New Hampshire Medicaid Care Management Focus Groups Summary Report
Year Three, Fall 2015

A report detailing the results of focus groups and qualitative interviews held with individuals receiving Medicaid benefits in the State of New Hampshire to explore their experience with the Medicaid Care Management Program.

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EXECUTIVE SUMMARY

Introduction

In support of the New Hampshire Department of Health and Human Service (DHHS) Medicaid Care Management Program, an external review of qualitative data from Medicaid beneficiaries will be gathered regarding their experience with the Medicaid Care Management Program over a three year period. For the first half of Year Three of the contract, two focus groups and telephone interviews were conducted with targeted Medicaid beneficiaries during January 2016. Four Key Points of Inquiry were identified to explore during this period's data collection efforts: *Access to Case Management, Experience with Health Care Management, Barriers to Receiving Care, and Suggested Improvements.*

Methodology

The targeted population included individuals currently enrolled in case management from the (Managed Care Organizations (MCO's) for at least 30 days and members discharged from case management within the last three months and currently enrolled with the MCO. The list excluded members enrolled in low intensity service levels such as education only care coordination. The area of the State with the highest concentration of members was the Manchester area with a total of 290 members from both MCOs combined. The entire population was included in the sample for recruitment because of the relatively small number of members. A total of 21 individuals participated in the project.

Results

The information provided in this report can be used to identify salient issues relevant to the population, provide contextual information for the larger assessment process, and identify avenues for further research, but should not be assumed to be *statistically* representative of the whole population because of the sample size.

Access to Case Management

Participants were asked to describe the extent of their contact with case management including the types, quality, and consistency of support and interactions with a case manager from their MCO as well as the availability and quality of educational materials they receive. In general, participants reported contact was initiated by their case manager once a month. The majority of participants reported positive experiences with case management including support managing medications, coordinating providers and organizing ancillary needs such as transportation and housing. Key challenges connected with case management for participants included difficulties with continuity between case managers, a lack of consistency in quality between case managers, and communication on behalf of family members. According to information provided by the MCOs, over half of participants were no longer actively receiving case management services. Few participants indicated that they no longer had a case manager suggesting that they were not aware that their case management services had been terminated. Overall, participants were pleased with the quantity and quality of the educational materials they received.

Experience with Health Care Management

Participants were asked to describe their plan of care, their experiences with their doctors, the level to which their doctors and health plan coordinated with each other and their perception of any changes in their health management since enrolling with their MCO. The majority of participants either did not have or were not aware of their plan of care. Most participants had selected their primary care physician and were happy with their care from their doctor. The main complaint with regard to physicians was the lack of availability of specialists locally requiring travel to receive care. Participants were divided on whether they felt their doctors coordinated well with each other and with their health plan. The majority of participants believed their health had been better managed since enrolling with their health plan.

Barriers to Care

Participants were asked to identify any challenges and barriers they have experienced in attempting to receive the care they need. The most commonly identified barrier to care was a lack of coverage for needed care, specifically with medications. Participants also pinpointed the pre-authorization process for causing delays in receiving care. Communication within their health plan was found to be a barrier for participants as were cultural issues and reduced time with their physicians.

Suggested Improvements

Participants were asked to offer suggestions for what would improve the care management they receive from their health plan. While several participants said they were pleased with their MCO and said there was no need to change anything, other participants had specific suggestions for improvement. The most commonly mentioned suggestion was to improve and enhance communication from their MCO and between their MCO and health care providers. Participants also would like improved consistency in decision making and continuity between case managers. Efforts to simplify information were helpful. Several participants suggested increasing coverage, better communication from providers, and offering more opportunities for member feedback.

Recommendations

Improve communication

The challenges participants most frequently mentioned were centered on communication. Specifically participants would like:

- Clearer communication about starting and ending case management including simple written materials summarizing whom to contact. Some participants were unaware that their case management had ended and others were unsure about the process when it began.
- Improved communication within the MCO so case managers would have access to more information from physicians and can more effectively help manage other aspects of health care.
- Proactive communication from case managers including recommendations for care and ancillary supports
- Proactive communication and coordination with family caregivers of participants with high medical needs

Improve understanding and addressing of cultural needs
Caregivers expressed challenges managing the care for their non-English speaking family members and that integrate specific cultural traditions. These caregivers suggested that allowing family members to be reimbursed for caregiving support rather than requiring hired caregivers would improve both the quality of life and quality of care.

Improve consistency
Participants noted significant differences in the quality of communication and support received from various case managers indicating a potential need for consistent training and skill development. Participants also noted inconsistencies in decision-making as an area for improvement.

Simplified Information
Participants said they would appreciate receiving simplified information about Medicaid in general. They suggested providing a basic summary of Medicaid and how it works as well reference materials of who they should contact to address various concerns.

Improved Coverage
Participants suggested improving the coverage they receive from their health plan for medications and dental care. Participants noted that denial of coverage may increase costs in the long run.

Better Communication from Providers
Participants noted a concern about how their providers' decisions may be affecting the cost of care. Members may not understand the reason for changes in medication(s) or dose(s); or why procedures and tests are ordered and better communication from the provider may help diminish these concerns.

Provide opportunities for member feedback
Participants were excited to share their experiences at the focus group and expressed a desire for further opportunities in the future.

INTRODUCTION

In support of an external quality review of New Hampshire's Medicaid Care Management Program, qualitative data will be gathered from Medicaid beneficiaries regarding their experience with the Medicaid Care Management Program over a three year period. For the first half of Year Three of the contract, two focus groups were conducted with beneficiaries in January 2016. The population targeted included individuals currently enrolled in case management from the MCOs for at least 30 days and members discharged from case management within the last three months, but still currently enrolled with the MCO. The list excluded members enrolled in low intensity levels such as education only care coordination. Both focus groups were conducted in Manchester, New Hampshire.

Table 1. Focus Group Locations and Dates

Location	Date/Time
Manchester	January 7, 2016: 4:30pm-5:30pm
Manchester	January 8, 2016: 10:00am-11:00am

Four Key Points of Inquiry were developed based on material provided by the Department of Health and Human Services (DHHS) to frame the information to be gathered from participants during this round of focus groups. The Key Points of Inquiry were as follows:

1. **Access to Case Management**
   Extent of participants' contact with case management including the types, quality, and consistency of support and contact with a case manager from the MCO and/or participants' doctors' offices and the extent and effectiveness of educational materials provided by the MCO

2. **Experience with Health Care Management**
   Participants' experience with their doctors, plan of care, and coordination between their doctors and the MCO and participants' perception of any changes in their health management since enrolling with their MCO

3. **Barriers to Receiving Care**
   Participants' identification of challenges and barriers they have experienced in attempting to receive the care they need

4. **Suggested Improvements**
   Participants' suggestions for improvements to their MCO and Medicaid and what information they would most like to receive from their MCO

METHODOLOGY

To complete the goals set forth by DHHS to qualitatively gather information from Medicaid beneficiaries regarding their experience with the Medicaid Care Management Program, Horn Research engaged a standard qualitative data gathering process as detailed below. A total of 21 individuals participated in either a focus group or a telephone interview.

Sample Size and Composition

Eight to ten participants were targeted for each of the two groups for a total of 16-20 participants. The group size is considered ideal for focus groups by being small enough to allow everyone the opportunity to express an opinion and large enough to provide a diversity of experiences. The MCOs provided contact information for all enrolled beneficiaries currently or recently receiving case management services (excluding low intensity level support) for at least 30 days. Manchester was selected as the location for the focus groups because it had the highest concentration of individuals (N=297). Seven individuals were excluded from the sample due to insufficient contact information leaving a total population of 290. Because of the relatively small number of members, the entire population was included in the sample for recruitment. The sample size proved to be sufficient to recruit the target number of participants.

Participant Recruitment

A letter (Appendix 1) explaining the project and asking for participation was sent on December 3, 2015. Based on challenges recruiting for the focus groups in Years One and Two, the incentive for participation was changed from a $20 gift card to a $50 gift card. The increased incentive had a dramatic impact on the ease of recruitment. The groups were filled to capacity by December 11, 2015 and a wait list was established. In addition, three individuals who were not able to attend a group due to health restrictions called and requested telephone interviews. Focus group registrants were called to confirm their attendance on January 4, 2015. A total of 18 people participated in the focus groups with an additional three individuals participating in a telephone interview. Four focus group participants were caregivers of people receiving case management who were physically unable to attend the focus group or participate in a telephone interview.

Participant Demographics

Table 2 shows the distribution of participants' MCO by location. Both New Hampshire Healthy Families and Well Sense Health Plan were represented by participants and in nearly equal proportions to the total sample.

Table 2. Number of Participants by MCO

	Focus Groups/Interviews		**Full Sample**	
MCO	**Number**	**Percent**	**Number**	**Percent**
NH Healthy Families	9	42.9%	134	46.2%
Well Sense Health Plan	12	57.1%	156	53.8%
Total	*21*	*100.0%*	*290*	*100.0%*

As shown in Table 3, the MCOs also provided information on their participants' case management status. Two thirds of participants Well Sense participants and almost half of NHHF participants were no longer actively receiving case management services which were in similar proportions in the full sample (57.9%).

Table 3. Case Management Status of Participants

Status	**Well Sense**		**NHHF**		**All Participants**		**Full Sample**	
	Number	**Percent**	**Number**	**Percent**	**Number**	**Percent**	**Number**	**Percent**
Open	4	33.3%	5	55.6%	9	42.9%	122	42.1%
Closed	8	66.7%	4	44.4%	12	57.1%	168	57.9%
Total	*12*	*100.0%*	*9*	*100.0%*	*21*	*100.0%*	*290*	*100.0%*

Participants represented a range of health issues from relatively minor to complex co-morbidities. Well Sense provided limited information on participants' diagnoses and simply indicated whether the participant was receiving case management for medical health or behavioral health and whether it was for complex needs. NHHF provided more detailed information on patient diagnoses as well as complexity. Overall, participants were similar to the full population in distribution of medical health versus behavioral health (Table 4).

Table 4. Number of Participants by Case Management Type

Case Management Type[1]	**Well Sense**		**NHHF**		**All Participants**		**Full Sample**	
	Number	**Percent**	**Number**	**Percent**	**Number**	**Percent**	**Number**	**Percent**
Medical Health	10	83.3%	5	55.6%	15	71.4%	206	71.0%
Behavioral Health	2	16.7%	1	11.1%	3	14.3%	41	14.1%
Both (WS only)	0	0.0%	-	-	0	0.0%	3	1.0%
Care Coordination (NHHF only)	-	-	1	11.1%	1	4.8%	30	10.3%
Multiple co-morbidities (NHHF only)[2]	-	-	2	22.2%	2	9.5%	10	3.4%
Total	*12*	*100.0%*	*9*	*100.0%*	*21*	*100.0%*	*290*	*100.0%*

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[1] The Case Management Type categories were developed using information provided to DHHS by Well Sense and NHHF, however, each MCO used their own internal definitions in capturing the sample for the study.

[2] Based on data provided by NHHF, it was not possible to determine if "multiple co-morbidities" were in the Medical and/or Behavioral Health categories, therefore this information was provided as a separate category.

Overall, the proportion of complex cases was similar between participants and the full sample (Table 5).

Table 5. Number of Participants by Case Complexity

Case Management Complexity[3]	**Well Sense**		**NHHF**		**All Participants**		**Full Sample**	
	Number	**Percent**	**Number**	**Percent**	**Number**	**Percent**	**Number**	**Percent**
Complex cases	3	25.0%	0	0.0%	3	14.3%	36	12.4%
Not complex	9	75.0%	9	100.0%	18	85.7%	254	87.6%
Total	*12*	*100.0%*	*9*	*0.0%*	*21*	*100.0%*	*290*	*100.0%*

Data Collection Process

The focus groups were led by an experienced facilitator with participant responses captured electronically with two digital recorders. Telephone interviews responses were captured in real-time through note-taking only. Focus groups and interviews were directed by a Focus Group Guide (Appendix 2) developed to address the Key Points of Inquiry. The focus groups lasted approximately 1–1 ½ hours while telephone interviews lasted approximately 20-25 minutes. All participants received a summary of the purpose of the project prior to the interview, and at the beginning of the interview, the facilitators read a statement verifying the confidentiality of the information collected during the sessions. All participants received a $50 gift card in appreciation for their participation in the project.

Data Analysis and Validity

When all focus groups and telephone interviews were completed, the information was analyzed by identifying, coding, and categorizing primary patterns in the data. The consistent patterns found in the analysis of the data and the representative sample supports the validity of the information gathered, but should not be assumed to be *statistically* representative of the whole population. The information provided in this report should be used to identify salient issues relevant to the population, provide contextual information for the larger assessment process, and identify avenues for further research.

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ACCESS TO CASE MANAGEMENT

Participants were asked to describe the extent of their contact with case management including the types, quality, and consistency of support and interactions with a case manager from their MCO as well as the availability and quality of educational materials they receive. In general, participants reported contact was initiated by their case manager once a month. The majority of participants reported positive experiences with case management including support managing medications, coordinating providers and organizing ancillary needs such as transportation and housing. Key challenges connected with case management for participants included difficulties with continuity between case managers, a lack of consistency in quality between case managers, and communication on behalf of family members. According to information provided by the MCOs, over half of participants were no longer actively receiving case management services. Few participants indicated that they no longer had a case manager suggesting that they were not aware that their case management services had been terminated. Overall, participants were pleased with the quantity and quality of the educational materials they received.

Contact with Case Managers

About a third of participants said their MCO case manager typically contacted them once a month over the telephone. About a quarter of respondents said that their case manager varied how frequently they call based on their needs. One respondent said, *"She'll call me for 3 months, but if I don't need her, then she'll stop calling. If I do need her, I have her number. She's always there if I need her."* Other participants said they initiate contact with their case manager when they need assistance. A respondent noted, *"It's more on me to be in contact with my caseworker."* Another said, *"I have a case worker and she's very personable. If I don't need her, she won't call me. But if I call she'll answer any question."*

Three participants noted they had experienced challenges communicating with case managers on behalf of their family member. A participant said, *"For a year, I've been trying to get in touch with my father's caseworker. I've left a lot of messages."* Another said, *"We couldn't get her a wheelchair. There was no caseworker as far as I know. I have the release, but wasn't finding the answers. It's very frustrating."* Another caregiver shared, *"When they (case managers) changed over, it was a little rough. They didn't get the paperwork signed. Nobody would talk to me because I didn't have the approval. The supervisor was taking over, but when I called later, nobody could tell me the name of the new person. They sent somebody over without even calling. It was almost a month without anyone. I now have the name of somebody that I can get a hold of."* One participant said that both her mother and father had the same case manager and that was helpful to her in coordinating their needs and communicating with the MCO.

Two participants noted that they were confused about how to contact their case manager and as a result had not received the help they needed. One respondent described, *"I got Medicaid when I found out I was pregnant. So throughout my pregnancy I dealt with a lot of different people. I was confused. I usually ended up calling a number on something I got in the mail and got filtered through the phone system until I got where I needed. I got a phone call from a really nice lady three times. She was probably my caseworker. I just talked to so many people. I didn't know who was who. I think she would have been super helpful if I had known better to contact her. It was a whirlwind time for me so I didn't know who to call."* Another said when her family suddenly had several health crises they had five different caseworkers which was difficult to navigate. She described, *"I'm relatively new to Medicaid. My husband suddenly became disabled and we were in need of Medicaid. And then my daughter had a health crisis and she was at in the hospital for a month. When we came back, our son had developed Tourette's from the stress. We had no idea where to go. I'd call and say I need help with this, this and this. They said to* *go to this department, or that department, but I said I needed one person to help me because we had so many different issues going on. I can't have a log book a mile wide of different phone numbers for each different thing. So after I asked for that I got five different letters from five different people saying they were my caseworker. I called each and asked if there was one person I could talk to. I'd say let's conference in – I'm constantly on conference calls with 3 or 4 people at the same time. And none of them have any idea of what the other is doing. I figured that a caseworker would be our best bet, but five of them!"* The participant was unsure whether all of the caseworkers were from her MCO or also from other agencies.

As previously noted in the Participant Demographics section, information from the MCO indicated that over half of participants were no longer actively receiving case management services. However, only two participants indicated they no longer had a case manager and a few participants mentioned they had not heard from their case manager in a while suggesting that the process for ending case management may not be clearly communicated with members. Of the two participants who were aware of the ending of their case management services, one said he wished he had one to help him coordinate his care. He said, *"When I had a caseworker, it was better. I was dreading going back to no consistent worker."* The other participant who said he did not have case manager said that he had not needed one, but felt that he would need to speak with someone soon.

Quality of Support from Case Manager

The majority of participants were pleased with the support they receive from their case manager. One person said, *"This is the first time I've had to go on a Medicaid or insurance like this all my life. I've had no complaints at all. They've been right with me. They said that if I ran out of medication, to contact them and let them know. I've had very good luck with communication and help."* Another remarked, *"I have the same Well Sense nurse once a month and she's wonderful. I will be doing my first walk-a-thon and she wants to walk with me. I couldn't walk a block before I started getting in shape. She's like my best friend. Anything I need, she'll send me in the mail. She was with me since day one. She keeps up with me even when I'm doing better."* A participant shared, *"She's actually wonderful. She's been a big help numerous times."* Another mentioned, *"She said if I need anything more, she would get it. It's nice when you need the help."* One gentleman said, *"She's been able to refer me to things and coached me through different things like the HCBC-CFI (Home and Community Based Care Choices for Independence) process. I got a nurse seven days a week to help me with my shower and medications."*

A caregiver cautioned that there are differences between case managers. She said, *"Some are helpful and some are not. The case manager he had wasn't good and we changed. I called the one we have now yesterday and she's right there for me."* Several other focus group participants agreed with this sentiment.

Other Types of Support

Participants were asked to describe any other types of supports their MCO case manager may have helped them with. Several participants said their case manager helped them access transportation for medical appointments. One participant described, "*When I had to go to Lebanon for oral surgery, they were able to help reimburse for gas. I provided my own vehicle."* Two people said their case manager helped them with their living situations. One participant shared, *"I was having a hard time with my living situation and she gave me a list of names of landlords. She is helpful to me."* Another said, *"I wasn't getting any money coming in and the case worker helped me get three months of my rent paid."* A participant said his case manager helped him get a telephone. He said, *"I was getting a lot of phone calls from the doctors because I had about 20 appointments in a month, but my phone got cut off. The* *caseworker helped me get a phone because I needed it to know about the appointments."* Another said her father's case manager helped him get needed medical equipment. She said, *"He needed a bedside commode, but the insurance wouldn't cover it. But she figured out a way of getting one and she brought it over."*

Two participants said they received additional case management support from palliative care organizations. One participant had very positive experiences with his palliative care case manager. He described, *"(The doctors) didn't want to give me the correct medications because I can't go there all the time to be monitored. Some are narcotics and I can't come to have urine tests. So (the palliative care nurse) comes here and now they're prescribing the right stuff. Before I was in so much pain, I took my pain meds and then didn't remember and took them twice and I fell down. Now I have a machine that spits them out. It's hooked to the lifeline and if I forget to take them, they call me."* He noted that the MCO realized the benefit of the additional palliative care support, "*I called (my MCO case manager) and she said she'd pass it through and they agreed that it is the best thing for me."* A caregiver participant said they did not have the same positive experience with their palliative care caseworker, but that they get good support from their MCO case manager. He said, *"The caseworker is terrible. The one from the insurance company yelled at her. She talks a good game, but doesn't do anything. The insurance company makes it happen."*

Problems with Case Management

A handful of participants described specific problems with their MCO's case management. One shared, *"One time I was speaking with a caseworker about my son's mental health. They were trying to push me toward somewhere I didn't want to go. I felt like they were trying to manipulate me to go where it was better for them. They were not in favor of us pursuing the provider we wanted to see even though they were in the plan."* Three participants complained about the ways their case managers were unable to help them with their needs. One participant remarked, *"They're extremely polite and nice to you on the phone, but nothing is ever accomplished. It's not the people's fault, it's the company. It's almost like their hands are tied."* Another said, *"The case manager didn't help get the medication (B-12) I needed so I go without."* Another noted, *"The case manager is not there on weekends or anything like that. Whenever I felt horrible or needed help was on the weekend, and there was no one there to call and clear it with. It's a nuisance, because they won't cover it because it wasn't cleared through them."* Another participant said they did not know about transportation possibilities. She said, *"My case manager hasn't said anything about transportation. I didn't know they would give you transportation to and from doctor's appointments. There were a lot of appointments I couldn't get to."*

Two participants said they had problems with continuity when their case managers changed. One shared, *"I had a caseworker with NHHF. She was fantastic and did a lot of follow-up. She helped me get things squared away. She was reassigned and since then I've had a very hard time getting in touch with my caseworker. I don't know who that is anymore. I can't get a straight answer. It's been about a year now."*

Educational Materials

About half of participants indicated that they had received educational materials from their health plan and all of them agreed that it was generally helpful information. One participant said, *"They mail me little books every now and again and yes, I read them. It has different things about how to make meals real quick and fairly cheap. They've been good to me."* Another participant shared, *"I did get information, because I'm diabetic. I'm not very good at taking care of it – especially when I go shopping and I see something and I buy it. The information is somewhat helpful. They give menus. I can't buy all* *the stuff they say and I can't cook all the stuff they say."* A new mother said, *"It was a lot of information on healthy pregnancy. I was a typical first new mom. I was nervous about everything. I liked what I was receiving and it was reiterating a lot of what I was receiving at the doctor's office."* One of the participants for whom English is not their first language indicated that she received information in a language she can understand. One participant noted she had not received anything and was surprised. She said, *"My daughter went into coma and came out with brain injury. My husband has disc injury. My son has emotional issues and we've never gotten anything."* Another noted he had not gotten anything since he lost his case manager.

EXPERIENCE WITH HEALTH CARE MANAGEMENT

Participants were asked to describe their plan of care, their experiences with their doctors, the level to which their doctors and health plan coordinated with each other and their perception of any changes in their health management since enrolling with their MCO. The majority of participants either did not have or know about a plan of care. Most participants had selected their primary care physician and were happy with their care from their doctor. The main complaint with regard to physicians was the lack of availability of specialists locally requiring travel to receive care. Participants were split on whether they felt their doctors coordinated well with each other and with their health plan. The majority of participants believed their health had been better managed since enrolling with their health plan.

Plan of Care

The vast majority of participants said that they either did not have a plan of care to help manage their health condition or did not know if they had a plan of care. Two participants were unclear on whether they had a plan of care. One participant shared, *"I kind of think that I do. I see a lot of different specialists. But when I'm talking to (my case manager) it's about one thing. There is no goal in mind. As things come up, they are managed. There is no long term goal."* Another said, *"Not really. Whatever comes up, comes up. I don't think they have any plan."* Only four participants indicated they had a plan of care. They all said they had been involved with the creation of the plan and were happy with the process. One participant shared, *"It has steps and goals of what I needed to have done and goals I needed to achieve. My nurse case manager did it with me. Anything I needed and any paperwork I wanted to know about, she would get it to me and get it in the mail."* Another commented, *"They keep up. They let you know what your next step is and help you with what you need to have medically done so you know that you can keep improving. There's a goal."* One participant anticipated changes in his plan of care due to new medical issues. He said, *"It will change a lot after being admitted (to the hospital) this time. I was involved with developing the original. We will create a new one between me and (my case manager). She's good people. She tells me like it is."* Two caregiver participants noted they would like to have a plan of care in place for their loved one. One caregiver said, *"There is no health goal. It's a terminal illness and will keep getting worse. But through the year, I try to make things happen."* Another remarked, *"I know for sure that wasn't done for (the person I'm caring for.) She was really, really sick and it took us at least four to six months to get a wheelchair."*

Experience with Doctors

For the most part, participants said that they had either selected their primary care doctor or chosen their MCO in order to stay with their current physician. Only four participants said they were assigned their primary care physician by their MCO. Two participants said they were assigned a primary care physician by their MCO, but that it was not what they intended to have happen. One said, *"I chose a nurse practitioner and I got a letter saying somebody else was chosen because I didn't choose. But I did. I* *decided to make it easy and keep it as the person they chose. It got a little messed up. I tried to choose somebody. They sent me something to fill out and they didn't get that back I guess."* Another said, *"They assigned me a primary care physician through the mail. This was when I had a caseworker. I said I didn't want to meet this person and that I had a doctor that I see. It wasn't a problem. I still get mail regarding the previous doctor, but I still see my doctor."*

Overall, participants indicated that they were happy with their primary care physician. One participant shared, *"I've been able to keep the same doctors. They've done a terrific job as far as helping me. No complaints, believe me*." A caregiver participant said, *"She likes her primary care physician. She's from the same country. She feels like she's more like her family, not like a doctor."* Participants who were assigned their primary care physician were less satisfied. One participant said, *"My primary, I'm not too thrilled with. He's so overwhelmed and whenever I end up in the hospital, I've never seen him once come to the hospital."* Another shared, *"I don't think my doctor is very helpful. She's a physician's assistant. She's about 23 maybe and it just seems like when I go in, nothing is really accomplished. My caseworker has gotten more done for me than she has. Now she's on medical leave and someone is filling in for her. She's only in a couple of days a week and it's a hassle."*

The most commonly noted problem with doctors was the limited availability of specialists. Several participants noted that the majority of their specialists are in Lebanon requiring them to travel to appointments. One caregiver participant said, *"There are only two places that have an audiologist. The one in Nashua is never available, so we have to go to Lebanon which is a good hour away."* Another said, *"The neurologist is in Lebanon and is pretty far from here. Thank god the insurance company will pay for transportation because I don't drive."* Another participant shared, *"My mom had a (specialist) she liked, but since being on Well Sense, she couldn't see him anymore. She could go to Lebanon, but that's too far."*

Coordination between Doctors and Health Plan

Participants were evenly split on whether they felt their doctors coordinated effectively with each other and with their health plan. Those participants who expressed positive experiences with their care coordination mentioned that their MCO and case manager had effectively managed both their health care and their medical bills. One participant described, *"They work together and they're doing a good job. Even my doctor from the community health center is glad that I have someone helping me on the side here. She doesn't have the time to spend. I have a part in decision making. They go by what I say. That's helping guide what's going on with my health. If I think something is too much, they'll cut it back. If something is worse, they're trying to figure it out."* Another participant said, *"I've not seen one bill. When I had Blue Cross/Blue Shield, I'd get bills for the deductible and I would be fighting with them. With Well Sense, not one bill has come to me."* About half of participants felt that their doctors and MCO do not coordinate well. These participants described a lack of communication between doctors and the health plan. One participant said, *"I don't feel like they work together. They don't contact each other. One hand is not letting the other know what's going on."* Another participant echoed, *"I don't feel like they're taking into account all my medications and health. The right hand doesn't know what the left hand is doing."*

Two participants noted that their doctors disliked dealing with the MCOs. One participant said, *"My doctor hates Well Sense with a passion. Everyone in the office hates them and complains endless times. I see her once a month at least and they're always complaining about billing and prior authorizations. The doctor has to take on more responsibility. She has one person dedicated to Medicaid. That's the only* *thing she does 5 days a week because it's such a hassle."* Another agreed saying, *"A lot of times they're bombarded with paperwork and the health focus suffers."*

Impact of Enrollment on Health
The vast majority of participants indicated their health has been better managed since their enrollment with their MCO. One participant shared, *"I have been to two of my three doctors in two weeks and they all had good things to say because I've been trying to follow what they've told me to do. It's been very positive."* Another said, *"I think they're doing an awesome job. They've been a big help. A lot of times I didn't know what I was going to do and called (my case manager) and ran it by her. And she's usually really good at getting things figured out."* A caregiver said, *"His care has been better managed. And I have someone to pay attention and listen."* A participant described, *"My experience has been positive. My problem is trying to put weight on, but I have no appetite. They got me on Ensures and Well Sense pays for them."* Two participants said they were new to having insurance and so their health care was much better managed now. One participant shared, *"I've never had insurance so having insurance is a weight lifted off my shoulders."* Only two participants said their health care has not been managed as well since enrolling. One participant new to Medicaid shared, *"All the roadblocks going from mainstream insurance to Medicaid has been stressful. It's been increasingly difficult to navigate. It's been a hard path."*

BARRIERS TO RECEIVING CARE

Participants were asked to identify any challenges and barriers they have experienced in attempting to receive the care they need. Participants most commonly noted a lack of coverage for needed care, specifically with medications, as a barrier. Participants also said the pre-authorization process presented delays in receiving care. Difficulty with communication within their health plan was identified as a barrier for participants as were cultural issues and reduced time with physicians.

Coverage Issues
When asked to describe what challenges and barriers had prevented them from receiving the care they needed, participants most frequently noted a lack of coverage for needed care, particularly with specific medications. One participant described, *"They prescribed me this one medicine and the insurance shot it down. Now there are two different medications they shot down and I'm being bounced from one doctor to another to another. I could tell it was getting worse and worse and worse. The medication (the MCO covers) is making me sicker. These certain medications aren't run of the mill and aren't something everyone can take because they're so powerful. It makes you think do these people have any common sense. Are they really going to turn this down?"* Another participant said, *"I have an illness that can kill me eventually and they denied me the prescription for it. Thank god I got it from the company itself. They gave it to me for free. They'll wait until someone is in stage III or IV liver failure to give them the prescription and by then it's too late."* Another participant described, *"I was using Lidocaine patches for my hernia, but the insurance didn't want to pay. So they give me the gel instead. It doesn't work quite as good as the patches."* One woman mentioned a concern that eyeglasses were not covered by her MCO.

Pre-Authorization
Participants generally agreed that the pre-authorization process was a barrier to receiving care. One participant shared, *"The pre-authorization system just changed as of October 1st and everything went to heck and we had to start all over again to get pre-authorizations. The pain regulations put extra requirements on doctors to have records and drug tests and a treatment plan. The insurance company*

had no clue on it. They had their own new policies start and that coincided with the new terrible emergency policies. It was a double whammy. I must have spent entire month of October dealing with pre-authorizations." Another said there was a delay in receiving care due to a pre-authorization requirement. She said, *"You used to need to have a referral and but then you could just see the specialist. Now you can see a specialist, but everything has to be pre-authorized before you can get anything done."*

Communication

Participants also noted that communication within the MCO was a barrier to receiving care. One participant noted, *"I don't think that caseworkers can access everything. I wasn't sure who was supposed to be handling what. They hide things from different departments. Nobody knows what else is going on."* Another participant shared, *"Why are the prescriptions separate from health part? Why aren't they coordinated better? If it's a medication that you can't stop and you can't miss a day and need pre-authorization, that's a problem."* A participant said he had difficulties contacting someone immediately at the MCO. He said, *"It's always a challenge, you always have to call somebody and wait for two hours to talk to them. Everything is machines these days."* Another participant noted that communication between caregivers was a challenge in caring for her parent. She said, *"Communication between the VNA nurses isn't happening. Every time they come they have to check the level of a prescription in his blood and every time the amount goes up and down. When the VNA nurse comes, I read all those papers, then the next week someone new comes over and he has a new dose. They have to do the same thing over and over again. I don't have time to sit with them and he cannot speak for himself. He gets confused and he doesn't know the names of his medications."*

Cultural Issues

A few participants shared that they experienced cultural issues that presented barriers to receiving care for their parents. Two participants said their parents do not speak English well and cannot effectively communicate with their health care workers. They said they would like the MCO to pay a family member for care rather than hiring someone who does not understand their language or culture. One participant described, *"My dad has dementia and he needs a lot of help. They put him in day care last year, but they speak English and he speaks Arabic. We were told no one could understand him and he had lots of problems there. Eventually they said they didn't want him to be there. I asked if there were other people who could come by. We want our dad to be at home and we want someone to come here to give us some help. We need someone to stay with him. It is too much for my mom and me. I have a new baby too. It's really too much work. We're trying to tell the case worker to sign paper to have someone from the family to work with him. The VNA only comes to see if he's fine with his diabetes and blood pressure. We need someone to help us bathe, dress, and feed him. My dad can't work with strange people and if he does say something he needs to be understood. We need a person from the family who can be paid."* Another participant had a similar experience saying, "*My mom stays home most of the time and paying the bills has been getting hard lately. She has a day care license to have up to five kids, but she can't leave my father alone becomes sometimes he goes off. She's been fighting to see if she can stay home with and be reimbursed for it. She's has been seeing if they can contribute to rent because he has to have his own room because of all his medical stuff. My brother has to sleep with my mom. But no one is helping my mom pay for this. I'm in college, my brother is in high school, but we cannot send him away. In my culture if you send your parent to a nursing home, you're considered the worst person. Housing will give him an apartment to live, but who is going to take care of him? He can't even put food in the microwave. Who's going to help him out? For him, English is a problem, the microwave is a problem. He needs someone to be with him 24/7."*

Reduced Time with Doctors

Two participants said their amount of time doctors spend with them has been reduced since enrolling with their MCO. One participant remarked, *"Everything has been cut back as far as what they will pay. I have a couple of doctors that are good in general. But if I have a referral, you're only allotted 10 to 15 minutes in there."* Another participant said, *"I have a doctor through the community health center and it seems like the worse I get, the less they want to see me. When I was able to breathe better, every month I had an appointment, but now I'm worse, and I only go every 2 months. I have a lung specialist that only sees me every 6 months."*

SUGGESTED IMPROVEMENTS

Participants were asked to offer suggestions for what would improve the care management they receive from their health plan. While several participants said they were pleased with their plan and said there was no need to change anything, other participants had specific suggestions for improvement. The most commonly mentioned suggestion was to improve and enhance communication from their MCO and between their MCO and health care providers. Participants also would like improved consistency in decisions and continuity between case managers and simplifying information. Several participants suggested increasing coverage, better communication from providers, and offering more opportunities for member feedback.

Communication

Several participants said they would like more consistent and engaged communication from their health plan. One participant proposed, *"Contacting us on an on-going basis and knowing your situation and asking how it's going. Asking whether you're having any problem with reimbursements, or if you are participating in this program that might help. Suggesting if you're on this medication, but you could try this one, it might work better. Because they know exactly what's in your files."* Another participant agreed saying, *"If the doctor sets an appointment, your caseworker should know that so they can remind you, know who you're seeing, what medications you're on, and how it is going for you."* Participants also said they would like to be able to get answers more quickly and not have to spend so much time on the telephone. One participant said, *"We'd love to get back to work. It's not making it easier to spend all day chasing people on the phone."* Another participant said she would like more individual contact. She said, *"I want more contact with individuals. It gives a little bit of a ray of hope. I don't feel as lost as if no cares."*

Consistency

Participants also suggested that improved consistency in decision making within the health plan would be helpful. One participant described, *"My mom called and they said they would reimburse any money you spend on the gym. The doctor ordered my father to go walk around and we thought we could go to the gym and get him on a treadmill. At the gym you need to provide a bank account so they can draw the payment out automatically. And then the health plan was supposed to reimburse us. My mom called the MCO and told them my father doesn't have bank account and asked if it was ok to put him on her membership and at the end of year be reimbursed. They said yes as long as she had something that said it used to be a single membership and added him then they would pay. But at end of the year, they said 'nope, you're not getting any money'."* Participants also noted they wanted more consistency with their case managers. A participant suggested, *"Have caseworkers know who they're working with and don't bounce them from person to person."* Another suggested that there be one caseworker for multiple family members. She said, *"I think if you have multiple health problems in a family, the caseworker should handle the family, not just that one person."* A participant suggested a need for better transitions when case managers do need to change. He said, *"Give some kind of notification if somebody is leaving. If they know ahead of time a caseworker is leaving, manage the transition better so the new caseworker can say, 'OK, I've already spoken with the caseworker and I'm familiar. Is there anything you need?' Then you're not left hunting people down. Improve communication within their own case management system."*

Simplified Information

One participant said she would like information to be simplified. She said, *"Medicaid is a complex thing and because I've only been on it for a year, I'm still a clueless about what to do for certain things. Sometimes I'd call a number and I'd ask questions. People were kind of quick and I think I needed more explanation of how it worked. Maybe they assumed I was experienced and knew, but it was a new experience for me and complex. Maybe take a little bit more time and simplify things instead of using terms that they might only be aware of. Stuff like that would have been helpful. Clearer communication in general, not just with case workers."* Another participant agreed saying, *"I'm somebody who likes to get summaries for things. For instance, once you're established with Medicaid, if you can get a letter with the list of phone numbers of people to have as a reference. What I have is a stack of envelopes that I write notes on. It's kind of messy and it's not a great system. Initially when the lady called and said to call her if I needed help, I was in the car in a parking lot. And I lost that note. And when I had an issue of my Medicaid number not being recognized, I didn't know how to make it work or who to call. The bills went to collections. I had a great credit score before. I just didn't know what was going on."*

Improved Coverage

Participants also said they would like improvements in the coverage they receive from their health plan and concerns that denial of services can cost more in the long run. One participant said, *"It seems like they're not good about preventative care and keeping things from getting worse. Like the nebulizer thing. It's common sense stuff. They're skimping where people's health is really put at risk."* Another participant said, *"Because of (the palliative care people) who have been working with me with my medications, I haven't been in the hospital in 3 months. I was going there every week. NHHF didn't want to pay for it. They wanted to pay for the ambulance and hospital. But they found out if I don't have my medications that is where I'm going. They finally sent a letter that I could appeal (the denial), they overrode it and decided to let me have them come to me."* Nearly all participants also noted that adding dental coverage is a needed improvement that would also prevent long-term costs.

Better Communication from Providers

Participants also expressed concern about decisions made by their providers affecting costs. One participant said, *"It seems to me that now health care is funded by the government, people are taking advantage. They're switching medications. It's the same thing, but more expensive. Or they're billing services that weren't needed. It's just pouring money into something, it's wasting. I have a real problem with it."* Another agreed saying, *"There's a portal where you can access your insurance and I'm looking at these charges and it's kind of sickening. I know what I'm going for and I'm looking at the charges associated with, and it seems like somebody somewhere is taking advantage."* Another shared, *"I take a medication that costs $80 a month. All of a sudden they switched it to patches instead of injections and its $780 a month. I called up and said 'Why are you doing this?' They said its part of the formula. I had to almost fight with them to save them $700 a month."* Members may not understand the reason for changes in medication(s) or dose(s); or why procedures and tests are ordered and better communication by providers may help diminish these concerns.

Keep the Same

Several participants said they were happy with their health plan as is. A participant said, *"I've been 100% satisfied. NHHF has always been awesome by me."* Another shared, *"I can't really complain. I'm quite satisfied."* Another said, *"No complaints at all. If it's not broke, don't fix it. I'm very grateful. Everything's going good."* This was echoed by another participant who said, *"It works, leave it alone."*

Continue Soliciting Feedback

Participants also universally expressed appreciation at being offered the opportunity to share their feedback in the groups and interviews. They said they liked being asked to provide their experiences and hoped that this would be an on-going option in the future.

CONCLUSION & RECOMMENDATIONS

The focus groups held in Manchester, New Hampshire in January of 2016 provided valuable information into the participant's experience with case management within the State of New Hampshire's Medicaid Care Management Program. Due to the sample size, the information presented in this report should not be assumed to be statistically representative of the entire population receiving case management through the Medicaid Care Management Program in New Hampshire. The data generated during the focus groups can be used to identify issues and concerns that may warrant further exploration. Below is a summary of the salient points expressed by the focus group participants.

Improve communication

By far, the challenges participants most frequently mentioned were centered on communication. In particular, participants would like:

- Clearer communication about starting, transitioning and ending case management services including simple written materials summarizing whom to contact and meeting the newly assigned case manager. Some participants were unaware that their case management service had ended and others were unsure about the process when it began.
- Improved communication within their MCO so case managers have access to more information from their doctors and can more effectively help manage other aspects of their health care and provide more consistent responses.
- Proactive communication from case managers including recommendations for care and ancillary supports
- Proactive communication and coordination with family caregivers of participants with high medical needs
- Assignment of all family members to the one case manager when more than one family member is in need of case management services

Improve understanding and addressing of cultural needs
Caregivers expressed challenges managing care for their non-English speaking family members and their cultural traditions. They suggested improved understanding of cultural differences that enable more flexible and perhaps non-traditional treatment planning such as allowing family members to be reimbursed for caregiving support rather than requiring hired caregivers would improve both their quality of life and quality of care.

Improve consistency
Participants noted significant differences in the quality of communication and support received from different case managers indicating a potential need for more consistent training and review of case managers' skills. Participants also noted inconsistencies in decision-making as an area for improvement.

Simplified Information
Participants said they would appreciate receiving simplified information about Medicaid in general. They suggested providing a basic summary of Medicaid and how it works as well reference materials of who they should contact to address various concerns.

Improved Coverage
Participants suggested improving the coverage they receive from their health plan for medications and dental care. Participants noted that denial of coverage may increase costs in the long run.

Better Communication from Providers

Participants noted a concern about how their providers' decisions may be affecting the cost of care. Members may not understand the reason for changes in medication(s) or dose(s); or why procedures and tests are ordered and better communication by providers may help diminish these concerns.

Provide opportunities for member feedback

Participants were very excited to share their experiences at the focus group and expressed a desire for further opportunities in the future.

Appendix 1. Recruitment Letter

Dear,

The New Hampshire Department of Health and Human Services is asking for your help with a project about New Hampshire Medicaid Care Management. The Department hired Horn Research to gather opinions from people like you to better understand the experience you are having meeting your and your family's health care needs.

We would like to invite you to a focus group where you can share your feelings and ideas about Medicaid Care Management. Because we are only asking a small number of people to take part, **<u>your participation is very important</u>**. You can help us understand what is working and what is not working, and receive a ***$50 gift card*** as a thank you for your time.

We will be holding two sessions in your area in early January, which will be filled on a first come, first reserved basis:

Thursday, January 7, 2016
4:30 pm – 5:30 pm
First Congregational Church
508 Union St.
Parlor Room
Manchester, NH

Friday, January 8, 2016
10 am – 11 am
First Congregational Church
508 Union St.
Parlor Room
Manchester, NH

All information you share will be kept completely private and will not affect your benefits or health care in any way; no one from Medicaid or the managed care programs will be there. Your name and personal information will never be made public in any way.

If you would like to sign up for the focus group, please call Horn Research toll-free at **(888) 316-1851** or email at Lisa@HornResearch.com to answer a few questions and register.

Thank you for sharing your experience and thoughts about New Hampshire Medicaid Care Management.

Sincerely,

Doris H. Lotz, MD, MPH
Medicaid Chief Medical Officer

APPENDIX 2. FOCUS GROUP/INTERVIEW GUIDE

Introduction

Each of you is covered by Medicaid and receiving Medicaid benefits provided through one of two Medicaid Managed Care organizations: NH Healthy Families or Well Sense Health Plan. Your feedback is very important and will help the State of New Hampshire make some important decisions about Medicaid Care Management. We want to know about your experiences so the program 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 receive through Medicaid Care Management.

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. No one at Medicaid or the managed care programs will listen to this tape. 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

We'd like to ask you some questions about how your health plan (Well Sense or New Hampshire Healthy Families) has helped you manage your/your child's health care. We are going to be asking you some questions about help you might be receiving from your health plan to manage your care. Sometimes it is called case management or care management, or you might have a case worker that helps you. You may also have someone at your doctor's office that might help you manage your care. We are interested in hearing about your experiences with both your health plan case manager and whoever else might be helping you, but please be sure to let me know who you are referring to (e.g. your health plan's case manager or someone at your doctor's office.)

1. Has your health plan (Well Sense or New Hampshire Healthy Families) communicated with you either by telephone or in person to help you with getting care for any health problems or conditions that you/your child have/has? *(note: not including contact by mail/email)*

2. Describe what it is like when you talk to your health plan about your care. (probe: Do you speak to the same person each time (e.g. case manager)? How long have you had this person in charge of your care? How often are you in touch with him/her? Does he/she call you or do you usually call?)

3. Do you know if your health plan created a plan of care to help manage your/your child's condition? Can you describe the plan? Were you involved in the development of the plan?

4. Tell me about your doctors through your health plan. (probe: Have you had a primary care provider/doctor assigned to you (internist, family practitioner, general practitioner, or pediatrician)? Have you been referred to any specialist providers to help manage your condition?

5. Do your doctors work together with you and your health plan to manage your care? Do you feel your doctors and health plan work well together or have there been challenges? What kind of challenges have you experienced in terms of your doctors and health plan not working together?

6. Have you asked for help from your case manager/health plan in any other ways, for example, with transportation, living arrangements, caregiver support, financial/legal issues, community support, etc.? If yes, did the health plan help you obtain the services you needed? If no, why didn't you ask? (probe: Did you not need any other help or did you not think to ask your health plan/case manager?)

7. Please describe any barriers or challenges that have prevented you/your child from receiving the care you/your child needed.

8. Sometimes health plans provide educational materials to help people manage their health conditions. Have you received any materials or information like that? How would you describe them? (probe: Have the materials been helpful? In what ways?)

9. Do you think you are managing your health the same, better, or not as well as before your enrollment in your health plan? Why is it better/worse?

10. What do you think should be done to improve the care management you receive from your health plan?