Vermont Dual Eligibles Focus Group Project Summary Report

A report detailing the results of focus groups held with Vermont consumers dually eligible for Medicaid and Medicare. February 1, 2012

PREPARED FOR:

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Acknowledgments

Finch Network would like to express our deep gratitude to all of the individuals who took time to share their experiences with us. The thoughtfulness and openness expressed by every participant offered us the opportunity to provide what we believe is an informative and revealing portrait of the experience of dually eligible people in Vermont.

We also would like to thank all of the many agencies, service providers, and organizations who helped us recruit participants for the focus groups. Without their assistance and support, the focus groups would not have been possible.

And finally, we thank the State of Vermont Agency for Human Services for giving Finch Network the opportunity to meet and speak with this diverse, articulate, and caring group of people. While many of the stories were difficult to hear, we feel enriched by giving a voice to the experiences of the dually eligible population.

Vermont Dual Eligibles Focus Group Project
Executive Summary
January 31, 2012

In January 2012, eight focus groups were held with Vermont consumers dually eligible for Medicare and Medicaid. The purpose of the focus groups was to gather information on participants' experience with Medicare, Medicaid and health and community-based service providers. Seven sub-populations were represented in the groups including consumers in: the Community Rehabilitation and Treatment program, the Developmental Services Waiver program, the Traumatic Brain Injury Waiver program, the Choices for Care program, individuals aged 65 and older with chronic health problems, individuals under 65 with physical disabilities, and caregivers of any of the above populations.

Key Findings

Medicaid and Medicare Eligibility

- Application and recertification: Participants universally reported challenges managing the application and recertification processes. They suggested the system should be simplified and streamlined to reduce the amount of information requested, the frequency of recertification and the redundancy between Medicare and Medicaid applications. Participants asked for improved access to alternate application forms and communication with Medicare and Medicaid personnel including in-person, on-line, and by telephone.
- Policies and coverage: Participants suggested eliminating the "marriage penalty" with Medicaid coverage and re-working the spend-down program to allow for increased flexibility with monthly income limits and allowable expenses. They also requested improved processes and flexibility around work and income limits.

Health Services

- Increased coverage for care: Focus group participants requested improved coverage for alternative care options including chiropractic care, acupuncture, nutritional supplements, and vitamins. They also asked for better coverage for eye care and eyeglasses, improved dental care coverage and increased access to preventive care including exercise programs, wellness programs, and nutrition services.
- Physician access: Participants said they faced challenges finding physicians who would accept new Medicaid patients. They suggested improved incentives and payments to physicians to encourage them to accept more Medicaid patients and increase their Medicaid caseload.
- Person-centered health management: Participants would like their health care providers to be more involved in coordinating their overall care. They would like to see better communication between providers and to have records more easily available to each provider.

Home-Based/Community Services

- In-home care and respite: Participants requested increased availability of home health aides and personal care attendants. They also would like to see better organization and coordination of in-home services as well as improved training and certification for providers. Participants requested increased respite funding and improvement in out of home respite capacity. To increase access and improve quality of care, participants suggested allowing a wider range of family members to be paid for taking care of their loved ones.
- Case management: Participants noted the importance of effective case management for facilitating access to service and managing Medicare and Medicaid issues. Participants would like to have more access to their case manager and increased availability of case management services for those who do not have it.
- Skill building programming and peer support: Participants and caregivers would like to see increased availability of skill building programming to work toward more independence. Consumers in the CRT and DS programs requested more facilitation and financial resources to create peer support and advocacy services.
- Individual budget flexibility: Participants and caregivers requested more flexibility in individual budgets to allow for more tailored supports.
- Ancillary services: Participants reported facing significant challenges managing other life circumstances including transportation, housing, food, and heat. They requested increased assistance in these areas.

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Methodology

To complete the goals set forth by the Vermont Agency for Human Services to conduct focus groups with persons dually eligible for Medicare and Medicaid in Vermont, Finch Network engaged a standard qualitative data gathering process as detailed below.

Participant Recruitment

Finch Network used a mix of techniques and strategies to recruit individuals to participate in the focus groups. A key strategy engaged was approaching potential participants through trusted support systems. We contacted 112 agencies, service providers, and gathering places via email and telephone to solicit assistance in sharing information about the focus groups with potential participants in each target population. The agencies were specifically targeted to be those providing service, support, or advocacy to the sub-populations desired to participate in the focus groups (Table 1.) A flyer (Appendix A) with details about the focus groups was made available to the organizations to share with the people they serve. The flyer included a toll-free number for consumers to call for information and to sign up and details on when and where the focus groups were to be held. In addition to agency contacts, newspaper advertisements soliciting participation were placed in the Burlington Free Press, the Rutland Herald, and the Randolph Herald, as well as on Craigslist. Participants were provided with a $20 VISA gift card in appreciation for their participation and were offered transportation reimbursement.

Focus Groups

Eight focus groups with Vermonters dually eligible for Medicaid and Medicare and family members/caregivers were completed between January 11 and January 13, 2012. Each focus group lasted approximately 1 ½ hours. In order to ensure a mix of rural and urban consumers, the focus groups were held in each of three regions: Southern Vermont, Central Vermont, and Northern Vermont. Seven sub-populations within the dual eligible population were targeted for participation in the focus groups (Table 1)

Table 1. Sub-population target groups for focus groups

Program	Consumer Demographic
Community Rehabilitation and Treatment Program	Service Users
Developmental Services Waiver Program	Service Users
Choices for Care Waiver Program	Service Users
Traumatic Brain Injury Waiver Program	Service Users
None, but dually eligible	Individuals over age 65 with chronic health issues
None, but dually eligible	Individuals under age 65 with disabilities
Mix of CRT, DS, C for C, and TBI Programs	Service User Caregivers/Family Members

Initially, focus groups were specifically geared to each sub-population. However, based on requests from participants to access groups closer to their place of residence, each focus group was instead integrated with a mix of target consumer groups. This change facilitated higher participation rates and allowed a wider scope of interaction and perspectives to be explored within each focus group. Three integrated

focus groups were held in Randolph, VT; three integrated groups were held in Burlington, VT; and two integrated groups were held in Rutland, VT.

Each focus group was guided by an experienced facilitator and recorded both electronically and by a note taker. Two facilitators were available at each focus group to ensure all participants were heard and involved in the discussion. An interview guide (Appendix B) directed the flow of the group and various techniques such as visualization, value analysis, and real life scenarios were used to facilitate participant engagement. Lisa Kendall, LCSW-R, CSW-G, was the primary focus group leader. Lisa has worked in the human service field for over thirty years in a variety of residential and outpatient settings, as a clinician, educator, and administrator. Formerly Senior Consultant for Work and Family Services at Cornell University, Lisa now serves on the President's Advisory Council on Family Issues at the University, and teaches at the Gerontology Institute at Ithaca College. Lisa holds advance certification in clinical gerontology. Kim VanNorman, LMSW, co-facilitated the groups and was the primary note-taker. Kim is an Ithaca-based licensed master social worker with extensive experience working with individuals and families with a variety of disabilities including families with children with emotional disabilities, people with developmental disabilities, people with traumatic brain injuries, and caregivers.

Telephone Interviews

Due to transportation and weather challenges, a number of people who signed up for the focus groups were not able to attend. In order to facilitate their participation, telephone interviews were conducted with these people following the same guide used for the focus groups.

Participation Rates

A total of 56 people participated in the focus groups and telephone interviews. The representation of each sub-population is provided in Table 2 below. Please note four participants represented more than one sub-population by having a disability of their own and also serving as a family member/caregiver to another consumer.

Table 2. Number of participants by sub-population and mode of participation

Sub Population	**Number of Participants**		
	Focus Group	**Phone**	**Total**
Community Rehabilitation and Treatment Program Service Users	12	0	12
Developmental Services Waiver Program Service Users	9	0	9
Choices for Care Waiver Program Service Users	3	3	6
Traumatic Brain Injury Waiver Program Service Users	4	1	5
Dually Eligible Individuals >65 with chronic health issues	6	1	7
Dually Eligible Individuals <65 with disabilities	5	4	9
Family Members/Caregivers of Dually Eligible Individuals	9	2	12
Total	48	11	60

Data Analysis

When all focus groups were completed, the information was analyzed by identifying, coding and categorizing primary patterns in the data. Findings were consistent across groups and individuals confirming the validity of the data gathered.

Participant Understanding of the Medicare and Medicaid Programs

In an effort to give context to participants' responses as well as provide facilitators the time to get people "on board" with the discussion, participants were asked various questions about their understanding of Medicare and Medicaid.

Participants ranged from being fairly new to Medicare and Medicaid to being long-time recipients. The groups exhibited a diverse understanding of the programs; some participants were very clear and others were quite confused about eligibility and benefits. The level of understanding did not seem directly linked to tenure of eligibility or use of services. Most participants understood their eligibility was due to disability and/or income, but could not describe the details of why they received certain benefits. Most people indicated they give each new service provider all of their benefits cards and let the provider figure out what they are eligible for.

Several participants noted their applications were facilitated or completed by case workers or hospital discharge planners and they personally had little understanding of why or how they were enrolled in Medicare or Medicaid.

Some consumers and caregivers noted they did not realize they were eligible for benefits at all and only found out after they had spent a great deal of money on self-pay and private care. One parent caregiver said, *"I have to say, I had a misconception for a very long time that he wouldn't be eligible because of our income. Vermont has a program for kids and I wasn't aware of it for a very long time so he didn't get it as soon as he could….My son was involved in some clinics through the state, and I worked for an early intervention program – but I got misinformation. I called the regional Developmental Services agency and asked about Medicaid and they said they had no idea – I don't know that would happen now – but when I really started exploring it, he was 8 or 9 and the best information I received was through other parents."* The experience of learning about program eligibility from friends and neighbors was echoed throughout all focus groups.

A small minority of participants, primarily seniors, indicated they had pro-actively searched for information about Medicare prior to retirement. One woman shared*, "I went to our local agency on aging and took a series of workshops on Medicare and understood the difference between Part A, B, and D. I think people do not understand how complicated Medicare is."*

Participant Experience with the Medicare and Medicaid Programs

Participants were asked a variety of questions related to the process of signing up for benefits, the experience of losing benefits, and the barriers and costs related to Medicare and Medicaid. Several broad themes were consistently repeated by participants and are described below.

Appreciation for Support

A majority of participants expressed their gratitude for the support and help they receive from the Medicare and Medicaid programs. A man with a chronic health disability said, *"Our state is really wonderful – if I call, I speak to a live human being exactly when I need to who will tell me what I need to know. They're very nice and very involved in helping me understand. I don't want that to slip or change. I don't want any tweaking to go on that would make that not work. I'm really proud our state employees are very human on that level. I want you to give them a fine 'how do you do'."* Other consumers expressed they would not be able to survive without the help they receive. Some individuals reported they believed they would be homeless in a month if their benefits were suddenly revoked for any reason.

Paperwork, Applications, Re-certifications, Decisions and Appeals
The paperwork required by the Medicare and Medicaid programs was universally noted as being stressful and a struggle to keep straight. Several consumers said it felt like a job trying to navigate the system. One noted, *"I have a part-time job and that's keeping track of my documentation."* A majority of participants remarked on the redundancy between the Medicaid and Medicare application processes. They articulated frustration that both between and within applications, the same questions are asked repeatedly.

Participants with advanced degrees noted they do not understand how anyone without a college degree could navigate the paperwork process. They frequently expressed concern about others who were less able to keep track and less cognitively able to be organized. One senior shared, *"My livelihood was teaching and writing. I was able to word it clearly in those days – so I got it the first time. I didn't have to go through hoops and hoops. Medicaid gives you big, long form with tons of questions and forms didn't scare me because I used to be a legal administrator. So they didn't scare me – I just did it. But if you're not on top of stuff and haven't found out how to do it all and forms scare you to death – oh I pity those people. I think seniors and disabled people are falling through the cracks like crazy because they won't persevere or they don't have that in their nature."* Another expressed, *"I know what the paperwork is all about. I can do paperwork – I am not intimidated by it and this was a challenge for me. How in the world are people with far fewer skills in this area going to turn around an application?"*

Participants with family members or other resources to assist with paperwork felt they were lucky to have the support. One participant who is eligible for Medicaid, but currently does not receive it, has chosen to continue to use his wife's coverage instead. He found the online application difficult to manage and had a hard time figuring out what to do. He decided to have an attorney file the application for him. He felt fortunate he had the financial and familial resources to do so.

Caregivers of people with developmental disabilities expressed that the recertification process seems burdensome and unnecessary. One caregiver noted it is an inconvenience to have to fill out the information every year when nothing ever has or will change. This opinion was shared by other consumer groups as well. A woman with a chronic illness noted people's incomes rarely change bi-annually and because of that bi-annual re-certifications are an unnecessary burden. Others noted certain illnesses are unchanging and life-long, making recertification of these illnesses a waste of state resources. One person said, *"The re-certification process is a nightmare, I have to collect all information throughout the year...it's very confusing."*

Several participants indicated they have to be very careful to watch the mail to make sure they don't miss anything and lose their benefits. A participant with a visual impairment said he had received a letter he could not read (it was not offered in Braille) and as a result lost his Medicaid. He noted that if they would agree to send him emails as he has requested, he has the equipment to read the notifications, but sending paper mail to him leaves him effectively un-notified. He also shared that the requirement to complete paper copies and provide paper documentation was challenging for him and posed privacy concerns, as he needed an assistant to complete this kind of paperwork. Caregivers noted challenges in keeping on top of paperwork as well. One caregiver said she had finally managed to have duplicate letters sent to both her developmentally disabled son and herself, which has made it somewhat easier to make sure no deadlines are missed.

A participant with a physical disability shared his stress, *"For me, the holidays are filled with worry and filling out paperwork for Medicaid. It's stressful to get the recertification letters the week of Christmas; I*

am worried it won't get there in time. I have to include my roommate's income, social security number, etc. I'm confused over what is meant by "household income". Why does my roommate have anything to do with my benefits?"

Participants reported not understanding the summaries ("explanation of benefits") that are sent to them and what they have to pay or not pay. They also noted a lack of clarity with the decision following an appeal of coverage denial, and not understanding why decisions about coverage had been made. Some questioned who makes the decisions regarding coverage. One participant asked, *"Is it health professionals? Or is it just about money?"* A consumer enrolled in the Community Rehabilitation and Treatment program shared, *"The appeal process needs to be improved – it is so difficult to navigate that people give up and end up going without what they need. The denial forms should be more complete and explain the reason for denial of coverage."*

Participants expressed difficulty in getting answers from the hotline. Several said it can take a long time for anyone to answer the telephone and they often received inadequate support when they did get through. A Choices for Care consumer described her experience*: "I asked the woman at the call center what my spend-down is. She said 'I can't tell you that, you'll have to find that out from your case manager, but you can't call her directly. I'm going to send her an email saying you want to know your spend-down and she'll send you a form letter telling you that.' This was my second request in 2 weeks and I'm still trying to find out how much my spend-down is. I don't know if they'll ever tell me."*

The change in process for contact with caseworkers has caused trouble for several participants. One Choices for Care consumer explained her difficulty with, *"You used to be able to go into your local office and meet with your caseworker face to face. If I had any issues, my worker explained them to me – she was wonderful – the thing would get expedited as quickly as possible. That's gone – all contact has to go through the call center at Waterbury, so now rather than being able to speak to a caseworker I have to go through the call center in Waterbury – I don't have a telephone so that becomes rather complicated. When I have to have my review for Medicaid, they say we have to have a phone interview. Last year I could go to the local office 3 blocks away, but my caseworker is now a 30 minute drive away."*

Understanding how to choose the prescription plan was noted as a significant hardship by a vast majority of participants. A consumer using TBI services said, *"Trying to understand whether the plan would cover the medicines you need is difficult, and the fine print says there's no guarantee to cover them anyway."* A senior with chronic health issues said, *"[Medicare] has become complicated with different insurances – I just threw names in the hat and picked one after reading them – it's a nightmare … I feel good that I picked one that's good, but that could turn any time."* A consumer using CRT services shared, *"Trying to choose who is paying for meds is a nightmare."*

Working for Pay

Several participants noted confusion about the effect of working at a job on their eligibility for Medicare and Medicaid. They expressed they were unsure how much they can earn and the impact of that income on their various benefits. Several participants expressed difficult experiences as a result of this lack of clarity.

One participant in the TBI Waiver program said, *"I went to work really quickly after my surgery and I was working disabled, so I was able to continue to qualify for Medicaid. As soon as I stopped working they relieved the service of Medicaid. So I lost it then. I just got it back now – this last year has been very confusing because I went on unemployment benefits which still put me over the income limit. But I didn't*

understand that – it still confuses me to this day. As a result, I had to stop going to my mental health provider, my doctor… It's been such a struggle the past year."

A person with a chronic disease said, *"I need my health insurance, but at some points I'm feeling pretty good and I want and need to work, but it's odd how those rules constrain me. And that bothers me quite a bit. I think on a lot of levels it's really therapeutic [to work]. I'll pay as much taxes as I can, but I'll lose health insurance which is ultimately the chain around my neck. One month I earned 13 dollars more for the year and so they wanted me to pay $75,000 back to them because of all the money ever spent on me – like I cheated them. And it turns out the pay came at a time when it shouldn't have. If it had come when it was supposed to, then I could have absorbed it. It's a bureaucratic hell to discuss these things with anybody involved … I'm not a bank executive here. I'm not cheating the system – I'm not actively pursuing trying to cheat anyone."*

Many participants felt that they are penalized or punished for working because their benefits are decreased or eliminated. Several noted they believed it ends up "keeping people on the system." One participant using CRT services shared*, "People need an incentive to leave their house, but the programs are a disincentive to working."* She explained her rent nearly doubled when she worked and that *"food stamps are also affected, Section 8, Medicaid, Medicare deductibles, prescriptions, all of these is impacted. You make $50 and end up paying $60, and the paperwork for that is terrible too, so there is no benefit to working."* Another consumer using CRT services CRT consumer said, *"It makes me feel that it would be easier to just quit my job even though I love it, and that adds to depression."*

One participant said he wanted to work so he could qualify for Social Security when he retired, but was concerned that if he did, he would lose his Medicare and Medicaid benefits. He believed working a minimum wage job would not make it possible for him to acquire health insurance.

A caregiver with a husband with chronic illness and a daughter with autism said she is able and willing to work, but believed that the additional income would eliminate the family's Medicaid coverage.

Participants also noted a "Catch-22" with trying to work and manage their mental health issues. One participant receiving CRT services said, *"I was 22 when I had problems with chronic depression and was hospitalized and that's how I got into Medicaid. I started working and lost benefits so I couldn't get medicines, and then lost my job because I couldn't get my meds."* Another said, *"I had gone on Medicare and then went off of it to try to work full time, but then had a relapse and I fell between cracks because I did not have insurance and yet I needed the help. It's hard working and having a mental illness."* She also shared that several months later she learned about the VPharm program from a drop-in center which was helpful, but she had struggled in the meantime.

A caregiver for her mentally disabled husband said*, "When my husband gets really, really sick and he can no longer work, there's a period of time where they 'punish him.' By the time we figure it out, he doesn't have Medicaid, and when he goes to the hospital, it doesn't cover it. When he went back to work, he got it again – but it took time."*

Lost Medicaid
About half of the participants said they had lost Medicaid at some point and then got it back. Most frequently the reasons the described for the loss of coverage were problems managing the re-certification process, job loss for those in the Medicaid for Working People program, or having too much income.

Some participants expressed confusion over why they lost benefits in the first place and then why they got it back. A caregiver for her developmentally disabled son reported when he lost his Medicaid coverage, she was never sure why it was lost and after making several phone calls the only way she knew it was reinstated was by going to the pharmacy to refill medications. A senior participant shared that while she was working with someone at the Area Agency on Aging to help figure out which Medicare Part D pharmacy plan to choose each year, she received a bill for a high premium she could not pay. She described being very confused about why she had lost her Medicaid coverage and is still unclear why it happened.

During their time without Medicaid, several people said they incurred medical expenses they had to pay out of pocket – many were able to negotiate payment over time or reduced payments, but the cost burden was still problematic and had impacted their credit.

Spend-Downs and Patient Share
Spend-downs and patient share were widely seen as confusing and difficult to manage. It appeared focus group participants who receive services from long-term care programs use the term spend down to describe patient share payments. Many focus group participants noted they were denied benefits due to being over the eligibility limit, but were not offered information on how a spend-down (or patient share) might make it possible for them to receive benefits.

A woman participating in the TBI Waiver program said, *"I was a full time LNA at a nursing home and had a back injury. It took 4 months to get a check, and in that time my car was repossessed. While waiting for the check, I applied for benefits and was $1.54 over for Medicaid services, but I was not offered to pay a spend-down to be eligible."*

A Choices for Care participant said she had received a cost of living increase from social security which kicked her off of Medicaid. She figured out how to do a spend-down, but it was confusing. She noted the program is not set up to be helpful and had to reapply to get back on Medicaid.

Others believe the spend-downs do not make sense financially. One person said, *"I am frustrated with the spend-down. I can barely live which is how I qualified in the first place, so how can I afford a spend-down?"*

Moving to Adult System from Children System
Caregivers noted challenges navigating the move from the children's Medicaid system to the adult Medicaid system. One participant said when her son turned 21 they received a letter saying he was no longer eligible, but provided no transitional information or assistance about how to apply for adult Medicaid. The change resulted in an eight year gap in finding a new provider. Another caregiver said with her own TBI disability it was too difficult to manage the paperwork when her daughter with special needs turned 21. A caregiver for her developmentally disabled son noted the shortage of primary care physicians made it very difficult when her son aged out of pediatric care.

Lack of Information about Program Services
Many participants expressed frustration with the lack of information on the services available to them. One woman with a physical disability said, *"Transportation is supposed to be available to people with low income if you have to travel long distance to see a medical doctor. I found out about this program after a long time paying out of pocket for transportation."* Another person said*, "I just found out I could be getting my IV treatments in my home instead of traveling to Boston."*

Marriage "Penalty"
A number of participants shared that getting married had caused problems with their ability to qualify for Medicaid. One woman said she felt like she was being penalized and punished for being married. Another said she and her husband are getting a divorce because they can't live on the amount they are receiving as a married couple as compared to before their marriage. Another participant shared that before she got married she had Medicaid, but now she doesn't. This experience was echoed by caregivers present in the focus groups. One caregiver said she suggests to others they consider not getting married in order to maintain their benefits.

Access to Services

Access to services is a key component in evaluating the care and services available to dually eligible consumers. In the focus groups and telephone interviews, participants were asked several questions about which services they have been and have not been able to access and the primary reasons for their lack of access.

Inaccessible Services
Nearly all participants said they were unable to access adequate dental care and eye care and the lack of access was a serious concern for them. One participant using CRT services said, *"I broke my bottom bridge and the quote to fix was $1,300 out of pocket. There was no way I could afford it. I called a lot of dental clinics to get a lower price but couldn't do it cheaper. I was offered a cheaper price to have my teeth pulled and get dentures."* Another shared, *"My husband has no teeth. Fortunately for me when I lost my teeth, my dentist took payments. We don't have anything like that for him – we can't find a dentist to get him dentures for nothing. He needs glasses and that's not covered."*

A Choices for Care consumer said, *"I was due for an eye exam but I don't have money for new glasses. I get SSI and Social Security, but after I pay my bills, I have nothing left. My church does not have any funds. A long time ago my church helped with back rent. Now they don't have money to help out."*

Participants claimed there were a number of other services they were unable to access including diagnostic tests such as blood tests, supplies for on-going chronic health issues such as ileostomy supplies, CPAP supplies, syringes and in-home accessibility accommodations such as wheelchairs, canes, special beds, shower chairs, potty chair, and shower heads. Others said critical personal care items were not covered, such as Depends, which posed a significant problem for them. One participant shared she had skin cancer and had two spots removed, but it was not covered because she was told it was not a terminal cancer and therefore a cosmetic procedure.

Participants agreed they are generally able to receive quality crisis care, but on-going supportive care to advance their progress is not generally available. Caregivers for developmentally disabled and mentally disabled children expressed this most frequently. One caregiver of her physically and developmentally disabled son said, *"I don't want him to stay stuck as a patient – I want him to go beyond his disability."* She went on to note the benefits would not pay for him to access a gym or other services to reduce his

weight, but will pay for prescriptions to deal with the health effects of his obesity. Another parent of a developmentally disabled son agreed, expressing she would like to see the possibility for more skill building for her son as opposed to only personal care. She said*, "I think there were therapies that he could have gotten when he was younger that we didn't explore. I believe his disability is more severe as a result, but we had no way to pay for them. He was going to therapeutic horseback riding which seemed very good for him. They gave us scholarships part of the year, but Medicare/Medicaid wouldn't cover that service – so part of the year he doesn't go."* The reduction in respite care funds was also noted as a concern for caregivers. A caregiver of a daughter with developmental disabilities reported her daughter's respite funding was cut. She said she is concerned this will result in more burnout for her home providers and will provide even more challenges in getting good home care in the future.

Many participants expressed disappointment in the lack of coverage for alternative treatments for their physical and mental health conditions. One physically disabled man said, *"For my back pain, the doctor recommends a chiropractor and gym exercises, but neither is covered. The gym is ¼ the price of what the prescriptions cost - which is covered."* A senior with chronic health problems shared, *"I'm trying to do as much as possible through natural means. I'm seeing naturopathic physician. I've chosen not to have back surgery- were I to have spinal fusion surgery it would be hugely expensive for the state. I am spending money out of my own pocket in order to take the natural route – I get acupuncture – that is helping me deal with my pain levels so I don't have to be on six different pain medications –instead I've reduced it down to one."* Many said they would like to have supplements and vitamins covered as well.

Nutrition services were an area frequently reported as being inaccessible. Participants expressed frustration that hunger and malnutrition are not considered a health issue and food stamps are not enough to cover healthy foods. A participant with HIV/AIDS noted having enough food was a serious problem for him. He said, *"I have issues with my appetite and need Ensure, but it is not covered. I need to lose a lot more weight before it will be covered, but I don't want to get that underweight. I would benefit from Ensure now, but the state wants me to lose 25 more pounds. My doctor has tried to help me but has not had luck."*

A consumer in the Developmental Services Waiver program said, *"I want to quit drinking soda and eating junk but it's hard to eat healthy when you don't have the money to buy the healthy stuff. Junk stuff is cheaper. I eat the junk because it's cheaper, but I want healthy food. I would want more food stamps and dietician or nutritionist help. I was supposed to see a nutritionist but I don't go because I can't afford to eat healthy, so what's the point."* This comment was supported by a service coordinator in attendance who said, *"I have many consumers who prefer to eat healthy but can only afford cheap food. With the prices of food going up, people can't afford what they want to eat."* A consumer in the Choices for Care program said, *"I also have celiac disease – that makes your food choices very hard. And it really eats through my food stamps. It limits my choices. I'm also diabetic – so I have to watch what I'm eating. Sometimes those things cost more. Celiac food costs more. They charge you a lot for what they don't put in."*

Availability of Providers

Location was a key factor in the availability of medical doctors who accept Medicare and/or Medicaid. Focus group participants from the Burlington area noted they were able to find doctors with little problem, but consumers from more rural areas said it took a long time to get in to see a new doctor or to find one who accepted Medicare and/or Medicaid. Several participants said local practices are "full" and will not accept new patients. A few suggested they can sometimes see another doctor faster, but not their preferred doctor. One participant with physical disabilities said she was not allowed choose a

doctor, but instead was assigned a physician's assistant and feels she isn't getting quality care as a result. Many people described very long wait times, up to 6 months, for an appointment with their regular physician.

Some consumers receiving CRT services said they felt they had difficulty finding mental health services that could meet all their needs. Others reported it was difficult finding mental health counselors who accept Medicaid.

The lack of in-home providers was shared as a problem for all participants eligible for the service. A Choices for Care consumer shared, *"It's just awful. You can't find anyone. It's the money; it's what they pay them."* Some caregivers expressed dissatisfaction that they couldn't be paid for providing care to their family members and suggested this practice could increase the availability of in-home providers and improve care for those not currently receiving in-home care.

The availability of dental providers was noted as a problem for many people as well. Several said they can't find a provider who accepts Medicaid or must travel up to 3 hours to find one. Developmental disability caregivers said finding a dentist who provides sedation and accepts Medicaid is nearly impossible. One shared, *"My son needs to pay up front for services in order to be seen [by a dentist]. He needs general anesthesia which isn't covered. We had to pay expensive up front co-pay."* Participants with HIV/AIDS also noted specific challenges finding dental care specific to their needs. One man said, *"There is only one person in the whole state of Vermont who will take AIDS Drugs Assistance Program and he has a long wait list and I can't get dental care as a result."*

The availability of specialists and services generally, not just within the Medicaid/Medicare system, was described as being a problem in Vermont. Many participants said they go out of state to access the specialists they need. A caregiver for a developmentally disabled child placed her daughter in another county due to the greater availability of services. She noted there are "geographic deserts for services" in Vermont.

Cost of Premiums and Co-Pays

For those required to pay Medicare premiums, the cost was reported as a significant burden. One participant said the premiums are comparable to other companies, but provide less coverage. Another shared, *"We have this term entitlement, that we're all "entitled to this stuff" like we're all princesses – that's not the truth. It's a very expensive program with the co-pays, even with Part A which is premium free is, it's enough to drive you into the poor house."*

Co-pays for office visits and prescriptions were generally considered reasonable by participants, but several said the costs add up in the case of multiple prescription needs or with a complicated medical problem. Many participants noted their budgets are tight enough that the $1 to $2 co-pays can be hard to manage. One participant receiving CRT services said, *"I had to pay co-pays the other day and had to borrow money from a friend."* A consumer with a chronic disease said he frequently cancelled specialist appointments and diagnostic tests because he couldn't afford the co-pays.

Cost of Prescriptions

A few people said they occasionally skip medication as a result of co-pay costs – particularly those individuals with several prescriptions. One caregiver said her physically disabled husband stopped taking a medication because it was too expensive.

Some participants said they had to skip medication doses as a result of challenges with re-fill stipulations. One person noted, *"The prescription is only for 30 days and can only be filled once per month, so months with 31 days leaves you a day short. You don't get 31 pills for the months with 31 days which is a big problem with my thyroid medicine."*

Another individual said, *"There are 5 different medications and usually they come due at 5 different times at the month. And then there's the problem of needing to go 90 miles to get them. And that's a real drag – it's not always easy to get around because of weather and stuff. It's a big burden."* Some participants had success using online pharmacies which were able to deliver their medications automatically to their homes. However, some participants reported they were not able to access home delivery.

Others participants revealed that skipping medicines were simply not an option for them because it results in serious problems. A consumer in the TBI Waiver program who suffers from seizures said, *"There have been times I've had to wait to fill prescriptions because even $1.10 can be expensive – it's not a luxury, it has to be prioritized – my prescription is as important as bread, milk, etc. I'm choking up a little bit because this last year has been hell for me frankly."* Another person shared, *"My medicine is more important than eating."* A caregiver for a consumer receiving CRT services said, *"We weren't able to pay the co-payment on blood work required for my husband's prescription for a few months and so couldn't get his prescription. He had to skip a couple of days and ended up in the hospital as a result."*

Generally participants said they are able to negotiate getting their medications if they run out. There was a general sense that pharmacists were helpful in negotiating problems with refill discrepancies though this is not a universal experience. The vast majority of participants expressed a constant fear their Medicare Part D pharmacy plan will stop covering their medications and the potential difficulties which would result. One man related, *"I hold my breath every year when the new list comes out."*

Coverage of the right prescription can be a serious challenge for many consumers. Several described problems with name brand vs. generic medications and the importance of being able to have name brand medications when generics have more negative side effects. One person said he took a generic and ended up in the hospital due to side effects. Another participant said sometimes taking medications in certain combinations is important, but is not taken into consideration in coverage plans. HIV medications are frequently dispensed as "cocktails" of 3 or more drugs, and he is limited to combinations in which all three happen to be covered by his Medicare Part D pharmacy plan. A caregiver for a consumer receiving CRT services explained when her husband's medicine was no longer covered, they were required to try out several other medications before approving his use of his original medicine – a process that had already been done in previous years.

Transportation

Many participants noted difficulty with transportation including a lack of understanding of the different options available and the rules associated with the programs. One person shared a story about how she had needed transportation for an emergency radiology appointment, but the local transportation service would only take her to the Emergency Room. She noted the organization had since changed its policy to allow for same day appointments with a doctor's verification. Other focus group participants expressed they were unaware of the rule change. Some people indicated the services they required were not covered by the Medicaid transportation (e.g. PTSD treatment) and so they had to stop getting treatment. A participant with a visual impairment noted difficulty managing transportation with his service animal.

Participants also shared that if someone in their household has a vehicle, they cannot get transportation assistance. One participant explained, *"My jeep was broken and in the shop, but since we owned it, [the transportation provider] would not give me a ride to a doctor. If it wasn't for my case manager I wouldn't be able to get to court hearings, etc."*

System of Care Priorities

Some consumers and caregivers in the Developmental Services Waiver program noted the challenges associated with wait lists for services based on the system of care priorities. They said that unless they are at risk for being homeless or have significant medical needs it is very difficult to get services. They added it can be a challenge getting access to out of home residential services if there is family available in the area, whether or not the family is an appropriate placement for the individual.

Other Issues

Many participants described other difficulties which impact on their lives and access to care and services. A frequently expressed difficulty was with housing – in particular, challenges with Section 8 housing subsidies. Finding housing that meets Section 8 housing subsidy requirements, but also accommodates disabilities, can be impossible for some participants. The waiting list for receiving Section 8 housing subsidies is also very long, one participant said, "*I've been on the list for 7 years and I struggle to make ends meet. I have to choose between rent, medications, and clothing. I only eat once per day at my restaurant job."* The cut in fuel assistance was noted as making things harder for many participants as well. Several said they were unsure how they were going to heat their homes for the bulk of the winter.

Quality of Services

Focus group participants' perceptions of the quality of services they receive were gathered through a variety of questions related to their experiences with their providers and the outcomes of those services.

Participants generally expressed satisfaction with their primary health care providers. Overall they felt their health care providers listened to them and answered their questions. A senior with chronic health problems noted: *"I saw several specialists and my rheumatologist was able to look up the files from my other specialists to compare notes. I love my providers because they share information and coordinate. I was so impressed with the providers there. My specialist doctors call me back personally; they do not have a nurse call for them. Go to Texas and you'll know the difference of how good Vermont is."* A person with physical disabilities said, *"The providers I'm involved with listen to me and don't get paid enough. They're really good."*

The availability of choice for all types of providers varies between locations. Unsurprisingly, areas with larger populations were more able to provide a choice of providers whereas more rural areas presented challenges. The perceived quality of physical health providers was highly dependent on area of residence, with participants from more rural areas expressing more dissatisfaction with their physical health care and choices. Participants' perceptions of the quality of mental health care providers ranged widely and were also highly dependent on the participants' geographic location. As with physical health, participants in more rural locations were more dissatisfied with their mental health care options and care. One consumer in the Developmental Services Waiver program said, *"My doctor is average, and my therapist is good. But I have to travel 30 miles to get to them."*

Many participants indicated they had been hospitalized in the past two years – most as a result of an emergency visit. Discharge planning was not universally provided and those with a case manager were more likely to have a discharge plan. Satisfaction with hospital visits varied widely among participants and was highly dependent on location.

Focus group participants reported that pharmacists were generally reliable in providing information about drug interactions and were helpful in dealing with coverage issues. A few individuals said they weren't satisfied with their pharmacy, but overall the participants were pleased with the services they receive. Several noted when they had difficulty making their co-pays, the pharmacies were willing to wait a few days for payment.

Vocational rehabilitation services were described as being good, but having room for improvement. Some participants suggested the assistance provided by employment services were nothing more than what they could accomplish on their own. One reported, *"I was seeing an employment counselor for 2 years and never once applied for a job. I did not find it helpful."*

Quality of in-home providers was extremely variable and many reported difficulty finding good quality help. Consumers in the Developmental Services Waiver program generally said their home providers were very good and supportive. Persons with physical disabilities and Choices for Care consumers noted communication and organization with the home care providers was frustrating. One person suggested, *"I think it's important that they stay in your home a long enough time that you feel safe or acclimated or not so rushed all the time."* Scheduling with home care providers was described as a challenge for several participants. One person said, *"They were good when they were there, but it was hard to work the schedule out."* Another said, *"I have trouble making sure they have a schedule so we know who's coming when and not have three people coming at the same time."*

Concerns were raised about state oversight and monitoring of service providers. Participants also expressed concerns about the backlogs for adult protective cases. They believed this is detrimental to people who do not have family to advocate for them. Others noted it's important to remember not to water down services and that while the closing of institutions was a good choice, communities need to make sure to provide sufficient care and the state needs to make sure oversight continues with private contracts with non-profits.

Consumers in the CRT and Developmental Services Waiver programs reported being very happy with their service providers. However, those with physical disabilities and/or health problems felt the adult day program available to them were less effective for people who had greater abilities and/or mobility.

Caregivers and consumers who receive residential services expressed nearly universally satisfaction with this assistance. They described feeling comfortable and well cared for.

A few focus group participants said they felt they were discriminated against by providers due to their ethnicity.

Coordination and Integration of Services

Participants revealed a wide range of access to and experience with case management support. CRT consumers generally reported a strong connection and support with case management services. Consumers in the Developmental Services Waiver program described good support from case managers. Seniors and Choices for Care consumers also indicated they had sufficient case management support. Individuals in the TBI Waiver Program and those with physical disabilities and chronic health problems indicated case management was less available or not available to them requiring them to be much more proactive in managing their services. Participants who felt they did not have an effective case manager, or did not have a case manager, were much more likely to struggle with managing the system and feel they were not receiving quality care. Several people noted their case managers' case loads are increasing which has made it difficult to see them as frequently as they need and want. Some noted they feel they have to take care of more issues on their own as a result which is a challenge because they believe the case manager has more information about services. Others expressed it made it more difficult to get their questions answered with managing their Medicare and Medicaid paperwork.

The majority of people indicated they feel they are part of their health care team and they have a voice in decision making. Many revealed they aren't told what to do, but rather work with their providers to develop the best course of action. Some expressed concerns that they are the only ones who know the "big picture" and communication between providers does not happen effectively.

Future Improvements and "Wish List"

Focus group participants' were asked to provide a "wish list" for how the Medicaid and Medicare programs and the health and community-based services they receive could be improved. The following represents the most frequently mentioned improvements.

Medicaid and Medicare Eligibility

- Application and recertification: Participants would like the application system to be simplified and streamlined to reduce the amount of information requested, the frequency of recertification and the redundancy between Medicare and Medicaid applications. Participants asked for improved access to alternate application forms and communication with Medicare and Medicaid personnel including in-person, on-line, and by telephone. They also suggested universal health care would eliminate the need for these processes altogether.
- Policies and coverage: Participants suggested eliminating the "marriage penalty" with Medicaid coverage and re-working the spend-down program to allow for increased flexibility with monthly income limits and allowable expenses. They also requested improved processes and flexibility around work and income limits.
- Information & referral: Participants suggested making a guidebook available which clearly explains Medicare and Medicaid coverage, spend-downs and the services available.
- Oversight and monitoring: Participants requested improved and continued oversight and monitoring of service providers. They also would prefer greater oversight on consumer fraud within the Medicaid and Medicare systems.

Health Services

- Alternative care: Participants would like increased coverage for alternative care options including chiropractic care, acupuncture, nutritional supplements, and vitamins.
- Vision care: Participants requested increased eye care and eyeglasses coverage.
- Dental care: Participants would like to see dental care allowance increases and denture coverage

- Non-prescription mental health therapies: Participants said they would like to see improved availability of non-drug based mental health therapies including goal and behavior based therapies and peer support.
- Preventive care: Participants requested increased access to exercise programs, wellness programs, and nutrition services
- Physician access: Participants would like to see physicians' Medicaid caseload limits increased to improve access. They suggested improved incentives and payments to physicians would encourage them to accept more Medicaid patients.
- Person-centered health management: Participants would like their health care providers to be more involved in coordinating their overall care. They would like to see better communication between providers and to have records more easily available to each provider.

Home-Based/Community Services

- Peer support: Participants with mental health and developmental disabilities requested more facilitation and financial resources to create peer support and advocacy services.
- In-home care: Participants requested increased availability of home health aides and personal care attendants. They also would like to see better organization and coordination of in-home services as well as improved training and certification for providers.
- Case management: Participants would like to have more access to their case manager and increased availability of case management services for those who do not have it.
- Respite: Participants would like to see increased respite funding and improvement in the capacity of out of home respite.
- Skill building programming: Participants and caregivers would like to see increased availability of programming in Developmental Services which focus on skill building to work toward more independence. They would like to see less reliance on the personal care model and more on a skill development model.
- Transportation assistance: Participants would like improved transportation assistance which allows them to more easily access their needs beyond doctor's appointments including shopping, entertainment, and work.
- Heating assistance and housing assistance: Participants requested increased and improved access to heating assistance, rental assistance, and affordable, accessible, safe housing.
- Information and assistance – Participants asked for increased availability of information and assistance including the development of a public place where people can ask questions face to face.
- Expansion of home care worker availability: To increase access and improve quality of care, participants suggested allowing a wider range of family members to be paid for taking care of their loved ones.
- Individual budget flexibility: Participants and caregivers requested more flexibility in individual budgets to allow for more tailored supports. The following supports and services are the areas participants most frequently requested access to:

    - Dental care/dentures
    - Eye care/glasses
    - Alternative care
    - Clothing
    - Nutritional supplements
    - Preventative care
    - Personal care

- Safe transportation
- Support for service animal
- In-home case management
- Peer navigators
- Fuel assistance
- Uncovered Prescription medications
- Housing
- Financial services
- Supportive employment/skill based recovery and therapy

Appendix A. Recruitment Flyer

Do you receive both Medicare and Medicaid? Would you like to share your experiences with the State of Vermont to help improve these programs?

Please participate in a Focus Group about Medicare and Medicaid in January and receive a $20 gift card.

▶ If you receive services from any of the following:

- the Vermont Community Treatment and Rehabilitation Program
- the Vermont Developmental Services Waiver Program
- the Vermont Choices for Care Waiver Program
- the Vermont Traumatic Brain Injury Waiver Program

-OR-

▶ Are 65 or older and have a chronic health problem

-OR-

▶ Are under 65 and have a disability

-OR-

▶ Are a caregiver/family member of any of the above

Focus Group Locations, Dates & Times

Day	Time	Where
Wednesday, January 11	9am – 11am	White River Craft Center Randolph, VT
	12:30pm-2:30pm	
	3:30pm-5:30pm	
Thursday, January 12	10am-12pm	Best Western Windjammer Conference Center, Burlington, VT
	1:30pm-3:30pm	
	5pm-7pm	
Friday, January 13	10am-12pm	Holiday Inn Rutland Rutland, VT
	1pm-3pm	

All Focus Group participants will receive a $20 gift card.

Refreshments will be provided

Transportation reimbursement also available

Please call us toll-free at **(888) 642-9331** to sign up. We will ask you a few short questions to make sure you are eligible and provide you with more information.

Appendix B. Focus Group Guide

Introduction

Thank you for your willingness to participate in this focus group. Your feedback is very important and will help the State of Vermont make some important decisions about Medicare and Medicaid. We want to know about your experiences so the programs can work better for you and others in the future. *I want to remind you that your participation will not affect the benefits and services you are receiving.*

1. I am interested in all of your ideas, comments, and suggestions.
2. I'd like to hear from everyone.
3. There are no right or wrong answers to the questions.
4. All comments—both positive and negative—are welcome. Please don't worry about offending me with anything you might say—it's important that I know your opinions and feelings.
5. Please feel free to agree or disagree with one another. We would like to have many points of view.
6. I'd like this to be a group discussion, so you do not need to wait for me to call on you.
7. This discussion is being audio-taped to make sure we don't miss anything important in our notes. Before coming into the room you signed a release giving us permission to audio-tape you during this discussion. All comments are confidential.
8. Please speak one at a time, so that the tape recorder can pick up everything.
9. Also on the release you signed, you agreed to respect the confidentiality of others in the group. This is very important. We will do our best to ensure that your identity remains confidential, but we need you to do your part in keeping everyone's name and what they said confidential.

Let's start with some introductions – let's go around the room and everyone can tell us your first name and your favorite thing to do.

Review of Dual-Eligibility and Medicare/Medicaid

A. Each of you has Medicare and Medicaid for your health care coverage. In Vermont, Medicaid is part of the umbrella of *Green Mountain Care*.

1. Do you know how long you've had coverage from each program?
2. Do you know why/how you qualify for each program? Do you remember where you applied for each program?
3. How are the two programs different?
   Probes:
   - Do you know what each program covers?
   - Do you get certain services through one program and other services through the other?

B. Medical Assistance (Medicaid)

1. Do you know why you were able to get Medicaid?
   Probes:
   - Was it related to a medical condition, a disability?
   - Did you have to show check stubs or other proof of income?
   - Do you get an SSI check?

2. Did someone help you with the application? Who helped you? What was it like?

C. Medicare

1. How did you learn you were eligible for Medicare?
2. Do you remember how you got on Medicare? Did you have help?

D. Experience with Medicare/Medicaid

1. Have any of you lost Medicaid, and then at some point got it back? What was that like?
   Probes:
   - How did you find out you lost Medicaid? How did you find out that you got it back?
   - Who helped you get it back?
   - Did you have to stop seeing a provider when you lost Medicaid?
   - Were the benefits/services different when you lost Medicaid?

2. What types of issues have you had in paying for your care or health services?
   Probes:
   - How about the premiums you pay – would you say they are reasonable?
   - What happens if you don't have the money to pay your premium?
   - Have you ever lost coverage because you couldn't pay your premium?
   - What about your "co-pays" for prescriptions or office visits, are they reasonable?
   - What happens if you don't have enough money for your co-pay?
   - Have you ever taken a smaller dose or skipped doses of medicine to make them last longer?
   - Have you ever skipped appointments or therapy because you couldn't afford the co-pay?

Evaluation of Care and Services

A. Let's talk about the services you might be using or wanting/needing to use. Here's a list of some different types of services:

- Medical care from a doctor including surgery
- Mental health care or counseling
- Dental care including dental checkups
- Dentures or eyeglasses
- Diagnostic tests such as a CAT scan, MRI, lab work, or x-ray
- Prescription medicines
- 'Over the counter' medicines
- Durable medical equipment or assistive technology
- Modifications to make your home more accessible
- Help in your home such as personal care, cleaning, shopping, or medication assistance
- Help in accessing other supports such as rental assistance, fuel assistance, food assistance, transportation

1. Have you ever needed any of these services, but couldn't readily get it? Which ones?
2. Why couldn't you access the services?
   Probes:
   - Were there enough providers available?
   - Did you have problems with your insurance covering the service?
   - Did you have problems with the provider not accepting your insurance?
   - Was the wait time for an appointment too long? Or was there a waiting list for services?
   - Did you not know where to go?
   - Did you have transportation difficulties?
3. Can you think of any other services that you need or want that you can't access? Why can't you access them?

B. Let's talk about the quality of the care and services you receive.

1. Overall, how would you rate your providers – would you say they are excellent, good, average, fair, or poor?
   - Your primary health care provider
   - Your primary mental health care provider
   - Your caseworker/coordinator of services
   - Employment services
   - Day programs
   - In-home staff
   - Other?

2. How would you describe the quality of your services and providers? Do you think they do a good job for you?
   Probes:
   - Are there enough different providers (ex. Doctors, therapists, etc.) you can decide between or is there only one choice? Do you feel like there are enough providers to choose from?
   - Do your providers listen to you?
   - Do they answer your questions?
   - Can you talk to them any time you need to?
   - Do you feel like they help you in the ways you need help?
3. What works well with the services you receive? What have been the best experiences you've had in receiving services?
4. What hasn't worked well with your services? Can you think of the most difficult time you had trying to get services or when you've received services? What happened? What was the main issue?

C. Let's talk about the coordination of the services you receive.
   1. Do you have a case manager or service coordinator that you work with?
   2. How often do you see or talk to your case manager?
   3. Has there ever been a time when you needed your case manager to help with a problem with your services? Tell me what happened.
      Probes:
      - Did you feel like your problem was solved?
      - How long did it take?
      - Do you feel like your case manager listened to you?
   4. Do you feel like you are involved in your care, that you are part of the "team"?
   5. Do you feel like you get to be part of deciding what the best treatment/care is for you?
   6. Who do you think is the leader of your "care team"? Are you happy with that leader?
   7. Do you know who to contact when you have a question about your care or services?
   8. If you were telling a friend how to get services or to manage Medicare/Medicaid, what tips would you give them? What are some things that you wish you had known?

D. Let's talk about some real-life situations of what it's like for you getting the health care services you need. Here are a couple of examples that maybe some or all of you have experienced. The first one is about prescriptions – what is like getting your prescriptions filled? Suppose that as you're taking your medicine this morning, you realize you are almost out of one of your prescriptions and you need to get it refilled pretty quickly. Can you tell me about the process of getting that prescription refilled?
   1. Do you have to call someone to get more medicine when you run out?
      Probes:
      Do you know which doctor you have to call– psychiatrist, primary care physician? Other?
      How do you find out? How do you reach that doctor?

2. What happens if you get to the drug store and find out from the pharmacist that the particular drug you've been using is no longer approved by your health plan? What then?
3. Is the pharmacist helpful to you in working this out? In explaining what you need to do in order to get the prescription authorized and/or refilled?
4. When you start a new medicine, who talks to you about possible side effects, interactions with other drugs you might be taking? The pharmacist? Your doctor? A Nurse?
5. Does your case manager help you when you have problems getting the medicine you need?

E. Has anyone been in the hospital in the last year or two? Can you tell us how you got admitted?

Probes:
A crisis visit to hospital emergency room?
Direct admission by physician?

1. Did someone at the hospital discuss a discharge plan with you -what would happen when you left the hospital? Were you involved in making the plan? Was your case manager involved in making the plan?
2. Did he/she tell you what services you would need and how arrangements would be made for you to receive them?
3. Do you know if your case manager, your therapist, your doctor knew that you were hospitalized?
4. Was there someone such as your case manager or doctor's office you could call who could help once you were discharged from the hospital?

F. Are there other circumstances when you're trying to get services or resources that are confusing or can be difficult because you are unsure about your health care coverage or who should be helping you?

Probes:

1. Do you have more than one health plan/health ID card? How do you know which one to use when you are at your doctor's or therapist's office?
2. Do you think your health care providers communicate with one another?
3. Who do you call when you're not feeling well or have a medical problem? Where do you go?
4. Do you feel there is someone you can talk to who is in charge of your care? Who knows what's going on overall? Who might that be? (Probe for case manager, care manager, therapist, PCP)
5. Do you ever have to change doctors/therapists because the one you were seeing is no longer on your plan? Who do you talk to about this? Who helps you to find a new doctor, therapist?

How to Improve Services

1. Let's think about your health services. What do you think could be done to improve health services? When we're talking about health services, we mean things like your doctors, therapists, hospitals, nursing homes, and nurses.
   Probes:
   If you were to imagine perfect health services, what would it look like?
   If you were the "boss" of health services, what would you do to change things?

2. What about home and community-based services? What do you think could be done to improve those types of services? When we're talking about home and community-based services, we mean things like respite, service coordination, employment services, home supports, transportation, etc.
   Probes:
   What would perfect home and community-based services look like?
   What are the most important qualities?
   If you were the "boss" of home and community based services, what would you do to change things?

3. If Medicare and Medicaid in Vermont were to change so you could choose how to spend some of the money, how would you use it? What types of supports or services would you want to "buy"?
   Probes:
   - Would you want to put some money toward other types of helpful services such as rental assistance, fuel assistance, food assistance, transportation?
   - Would you rather put it toward other types of health care such as dental care or eye care that may not be covered by your current program?
   - 'Over the counter' medicines
   - Durable medical equipment or assistive technology
   - Modifications to make your home more accessible
   - Help in your home such as personal care, cleaning, shopping, or medication assistance