours of services which are needed
    - Choices are limited
    - Not enough choice to say that a participants get a choice about services
    - Impact of the MNG process on the participant can be demoralizing
    - Not very broad range of services
    - Do not respond to all of the needs of the participant
  - Changes to make MNG more person-centered

  - Participant allowed to say what is helpful and how it is helpful
  - Ability to use other agencies that just provide home maker services
  - Able to hire as done with Flexible Choices
  - Participant have more choices
  - When there was competition/more than one choice of agency, agency seems more responsive to needs of the participant
  - Give power back to the participant, only done with more choices
  - Give participants money and allow them to spend within reasonable bounds
- No change needed
  - Person-centered is just a buzz word
  - More about what the participant wants than what the participant needs

➢ **Assessment Process**
- Provides needed information
  - Gives fairly holistic picture of the participant
  - Good at asking what the participant needs
  - Good process
  - Check list
  - Process which is known and understood by those using the tool
  - Allows the participant to get into the program without too much red tape
- Information provided not useful/difficult to use
  - ILA form is cumbersome
  - Doesn't evaluate for participants with dementia and cognitive impairment if this is the primary reason for seeking assistance
  - Need to update the form, the long-term care system has changed since its creation
  - Adds additional stress to the consumer and family because ILA short form used for MNG participants; Adult Day required to do a complete ILA)
  - Information provided by case manager sometimes different than that given to the Adult Day
  - Series of questions about memory, awkward location on form
  - Great subjectivity by the person doing the interviewing
  - Not comfortable using the ILA/check list to quantify individual's needs; should trust the individual to decide for themselves

Self-Direction Option

To ensure that respondents were answering the same question, respondents were read the definition of Self-Direction, "Hire fire and manage their own services".

➢ **Benefits for the participant**
- Happier, can get their needs met
- Independence
- Dignity
- Autonomy
- Take control of their life
- People with early stages of dementia can self-direct
- Person stabilizes well once program set up

➢ **Benefits for the Long-Term Service System**
- More person-centered
- Case management or family can direct care
- ARIS can manage all of the money

- **Drawbacks for the participant**
  - Too many choices
  - Participant identifies needs differently than the person doing the assessment
  - Participant may become isolated and unable to have social interactions because family keeps dollars and says can provide the services offered at the Adult Day Center
  - Participant could choose services which do not meet needs and his/her health ultimately suffers
  - Participant wants to help others and does not speak up even when decisions/actions taken do not meet the participant's needs
  - Once a participant with dementia starts having problems with ADLs, he/she needs to have a care partner or someone who can coordinate

- **Drawbacks for the Long-Term Service System**
  - More providers can negatively impact the finances of current providers
  - More providers will destroy the current Long-term support service system
  - Model usually works for younger people with disabilities but not elders
  - Adult Day programs unable to remain financially viable if participants choose to purchase Adult Day via a sliding fee scale and Adult Days then need to subsidize the rest of the fee.

Even as respondents voiced their concerns and objections to Moderate Needs Group participants having the option to self-direct, many respondents shared their ideas on the type of assistance someone would need in order to self-direct.

- **Information and assistance needed to self-direct**
  - Nearly all of the respondents stated that the Case Manager would be crucial to assisting a participant to self-direct. Respondents noted that the Case Manager's role would include:
    - Educate the participant about the option to self-direct
    - Assist the participant to set up
    - Approve whether the participant can or cannot self-direct or needs a surrogate
    - Provide the same type of assistance as is done for participants in the High and Highest Needs Groups
    - Advocate for the participant
    - Oversee and monitor the participant's use of services
    - AAA Case manager could aid participant in self-direction
  - In addition to the Case Manager, respondents identified other types of assistance such as:
    - Participants need to know who to contact if have a question and/or there's a problem
    - Assistance on hiring, managing and firing workers
    - Participants understand the parameters of self-direct and their responsibility
    - List of approved jobs in the program
    - Participants receive Options Counseling
    - Know what actions are fraud
    - Assistance with fiscal management- pay roll, documenting expenses
  - When asked, providers (LTCCC, Home Health and Adult Day) did not think there would be a role for them in this type of option. However, because the LTCCC sometimes may suggest to an individual that the MNG program may be more appropriate than CFC, the LTCCC should be given information about a MNG flexible option
  - Opportunity for the state to set up a case management service that is wholly independent of all providers.

Individual budget

The majority of respondents did not view the individual budget as a positive option for Moderate Needs Group Participants.

- **Benefits for the participant**
  - Greater flexibility

- Perceived benefit of being able to purchase Lifeline and other supports which can help keep the participant home and not move into higher level of need
- Use to purchase transportation
- Allow someone to get out into the community
- Allow someone to purchase activities could not afford: membership at a gym, therapeutic riding
- Gives someone control of life

➢ **Benefits for the Long-Term Service System**
- More hours for case management
- Case managers involvement
- Case management as Care Advisor

➢ **Drawbacks for the participant**
- Potential to increase vulnerability of the participant
- High turnover among workers
- Potential to increase victimization of the participant- family see budget of avenue to take care of its needs and not the participant
- Budget not enough to allow a participant to purchase case management, adult day and home maker services
- Concern that participants will purchase goods and services which do not meet needs

➢ **Drawbacks for the Long-Term Service System**
- Could negatively impact the financial viability of service providers
- Could create another level of bureaucracy

Despite the objections to the option of an individual budget, many respondents shared ideas on assistance, information and issues to be considered for setting up a system which allows an individual budget.

➢ **Ideas for setting up: Information and assistance**
- Education that Individual budget is an option
- Education on how the individual budget can work for a participant
- Identified things which can and cannot be purchased with a budget
- Reporting requirements
- Participant made aware of how will be held accountable
- Participant given support to develop a budget and purchase goods and services
- Participant made aware of community resources in order to not use budget to purchase goods and services which can get through other sources

➢ **Ideas for setting up: Issues to consider**
- Need to identify an entity which is responsible for oversight and monitoring of the system
- Ensure that a process exists to resolve any disagreements which may arise about how the budget is being used
- Establish a process or use the processes which exists to ensure that fraud and abuse are not happening
- Develop a mechanism that would allow someone to intervene if a participant is not using the individual budget to meet assessed needs
- Use assessed needs/ILA assessment to determine the individual budget
- Allow for looser guidelines because will allow participants and families to more easily meet needs
- Provide periodic classes on-line and in-person for participants to learn about how to self-direct and to manage an individual budget
- Ensure that program management is done by organization which views flexible options as an opportunity for flexibility, the participant to control his/her life, dignity, autonomy and outlook on life

- **Types of goods and services purchased with an Individual budget**
  - Parameters and Guidelines
    - Assist with paperwork
    - Several respondents commented that a program without any parameters or guidelines would show the full realization of a person-centered system (not allowable by CMS?)
    - Range of permissible items should be as wide as possible
    - Goods and services should only be purchased if they help realize the MNG mission
    - Participants cannot purchase anything which is illegal
    - Use the list which is established for participants on the Flexible Choices program

- **Role of the case manager**
  - Case manager is crucial to:
    - Assist with paperwork
    - Aid with doing background checks
    - Assist with advertising the position for an in-home worker
    - Provide oversight
    - Assist client to identify and to access services beyond the scope of the program
    - Work with participant to look at needs and to determine how to spend budget
    - Advocate and negotiate with the participant
    - Be the person a participant can call with a problem
  - There isn't a clear role for the LTCCC, the Adult Day or the Home Health Agencies.

Measures to evaluate outcomes and quality of life

Many respondents provided specific measures and outcomes. However, for some, the question of the measures which the state should consider to measure the impact of changes on the individual participant, the caregiver and the Moderate Needs group program, was large and respondents needed more time in order to be more deliberative.

- **Individual Outcomes/Measures**
  - Participants remain in their home
  - Participants not moving into the higher needs groups
  - Maintain health and independence
  - Number of participants going into nursing homes
  - Number of visits to emergency rooms and hospitalizations
  - Status of mental health and physical health: are they better?
  - Monitoring diabetes
  - Participant satisfaction that life is moving in the right direction
  - Add to the ILA a question about the participant's connectedness to the community
  - Assess what the case manager has done to increase the participant's involvement in the community
  - Assess the participant's sense of well-being
  - An assessment should be done annually
  - Nutritional status
  - Identify and measure those things that cause deterioration
  - Determine and measure that the basic needs are being met for someone with dementia
  - Determine whether the quality of life is the highest possible for someone with dementia
  - Determine whether an individual with dementia knows how to access services
  - Assess if dealing with safety issues as dementia progresses
  - Ask the participant if the program is working for them
  - Ask if the participant is happy
  - Determine the participant's longevity on the program
  - Assess medication management

- **Caregiver Outcomes/Measures**
  - Family
    - Care givers relieved of duties for some time
    - Care givers given respite
    - Families have supports to take care of someone with dementia at home
    - Assess the health of the care giver
    - Transportation to help relieve stress from care givers
    - Stress reduced
  - Hired care givers
    - Livable wage
    - Develop a way to let the care giver know that the work doing is valued and important
    - Provide trainings and certificates in continuing education
    - Establish groups for workers; wherein can share ideas and learn from each other
    - Provide trainings through rewarding Works
    - Provide pay for attending team meetings
    - Develop supports for workers dealing with participants with more complex needs

- **Moderate needs group program**
  - Assess participant satisfaction
  - Establish checks and balances to know that services delivered
  - Conduct a retrospective study of participants who ended up in nursing home
  - Conduct observation in the field- observe the provision of services
  - Conduct a comparison of outcomes for participants using flexible options versus participants using agency services to determine cost effectiveness and participant outcomes

- **Fraud and abuse/Oversight**
  - Use the case manager to provide oversight
  - Allow for intermittent check-in
  - Use the quality assurances which are already being done
  - Case managers check in every month
  - Use monitoring similar to Flexible Choices and Adult Family Care
  - Conduct assessments more than once a year
  - Monitor the people going into a MNG participant's home
  - Program underfunded; question how much dollars want to spend on oversight
  - Suggestion to take a sample of the program for an audit, in such a way that it is not burdensome for the participant, family or the case manager
  - State has a system which already deals with fraud and abuse and can use this system
  - Use reinvestment dollars to improve the adult protective services

Additional topics/thoughts

- **Information**
  - Moderate Needs Group information on the website not clear; need to have the information easily accessible to the general public
  - Not sure participants know what programs they are on
  - Question interpretation of the Consumer Satisfaction Survey as driver for making changes to the current Moderate Needs Group program
  - Need to increase physicians awareness of the Adult Day program

- Depending on the individuals' conditions (i.e., dementia), the program through the ILA may not get complete and accurate assessment of needs

Financial

- DAIL needs to sustain funding for current program
- Cost of putting in new structure to support new options
- Question the sustainability of funding, if using reinvestment dollars
- MNG dollars will go further if can pay $10 per hour for a worker rather than $23 per hour
- Where are the dollars for a new program coming from?
- State cannot take from the current program
- Better to make sure that the Choices for Care budget includes funding for the MNG program
- State cannot experiment with dollars while the Adult Day programs are going broke
- Concerned that current MNG funding allocation process is not working and wonder if the state should fix this before introducing flexible options

Program

- Flexible options can be an opportunity to help people live out their life with quality
- Worker in a person-centered process has to be a good listener
- State should be aware of the success of the current Moderate Needs Group system
- New option may lead to fragmenting of the current system, should focus on basic structure
- Need to develop the connection between primary care providers and the community health teams to better help individuals with dementia
- Would like flexible option
- People need another option
- With flexibility, people can get more services because can be creative with how dollars are spent
- State should be mindful of the mental health benefits of someone getting out of their home
- Consider covering transportation
- Disservice to Vermont, if by giving choice, Vermont takes dollars away from current organizations/systems
- State could use the introduction of these options to create a neutral case management entity for CFC
- Need to get participants into the program earlier
- Question whether DAIL is responding to a need that does not exist
- DAIL has to work with providers to look at possible changes
    - Depression for elders is a big issue; having choice and control over decisions can help alleviate depression

APPENDIX: RESOURCES

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