Appendix C
Discussion Group Transcripts

1. BEEP'M Counselor Discussion Group
   September 21, 2004, 2:00-4:00 p.m.

2. BEEP'M Counselor Discussion Group
   September 22, 2004, 10:00 a.m.-12:00 p.m.

3. BEEP'M Counselor Discussion Group
   September 22, 2004, 2:00 a.m.-4:00 p.m.

4. BEEP'M Hotline Volunteer Discussion Group
   September 28, 2004, 2:30-4:30 p.m.

5. BEEP'M Hotline Volunteer Discussion Group
   September 28, 2004, 6:30-8:30 p.m.

6. Langeloth Counselor Discussion Group
   October 12, 2004, 10:00 a.m.-12:00 p.m.

7. BEEP'M Supervisor Discussion Group
   October 12, 2004, 2:00 p.m.-4:00 p.m.

8. Langeloth Counselor Discussion Group
   October 13, 2004, 10:00 a.m.-12:00 p.m.

BEEP'M Counselor Discussion Group
9/21/04
2:00 pm-4:00 pm

Good morning/afternoon. My name is Ruth. I am a communications consultant. I am conducting the evaluation of this project. How many of you have ever heard of or participated in a focus group? The whole purpose of this discussion will be to get your thoughts and opinions on the Medicare Interactive program. So today my role will be to ask you questions and to moderate the discussion.

There are just a few guidelines I would like you to follow

- This session will be tape-recorded. The recordings and the notes that (name) is taking will only be used to write the final report.
- All discussions will be completely confidential. No one's name or affiliation will appear in the report.
- Please be open and completely honest. The results from these discussions will help to improve the Medicare Interactive program. So your opinions and experiences are very valuable.
- Please speak one at a time. This will ensure that we will hear everyone's comments.
- Please avoid any side conversations or comments. We all want to hear your thoughts.
- This session will last about 2 hours. Please feel free to help yourself to the refreshments.
- The restrooms are around the corner to your right.

Introductions/Warm up

- Go around the room and give your name, affiliation, and primary focus of your program.
- What do you love most about your job

G -- GMHC Managed Care Specialist at Gay Men's Health Crisis (GMHC), which is the largest and oldest AIDS organization in the country. The advocacy unit at GMHC helps HIV + clients with all manner of health insurance, public issues housing issues, whatever. Our Medicare population is both over and under 65, ssdi, esrd, we deal with in various scenarios.

ML-- Red Hook Senior Center, which is a part of Raices. My job there is caseworker. We have said sometimes up to 180 seniors who come to the center daily basis always around 100 and we serve meals and so forth. We have a lot of people come and do presentations on every subject that you can think of: HIV, DFT, name deleted represent quite a few different subjects Medicare-- we also have sometimes from the Brooklyn health center to talk about Medicare, Medicaid. Most or our seniors does not come to ask us anything about Medicare/Medicaid because it is a senior center. They get mail to tell them what's happening with Medicare/Medicaid. They hardly ever come to me or name delete for that

matter. When it comes to the system part of it, name deleted is the expert. Most of the time, seniors are coming to ask me different. questions about different subjects, everything but Medicare. My thing is I'm a senior and I get a lot of mail and I have a little bit of knowledge about as to what's going on in Medicare.

M—Forest Hills Senior Center. If I repeat the same speech. We do this daily—feed 100 people. The problem—the difference between your centers and our center—we're located in a Russian speaking community, each person who got this mail, they come with this mail. For example, we have 57 people they come to the bilingual social worker and ask "can you translate this long 3 or 4 page letter for me" and because each person needs attention, it's impossible to explain to them what's going on with Medicare This is our big issue--to translate exactly what it means about Medicare because it is very important. Kate knows about our Director. We split responsibilities for this program. She does her job and I do our job with different languages. This is what we're faced with every day.

D--IPRHE Corona Senior Center. Some things have already been mentioned: recreation, trips, educational and also case assistance. Those who come to our center are fairly new immigrants from Central America. We have individuals born and raised here. What's very complex now is the Pharma program through Medicare. A lot of information and they struggle. One day hearing one thing, one day they're hearing another. It's very confusing for them. Drug program is different and selecting which health coverage through Medicare that will best meet their needs and it a lot of it has to do with the information. Too much information, language. barrier, need to be simplified for them, depending on the audience. Come to us for more of a breakdown what are these plans about, what meets their particular needs because everyone is different.

JJ -- Raices Red Hook Senior Center case worker. We basically help with all kinds of stuff. Different people coming for different workshops such as Medicare. They receive letter. Sometimes I ask them, "Do you need something? "Do you need information?" and they say I already understand that letter. Sometimes I go in to get information on my own, but they don't come to me for that. Why this go into the computer? When the computers are working.

Ruth—Well, welcome. I'm glad all of you could be here. I admire all the work that you do but tell me one thing. What do you love about your job? Anybody?

JJ—Working with seniors, helping seniors. Sometimes they give you a hard time.

Ruth – Like everybody else.

ML—I love my children. Everyone of the seniors they love me. They come to me with personal problems as well as job problems. I just love my job. I love people. That's why this is something I've done all my life. I was supervisor for launching Aetna as well. I've always been around a lot of people and helped people. JJ, you can verify, and Kate can tell you too. I just love people.

GO-- I used to teach piano to students who didn't want to be there and I wondered what I was doing in life. In this job, I see that I'm tangibly making a difference, giving real resolutions to serious problems in a tangible way they wouldn't solve on their own. That's what I love.

M—All my life I worked with people and I love it. And they love me too. I see people need some help and we try to do our best. Not all the time but we try.

D— I've been working with seniors 16 yrs in various capacities. I just enjoy working with that particular population. It's nice to see positive changes, to make sure they are informed. It's up to them to decide whether or not they want to utilize, but at least to be a more informed consumer -- that's all we are all trying to do.
Ruth- Well you've talked a little bit about your clients and what services you provide and I know that not all of you necessarily work with Medicare but for those of you who get questions about Medicare when it comes up, what are the questions that come up most frequently?

D—The changes with Medicare Rx cards

M— All the time. still have to use Elderplan, main pharmaceutical? Which one is better. All the time.

D—epic, elderplan, Medicare plan. Many who receive letter may be receiving Medicaid and I say just leave this paper alone, you're in the ideal situation, but it's very confusing because they continue receiving mail from all these different companies.

M—Even with this case we have problems. This client he has Medicare/Medicaid and still he has a problem.

D—My understanding of the program—the Medicare Rx plan will help seniors those above Medicaid. People on EPIC will get $600 for a 6 month period and that's really it, because the fact is they are locked in if they do the Medicare. From what I see it will assist very few individuals. The prescription listed two weeks ago may not be in effect a month from now. Different in the fee to actually be a member, you can go across the street and the same medication will cost you more [than at the other pharmacy]. It will assist very few seniors. The ones in the ideal situation are those who are eligible for EPIC because they will get those 600 dollars. They also are accustomed to being able to getting out of a plan. Not with Medicare. Once they're in they're in until the time comes for them to get out and that's something we have to tell them. It's not like the regular insurance. If you switch for say medical reasons you do not have that flexibility.

M—How can you predict? If they want to change?

Ruth—You have to let the senior be aware that these are the regulations. We need to not get into the specifics of it. I think it is really important and I want to give you a chance to catch up on all of it. Let's keep it a little more generic.

JJ—one of the seniors came to me, confused, thought they would send him $600, It’s not like that. He was confused.

Ruth—And how did you resolve it?

JJ-- I read the letter, because he is Spanish guy and filled out a questionnaire asking Social Security to send it in Spanish because they do. So I explained to him. He said “oh but someone told me that they’d give me $600.” I explained to him. That’s the only case—the rest of the people understand what’s going on.

Ruth—What kind of questions do they ask you?

GO—How am I going to get Rx coverage? People with HIV need $15,000 plus more advantage for Medicare right now other than the $600 credit below income just doesn’t cover it prescriptions. How am I going to coordinate Medicare with whatever other insurance I have? How do they fit together? Then we have to talk through all kinds of things just to make sure they have good private insurance before Medicare starts because they don’t have any options to buy insurance once the coverage begins, so it’s a lot of coordination issues.

Ruth—Well good. When you think about all your personal knowledge about Medicare what do you consider to be your strongest area?

ML—Would you repeat that?

Ruth – When you think about your knowledge, your understanding of Medicare what part, what topic do you feel you have the most information? What do you personally know the most about?

ML—Like I said, being a senior, like the others I get letters to read and mostly I guess my strongest point would be, really and truly, I don’t have any real strong points about it. Biggest thing I could say if they bring a letter, I explain to the best of my knowledge what the letter is telling them. As far as knowing if I have to know directly for myself then most of the areas I can speak on.

Ruth—Good. Anybody else? JJ? What do you feel off the top of your head is your strongest area in Medicare?

JJ—read the letter and whatever the problem is—they come in with different problems—I read the letter and try to help to the best of my knowledge. If I get stumped then I run to Marie.

Ruth—What do you consider your weakest areas? What area do you think is the hardest for you to navigate?

ML—Different programs that they have in Medicare. Because sometimes you may think this is good for you and you really have to study to see if that part is good for you or another Medigap. That sometimes stumps me to, answer anybody, if they're going to ask "Marie, what do I do? Do I get in this program or this one?" You can't say because they're not giving you everything you need to know about them. They're just telling you certain things and they may want get into one program that can help them better than the next program. But you still do the best you can by telling them what you think is good for them. But saying off the top of my head I can't remember all the different programs in Medicare.

D—Basically what she was saying. Our clients are sometimes not so forthcoming with telling you everything we need to know so that way we can choose. I try to say, these are the plans, this is what you're saying to me, but you need to choose. The reason I do that is first of all they should be the one choosing and also for them not to say "You told me to choose this plan" So I make sure that it's explained to them. So they can make a choice. What meets their particular needs? But sometimes we have members that they listen to the information when we have speakers and they don't let time to sink everything in and they're signing and I have constantly tell the members "Make sure you have a clear understanding of what you're signing because once you're signed it's very difficult, it's not impossible, but it's very difficult."

JJ—Same thing we say over there. We can't tell them what to do. It's difficult to find out which one is the best one. But we can explain to them and let them choose.

ML-They have to choose.

JJ—near around the center-they give you the whole chicken, they run over there, they get the chicken, sign the paper, and you get a letter, "this insurance, that and that" so when they go to the doctor and the hospital with the new insurance. Doesn't cover that no more for you are on this plan now. The come to us, two of them came to us for one of them passed already. He came and he needed a power wheelchair and the doctor was all ready to give him the wheelchair until they found out that his current insurance doesn't cover it. So I call the insurance and they tell me that he needs to make a letter, sign it and blah blah blah and R makes the letter and we send it and we wait 3 months for him to get the wheelchair.

ML—one person he passed another at the center, and he's still having problem with this company that he signed up with without knowing he was signing up with them. They came to the center and it sounds like a joke but they offered him the chicken. Okay. They offered each person a chicken and he's thinking that he's getting a free chicken. He did not know that he was signing up for the program.

JJ—It was not part in the center. They were passing by the center outside, they said "got the chicken? I got the chicken." I said don't do that. You can't stop them from signing, but just make sure you got everything clear before you sign anything.

Ruth—Tell me about how you find out about your changes. When you heard about this drug change, any changes in the past when you hear about Medicare. Where did you get your information? How did you learn about it?

ML—My personal mail

GO—email, I'm in a lot of lists and partnerships about insurance. I get updates every week.

Ruth—So you guys get stuff through your email and through mail. What about you M?

M—Information coming to us, letter from Medicare, all the time, we have every month, updated information from Albany. We have letter from Spritzer, which we have in our book.

Ruth— Do you put it in the book or do you read it first?

M-- We read it first, a couple of letters every month. Then I want to return to this problem—additional problem when people sign and they don't understand the language. The age. They're not alert to what they're signing. They complain "You didn't translate right. You gave us wrong information. Why you did this?" It's a problem. How to translate right. Spanish. Russian. Chinese. We have all these problem.

JJ--we don't allow them to get people to sign at the workshops. Give information, let them call you if they need that. We don't allow anybody to come from outside and sign people up.

M—We gave Dept. for Aging very strict direction "don't do it at all". First, you have to affiliate this program or ask them before. First Health, Family Plus, whatever. We have strict instructions don't do this at all [no one can register, sign up at the site]

Ruth—When you say "don't do this" you're saying they're only allowed to present information but there's no sign up. No one can register to sign up. That makes sense.

ML—Like I was saying from the beginning we also have presentations, people on installment contracts, Medicare/Medicaid, someone from RAICES does Medicare presentations. We get people to come to the center and give presentations on different subjects.

Ruth- Let's move on and talk a little bit about Medicare Interactive. When did you first here about Medicare Interactive(MI)?

ML—When we first learned about Medicare?

Ruth—Interactive. The program.

JJ—When they sent the paper to the center and sent us to training.

Ruth—So you heard about it because they sent you a flyer. Is that how pretty much heard about it? (murmurs of agreement from participants) So what did you think about it? What was your initial reaction?

JJ-For me the program is good. You can check, go on Internet and check every subject, but they don't come to me. I can do it practicing.

Ruth—When you heard about it did you think I can check a lot of thing or I can check on Medicare.

JJ-- I can check on all Medicare, all that Medicare brings to us

(Side B)

Ruth – Were your suspicions confirmed?

GO—Partially. I suspected it might be senior focused not for people with disabilities.

Ruth—were they confirmed?

GO—Partially but with our input it has gotten onto the site.

JJ—sick people are in Medicare. My sister in law has MS and nothing is covered so she has to pay for her Rx. $1300 monthly for one medicine. We brought her in from PR, Medicare and Medicaid covered all that. She's much better. She came in a wheelchair, she's walking now.

GO –I was pleased to see links to Rx programs, various things, Medigaps, different. directions

D—I think it's a good program because the way it has evolved, the person doesn't have to be a computer expert. Anyone can use it. It's Friendly. Anyone can access it.

M—we try in our center to do free computer classes in different language. For seniors to access the computers for this program exactly, they know how to use computers but when they got information, they need may need 1 page in Russian, Spanish, Chinese. I remember mentioned in the last meeting, someone mentioned that we will have it soon.

JJ—When you search for different things, it's only in English.

Ruth—Actually we are going to have an opportunity to mention that more later on. If I can just ask you to talk about a little bit about your initial impressions. When you saw

that did you say “Oh this is pretty good.” Craig pointed out that, he was concerned, that it would not include his target audience, his clients. Were there any other concerns that came up for you? What you though when you first heard about it? Online access to Medicare access. Questions? Sounds great but…is there a but?

GO –Another thing—is it going to have really specific complicated things, beyond general information

Ruth—Did it

GO-- No. I’m not sure it’s appropriate for certain things. I do a lot of computer searches doing arcane facts about Medicare specific to a client but not really on the site. It won’t cover every arcane rule Medicare has, nor should it. I use Google searches.

Ruth—Did all of you think of any other concerns? If you don’t have any its fine. So you heard about it. Sounds good to you. Then you were taken to training. Did all of you participate in the training? Just describe it briefly. Somebody?

JJ-- It was fine. I learned a lot.

Ruth—Really? What did they do?

JJ--They put me in front of computer, but I was sitting in front of computer before, so it was not really difficult. Marie has problems with the mouse,

ML—Can’t stand that mouse

JJ—The training was good

Ruth—So when you left you felt prepared to use MI?

JJ-- Yes. Very friendly. For anybody.

ML—I had a good training and I want to thank Miss Kate for that. I have arthritis in this finger so the mouse and I don’t get along. Thanks to Kate I got through the training real good. That’s only because JJ was on the other side. Thank you Kate

Ruth—Teamwork. That’s what it’s all about. Can you think of anything done during the training to make it more effective. Any ideas to making this experience, to optimize people’s abilities to use it.

ML—just a comment here that is not good. When they have a trainer, they have to remember that not everybody is computer trained. If you’re not computer trained and the person is talking like you’re talking, you’re lost. You can’t talk right through. You can’t do that. The person giving the training should realize that. They should know they have people not all that familiar with computers. Not everyone has one even in this day and

time. I suggest that person training needs to be a little more considerate for those who don't have a computer.

GO—might be good to have different classes, might be too fast for someone with no knowledge, way too slow for someone with basic computer knowledge. Training clients might be good.

M--Or volunteers.

Ruth—So when they do the training, you're suggesting that they not only extending not only to your counselors but to some of your volunteers.

M --Yes

D—That had been offered to us. The people we had is that unfortunately the people who trained. They enjoyed the information but they didn't stay with us. The other thing was the people were interested but couldn't come to Manhattan. It was a shame. They wanted to bring that to us. BY Shay's stadium. We have to take that into the equation. The Commute. For many of the seniors it's a hardship walking up and down stairs, but they're interested.

Ruth—So one of the considerations is doing some outreach. Going into the community and offering it on site versus having them in a centralized location where everyone comes in.

JJ--Medicare Rights gave us two computers. One is not working. The other one is not…

Ruth—Did ML break the other one? (laughter)

JJ--They have the computers already. Make arrangements for a little classroom and whoever wants to learn can come. I tell them you want to sit down with me I'll teach you. They don't want to learn from me. If someone else came in maybe more interested.

Ruth—Let's talk about your using MI. How long after you took the training did you first use MI.

ML--I don't know

GO—a week

M—I didn't know two of us have it. The Director use it. I thought she was first, then I used it. She went first.

Ruth—How long after the training did you use it?

M--One month maybe. We had one client who asked for help. As JJ mentioned, very difficult for our people. They are old people. They have different literacy. To use a computer is very complicated for them. To jus understand is a computer error. Easier to use computer for us, but for them, if we tell them EPIC is better than everything, that's better than if I bring them a new letter with information. I call this the black telephone, translate from Russian, what I mention for them in doesn't work. If she told them, they know her better.

Ruth—How abut you D? How long did it take you?

D--I think it was 2-3 weeks.

JJ--as soon as I got the computer. Got it 3 weeks after the training.

Ruth-- Maybe close up the time between the training

JJ-- Still now, sometimes I sit down and I go look at the computer—I don't print anything, I just check the different MI things. Every subject

Ruth-- what motivated you? When you're sitting there in front of your desk, three weeks after MI what made you think Hmm I'll think I'll sign on to MI? What motivated you to do that?

ML--I don't go in the computer. If I have something to do. I am busy all day long. I hardly ever get to the computer. Seniors always at my desk talking about different things. I usually have no time. With what I'm supposed to be doing.

JJ—we use the DFTA computer because we have to put the information in the computer. We use that the most. Any change we have to look up.

ML—that one I work

GO—to be honest, we wanted to see how well they did with our specific issues. What are you going to do if you get Medicare coming up if you wanted to make sure you're covered, you have COBRA and it's running out and you need to buy independent insurance—we were checking some of that stuff. I remember at the training, we found a mistake, pointed it out, got it corrected, watching to see how it handled our specific issues and there are many wonderful things about it.

D—I basically use it because it was a question. When I went to training they were just about to raise the social security deduction they take out in your social security check. I had an individual who didn't have A or B so she needed to buy in and we had to see how much would it cost her.

Ruth—The first time you went on how did it go? Did you feel comfortable? Was it user friendly? Helpful?

Yes (all around)

M—yes, it was very helpful

Ruth—For all of those who use MI how has it or has impacted the way you service your clients. …No? It hasn't really had an impact in how you serve your clients?

GO—I think a lot of the things we tell our about clients are so second nature that we don't need to look them up on BEEPM to get it. Some of the really specific that we don't find them on BEEP'M. What I have found are some good things, layouts. For example there's a really good chart on MSPs, presentation-ready materials are good to present to clients. I think it would be good to give them print outs of relevant information for clients.

Ruth—Some good materials to pass out. Anything else that you can think of that can be added to it can be more relevant and useful to you?

GO—I think there could always be more search terms. It's good for anything for someone who doesn't know anything to go through the Q&A good to see what they're eligible for, but when you know what you want get right to a point. Sort of have a comprehensive indexing, links. We tried something the other day. We looked up Medicare savings plan and we weren't able to easily find out using the search function. We found it under "Help paying Medical costs". It was a generic link and that was the one we had to click on to get to the MSP information. As many good search terms as possible to quickly hone in on information. Usually with a search system, I'm afraid I won't get information fast—I have a client waiting and I don't have time to search around for the information. I may just ask someone who knows.

Ruth—Can anyone think of anything else that could be added? What make it more relevant and effective for you?

D—I think it's already been brought up. The language.

JJ—Yes.

Ruth--When your clients come in what types of materials do you give your clients to take home? When you're talking about Medicare or in general?

M--Something they bring us too They have letters to translate explain, comprehend what's new.

JJ—brochures, information when we give the workshops and they bring information and we get it from different subjects, not only Medicare Rights Center.

Ruth—Do you have it set up so you can just pull the information when someone comes to your desk?

JJ—Yes

ML—we usually put it where they could donate. The lady at the desk has a stand with resources and they pick it up and if they don't I hand them out at lunchtime.

JJ-She usually goes "You gotta listen to this." So she don't let her pass. Here take one.

GO—we have a Medicare Fact sheet. We use MRC's compilations of information about Medigaps and HMOs. We have premium rate sheet for private insurance and we hand that out.

Ruth—So you have quite a few materials.

M--I do is not only have the resources out when they do a presentation, put the extras in the office for when they have a question 2 weeks down the road I have it there. Last Sunday we had a health fair last week. Assembly woman was there.. Hospital brought a lot of information, branches of different brochures, now we have it all over our senior center. It's very good. It was Sunday, not our day. Try to bring people in the weekend to community house. Family Insurance Day.

Ruth—It was broader. For families as well as seniors.

M—Right.

Ruth—What about MI? Have you ever printed anything from MI and given out that information?

Yes (D and M)

Ruth—What did you give out?

GO—chart form MSPs

M—don't remember. We did.

Ruth—When you think about MI and counselors what level of knowledge should they have before they can use MI. Or do they need any. Should there be an existing understanding of Medicare to be able to use MI?

GO- I think with the question and answer section you can go in fairly cold and get led somewhere. Are you over 65? Do you have other insurance? Whatever those things are a series of questions are at least with very little knowledge and get a basic understanding.

Ruth—Do you agree?

D & JJ—Yeah

Ruth—When you were using this the MI, tell me about the technical support you got? Did you use any of the technical support when you were having problems with it? When you're having problems with the computer?

JJ—Oh yeah, when the computer doesn't work, Kate fixed it

M—we have special computer department to help us

Ruth- For the MI specifically? When you're getting online if you have a question and you weren't quite sure GO brought up the fact that you were looking for the MSP and you couldn't find it. Did you find it or did you call anybody?

GO—I found the MSP, it just took longer. I didn't call. We've given feedback to MRC they've been receptive

D—What I end up doing I guess it's just I habit that I have I call social security, I have to get out of that habit. You know you're just used to doing things a certain way.

Ruth—are there other reasons that you call them instead of using MI?

D—No I use MI but I'm saying that…

Ruth—I understand what you're saying and I understand but it's a habit that's familiar but is there another reason? Something else you feel is beneficial for calling that office specifically?

D—I find for me personally in my experience that it's something that's a little complex then I don't have to wait that long. I wait a few minutes, they put me on hold and I just give them the Social Security # from the client and I tell them.

M—I like to do this too. You can ask individually, personally. We did this before. It's easier sometimes.

D—The other thing is confidentiality. We have our computers where members are going back and forth. So we have to be very conscious of that. They don't want to be sharing their information with all these other individuals with all these persons passing by. That's one of the reasons I call. I can take a senior to my office and make the call, and no one is passing back and forth and listening to their particular problem.

GO—There's a whole pro/con thing as to computer research versus book research. Computers are good because it's fast and you can search terms very quickly, but its' not as flexible as books where you can leaf through the pages, look in the index and if it's not

there, look 2 pages before and find the answer. There's just a certain flexibility that isn't there on the computer for you only have one screen at a time. You don't have time to flip through the pages.

Ruth—Do you ever look at the usual manual? Do you find it useful?

ML- We have that

GO—We went in-depth during the training

Ruth—Did you refer to it again?

GO—We've used it twice but since I know computers it's pretty evident how to use it.

ML—It's on the desk.

Ruth—It's keeping the desk from floating up. It's weighing it down.

JJ-We have it around in case we need it.

Ruth—But you don't really need it. Can you think of anything else we can add to MI. Anything else to make it easier to use. To make it more desirable to use. Anything else.

GO—I don't know how much we want to talk about Part D—new Rx law—there's already information on there about it almost prematurely. There's a whole description of Part D which doesn't exist yet. When it does come I would hope to see a lot about the Rx drug plans. Formularies. Comparisons. How they coordinate with other private insurance.

Ruth-- A quick turn around. When something happens they have an immediate response.

GO-- Almost too efficient, almost premature.

Ruth—Too efficient. So you can have an immediate response so you can have a sense of the lay of land of what's coming up. What it might entail.

GO—It's going to be crucial because it's such a messed up law and it's complicated to have information readily available. It's going to be useful for that.

Ruth—Wanted to ask you some questions. Specifically about the different components within MI. My community. Local services. MI University. Have you looked at any of these? Which one do you use most frequently?

JJ—I go in there

GO- Local services

Ruth—Have you gone into MI counselor? This is where you get your answers.

(no response)

Ruth-Have you looked at this section

D—Yeah

GO—The counselor? We use it the most. It's where you we get the nuts & bolts of the program.

Ruth—What about MI Community?

GO—Is that related to Dear Marci?

Ruth—It is part of the BEEP'M Program.

Ruth- What about the feedback? Have any of you gone to the feedback section? Oh go there! Give them lots of feedback.

JJ—Like I say, you just go on the computer play with it.

Ruth—Do you find local services interesting? Useful?

GO—It has community organizations all over the country. As I recall the mention about us is a little old.

Ruth—Do you take any classes at MI University?

D—No.

Ruth—Anybody use MI Help?

(No feedback)

Ruth—Let's get away from MI and talk a little bit about technology. When you have to research a problem what resources to you use?

ML—books and magazines, flyers

Ruth--is there a place where you get them?

ML-- My night table drawer. I like to read. I'm a reader. Love to read.

GO—I use google.com a lot and it leads me somewhere that takes me through the Internet.

Ruth—That's good. So you've abandoned hard copy?

GO-- If it's looking something up I have the book published by the govt. They're also available online too.

ML—the rest I keep in the center. A lot of drawers in the center in case the seniors come to me

Ruth-- quick reference – on anything

M—I love computers. My new toy. I just change my life, I got married and the first thing I did, bought a new computer. I did research, bought a very good one, play with it all the time. Encourage him to do it because he's not a computer genius at his age. It's the new literacy for our age.

Ruth--my daughter can do those things.

M—I have to repeat. Before I couldn't live without books, now can't live without computers.

Ruth—How long have you been using the Internet?

JJ—I have a computer at home, sit in front of it, sometimes playing. At work, we have the book, they come in for the first time, and we look in the book. They send us new information every time. That where we get most of our information.

D—I use it for personal use. There are times we use it. If we are going to have a celebration and need to find national anthem of a particular country. Rely on the Rolodex, interaction with community agencies, go to the people, my rolodex and the books.

M—My director come to me and says you don't need this paper, the computer has all of it now. Google. And it's true.

Ruth—When you think about paper versus using information online what do feel about having the information versus using books?

ML—my source is books.

Ruth—What do you like about hardcopy? Why do you like that better?

ML-- It's not that I don't like looking in the computer, but naturally it's faster,

JJ—saves space

Ruth--it's ok to like hard copy.

ML—mostly what I can’t deal with on computer. I was supervising computer practically my whole career, only 3 jobs in my life, even when we had cards, I supervised the computer. There wasn’t a mouse then—it was on the keyboard. That’s fine, but having to move that mouse around and you’ve got that bad hand.

GO-- you can do it left handed.

ML— I don’t want it at all. I’m right handed With the left hand I couldn’t do it at all. On the keyboard it was typing, address, state. It’s just that lousy mouse.

GO-- If I’m impatient or it’s after hours and I want to know right now or I feel stupid because I don’t know, the computer is good. I don’t have to ask someone and embarrass myself. On the other hand, if I have a client waiting I call Rina a lot at MRC. Maybe I don’t know how to formulate the question, maybe something I think she knows I’ll call and maybe I get the answer right away.

Ruth-- sometimes faster just to call. Sometimes don’t know how to phrase it to help formulate and distill what you’re trying to get. On the other hand, the universe is available online. Hard copy is good because it’s there.

GO—more flexible

M –people in the age like to read, it’s easier for them to understand, maybe information goes fast can’t concentrate

D—I think time is really a factor, depending on responsibilities, things you need to accomplish in a certain timeframe. Sometimes I’m seeing clients, need to take calls could be an official and you’re making people wait., and then the –you’re multitasking—computer is good for me only if I have time, generally its not during work its after work hours because I can take my time.

GO—sometimes the Internet can be a bottomless pit. Something that can seem like the obvious answer entering search terms, go from here to there, a lot of Google hits irrelevant, have to revise my search.

M—It’s a problem we face every day like Debbie explained, 4pm I make an appointment., maybe 3-3:30pm when I can concentrate, follow directions, sit and relax, then we can do it together.

Ruth-- in afternoon not inundated by phone calls.

D-I know that center. Also, people walking in, unannounced especially health insurance companies, want to donate money for an activity, give presentations, officials, these are people you aren’t expecting. All those other factors come into play.

Ruth--Internet can require time, attention. Can't do it when you're doing a lot of things. Have you or your agency trained your clients on using a computer? The Internet?

ML-We were supposed to but we never got around to it

Ruth –Do you think interest exists?

ML—Eventually, we might get around to it. Once we trained. The rest were supposed to be 4-5 to be trained on Medicare, but we haven't gotten around to it.

D--Kate came to our center and provided training, they enjoyed it, but in my center it's going to have to happen more than once for them to break the ice and feel more familiar, but they enjoyed it so when she came back more people wanted to do it.

Ruth--the interest is there. Have to repeat it frequently so they can buy into it. Repetition.

M--we tried to organize computer classes. A lot of people asked daily. We did a Russian computer class. We had a very good volunteer. For three months he did this. Then we had some problems with the computer room and maybe we'll start new classes in October. Different languages. Every day they ask about computer lessons.

ML—I don't think we have that much people interested. We even have the library across the street give computer classes and we only have 2 people enrolled from the center. Being the age they are I don't think they're greatly interested. There are a few. The majority no, they wouldn't bother.

Ruth—Can you think of any strategies that would help your clients to become interested. I know you need an ongoing project and not a single presentation.

D-With our centers it's basically funding. We don't have a volunteer who will come in and dedicate this hour the city. We just don't have the money. We're getting more memberships but we aren't getting more $$$ They've some programs, they cut ESL, which is needed if they could provide funding to provide that that would be wonderful or at least someone to volunteer.

M—Yes, money is the problem.

Ruth--What were some of their concerns? Do any of your clients have access to MI?

Yes (all).

JJ—I tell them if you want you can use the computer sometimes we as a staff we don't have time to sit down and teach them we have other programs we have DFTA, DYCD, and other programs, she's involved with the trips, me too, and I have to take care of my

clients for DFTA and DYCD and sometimes it's not easy to keep in all straight and teach someone to sit in front of the computer. It takes time.

Ruth-- How important is it to provide your clients with direct access to MI?

D—Definitely it's important. We should empower them. Even if we're not available, that day, maybe were on a trip or the Assistant Director is doing something, they can go in on their own, that that's something viable for them.

GO—We have a center on the 6th floor that they can use. I just wish we had the resources to spend time with them to train them how to do it. Or spend a few minutes to get them started If they're really computer literate, ok, but if not they need more time. Anything to empower people to make decisions, research things. A lot won't but I think there's a good number who will use it.

Ruth --Given your experience with MI, how would you change it so it would generally be more effective?

M—It's very easy.

Ruth-- How important is translating MI into other languages? Which languages do you think are most important?

Very very important (all)

JJ—Spanish and English. For us it's Spanish and English.

M--Chinese and Russian definitely, in our area. In Corona, too.

GO—With Chinese, Japanese and Russian and we need to have keyboards to accommodate those languages. How are you going to type in Russian? I think you can view, but not type.

M—for DFTA we have a Cyrillic keyboard. People complain, why do you have flyers in Russian but for 50% of this population speak it we need it. We have to provide information in both languages. We tried to do Chinese, we have a volunteer, they did this many times. Chinese flyers. International club, we tried monthly different languages activities. Without language, cultural. It's worked very well. We try to encourage people to help people with the language barrier, to help them speak with the language. Some people like this.

Ruth--When translating, what should MRC take into consideration? (PROBE: important features and considerations.

GO—Vet the translations to make sure they're accurate.

M—it's not easy.

GO—make sure they're bilingual.

M—sometimes you can't even translate flyers a couple of sentences. Big problem with this program. How to reach people. Try to comprehend the problem. It's a problem

Ruth--to even recognize beyond language

D—keep it simple. I'm still learning different Central American Countries people have different words in Spanish than I have from PR. They pick up words from where I'm from. Need to keep it simple so no matter where they're from everyone will understand.

Ruth--What cultural factors are particularly important when developing MI for other languages?

D—when you're interacting it seems yes. Of course if you're going to be…proximity of your closeness with a senior. Some individuals don't like to be touched. Each country is different. If you're seeing someone new have to keep it in mind. Unless there's a relationship already established. If you are seeing someone relatively new you have to keep that in back of your mind.

Ruth--MRC? Keep it simple. Be aware. Any cultural issues they need to be mindful of?

Go --Example?

Ruth--decision making – might be with husband, children, so if you talk about it, you won't say "you" because they wont' be making the decisions…

GO—I would leave the option open. So you're saying the term you maybe be seen as broader.

Ruth—Keep it simple because there are cultural differences.

D—It's just like the word you—you don't use it in Spanish. Unless it's someone you know. That's something that really plays into the language. A term you use out of respect.

Ruth-- In your experience, what are the current trends in information needs or services? What are people asking about? For your clients? What are you having to address more.

D—now they're concerned over the premium being raised.

Ruth--everything, not just Medicare. What are your clients concerned about.

D—there will not be all the services available now. Diminishing funding. That's a major concern. Especially when you're dealing with immigrants whose only source of income are government programs. They are worried. How are they going to survive? They're concerned, losing funding for ESL classes, not just services. They're hearing it more and more often.

Ruth—So they're hearing increases in Medicare costs, premiums, but government is cutting costs all over the place, programs are having a hard time.

ML—election day coming, politicians will come, speeches, mention Medicare, makes them nervous. They are covered, have insurance all ready, but when they hear this, it makes them nervous, they don't even know why their nervous. Maybe age? They are nervous and they don't understand.

D—last year, they were talking about considering giving them a lump sum to find insurance and that was a major thing the fact that we had to lobbying in Washington didn't want that to pass. Let's say you give them 350 dollars, what health insurance will be available to them for 350?

ML—I'm hearing mostly the same thing. Health insurance. How they're going to get their Rx drugs if everything keeps going up and up but they're not getting anything more in their checks. Those that get SSI, those that get Medicaid even, some just get SSI, so if they're old enough they can get Medicare/Medicaid. Still worried even if these two are paying for it. They still come to you—even if they get the "not a bill" they still think it's a bill. I tell them it's not a bill, just ignore it, they're telling you what they paid. They're nervous about their medicine, rent gone up, but my check didn't go up. Mostly what I hear is them worrying about something checks too small for the way that they're living. I couldn't get a job. Concerned about rent increases and less check money.

Ruth – Some of the changes I hear – reduced funding, increased cost of health care, any needs changed this year?

D—I'm making more referrals to food pantry difficult choices now, majority of income going to rent even though there are all these programs. Many seniors live in private home, can't get SCRIE to freeze rent, needs to be I think 6 apts. Difficult choices they have to make, Seniors cut medication, not drinking as much as they should, cut the amount, getting sick because they're not taking it as prescribed because of the high cost.

Ruth--What do you think is coming next? What do you see looming in the future?

ML- It's going to be rough.

GO--problems with the new Medicare drug law. Dual eligible they'll lose comprehensive Medicaid coverage, limited formularies on Part D, drugs I used to take not covered and my doctor says I need it, telling me I can't have it, need to try something different. Out of pocket expense.

Ruth--Cut dosages, self-regulate to make it last—well that's a happy thought—getting the word out that although enrollment continues to grow, at least they have some place to go where they can navigate the system as effectively as they can as bare bones as it is becoming. Extremely important. I want to thank you guys for coming. You're just amazing. It's usually tough to carry a conversation. We usually have 9 people You really did your work and I know you are just exhausted. Thank you so much and you did it in the time we were supposed to. The information you gave is tremendously helpful. You were wonderful. Please take some food or take it home for dinner.

D—Okay I'll take some home

BEEP'M Counselor Discussion Group
9/22/04
10am-12pm

Good morning/afternoon. My name is Ruth. I am a communications consultant. I have been hired to the evaluation by the BEEP'M Project. Today we will be talking about the project and your experiences. Your opinions are very important. Be honest and as forthright as you can be for it will make a huge difference to the project.

Today the discussion will be recorded but your names will not be used in the reports. No one else has access to these tapes. Kate will be taking notes. I will be handling the recording today. There are some general rules:

- Please help yourself to some refreshments.
- The bathrooms are outside to your right.
- Since we are recording please speak up in a clear and loud voice.
- Please speak one at a time so I can answer all of your questions.
- Avoid side comments.

We will be here for about 2 hours and occasionally I may stop a conversation because of the time but I will give you a chance to make any final comments toward the end. Why don't we go around the room and give everyone a chance to introduce themselves and tell me about the main focus of your center.

MRol –I'm the case manager at Elmhurst. I provide services for the elderly over the ages of 60. Some of these services are entitlement benefits. One of the services that they ask most about is Medicare.

DD—I'm with Project SOS. I'm a social worker and I do the same thing. Benefits. Entitlements. Deal with Medicare a lot and provide Meals on Wheels and in some instances home care.

NR—I'm from Raices Corona. We work with elderly and help with Medicare and all the things they need.

LW—Case worker at Times Plaza, also do case management, telephone reassurance, case work, visits, go out to clients home to visit. Medicare Rights Center of course.

MRod. –We provide services to the elderly especially Spanish speaking. We provide information for whatever they need: applications for programs available, benefits, Medicaid/Medicare. We have a lot of information to get to clients. Also do home visits.

Ruth—Tell me what you love about your job?

LW—Basically helping to take care of the elderly with whatever they need. Doing what I have to do to help them.

MRol. –I accomplish something. It's very rewarding when they get the benefits they come ask for.

DD-- Absolutely the same, when I accomplish something and really help someone it's fulfilling.

N—I love my job and I love to help the elderly, especially now they're so afraid even to show social security number because their afraid that someone will get the number and do identity theft so I'm happy that I can explain we are there to help them. I'm happy.

MRod-I love my job and always feel like I'm home. People I work with are nice and am happy to know we've helped someone. Love to get all information I can to them. So that they can trust that what we're doing is best for them. I'm very happy helping.

Ruth—I think you are all doing a tremendous job and providing a vital service especially for our elders that is invaluable toward a system that is becoming more complicated not easier. Let's talk a little bit about Medicare. What questions do you get most frequently? What seems to be the primary area of concern in Medicare among your clients?

L**--** The part a and b. What's the difference? Will one help the other? We get a lot of that.

MRod--Now that they have opportunity to get medications, they like that most. Low income, but not getting Medicaid, now they can get a program for medications.

MRol—We get a lot of questions about the Rx discount drug card. Literature comes in the mail that they do not always understand and they want to know if it applies to them. Some of them don't qualify and some of them do.

DD-- Recently it's been about medications & options. What will it pay for? How does it work? That has really been a hot topic.

LW-- One or two seniors complained about the card, the Rx card, that they hadn't gotten it on time, for a month or so, took too long to come. They wanted to know how long it takes to come.

MRol—A lot of them don't realize, those who have had it for some time and they come with a bill—why doesn't Medicare pay all of it hospital & clinic but not Rx. They've had Medicare for a long time and they don't understand what it covers.

MRod—This is not a bill. They don't understand MSNs. They don't understand that it has been paid by Medicare and bring the paper. I tell them to keep it because of something happens they have proof.

LW—Even when you explain it to them they still want you to call, although you tell them you don't have to pay because it was paid already, they say no but it says I have to…(regarding seniors) What could you do?

N-- In our center we have about 111 cases that Lucia/Pia have done. We do translation from "the bill that is not a bill" (MSNs), they worry they have to pay. For Rx we make an appointment every Thursday to talk to Pia. Sometimes we do call to make sure they don't have to pay.

Ruth—When you look at your own knowledge of Medicare what do you consider to be your strongest area? What do you feel most secure about talking to seniors about Medicare without referring to someone?

MRol—Part a and b. The fact that they have to pay deductible and premium. I'm comfortable with that.

MRod--Same.

Ruth—What's your weakest?

(No response)

Ruth—What do you feel least secure about?

MRol-Medicare gap that information linking to the list of services that providers? I have to research that.

Ruth—What was the last change in Medicare that you remember?

MRod—The prescriptions.

Ruth—How did you find out about the changes in Medicare?

Rol—From a meeting.
Rod—I saw an ad on the television and the supervisor gave me the information

(all) meetings
N—Last year I went to classes with Kate and Lucia and they came to the center.

LW-Yeah, came to the center.

Ruth—Where else do you get your information from Medicare?

Rod--The clients themselves bring literature that they receive in the mail.

N--Sometimes we receive booklets, they seniors don't understand and they bring to us.

Ruth—Do you know where the booklets come from?

N—I don't know exactly where because I'm not the one who opens the mail.

Rod—The supervisor sometimes gives us the new information from Medicare.

D--I've got the information from different places. My father recently retired and I became involved in that. I found a lot of information from his papers coming in. We also have a resource book at the project. Anytime a client calls and we have a situation we can refer to the book. It's always updated.

Rod-The number at social security, if I'm not sure I always call.

Ruth—Where do you keep this information? Is it in a binder?

DD—Yes, It's in a binder in the office.

Ruth-It's in a central location and in the computer where everyone can refer to it.

LW-In the computer

Ruth—Let's talk a little bit about Medicare Interactive (MI). When did you first hear about MI?

(everyone) Last year.

Ruth—Who told you about it?

N--When Lucia visited the center She did a presentation.
D-The same and a lot of us had used that binder less when it came to the Medicare portion because it's easier. You just type it in and you are there.

LW-You just type it in yeah.

Ruth—What was your initial reaction about MI? What did you think?

Rol--I had no knowledge what my boss was referring to until Kate came and I was exposed to MI was uncomfortable. But when they had it on the job and I started playing with it until I got comfortable.

LW-have to work more with the computer to get comfortable with it.

Rod—You can get the application for the premium online.

LW—The computer helps. You can get the information on the computer and do what you have to do. Kate came and would update us. That was a lot of help.

Ruth—Did you all receive the training? What do you remember about the training session?

Rod--I went for the training in Manhattan and they showed us how to get on the computer. How to answer a question.

D—Initially, my director came in for the training and she went around with everyone and went over everything and we saw it and went through everything for a few hours.

Ruth—Your supervisor trained you?

D--Yes.

Ruth—When you finished the training did you feel prepared to use MI?

MRol-- Only in areas I knew well.

(others) Yeah [hesitant]

Ruth—What do you think could have made the training more effective? Anything?

Rod—If you had the answers right away. If you know how to go to, I don’t have too much time. If you have exactly what you needed then you have the information updated.

Ruth—How could they make the training more effective? How could they make you feel more confident about the system?

Rod—We have computers at work so it is easy to go back and look around anytime.

LW—It was a lot of information. I have to go over it. Take my time. A little at a time with me. When it’s too much I get overwhelmed.

Ruth—Breaking it up would’ve made it easier for you?

LW--It was a little too much. I have to look more at the forms that they give us, the booklets to get information on what I know I would need to know

N--Sometimes I use the computer but I have to practice more. I told Kate that I have to practice one of the days she comes go downstairs because I get a little lost.

Ruth – How long after the training did you go on MI for the first time?

Rol—I used it right away. I picked it up that same week because I got to learn it because they'll come for answers.

DD--Right after the director said back to your desks everyone. That was a Wednesday.

Ruth—When you received your training it was the same day?

DD-- The same day. We were really excited because we felt it was great. If the clients call we have access right there at our desks. It was great.

Ruth—Does everyone have access at there desks?

LW—No

MRol—Yes

N—No

Ruth—So that certainly is more of an incentive. Access right there. What motivated you to get started on MI?

D—It was easy to use. Simple to use, always questions coming in, so many clients, if it's not one thing its another. There are times when you have to tell them I'll get back to you and I've always hated that. This was my chance to have it right there. I found it easy to use. When the Rx change came in, that's when we started using it more and more. More we used it the more we realized it's really easy. That in itself was the motivation.

N—Two weeks after the training. It was a mess. After Pia came, I said. We are so busy. Can't always go downstairs, clients waiting, seniors get a little upset. So I told Pia one day when we have no clients show me since I get lost.

Rol—The more you're into the computer the easier it gets.

LW—It's hard when you have a lot of things to do, case notes, telephone reassurance, visits, it's a little hard to stay with that one thing. I don't have the computer in my room When we get to the computers and we had problems, had to wait a little bit, wirings, Kate had to come back. Difficult for me to get right to it. It's there now.

Ruth—I think that anytime you're learning something new it's important to have the opportunity to practice and becoming comfortable with the computers. It's all reflective of what we have heard over and over from people. How often do you use MI?

LW—Twice. If that.

Rol—I usually use it when day is slow and I know my clients don't come to the center. Try to log on as often as possible, even when day is over. Kate can tell how often I log on.

Ruth—What do you think could be added to MI to encourage you to use it more? What could they add to make it even more wonderful than it already is?

Rod—Everything is there.

Rol—The latest information 2006 changes, would like to know first hand, what the changes are.

Ruth—What kind of materials do you give your clients to take home? In general? What are the types of papers, products, etc. do you typically give them to take home?

N—Besides Medicare?

Ruth—Anything

Rod—We can print out a monthly schedule

N-- Monthly schedule. Center activities.

Ruth—Do you ever print out anything from MI?

LW-- Mever
Rod—premium application (MSP?)

LW-- Application we make a copy of it.

Ruth--From a file not on the computer?

LW--If I Have to.

D--Our clients are home bound. They don't come to us. I Don't give any pamphlets, if there's something I look into it and see what can be done and share it with them. Applications, if needed.

Ruth—What level of information or knowledge do you think someone needs to use MI?

D—They have to know computers and the Internet. If they can log onto the internet it's simple. If they have problems with computer to begin or they are not familiar with the Internet or computer they'll have a problem.

Rol—Very few know computers. They go to the library. A lot don't own computers.

Ruth—What about prior knowledge of Medicare? Do they need to know anything about Medicare to use MI?

MRod--Yes. Even if I open it, I have to know what is Medicare, the basics about Medicare.

Ruth—Do you all agree?

(everyone) Yes.

Ruth-- What do you think a center needs in order to successfully implement MI?

D--Not sure.

Rol—All the resources in order to provide them with any information.

Ruth--But implementing BEEPM? Do you think other centers have been more successful because computers of computers on desks? What kind of situation would you look at to say this is a good place to put MI from BEEP'M?

Rod—Willing to help. Use the computer to help someone.

Rol-- Someone to have more time to come in and focus just on Medicare information, once a week. Sometimes we don't have time. We have other thins. Having someone there, perhaps a Title 5 worker, senior who is there with all that information every week. To Give me a break.

Ruth—Tell me about when you implemented this program. Did any of you use the technical support that was offered when you first started? What kind of programs did you have?

LW—If there's a problem we call Kate.

D--My director may have had problems, before but I don't know.

Rod—My supervisor does that.

LW—Supervisor.

Ruth—Can you think of anything else that would make MI easier?

LW-It's basically easy. You just click on the icon & look up whatever you want to look up.

Ruth—As for the different components for MI I would like to ask some questions.

Have you used the MI Counselor?

(all) yes we've used it

Ruth—How was your experience with MI Counselor?

LW-it was basically easy to get to. No problem. Like I say, you go in and look at the icons.

Ruth—What about MI Community? Has anyone given feedback? No. Hit click and send Kate a message.

LW—Kate did show us everything, but I'm blank. You have so much other stuff to do it turns you off the Medicare. I have to just do Medicare to know everything about Medicare. Once I'm off I'm elsewhere. Kate did what she had to do and told me everything. She made sure that I knew everything and to call her with questions.

Ruth—What about MI Local Services?

Rol—A few times that's it.

LW-Yeah

Ruth—How about MI University? Did anyone take a course?

LW/N—no

Ruth-- Have you ever used MI Help? What did you like most about it? Least?
No. So pretty much everyone went to MI counselor found everything you need there.

LW—the basics

Ruth—Let's talk a little bit about technology in general. When you or a client has a problem or question where do you go to research it?

LW—If I don't know it I go to my director and she would explain it.

Rod—I have a lot of information, forms, Medicaid, Medicare, also numbers to call.

N—The same. If we have to call any of the offices for immigration, go and ask supervisor for what I can't solve, ask what other steps I have to take.

D--I get information from contacts or agencies we work with, manual that we have, Internet. Discuss with director to see what other options.

Ruth—How much do you use the Internet to get your answers.

MRod-no I don't have computer at home. Maybe if I did have it at home I would use it. For Medicare, my supervisor said I have to do time so I do time.

Rol—When I don't have my information or my rolodex in front of me, I have to go online, immigration, New York State. So many questions—once you tell them something they think you know everything. Sometimes it's discouraging because I don't always find what I'm looking for.

Ruth—So not too much on the Internet. What do you like about having access to information online? What do like about the Internet?

LW—It teaches you. Shows you different things. You get more information faster about what you're looking for. Faster.

Rod—It's updated. The information is up to date.

Rol—some of them aren't.

LW-Yes.

Rol—a lady came about a job. When we went online, it wasn't even a school it was a grocery—she got wrong information through the Internet. She wanted to go to school, but it no longer existed. She came back to me and told me it no longer exists. She's bright, and she said I don't know about computers but she went there for information, was disappointed when she went to this place. Don't always know whether the information is reliable or not. You're taking a chance. I've ordered something and the phone number online did not exist. Have to be careful.

Ruth—What do think about hard copy vs. paper vs. the Internet what is the strength from getting access from hardcopy books?

LW—easy access.

Ruth—Why is that easy?

LW--Because you just click and type in what you want.

Ruth—No from books, not the Internet. What are the strengths?

D-I think computers are great, but the Internet doesn't always work, system is down sometimes. If you need to get to work you're stuck if you don't have the hard copy. Computer saves you time, but you should always have a hard copy if anything happens. The college will send us information—until noon you won't have access—and what do you do for 3 hours?

LW—Computer can go down, so the book is more reliable. Lights go off, the power can go off. Someone I know had to do that—luckily they had all the documents in the book with all the information because the computer went out. This was in a clinic.

Ruth—What are your favorite resources? Not just Medicare. The ones that you trust and always go back to.

Rod—We have a big book at the agency—social security and housing. We always look there.

Ruth—Who keeps that book up to date?

Rod-- The supervisor keeps it up to date.

Ruth—How is it organized?

Rod-- Alphabetically. When they open a new center, they add that information. If you're looking for housing, you look there. It's like a bible. Everything is right there.

Ruth –Do you all have something similar?

LW/N- Yes.

ROl-We need to develop ours. My coworker and I are trying to develop a binder. I feel we should not be responsible for it.

Ruth—Do you mean someone in the organization?

Rol--Someone else in the organization should be doing that. I'm just a worker there. It should've been there in the first place, particular to our work. We brought it up to them. Suggested it to our supervisor. In the meantime I keep it in my drawer.

Rod—When I started they said if you have any questions go there. You can find the information there.
N—We have the same a big binder with information from A to Z, always updated with information from the main office and we put it in the binder.

Ruth—What are trustworthy sources of information?

ROl—Medicaid when I click on it, that's good information.

Ruth—So you trust that website to have the correct information?

D—Those types of sites, anything to do with the government. They are updated. Independent websites, stores or schools, might have a problem like that lady. With Medicare or Medicaid, I don't think we'll ever run into that. When it's not updated.

Ruth—Which site do you think has the most trustworthy information?

N—I agree Medicaid, Medicare.

Rod—Social Security. If I get those questions, Medicare and Social Security together.

Ruth—Have you or your agency trained any of your clients on using a computer?

Rod--Not in my office.

LW-we were in the midst of training one or two seniors to go online. We're in the process of doing that. Haven't done it yet.

Ruth—Are they volunteers or is it for their own use?

LW—Volunteers to help other seniors. Or to get information for themselves.

Ruth—You have already started this process?

LW—We haven't started it yet.[interest?] one or two so far. I have been trying to get a big group 4 or 5. Once I get that, then we'll start.

N—Last year they got a group of seniors, but this year they don't want to do it again, so the director brought up the issue, and only 3 raised their hands. Need more people. We trained them only to do basic computers, and the Internet as well. [how to use computer, how to get online] Last year it was 10 or 12 people. This year director needed more.

MRol—Kate tried to develop one, but it's not working {computers in addition to the computers we installed for beep'm}. The only ones that work are mine, the director's, and another coworker's. They had a room full of computers but they're not working. Kate tried to fix them, but they're very old, too. If it were it would have Internet access.

D—their situation would make it difficult, finances, can't afford, homebound. Depends on clientele; a lot are really ill, couldn't sit on a computer even if they could afford one. Exception—one woman is blind and uses a computer that speaks to her. She is the only client who actually has a computer.

- What were some of their concerns?

- What do you think were some of the obstacles to their using the Internet?

Rod—office where we work, we don't have the space

D—Initially affording one, if they're well enough. What type of …who your clientele is. People come to your center (to Miriam) Ours are different

N—At my center, maybe if we get a bigger space and they don't have to go downstairs to the basement. They don't always like to go to the basement. There are two computers in the basement but we need a bigger space, more computers [access] Yeah.

- What were some of the strategies you used that helped seniors to use the Internet? [access is easy. What else?]

LW—Big letters on computers maybe colorful, because a lot of seniors can't see
[large letters on screen]

LW—Easy access for seniors.
[No stairs going into the basement]

Rod—Maybe we need someone for the seniors to help start a course, make them feel that they will be together and in classes. So they have someone else to take it with. If they had the computers available, a few would be able to start.

- Do any of your clients have access to MI?

- How important is it to provide your clients with direct access to MI?

Improving MI

- Given your experience with MI, how would you change it?

- How important is translating MI into other languages? Which languages do you think are most important?

RO— Very important. Spanish—our center is Korean, Chinese, and also Spanish. It would be wonderful if they could do that.
Spanish (LW, Rol)

Rol—Russian also, Russian is also a growing population.

Rol—Spanish and English, for those who want to look on their own and can't understand English.

LW—It would also be good to have a few Caucasian and Chinese clients, Portuguese, Philippine, It's good to have other languages on the computers, easier for them to get into it.

- When translating, what should MRC take into consideration? (PROBE: important features and considerations)

LW—Having a person who speaks the language

N—Make it as easy as possible for them to be comfortable going through that information

Rol—Be brief. Break up the paragraphs.

LW—Have someone come in who speaks their language so they can relate better to that person.

Rol—In our center we have Korean and Chinese social workers which is useful for them to work with those clients.

- What cultural factors are particularly important when developing MI for other languages?

If there is extra time…
Information/Services Trends (not for Hotline) (MAYBE)

- In your experience, what are the current trends in information needs or services?

Rol—Getting access to benefits and making enough to make ends meet, that's a concern.

D-I'd say the premiums going up again, that's been a recent problem

Rod—Thinking that the future benefits, what is happening with social security, worry that it will go away. More years without benefits…
[clearly growing costs. What does the future hold for them?]

Rol—So many cuts, govt., the city, there are no funds. [Funding is it?]
If they're cutting funds now how will we survive in the future? They come in with heavy questions.

Rod—What do you mean? more people coming in, less funding, you need to be the sources of all information. What pressures on you in delivering services to clients? How are you handling that?

Rol—Our center is so huge, we provide services for so many kinds of people, 400 people on a regular day. Over 500 if there's an event. I'm the only Spanish case worker, also have Korean and, it's getting overwhelming, the number of people with all kinds of issues and concerns. For me it's really overwhelming. There are also clients who are just walking in. I've only been there about a year. It's a big increase especially since the card came out, the discount card, wanted to know more about it, when the EPIC came into the picture, EPIC workshop in center, they all wanted the discount, but it's only temporary, Don't know what will happen in2006 Seeing more of that.

LW-I just had instance where some of them complain about the Rx cards, how long it was taking to come. They get it and it's not what they expect so they want to drop it and go back to what they had at first.

Rod—People not qualified for Medicaid, Medicare only and want their medications to be covered I ask will they be able to cover the medications? The last few years, they are getting more social security and they won't be eligible for Medicaid, so their medication is not covered fully with A and B. Now they have EPIC or discount, they need money to pay for medications. I want to be able to find out if they can cover the medications fully.

LW—They have part a and want part b

N—Everything is about Medicare, the premium went up, if they apply for Medicaid, not eligible because it went up. They say I worked all my life and I can't have Medicaid, but other people have it

Rod—It's not fair

N—Yes, they say it's not fair. Working all their life and they have to pay for Rx. They apply for EPIC and even then they have to pay a lot

LW—I try to tell them their income is too high and they don't want to hear it. I have a client who is disabled and she needs a home attendant and she doesn't want to get one because she has to pay a portion. She refused to pay. She said, do you know anyone who can just help with this? I say no. She doesn't want to pay—other seniors say she saved that money for that, so she should pay. I can't do a thing. She says can you find me this and that? No one's going to do anything for free—that's what your money is for—fi you need the help, spend it. I couldn't do anything about it. I felt for her but I couldn't. [what can orgs outside your agency do for you? How can they help you do your job better?]

Rod—At the agency we provide housing services. Senior housing and disabled. A lot of places I call, they have applications, we have to find where senior applications are available. If you can work together to find these places. We have a lot of info, applications for sr. housing. People who have 800 and they find apt for 1400.

Rol—The waiting list can take years. I have a homeless client and they still make them wait. This is just public housing. They want a specific area

LW—They say "I don't want to go to Manhattan" It's always something with these seniors. Am I going to get like that?

Rol—I know.

D—Has social security return your calls!

Rol—They're very rude

D—I've been dealing with an office in Westchester and at first I felt bad, but I realized it's just how it works—nothing personal, you just have to wait 6 months.
[be nicer]

N—So many things. The main is the government—a good plan of participating for these seniors, especially if they're not on Medicaid. If I buy Rx, I have to buy less food at the market, they say. It is a big issue of frustration for the seniors.

Rod—Money through the agencies. If the agencies had more money, we could have more workers for the community.

BEEP'M Counselor Discussion Group
9/22/04
2:00 pm-4:00 pm

Good morning/afternoon. My name is Ruth. I am a communications consultant. I am conducting the evaluation of this project. How many of you have ever heard of or participated in a focus group? The whole purpose of this discussion will be to get your thoughts and opinions on the Medicare Interactive program. So today my role will be to ask you questions and to moderate the discussion.

There are just a few guidelines I would like you to follow

- This session will be tape recorded. The recordings and the notes that (name) is taking will only be used to write the final report.
- All discussions will be completely confidential. No one's name or affiliation will appear in the report.
- Please be open and completely honest. The results from these discussions will help to improve the Medicare Interactive program. So your opinions and experiences are very valuable.
- Please speak one at a time. This will ensure that we will hear everyone's comments.
- Please avoid any side conversations or comments. We all want to hear your thoughts.
- This session will last about 2 hours. Please feel free to help yourself to the refreshments.
- The restrooms are….

Introductions/Warm up

- Go around the room and give your name, affiliation, and primary focus of your program.
- What do you love most about your job?

TM—client advocate for GMHC Chelsea everyone is HIV+ some at risk, mostly HIV and AIDS. Helps with insurance entitlement benefit housing issues

EY--JASSI, located in Chelsea as well, senior citizen outreach coordinator/case worker. JASSI as a whole is focused on the Japanese-American community. Senior program is large within the org. Started with seniors. We provide social get together, case management, crisis intervention, benefits assistance, health, immigration. 9//11 community service, hotline for the Japanese community.

YK—Benefits for those who don't speak English, like Medicare Rights Center

TM—Love putting pieces of a puzzle together and call our helpline, more comes up as you're speaking helping to navigate diff. bureaucracies, letting them know what options are, empowering them.

YK—People who are worried can get benefits, Medicaid Medicare, when they can get that I feel very happy, they're happy, I'm happy.

EY—To be able to help in their lives and see the result of what we have done as an organization, fulfilling for my own heart, meeting with amazing people, seniors who live in New York from Japan for a certain purpose, to become an artist or musician, maybe a professor, someone who have had an amazing life, hear the life stories.

YK—Most people have their own Medicare, they don't have their own bank book, but now they have their own, gentleman visits our office and asked do I need another for my wife or do we both use one Medicare card and I told them that they need their own. They're happy to have their own thing.

Ruth—What questions are you asked? What services do you provide?

YK—Medicare doesn't cover that much now, they complain that Medicaid covers much more.

T—I would say people with Medicare and Medicaid, a lot of questions about how M. coordinates with Medicaid or individual insurance. A big issue, not necessarily. Number one

EY—Medicare drug discount card, publicized around June, people started to get confused about what it is and started to call us. Because it doesn't cover Rx, there is a need for supplemental insurance and they don't know what to pick or if they can afford it.

YK—Sometimes we have a problem with original Medicare—doesn't cover much, must tell them there's something else. Can't provide information because we don't know which one they should pick. They have to choose.

Ruth--What do you consider to be your strongest area of knowledge on Medicare?

E—We had a workshop for Japanese community about supplemental insurance, I had to study it a lot , so I can go back to the material to be able to answer some questions, if I don't understand it I can go to MI or call Kate. Hopefully I can be more independent. Using MI. I think it's really well made, resourceful. Those are the things I can somehow answer.

T—We were deputized by MRC to enroll people in MSPs. I can process those applications and I can keep that in mind if I'm meeting with people and their income is below a certain level.

K—Were you successful?

T—Yes

K—We tried but we weren't successful.

Ruth--Your weakest?

T—Specific questions—how many days in skilled home care—I constantly have to refer to BEEP'M or our handbooks

K-Don't know much about nursing home things, how Medicare can cover it. Mostly they cannot go with only Medicare nursing home—a problem with the people sometimes. A lot of people want to go to the nursing home if they are very sick and have a problem because they don't have Medicaid.

Ruth--What was the last change in Medicare that you remember?

T-Part D bill

E- Yes

T-The discount cards

T-The premium for Part b is being increased a lot.

K—SSI people getting Medicare Part A now—people who paid taxes for 10 years, how come I get Medicare A, usually they have only B, now SSI people are getting Part A. Doctors are complaining they're confused why people who never paid taxes are getting

A. They don't know how to use it. They are arguing with the clients, you didn't pay taxes why are you getting A?

Ruth--How do you find out about the changes in Medicare?

K-Customer came to ask with a letter or something changes.

T-Part of a group of NYFAC New Yorkers' for Accessible Health Care. I hear from their people from MRC often come, newsletters emails

EY-Emails from MRC, emails from the advocate movement, info from there

T-Newspaper

E-News, radio, public radio, especially now that the election is going on they're talking about Medicare

Ruth--Where do you get your information about Medicare? (When other sources are mentioned, probe for what they like about those sources.)

E-We have a newsletter that goes out quarterly, so if something like that comes up I try to collect them and put them in the newsletter, but we're not a center, so we don't have a place where seniors gather, putting a poster doesn't help in that way, so we try to put it in the invites for the monthly event or newsletter

T-We give out fact sheets and update them periodically, keep them posted in the health line area when people call, file it away, and hand it out when they walk in

Ruth--How did you first hear about MI?

EY-when I got this job. I got this job this year in January and met Kate she came in the office to see what's going on. That's the first time I heard about MI, we came to the

BEEP'M meeting and she came for the orientation for the staff because a new group of people came in, 3 or 4 people came in and she explained to us

T-Kate came to GMHC, supervisors explained that we would be using the new program, came to MRC for the training

K-Our director told us to go to MI

Ruth--What was your initial reaction?

K-It's good. I don't like to go out so I can sit there and use the computer

T-I wondered if it would answer the specific questions my clients have because they're not seniors and they have HIV issues, special population, would it address their needs

EY-I felt like MI was underused by our clients, mainly because of Japanese language, and computer skills clients don't have access to comp and don't know how to use it, don't speak English, if it's in English, speakers themselves have trouble figuring it out, so for foreign speakers, wouldn't be helpful, That's why we came up with the idea of the workshop to put it out there
[Concerns?]

K-We sometimes people with Medicare don't have coverage for Rx, they're worried so we're worried to. It's a problem. We can't recommend any programs, ask primary doctor to recommend something.

Ruth--Did you receive training on MI?

Yes. (all)

Ruth--Describe the training session.

T-Useful because we practiced going into the diff areas, interactive part, linking up with other resources, hands on is good

K- I went to Medicare computer training too. So that was useful. At the same time, technology computer school, two sessions. Learned the computer first and then started using MI. It was good.

E-For me too the hands on part was a good thing, it was a small group in my office so she was helping us to navigate.

Ruth--When you left the training session, how well prepared to use MI did you feel?

T-I felt well prepared.

E-I still felt like I needed to learn a lot about Medicare in general because I wasn't knowledgeable, there was a lot of info I needed first to navigate these things, like what to look for, like when you go to index and there are diff subjects, if you don't know about what those subjects are I don't know where to go. As I spoke with clients and really, with Kate's help, as I used it more, go used to the program and now I feel more confident. Right after the session didn't feel confident.

Ruth-- What do you think could be done to make the MI training more effective?

E-I think the training was good. Just my part, I needed to learn more.

Ruth--How long after the training did you first use MI on your own?

T-I would say the next week, right away. WE get a lot of calls on our helpline; I remember trying to go on a lot print things to give to people. Good at describing the basic areas and then dig in get really specific things.

K-When I have time I try to go on the computer, see how they give information. Right after when I have time

E- Not right away—I'm part time and I deal with a lot of diff issues, not just Medicare, organizing events, when there's a need with a client I research using those tools, but not a daily basis, the first month after the training probably I went on MI a few times.

Ruth--What motivated you to start using MI?

E-The phone call, questions, they come to us thinking we are the one to turn to so I feel like I should be able to answer. If I can't answer right away with the tool, I answer if I don't know enough I call back. If I don't find it on the comp call Kate and call back.

T- When they ask specific questions about coverage HMOs, I turn to that

K-Nothing else in our office, so if we have questions on Medicare, that's what I turn to.

T-The computer is on my own computer but in a separate computer too

K-In my office.

E-In my office.

All—2-3 times a week.

E-Depends on the week, 2-3 maybe once a week.

Ruth--What types of materials do you give your clients to take home?

T-Packets of info, print outs from DOH, D of Ins. Stuff printed from BEEP'M

K-Nothing. Just answers from my mouth.

E-Newsletter, senior news, different pamphlets.

Ruth--Have you ever given them anything printed from MI?

T-Yes

E-Never

K-They cannot read English

E-That's true

Ruth—It changed ability to serve.

T-I can find the answers immediately and not just say I think but I know
Helps to have in writing from a good source

K-I can say ask a question, and not just say I think, but that I *know* everything

E-Like in her case, clients don't have internet access, or the language, I usually interpret for them, in that sense I have more tools to serve clients, but cannot really give them the user ID and password so they can start using it. Not so much opportunity for that.

Ruth--What level of knowledge of Medicare is necessary to get counselors to use MI?

T-I think you may need to know what questions-many clients need to know what Medicare is, the might be able to find out , it starts out with a brief overview, I think it would be ok for most of my clients to go in without knowing much about Medicare

Ruth--What do you think a center needs in order to successfully implement MI?

E-In terms of staff?

T-Training. The training that we had at MRC.

E-Training

T-The manual

Ruth--Did you get any help or support in using MI?

T-Yeah, I did

E-All the time

T-I emailed and they email you back. Couldn't find things in search engine and they would get back to us

E-I tried to call the MRC hotline, but I couldn't reach a counselor because of the time or busy, so I said it's faster to call Kate.

Ruth--Have any of you ever used the MI User Manual? (PROBE: topics consulted) Did you find it helpful?

K-Yeah, I have used it

E-I think I used it for training, to go through

T-At the beginning I used it, brought it today. Initially to figure out what I could find in

MI-What was available.

Ruth--What did you like the most about MI Counselor? Why?

T-They list commonly asked questions helpful because it gives you an idea of what you need to explain to clients.

E-Different steps, if you go to index, choose topic, they give you another series of choices to get to the specific choices, guides you to more specific points.

Ruth--What was the most valuable feature of MI Community? Why?

K-Not much

E-No

Ruth—What about the feedback button?

K-Sometimes we need it but I didn't use it b/c they might need that…

Ruth--What about MI Local Services?

T-yes, it was helpful for referring people to diff local services. You should just be able to print it out and say here's the number. Easy to use

Ruth--Have any of you used MI University? Which course did you take? Was it helpful? Did you take another?

E-Yes Supplemental insurance. Also printed some material for director and state program-EPIC used as a handout.

K-Because of the medicine. Not that useful when I tried. At the time was not detail but I don't know now. Not enough detail

Ruth--Have you ever used MI Help? What did you like most about it? Least?
No (all)

Ruth--When you have to research a problem, what resources do you use?

T-Mainly to my coworkers, or I make a phone call. HASA—HIVAIDS services Administration. It could be someone's case manager, other Community Based Organizations, Medicaid, and Social Security.

K-Computer, discuss with computer, get answers from there we don't have that many serious questions. We call somebody, and use the telephone book.

E-DFTA. Different resources about housing or health, jobs for seniors. I call them and NYC.gov website for NYC offers housing information, low income housing, different projects they offer. We have an Asian organization booklet for NYC area, Asian legal defense education fund, and free clinic for legal advice, Immigration or labor law, special …other organizations have free legal sessions at diff sites, give us the calendar, they can walk in and talk about it for free for a short time

K-311 for everything

E-Yeah, 311 too

K-Don't use it but I know I can if I need it

E-Sometimes around in circles, call 311, they send me here, then they send me to here and they tell me to call 311

Ruth--What do you like about having access to information online?

K-Saving my time

E&T-Yeah

T-You can find contact info

E-You don't have to know that certain information to get there, you can Google search and it will give you all the places, then if you want phone book you would have to know category or organ name, with Google you don't have to

Ruth--What don't you like?

T-When you don't have a person to speak to live, you wonder if the info is current and you have questions a lot of times, people's home page; it's hard not to be able to interact

E-Talking to someone on the phone with a live person makes me feel more confident than going through with no interaction.
[You can ask questions]

E-Specific questions and they can answer specific to this case.

K&T-Agreement

T-The computer is slow, frustrating when it freezes

K-True.

Ruth--What are the strengths about getting your information from the Internet and hardcopy resources? Weaknesses?

K-We can save it. We cannot make the computer, have to print all the time, with a letter you can save it

E-You can print out, don't have to make copies (with the Internet)

T-Can easily refer back to it, don't have to remember to cut and paste

T-It becomes out of date, becomes old news.

E-Rigid. With internet, the interactive, you could give us the choice as a provider. If you want to do this, you can click and go to a new site. Hardcopy, one story and answer question, then a second chapter to explain something else.

Ruth- You have to wade through materials.

T-If you work in a large office, someone can hold onto it and you won't be able to find it again.

Ruth--Have you or your agency trained your clients on using the Internet?

T-Yes. It was fun. Interesting to teach them how to use the mouse and it went well.

E-No-not in our agency as far as I know.

Ruth-What were some of their concerns?

T-That they wouldn‘t remember what I was telling them so they would want to write down every step. They were easily frustrated.

Ruth --What do you think were some of the obstacles to their using the Internet?

E-If they own a computer or not. If they have to go to internet café, extra trip or money, fear of computer. The elderly don't want to deal with machines, want to deal with people, call get answer from a human voice. Difficult to erase.

T-Intimidating

Ruth--What were some of the strategies you used that helped seniors to use the Internet?

T-Instead of doing it myself, I get them to take the mouse, show them something quick and simple, so they say I can do this, this isn't so difficult.

Ruth-When you used it what made you more comfortable?

E-Having someone right by you, knowing you can ask if you get stuck.
[Kenya?]

K-No training for seniors in the center. You get all the answers that you need, right away. It's really helpful.

Kenya—I use it about 2 times a week. Most seniors are more into the Medicare Summary. Where have they been? What they've paid for? I look through it myself to see what's new. They're mostly into the MSN

Ruth-what would you change about MI to make it better?

Kenya-Nothing

Ruth- Anyone else?

T-Specific things, I'll go to the Go To box and I can't find what I'm looking for or it won't be worded in a way that I can find it easily. Maybe it could be made clearer.

E-Translating it into another language.

Ruth--How important is translating MI into other languages? Which languages do you think are most important?

E-Very important at least Spanish

T-Very

Kenya-Spanish at least, mandatory

E-Chinese

Kenya—I think they should have every language.

Ruth--When translating, what should MRC take into consideration? (PROBE: important features and considerations)

K-Medicare persons will not use Medicare Interactive. For one they're old don't like machine things.

Ruth-Already for Koreans resistance because they do not like machines.

K--Mostly they don't like to look for information through the machine. They like visiting us. We have misunderstandings sometimes, even in Korean language.

Ruth-If it were in Korean, would you use it?

E-Yes.

Ruth--Would you use it in other languages?

T-Yes, printing it off to mail it to them. Handing it to them when they come in.

Kenya-Yes. I would be too all the time.

T-Exactly. Find the Spanish version and print it off

K-Even after the computer, they would have questions of us

Ruth--Even if it's in the language and they have the material, you still need to go over it with them, sit down with them.

Kenya-You've got to break it down, this, this and that

K-Short, simple easy words.

Ruth--What cultural factors are particularly important when developing MI for other languages?

K-Yes. Old people think they cannot use computer because they are old.

Ruth--General resistance for the aging.

K-In US, older people don't think they're old, but in Korea they think they are old and should not do that.

Ruth—Anything else should be kept in mind about your clients cultures?

E-Translating can be challenging because in Japan people used to be treated as God, customers, and you have to use certain terms. English is more direct, you use one term for anybody. In Japanese, all the different ways of using different terms depending on whom you are talking to.

Ruth—They have to be mindful that whatever you're saying you need to say it in a way that would show them respect. It has to be clear.

K-Yes.

E-Right. Still it has to be clear I have spoken with a senior's daughter who needs Medicare coverage but she's comfortable on a computer and I gave her the user name to go on herself. It would be easier if it were in Japanese and she doesn't have resistance to the computer. Easier if there were the language.

K-If we tell them to use the computer they would think it was very rude. You are not kind to them.

Ruth--Yeah, go get it yourself. They came for human contact.

Kenya-Yeah, that's true.

Ruth—Let's give Kenya a chance to talk about her experiences with MI. Likes? Dislikes?

Kenya-I like everything. It's not only Medicare, they have housing, the toolbox has a lot of housing. Other programs.

Ruth--MI Local Services?

Kenya—Yes. Local services. I like when they update it, something new is coming out, they come to me with a letter and they say such and such and I look in there and it's updated. I can't complain.

Ruth—Is there anything they can do to improve it?

Kenya-- It was fine.

Ruth—Anything about the training

Kenya—No. It was fine.

Ruth-What are the emerging needs of your client?

E-In general?

K-When they go to the doctor, the doctor denies service will not do anything for them. Recently it's happening now. Fewer doctors receive Medicare. Some don't take Medicaid

Kenya-Yeah they have problems. They bring the benefit card, but ii doesn't pay all of their coverage and they get a bill and they don't understand why. I ask them do you have Medicare. So they have to show the Medicare so it will pay the other part of it. They don't understand one part is this, one part is that, not the whole thing in Medicaid. That's the same problem every day.

Ruth—Do you see any other changes in the last year?

T-More people coming in unemployed, getting laid off, uninsured, can't hold on to their insurance through COBRA because they didn't realize there are programs that could pay for their premiums. People who work for the city and their coverage aren't covering the yearly cap on their HIV medications. A lot of people who are underinsured or uninsured people

K-More Korean people with only Medicare so they have to look somewhere else for medicine.

Ruth-- What do you think is coming next? Anything that you notice may become a bigger problem?

T-The confusion around the new Medicare Part D bill and for people on Medicaid what that will mean. I can see people not understanding. Wondering what will that mean to them.

E-National deficit. No coverage, Medicare not existing. The future of social security. What's going to happen to the aging population?

Ruth—If you were to talk organizations, government agencies, funding agencies in general, what can they do to make your job easier?

T-Policy reform.

E-Funding.

K-Make it easier to file and process Medicare. It would make it easier to explain things to them.

Ruth—Anything else? This may be your one chance to let Washington know.

(laughter)

K-The thing they need insurance from 62-65. They cannot see the doctor because they can't pay. They are talking but they haven't done anything. Why are people with SSI getting part A? They have Medicare B.

Ruth—Is it possible they are being enrolled in Medicare Saving Programs?

K-I don't know. Medicare A usually is for when you pay over 10 years tax.
I ask around and no one seems to know why they have Medicare A. I've been getting a lot of complaints about this.

Ruth—Is there anything else? Thank you for coming.

BEEP'M Hotline Volunteer Discussion Group
9/28/04
2:30–4:30pm

My name is Ruth and I an independent consultant hired to do Medicare Rights Center (MRC) project. We're here to talk about the MI project – using the information to improve the system as we roll it out to other communities. Your honesty and your comments are invaluable…introduce yourself; tell a little bit about the day you volunteer, a little bit about your background.

E: I've been a volunteer for 2 years, I'm retired. I retired from Tokyo Insurance Corporation, the largest insurer in the world. Prior to that, my husband and I had our own business; a limousine service.

Ri: I retired from federal government in June and started at MRC in late June. I've been working originally Tuesday and Thursday but a few weeks ago I changed to Monday and Tuesday.

R: I work on Mondays; I've been a volunteer for 6 months at MRC. Prior to that I studied law. My longest job was as a waitress.

H: I worked as a CPA for over 50 years. When I retired, someone suggested MRC. I've been doing this for about 5 or 6 years. I either come in Tuesday or Thursday. I find it very satisfactory – most of my satisfaction is from the people I talk to.

Ruth-What do you love about your job at MRC?

E: Helping people. Some people seem to be so confused. I'm confused myself, but not as confused as they are. It's a good feeling when they thank you very much for helping them.

R: I agree. I love the people I work with. Really intellectually curious and good-hearted.

H: I have a strange feeling in the morning when I come in. I'm a bit nervous even though it's been 5 years. When I go home in the afternoon, I feel different it's just great. Knowing that you can help someone.

Ri: It's almost universal. Some are more expressive. Some are more appreciative. It's almost as if they're amazed to hear a human voice. They're used to calling doctors and Medicare and waiting and waiting and hearing recordings, pushing buttons. There are many questions we can't answer immediately; I tell them they may have to wait. It's practically never been a problem. They're always so patient because they feel they're getting personal attention, their question requires a bit more investigation. I'm contributing to helping people who are in desperate need for the best information that they can get. I get a lot of satisfaction out of it.

Ruth--General knowledge about Medicare? What questions do you get asked more often?

R: Supplemental insurance. The person has Medicare and would like something to supplement coverage. That's probably the question I get the most and then typically they've called 1-800-Medicare and been given our number. Sometimes they don't even know the name but they know there's something out there that will help fill the hole.

E: There's also a tremendous amount of calls regarding prescription coverage. That's what I find to be the most Frequently Asked Question (FAQ) to me.

H: I find that too. Possibly 50% of the calls have to do with Rx. Maybe half of that are from people who are disabled who can't get into the NYS EPIC program.

Ri: It's a wide assortment, but usually there's at least some confusion, they know enough, they have some basic information down. Most cases they don't know the difference between a Medigap and an HMO. Not in all cases is the person in financial difficulty, one way or another, sometimes they fall through the cracks. Their income is just a little over the amount. They're over the government limits, but not really enough to survive easily. It's going to be a struggle. I can't say it was common, but there were 3 or 4 calls in a few weeks where a treating physician recommended them to Sloan-Kettering, which has the best reputation, and only finding out at that point that they can't use their HMO, so then they're looking to get something in place so they can follow up and get the medical condition treated. There are very few people who can pay out of pocket.

Ruth—What do you consider to be you're strongest area regarding your knowledge about Medicare?

H: Medigap is pretty easy. Everyone knows that's the supplemental plan and we have the list. What else is very simple…also you can be on Medicare, A & B, but if you join an HMO, you're off of that. I think people are getting to know that. I think those are the areas that are very simple. One question is finding out what kind of other insurance they have. They say, oh I have Blue Cross Blue Shield (BCBS). First find out, are they paying the 20% that Medicare doesn't pay? Then you know it's a Medigap.

E: I think basic knowledge of A & B. I feel very secure when I talk about that.

Ruth—What area your weakest area?

E: Where a person is having a problem with their billing, that's where I kind of get a little shaky. We refer them to…it's very complicated. I refer it to a case worker, the supervisor.

H: I also find it's hard to get people to understand why they can't get home health care. That they must have some skilled nurse come to their house, and then they can get their

personal needs taken care of. They say, “But I can’t do anything, I can’t get out of bed.” It’s not understandable to them that that’s not called home health care.

R: COBRA is a little difficult to get my brain around. How it works. If there’s a couple that’s one is retired, one’s not. Sometimes a caller, they speak for three minutes, give this data, it’s hard for me to sort through, get dates and coverage sorted out.

Ri: I think Medicaid, even though we’re not the Medicaid Rights Center, we do have a certain % of clients that income is low that they qualify for both. I’m not that familiar. When people have both, how do they interact? The other thing is…it’s common for people that are close, their income is so low, so close that they have to spend down. The economic may not be so hard for them to do, but the stigma. Medicare you could get at age 65 if you’re a millionaire or a pauper. There’s no solution, but occasionally it comes up. This afternoon…there was a therapist calling on behalf of a patient, she had to spend about $200, she was having difficulty making ends meet.

H: I sometimes find that determining primary and secondary coverage could be difficult. I have a chart in front of me to acquaint me or refresh me.

E: The areas I feel comfortable in: the various MSPs. I feel very comfortable counseling on them. Also people that don’t have insurance or are underinsured – we have lots of literature and resources to help them. I feel comfortable with them too.

Ruth—What’s the last change in Medicare that you remember?

Ri: Last? It’s always changing.

R: The announcement that the Part B premium would be $78.

Ri: I think when I came in June, it was discussed, but when it was announced two weeks ago, it was a big surprise to 99% of the population. I haven’t been really involved in the experimental drug program, I read in the paper. They estimated that there would be so many people trying to get involved, but there’s only certain categories, they’re offering now, they figure it’s going to have to be a lottery, but nobody knew about it. There’s so much going on constantly that it’s hard to keep up with it. I can just imagine what it’s going to be like in 2006.

E: That’s basically the same, that the Part B is going up, I think in 2005 the deductible is going to be $110 rather than $100. We get a lot of questions about the discount drug cards. I do presentations on this particular subject with my partner. It’s so totally useless for anybody that is above the income level where they would get the $600 loaded on for this year and next year. I always try to tell people, you know, I send them our discount drug chart; ask them if they have access to the Internet, try ordering drugs, you get just as much discount from Costco or the other big chains. I get questions on that. When we do presentations it’s like, Shoot the messenger!

H: One of the last changes I remember is I'm not sure whether there is a cap on physical therapy. I think I read that it has to be renewed in 2005, that it will expire. You're always waiting for some deadline.

Ruth--Where do you find out about changes?

Ri: We have monthly staff meetings that covers changes in Medicare, changes in our procedures, somebody's doing…in some cases it's an official change's in some cases it's internal to MRC, changing our procedure. I subscribe to Dear Marci and to…I can't pronounce it [Asclepios?] It always starts with, Ouch! We're there to be advocates, we're not supposed to be telling people, call your Congress about this, change the world! We're just trying to put Band-Aids on them.

H: We also get a Volunteer Update; I think it's put out by MRC that sites all these changes. We get it in our mailboxes. Informed at meetings.

R: One of our changes I found out through a caller, they received something through a Florida company about MSPs, they were suspicious…apparently HMOs get a benefit if they sign people up, get a higher reimbursement rate. Even from callers you hear about what's going on.

H: HMO's reduced their charges per month because they were getting more money from Medicare, in order to get more customers; they reduced their monthly charge for their HMO plan.

Ri: A lot of them have no charge, I think they highest is…
[group discussion]

H: in NYC five boroughs, at least 5 or 6 are $0.

Ruth-Where you first heard of MI?

E: At the office.

H: At the MRC, our manuals that we had were heavy with all this information. One day, removed. We were told we were to use the screen to access any questions we had.

Ruth-Were you warned the books would disappear?

E: Yes.

H: Yes.

Ruth--What did you think?

H: I thought it was a great idea, I'm very computer oriented. I would just type in and everything would be there.

Ri: I came in June, it was there already. If our days of training, I think a whole day on MI. More emphasis on the content, to learn the type of questions, but there was some procedural, this is how you log on. I didn't have that comparison. We still have blue books that probably duplicate some of MI. There are listings of where Social Services Department offices are. They supplement each other but in some way they duplicate.

E: The other books, they were this thick. The other books we used to have our names on. That's where I started. Even though I like getting on the computer that was a kind of crutch at first. Now I'm weaned off it.

Ruth-What impressed you?

H: Everything we had in the manual, if you knew how to go about it, was in MI. I made an index for myself. You know, which category to GO TO if you wanted to find about COBRA. I made an index of everything I could possibly think of and eventually found it on MI.

Ruth—When you are looking for a topic, say COBRA, first you refer to your index, then you get online?

H: Yes. There's Cobra overview for point F in question 1 or 2 so I can go directly to it. I can go exactly where I want to go.

E: To add to that, I know Harold initiated this, but we all use it now because we've all gotten copies of this because it's so comprehensive. It's really excellent. I have a copy, there's a copy in the blue books. I carry it around with me.

H: I imagine it could be enlarged, cross-referenced, whatever.

Ri: I haven't used MI as much as I probably should be using it. I'm into using computers but not that much. Using the facts that, basically after a certain point I'm going to know if it's a simple thing, what is Part B, what is a Medigap, I could answer. In most situations I find if it's a question that I'm stumped with, I GO TO the supervisor; they either tell me directly or GO TO someone else. The staff has specialties…whatever it is. I realize I'm not using it as much as I should. In some cases, it might be that it's so unique I'd be doubtful that it could answer the question…I do know that one thing I was doing wrong…I was going to the index…when I did a search is I only went to the first screen, that's a common, simple computer mistake. It seems to always give you the glossary first. If it's not such an obvious one. The first screen may not be addressing the particulars. The glossary may not even have it listed. It just says GO TO Glossary.

Ruth--What were some of the concerns?

H: I felt if I didn't put in the right word in the search box that it might not understand that word….in here I have the words primary and secondary, you can go right to that.

R: I thought it was fantastic, it was a didactic tool, it was so well-written. They said it was written in a way you could read it to the person. Often, if the person is educated and savvy, they know if you're reading to them, they don't want that, they just want someone who knows. I don't know what way MI will be launched. I find as a hotline tool, it's less than effective. Part of my job is to make the person feel comforted. I can't comfort them if I don't know the immediate answer. I think the person on the other line feels a little bit nervous…I think they want someone with a little more experience. I like it as a teaching tool, but as a hotline too….if there's something complex, it won't be there. If there's something basic, you'll know it. Do you know most of the stuff?

E: Most of the things that people ask as you say, you don't even have to GO TO MI. Certain things that I need to look up, I get a little frustrated because I'm not able to access it immediately. Usually your supervisor will come right over and zoom to it.

H: I mentioned, you're talking to someone and you have to type in, it takes a while, you feel frustrated because someone's waiting. We've been told when someone calls any agency they have to wait. I'm feeling better about having someone wait while I look it up. But they don't mind. People on the phone have never minded waiting. I can have them wait while I get a specific, correct answer.

Ruth-So you're finding that in people don't mind waiting?

All: No.

Ri: People know that you're trying to assist them. You've probably spent 5 to 10 minutes listening to them. Sometimes 20 minutes. After that amount of time they're you tell them you will have to get back to them and they are perfectly content. They're used to waiting, hearing music, getting a recording and waiting forever.

Ruth-Tell me about training.

E: Harold and I probably had the same training. We went in and we had several hours that Betty went over the whole thing, plus we had the very comprehensive book that she had given us. How to navigate through MI. So what you didn't remember from the training session…I still carry the book around with me. I thought the training was very good.

H: The one I used mainly is the MI Counselor.

Ruth—Let's get back to training. Tell me a little more about it.

H: I'm very familiar with the computer in my accounting practice. So I like doing that, I like finding things more quickly, so training was interesting and it introduced me to it.

R: A PowerPoint presentation from Betty maybe? We all sat around the table and she put up the screen and would walk us through it, she tried to simulate problems, she tried to use the GO TO box to show us how to link out of MI. She would make a case scenario, one that they actually had. She showed us in the search you had to use the exact word. She tried to show us the benefits but also where it might frustrate you.

H: I think we had a practice set. There were certain things to find, see who could find it.

Ri: You had hands on?

H: Yes. We all sat around with a sheet full of problems.

Ri: The use of MI to answer questions, there was a projector there where it was shown, but each one of us didn't have access.

H, E: We did.

R: Did you all use the computer afterwards?

Ri: Only to log on. I know that Betty had to be out that day, she was lobbying city hall to get us money. The person that took over, there were a couple areas that she wasn't really that familiar with.

H: I used to rely very heavily on the manual because I knew just where everything was. I was very disappointed when I heard Betty had taken them away. I was distraught. After a week or so, even now, I could never even think of using it.

Ri: But if we're giving someone advice to give to somebody, it's not, use this HMO or that, if you're just going over the options, going over where they live in NYS, what options they have, I don't think that information is on MI. I find I'm only dealing with it only to give people an idea of what their options are, what the plans have to offer and what they're looking for.

Ruth—Did you get any help with using a computer?

Ri: There are many questions I could answer myself. Some questions I GO TO the charts. I had a question that I answered on MI just yesterday. It's not the first time, I knew the answer was going to be there. It was just a question of skilled nursing care.

Ruth--You GO TO MI if you know the answer is already there?

Ri: I know if there's a chance it's going to be there.

R: I think there are a few volunteers whose computer literacy prohibits them from being effective computer users. I've spent much of my time showing them how to be a

computer user. Not so much with MI, but with the basics of computer usage, maybe that might be lacking as far as the training is concerned.

Ruth-When did you use MI on your own?

R: Right away.

H: I practiced at home. It's from that that I made this index. It took a number of hours. I did a lot of studying at home on the actual MI.

E: I have a computer at home, too. I used it right away.

Ruth-How long after the training did you use it?

E—Right away.

Ri: I have it there, and I use it occasionally, but typical call, no. Either I know the answer or I'm going to the supervisor. This question that I had yesterday…the number of days was an issue, and I looked that up. What was the question?

H: I used another technique, if someone calls and asks a question, I call them back after rather than have them wait. I've gotten the answer on MI. They're very appreciative that you call them back.

Ruth-Did you find anything confusing? Terminology? Search techniques?

E: It takes longer to zero in on what you're looking for. Once you've done it a couple of times, you've got it in your head.

H: It might mean that the terminology needs expanding. Maybe expanding that area would make it much smoother.

R: I find the GO TO boxes confusing sometimes. If you're reading the text and it says GO TO then you'll look over and there'll be a laundry list of topics, it seemed like there would be a clearer correlation. There were so many topics.

Ruth- Are they all related?

R: I would imagine.

Ruth: But you don't know the relationship. Sometimes you click on it and it's not clear.

Ri: Sometimes the GO TO from the main screen you would know that this question is about Social Security, or the VA, because you have a question about a veteran, so you might know that you're going to a VA site or a social security site. But sometimes the GO TO is not really clear until you click it. I don't know if the problem was in MI, I saw

it there and I was confused. When a person gets Medicare and has insurance from an employer, I just read that in a way, I think it was me, I thought that if they had continuing insurance coverage from an employer, then they don't have to get Part B, but if they have part B their employer isn't going to carry it. I know I looked at it in MI; I just had a false impression of what the practical side is.

Ruth—The response did not give you enough detail or was unclear?

Ri: I got the impression, incorrectly, that you were exempt from the Part B penalty...it's more of a practical thing because no former employer is going to be your primary. I found something in the concept or the wording that was confusing.

H: (corrects Ri on the concept)

E: (more correction of the concept)…we're getting off topic.

Ruth--How has MI changed your ability to serve your clients?

H: We don't have a big fat manual, which is much easier. Sometimes I couldn't get the pages apart. They were not all lined up exactly right. It was very hard to turn the pages.

R: You think you're quicker?

H: I think so.

R: I've only had MI.

Ri: Same.

R: I've only had this happen once. It might be a fluke. I was reading one of the pages in MI but it sounded incorrect to me. I asked around and they all agreed with me. It said New York but it was not New York's data, but the national, somehow there was a glitch. There's a woman who is in charge of MI at our office and she came out and set it on to say Oklahoma, then onto New York and it was okay. That could have been…had I not asked I could have given someone wrong information. I guess with computers there is always that risk.

H: I don't know how frequently MI is updated. That seems to be important. We get this volunteer update and I want to inquire, when does that get into MI?

Ruth--Was there ever information in a piece of paper but not in MI?

Ri: I depend on the paper, the charts. Is that accessible through MI? Medical Saving Programs? SSI?

E: Yes, it's all on there. The thing is it's easier just to pull the information out of the cubbies than to start getting on the computer.

H: That's paragraphs 6c, questions one to five.

R: There is a feedback mechanism. If you ever learn something you can just type off a little note to whoever updates it.

H: (agreement)

Ruth--You sometimes send printed material?

E: Fliers, discount drugs cards, tips on applying for MSPs, sometimes when you speak to someone on the phone and you start rattling off what their income should be, in order to get this, that or the other thing, it's easier to follow it up with the actual information that they can see it with their own eyes.

Ri: In some cases, the caller may not really know that they're getting the Part B taken out of their Social Security check; it might put them over the top. We send it out any time we're discussing drug charts, Medigaps, HMOs, we sent the material to them so they have the numbers, the list of companies. They could give the impression because they're not really clear themselves that they could qualify but they don't really qualify.

R: I would guess maybe 10% of the time I print something out from MI and send that. If it's an explanation of how HMOs work. Very rudimentary…I imagine people would be appreciative to read that.

Ri: Sometimes it's cases, right? It may not be 100% a person's question; this may be as close as practical to meeting their certain situation.

Ruth-Have you printed off of MI?

Ri- Yes.

E: Very rarely.

H: Not frequently, but I have printed from MI. They have something in print, they believe that it's true. Particularly when someone else has told them differently.

Ri: When I use MI…one reason is if we don't have a printout. Every once in a while we get a question about the appeal process. If we don't have a chart, I would #1 use MI, then I might want to tell someone, make sure it's 120 days from the notice, not from the day you were released from the hospital. I would use MI to get information about the appeals process.

Ruth-How much preexisting knowledge about Medicare does a counselor need in order to use MI?

H: I think it's like anything else. If you don't know how to spell the word you can't look it up in the dictionary. You have to know what you're looking for. You have to know something about it, what word to look for in an index or anywhere.

R: I speak from experience having had no knowledge of Medicare other than the training, I found that I would use it more slowly. I would go through the topics, often with the caller on the phone, saying, oh that's not right. I was teaching myself and finding out how to use MI at the same time. As a pedagogical tool, I think it's good. It walks you through it.

Ruth- Not only as an information source but also as a training tool.

Ri: I don't think you could just throw it at somebody without assuming or knowing that they have some basic knowledge. I think they have to have a minimum of 1 to 2 days of training, preferably face to face, on what Medicare is, how you qualify, age, disability, you could say it's duplicating what's in there, but if you don't have the basics…I think a lot of people do, but if you don't, I don't think you could assume it, and just give someone MI and say you're an expert.

E: Previous knowledge, I think it's extremely helpful. Obviously Rel has managed to overcome her lack of knowledge with the MI but…you just approach it from a different angle.

H: It's starting something you know nothing about. For example, when I wanted to get on computers, I wanted to know spreadsheets, so I got a book on Microsoft Excel. I only get that information from reading and trying each step….Possibly someone could go in pretty cold. It might take a little longer, but, they could do it.

Ruth-Anything that could be added or changed to MI to make it easier to use and navigate?

Ri: We get a very small % of calls from other states, but if they're asking about info about HMOs and Medigaps…I don't believe that's in there now. I don't believe there's that much of a need for it for us. We're the SHIP for NYS, but we get calls from Florida. I don't think it's a problem to do that [refer people]. We shouldn't be expected to know about every HMO in the country, it would just overwhelm us. Listing the SHIPs is probably good enough.

Ruth--MI components. ..which do you use the most?

H: MI Counselor, 90% of the time. Although in more recent months, I found out there's a section with various sources. For example if someone wanted a Medicaid doctor or a

place to go for dental work there's a section with lots of places to go. Now I realize that's accessible and can be used quite well.

E: MI Counselor. I use that the most.

Ruth--What do you like about MI Counselor?

E: Everything is there.

R: It's an outline.

Ri: The outline, everything is there. I should probably do what Harold did and see that there are other sections. But there, I had the index page set up on my computer, because if I am going to MI, I'm going to go to that or the search. I haven't really explored what was there. It's a drawback on some respects.

H: I was talking about MI Local Services which is fascinating. I've used it infrequently but I have gone to it.

R: I've used it. I alternate between that and using the search engine on the Internet. I've noticed that it's easier to use Google.

Ruth—When do you decide which is easier?

R: That's a good question.

H: How do you use Google?

R: I had a woman call about ALS. I knew that I could probably find information about a local ALS group but I went with Google because they probably had a national chapter. On the MI counselor, that's the one that comes up with the topics, I think my biggest problem with that outline is that it's not detailed enough. It's made so compact that something like what you've made (H) should somehow be coupled. When you click on a subject heading you have to keep clicking. I find that very inefficient. They had wanted to make it so plain or navigable. I'm not sure why they made it so truncated. You really have to dig once you get inside.

E: They did that to follow the book we used to have.

Ri: So you're sheet that lists alphabetically by topic is that in our blue books?

H: I think I would say, this might be enlarged or incorporated in some way, maybe scientifically, someone who knows how to make these things. I find now that you mention it, many people call, they know a lot about Medicare, but they don't know where to go for a service. Fro example, dental care, they don't know where to go, who to call. That's where Local Services comes in handy. It lists many places

Ruth—Have you ever used MI Community?

H: the feedback, yeah.

E: No, I've never used it because I'm already on Dear Marci and I don't have much feedback.

Ruth-How about MI University? Has anyone taken any of the courses?

E: I did the whole thing. It takes about 25 minutes or 30 minutes, yeah, I've done it.

Ruth—What did you think about it?

E--I thought it was very good. I did it basically because I do presentations; I thought it would be an aid.

H: What is it?

E: It tells you how to do presentations, that's what I used for.

Ri: Is it more geared for a layman? To just go out to the public and just cover in 20 minutes what Medicare is or what the options are? Is it more for the public than for us?

Ruth- Is MI University more appropriate for the general public or for volunteers/counselors like yourself?

E: I would say it's (more appropriate) for counselors.

Ruth- Did anyone use MI Help?

All: No.

Ruth—I would like to talk about technology and the Internet in general. When you research a problem, what resources do you use?

H: I go to a search engine, I normally use Yahoo. I put the words I think are the most appropriate, and 99% of the time I get what I want.

Ri: If you're talking about dentists, I have my own dentist. I would go what type of dentist do I need, who recommends it.

Ruth-No no, more about content, where would you go to look?]

Ri: I would use the computer, WebMD, I would do a search, (depends on what kind of information I'm looking for). It depends on the facts.

R: I use the Internet and I go to the library. I go to nonfiction and get that book on X topic.

E: If I want a real quick fix I use Yahoo. Otherwise I've got a lovely set of encyclopedia Britannica's.

R: I rarely call people because I find most of the information I get from people on the telephone is not believable. I think it's very hard to find someone who's willing or capable of giving you what you need.

H: I've accumulated about 150 favorite places. I've got categories, you know, "Medical," under that I've got the NIH, where I get information about health, diseases. So I can go fairly quickly to a site. I have several dictionaries that translate from one language to another. It's one of my favorite things. But that's me because I like to put things in little piles. Only on the computer.

Ruth--What do you like about the Internet?

H: It's quick. With the setup I have I can go to something within a minute and get a reasonable answer by some authority. I have my computer on all day long. Since it's on and I live in an apartment, I can go right to it. We sometimes (look for) answer on the crossword puzzle. (laughter)

Ri: I think it's good but it's…you have to sometimes take it with a grain of salt. You know if you're going to the NIH, you know it's reliable. With things about diet, they tell you one thing one day and another thing the next. People use the computer information maliciously. Con men use it. If there's technology, it's good and it's bad because there are people who will misuse it. I use it quite a bit for my own enjoyment, information and so forth.

E: It's a quick fix, as I said. I use it, I like to read more than I like to sit in front of a computer. Basically I'll do a few little things on MI. I'll go for my email, and I'll look up what's playing locally. That's basically what I use it for. If I want some information real quick I'll go to Yahoo. I don't turn it on in the morning and turn it off at night. I turn it on maybe every other day to pick up my email and that's it.

Ruth-What do you like about hard copy vs. online info?

R: It's free. It's accessible to everybody (hard copy). Internet you have to pay more and more every year. I take a lot of public transportation, I like being able to take it. There's something so ephemeral about the Internet. I like hard copy. I like the ink on your finger.

H: I print out a lot of things. I'm taking a course where the professor said you've got to get a copy of the declaration of universal human rights, so I looked it up on Yahoo and printed it out. Then you can have it as a permanent thing in a binder that I keep it on.

The other day my professor said to one of the students, “I’d like you to give the other students a copy of the United Nations Charter” He said fine and later put it on a special FDU discussion board on the website. It was about 20 pages. I keep it in a binder.

Ruth-How important do you thinks is translating MI into other languages?

H: For people in the US, I gather.

Ri: We get Spanish speaking calls, I’ve had a few in just a couple months. Fortunately, we have a couple of people on the staff so that they can answer the question and deal with that call. It’s not that frequent. Really, my experience is that it’s such a small % - I just mentioned Spanish because I don’t recall any other languages. In NYC, there’s concentrations of people who only speak Chinese, Russian…I don’t think the volume that we get would justify getting it translated. I wonder if our calls are representative of our population. You would think that we would get a little more volume of calls from people who don’t speak English. Medicare is a little beyond the very basics. I could see the need for it, but for us, I don’t know, with the few calls that we get…I don’t know.

H: Is it anticipated that the general public would get access to MI? If yes, then, Spanish would be something that was very important.

(Rel leaves)

H—First you need a computer. Very few people who call the hotline have one. Maybe 2 or 3 %. Many are very low income and cannot afford it. Many people call about drugs which they may be able to get from the manufacturer. They don’t know about the websites where companies offer drugs for free or very low amount.

Ri: I ask them if you or anyone in your family has a computer. But there are still a fairly large % of people that are elderly, don’t have a support system or relatives, but it’s not that substantial enough to be a problem. But we’re not looking at the language problem we’re looking at the computer access problem. There’s a fairly substantial amount that they’re alone, they don’t have family or friends that could go and access the computer.

Ruth--Anything else that we haven’t mentioned that you would like to put on the table for the Medicare Rights Center?

Ri: I just had the thought when you said that it might be offered to the public, I think if it was, could there be a reader’s digest of it, could there be just the very basics in very simple language. I think it would be a problem of computer literacy and the amount of information that’s there. Even if some of our clients had access to the computer, is there something else, I don’t want to make it patronizing, but would just be the basics of Medicare? Just throwing that out. Just two levels, one the very basic facts on a very simple level without going in too fine.

H: They do get a handbook.

E: That’s what I was going to say.

Ruth—What is the handbook?

H: Medicare & You, you get a new one every year, it’s a volume of maybe 80, 90 pages.

E: It comes from the government.

H: People ask us questions that they found in there, well, what does this say? And they ask us what it means.

E: Our phone number is on the back.

H: I think MI is really best for people who are knowledgeable on the subject because it’s sort of technical. For the layman, it would be too much and maybe not too useful. But for experienced, knowledgeable people in all states everywhere, it’s a good tool.

Ri: Providers, if they’re fairly large and have a clerical staff, they would know the information. But some of them, they don’t know. A certain % of providers would get it every so often and do a little research instead of calling Medicare.

H: The government services in answering questions I guess is a bit Waverly. Playing games with Medicare telephones, getting someone to talk to you and stick with you is very rare.

Ri: There is this add that must be sponsored by Medicare itself. You could get drug discounts, call this number, it’s the 800-MEDICARE number. It’s a good thing to let people know, but I’m quite sure that if they call and say “What drug discounts should I get” we know they’re not going to sit down with them; they’re going to refer them to us.

E: Which they do, all the time, we’ve been asked to keep track of inappropriate referrals.

Ri: I had an irate caller who was upset with misleading advertising. I called up, they send me to you, now it turns out there’s 100 options, in some ways it is (misleading). They want to let the public know, but it’s sort of misleading to some extent.

H: We need lots of volunteers throughout the country. They have some feeling for the person calling. I may be reminiscent, sometimes I don’t ask them for their name, phone number, statistics, immediately. They want to tell their problem immediately. It reminds me of this skit I saw of a person in an ER who was dying and this woman is saying “Where’s your insurance card?”

E: What happens is they’ll be so glad to get a live person on the phone, and then they’ll go through the whole thing, and now I say, okay, I need some information from you.

Ri: I find that if I get too involved, I find that I get their name, address, but sometimes I don’t get their phone number, even entering the information in our database, it’s a problem. I want to follow up and get back to this person. That’s a disadvantage if you’re forgetful. You’re too engrossed with their problem.

Ruth--Thank you so much. You’ve been extraordinary.

BEEP'M Hotline Volunteer Discussion Group
9/28/04
6:30-8:30pm

E-I came to MRC, I found it on the Internet when I was slowing down work towards retirement. It sounded really good to me because I worked in health care most of my life. I knew a fair amount but I didn't know a lot of details about Medicare. I was just about to get onto Medicare. I've been there for about a year.

J- I've been volunteering at Medicare Rights Center (MRC) for nine months. I came because I was attending a meeting of the financial planning association when Betty was there working for the draft so I signed up and here I am.

K –I am an ESRD patient and advocate in my dialysis unit. I found out on volunteer match about MRC off the Internet. When I saw that MRC needed people I decided to get information to bring back to the unit. It was a dual payoff helping and getting information at the same time. I am also a CAB member. What does that stand for? Consumer advisory board. That's been interesting because I don't represent NJ and I don't do the phone calls, but we are a group that goes across the country and talk about Medicare all the time.

H—I got involved with MRC in June. I found out about it through a website called idealist.org. I just switched jobs and was looking for volunteer opportunities. I work in healthcare consulting and need to learn about Medicare and managed care issues for work, use it to benefit society and help people. See it every day from pharma point of view (pov), but then I talk to patients on Medicare. It's an interesting dynamic, issues with job because of it. It's been great. I've been volunteering for a couple of months and it's a great opportunity. Would love South Asian focused community work. Family and friends express a need in South Asian community. Older people don't know about it.

S-Volunteer for about 5 months. At same meeting as J when Betty came to the financial planning association meeting. It sounded rewarding to learn about Medicare and help people at the same time. The topic interested me. Didn't know as much as I wanted.

T—Just finished training last week. I'm a brand new volunteer. Learned about MRC through H. Worked together in consulting health care managed care. It seemed like a great place to go learned how much I didn't know. I'm excited about it.

Ruth: What do you love about work at MRC?

K—I'm a people person and I love to talk. Have been talking all my life, customer service. I'm not really a customer service oriented, but I end up doing it. Don't like children but end up working with them all the time. I also do Horticulture Therapy. Hate doing it but wind up doing it all the time. Since being with the Medicare thing, my sister on Dialysis 25 years. 25 years in Medicare. 25 years ago things were not happening, had to develop yourself as an advocate then. Learned from my sister. She was having a hard

time. She was not going to die. They told her a dialysis patient has 18 months to live at 24. She's beat them out, Ha ha. 25 years as a dialysis patient. That's why I do it.

E--Love talking to the people. Wish I could be in the room with them. Some of them need to have (Medicare) explained to them Would be better if I could show them instead of mailing it. Some people can talk for a short while, but the more they need the more involved I get. Very rewarding when you can give people a bit of guidance and help them appreciate that they're not alone and the confusing ness is for everyone. Complex now. Medicare originally was much simpler. Think it has become complex with the new Rx and things.

J—I like the stories people come up with. Interesting to see how different people deal with similar situations. Some people totally depressed, unable to act, others are totally the opposite, very positive, interesting to see that range.

S—I like the volunteers and the staff.

J-- Thank you S.

Ruth—Should I thank you too?

(laughter)

S—The people on the other end of the phone sometimes scare me because you never know what will come out of their mouths. Like doing the research. Finding out a lot of stuff of on Medicare Interactive (MI), staff know things I can't find on MI. A nice learning environment. Nice people environment. Good place to go.

Ruth-- Knowledge of Medicare. What questions seem to pop up most frequently?

S—Medigaps.

H—What complimental insurance should I get? How do I choose an HMO? What's a Medigap?

E--Tell me what to do?

H—What would you tell your mother to get?

K-Yeah, Tell me what to do. I have to tell them I can't tell you. I'm supposed to guide you. Flavor of the month kind of question. As things come up, discount drug card, that's all we got for a whole month. Medicare savings program, that topic was hot. Next month it might be something else. October it will probably be who is leaving, HMO's my company left, what do I do now? Sometimes flavor of the month, also "How can I make Medicare better?" How can I get better coverage?

J-- Echo that. But affordability comes up a lot. A lot of people are struggling to pay for health care, basic needs.

S—Rx

J-- Prescription drugs, people with diabetes, can't get full coverage of everything they need.

H—A lot of disabled folks, less coverage especially Rx, confused about employer coverage and when Medicare takes over. Supplemental insurance and then also disabled people and coverage have less in the system for them.

K—I disagree. They don't get less benefits, Medicare is Medicare for seniors and people with disabilities. Seniors might get more perks because of over 65 programs.

H—like EPIC.

K—the programs are there but you have to find them. Medicare is the same but you have to find the programs through the community.

Ruth—What do you consider to be your strongest area? T?

T—Based on my training?

Ruth—Based on your training and your long standing experiences.

T—I would have to say the enrollment and eligibility because we spent a lot of time on it.

E—I have a pretty good idea of the distinctions between the choices, HMO's, medigaps, can explain pretty well. Upsides and downsides, to get that concept through to the people is important. If there are HMOs in their area which there aren't always.

S-Or PPO's

E-Don't like to get into PPO's. It's another level of complexity.

Ruth—What area do you consider to be your weakest?

K—COBRA. Knowing other insurances and how they coordinate with Medicare. Most different to figure out sometimes.

S—Still baffled when someone calls and says their having trouble getting Medicare to pay for XY and Z. Trying to figure out whether Medicare should or shouldn't pay for it. Someone like Kate will troubleshoot with me about appropriate answer for the person.

H—Sometime the Medicare Savings Program (MSP), the nuances of the rules, sometimes get lost. Have to call Melinda or whoever has the most information on that.

Ruth—What was the last change in Medicare that you remember?

J—The change in the MSP enrollment, people have to recertify by the end of the year to continue being in them(program).

S-Raise in Part B premium next year.

H—specific amounts of money $600 toward RX—people on EPIC calling to find out how it impacts them.

Ruth- Where do you find out about changes?

H-Volunteer updates.

K-Volunteer updates and the three newsletters Dear Marci, Asclepios & Medicare Watch.

S-- those are great.

K—And I signed up with Deane to get what's in the newspapers and I'll click and if something looks interesting I'll click on that. The Canada Rx –it was opportune. My sister's supplemental insurance dropped her so she didn't have Rx coverage. We were scrambling I was just reading and there it is on CanadaRx.com on one of these newsletters. That particular website that company the United States was using. The Municipal offices were using. Several combining to use that company because they were safest and most reputable. If U.S. wants to back them, I'll call them. Got her prescriptions for 10% of what she was paying Predazone. That was a huge helpful thing. She now has insurance from talking to someone in the office. Don't know what she was talking to them about. She was doing a blood fair in NJ, while trying to get help with that, talking to someone in the office, ended up talking about new plan like Medicaid in NJ, not charging people yet, so she's now got a deal with the 20% which is a lot with dialysis. The hospital with bill and bill and bill. Got 20K in bills but can't pay anyone yet.

R-You have the MRC.

H—Medscape has good weekly updates. Signed up for work

R—Let's move on to talk about MI. How did you hear about it?

J, H, S, E—training.

Ruth—What was your initial reaction when you heard about it?

K—Oh la la! You can ask a question and almost get an answer, like a normal search

engine, doesn't always work that way but when you go to www.CMS.gov it doesn't work that way. People oriented, when I saw it from other government websites. Oh boy! It was interesting.

T—Relieved. Coming from training, it was a relief to know I wouldn't have to keep it in my head.

K—That's right! We had binders I had a binder and didn't use it. I used my memory and my noggin and maybe training, but when (MI) came on, I didn't like that binder so much, so much page-turning. I wasn't using it but when MI came on I use that all the time. I'm a computer person. Like I said, oh la la?

Ruth—What impressed you the most when you saw this MI?

S—Blown away by how well laid out it was to find answers. Used a lot of financial programs to find similar situations and none are laid out and as user friendly as MI is.

J—One thing that makes it user friendly—multiple ways of finding an answer. That's good because I use one or two of them but people conceive of questions in different ways, look for answers in different ways. The fact that the system is set up to permit that makes it accessible that it's set up in different ways.

H—I like the go to boxes for related information. I don't necessarily read the scripts—information per se—but links are most helpful.

J—I find it different to find specific links sometimes. Finding main body fairly easy, but if there's a link I remember, I don't know how to retrace steps to find it

E—I've had that experience too, but I think last week I was at this thing, But how did I get there? I forget exactly the route that I took.

K-Which keyword did I use

E—but last week someone said go to keyword and I got there more quickly. Sometimes I still use those small binders because I don't want to find it in the computer, easier to have certain information on paper

R-What were some of your concerns when you first heard?

K-I don't understand the question.

Ruth—When you first heard of MI? What were your concerns about it?

Tam- One of my concerns with search engine function—sorts by alphabetical order than relevance. Sometimes less useful—if something is at the end of the alphabet have to scroll through all of them. I find myself concerned about that so I use the index.

J—concerned that I couldn't find the answer quickly enough and that people would expire on the line.

(laughter)

Ruth—Did you find that to be true?

J--No one has expired on the line.

K—I was nervous. Anticipation of whether I can find the answer fast enough in my head or on the computer? Will it be faster. Also putting the information about the person (into BEN) would I be able to be a telemarketer, get the information, answer the question, all within a normal conversation making it comfortable for me and the caller. But I found if I say I'm moving slowly they all understand.

E-I find that too.

J—Some are more than happy to hold, most entertaining thing all week for them.

K—They've called someone but when you get 800-Medicare number you get the phone tree, and they're not for that any more. They'll have to come up with something different. Especially when the information at the other agencies is almost anyone, not just Med, not giving information, not answering the phones or calling people back. People are grateful that we called back or that they got a person. They start out angry sometimes "finally!" but I say I don't know what happed over there, but I'm here to help if you tell me. Get that human touch, and it's so much easier then.

S—Worry about not giving people the right answer. Ask about supplemental to Part A, B what can I do? And maybe I should ask about EPIC or MSP eligible. Medicaid, so it doesn't give you all the q's you should ask, just the answer to what you're looking for but not all the other areas you should be inquiring into as well.

J-- I worry about that too, but you kind of have to pare it down to a couple of things for people to consider there might be a dozen elements for the optimal solution, but people can't take all that in, the more you ask them, the more uncomfortable they get and nervous. Better to keep it to "you've got HMO's and Medigaps, but not going into all the other permutations already helps people.

E—I've sometimes called people back because I forgot to ask them about EPIC or Rx coverage. They seem focused on wanting to knowing about a Medigap, but thinking about what they need I tell them about the Medigap and then I think maybe I should send an EPIC application. I'm not always comfortable asking about income, but I find ways to say "for some people if income is below…they're eligible for something else."

K—I've called people back. I'm reading the case report and I think of things to talk to them about. I call back "when we were talking…do you think of joining this program? I saw something else. I found another page…" sometimes I go to one page, COBRA issue, happened just today. We started with COBRA and flipping around I went to another MI page, clicked on a sidebar and found more information for a person and I was able to go back at the end and say to them "You know what going back to that COBRA thing."

Ruth—Any other concerns? Anything challenging that could make it easier?

J—The most challenging—not MI per se—the intake forms for taking information for callers. Awkward to use.

Ruth—The paper ones or the computers?

J--Started on paper, but leapt into computerized format. It is easier in some sense but it doesn't allow you to put multiple issues, for example.

E—Annoying. When a person calls for the first time and say "I'm going on Medicare for the first time, I don't know what to do." I talk about Medigaps and HMOs, you can't check both so you end up having to enter it twice. Why can't you do both at once?

J-Exactly. It takes more time.

Ruth—What does it mean to have to do it twice?

J-- You have to treat it as a new issue.

K—That's BEN. I would like to be in a focus group for that program. Intake form, name, etc. You can only put in issues –enrollment, questions, problems—you can't enter a problem and a question at the same time. Have to put one specific thing in each time. Sometimes you want to cheat and just put in the most pressing issue. Sometimes you want to put in all of them.

Ruth-When you do it online with MI, you have to put in one and you would like to be able to do multiple issues.

S—I always choose the most important issue and then I put all the other issues in the notes.

K—You don't know whose going to read all the notes all the time. You don't know whose going to look at the issues all the time. How do they do it? Do they do both?
I think they do both.

J—I write really big notes. Everybody wants to see my notes.

K—I don't write good notes. I write abbreviated notes. I have seen people who do the written intakes and I don't want to do hers intakes because she writes pages and pages. Sometimes you just have to do the issues. You want to be clear.

Ruth-Let's talk about training. Some started up with blue book. Describe MI training you went through.

K—Amazed that Betty could do it she was not a computer person she kept saying. Her not being a computer person and being able to teach it made me more comfortable. If she can't work it and can teach it, as a computer user this should be a whiz. It wasn't a whiz, but her tips and getting you in there gave me more confidence I was nervous all the way from the beginning. A lot to think about even before I started taking phone calls even though I do know how to talk and like to run mouth off, thinking I do know how to do it.

T—Betty introduced it very well, fact you could access links, resources, Betty went to the pages she was talking about, topics, showed how to find the topic and other resources. Most useful exercise Betty printed 10 topics, and spent 20-30 minutes practicing how to use MI, getting accustomed. I think it was the most helpful.

J- The training is well structured and planned. Builds well. Good progression of conveying information and then doubling back to test it, make sure it's been taken in to some degree and then practical application as T was saying. I think it is very well structured.

H-I agree. It was—I had two sessions a week for 2 weeks I was familiar for some elements of managed care. Broke up the system in a way that was digestible. Quite well done, given how complex it is Not as easy on CMS.

J—Very important that the refreshments were always very good.

S—baked goods

Ruth—I've heard about those too. So when you left the training how well prepared did you feel to use MI?

K—I'm from Binder 2 MI so I felt pretty comfortable. I was looking and looking but I was coming in with some Medicare knowledge already.

E—Felt more comfortable using MI at first than talking on the phone. I was afraid I'd get confused and they would ask a question I didn't know. When I'm in between people I look through it to refresh my memory.

K—Make up scenarios? I've done that a few times. What were we talking about in dialysis?

J—Live calls? In the evening it's all callbacks.

K—I do it all—callbacks and live.

J—I feel there is not downtime—30 calls to make and I have to get through all 30. It's just exhausting.

H—form a MI view-I wish we could've done the training in front of the computer. First day overwhelmed by MI because I hadn't used it on the training, took me a couple of times to get used to it. The flow wasn't intuitive in terms of the logic. If we could've done more of it in the training as we went.

E--Think about people who have never used computers. How hard it is for them. Worked with colleagues in daytime it's very hard for them.

K—Tuesdays during the day Dieta, doesn't use the computer. Uses written intakes and blue book if she needs to refer to anything, but she gets through a good bulk not using the computer.

Ruth—Having to use a new system plus taking on challenge of being a new volunteer is a lot to start off with. Maybe needed more training before live calls. What other things can be done to prepare you to use MI?

E—What you said puts me in mind. Training could include someone in another room and pretend to be a caller and someone could observe you. Actual practice of doing it.

S—we did that

H-role playing

K-us too

J— Role playing is always artificial. It would be effective if it wasn't Betty or someone you have met. Someone else on staff could call in. Observing someone actually trying to do it would give the observer an opportunity to say ok, when you have this question, you went here but here's a different shorter way to do it.

T—it might also let you know what questions you didn't ask which would be helpful.

R-A person in training or the system itself would prompt you "did you remember to ask"

H—As a group you could say what you could've done different.

S—It's a lot to get used to Medicare overall, the calls, and MI I was definitely a bit nervous, afraid, but it was great. The staff who are there never make you feel stupid in any way so you end up being not nervous at all, call them over, ask questions and it becomes easier and easier. No simple answer but practice makes perfect.

H-maybe doing –the same questions come up. Discount drugs. Supplemental insurance. Issues for disabled people. Maybe a summary of the top 3 or 4 things that come up. A lot of things in training have never come up. MSPs—I always have those on hand, HMO questions, things that come up often. Maybe just having survival kit, top 4 things that come up. There will always be random things.

E—agree with S on 80% of calls, ask supervisor about the nuance or detail. I call on supervisor. They sometimes go to MI to get it.

S-Or to other supervisors. Rina!

R—How long after training on MI did you start using it?

H-the first time you volunteer.

J—within 2 weeks

Ruth-did you retain?

H-yes, I started the following Tuesday. It was easy to remember.

T—Start today.

Ruth-how often do you use MI instead of other information resources.?

K-what else are there.

H--binder, supervisor

J—Medicare.gov

Ruth—Resident knowledge.

E—Sheets for suburban HMOs.

J—I count that as part of MI.

K—Since we're doing that survey—that q. did you use other resources—what other resources are there than another person? I was putting "my memory" Didn't think that was relevant.

R-knowledge, another person

S-Needy meds, Medicare.gov, Google, NY Dept. of health,

K-I've gone to those other sites but found very little with a caller from other places, if I can't get it from MI during the call then I have to get back to them. Either with counselor or in some other place, either from MI or another website. I answer all my questions through MI usually because everyone else is too slow. Government websites difficult to navigate through.

Ruth—Difficult because?

H-They're not structured well.

K—They're national and we're NY and they're not structured well and searching for the topic doesn't always get it or it'll give me part of it or it will give me 10 irrelevant results At least with MI, I'll pretty much pinpoint it with one word "COBRA, Medigap, Home health aid" sometimes I'll just put in HHA and something will come up. Sometimes I get "I don't know what you're talking about" but live and learn…I try to come up with bad things, but right now I can't.

Ruth—what could be added to MI to use more frequently?

S—I don't know more frequently, but they could use a bigger budget. Whenever there are suggestions, they can't change it because the budget is not there to change it. The notes screen, there's a tiny box, can't see anything you're writing except 2 lines. Then there's a lot of stuff that's never used. It would be great if they had the budget to start editing things that could be a little bit better. MI itself is great.

K—The rolodex is a little different to navigate.

E-Community resources?

K-No the rolodex. On the top—search index, rolodex is up there, the phone numbers of the agencies. Only recently discovered it. It's hard to find what I'm looking for a specific agency. Difficult to find.

Ruth-why?

K-not putting the information right.

J-Organized by category.

K-Organized pretty good—part of name, nature of the business, but it does give you something, but for a while I couldn't work with that one pretty good. It takes me a little while.

R-So it would be better if you could search the contacts listed.

K-you start at page one and I'm trying to find the PA ship phone number.

E—I need to look in the book for that.

K—I'm not talking about the binder—I threw that away.

E—thin binder not fat binder.

K—threw that away too. I was looking in HIICAP and nothing was coming up, and I was wondering how can I fix it. Got to put the right words in. Have to put in SHIP, but I was putting something else in.

Ruth—Anything else to make it easier?

H—I like case examples. Reading through—scripts are good for basic information. How do you apply that information to a particular person. I often go to case examples Only 2 per page would like more.

S—It would be nice if you came across something not in MI, that you could submit it. There's a form to submit things—someone could submit it and post it—

K-like a suggestion box.

S-yeah, so the depth of the program grows and improves

Ruth-have you ever used the feedback form on MI community. Not all this is totally operational, but you can post questions queries suggestions there. Not widely…
What type of materials do you send your clients?

E—Medigap progs, HMO's for their area, circle the part in their area on Medigap chart. When training, MI was being introduced. Thought I would be able to put in zip code and just get the column for their area, but wasn't true. Usually NYC but also upstate. EPIC information, MSP's. When I send MSP's I sometimes send the application form off Medicare Interactive. I sent them the questionnaire—what you should consider if you're going to do

S-I love printing out from MI, when I find an example and print it out put it in an envelope.

K-That reinforces exactly what you've said. Caller says "are you sure" and I say "I'm really sure" because I'm reading off a piece of paper and so will you. You're going to get it If they're not believing me or they've gotten conflicting information. I try to find whatever I can in print so I'm not just telling them from MI, if I can find scenario or the question that goes with their question and that answer. If I can get that printer friendly that's the best helpful thing to send. Alleviates their fears so they say "oh I don't have to get a medigap right after because the paper says so" even if there are other people telling

them they have to do it right away. Because in NJ the rules are different and I just found that out.

E—That's terrible.

K--The answer talking to the NJ rep is that they don't have to sell to you It would be at their discresion. In NY you can get it at any point so long as you … it's harsh that it's not regulated nationally. Whatever reasons they have you just deal with it. I had to print that for someone I said "no this is NY" and I said it 4 times before we went on and I printed it and sent it.

Ruth-It's a good way to confirm the reliability.

K-Sometimes people ask do you have anything in writing. They can't access from home. Sometimes people have gotten poor information. Tell them the document is right in front of me. Sometimes superceded by the information they got from Medicare or Medicaid which is wrong.

H-I haven't printed stuff of MI, it's colloquial, not a legitimate source, maybe once when I didn't have another way to communicate the info. Maybe people would appreciate it—if I got the information in the mail I wouldn't put a lot of weight behind it. I'd say "where is the source from?"

J—Not identified from a reliable source.

H-It doesn't look legitimate. It's speaking tone. For us to read, not for them to read. Not official looking enough.

E—Sometimes they have references at the bottom.

H—I would rather send something from CMS.

K—I think they always have something at the bottom.

E—Sometimes Rina prints something from somewhere that looks more official.

H—CMS has a Q&A and I've printed off that because it's from CMS and because it's not from some random nonprofit. If I had heard conflicting information.

J-Many callers don't know the different between us and Medicare, they think we are Medicare Rights Center.

R—When you think about MI, how much previous knowledge does a counselor need to use MI? Do they need any knowledge?

H—I think training was sufficient in terms of building your knowledge.

J—Me too.

K—Knowledge of the search engine—know how to search.

E—Computer skills of some sort.

K—Computer skills are automatic. My mother all she does is email, a whiz at email but she doesn't search for anything. Can't figure out how to search or even bookmark. Even I can't always come up with the right keyword. Good search engine knowledge.

Ruth-Basic Medicare knowledge. Do you agree with that S? Basic knowledge from the trainees/volunteers is necessary to be able to get on to MI to use it effectively.

S—Core knowledge about Medicare in training really useful. To use MI, a couple more case examples where we are utilizing it would be useful before we use it on the phone with clients. If you're learning a) how to use a computer, b) about Medicare and c) talking on the phone about it and about MI at the same time that could be a little overwhelming.

K-but there's always somebody there you can ask.

S—always someone there

K-every 15 seconds when I started even in one phone call I would ask. Even with the binder there. The binder was very difficult for me. Taking it home to study it to memorize it because I couldn't use it and be on the phone at the same time. Would be answering it out of my head or asking a person. A little easier with MI. If I couldn't find it there was still always someone there.

H—I want to couch that. The way you phrased it—I don't think you need the training to use MI if you had the time to read through all of it. You would be more prepared to deal with people

R—you could navigate your way through it.

H-Exactly. It's user friendly You could get through it if you were thinking about rolling it out to other states,

K—I think you would always need that training. You need that foundation.

E—the training is important for knowledge of Medicare, but if someone is comfortable with a computer and using other things. I got a lot out of this session—realized I'm not using it fully—put MRCCREw and 1prime to get in from home—I want to go home [and look at the things I learned about today]. You can practice at home that way.

K—I didn't know that. Want to talk to other CAB members—link to other members of CAB. Need to talk to Ross.

Ruth-components (reads all). Which one do you use most often?

All-Counselor (H, J, K)

R-Community?

J&H—no

Ruth-Know what it is?

J&H-No

E-some was not operational when started, so I think I looked when I started and it wasn't operational

Ruth-MI Local services?

J-That's something I've started using.

S—That's the rolodex. Occasionally.

H-I haven't use it ever.

K—I have used the rolodex.

Ruth-Yes, even though it's different to navigate. MI University?

H—I didn't even know.

S—I think I went there for the MI Discount Drug card.

J—Did it help?

S—I got 30 pages off somewhere. I have it in a binder where if people ask I look for information.

Ruth—anyone else ever look at it?

(no response)

Ruth—MI Help? Anybody looked at that?

H—Nope

Ruth—MI Feedback—this is what it looks like.
I would like to move away from MI as a program open up to tech in general. When you're researching a problem, what resources do you use?

S-Google

E-Google

R-not just online

J—supervisors

R-everything not just Medicare

H—almost all research on the Internet.

E—books. I found out—linking books on computer—I read NY review of books, times book review. You can put in your library card and get books sent to local branch, get on a wait list, I'm 60 on bio of Alex Hamilton.

S-that is cool.

E-I have too many books in my house already. A lot of magazines and newspapers as well.

J—How do we get information in general? I ask people.

E-dictionary

S—contact friends if someone might know.

J-Contacting people. I'm big into building my network, so if it's something someone might have knowledge of I use it as an excuse Establish contact and get information—get two things.

K—Internet. Since a lot of stuff I'm looking up is social services. It starts with the Internet, idea grows, I localize it, from Internet to localization.

R—What are the strengths/good news about the Internet?

S—information is their mostly.

H-one stop shop

E-sometimes too diverse

S-You need to know that it's right what you're looking for

K-can use yellow pages

J—it's a lot of information. Easy to get lost, not lost but involved in this, that and the other thing, easy to get distracted. You kind of have to look at a lot of sites and a lot of information, depending on the topic, before you can judge what is valid or not, already need some context or you don't know if the information that's there is good or if it has a bias. If you're looking a couple of times I've looked to get information about drugs and you don't always—what are side effects?—not always clear. A lot of those sites have biases. Either paints positive or negative picture and you have to look at a lot of them.

E-average it

K—I have a book, a little program; drug dictionary. I get a lot on the Internet and it's an unbiased resource.

E—no such thing in the world.

Ruth—like a physicians' reference. Easy to find specific information but it sounds like sometimes the downside of using the Internet is you have to wade through a lot to clarify, see the forest for the trees to see what you really need to be concerned with, weigh a lot of biased materials to find the middle ground.

T—Information on Internet not personalized not relevant to me. Sometimes want to call someone. Like looking for a doctor want to find someone best for me. Not personal on Internet, the downside

R-Books strength?

E—Can get a full rounded picture of a topic.

S-snapshots

E-a book almost has a point of view, we have to read 3 books but you get a much fuller picture than on the Internet or in the newspaper. Doesn't anyone read the newspaper.

T&H&K—online!

J—you must be a blackberry person (to H)

H-yeah

K—I like to read papers in other countries/counties I go to a lot, like Abelene.

E—earthquake in CA. Parkside, town with 37 people. I found this on the Internet, but someone heard it on TV and I looked it up. 6.0 earthquake. The town didn't have much damage. Felt from San Francisco to LA.

J-Maybe I should call home.

Ruth-finish up talking about improving MI. How important is it to translate into languages?

J-Very useful in Spanish. I do a lot of the callbacks in Spanish, to be able to print things out and send them to people.

S—Important, but too bad for other languages, but Spanish is the most common.

H-I haven't come across anyone. Having resources multilink at the centers important but the effort it would take I'm not sure if there is a need.

K-for other people?

R-however you would think

J-I'm not sure it would be worth the investment even in Spanish.

K—I don't think most people will be looking for information for themselves.

E—there were Spanish versions for MSPs but I couldn't find it this week.

K—We have Spanish Publications, but I've had Spanish clients and I've had to explain it to them and I don't think the paper would have gotten through. It may have been easier.

Ruth-Not sure of the value.

K—you're in America and this is an English speaking country, if you have Medicare you've been here long enough to learn the language. My family from Equador, my grandmother can only speak 5 words after being here for 50 years. I know there are communities that only speak another language-Asian languages—but would it be helpful to do MI in Taiwanese for that group? Would it be beneficial for them?

H-I speak Hindi and can read MI in English and translate in Hindi. As long as you're English speaking as a counselor, things for them to read would be important but scripts would be of limited use.

Ruth-anything else?

J-new keyboards

S—the occasional tutorial. Reminders of “have you been using this or that” “this is there that is there” This is new.

E-This is no longer under construction

J—I think the volunteer updates are meant to do that to some extent but it might be good if supervisors did a little of that on an ongoing basis.

S-I take my hat off to whoever designed that system. Very useful.

Langeloth Counselor Discussion Group (BEEP'M)
10/12/04
10am-12pm

Good morning/afternoon. My name is Ruth. I am a communications consultant. I am conducting the evaluation of this project. How many of you have ever heard of or participated in a focus group? The whole purpose of this discussion will be to get your thoughts and opinions on the Medicare Interactive program. So today my role will be to ask you questions and to moderate the discussion.

There are just a few guidelines I would like you to follow
- This session will be tape recorded. The recordings and the notes that (name) is taking will only be used to write the final report.
- All discussions will be completely confidential. No one's name or affiliation will appear in the report.
- Please be open and completely honest. The results from these discussions will help to improve the Medicare Interactive program. So your opinions and experiences are very valuable.
- Please speak one at a time. This will ensure that we will hear everyone's comments.
- Please avoid any side conversations or comments. We all want to hear your thoughts.
- This session will last about 2 hours. Please feel free to help yourself to the refreshments.
- The restrooms are….

Introductions/Warm up
- Go around the room and give your name, affiliation, and primary focus of your program.
-

R—Jewish Home and healthcare, referral services. More and more facilities recognize the value in doing information and referral. Particularly with a different focus. It's not just "Here's the question. Here's the answer." It's assessment and analysis of the climate in which the enquirer or potential applicant lives. The questions that we get and the referrals that we make are more than 50% outside of our system. Thank God for Medicare Interactive (MI) and the Internet.

M—Stanley Isaacs center. Lately I've been getting a lot of questions about Medicare. A lot.

P—Storefront services for older adults. Gathering information

D—I'm a caseworker at Spring Creeks Senior Park. Were at partnership with JASA and transportation and development. Our main goal to help our seniors to stay at home. We facilitate that by providing them with social services assistant and helping them interact

with each other. We have volunteer programs where they can come out of their home or visit others who are homebound.

I--I'm a social worker. We have almost 300 people in client social work, nursing and claims that involve a home visit by a nurse. We also run groups in our facilities, town car transportation.

Ruth--What do you love most about your job?

R: Just this morning, I said, my job is so much fun. For me, as someone who was facility based, I was the administrator of a senior housing facility. I have an opportunity to impact through information and empower without having the downside. While there are people who call me regularly because we have made that connection. It's the best of all worlds. Being able to assist without getting sucked in. It's a lot of fun.

P: It's a great place to work. I get to make home visits to people. There's such a rich fabric of people. I get to really help people. I get to explore neighborhoods I would really never be walking around. Really being able to make a difference in someone's life, befriend them, and provide them with services, friendship and camaraderie.

M: I like working with the seniors, they're a fun population. They have so much knowledge and history. I have a walking group, and they tell me where Walter Cronkite lived in this building. Rockefeller lived here. The knowledge that they have of the history of the area and what it looked like in the early 1900's…just the knowledge that they can come to me when they have a problem. I can just sit there and listen to them. Making there feel that they are not alone. They are very isolated. Don't have relationships with their children. They really depend on the center to socialize. We have a lot of programs going on all day long. I just love working with them. Even though I'm close to being a senior myself. It doesn't really matter. It's very rewarding. No money, but…

Di: I think it's the best job I've ever had. It's very nice when I see faces happy when I solve their problems. I just had a client, she had been working for 5 years after she had been 65, so she received a penalty. I found out that SS calculated a penalty incorrectly. Finally, after 3 months of hard work, we won. She's going to receive a check of $1000. Her penalty is being reduced from 60 to 10 percent. She said, "I didn't expect that." Sometimes, you meet people who are just adorable…It's so nice just to deal with such people.

D: I agree, the look of relief when you help them. They come in and they wait for ½ an hour on the phone with Medicare, Medicaid. They just don't have the time. My favorite part is when they come to visit me just to say hello. This means that I've helped them in some away

I: There is some flexibility for professional development. I've been seizing these opportunities to go to trainings and so forth. I get a lot of satisfaction when I'm able to get an entitlement or a benefit for my client, when they have the services they need.

Ruth—I know you probably don't here this enough but you do such a tremendous service each and every one of you. You're not only helping them with their problems you're touching their lives. It's the whole thing of recognizing the person versus body parts. I think that's what so many of our elderly face. That they are just a number and I think you all just bridge that. What Medicare questions are you most frequently asked?

R, P: The drug card

P: Do I need it, how do I get it, what will it do for me, how does it work with EPIC.

M: A lot of clients, who are hitting 65, want to know about supplemental…he came in with a shopping bag full of brochures. I said what are you looking for, what do you want…so kind of weeding out, narrowing it down for him. I said to him, now you have to make a decision on what you want. If I find it as a professional, complicated, and have to go into my computer and read up on it, imagine what it's like for these people who come in and have no clue. They think Medicare will take care of everything.

P: They don't understand the difference between an HMO and a Medigap, and they sign up because they have a coffee cup from an HMO and they don't know what they're getting.

M: The difference between A and B…not enough information at a simple level that they can understand it. It's a very complicated system.

Di: Most of my clients are Russian speaking; it's a problem for them to contact government agencies. They are very confused about the system in general. I have to explain what each part covers, what rights they have. Most of the questions are, "explain, tell me please, and how do I do it because I don't understand."

R: It's equally a problem with English speaking people, even their children. It's not just seniors. It's true across the board, any age. Not understood.

M: I used to work for a consulting firm, and I would ask the children what kind of insurance their parents had, and they would say, isn't it Medicare or Medicaid?

Ruth--Interact frequently with their children?

M: In my old job.

P: 50/50

I: Same.

R: There is a perception that you come to us at the point of decrepitude. They're calling in a panic about services. That's probably 98, 99% of the calls. It's a little bit crisis intervention.

Ruth--What do you consider to be your strongest area of knowledge on Medicare?

I: Part A and Part B, I have general knowledge about both. I had a client recently that went to the hospital and was transferred to a nursing home, and he had a Medigap policy. He had a bill of $19,000 and he kept arguing that he shouldn't have that. He kept going back and forth, that's when I got the knowledge about how the Medigap policy would not cover him (for the same benefit period).

M: Part A & B. I've been to every seminar that's been out there for the new drug card. I think I'm pretty knowledgeable. That's a long time of experience, though.

P: A and B, what will be covered, when it will stop, how that will change. The benefit period just confuses people. If they're in a SNF for a period of time. It's hard for people to grasp that if they don't progress, Medicare won't pay for it.

D: People don't understand that it's for a short period of time, and they may or may not get physical therapy that's needed. That's what I have to explain all the time. It may be 2 hours 4 days a week or just once a week.

Ruth—What do you consider your weakest area?

R: The unusual issues. Veteran benefits for example. Certainly C and D, what's coming down the road? Though I've been in the field for many years myself, there are times that I find that I'm not clear about when Medicare will do more than just pay the hospital and the doctors and found myself encouraging people to explore Medicaid because it's almost a blanket coverage.

D: The coverage for mental health, I'm still learning. I went on the site just the other day and they have a whole tutorial on it. I didn't finish it. I'm going through it now. That's my weakest part.

P: This new drug card, I have to have a crib sheet. I feel like I'm confusing them more, if they have a question…and the benefit period stuff. Even if I think I know it, by the time I have the conversation I'm so confused. Tracking it is like doing a genogram of their hospitalizations.

M: Trying to tell them that Medicare will pay 80% of the allowable charges, I try to explain and it's very difficult for them to grasp it. They assume it's 80%.

I: Accepting assignment?

M: Yes. Whether there's a language barrier or whether they're well educated, it doesn't matter, it's very confusing.

P: I get all their statements from Medicare, they come in with a shopping bag of it, and they ask, what is this, and trying to sort it out takes days! These people won't live long enough to get an answer.

M: Just weeding it out, all that paperwork, this doesn't matter, they say, "Yes I will need that some day!" I have people that don't even open up their mail! They panic, anything that comes from Medicare or Social Security, it's not good news.

Ruth--What was the last change in Medicare that you remember?

M: Prescriptions. The Part D, I went to a lot of seminars, I did a workshop at the center. I got a big turnout. I did another one. I had seniors who brought friends. They're all asking me when I'm going to do another one, it's just so confusing. They're just sitting there with their mouths open saying, "this is awful." I'm encouraging them for EPIC, I have a lot of clients with Medicaid, that's going to be a huge issue, a lot of them are really concerned.

R: There hasn't been enough information out there in the professional community about the MSPs, about those individuals who can get their Medicare Part B paid for, all of it, $600, this amount, that's information that we need to, understand better. We always talk about if you're really poor, you're in good shape, if you're really wealthy, you're in good shape. It's those people who are not eligible for Medicaid, we need to know about every entitlement out there.

I: Actually, the Medicare Interactive lays it out very nicely, the MSPs, there's a schedule that breaks down, if you make this amount, QI-1 or SLMB. I just researched it yesterday, I chose the first option, which is, if you have no idea what you're doing.

Ruth --How do you find out about the changes in Medicare?

All: Email.

D: Dear Marci.

P: Dear Marci, other collaborations in the city. I'm always on somebody's email list that will tell me, have you seen this, do you know? I think Dear Marci is really helpful.

R: It will tell you what the issue is. It tells me literally, to get that information.

M: I save all the Dear Marci's, I can go into the file, and this way I have it in there.

R: So if I ask you to mail them to me…

All: [laughter]

Di: I also receive Dear Marci, but the main office downtown, managed care consumer assistance program, I go there for trainings and workshops, and they send emails with updated information. I have a direct contact with Rina, so if I have any questions, I can talk to her. And then Medicare Interactive, it's really good. I tried to use it, and I found answers. You don't have to bother people, you can find the answer on the web.

Ruth: Where do you get your information about Medicare? (When other sources are mentioned, probe for what they like about those sources.)

R: Occasionally, the American Association for (garbled)

P: Newsletter, or DFTA.

M: DFTA.

I: the Internet in general.

Ruth: Where do you keep this information? (Binders, files?)

All: hard drive.

P: I read it, I may print it out and pass it along to my colleagues. We have very limited storage in our computer system, but I think it's a good idea to save them to have a reference. It would be great to have a bibliography of the Dear Marci articles in MI. Then you wouldn't have to take up your hard drive.

D: We keep Dear Marci hard copies in a folder for everyone in the office. A central resource center with all our information for anything, Medicare, SS, Medicaid, etc. We also have meetings where we information each other of updates, etc. I keep it up to date.

M: I have folders on all that. Everyone knows where it is, so if they want information, they can have it.

Ruth: How did you first hear about MI? In what way?

Di: from MRC, by email.

P: Me too, I don't remember, it just started appearing.

R: We got it through the Jewish Federation. They let us know that there was going to be a seminar, they introduced us to MRC.

D: I think that through a seminar, also.

P: I think also when I was in San Francisco at the ASA conference, there was something there.

Ruth: What was your initial reaction?

I: Let me try it and I'll find out, I found it to be very useful.

M: I found it to be very helpful.

R: I found the interactive part to be very useful. It really wasn't until I did a little trolling on it that I found it was so different, certainly very user friendly.

P: I still have this guilt thing that the time I spend on the web is not okay time, I'm not really working, I'm sneaking in and out, but this is so valuable. Just the index page gives me answers to everything.

Ruth: What impressed you the most?

D: the information that's available, resources, the categories. I'm a computer person, I enjoy it, I know exactly where I need to go to get a list. As you said, its user friendly, it's very easy to use. You can get exactly where you want to get. There's one link at it takes you exactly where you want to go.

P: I can access it anytime I want. I can do it from my laptop at home. If a question comes up on a Sunday, I can just go to it. The accessibility on the Internet is extraordinary.

R: Timeliness. I often find myself doing Google searches and after that I go to sites, I find that everything I read it's from 1998, obviously the proactive piece.

I: It's very thorough; it highlights your questions with examples. You go on websites and they just tackle one thing and not others, you have all kinds of information.

D: it gives you fliers you can download and presentations. It makes it much easier.

Ruth: What were your concerns?

All: none.

I: I thought, it's too good to be true.

Ruth: Did you receive training on MI?

D: I had the training. Tamara came to our office and gave a staff training, I also participated in a presentation that she had.

Ruth: How many people came to the session?

D: 6 people attended that session. There are those individuals who are very hesitant to use the computer, they found it very simple to use. In the office, I'm technically the computer person. It was just a breeze for me. It was very simple for them to go through.

Ruth: No other trainings. How did you find out? How did you learn about MI?

R: Quick overview on a screen. Now I'm thinking, is there any reason for me to go through training, I feel like I'm using the site as I should be using it.

P: I think I became exposed to it when I took the Medicare drug benefit training online. It was a couple of months ago; I got an email asking if I wanted to take this training. So I took the class online, I took the tests. It wasn't a big deal. Don't know if it was through MI. Then I just started going online with it.

Di: I received the user name and password from the email. I expected it could be good because everything that comes from Medicare Rights Center (MRC) is good, but I was still surprised. I just tried a little bit and then I found how to operate it.

Ruth: Logging on. You found that you could navigate easily?

M: Same thing, I got a password, just went in it and navigated around. I'm not a big computer person, but I found it easy.

Ruth: After the first time you used MI how frequently did you log on? Once a week? A couple of times a week?

Di: When a question arises.

P: in the beginning, when we were talking about the drug cards, I probably went on more frequently, then it's as it's needed. Sometimes there's weeks that go by that I don't even think about it, but it's there and I know that I can go to it.

R: I don't go on often except when Dear Marci raises and issue, and I realize I don't know about it. Or obviously when a question comes up.

Ruth: What could be added to MI to encourage you to use the site more often? What could be changed?

R: If we're saying we use it when we need it, why would there be any reason to use it more?

P: No, it's driven by my need.

I: I'm still in the being impressed stage…I did not get to that level yet. Maybe a couple of months from now.

Ruth: How did MI change your ability to serve your clients? In what way?

P: I can get an answer right away, I don't have to wait for fifteen phone calls, I can go on, find the answer, and then give it to them. Makes me look much smarter.

R: Greater credibility.

M: I don't have to go through all my files. It's always easier. You don't have to sit there with the phone in your ear.

I: Some forms you can fill out there and then and print it out. Medicare Savings Program (MSP) forms.

Ruth: What types of materials do you give your clients to take home?

R: Materials that I have culled from other sources because those sources tend to be verbose and technical. Whether it's, I'm using a larger font, simpler language, easier words, I have been putting together some of my own documents.

Di: Some materials in Russian. I have a lot of very good handouts in English, on drug discount cards, Part A &B, on EPIC…If my client is English speaking, I can give this to them. But if they speak Russian, I have to explain it to them.

R: The literature that you have, where do you get it from?

Di: MCCAP, materials in different languages.

Ruth: Have you ever given them anything printed from MI?

D: Fliers, on home health, hospice. I did have one issue where the font, my computer didn't acknowledge the font that was used. It gave me an error, it gave me a blank sheet with maybe one line and a few words. I went and I did it at home and it was fine. Only that one time. It was a flier on the home health. And the PowerPoint presentation as well.

Ruth: How about using the presentations?

P: I really wasn't aware that it was available.

Ruth: What level of knowledge of Medicare is necessary to get counselors to use MI? Is it a prerequisite knowledge available?

All: None.

P: Log on and go.

R: The site is also available for the lay community. I think that the work that was done was done with a particular sensitivity that you have people with different knowledge levels, so it goes from basic to details.

D: And it gives you that option of not knowing what you want to having a specific question.

Ruth: What do you think a center needs in order to successfully implement MI?

P: For seniors, you have to have a larger screen, the equipment that you're going to use have to be different, accessible, visible.

D: The site has the ability to enlarge the font.

R: Visual impairments, they do better with a white screen with black print or vice versa.

Ruth: Did you ever need or get any help or support in using MI?

(All shake heads.)

Ruth: We have talked about the different components in MI. Of all these sites which do you use the most?

D: MI counselor.

R: MI Community.

Ruth: What did you like the most about MI Counselor? Why?

R: the search.

D: (agrees)

I: I click everywhere.

Ruth: What features have you used on MI Community? Why?

R: I've done the post a message and the give feedback, I haven't done email news.

(No one else has used that part.)

D: I'm usually on Counselor.

Ruth: What about MI Local Services?

(D nods I nods.)

D: To see in my area, what resources, agencies they have.

R: I've never done that.

Ruth: Have any of you used MI University? Which course did you take? Was it helpful? Did you take another?

D: I did the discount card one, then this week I went to the mental health tutorial, but I haven't finished it, but it's good, that way I can stop if I need to, and just go back to the page where I was. The ability to stop and continue is what I like.

Ruth: How long did it take you to go through it?

D: It took about 10 minutes or so. You just read through it, if something strikes you, you can jump back to the other page, it gives you the list of what it covers, you can skip if you have a specific question.

Ruth: Have you ever used MI Help? What did you like most about it? Least?

(No one has used it.)

Ruth: Would you use these other services?

M: It's hard to find the time to sit there uninterrupted.

D: That's why MI Univ. is so good, if you have to stop and continue. You can just go back.

Ruth: What are obstacles to getting to use MI?

M: I don't have a private office, so people are always coming in, and the only time I have time is late afternoon, for about an hour. There's always emails, voicemails you have to return. What I really like to do is if I get in earlier, I get on the computer, it's quieter.

D: The time on the phone, getting services, there's always problems. It's a lot of with the client sitting there, you have to be on the phone.

P: I spend most of my day making home visits, just to wander is really rare.

Ruth: Ever do it with a client sitting there?

D: There was a link in the Medicare site through Dear Marci so that you can pinpoint the card according to the medication you take, your income, I've done that with the client sitting there. I input the information and I look for it. It gives you a list of the cards that are there.

Di: I used the same site for finding the proper card, but I didn't use MI with the client. When I have questions, I log on without the client.

Ruth: Reaction of the client? Problem? Concern?

D: My clients enjoyed watching me; they're amazed how quickly you can get the information. Even faster than over the phone. It's a lot of information to sort out. They like it, simple and sweet.

R: You don't have to second guess.

Ruth: When you have to research a problem, what resources do you use? In general?

R: Google.

D: Any search engine on the Internet.

M: I'm starting to use the Internet more and more. Some of them are easy, I use the SS one a lot now, they have really updated the website, it's really easy to navigate. If someone loses a Medicare card, if they need an award letter, I can do that on the computer now. I'm finding I'm using the computer more and more than going into my files or making a call. But then the last three weeks we haven't been able to use the computer, so it's been rough. You don't realize how much you really depend on it, all your files, everything is in there! It's really difficult.

R: MI is far superior than doing Google, because you know the links are timely as well. The problem with Googling is that you get 67,000 places to go and you've gone through the top ten and it doesn't mean that they're the most current, most accurate, it could be a sponsored site. While I do Google, when I have used the MI links, I've always been very pleased. MI has credibility with me.

P: I work in a bullpen kind of environment, so it's always to say, does anybody know anything about this? The Internet is always my second resource.

Ruth: What are the plus & minuses of using the Internet?

D: You can get inundated with information, you get so involved, it takes you on, when you're researching one topic; it can get very involved. You all of a sudden have all this information. Sometimes it's good to go to just one place and get the answer.

R: it takes me much longer if it's focused, if it's a link.

P: I get sidetracked.

M: Sometimes I find I can only read one page at a time on the computer, I find I have to print it out, I'll have it on my desk. I don't like to read the screen for that length of time, it tires my eyes out. Then I can read it on the train or while I'm having my lunch.

Ruth: What are the strengths about getting your information from hardcopy sources? Weaknesses?

M: You can always make a copy and give it to someone else.

Di: Some pages are interesting for me and my clients, and I can just give them a copy. Sometimes it's really convenient to have it ready.

I: Sometimes it takes up a lot of space as opposed to having it on the Internet, you could just lose it.

R: Helps you organize it better.

Ruth: Have you or your agency trained your clients on using a computer? The Internet?

M: We do, we have computer classes for seniors for free. We've been getting quite a good turnout. They're really afraid to navigate, when they get better they know that they can email me. You say, you'll get to like it! They don't see what the plusses are, that they can email the grandchildren, I have two daughters in California, that communication is so much easier. They're a tough group to get into the technology.

R: There was a wonderful article about why seniors don't accept technology, about how General Electric made washers and dryers with big buttons and big print, but they didn't use it. It comes down to self image, for many seniors, they are concerned that they will fail, that they will feel foolish. The technology is not being accepted so easily because it runs counter to their self image. Not wanting to accept assistance, whether it be a passive or an active assistance, makes introducing technology to other than the most daring, confident and youngest seniors' almost inevitable failure. We have free computer classes.

Ruth: Given your experience with MI, how would you change it? Make it more accessible to seniors?

D: The only thing I can think of is if they would have more information about other agencies, other benefits, to make it that one site to go to for questions about Social Security, Medicaid, food stamps, EPIC, if they could encompass information on those, even just to touch on it or to tell you where to go to get information that would make them use the site more.

R: Does the tutorial talk you through it? I don't know how crazy expensive it would be, but if the site spoke to you. I can only make the assumption that it would make it more attractive.

Ruth: For seniors?

R: That's what I was talking about, but it would appeal to me as well. Whether we're aware of it or not, we're using the oral and the visual. If it's going to mimic real communication, it should talk.

P: What D said, having information about other services, then I don't have to bother searching other sites, I know it would be specific to every county in New York. Then it would be like my Google.

R: If it couldn't have all those links, if it had a health care related search engine. So that by definition, it's already prescribed and limited, it's not the entire universe that you're searching.

Ruth: How important is translating MI into other languages? Which languages do you think are most important?

I: very important.

R: That would be fabulous.

I: As [Di] pointed out, you have to translate to clients. If someone that speaks another language and I cannot communicate with them, maybe I have access to information in that language, I could basically get that information and print it out or make them read it, it there isn't a staff member.

D: Being able to print the information in other languages.

Di: Sometimes it's possible to connect with the children, they could log on and use the site.

R: Empowerment.

Di: Parents are not sure how to log on, it's better to speak with the children; they can make copies and print out the information.

P: Spanish.

Di: Russian.

R: Chinese, Cantonese, it's difficult. It's Spanish, Russian, and it's Asian.

Ruth: When translating, what should MRC take into consideration? (PROBE: important features and considerations)

R: The answer is no doubt, yes, there are always cultural issues that one has to be sensitive to, but I'm not sure that at Internet site can, I make the assumption that whatever exists in English, it would be a simple translation rather than sensitive to a cultural issue, I don't know how you disseminate information.

D: Sometimes it's hard with information because you lost the meaning or the point that you're trying to make is lost in translation. Sometimes they get information on Medicaid in Spanish, in their language, and they still don't understand it. Since they're trying to translate it exactly, and the terms they're trying to use might be above their education.

Ruth: What is it about those documents that fails to communicate?

D: It might speak to some seniors about their educational level.

R: it's true of English as well, though. I think most documents, it's like, I want to impress people with the legalese, jargonize. That is also one of the delights about MI, it feels very sensitive, this is about helping you understand, not about giving you information, but about helping you understand.

Ruth: So many of these documents tend to talk to seniors above their head? (Not communicating clearly)

P: Regardless of the language they need to watch losing site of the goal of communicating the essence versus creating credibility through classification.

M: Not giving you information but helping you understand.

Ruth: That's an interesting distinction.

Ruth: In your experience, what are the current trends in information needs or services?

R: Home care, home care, home care. At least for me, more than 50% of the inquiries I get are, I want mom to stay at home, she needs help at home, how does she get that help, and does Medicare pay. Or, of course Medicare pays, doesn't Medicare pay?

M: Home care is a big issue for me, too. I think another issue that we need to start thinking about is the new generation of the young seniors who are coming up in the ranks. How to get them the information about all the different programs, how to educate them a little bit more than my mother was. I don't think they know enough about Medicare or Social Security or other resources until they need it. I think it's something that, since that generation is going to be healthier, I think they should be educated about what's coming down the road when they hit their 70's or 80's.

Ruth: When you say educated can you be more specific?

M: They need to read more about the resources that are coming. Like the IRAs, they need to learn that you can't live on Social Security like my mother did. They need to plan what's going to happen when they can't take care of themselves. Can I afford home care, are there agencies that can provide it for me? I discuss it with my children, and I know I'm very aware of it, and I'm planning on it. I think the young seniors need to start educating themselves.

Ruth: Self preparation.

R: I was thinking, long term care insurance.

M: But it's very expensive, it's really very very expensive. We need to find other options that can help the future seniors.

P: I still think though that the younger seniors are still in such grave denial about the fact that this is going to happen, they're still thinking about their parents.

M: I have three children, and I talk to them about what's going to happen, they ask to leave them notes. They see what we're going through and having to put her in assisted living. We didn't have much of a choice, she couldn't live on her own, we were all working, as much time as we spent with her.

R: Advanced directives.

M: People need to know about what's going to help them be better seniors.

P: I have a client who works with seniors, who says, this is my dress rehearsals, so many people hire people, I think that television and Hollywood just romanticizes it, it says we're just going to get older and then we're going to gracefully die. Even just a simple hip fracture…

R: My friends don't want to talk to me anymore, I'm so morbid.

P: My husband is over 65, he's in total denial. He could not tell you what Part A is, or what he has. I think he's pretty typical of our social circle of men his age.

M: When you read about the Rx program, they don't tell you about the donut hole, and the $35 that they might be taking out of your Social Security check or that it's mandatory. Those are issues that are not out there, until it hits the new generation of seniors, they just don't know! How much can I get the information out there? Even watching the debates, nobody said anything!

Ruth: Why do you think there's a lack of awareness, why doesn't it come up?

M: It's not good news.

R: I think that a lot of people, whether it's assumptions that they make, they're very inaccurate. I don't need to worry, Medicare is there for me. They're not saying that about Social Security, but they used to. So we've debunked that myth, but not so the Medicare health care myth. Maybe you'll get Medigap if you're concerned about the last 20%.

M: I think that's changing.

Ruth: How have the needs of your clients changed in the last year?

D: Most of the problems that I have are home care and transportation, getting them to and from the doctor's, their children's house, I have a lot of independent seniors who don't want to say I have a problem getting on the bus, so they stay at home and we want to get them out. If there's transportation, it's only within a limited area. If you live in that area, you're provided bus services, but if not, you're not. Access-a-ride is not as helpful.

R: Seniors are not necessarily proactive. There was a study about EPIC, why it's not more successful. They found that most seniors don't even know about it. In terms of entitlements/empowerment, they know that those who happen to be fortunately connected or proactive with social service agency. But that doesn't address the majority of seniors who don't even think about doing it.

P: Maybe it's a responsibility of our employers as to what is really out there.

R: I've had an opportunity to speak with seniors who are absolutely eligible for Medicaid but they don't know. We haven't done a good job in being proactive.

Di: A lot of my clients don't know about penalties because they don't understand it, so we have to explain it to them. We have to educate them about the system, what are your rights and responsibilities. I always show a bill of rights for the patients. You have to know that if a health plan, for example, denies a treatment, it doesn't mea that you have to stop the treatment.

R: TV could be a really good resource for seniors. They have all these infomercials days and night; many seniors don't sleep well and may be up into the wee hours of the morning. Why aren't they getting this information about it?

P: Get Oprah to talk about it one day.

I: Home care is probably number two issues, but the number one issue is lack of subsidized housing, especially for the baby boomer generation. They say that my rent is two thirds of my income. They only rational option is to relocate.

M: If you fill out your application when you're 50 and then wait ten years…you can't even get on the waiting list.

I: That's the dilemma that's facing me now.

BEEP'M Supervisor Discussion Group
10/12/04
2:00 pm – 4:00 pm

Good morning/afternoon. My name is Ruth. I am a communications consultant. I am conducting the evaluation of this project. How many of you have ever heard of or participated in a focus group? The whole purpose of this discussion will be to get your thoughts and opinions on the Medicare Interactive program. So today my role will be to ask you questions and to moderate the discussion.

There are just a few guidelines I would like you to follow

- This session will be tape recorded. The recordings and the notes that (name) is taking will only be used to write the final report.
- All discussions will be completely confidential. No one's name or affiliation will appear in the report.
- Please be open and completely honest. The results from these discussions will help to improve the Medicare Interactive program. So your opinions and experiences are very valuable.
- Please speak one at a time. This will ensure that we will hear everyone's comments.
- Please avoid any side conversations or comments. We all want to hear your thoughts.
- This session will last about 2 hours. Please feel free to help yourself to the refreshments.
- The restrooms are….

Introductions/Warm up

- Go around the room and give your name, affiliation, and primary focus of your program.
- What do you love most about your job?

BG-Community Health Alliance Harlem North Manhattan. Faith based coalition. We work with 40 churches around issues of health disparities, education, exercise, mental health, childhood obesity, others, Harlem focused community.

M--Wyckoff Gardens Senior center work with seniors and disabled people. We translate letters from Medicare. Serve breakfast and lunch to seniors in our community.

E --Raices Carona Senior Center in Queens. We offer meals no breakfast and provide the senior community plus regular community with education and referral all benefits and entitlements, case assistance, a lot of food stamps, outreach, getting people to apply in community, system of Medicare computers now we're getting people to come to resolve issues they have. Recreation and cultural activities, budgeted for 70 meals daily, getting 80 to 100 people. Problem is the space. Supposed to have 70 people in general, small. If we got a bigger place could accommodate more people.

RB-Red Hook serves elderly and disabled. SSD breakfast and lunch, entitlement, benefits, referrals, information whatever.

Cuad. IPRHE . Direct one center and oversee 4 others and caregiver and mental health programs. Case assistance in all our centers.

Ruth—What do you love about your job?

RB—Serving seniors. Helping them have a better quality of life; make them smile or make life happier more comfortable, more rewarding. That's what I get out of it.

M—I have the opportunity to learn and find out what is outside –get all the information, having the information is the main most important thing in my job. The only way I can help my community. If I don't know what's outside for them I can't help them. Then I'm prepared from them. I know what to do.

E—doing this all my 35 years in the United States I've been dealing with seniors. I enjoy everything I've done everything in aging. Administration, supervision, staff, I have belonged to different boards. And my seniors are the most interesting a challenging thing I have. I have in my center from 22 Spanish countries, 14 are represented. In September, we celebrate all the independence, costumes, dance, poems, prepare dramas, I enjoy preparing all that. Next week JP Morgan is celebrating discovery of America. Raffle with seniors, everything is free, food and everything. When free, so many people come. I can only accommodate 70 with the staff I'm expecting 100 where will I put them? It's very challenging and rewarding to see the seniors happy. Not just my center, any center, seeing them come out of the isolation of the house, make friends, get phone numbers of everyone, gossip about what happened in the center today. Give them an incentive to continue living.

BG—Why do I like this job? Obviously I do. I took it 6 years ago for 6 months. What I really like about this job is that I have a history of running big systems on the Medicare care side—insurance—I got tired of running systems. This job affords me to take what I learned and keep it simple. A lot of people in our community don't receive the benefits available to them because they don't get information. This gives me an opportunity to work with ministers. They're much more difficult than hospital insurance CEOs.

Cuad—My turn. What I like is—been in the job going on 6 years. I like ability to innovative things, showcase things, opportunity. Elmhurst senior center, mixed population, 350-400 people a day. It's a large place. It's supposed to have 200. To make it really function as multicultural setting has been a challenge and an achievement and it's really shown in the city and a model program. That makes me feel good. When I took over the position of executive director I talked about mental health clinic I said "not my thing" in the back of my mind "don't talk to me about mental health program" but we set up a clinic in the center, functioning beautifully. We were licensed in 1999 moving it to its own site now, keeping it in the center as a satellite. Good to see growth. As I was

saying I didn't want to get involved, but when I see the needs to be met, Spanish speaking elderly coming from all over for help, providing something that's really needed.

[Wilfredo comes in—Ruth introduces the point of discussion]

WG-- Project SOS. We provide case management to home bound senior citizens in the South Bronx. Provide meals, home care, assistance with whatever they need is the way we look at it. And the Beep'm program was good for us because when we had a question we needed answered we can go and look it up.

Ruth—Tell me what you love about your job.

WG--Well, I've been in project SOS for 14 years and I've been involved in social work with a variety of ages, started with seniors 15 years ago. I find it very rewarding, a little more gratifying than other populations because with seniors we can help them almost immediately, quickly. Different than kids, wait until they become adults, teachers that made an impact on me, wish I could tell them so. Unfortunately we can't. I like helping seniors, people out, no longer have one on one contact as supervisor, but I get gratification making sure the people I supervise give the help that seniors need.

Ruth—I have tremendous respect for everything you do. The gifts and human contact you provide very important. Medicare I want to talk about first. Which questions come up most frequently? How often do you even deal with Medicare?

WG-We don't have a center. We go to the clients' houses and deal with them one on one. Some questions have to do with other if they're considering an HMO or why they don't get this if in an HMO, and most recently the prescription questions have been coming up. People are really confused, don't know which card they should get. That's ..those are the areas.

BG-We work with almost 40 churches. Medicare is a constant issue in every church. Very basic kinds of information. People who are 65 and don't even know they're eligible to apply. People where you get forms, how you fill them out, eligibility, prescription, enrollment; everyone is basically confused by the cards.

E—In my center one thing that happens is 85% is monolingual Spanish and maybe with a no schooling or 3rd or 4th grade of schooling, although the information comes in Spanish sometimes they still don't understand what it means even in Spanish they have to bring it to me to read it to me, even if it's Spanish they bring it one woman brought 13 unopened letters for me to read. The rx card, the visit during the year, things like that. Food stamps continuation, Then we have Medicare this is not a bill, but they see it and …

Cuad—Looks like a bill.

M—the way they put it they confuse things; they put this is not a bill, but on the bottom on this day you visited this doctor and Medicare payed this and "you don't owe nothing"

at the bottom but they don't see this. This is one of the biggest questions that we have in the center.

E—sometimes... some doctors accept assignment but they don't know that—there's a balance (on the MSN) but they say "its 300" and I say you don't have to pay that. Lately since we've been promoting that we have this system "come see us" I make the appointment on Thursday for Pia to talk to them. A lot of the questions that Pia has had are HMO's. Most of my seniors have Medicare and Medicaid but they hear about these other programs and want to change. Some go to Elmhurst Hospital. Over there they have these other insurance programs and they sign up for that, so they go to the doctor and they say they can't see them because they're no longer a Medicare recipient. They come to me "why did they do this to me" and I say "apparently we switched'. Then we have to go through the disenrollment process.

RB—agree with everything they're saying. Biggest problem they have is if they have Medicare, even with an HMO won't cover Rx. Might be seeking hearing aids and glasses, seeking a plan or HMO or anyone that will pay whatever they need because they don't want to pay out of pocket expenses. It's too expensive for them.

EC—health 65 I have someone on that program. I have someone who has to buy the needles for diabetic testing. She also has epic so in the pharmacy she can use either. Once they charged $25 for the copayment. Fine she paid that. No $5 one month, $25 the next month, and in the 3rd month it wasn't covered in any of the plans. She said "what am I going to do" she was spending $225 a month on copays deductibles, whatever. I have a pharmacy on the other side of queens, he waives the copay, If it's high, he gives them half price. The lady was able to save some money to do it there.

MCuad—That's the main thing that happen with seniors on Medicare. They're on the mercy of companies that sell them something without explaining all the details or the small print. Don't know that things can change from one day to the other in any of these plans. Seniors who didn't go into Medicare at 65 years later realize they have to pay retroactive fees.

Ruth-What is your strongest area of knowledge about Medicare?

Cuad—Basic eligibility and what it provides. Problem with Medicare is it has been changing from one day to another. You really have to keep up with the subtleties People even involved in the legislation don't understand everything that goes into it.

E—I used to know a lot about entitlements, I could catch seniors with nothing and link him to everything and left the office with…that was when I was just doing entitlement, and reading and trainings and everything, now it's difficult because I'm in a different position. Now just if there's something I need to know right away I read it and explain but also with the staff I don't know if you have much staff—we don't—I only have one case worker and myself and we run the whole center and do everything in there. Some centers will set up hours –only see case worker M-W for Monday and Tuesday from 10-

2. My case worker is flexible will see anyone any time. Will put things aside and do what needs to be done. We don't have the staff for the population—mari that has a big staff—need special case workers that will do entitlements.

Cuad—And the languages. We have one part time Chinese case worker, Chinese is Title 5 person, Korean that is Title 5—these are 55+ people employed at minimum wage, 20 hours a week and you train them as well as you can, try to get the best people you can and train them on the benefits –they're seniors themselves, train them to work with the seniors

El—you have to supervise what they're doing because they might make a mistake

Cl—give the wrong information

E—these are the ways we're running our centers. Everyone tries to do the best they can. My youngest title 5 is 67. My oldest is 82.

MariCl-mine is 65

Cuad—the program is getting tougher because they sued to let them in year after year. Now you get them for 2 years and you lose them. You have to move them on to actually paying jobs and we don't have positions to hire them in.

Cl—and who is going to hire someone 80 years old

Cuad—it's ridiculous. We can't hire them.

Ruth--Weakest areas?

RB—the weakest are for my staff is to be able to convince them to take a Medicare buy in or a Medigap they would rather have Medicaid and you tell them they might not be eligible or they might have something called a spend down where they still have to spend money . It's difficult to convince them to accept this because they don't want to spend the money for quality healthcare. Feel bad because they're blind and convince them to get the Medigap for home care and their families are not willing to spend the money. That's sad.

Ruth—It's finding the services.

BG—the site works very well providing basic information. We did the program with two churches one worked very well with one church the other did not. The key was the people who we paid to do it. At one the young woman was very good, took to it. The other church, we couldn't find someone the right person. to pick up the information very quickly and communicate it articulately. Sometimes you have people come in with very complicated information. Difficult to get them to understand you have options A, B and C, but one might be better for them, but it's difficult to explain that it might not happen.

Some people clearly have complicated issues and bring baggage. You can give information, but you can't necessarily do that much because they're not ready. How you can identify the right person…we employed a young woman, quick study wanted to work 20 hours or so. That was critical to making the project work in that church, seniors gravitated, brought friends, even people not eligible for Medicare. The basic information is there, fairly easy to navigate, most difficult. The problem is when you get people with more complicated issues or who bring baggage to it. They tell you "Don't want to get involve in this. I'm not telling you anything."

Cl—Medicare the person is supposed to be 65 and up or disabled after 24 months. I think our centers, we sign in seniors between 60s and up to be members and I think it's good for us to give the new people information, inform them about what will happen when they hit 65 and apply for social security, get a letter to let them know 3 months before, to let them know "if you want your Medicare card keep it, active starting this date—if you don't want it, sign this card. We have to explain.

Cuad-They don't know the difference (between a and B)

Cl—They're thinking if I take Medicare they take the 61 dollars from my check for SSI and Medicare so I don't want to take it. We have to explain that they need the Medicare because if they get in late they pay more—67, 68 years old your premium will be higher if you take Medicare then. Have to inform the community informed, not just the seniors.

Ruth-How is information distributed to your staff about Medicare?

Cuad—Trainings. Every flier that comes in from Medicare Medicaid I give to each staff.

Cl—Information we pick up from the social security office. Let them know what's new & going on.

E—I don't have the time, but whenever I can go in the computer, I didn't want to do it because I didn't like the computer. Pia wasn't around and I went into the system and I was amazed by how easy it was and how fast I got the information. But I don't have enough hours in the day.

Ruth-- Do you mean Medicare Interactive?

E--One time and I was really really happy I was able to access it.

WG—We have regular staff meetings and whenever there is something new the director brings it up at the meeting and makes sure it's discussed to make sure people understand any changes with Medicare or anything else.

Ruth—How do you find out about the changes?

WG- We get notices from DFTA, from the Brookdale center on the Aging, Medicaid itself, whenever.

Ruth—These notices come how?

WG--by mail and recently they come by email.

RB—We get information from our main office. Raices access service where they train the case workers give them information. Manual—ACS manual that's updated. A big bible.

Ruth—Where does ACS come from?

RB--Comes from Brookdale We get all the updates on all the entitlements. We information from elected officials. They send information. We get it on our own on the news and stuff like that. We try to share new information with the seniors and whatnot.

E—if there's any new program in the community we're on their mailing and they send it to us. Elmhurst hospital always sending

Cuad—Lani Sanchack; she works on policy organization. She keeps us up to date by email on different changes that are coming up. How the organization is advocating. Also the Council of Senior Centers.

BG-CMS

Cuad—and this of course—Medicare rights.

Ruth—Do you give individual training or do you send them out?

Cuad-Send them out.

E-Send them out.

Cuad—DFTA, MRC gives trainings. Brookdale

E—The Brookdale Center on Aging.

W- They're a part of hunter college.

Cuad—The seminars they give sometimes. The Queens Interagency Council will address the issue. Different councils throughout the city.

Ruth—How do you manage turnover?

BG—no turnover.

RB—staff, what staff?!

E—My center is only 3 people. Me, my case worker, title 5 workers, and kitchen worker. Some of the title 5 are "bilingual" but not 100%. One person is a volunteer. She used to be working but had an accident, but still works part time 2 or 3 days a week. She's part of Amy Berstein's hicap program. She helps out a lot.

W- DIFTA does training throughout the year.

Ruth—how familiar are you and your staff with the Internet?

Mcuad-Varies.

E--Have a computer at home. It was out for a year and 3 months and I didn't miss it. My daughter told me to learn how to use it—I still haven't turned it on. In the office we have the PDS system. I forgot to do the export today. Another program we have to deal with and I'm the only one who deals with it. The other 2 who went for training, and I'm the only one left. I have other things I have to do. There are 2 different systems—PDS and MI—but I only use the Internet it if it's an emergency.

Cuad-I use it for research, to find out what's going on. A lot of messages going back and forth. First thing I look at are messages on the phone and email.

BG—I'm a strong believer of technology. My wife calls the computer My mistress. We've invested resources with staff—constantly send them for training. Once you get through the training, you find it makes your job not necessarily easier, but better. Getting ready to work with churches to use Internet resources to address health education resources.

Elb—When you send staff for training, who stays in the office? I only have one person so if she's out I have to be there.

BG-My assistant never gets sick. She's worked with me for 20 years. Today's the first time in 2 1/2 years. "My wife at work."

Ruth-Do any of you have an onsite technical staff to help with your computer?

Cuad—We did until last week. We lost him. He was the one who we called. That was his job (to troubleshoot). He was pretty good.

Cl—we don't have one

BG—we have one that will come within 6 hours.

E—I have one. Kate.

W-Bronx community college campus. Everyone has computers on their desk and we have access to the college Internet system. They also provide some tech support.

RB-We don't have an on site consultant or technician. We call Kate and with the other computer system DFTA –if there's a problem they come out right away to take care of the problem.

Ruth—Do any of your organizations have policies surrounding the use of the Internet?

Cuad-Yes

BG-yes, particularly with abuse, sending emails or going to inappropriate sites, taking care of computers. Not elaborate, we're thinking about more detailed procedures.

Ruth-Any area in particular?

BG-People don't get the benefit of computers because they haven't been trained or don't know. My bugaboo is getting staff to treat the computer like a third arm. Spend less time on policy, but we have some because of liability issues—may lay out more stringent detailed policies. Talking it over now. A few policies about proper use of the email system, staying on work related sites.

R—When you were first introduced to Medicare Interactive (MI) what did you feel? What were you told?

Cuad-That we had to work on it. Put it together and work. It was a matter of working up resources, giving ideas about what topics should be there. Testing it out, giving feedback.

Ruth-So you knew you would be involved in development?

Cuad—An active role.

E-We got scared when talking about deputizing.

Cuad-SLMB and QMB—what happened with that—sometimes you sent applications and they went up in the air.

E-Alba went for deputization and she's been gone for a year or so. Kate always responded to questions and then we got Pia. Pia has been very helpful with helping out with the seniors. Two weeks ago we had done 111 cases in my center since we started. Sometimes with a client it's not just 15 minutes, you're there for 2 hours.

RB—I heard about the same as they heard. I wanted to add that it would involve seniors participating in this also, that they could go on the computer and look up their benefits and whatever their entitlements.

E-Yes. We had computer classes. Were you the one giving the classes? I had 8 seniors interested and I only have 2 computers. They didn't even know keyboarding. The mouse was out of this world. The person giving the classes only had 10 or 12 sessions for 2 hours twice a week. Time flew by and no one else to teach them and whatever they learned went out. 8 understood a little English but the thing of keyboarding, moving the mouse, took time. To leave them alone in the basement with the computers was a little problematic.

RB—There was something else. Everyone was going to get training on the computers. Everyone involved. Case workers. It was nice going to New York Technical school to get computer lessons with the young people.

Ruth-- Did your initial perceptions match the actual system?

Cuad—I think it came out pretty nice from what I expected and I agree that getting the seniors to use it has not worked out as well. I don't think it's a problem with the program, but the limitations that they have. My dream is that at some point it will be open to the public so everyone can go in there and answer their own questions. That could happen.

Ruth—How did you introduce MI to your staff? How did you make that transition?

Cuad—Called Kate.

BG—I called them in and said we need to go through it, learn it. Here's how you navigate the site.

Cuad-it's simple.

BG—In a way they undersold. When the project was first introduced as an interactive they didn't describe how good the system is and that once you got on it and started to use it you really started to learn that this was a resource that could provide people with information. This didn't come through in the initial conversation, but as you started to get online particularly if you're comfortable with computers. It's a positive resource that we need to build on

Cuad-I saw on my computer how it could be used and had Kate come over, sit with them and go over it with groups.

Ruth—So you did outside training.

WG-We had a demonstration during one of our meetings how to get on the site and navigate and then everyone tried it. People react differently. Some people had computer phobia at first, didn't want to touch it at first others computer literate, interested, spent the time going through it. As they became familiar, realized it was more computer friendly than they thought.

Ruth--What was the initial reaction? What were their incentives for using MI? Obstacles?

WG- Getting the information. Some things are easier to find there if you know what you're looking for.

Ruth-If you know what you're looking for, easy to find it.

Cuad-another type of person you would tell them about it, they would say "I know it all. I don't need the computer" People like that never learn anything new.

BG-those are the ones that have the wrong information.

Ruth-Do you find their resistance to learning new information is equal to things that are not on the computer? Fliers or trainings?

Cuad-This type of person doesn't want to sit in front of the screen. On a paper they got used to looking through these books, with the stuff on their desks. They don't want to turn the computer on. Some people don't want to turn it on even if it's on their desks.

Ruth-The obstacle is getting them to change the way they operate.

WG—it might be faster for them to go to the book if they know how to use it already.

Ruth--What about your existing work environment made implementing MI easier?

W-Having Internet access and having the computers on their desk.

Cl-the same

Cuad- Some sites—all different—some attracted to it, others are controlling and it's difficult to get them on it. The other places are pretty open and there were computers there to start with. We placed the computer accessible to seniors—at one we had it stolen because it was so accessible.

BG-that happens

Ruth--Was there any other factors that made it harder?

E- I have obstacles. My computers are in the basement. It is not supposed to be used by anyone, as an office or anything. I use it for storage but I said, I need space. There are steep stairs, so to have seniors coming up or down, any time you have to go with them, have a staff or stronger man help them down. Not enough space upstairs. If someone calls up there you have to yell because of all the noise. All the computers are downstairs. Any time if I'm upstairs and need to do anything I have to go downstairs. The caseworker and

I don’t have computers on our desks. All three in the basement, the one for DFTA for PDS and two for the Medicare.

Ruth—Can you think of anything that could be added or changed to MI to attract you or your staff to use MI more often?

E—Can’t think of anything.

Ruth--Has MI changed your ability to serve your clients? In what way?

Cl (nods)-. It’s been very easy for us to go right to the information, especially when you don’t have the time to look in the big bible, you click and right away you have the information that you need it’s faster. We know the information is there and up to date. We only have to go and look for it.

BG (nodding)- It’s very easy to navigate through that system if you have basic familiarity with the Internet. One of the easier sites I‘ve looked at.

Ruth--What level of knowledge of Medicare is necessary to get counselors to use MI? Does the person need to have a preexisting level of Medicare before they use MI?

Cuad-The questions are there, they come to you with the questions. The topics are right there and you find the one you’re looking for.

ClU- You just need to know how to use the mouse.

BG-The questions are there. Listed. Biggest problem is having someone sufficiently computer literate to use the site. That’s the biggest issue that decides whether people go to the site and use it or not.

E-You need computer knowledge.

RB—It’s such a simple program that even if my workers are too caught up to use the site. They have showed it to a senior and have them go and use the Medicare Rights and go straight to the information they want. It’s a very good system. It could be utilized by seniors so they can look up their own information. I find it to be true because I’ve done it with my seniors. Especially if they’re not afraid of the computer. They can go straight to it and use it.

BG-Make a distinction between computer literate and computer comfortable. There are people—true in this project—who don’t feel comfortable going beyond turning a computer on. In some cases this is the issue. People say they don’t know anything about computers, can’t learn anything.

Cuad--Yeah, they’re afraid they’ll break something.

BG—That's an issue I think with this program. As I move forward I will focus more on the people we have doing this, more focused on people being computer comfortable and literate, particular if teaching seniors

Cl—Regarding seniors navigating to find Medicare information, it's a good idea, but what I see with my seniors maybe, is that if I check information in the computer they might be reading and reading and reading but the problem is making sure they understand what they're reading. We have to make sure they understanding the information the way they're supposed to be. They're reading but sometimes they don't understand what the words mean. We have to be next to them to make sure they're getting the information the way they're supposed to get it.

Ruth--What do you think a center needs in order to successfully implement MI?

Cuad- Computers on the desk of course. People that have some kind of familiarity with computers and in my center I was trying to get the seniors to take a class on computers. Unless you really show them they aren't going to use it. It hasn't materialized yet, but it's one of my goals to get seniors to use it.

BG-If the ultimate goal is to get seniors themselves to come into the center and use the computer, it's not just simply having someone whose computer comfortable. It requires someone who can teach and train people, people who can articulate at some level to make seniors and people feel comfortable that they can get help and have the ability to learn and do new things. Sometimes people who explain computers are the last people to teach anyone. Not because they don't know but because they can't teach anything.

WG- The same people who write manuals.

Ruth—What other strategies are used to get seniors involved?

E—I just need the space. A computer room where the computers are there and people can go there to use the computer, read about MI and whatever, sit and do whatever they need to do. I don't have the space.

Ruth—You need an MI mobile like a Bookmobile that goes from neighborhood to neighborhood. How important do you think it is to provide access to MI for seniors?

BG-Very. Probably 80% have Medicare question's makes them anxious. A lot could be relieved if they just had basic information. The issue of the MSN/bill—go through it with my mother all the time she immediately pulls out her checkbook. The information MI provides is extremely important for a high percentage of seniors, many of them don't admit it until the issue becomes an emergency. It's a good and important product. I intended to continue to make it available.

Cuad-Especially with limitations in staff. In some situations you have to advocate for a senior, call an agency, but in cases where they can get the information it would relieve staff time.

E-In my situation, it's different. My seniors don't read or write English. Even if I get it on the computer I have to translate and explain. If it was going to take 45 minutes in English, it would take an hour and a half.

Ruth-So translation is extremely important.

EC-If someone wants to present I ask if they have someone who speaks Spanish and if they say no I say you're not coming because I'm not going to translate. A lot of technical information and if you don't understand, you can't translate it.

Ruth—Why do you think that is?

EC—They don't know the topic. Sometimes even if they don't translate, and the information that's being translated is completely different from the English—if they're not assimilating the information and communicating it meaningfully.

Ruth--When translating, what should MRC take into consideration? (PROBE: important features and considerations)

EC-if you want seniors to get to the information and read it it has to be translated.

Cuad-You could summarize. They don't need all of it.

EC-If you summarize, it should be everything in Spanish if it's everything in English.

Ruth-What other languages?

Cuad-Korean and Chinese too. Philipinos in our center too, but a smaller population.

E-In our area, Koreans, and Chinese. Some Japanese in Flushing. Spanish.

Cuad—Especially Queens is multicultural, multilingual.

Ruth--What cultural factors are particularly important when developing MI for other languages?

E—They have to know exactly what they're translating. The concept of the topic Can't translate word by word.

Cuad-literal vs. concept translation

BG-What does it mean in the culture you're translating into. HIP recently converted its site to both Spanish and Korean (HMO). Covers a million people here in NYC. An increasing issue given multiculturalism in NY– you'll see more and more of this regardless of economics; people don't fully understand unless it's in their own language, whether or not it's preference or other or it's the only language they speak.

Cuad-When it comes to those bills you don't understand it even in your own language.

BG-HIP have a constituency that is sufficient in numbers of Korean and Spanish. That it made sense to translate it.

Cuad-once you have it translated, have it reviewed by 2 or 3 people.

Ruth-What cultural factors should be taken into consideration?

E-nods. Spanish is Spanish and we all speak differently in 22 different countries. I've learned so much from my seniors. When I started there were some words that are really bad words for us and they were saying them like it's no big deal. The same way I'll say something bad to them but to me it's nothing.

BG-Is there a word for formulary and what does it mean?

Cuad-Formulario.

E-it could be like an application, a form, but then also when you use the word application, some say "application" and it's not right' It's solicitude. Things like that you have to watch out for when you're writing.

BG-It's not just simple translation. You have to ask when translating what does it mean; could have a completely different meaning or broader.

Cuad-That's why I say 2 or 3 people.

BG-There are an 100 different things in a benefit manual that simply have no meaning or a different meaning in a different language.

E-I never read anything in Spanish. Always in English because I know that's the original language. Sometimes the translation can be a poor translation.

Ruth--When you think of all the different programs you've worked with, which ones endured? Why?

Cuad-Because they meet a real need. Serve a purpose. Versus something cosmetic. I think also it's a matter of marketing if you get people to really understand what is out there, available and it becomes part of the day to day vernacular. It persists.

Ruth-Did anyone do marketing around MI?

BG-Yes. One church did a breakfast, created a relationship with a couple of churches that send seniors. I would do it more intensively and continue it. They got a moderate response. Could have been planned better but we'll fix it.

E. We did a big mailing, over 500 letters. We sent it to all the seniors, the ones that come every day, some that haven't seen in a while. Sent it out to different agencies, different communities. Outreach with the letters has brought a lot of new seniors into the center. I have a lot who come in, received the letter a while back and they keep coming.

Ruth—Did anyone else do marketing for their center MI? To let them know this service was available.

Cuad-Mainly with my own case workers.

Cl-So they knew.

R-Internal.
(agreement)

E—also at lunch time we do announcements to let them know what's available. The Rx drug.

Cuad-the Rx drug mess.

E-tell them they'll receive the letter don't sign anything until we let them know. If there are changes, questions, you can talk to me.

Ruth-Real need versus politically correct or meeting current funding streams. More specifically, what will make MI endure in the centers?

Cuad-If it keeps Medicare information up to date and people know it's an easy way to find out what is the latest it will be very useful. I think it's time to go to all the senior centers. There are about 300 of them. I don't see why they can't have access. It's working well, has proven itself and that would be useful. There are 330 centers and in all of them people are coming to the case workers, all have limited staffing.

E-If we can do it with our little staff, they can do it too. I was thinking that maybe I haven't announced that it's there for the public, but maybe other people. Doesn't have to be a senior. Could be the children of the seniors who come in and get the information. Announce that anyone who needs the information they can come. It's easier for a younger person to go downstairs.

Cuad-Too bad you don't have space for those computers.

BG-What makes it sustainable is the degree to which people use it. Need to look better at how you gather information on its use w.r.t numbers and what types of issues people go online to get information about. If it gets done a little better and numbers are worked out to make the case why the project is important in NYC or elsewhere, whether at centers, churches or wherever.

E-Can anyone access MI through the center?

Ruth -Only with a password. It's not public. You're an exclusive club.

E-I had a lady who retired and I think she was 64 and she wanted to start looking for information when she reached 65 what other insurance she could take. Someone told her to go to the MRC. They told her to go on the Internet from home. I think she did something.

R-MRC is separate from MI.

E-She couldn't get what she was looking for. I went into MI and found it

BG-look at who they are and whether the Internet and computers are accessible do they have the staff there. Do they have access to organizations or seniors to have the potential for it to be used appropriately?

Ruth-One thing you need, individually, to keep using MI?

WG- think if I can put in any question like I would ask a person, if I could do that, that would be great.

BG-Not navigate it. Smart man!

W-I think that's a drawback that keeps some of our workers from using it. Might be why they use the book because they have to search out their question. The questions that are very common maybe that can be done but expand it so encompasses more difficult questions.

RB—As long as it is still there, I use it and staff will use it and seniors who are able to use the system to get the information, we will still be using it as long as the system is still operating.

Ruth-probably still a good idea to have tech support at MI.

Cuad—Keep it up to date.

Cl-Yeah. That's the most important.

BG-We probably need to look more at two things-one, looking at standardized utilization. Probably may or June next year, call us back together, see what happened in the last 6 months since you've been on your own. We all have varied experience and want to continue to try to use it, It would be helpful if all the participants agreed to basic collection of data, even if it imposes on some of us, to come back together in may or June see how are you guys doing on this stuff.

Langeloth Counselor Discussion Group (BEEP'M)
10/13/04
10:00 am-12:00pm

Good morning/afternoon. My name is Ruth. I am a communications consultant. I am conducting the evaluation of this project. How many of you have ever heard of or participated in a focus group? The whole purpose of this discussion will be to get your thoughts and opinions on the Medicare Interactive program. So today my role will be to ask you questions and to moderate the discussion.

There are just a few guidelines I would like you to follow

- This session will be tape recorded. The recordings and the notes that (name) is taking will only be used to write the final report.
- All discussions will be completely confidential. No one's name or affiliation will appear in the report.
- Please be open and completely honest. The results from these discussions will help to improve the Medicare Interactive program. So your opinions and experiences are very valuable.
- Please speak one at a time. This will ensure that we will hear everyone's comments.
- Please avoid any side conversations or comments. We all want to hear your thoughts.
- This session will last about 2 hours. Please feel free to help yourself to the refreshments.
- The restrooms are….

Introductions/Warm up

- Go around the room and give your name, affiliation, and primary focus of your program.

St.: Nazi Victims Unit at Selfhelp Community Services; working with Holocaust survivors and helping them to continue to live independently in the community.

S: Social worker and enrollment coordinator at Senior Health Partners; also a co-chair of East Harlem Health Community. SHP is a Medicaid managed long-term care provider in Manhattan. We service Seniors 55+. We have an adult day program, provide counseling on services.

Sh: Work in NORC program in Jackson Heights with Selfhelp; serve 6 co-ops; about 1000 people over 60 that we serve; there's a continuum – some are homebound and some are active; we provide counseling on benefits, entitlements, 1-on-1 counseling and group services; social worker and director of program.

A: Social worker with Caregivers Resource Center through Mt. Sinai; mostly with caregivers in New York but also nationwide.

Al: Social work Coordinator at Linkage House; senior residence in East Harlem in partnership with Mt. Sinai; provide quality housing for low-income seniors but also social work services, health education and maintaining quality of life as best they can in the community.

Ruth: What do you love most about your job?

Sh: I love working with senior citizens and I think Selfhelp is a really terrific organization. I'm very happy there; they're very nurturing people that I work with. People in housing unit are wonderful. From that perspective, my job is great.

S: in the field of aging for many years; truly enjoy it; I have the great pleasure as a result of the job I have to provide services in the community where I reside which is East Harlem; ability to provide concrete services and have flexibility to interact professionally with my colleagues, looking at broader issues (policy, etc.); I feel very productive; It's a lot of work. It's frustrating many times. That's what I like about my work.

A: definitely what I like is the interaction with other professionals; to do more, learn about advocacy and to educate more; there is a selfish element; the information I learn is tremendously useful in different levels. Caregiver work is different level of work, but through assistance through the caregiver and working through the hospital; just the element of working with the caregiver is an interesting element that I like very much, looking at the whole picture but it's the bigger support system that needs to be worked on and put into place to better the situation.

Al: Definitely working with seniors. They bring a lot, their life experiences, there histories. I have a really international group and working with people with different languages and backgrounds, working with my colleagues to develop programs and resources for the seniors. I enjoy it very much.

St: My sentiments echo a lot of what everyone else has said. One of the things I love about working with the population I work with (I came from a foster care background) is there is a rich history; I work with the clients long-term; it's very inspiring to get to know them individually and get to know the experiences and what they've had to endure and what they've been able to create for themselves. These are people of tremendous character and strength. As they're getting older, really an obligation to help them live with dignity and independence for as long as they can.

Ruth--What Medicare questions are you most frequently asked?

A: changes in Medicare; confusion between Part A, B, eligibility premiums. As we move on, it feels like it's only going to get worse with confusion about Part D; entire Medicare system is confusing and not clear to most of seniors I work with; what do they have? What are their premiums? With Part D now coming in, it's going to be a mess.

S: many people tell me I didn't even know there was a C! I have to second that now with the increasing parts there's a lot of anxiety and probably some resistance. I'm also hearing a lot of anger amongst some seniors, those who are vocal, where there are advocates presenting on some of these changes, and I was struck by some of the comments. There was a 73-year old woman who said I'm 73 and I've never been as upset with my country as I am now. Very powerful words. Another gentleman, his statement was "you are all so knowledgeable; you have access to all this information; why are you wasting your time and our time with minutiae, we should be looking at what is good about this system, making it stronger rather than weakening the system." I've been struck by the comments of many of the seniors; seniors in our community, many are not aware, many that are not active and participating in senior center activities, are oblivious to what's coming down the pike, and it's quite frightening. There's a segment that seems very well-informed and there's another segment that isn't aware, and there's another segment that's very confused, as are many of us.

A: I can't tell you how many people I spoke with to try to figure out what's going on with Part D; there are so many elements and it's just not straightforward, and I just can't imagine. If you find out what you have is usually a time of crisis when you are in desperate need and there's a lot going on. If I'm having a difficult time on a regular day and I'm imagining a senior with other financial difficulties and loads of information and then a health crisis. System relies on people just giving up.

Sh: I do a coffee hour every month and seniors can socialize and they can schmooze with their friends. They do a question and answer session. What am I entitled to? How do I get home care? They don't know the differences between Medicare and Medicaid. They don't know how to access the system. Questions even about who to ask. The social worker that works with me gets confused. United Hospital Fund had a seminar for us and they gave us a tutorial and that's how we learned about MRC and the website; I go there and read it on the web; now the increase in Medicare premiums are really scary; this is a fixed income group. They're upset and angry. No one's hearing them except they're using maybe their voice in the election.

Ruth: Why do you think they don't truly understand Medicare until "a moment of crisis?"

Sh: when they go to the hospital and they find themselves against the system; for the first time it's in their face. It's usually taken for granted; card is in the wallet. They think Medicare is going to cover everything. Then they learn very quickly that it doesn't.

S: When I was working with Mt. Sinai, whenever the issue of home care was dealt with there was confusion with Medicare and Medicaid. There was an assumption that you've paid into the system for so many years that now that you're older that you need it. There's a lot of resentment because from their end they worked hard and paid into the system and now they need something and they're not getting it. There's also an issue of pride. Many seniors are at the border for eligibility for Medicaid. They feel so strongly that they don't want to "impoverish" themselves, these are minuscule savings, but these are their life savings. Now at my late years when I need this extra help. Maybe I only

need it for a year or two, but I should have access to it. I hear a lot about that especially with the issue of home care. It's not until you need it, and I wouldn't limit it to just seniors, I've spoken to daughters who've said "I'm an attorney and I'm overwhelmed by what you're saying." There are limitations and barriers.

St: I deal with Medicare; it's funny because a lot of it is still very new to me. A lot of what people are expressing I am right there with them. I feel just as lost as the rest of you [people I'm helping]. It is very complicated. One of the things that are difficult is that if you don't have all of the information you can get lost in this sea of everything that's out there.

Ruth: What do you consider to be your strongest area of knowledge on Medicare?

(Laughter)

A: nothing. I almost never answer a question before I go and check. And even then I say I'm not an expert. I'm never sure I'm actually saying the right thing.

Al: How much do I know? Every day I learn more and understand it a bit more. I remember being under the assumption for a while that once you turn 65 you automatically get Medicare. I have many seniors who have Medicare; Medicaid; they use the terms interchangeably because they don't know the difference. It's very difficult for them. I have other seniors who are Medicare, not Medicaid, eligible, and if you don't have a secondary insurance…it's very difficult for them to understand, "I need this, how come I can't get this?" I remember a man so vividly, he was blind and diabetic, he lived alone, he only had Medicare and he had all these savings. He had created informal support systems but he didn't acknowledge it. Visiting nurses was trying because of Medicare guidelines said you can't have home care indefinitely. There has to be something else in place. They were trying to get him to understand why it didn't work that way. He told me clearly, you might as well kill me, because I worked all my life, I paid my dues, and I deserve this. Supposedly this is a great country. Feels like I worked, and other people don't work, and they get benefits.

A: it happens a lot, resentment with Medicare/Medicaid. A big issue.

Al: for people whose income is very limited. They don't have any other income. What's my choice, between paying my rent, my drugs, the hospital or food?

A: I think about myself, I had the choice among four insurance options. When you buy something for your home, you don't look at the manual until it breaks. They don't look at their options until they need it. Then they need Medicare very frequently and then they realize what they don't have.

Ruth: What was the last change in Medicare that you remember?

A: are they changing premiums now?

S: Medicare Modernization Act, prescription drug Part D; before that it was C, but we kind of didn't focus on that.

A: I heard they're raising their premiums.

St: I haven't been working with it long enough to know what's new.

Ruth: How do you find out about the changes in Medicare?

S: combination of reading the Times and because of the number of meetings, I go to a lot of what's referred to as interagency councils, they all have different names; other advocacy groups. One particular group picks up on something and others learn and it moves around the network.

Sh: I go to the UHF meetings of NORC directors, monthly meetings, department of aging websites. I get Dear Marci; I read that; I use a lot of resources to keep me up to date.

A: Dear Marci, emails from different sources, sometimes when I'm in the hospital, people photocopy information.

S: Medicare Rights group is known among our sisters and networks, they present frequently and they're an incredible source of information, very descriptive, very detailed. We've used them and called upon them to help us sort this out and to get information.

A: sometimes from the seniors themselves. I got something in the mail, something happened, in the exploration process, they would either tell me the change or through the exploration process I'd learned something had changed. Example: I got a bill for something and I wasn't supposed to. I start questioning people in the office then I go on to Medicare Interactive (MI) website and find the sample cases and see if I can find any information based on what the person is telling me. There's another element to that website: benefits checklist.

S: national group, answer questions without person's name; give you a checklist of possible benefits.

A: I always give out Medicare Rights Center's number. They can be more precise.

St: A lot of the times I have to get back to them and speak to somebody or go to resources I have; sometimes we'll have things floating around the office; I'll ask supervisor a gazillion questions; I'm efficient at the computer; I'll go onto Google sometimes and I'm led to department of the aging and I just kind of throw it out there and see what comes back to me. Sometimes I'll come across different areas that I would never have thought to access before.

Sh: I'll refer people to MRC or if it's a general insurance question, I'll refer them to HIICAP. I've gotten good feedback.

S: In the past I was using the Medicare book and many times what I've found is I don't have an updated one; we should automatically get these books. I remember once I was posed a question, what does it mean when it has an S or a W? There's nothing in that book that says what those letters mean. I've never found what those letters mean. I've been frustrated; you'd think you'd find something there. Increasingly I've been using websites; benefits publication is an extensive resource (what we used to refer to as the ACES manual). It's available online and once you pay for it all your social workers have access to it. A number of resources I tap into. With very rare exceptions I don't answer in absolute. I wouldn't even dare go through the whole list of what medications are covered; list is so extensive. Increasingly, not everyone on our mailing list doesn't have access to email; in our poor communities this is a serious problem. If the providers don't have access. How many of our organizations don't have computers? Or they're so slow and the staff doesn't have access. Forget about it if it's not available in another language. It gets complicated. Access to information and the dissemination of information become much more complicated. We don't want to give disinformation. It takes longer to do the research.

Ruth: When did you first hear about MI?

S. In April, we had MRC speak about prescription drug cards to providers in East Harlem; maintained contacts. Through that meeting, we distributed the flier to the East Harlem Community Health Committee; not sure if a presentation was done at the East Harlem Health committee.

A: at Mt. Sinai Grand Rounds last spring.

Sh: United Hospital Fund meeting. I think it was April.

St: gotten emails about Medicaid Interactive (Medicare! Interactive – see what happens?). Wasn't ready yet. Had a meeting a few weeks ago at Selfhelp, already singing its praises in the office even though it was just a few weeks ago.

Ruth: What was the rest of your initial reaction?

S: had a practical logging in problem; I thought that the same way I had the difficulty other people might. Tamara helped me through it. I tried multiple times to log in and just could not get in and I did it over and over. System was limited by number of characters; once I left out the last character it worked. That would be a recommendation to alert users that that can happen. I find the information to be easy to find and read. One problem: how can I get drug coverage? (System gave me "cannot be displayed")

Ruth: What were your concerns when logging on to MI?

Sh: I had first thought it would be too complicated. I also had a log-in issue. Tamara helped me; when I got there it was very much clearer than I expected. Very clear.

Ruth: Did any of you receive training on MI?

A: Tamara showed us. This is Medicare Interactive; I'll put you into the system so you can log in. She showed us some sample pages of how it works. I think it was sufficient. I think I once had a question, called Tamara.

S: not being online, but went to training where it was demonstrated.

Ruth: How long after the demonstration did you log on to MI?

St: almost immediately, the following day, I had a question about something with prescription drugs; I had a login problem too; went right on; I'm not sure training is really needed but it's so easy to navigate. As much as I love the computer I hate reading things on the screen. But this is concise. Within a day or so I went on.

Sh: got in a week later.

Alma: wasn't able to attend the presentation. Usually attend the presentation, but couldn't. Tamara walked me through it on the phone. I haven't really utilized it.

Ruth: When did you last use MI?

A: April

Alma: just started

Sh: April

St: last week

S: about 3 weeks ago.

Ruth: How often do you use MI?

Sh: I don't get that many questions about prescription drug plans now; we had a big initiative getting people onto EPIC; we've got people on EPIC who are happy with what they have; people who don't have EPIC want to wait until 2006. Home care is the issue I'm dealing with now.

Ruth: Have any of you printed information off MI? What?

Sh: I printed out information on prescription drugs and they liked reading it but I didn't get any questions. They are more concerned about the 17% increase.

A: combination of Medicare/Medicaid; hard to limit yourself sometimes with what to give people and what's relevant and what's not going to be overwhelming; printed out some information on MSPs and also a sample case; how often I use it is hard to say. I use it as often as a question comes; whenever; recently because I've been doing a lot of presentations in the community, I've been using it more.

Ruth: What level of knowledge of Medicare is necessary to get counselors to use MI? Do they need any?

Alma: no, they just need to know how to utilize the computer; searching for a specific topic; be able to tap into it. I don't think you really need knowledge.

St: I have to agree. It's a wonderful tutorial. For somebody like me, logging on, as if there's ever going to be a free couple of hours to sit, I'd stay after work or do it at home, like A was saying, kind of flows and leads you to one thing and the next. As long as you're not computer-phobic and you know how to point and click, you're fine.

Ruth: Which of the MI components have you used? (Hold up list of components)

S: MI Counselor & MI University.

St: MI Community & MI Local Services.

Ruth: What did you think of MI Counselor?

A: Very straightforward and precise. Leads you to one point to the next even when you don't think it's related. There are other options. You see "oh, there's a case with it!"

Sh: I found it fascination. Step-by-step and very clear.

S: comprehensive but not overwhelming; having something you know is simple to read, not voluminous; you can find what you need quickly and easily is always good.

Ruth: How many of you looked at Local Services?

[People didn't use it.]

Ruth: Have any of you printed out information?

Sh: I didn't want to print too many pages. Printing is an issue. Need to save ink.

Ruth: MI University. Who's taking a tutorial?

S: I did. It was good. It was one of the first ones I did. It wasn't very expensive and was to the point. It was what I needed. It was worth the time to explore that issue. I didn't read every line. I read the relevant information.

St: Here's a suggestion. Wanted to go into MI University but I didn't have the time. If there was something that didn't take so long I would be able to focus on it. That would be helpful.

Ruth: Have you ever used MI Help?

(No)

Ruth: When you have to research a problem, what resources do you use?

A: go online; for Medicare go to Medicare Interactive; if I still have a question then I'd call and e-mail Tamara.

Sh: go to Department of the Aging; 16 benefits for Older New Yorkers; specific to Medicare I'll go to Medicare Interactive

Alma: I tend to call my colleagues first; now I'm getting used to utilizing the computer a lot to search for many things. When I didn't have a computer I relied on information I collected and colleagues.

S: I've developed my own file system; because I go to so many events and conferences I try to keep everything I have; if it's a very technical question, sometimes I call the REAP office; they're doing entitlements and benefits everyday. I know a lot of social workers in the center where I am communicate a lot with the Social Security office. Personally my on file is where I go first, second to that would be the computer, third would be my network of colleagues.

St: first thing, straight to computer; because I'm not even familiar with that many sites, I'll just do searches (keywords) and go from there.

Ruth: What is the difference between ACES material in hard copy and online? What are the strengths and weaknesses?

S: there are times when you don't have access or the computers going down or you don't have access to the Internet, and that's a practical issue – sometimes you don't have access because of the technology. If you have it in hard copy you can always make a copy for a colleague. The downside is if your manual is not up to date. You learn to scan to really find what you're looking for; the more you use these programs and the more you learn to search this particular database or program. Many times you encounter more information. I always like to have the hard copy, it's a security blanket, some of us didn't grow up with computers, had to write with typewriters, you go back to your level of comfort (file

system, manuals, books). What I find is things are outdated so quickly, that at least when you go to the computer you get up to date information.

St: Especially if you're working out in the field and because I work so much on the computer and I'm so comfortable with the computer. The portability issue…because of the work I do…my clients very rarely come into the office. A lot of it is field work, many people don't have access to the computer. It's either that or lugging stuff with you. There's pro's and con's to both.

Sh: I have a small office and I don't have that much room to store things; I don't like to store that much paper. When I go online I seldom print anything out. But I don't mind reading off the computer. I prefer the computer.

A: There's a binder at MRC about Medicare. It's so much easier to go online. With a folder it's flipping through pages. Just sorting out the information is so much easier. I can just click, click, and click, until I get the answer. It saves time.

Alma: I think there are instances we need to have it. Every time I have to enter the Internet to work on a special project or program I have to be off the Internet. If I'm in the Internet then the computer freezes if I need to receive faxes or send faxes. It depends on the system that you're in. I need to have access to things that are right there. It's great that all these things are available but there are times when you are very limited. Depending who you're working for or what you need to do.

Ruth: Have you or your agency trained your clients on using a computer? The Internet?

Alma: A group of my seniors; they had already been working with computers. I remember when the web came out and as I started working with it, and it can be difficult to get to the information you need.

S: One of the housing sites in the community has classes. I don't know if they had the technical support to do the classes and they taught them some basic.

Alma: That type of program we don't have too many. It's supposed to be user friendly. It takes hours to find information. That generation that never really had access. Many people are curious but many people aren't interested.

Ruth: How important is it to provide your clients with direct access to MI?

Alma: I think it is valuable, but it's based on their interest, their wanting to do the search. I think the generation that comes after them, but a lot of people, that wasn't what they were interested in, they don't want to learn. Comfort level with the computer.

A: Medicare Interactive, it looks good, so in terms of the visual look of it, I think it would be very easily accessed by seniors. Bigger question is level of comfort.

S: I don't know much about the visual limitation of whether the size of the screen makes a difference of the colors of the lettering; for us it's simpler in terms of context and spacing, but if you're working with someone next to you with visual impairment. I think there really is a technological divide. A lot of people are not going to have access for a number of reasons.

Ruth: Given your experience with MI, how would you change it? Make it easier to use? Enhance people's experiences with it?

St: Time the course takes – should be more obvious.

S: The spacing and font was good. Was thinking of colors of some of the letters; maybe should be a little darker. I'm sensitive to font size.

A: I must say the last time I used it was about a month ago. There's a search option; it would be nice if the website itself has a search option so it would take me to relevant pages in the website. That says you can get information on this page on MI University, MI Counselor, etc. Or this is where the latest posting is on something. If I could put in some keywords and point me out to relevant pages in the website.

St: I had a similar idea. Links on the side. If there's an index you can click on and there are key topics and what's listed underneath, it's helpful not if you know what you're looking for but if you don't know what you're looking for. You can see mapped out for you how one thing might interrelate with another with a broader type of a topic. This might be helpful.

A: having MI Counselor in question form is helpful to me – I can look at it and see what my question is

Sh: if you can limit the certain number of pages. Depending on the sites sometimes you can't designate what you want to print.

S: when things were recently updated; it would be very important to know if there were any changes or to cross-reference it with any regs, changes.

Ruth: What features have you found to be most helpful?

S: public benefits website; when you do a search it opens up a whole sub series; gives a whole list right under that; there are multiple subunits of that; will hopefully help you go straight to what you're looking for; you're still within that page. I find it frustrating when I click something I leave the page and I don't want to leave the page and I can't always go back. Stay on that page but at least you've had subheading options.

Sh: Back function doesn't always work on some of these things; have to go out and start over.

St: from architectural standpoint, we sort of need the ease of being able to compare pages and flip back and forth.

Ruth: To be able to compare different pages at the same time.

St: Right. It's not a technological issue but maybe but a content issue. I could go in and say "I have Medicare part A and part B. You can look at different parts.

Ruth: How important is translating MI into other languages? Which languages do you think are most important?

A: Very important. [All nod emphatically.] All parts. Spanish, Chinese, maybe Russian. I wish to be able to print out the information and print it out in different languages and just print it out in different languages. Even presentations, I wanted to do a presentation in Spanish on MI but it was only in English.

Sh: That's what's good about Department of Aging. They have it in different languages.

Ruth: When translating, what should MRC take into consideration? (PROBE: important features and considerations)

S: Keep it simple. The more simply you use a language the less chance you have of making things so technical. Has to be a creative component to it to really develop and translate the concept; it's not a term you would normally use in Puerto Rico or Argentina – how do you translate it? It's a challenge – how do you come up with the most understandable term?

Sh: no jargon. Not everyone is a professional.

A: I would include some technical terminology and then explain it. I found a lot of times there's reference to terminology and they recognize it but they don't really know what it really means. Not about the reference but about the explanation. Then next time someone uses the word "spend-down" they have reference to it.

Ruth: What cultural factors are particularly important when developing MI for other languages?

A: in terms of translating it, no. Should be straightforward and what the program is about. No coding of it. It should be what it is.

Ruth: Any parting thoughts about MI? Things they should or should not be doing.

S: maybe if people not just hear about it in terms of a concept but see it. Because people are extremely busy, crises always happening. When/if a presentation is done, a PowerPoint presentation about how it works could be helpful to get people to use it. Word of mouth – easy access to people; make it easy to log in. Dear Marci: I passed it

on to other people, the easier it is to get into things, the greater the likelihood of using it. We're a very visual society. Seeing it right there is very helpful.

Ruth: General thoughts. Not just about Medicare but your clients in general. In your experience, what are the current trends in information needs or services?

Alma: It's changing for us. It's somewhat difficult to access information for seniors. They mainly get their information from other seniors, from mail or television.

Sh: I think they're getting conflicting information. Now a lot of them feel abandoned and betrayed by AARP – who should I believe? There's a gap in the information they are receiving. They're going to different places to get answers, and they're not really sure who the credible and reliable source is?

S: names are not always what they appear to be: names of groups. People are getting suspicious. Names and titles may seem a certain way, but then there's sponsorship issues. Don't assume that that nice title really is what it says. People are learning about corporate sector, presenting themselves, saying things, maybe it's not in the interest of the community at large. People are becoming less accepting of policies. Taught me: I need to do more homework before I present someone and make sure I know who that entity is. What are they truly representing? People are becoming skeptical. Advocacy groups. Corporations. Legislation. You name it.

Ruth: Can you think of anything that's coming up the horizon that is coming next?

A: housing, nursing facilities. Nursing homes, people having an understanding of the differences between a nursing home and a skilled nursing facility.

S: home care.

A: prescription drug coverage with other options. Hospitalization issues – what is paid? What's not? What services can you get? Perhaps listing of Medicare providers is an issue.