

Vermont Choices for Care Policy Brief: Enrollment and Waiting List

Purpose of Policy Briefs:

This policy brief is the second in a series of reviews of policy issues related to the implementation of the Vermont Choices for Care (CFC) initiative. The purpose of these briefs is to examine key policy questions and provide an external perspective that will assist the Vermont Department of Disabilities, Aging and Independent Living (DAIL) to assure that policies and procedures are as effective as they can be in supporting the goals of Choices for Care. This policy brief focuses on enrollment issues, specifically related to the high needs waiting list.

Key Questions for this review:

- A.** What circumstances led to the establishment of a waiting list?
- B.** What is known about individuals on the waiting list?
- C.** Are waiting list/enrollment procedures being implemented equitably across regions and settings of choice?

Policy Overview:

Eligibility and enrollment procedures are tightly linked and relatively indistinguishable to Choices for Care (CFC) participants. Individuals learn about the program's availability through a variety of sources, including referrals from existing agencies, family members and health practitioners. When they contact the DAIL office, arrangements are made for a visit from a Long-Term Care Clinical Coordinator (LTCCC) who meets with the individual in his/her home to describe program options and conduct a clinical assessment. A determination of clinical eligibility is made by the LTCCC and financial eligibility is determined by the eligibility worker at the Department of Children and Families. Once the individual is determined to be eligible, he or she is "enrolled" in the setting for which they applied. The enrollment is, in this sense, the culmination of the outreach intake, assessment, application and eligibility determination processes, or in its simplest terms, the activation of the individual's status in the Medicaid eligibility system. Therefore, many of the issues related to enrollment have been addressed in the first policy brief on eligibility.¹

The notable exception to this linkage between eligibility policy and enrollment is when a waiting list is established for all or part of the program. Under such circumstances, an individual who meets all qualifications for the program experiences a delay in enrollment due to the lack of funding in the program.

Waiting lists for home and community-based services (HCBS) have been a common occurrence across the country because the federal 1915(c) waiver regulations actually require that states project a specific number of “slots” for each year of waiver implementation and not enroll new individuals once those slots are filled, unless the waiver is amended to increase the number of openings. At the end of federal fiscal year 2005, there were more than 260,000 individuals on waiting lists for Medicaid HCBS across the country (Kaiser, 2008). The majority of individuals (53 percent) were persons with mental retardation or developmental disabilities. Elders and people with physical disabilities made up 42 percent of persons on the waiting lists, while children made up approximately 5 percent and persons with brain injuries less than 1 percent (Kaiser, 2008). Vermont, at that time, reported 260 individuals on the waiting list for the waiver for adults and elders with disabilities and had 241 waiting when CFC opened in October 2005.

The unique feature of Vermont’s 1115 Research and Demonstration Waiver was that it established a national precedent for allowing a waiting list for individuals who met the high (but not the highest) level of need for all long-term care settings, rather than creating a waiting list only for HCBS and enhanced residential community (ERC) settings for individuals regardless of level of need. If financial pressures led to the need for a waiting list for CFC, a waiting list would be applied equally to high needs individuals seeking access to nursing facilities as well as ERC and HCBS. Although many individual nursing facilities have waiting lists from time to time due to limits on bed capacity, no state had ever implemented a waiting list for Medicaid nursing home enrollment based on availability of funds.

In equalizing Medicaid eligibility rules between nursing facility coverage and community-based services, the Vermont Choices for Care (CFC) waiver was designed to eliminate the institutional bias in Medicaid coverage of long-term care. Under CFC, Vermont established an equal entitlement to nursing facilities, HCBS and ERCs for those meeting the highest needs category and, as long as funds were available, assured equal access to all of these long-term care settings for individuals who met the high needs category. (See Eligibility Policy Brief for descriptions of highest and high needs.) The Vermont criteria for high needs enrollment include individuals who would not be eligible for any Medicaid Long-Term Care (LTC) services in some states.

In developing this policy, Vermont received approval to establish waiting lists if needed as a “safety valve” to enable the state to stay within the waiver’s spending limit. This created a trade-off: improved access to HCBS and ERC for people with the highest levels of need, accompanied by potentially reduced access to all Medicaid LTC service options for people with high but not highest needs.² The potential for delays in access to HCBS had been common under the previous HCBS waiver, which had a long waiting list at the time that CFC was established. The flexibility of CFC enabled Vermont to serve all individuals waiting as of October 2005; new individuals in the high needs category were placed on the waiting list but were generally able to be served within a few months. The waiting list was totally eliminated for the high needs group by May 2007.

In February 2008, approximately two-and-a-half years after establishing the CFC program, Vermont faced the need to reestablish a waiting list for the high needs category of the CFC program. The initial projection from DAIL was that individuals might need to be on the list for at least six months and potentially up to eighteen months. Some advocates suggested that it was misleading to call this a waiting list, given the long period of waiting; instead, some refer to the list as an “applicant list.”

A What circumstances led to the reestablishment of a waiting list in CFC?

When CFC was established, the message given to providers and advocates by DAIL was that reductions in nursing home expenditures achieved by reducing nursing home utilization would be retained by the program in order to expand HCBS and ERC options. As the first state that had directly shifted dollars from the nursing home budget to the community (through Legislative Act 160), this “promise” of retaining revenue for community options was consistent with the established commitment to expanding community choices. However, since only the legislature could make fiscal commitments and could reduce appropriations if necessary to balance the budget, DAIL could not assure that reductions in nursing home expenditures would be reinvested in the community.

DAIL cautiously expanded program enrollment in order to assure that actual spending for the high needs group would not exceed the budgeted amount for FY '07. By December 2006, the waiting list had dropped to 99 persons, and it became clear that all individuals waiting could be admitted without exceeding the budget.

This led fiscal staff at the Agency of Human Services to assume that the projected funds for the year were higher than needed and thus could be redirected for other purposes, with the approval of the legislature. As a consequence, over \$4 million in the projected CFC budget was designated an “over-appropriation” and removed from the FY ‘07 budget.

Advocates raised concerns at the time and viewed this as breaking the state’s “promise” of reinvesting savings into HCBS. However, they recognized that the commitment to retain savings for future program growth was not stated in the authorizing legislation for CFC and that budgets were subject to legislative approval. In response to the advocates’ concerns, the Vermont legislature inserted language in the 2008 appropriations act to assure that the reinvestment “promise” would be fully honored in the coming year,³ and authorized a large budget increase for FY ‘08. However, the legislature’s budget increase did not take into account the fact that expenses incurred from the growth in the caseload during FY ‘07 had to be annualized for subsequent years. Early in FY ‘08, it became clear that to continue serving existing clients throughout FY ‘08 and allow unrestricted enrollment into CFC for the highest and high need categories was not possible within the projected budget.

The Vermont experience highlights the difficulty of mandating a reinvestment of savings back into the program. Prior to the establishment of CFC, if the funds had been “over-projected” for nursing homes, such adjustments would have been routine, and under Act 160 those funds might have been shifted to HCBS. On the other hand, if funds had been needed for nursing home growth, they would have been allocated even if not originally appropriated due to the “entitlement” nature of the Medicaid nursing home benefit, and this might have reduced available funds for HCBS.

As noted, CFC was specifically designed to allow a waiting list as a safety valve to assure that program growth could be accommodated within the budget, while keeping HCBS, ERC and nursing facility (NF) options equally available. CMS considers the high need group to be “entitled” to CFC benefits; however, the potential for delaying access for an extended period due to funding shortfalls represents a unique use of the term “entitlement.” States that choose to follow Vermont’s path would benefit from clear statutory language about how funds will be allocated to the program, how inadequate appropriations will be managed, how future spending projections will be made, and whether savings or excess appropriations will be reinvested in the long-term care budget. Even with such precautions, budget discussions are by their nature part of an ongoing political process, and a subsequent legislature could rescind decisions through subsequent statutory changes.

The financial challenges that Vermont has faced highlight the difficulty of forecasting growth in HCBS services, especially during program start-up and transition periods (i.e. following pent-up demand due to a previous waiting list). It becomes

particularly critical for programs to have a good grasp of their enrollment and disenrollment patterns and the average monthly costs by service setting or client level of need. One of Vermont’s challenges has been the need to track disenrollments in order to be able to project future program expenditures from current enrollment. In particular, nursing facilities have not been consistent about reporting to DAIL when their residents disenroll from CFC. To address this, DAIL has developed a mechanism for matching all active participants’ client identifiers with the claims payment system. States that seek to replicate Vermont’s approach would similarly need an approach for monitoring overall program growth and expenditures for both nursing facilities and HCBS.

B How are individuals on the waiting list being monitored for enrollment purposes?

States use a variety of procedures for administering waiting lists. Many states do not complete any specific screening or assessment and allow all individuals who express interest in the program to put their names on the list. Such lists are often called “interest lists” or “planning lists” because individuals on the list may not actually qualify for services when their names are reached on the list (Auerbach and Reinhard, 2006).

Vermont is among the more progressive states in conducting a clinical eligibility assessment on each individual prior to placing the individual on the waiting list. While only a small amount of this information is maintained electronically, the available information does allow the state to create a snapshot of the population waiting by age, region, and preferred long-term care setting (nursing facility, enhanced residential care or home and community-based services).

Vermont’s procedures also call for a monthly follow-up contact by case management agencies to monitor the individual’s status and to discern whether a change has occurred that would have made the individual eligible for immediate enrollment. However, through discussions with DAIL as part of the research for this brief, it became clear that such follow-up contacts were not consistently being made.

Since CFC allows some individuals to be enrolled under special circumstances when a waiting list is being implemented, the lack of follow-up regarding individuals on the waiting list could result in the failure to identify individuals who experience a change in circumstances that might qualify them for enrollment based on special circumstances. As of June 2008, DAIL had reinforced the expectation of monthly monitoring of individuals on the waiting list by case management agencies, and was working with providers to implement a system for documenting these monthly contacts.

C Are waiting list/enrollment procedures being implemented equitably across regions and setting of choice?

The rate of applications into the Choices for Care waiting list during FY '08 has been relatively slow. This could be due to lack of need, lack of outreach by local agencies or active discouragement of individuals from putting their names on the waiting list by providers or discharge planners who don't expect the individual's name to be reached in time to meet their needs (a phenomenon that is discussed anecdotally by providers but that is difficult if not impossible to document). In order to examine possible effects of such influences, in this brief we looked at the distribution of applications by region and setting of choice. In the first five months after the waiting list was reinstated, there did not appear to be regional differences in applications though there appeared to be a greater tendency for high needs individuals seeking nursing homes to be admitted under special circumstances and for those seeking HCBS to be put on the waiting list. Waiting list and enrollment patterns should be monitored over time to assure that unintended biases do not arise.

1. Potential for regional variation

The LTCCCs across the state received consistent notice of the waiting list on January 10th and thus each region had equal opportunity to enroll individuals prior to the effective date of the waiting list, February 1, 2008. There were two potential opportunities for regional variation to occur in implementation of the waiting list: a) variation in the rate of enrollment immediately prior to the establishment of the waiting list and b) variations in interpretation of highest needs or special circumstances.

Overall, the statewide number of high needs enrollments for January (27) was slightly lower than the average monthly enrollment statewide in the previous six months, so there did not appear to be any increased activity due to the announcement about the upcoming waiting list. Seven regions had no high needs enrollments that month, and the range was from one (Caledonia) to seven (Orleans).

Data for the first six months of FY 08 (prior to the implementation of the waiting list) and the last six months of FY 08 (including the month the waiting list was announced and the first five months during which it was implemented) were examined to determine whether there were any potential regional patterns in the numbers of individuals placed on the waiting list and individuals admitted under special circumstances or highest needs. There were very few first-time enrollments for special circumstances (12 enrollments) and these were distributed across five regions. With such

a small number of special circumstances enrollments, there is no reason to believe there is "abuse" of the special circumstances admission criteria (See Table 1).

The number of highest needs enrollments during the second half of FY 08 was actually lower than the number of enrollments for the highest need category in the previous six-month period. Only 2 regions had a substantial increase in the number of enrollments in the highest category (Rutland increased by 45 percent; Windham increased by 80 percent), but again the numbers are sufficiently small that it would be premature to assume that this reflected any change in application of the highest needs criteria compared with the previous six-month period. If the waiting list continues for an extended period of time and these two counties continue to have a higher rate of enrollments for the highest need, it may be appropriate to evaluate whether the criteria are being applied consistently across all regions of the state.

2. Potential for variation based on setting of choice

Prioritizing individuals on the waiting list in order to serve those most in need had been a part of Vermont's HCBS waiver program prior to CFC. The waiver teams in each county had reviewed their waiting lists on a monthly basis and made judgments about which individuals should be served first when resources became available. Such judgments enabled DAIL to assure that the neediest individuals were served when openings became available.

As noted, in contrast to the previous HCBS waiver program, the waiting list under CFC applies to all high needs individuals, regardless of the setting of their choice. Individuals on the waiting list who do not meet the highest need criteria may still be enrolled if staff determines that they have a "critical need for long-term care services that may adversely affect the individual's safety." Such special circumstances include:

- a. Loss of primary caregiver (e.g., hospitalization of spouse, death of spouse)
- b. Loss of living situation (e.g., fire, flood) or
- c. The individual's health condition would be at imminent risk or worsen if services are not provided or if services are discontinued (e.g., circumstances such as natural catastrophe, effects of abuse or neglect, etc.)

The special circumstances criteria do not specifically favor individuals who are seeking nursing home placement, and DAIL staff's expressed intent is to enroll individuals under special circumstances equally, without regard to their setting of choice. Nevertheless, the application of the special circumstances criteria could, in practice, favor individuals seeking nursing facility placement because persons seeking nursing facility admission may be more likely than persons seeking HCBS to meet the special circumstances criteria (e.g., loss of caregiver, loss of living situation, health risk).

Individuals meeting the special circumstances criteria may also be at greater risk of hospitalization and may be admitted to nursing homes following hospitalization on a short-term basis. If they are on Medicaid only or if they need to cover the copayments/deductibles related to their short-term nursing facility stay, they will need approval under CFC. In contrast, if these same individuals are discharged home with rehabilitative services from a home health agency, DAIL policy does not require that they be enrolled in CFC; therefore, the existence of a waiting list would not affect them.

Data available after the first five months of the waiting list in 2008 raise the possibility that there may be a bias toward admitting nursing home applicants when there is a waiting list for the high needs group. Of the 12 CFC initial enrollments under special circumstances, 10 (83 percent) were admitted to nursing facilities and two (17 percent) were admitted to enhanced residential communities. No individuals were enrolled into HCBS under the special circumstances criteria. In contrast, of the 42 individuals placed on the waiting list during this period, 35 (83 percent) were waiting for HCBS, three (seven percent) for ERC, two (five percent) for PACE, and two (five percent) for a short-term nursing facility (See Table 2). The difference may in part be related to the greater access to non-CFC home health services for individuals in the community, but DAIL should continue to monitor the waiting list to assure that potential HCBS enrollees are appropriately being considered for special circumstances in order to meet all of their needs.

As mentioned, the procedures for allowing certain individuals to be enrolled in CFC under “special circumstances” have the potential to reintroduce a “nursing home bias” into the program, something that CFC was specifically designed to eliminate. Therefore, a critical question in relation to the waiting list is, “Does the waiting list create any incentives that favor individuals who are seeking nursing home placement?” Vermont has established internal systems that will make it possible to monitor this potential by tracking admissions over time by setting of choice (e.g. HCBS, ERC, and nursing facility).

Conclusions/Recommendations:

The potential for needing a waiting list in order to manage the growth of the CFC program was anticipated from the beginning of the program and was viewed as a safety valve to assure that the program would not exceed available funds. The trade-off of having a waiting list for high needs individuals was the guarantee of full choice of long-term care services regardless of setting for those in the highest need. By allowing the waiting list to keep the overall program within budget, CFC has made it possible for Vermont to dramatically increase HCBS enrollment and assure that individuals in the highest needs group always have the option of HCBS as well as ERC and nursing facilities.

In relation to its previous waiting lists for HCBS, the current waiting list for CFC is relatively small—39 in June 2008 compared with 241 in October 2005. If growth of the waiting list continues to be slow, and if some individuals continue to be served from the waiting list, the presence of waiting list will not be inconsistent with the goals of CFC.

However, the slow rate of referrals should not be assumed to reflect lack of need. If the program is able to reopen enrollment for high needs individuals, DAIL may find that referrals suddenly increase and that there is pent-up demand. While many factors are taken into account in the budget development process, to avoid future shortfalls DAIL should make efforts to clearly communicate to the Agency of Human Services the importance of including the annualization of current caseloads and anticipation of future growth in developing future budget projections. The legislature should ask detailed questions to assure that estimates of need take into account both current clients and the potential pent-up demand.

If the waiting list continues to exist over an extended period of time, it will be important to ensure that processes are consistent across counties through monitoring and continuous improvement activities. Through the process of gathering information for this policy brief, CHPR and DAIL discussed the following next steps in strengthening CFC waiting list processes and monitoring the impact of the waiting list on potential CFC participants. DAIL has already begun to take action on these steps:

1. DAIL has reinforced the need for case managers to complete monthly contacts with applicants on the waiting list in order to update their status and determine whether individuals have experienced a change in their circumstances that could make them eligible for enrollment based on special circumstances. As of 9/08, DAIL has begun to receive these forms.
2. DAIL has begun gathering information on the status of waiting list applicants and maintaining it in a central location in order to monitor potential differences in application of the waiting list criteria. Specific areas that should be considered for such monitoring include:
 - Determining whether there are regional differences in the application of the waiting list procedures and the application of the special needs criteria; and
 - Confirming that individuals waiting for HCBS and ERC have been appropriately considered for enrollment under special circumstances and/or whether they may qualify for other available services while waiting for CFC enrollment. This could be done by randomly selecting waiting list applicants from the data base and conducting a manual review of their assessments.

¹ The Eligibility Policy Brief can be downloaded at <http://ddas.vermont.gov/ddas-publications>.

² The moderate needs component of the program is also subject to availability of funds. However, because the moderate needs group is not nursing home eligible and did not qualify for Medicaid waiver services prior to the development of CFC, and because the moderate needs waiting lists are administered directly through providers, the enrollment limitations for the moderate needs group are not included in this discussion.

³ FY '08 Appropriations Act language: "Any savings realized due to the implementation of the long-term care Medicaid 1115 waiver shall be retained by the department and reinvested into providing home and community-based services under the waiver. If at any time the agency reapplies for a Medicaid waiver to provide these services, it shall include a provision in the waiver that any savings shall be reinvested" (H891, Sec 1(g)(1)).

Table 1
Comparison of CFC High and Highest Need Enrollments by Region
First Half of FY '08 compared with Second Half of FY 08

County	Enrollments High Needs 7/07-12/07		Enrollments High needs 1/08 - 6/08		Enrollments Special Circumstances 1/08-6/08 (Highest) 1/08 - 6/08		Enrollments Highest Need 7/07 - 12/07		Enrollments Highest Need 1/08 - 6/08		Total Enrolled High & Highest 7/07 - 6/08	
	#	%	#	%	#	%	#	%	#	%	#	%
	Addison	4	2%	1	2%	0	0%	44	10%	35	9%	84
Bennington	11	5%	1	2%	3	22%	60	14%	34	9%	109	10%
Caledonia	10	5%	3	6%	0	0%	26	6%	27	7%	66	6%
Chittenden	45	22%	10	20%	2	9%	53	12%	34	9%	144	13%
Essex	4	2%	0	0%	0	0%	5	1%	3	1%	12	1%
Franklin	18	9%	7	14%	0	6%	29	7%	20	5%	74	7%
Grand Isle	1	0%	0	0%	0	0%	3	1%	2	1%	6	1%
Lamoille	1	0%	0	0%	0	0%	17	4%	16	4%	34	3%
Orange	11	5%	0	0%	0	0%	15	3%	14	4%	40	4%
Orleans	20	10%	7	14%	0	0%	29	7%	28	7%	84	7%
Rutland	10	5%	0	0%	0	3%	51	12%	74	19%	135	12%
Washington	28	14%	7	14%	1	34%	44	10%	35	9%	115	11%
Windham	20	10%	7	14%	4	19%	20	5%	36	9%	87	0%
Windsor	18	9%	8	16%	2	6%	32	7%	29	7%	89	8%
(out of State)	0	0%	0	0%	0	0%	4	1%	6	2%	10	1%
TOTAL	201	100%	51	100%	12	100%	432	100%	393	100%	1136	100%

Source: Vermont SAMS data, DAIL data run, 8/08.

Table 2
Comparison of CFC Waiting List by Region and Setting, 2/08-6/08

County	HCBS	ERC	Nursing Facility	PACE	Waiting List High Needs 2/08-6/08	%
Addison	0	0	0	0	0	0%
Bennington	3	0	0	0	3	7%
Caledonia	2	0	0	0	2	5%
Chittenden	8	1	0	2	11	26%
Essex	0	0	0	0	0	0%
Franklin	4	1	1	0	6	14%
Grand Isle	1	0	0	0	1	2%
Lamoille	0	0	0	0	0	0%
Orange	0	0	0	0	0	0%
Orleans	0	0	0	0	0	0%
Rutland	0	0	0	0	0	0%
Washington*	4	0	1	0	5	12%
Windham	7	1	0	0	8	19%
Windsor	6	0	0	0	6	14%
(out of State)	0	0	0	0	0	0%
TOTAL	35	3	2	2	42	100%

*Note: 2 of the Washington HCBS waiting list participants were enrolled under highest needs during this period.

Source: Vermont SAMS data, DAIL data run, 8/08.

Appendix

Vermont Resources Reviewed

As part of the formative component of the evaluation of Choices for Care, UMMS/CHPR conducted key informant interviews with 16 staff in DAIL and the Department of Children and Families (DCF) and six community advocates. Interviews with the following individuals were particularly informative for this policy review: Patrick Flood, Deputy Secretary, Agency of Human Services; Joan Senecal, Commissioner, DAIL; and Dolly Fleming, Coalition of Vermont Elders

Materials reviewed for this policy brief also include relevant CFC regulations, policies and procedures, application forms, and national reports. National sources are listed in the references section of this document. The following is a list of DAIL documents that were reviewed for this policy brief:

Choices for Care: 1115 Long-term Care Medicaid Waiver Regulations, State of Vermont, Agency of Human Services, Department of Disabilities, Aging and Independent Living, Division of Disability and Aging Services, Effective October 7, 2005 (and annotated draft, revised March 2, 2007).

Choices for Care, Long-term Care Medicaid Program Manual, Section V.1, Application & Eligibility Determination Procedures, revised 01/06.

Choices for Care, Long-term Care Medicaid Program Manual, Section V.3, Assessment & Reassessment Procedures, Revised 10/1/05.

Choices for Care Program Application, CFC 801, 02/07
 "Vermont Choices for Care" Demonstration Waiver: Operational Protocol, Section G, Notification of Program Participants, Revised 11/14/06.

"Report on Attendant Services Program Waiting List," Agency of Human Services, Department of Disabilities, Aging and Independent Living, January 2007.

References

Auerbach, Roger and Susan C. Reinhard. Challenges Posed by Waiver Waiting Lists. Rutgers Center for State Health Policy, Community Living Exchange, August 2006.

Caldwell, Joe. Consumer-Directed Supports: Economic, Health and Social Outcomes for Families. *Mental Retardation*, 44(6), December 2006, 405-417.

Kaiser State Health Facts. Waiting Lists for Medicaid 1915(c) Home and Community-Based (HCBS) Waivers, 2005, <http://www.kaiserfamilystatehealthfacts.org>.

Kitchener, Martin, Terrence NG, Nancy Miller, and Charlene Harrington. Medicaid Home and Community-Based Services, National Program Trends. *Health Affairs* 24(1), January/February 2005, 206-212.

Real Choice Consumer Work Group Position Paper—Waiting Lists, not dated.

Vermont Department of Disabilities, Aging, and Independent Living. Response to Comment to 1115 Waiver by Coalition of Vermont Elders. <http://ddas.vermont.gov/ddas-publications/publications>.

Prepared by

Center for Health Policy and Research, Long Term Care Policy Unit

for the Vermont Agency of Human Services,
Department of Disabilities, Aging and
Independent Living

Project Team

Center for Health Policy and Research

Darlene O'Connor, PhD
Emma Quach, MPA
Jennifer Ingle, MS, CRC

Vermont Department of Disabilities, Aging and Independent Living

Bard Hill

Reviewer

Judith A. Savageau, MPH
*Associate Professor, Department of Family
Medicine and Community Health, University of
Massachusetts Medical School*

For more information, contact:

For more information, please contact
Darlene O'Connor at (508) 856-8148.

333 South Street
Shrewsbury, MA 01545

tel 800-842-9375
fax 508-856-6100

darlene.o'connor@umassmed.edu

www.umassmed.edu/chpr

