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## Summary Report of the MaineCare Listening Sessions

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# Summary Report of the MaineCare Listening Sessions

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December 2010

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### ***Background***

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In September of 2010, the Muskie School of Public Service conducted four Listening Sessions with MaineCare members to gather in-depth information about their experiences on MaineCare, their likes and dislikes, and suggestions, needs and wants for improving the program. The overall goal of these sessions was to provide rich information to help inform DHHS in their design of a new managed care initiative. Funding for this project was provided by the Maine Health Access Foundation (MeHAF).

Participants for the Listening Sessions were recruited by staff at Maine Equal Justice Partners (MEJP). Members were recruited with flyers, letters and through word-of-mouth through Head Start programs, CAP agencies, child care programs, domestic violence agencies, FQHC's and other service providers. Efforts were made to include the diverse populations served by the MaineCare program, however, to ensure members' privacy, we did not gather information on members' service usage or demographic information. To allow for geographic diversity in the members that were reached, the four Listening Sessions were conducted in Lewiston, Portland, Presque Isle, and Bangor. A total of 50 MaineCare members participated in the Listening Sessions, and individual sessions ranged from 9 to 15 participants. Each session lasted approximately 90 minutes and was facilitated by a Research Associate from the Muskie School of Public Service. Participants were reimbursed for travel and childcare arrangements, and were given a \$30 gift card to Hannaford as an incentive for their participation.

As with any qualitative data collected from a small sample of the target population, results from these sessions should be interpreted with care. The opinions expressed during these Listening Sessions may not fully represent those of the general MaineCare population. It is unclear as to whether members who chose to participate in these sessions have different ideas, opinions and criticisms about the MaineCare program than members who did not participate in the Listening Sessions. We know, for example, that participation may have been skewed to those with more complex medical and behavioral needs of the general MaineCare population. With that said, the recruitment process and Listening Session questions were designed in such a way to encourage open and honest dialogue about the experiences of a diverse group of MaineCare members.

In order to protect the privacy of Listening Session participants, results are presented in the format of common themes that were discussed across the four sites. In some instances, regional comparisons are made where appropriate.

## ***Common Themes from Listening Sessions***

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### **Many members are grateful for the services they receive through MaineCare**

Since one of the primary purposes of the Listening Sessions was to hear from members about changes they would like to see in the MaineCare system, much of the content of the sessions revolved around problems they have encountered with their coverage and changes they would like to see made. There were also many conversations, however, about what members appreciated about MaineCare and the parts of the program that are working well for them. Overall, members were grateful and appreciative of the fact that MaineCare is available for them. Members described situations and emergencies where, if they did not have MaineCare, their life could have been in danger. Many have had very positive experiences with their coverage, their providers, wait-times to see specialists, communication with their case-managers, and their overall medical care. Some explained that they understand that because of budget constraints and the current state of the economy, MaineCare cannot cover everything. There are changes that, in their eyes, would make taking care of their health easier. However, they are happy that this health insurance option has been made available to them.

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*“[I like] the fact that we have it. The fact that our state, our little po-dunk state actually has something like this.”*

*“I went to Portland for my heart. A doctor alone, one was over \$10,000...that didn't even include the hospital, the medicine...I couldn't have – they might as well just have left me laying there because there is no way I could have paid for it all.”*

*“I absolutely love that it pays for the services for my autistic son...I have people that I can count on that are helping me figure out how to guide him and I love that, I have only had that since we have been on MaineCare...it has been such a burden off my back.”*

*“[MaineCare] gave me really good prenatal care and the options as to whether I want to go to a primary doctor or to a family planning association. If you have a problem with your doctor...you can transfer, so that is another good thing too.”*

*“I have depression issues and I have had nothing but good luck [with MaineCare] ...I have a lady from Schaller Anderson and she calls and says how is everything going. I have found it to be very helpful.”*

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*“My experience [with MaineCare] has been almost unfailing – the people have been extremely courteous to me...I certainly appreciate the fact that they work very hard. I have to say I wanted to come today primarily for the reason of saying that there were a lot of things right with MaineCare. I think given the climate with their limited resources, everybody is working as hard as they can to make those resources stretch to cover the issues that we are facing...So thank you.”*

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*“I have gotten to choose my doctors and choose the good ones... [MaineCare] kind of gives me the care that I need.”*

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### **Better patient/member supports would improve care**

Participants expressed a great need for stronger and more accessible patient supports.

#### *Case Management and Communication*

Suggestions for improving patient supports included reminder calls to patients, especially for mental health services, and more efficient case management. Participants explained that members with mental illness may have a difficult time keeping track and making it to all of their appointments. When they miss a certain number of appointments, they report being cut off from services by their provider. It was suggested that reminder phone calls for appointments be included as part of their case management.

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*“When the doctors don’t call you to remind you or send you a note about it, then you’re fired from your doctor for missing three appointments a year.”*

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*“Especially those of us that have mental illness diagnoses. I mean, that is just a little bit more than I am capable of remembering appointments.”*

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At the same time, participants explained that they receive many unnecessary calls from their case managers. It was expressed that in some cases, case managers call members simply to check in, which participants find to be wasteful.

Certain members also expressed concern that Schaller Anderson’s case managers seemed to make uninformed decisions that cut off services prematurely, without knowing or seeing the member or their family. More generally, members talked about the high turnover rate of case managers that resulted in having to explain their situations over and over again to new case managers. (Note: The members did not identify which case managers had a high turnover rate, so while the concern over decisions on services was specific to Schaller Anderson, the turnover rate was not.)

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*“Something really needs to be done about Schaller Anderson’s process of ignoring true situations before they cut services and do denials – they are prematurely [cutting services].”*

*“Regardless of the decision made [by Schaller Anderson] there needs to be access to either a hearing or some other remediation that is clear.”*

*“Case management should be there to provide the service for the family when the family needs it...The case manager, I don’t feel has to call up once a month to ask how you are doing and then bill MaineCare...I think they should be there for family calls. [We] need to know that somebody is there.”*

*“It gets tiring having to explain your story and over and over...You get a new case manager who is not as experienced...it’s frustrating having to go back and explain everything, you know that you have already explained to the previous person.”*

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### **Transportation is Problematic**

In the Lewiston area, members appreciate that there are transportation services available to them in the community. However these services were reported to sometimes leave members stranded either at their appointment or with no means to get to a pharmacy or to lab tests following an appointment. The required two-day prior notice for arranging transportation services was seen as a deterrent to accessing primary care in an urgent situation, leaving members to inappropriately seek help at the emergency room. Members in the Lewiston-based Listening Session suggested that better transportation services and coordination are necessary for them to receive all of the medical care that they need.

It should be noted that in the Portland, Bangor and Presque Isle Listening Sessions, members did not report using transportation provided by MaineCare. It seemed that most of them rely on their own vehicles, family or friends to get to and from appointments. Members in Presque Isle expressed some frustration in waiting to get reimbursed for mileage and lodging for medical appointments that are far from home, and an interest in telemedicine, which would help them avoid traveling and could be both a time and money-saving measure for themselves and the Department.

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*“MaineCare and whoever provides rides really have to work together because... [the transportation service] wants two days [notice] in advance. Well, your doctor doesn’t see it that way and MaineCare doesn’t see it that way. So they really have to get together and work it out.”*

*“There are times that the doctor wants you to have a test. He can get that test set up just like that. But how are you going to get your butt there? Now you can’t call [transportation] and give them 24 hours.”*

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*“A lot of times after you go to the doctors, you have to pick up a prescription. They won’t take you to a pharmacy to get your prescription. So then you might have to wait two or three weeks for somebody to give you a ride.”*

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### **Members strongly support including dental coverage for adult MaineCare members**

The lack of available dental coverage for adults enrolled in MaineCare is a topic that was brought up at every one of the four Listening Sessions. Participants felt that preventive dental care is essential for maintaining overall health. They expressed frustration that MaineCare will pay for dental emergencies rather than paying up front for routine, preventive care. Many believed that a system offering preventive dental care would save MaineCare money in the long-run, while allowing them access to basic routine care for keeping their teeth healthy.

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*“Preventive dental care isn’t just about your teeth. When it comes to diabetes or heart disease, even self esteem issues, preventive dentistry can help alleviate the high blood sugar and it helps prevent heart disease, which will actually save the system money in the long-run.”*

*“Studies have shown preventive care works way more effectively, efficiently cost-wise and every other way as far as protecting your teeth.”*

*“I am only 29 years old and in three weeks I am losing the rest of my regular teeth and I have to have dentures paid out of my pocket by myself.”*

*“The only thing that MaineCare allows right now for adults is emergency pulling and emergency fixing...If you are a diabetic they will pull your teeth, but you have to have uncontrolled diabetes before they will do that.”*

*“It would be really nice just to be able as an adult to see a dentist once a year – a general appointment and a cleaning – once a year.”*

*“If you don’t have the preventive [coverage] on the dental, it is going to go into medical anyways eventually and MaineCare is still going to pay – why not pay up front and it would be cheaper...Because you are going to end up in the ER – that is what I am saying...Preventive care!”*

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### **Some members report a lack of access to mental health providers**

Some members reported difficulties in finding mental health providers who accept MaineCare and explained that wait-times for mental health services for those who do were unreasonably long, leaving those suffering from mental health issues with major gaps in care. Gaps in services often leave patients in crisis situations, where they have no

other choice but to go to a hospital emergency room. Participants believe this to be costly for the system, not to mention traumatic and dangerous for those with mental health diagnoses.

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*“A lot of mental health workers don’t accept MaineCare. You finally get your referral, you finally leave 3,000 messages, finally you connect and you actually get to talk to the person...you say well I have MaineCare. Oh, I don’t take [MaineCare]. Okay, now you have wasted two or three months trying to track down this specialist and now you are right back to square one again.”*

*“There is a problem...my psychiatrist among many of them now are leaving private practices because of MaineCare and the new rules... We are trying to get them to stay and there is no way they are going to stay just for us. What can we really do about that?”*

*“When you are coming out of the hospital out of a crisis and you are trying to hook up with a psychiatrist to keep you out of the hospital again and then you have to wait three months and in the meantime you are having trouble getting your prescriptions and you are having trouble with everything else, it sends you back into the hospital! The state needs to realize that costs them a whole lot more money.”*

*“I think people with mental health issues they need more continuous care and follow up and reminders. A person with a mental health issue is going to miss more appointments, is going to have more crisis in their life that prevents them from getting an appointment or more difficulty finding a ride or even just coordinating all of these things. The neediest people are the ones that need to be helped and they are also the ones that have the hardest time accessing what is available.”*

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### **Prior Authorization (PA) for medications and changes in the Preferred Drug List (PDL) cause problems for members**

Participants explained that going through the PA process causes significant delays in getting medications prescribed to them by their providers, often resulting in their condition getting worse and becoming more costly. Members questioned why it is necessary to get authorization every three months for medications that they are taking for lifelong, chronic conditions.

Adding to these delays are complications created when there are changes to the PDL. Members described the frustrating process of having to go through a series of medications that they know do not work for them, only to eventually end up on their preferred medication originally prescribed by their doctor several months later. In the meantime, they explained that being forced to use ineffective medications for several months can cause their condition to deteriorate. Many participants in the Listening



Sessions seemed unaware of MaineCare's existing grandfather clause for PDL changes, and/or were not able to be grandfathered after a PDL change. Members asked for better clarification regarding this policy.

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*"MaineCare requires PAs for something that [my son] has been on since he was four – he is now 17. I still have to have a PA every three months in order for him to take his seizure meds."*

*"If you already found a treatment that is working, why go backwards? It is not going to save money - it is going to cost extra money."*

*"If a prescription is working for someone, they shouldn't change it."*

*"I think when MaineCare is going to make changes as to what is covered and what is not, they need to like grandfather the people that are already on things."*

*"I am trying to get Prevacid again. It worked - I was taking it for years. All of the sudden they decided they are not going to pay for Prevacid anymore. So I am on this new one now, it is not working."*

*"It took me eleven months to get my Prevacid back when I was taking it for over 12 years."*

*"It is not easy bouncing from medication to medication."*

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### **Sometimes access to PCPs and specialists is difficult**

It has been the experience of some MaineCare members that many PCPs and specialists in their region do not accept MaineCare patients. For those that do, the wait can sometimes be very long. Participants, especially those in more rural areas such as the Presque Isle region, understand that there is a general shortage of providers and that even those patients with private insurance often face long wait-times. However, some members believe that being on MaineCare puts them farther down the list and at a disadvantage when trying to schedule appointments. One member in Portland described a practice that only sees MaineCare patients on certain days of the week. Some members spoke of practices where they never see the same provider twice, making it hard to establish a relationship with their PCP. While some members reported that their PCP and their specialists communicate well, others have experienced very little coordination in their care when seeing specialists.

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*"I waited four years to find a doctor that took MaineCare...there is nobody that takes MaineCare and if they do they are all full."*

*“Trying to switch the PCP that I didn’t like to get into another one that took MaineCare, the wait was like a year and a half to get in for a physical. You couldn’t just go in for an issue - you had to be an established patient. So you are forced to stay with a physician that you don’t like...because there is no availability anywhere else.”*

*“I have a situation too where we are established in a facility and they decided that they are no longer taking MaineCare.”*

*“A lot of places [that take] MaineCare...you are not seeing the same doctor every time and these physicians leave. So you’re really not building a relationship with them. They really don’t know you...it is difficult to get the care if you haven’t built a relationship.”*

*“My problem is I get somebody different every time. They don’t know anything about my care. So I just feel like I am a number. It is very depersonalized.”*

*“They only see MaineCare patients on certain days...the rest of the week is for people who pay. Sometimes it is weeks or months before you get back in.”*

*“I have three special needs kids and trying to get them to even see specialists can be absolutely horrific, especially if you need something like a neuro-psych. You have to set it up three years in advance to be able to have a neuro-psych.”*

*“[The doctor’s office] showed me which doctors will actually take which insurances. MaineCare has a very short list...unless you have a child. But for adults it is horrendous. They have to call each and every one trying to get you in...If you need to see a cardiologist, sometimes you have to wait three or four months. Not necessarily for the referral, but to get in.”*

*“I waited a year to get into a neurologist.”*

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### **Providers are not paid in a timely manner**

Several members expressed frustration over the fact that their providers are not paid when they should be. They believe that one of the main reasons why providers do not accept MaineCare is because they do not get reimbursed in a timely manner. Members recognize that their doctors need to get paid in order to maintain their practices. Those that are happy with their providers are worried that this lack of timely reimbursement will result in refusals to accept MaineCare patients in the future. This will narrow the availability of competent PCPs and specialists in their regions even further.

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*“Doctors are so tired of not receiving their payment that they are just doing away with taking MaineCare patients.”*

*“Some of these physicians are three and four years behind on payments. Then when the state cuts the reimbursement, they get less money - they are not getting paid at all. Well, they have staff to pay. If they don't have the money they have no option but to bow out...they just can't run a business like that.”*

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### **Paperwork sent from the Department is often redundant and communication could be improved**

Members described feeling overwhelmed by the amount of paperwork they are required to fill out under MaineCare. Many are asked to complete the same paperwork over and over again, and some are confused by form-letters that do not even apply to them. They believe that a more efficient and streamlined system could help improve communication, while saving MaineCare money by reducing unnecessary mailings. Members would also like to see more user-friendly communication – often the materials they receive in the mail are vague and difficult to understand. At the onset of enrollment, a suggestion was made to offer an educational seminar for members explaining how MaineCare works and what will be asked of them.

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*“You get these letters in the mail and you read them like three or four times – it's like, why did I get this letter? So you get on the phone because it really doesn't say anything. It is one of the vaguest [letters] ...so you call up, you spend three weeks trying to get someone to call you back... You get to the person and the answer that you get is that oh, the computer just pumps those out – it doesn't really mean anything for you!”*

*“How many times do we have to fill out the same information in triplicate and then, oops somebody lost it, you have got to do it all over again!”*

*“The paper work is incredible – the money that is wasted on paperwork and sending it out...”*

*“When people go to get on the system, they have a little seminar for like two hours that tells them we can do this and we can do that...”*

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### **Prevention should be a priority**

The members that we spoke with were passionate about the value of investing in prevention. It was pointed out in many of the sessions that the lack of access to preventive services often results in costly treatments and unnecessary and expensive

visits to the ER. Suggestions were provided for various preventative programs that have the potential to help members take control of their health, engage in healthy behaviors, and avoid costly medical procedures and medications.

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*“More preventive care access including things like...gym memberships at local fitness centers. Something like that compared to what the cost of chronic care is - preventive care is a lot cheaper.”*

*“There is a big problem with obesity and you can’t get a program where you can get exercise or swim or different things to help yourself...You have to get a membership at the Y and it gets expensive.”*

*“We are caught in that system, but the system finally is listening. I do hope that they will continue to make progress and yes, it is expensive, it is massively expensive in a small poor state like we are. But, you know, what are the alternatives if they don’t continue to improve? The emergency rooms and the hospitals are going to be bombarded with people too poor to pay for the services there.”*

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## ***Conclusion***

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The MaineCare members that we spoke with were very experienced with and passionate about the system in which they are enrolled. The majority felt lucky and grateful to have access to health insurance coverage. Many have had extremely positive experiences with their providers, their case-managers, and their MaineCare coverage overall. At the same time, all agreed that there is room for improvement. While it is understood that there are limits to what the state can cover, common themes from these Listening Sessions suggest gaps in coverage that contribute to poorer physical and mental health and a more costly system. Emphasis was placed on stronger patient supports, better access to dental and mental health services, a less cumbersome process for obtaining medications, better coordination of care, an improved system for reimbursing providers in a timely manner, more efficient and user-friendly communication between MaineCare, case-managers and members, and more opportunities for preventive healthcare. Participants believe that such improvements will help them maintain and improve their health and will save the state money in the long-run.

## MaineCare Listening Sessions

### Script and Questions

Leader:

*Hello, my name is \_\_\_\_\_ and I am from the University of Southern Maine. Also here with me is Katie Rosingana, also from the University of Southern Maine. Thank you all very much for coming today. I am here to listen to you talk about your experiences with MaineCare. The Maine Department of Health and Human Services is in the process of improving MaineCare and they are very interested your input and ideas. The purpose of the group is to collect information about your likes, dislikes, comments and suggestions about the MaineCare program. The input that you provide about your experiences with MaineCare will be put in a written report, along with information collected from MaineCare members in three other Listening Sessions across the state. The report will be shared with people in the state who are trying to improve the MaineCare program and will also be posted on the MaineCare website ([http://www.maine.gov/dhhs/oms/mgd\\_care/mgd\\_care\\_index.html](http://www.maine.gov/dhhs/oms/mgd_care/mgd_care_index.html)).*

*This group is scheduled to last for 90 minutes. All of the information you share will be kept private and we will not use your name. Your participation is completely voluntary and your MaineCare benefits will not be affected in any way by what you say. Your name and contact information will be not be included in the report. As a thank-you, we will be offering all participants a \$30 gift card to Hannaford's, which will handed out at the end of the session. We will also reimburse you for travel costs and childcare if applicable. A staff member from MEJP will be available at the end of the session to help you fill out the forms for reimbursement.*

*Do you have any questions so far?*

*Next I will need to get written permission or consent from each of you saying that you want to participate in this Listening Session. I will read this consent form aloud to everyone before you sign it.*

*(Hand out and read consent form aloud and ask: "Are there any questions about this form?" Have each participant sign and date the form and hand back).*

## Listening Session Questions

*Interviewer: Thank you all very much for agreeing to participate in this Listening Session. Our remaining time together will be about 90 minutes. You do not have to answer any question that you do not want to. You may also leave the group at anytime. We ask you all to respect each other's privacy by not sharing anyone's specific responses with anyone outside this group. At the same time, we know that some people in the group may have different opinions. We ask that you try to respect each other's views and ideas, even if you do not agree with them.*

*Because of the short time that we have together, I want to make sure that everyone in the group has a chance to participate in the discussion. This means that I may have to place some time limits on a person's response. This does not mean that the person's opinions do not matter - it is just a way to make sure that everyone in the group has an equal chance to share in the short time that we have together.*

*If I have everybody's permission, I would like to tape-record this session. Sometimes it is hard to keep up and take notes on everything that is being said so having a tape recording of the conversation helps to make sure what you say is represented correctly. There will be no names or contact information included in the recordings. The recorded information will be stored in a locked file cabinet until it is erased and destroyed when the project is over.*

*Do I have permission from everyone to tape record this Listening Session?*

*Finally, if you have any questions about this study you may call Anush Hansen at the University of Southern Maine at 207-228-8217. If you have questions about your rights as a research participant you may call Ross Hickey at the University of Southern Maine, Office of Research Compliance at 207-780-4340.*

*Do you have any questions for me before we begin? Okay, let's get started.*

*(Begin tape recorder if given permission))*

## Introduction

*Just to remind everyone, DHHS is changing the way it pays hospitals and physicians in order to improve the quality of services and the way services are delivered to members. So the purpose of this group is to hear directly from you about your experiences with MaineCare and your ideas for improving it. First, we would like to ask some questions about your current experience in getting health care services. Then we will be asking some questions about your ideas for improving the ways services are delivered.*

*These first questions are about your current health care experience:*

**Q1.** Under MaineCare, what has your experience been getting **routine primary care** such as going for regular check-ups, seeing a doctor or going to a clinic for non-emergency situations?

*[PROBE: Are you usually able to see a doctor or get to a clinic when you need to? Have you experienced long wait-times to see a doctor? Have there been other problems in getting basic care?]*

**Q2.** Under MaineCare, what has been your experience in seeing medical **specialists**, such as a heart doctor or another doctor for a more complicated condition?

*[PROBE: Did your primary care doctor help you get an appointment with the specialist? Did you have to wait long periods of time to see the specialist? Do you feel there has been good communication between your primary care doctor and your specialist?]*

**Q3.** What about other healthcare services such as physical therapy, occupational therapy, mental health counseling, getting prescriptions filled or getting lab-tests? What has your experience been getting these types of services with MaineCare?

*[PROBE: Have your needs been met in getting these services? What has worked and what has not?]*

**Q4.** What about health **emergencies** such as accidents or sudden serious illness? Have you been able to see a doctor or get to a clinic in a timely manner?

*[PROBE: Where do you go for care on weekends or at night when you feel you can't wait too long for care? In your experience, what has worked and what has not worked in these situations?]*

*Now I would like to hear about the parts of MaineCare that are working well for you, but also about what you would like to see changed in MaineCare.*

**Q5.** Let's start with what is working well for you.

*[PROBE: How do you feel about your relationship with your doctor? Are you able to get prescriptions when you need them, etc.?)*

**Q6.** What changes in *where* or *how* you get your care would be a concern for you?

*[PROBE: What would you like to make sure does NOT change?]*

**Q7.** If you could make changes in the way your health care services are delivered to you, what would you change? What would make things better for you?

*[PROBE: Are there services or supports that you need that you aren't currently getting? What is most important for MaineCare to know?]*

**Q8.** Do you have anything else that you would like to share about your experience with MaineCare or about how you would make MaineCare better?

*Interviewer: Thank you for participating in this Listening Session. Again, if you have any questions about the study, please do not hesitate to contact the Director of the study, Anush Hansen at 207-228-8217. Before you leave, please make sure to pick up your gift card at the back of the room. Thank you!*