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Participant Experience Survey and Work Book for Improving Quality Audio Conference Transcript

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Roger Auerbach

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Participant Experience Survey and Work Book for Improving Quality Audio Conference

Gentry*:* Welcome to the *Participant Experience Survey and Work Book for Improving Quality* conference call. At this time, all participants are in a listen-only mode. Later we will conduct a question and answer session. If anyone should require assistance at any time during today's presentation, please press the "*" followed by the "0" on your touchtone telephone and you will be entered into our support queue. As a reminder, this conference is being recorded today, May 21, 2003. I would now like to turn the conference over to Mr. Roger Auerbach, senior consultant for the Rutgers Center for State Health Policy. Please go ahead, Sir.

Roger Auerbach: Thank you so much, Gentry. Good afternoon everyone and good morning to my friends in Alaska and Hawaii. Welcome to this audio conference on the Participant Experience Survey and the Work Book for Improving Quality of Home and Community-based Services and Supports. My name is Roger Auerbach and I work with the Community Living Exchange Collaborative at the Rutgers Center for State Health Policy. I will be your moderator for this afternoon's call.

This audio conference is funded by a grant from the Centers for Medicare and Medicaid Services and has been organized by the Rutgers Center for State Health Policy in collaboration with the Independent Living Research Utilization, our technical assistance exchange partner.

A number of CMS grantees are working on quality assurance and improvement initiatives as part of their Community Living Grant activities. This audio conference was organized specifically to meet the needs of grantees who expressed great interest in hearing more about two CMS-sponsored tools designed to help states develop and refine their quality assurance and quality improvement systems. We hope this conference will build upon the presentation two weeks ago by Thomas Hamilton and Glen Stanton on the Quality Framework for Home and Community-based Services and CMS's overall approach to quality assurance and quality improvement.

Although this currently is our last scheduled audio conference on quality, we want you to let us know if you would like more information on other topics in the area of quality assurance and quality improvements.

Now to today's conference on the *Participant Experience Survey and the Work Book on Improving Quality*. We will begin our conference with a presentation on the Participant Experience Survey by Sara Galantowicz, research associate at the Medstat Group. After Sara's presentation, we will take questions on her presentation before asking Maureen Booth to present on the Work Book.

During their presentations, all participants will be in a listen-only mode. After each presentation, and actually Sara is going to ask for questions during her presentation, we will open the phone lines to allow people to ask questions. At that time Gentry will get on the phone and tell everybody how they can get into the conference to ask questions.

I hope all of you have had the opportunity to review the materials we sent to you prior to the call. The Participant Experience Survey is for both elderly and disabled and mentally retarded, developmentally disabled participants, the Users Guide for each of those surveys and the PowerPoint slides for both Sara's and Maureen's presentations.

It is my distinct pleasure now to introduce Sara Galantowicz of the Medstat Group. Sara is a research associate with the Medstat Group's Chronic Care and Disability Group and has been with them since September of 2000. She is responsible for the development and testing of the Participant Experience Survey for Medicaid Waiver participants. She has overseen the development of three population-specific versions of this survey including performance indicators for quality monitoring and is currently managing the development of the automated Participant Experience Survey software.

Prior to coming to Medstat, Sara spent seven years with the U.S. General Accounting Office in the Boston and Detroit offices, most recently as a senior evaluator. Sara holds a Master's degree in public health from the University of Michigan and received her A.B. in economics from Princeton University. Sara, would you take it away?

Sara Galantowicz: Sure thing. Thank you, Roger. Hi everybody. I am Sara Galantowicz from Medstat and before I get into sort of my prepared remarks on the slides, I just wanted to offer two comments. The first, as Roger mentioned, I have been with Medstat for about two and a half years working part time and during those two and a half years I have been working almost exclusively on the Participant Experience Survey, which is just to say that I could talk about this for several hours if we had the time. But what I would really like to do today is cover the material in the slides that were sent to you, the PowerPoint slides, and allow as much time for questions as possible because I think this tool is most useful if we can discuss in detail how it might be used by states and respond to your specific questions.

The second comment that I want to make is as Roger mentioned you all received four documents in conjunction with this presentation. Those documents were labeled "The Consumer Experience Survey." You will notice the slides talk about the Participant Experience Survey. I just want everyone to rest assured that they are indeed the same thing. The Consumer Experience Survey had a name change a couple of months ago and became the Participant Experience Survey, but it is the same document. I thought I would clarify that before we started.

I want to talk, going to the first slide, just a little overview of what the Participant Experience Survey or the PES is and what it is not. It is a technical assistance tool for states. It is designed to solicit participant feedback on home and community-based services and supports. This data can be used then to generate performance indicators for quality and monitoring. The idea really is that these data can be combined; the performance indicators can be combined with other quality management strategies again as a way for states to both monitor and improve the quality of services that they provide through the waivers. As we mentioned before, it was developed by Medstat under contract to CMS. So that is what it is. It is a quality improvement tool.

I want to clarify also what it is not. It is an experience survey for participants only. That is so that the important parts of that is that this is not a satisfaction survey. It has got a broader focus than just sort of participant satisfaction with services to cover some other areas such as unmet needs, respect and so forth that I will get to in a little bit more detail later.

There is also no proxy version of the Participant Experience Survey. This was a deliberate philosophical decision during the development not to create a proxy version. The idea really was to create a survey that could be as accessible as possible to as many waiver participants as possible and that there was sort of a desire to at least ask everyone about their experience with services. So there is no proxy version. Which isn't to say that there won't be some waiver participants who won't be able to make any kind of commentary on their lives, no matter how simple we made this survey. But the goal was to make an instrument that was accessible to all participants.

The PES is designed to be administered in person. This is not a mail survey. It is not a phone survey. There are several really problematic issues with doing telephone surveys with people with disabilities. We felt that it was not an appropriate method for collecting data so this is an in-person interview instrument.

Finally, this is an optional survey. Again, CMS commissioned this to be something available to states as a technical assistance tool but it is not a required survey. There are, you should have received four documents. As Roger mentioned, there is a PES/ED survey tool, the User's Guide and a PES/MRDD survey tool and users guide. The final versions of these tools and users guides should be distributed within the next two months I believe. You all have draft copies that say

"Unauthorized Draft" all over them but they really do not differ significantly from the final versions that will be released soon.

Let's talk a little bit about the two current versions of the survey that are available. The first is the PES/ED, the elderly disabled version. The target populations for this survey are frail elderly and adults with physical disabilities. We have found based on field testing that the approximate administration time for this survey is 15 minutes. I think sometimes these surveys look daunting because there are so many pages, but our experience has been that the average interview, in-person interview, lasts no more than 15 minutes. From the data that are collected from the Elderly Disabled version, there are 33 performance indicators, which can be calculated. We are as mentioned in the introduction, currently working on developing automated survey software which will automate both data collection, will allow interviewers with laptops to enter the data directly while interviewing participants and will also automate analysis of these data. This survey software is currently projected to be available sometime this fall.

The second version that is currently available is the PES/MRDD, the mental retardation and developmental disabilities version. That is the target population, adults with those conditions. The approximate administration time for this instrument is a little bit longer. It is 30 minutes. It is just a longer instrument. It covers more areas of participant's lives. There are 51 performance indicators that can be calculated from this instrument and the MRDD instrument also includes or a subset of the questions of this instrument are what we refer to as "core questions." These are questions for participants with severe cognitive impairments. As I mentioned, there is no proxy version of this survey, but we wanted to designate this subset of questions that were the most simple based on our testing and the most straightforward and accessible so that if an individual couldn’t respond to the full body of the survey, they may be able to at least respond to these eight core questions and thereby provide some snapshot of their experience with waiver services.

Another point about these core questions. Not only are they the most straightforward of the questions on the survey, they are all “yes/no” questions so that persons who are non-verbal can respond in other means, either by nodding or by hand gestures and so forth, which was our experience in testing the instrument, that these questions could be responded to by folks who were non-verbal.

Future versions. We are currently field testing another version of the Participant Experience Survey for adults with acquired brain injuries. That survey is undergoing field testing in New York State right now. Some version should be available at the end of 2003 or at some point in 2004. If anybody is interested in more about the acquired brain injury survey, they can contact me directly because we are still refining that survey. Any input is welcome.

So what do these surveys address? Well common to all the surveys there are four priority areas of interest. The questions may vary from instrument to instrument, depending on the disability group, but they all fall under one of these priority areas of interest. There are many items that are common to all surveys regardless of the disability group. These four priority areas area as listed, access to care, which essentially is a series of questions that seeks to find out if participants need personal assistants, adaptive equipment and case manager access are being met. Choice and control. Looking at whether program participants have input, can make choices about the types of services they receive, who provides them, how they spend their time, issues relevant to them. The third area is respect and dignity. That includes whether or not program participants are being treated with respect by providers and also includes some items around, some standard safety items around theft and abuse. The final area is community integration which looks at whether program participants can engage in the activities they want to, activities of their choosing when they want to and whether or not they have other unmet needs for involvement in community activities.

I want to go through a couple of sample items for each of the priority areas to give you sort of a flavor of how the survey questions read and how they differ a little bit from instrument to instrument.

On the slide that shows under the Access to Care, some sample items, and these items under Access to Care exist in all copies of the instrument. Do you ever go without eating when you need to? Is this because there is no one there to help you? Again, the focus of the Access to Care section is the effect of unmet need or the outcome of not having services. The third item, "Have you ever talked with your case manager or support coordinator about any special equipment or changes to your home that might make your life easier?"

Some sample Choice and Control items. Again these are common to both instruments. Do you help pick the people who are paid to help you? Would you like to help pick the people who are paid to help you? The third item is an MRDD item only. When you are at home, can you eat when you want to? The final item is common to both surveys. Can you talk with your case manager or support coordinator when you need to? I will just draw your attention to the last item. You can see we have included two different terms, both case manager and support coordinator. Again, the idea was to, well this is a broad survey that is designed to be used in any state that wanted to offer an opportunity to sort of modify the language where it might be appropriate so that the terms will be most familiar to the individuals who are being interviewed.

Sample respect and dignity items. The first two items under Respect and Dignity are listed here show you some of the changes we made from one survey to the other to accommodate the different populations. On the elderly disabled survey, the question reads, “Do people paid to help you treat you respectfully in your home?” A similar question for the MRDD instrument, which actually refers to services outside the home asks, “Do support staff in other places such as at work or at a day program say ‘please and thank you’ when they ask for something?” The reason those items differ is that when we were dealing with the more cognitively impaired population, one of the things we learned about in our testing, which I will talk about in a bit, is that the more concrete and the more descriptive the question can be for a person who is cognitively impaired, the more likely that individual will be able to respond to that question. So we have substituted using “please and thank you” for the more abstract term “treating respectfully.”

The third item is just an example of the type of Theft and Abuse questions that are included in the survey. Does anyone ever do mean things to you such as yell at you? That is an MRDD item. Just a little aside. When we first developed that question looking at physical abuse, we had some questions about hurting, about physical abuse and we used the term “hurt”. We had participants describing to us times when their feelings had been hurt, not their bodies had been hurt. So we have learned through that process that the more concrete and clear we can be in the questions, the greater the likelihood that they will be understood and answered appropriately.

The final sample items are from the Community Integration section of the survey. Again, the first three show you some of the questions that are unique to the MRDD instrument. Do you like to go out to eat? Do you go out to eat? Do you help get to pick out where you go to eat? Not just, "Are you involved in the community, but is it involvement in activity that you like, going out to eat?" And are you able to have some influence and control over that activity? Do you help pick where you eat out?

The last question is common to all the versions. Just a general community question. Is there anything that you want to do outside your home that you don't do now? That is just a subset of the many, many questions, but I wanted to include those to sort of give some depth to the priority areas that make up the survey.

I want to talk now a little bit about the Performance Indicators. The Performance Indicators are really the reason the surveys exist and the reason that the surveys were developed in the first place. The real purpose of the PES is to generate population-based indicators of participant's experience with services and support to give states an idea of what the participant's experience is? How the people who are participating in their program are experiencing those services and supports and where problems may exist. The idea being that the information about where those problem areas are can help states allocate their scarce quality improvement dollars. If there is only so much money to spend, and I know that money is getting more scarce with each year, it is helpful to know where you may want to take a closer look at your program. So the performance indicators can either guide quality improvement projects themselves. They may indicate an area where intervention is warranted or they may just indicate a need for taking a more focused review of the program along that particular issue of respect or access to care or wherever the indicators show that more attention is warranted.

The Performance Indicators are organized by those four priority areas of interest. There is detailed information on how the indicators are calculated included in the user's guide. One thing we are particularly excited about is when the software is released; the software will calculate those indicators automatically. So once the data is collected on laptop, then a report can be generated that can show the values for the indicators not only for the population overall, but subsets of the population if that is of interest to the state.

I have also included some examples and some sample Performance Indicators by priority area. Unless I have indicated otherwise in the slide, these indictors are common to both surveys. The first example under Access to Care has to do with bathing. Specifically indicated, that would be calculated to show the percent of program participants who require personal assistance with bathing who report they sometimes are unable to take a bath because there is no one there to help them. Again it is that subset of people that are interviewed who actually need personal assistance with bathing, what percent are reporting unmet needs, that they are unable to bathe because there is no one to help them? Those types of indicators exist for all the ADLs and IADLs included on the survey.

Sample of Choice and Control Performance Indicator. The percent of program participants who do not help direct their staff but would like to. Again, this indicator is targeted to the subset of the program participants who want to have more control over what their staff are doing to assist them who don't currently have that control. It is different than a satisfaction item. It is not "are you happy with what your staff do" but "do you want more control that you don't have currently?" Some people don't want to direct their services and so it is a more meaningful statistic if you look only at the population who is looking for some control over what kind of care they receive.

Turning to Respect and Dignity. Careful listening by staff at home. Percent of program participants who report staff do not listen carefully to their request for assistance in their homes. We have a standard physical abuse item for program participants who report being injured by caregivers.

Finally, under Community Integration, you will see, both of these indicators actually come just from the MRDD survey. Again they focus on whether or not the need for community integration is being met and an activity that the respondent has indicated is important to them. For shopping, the percent of program participants that enjoy shopping who report that they do not get to go shopping. It is a little different than just a percent that get to go shopping overall, but of those who actually indicated that shopping is something that they enjoy, what percent are reporting that they don't get to go shopping?

I want to take just a break here now that I covered what questions are on the surveys and the Performance Indicators so Gentry, can we take any questions now?

Gentry: We certainly can. Ladies and gentlemen, at this time we will begin the question and answer session. If you do have a question, please press the “*” followed by the “1” on your touchtone telephone. You are going to hear a three-tone prompt acknowledging your selection and your questions will be pulled in the order they are received. If you would like to decline from the polling process, please press the “*” followed by the “2” on your touchtone telephone. As a reminder, if you are using speaker equipment, lift the handset before pressing the numbers. One moment please for the first question.

OK. Our first question will come from the line of Andrea Williams. Please go ahead.

Andrea Williams: Hi Sara. Thank you very much. I really enjoyed these materials. My main question is have you had any input or do you think you can have any input into who actually does these surveys, particularly since they are done in person?

Sara Galantowicz: Yes. Actually that is a really good question. I think we cover it a little in the User’s Guide. The guidance that I generally give when asked that question is first of all, the interviewer should never be anyone who is directly involved in providing services to the program participants because there is a huge potential for conflict of interest. We have found during the testing that waiver participants are nervous enough about answering questions about their services if they have any fear that they might lose benefits if they express any negative opinions so it is doubly important that it not be a provider who is asking the questions. That includes case managers because there are questions about case managers on the survey. But then just in terms of a general type of person, generally I think that you need to look for interviewers who are both very familiar and comfortable with disability issues, who have worked with disability populations so that they are familiar with the group that they will be interviewing and that have the ability to maintain sort of a professional, to maintain, to develop a warm rapport, but also maintain a certain amount of professional distance while doing the survey because people need to feel comfortable giving responses, but at the same time it can be very easy to get sidetracked onto a particular problem that the respondent may expect you to solve and if the person can't sort of keep the interview moving forward and maintain a distance from actually providing them fix services and fixing problems, that can be difficult. Does that get at your question?

Andrea Williams: Yes it does. You had said that we could contact you directly on the brain injury survey?

Sara Galantowicz: Yes.

Andrew Williams: Is your email on here somewhere that I didn't see it or...?

Sara Galantowicz: It should be on the very last slide, PowerPoint slide. It should be my phone number and email.

Andrea Williams: Thank you.

Gentry: Our next question will come from the line of Kelly Scott. Please go ahead with your question.

Kelly Scott: Yes, we were wondering what kind of software package would be required to support the application that you are talking about or will it be a stand-alone software?

Sara Galantowicz: It will be a stand-alone software so that you won't be required to purchase any additional software to run the PES survey software.

Kelly Scott: Thanks.

Sara Galantowicz: And if you have any interest in helping test that software you can also contact me.

Kelly Scott: Yes we do. Thanks.

Gentry: Thank you. Our next question will come from the line of Deborah Wilcomer. Please go ahead with your question.

Deborah Wilcomer: Hi Sara. I was wondering, we are going to be doing some surveys but they are particularly directed for folks with mental illness and co-occurring disorders, but you are giving me some certainly really solid ideas on how we can approach this. But I was wondering if you had built in any kind of mechanism for reporting if someone is administering the survey and they think that this person is at risk of homicidal or suicidal ideation or if they think they are at risk in their situation, their living situation?

Sara Galantowicz: Yes, we have directions both in the survey and the User's Guide. We talk a lot about the issue of confidentiality because the idea is to generate population-based statistics, but all interviewers in the training are clearly directed that if they fear that there is any immediate danger in the respondent's situation that they need to take steps to address that danger. In many instances the person doing the interview may be a mandatory reporter in terms of anything that they observe. So that is really where you have to make a judgment between stepping outside of that interviewer role and intervening when a situation is truly dangerous.

Deborah Wilcomer: Is there anything then in place when it is not a mandatory reporter? Is there anything in place that helps to train folks in advance on how to look for those indicators?

Sara Galantowicz: It is not addressed in any great detail in our training, but that certainly will be something that a state who chooses to use this survey could include in their training as another also variation from program and state and personnel types as to what the responsibilities are. But that is an excellent point.

Deborah Wilcomer: Thank you.

Gentry: Sara, do you have time for one more question?

Sara Galantowicz: Yes.

Gentry: OK. That question will come from the line of Beth Kidder. Please go ahead with your question.

Beth Kidder: Hi, this is Beth Kidder from Florida Medicaid. I had a question about what the sample size would need to be in order to make the outcomes valid?

Sara Galantowicz: That is a good question. In the User's Guide there is directions to a website that can be used to calculate sample size. Sample size is really going to be a function of the size of your waiver and of the desired level of precision of your estimates. When we did our field testing, which I am going to get to next, we had sample sizes of about 400 participants. If you want to do more focused reviews though, if you want to compare say two different counties, a couple counties or a couple different provider groups, your sample sizes need to be larger if you are going to subdivide your analysis into different types of groups. But there are definitely resources available that can help you figure out those numbers.

Beth Kidder: Great. And one last question. On the cost of the software, will that be free or will it be something we need to purchase?

Sara Galantowicz: The software will be free.

Beth Kidder. Great. Thank you.

Sara Galantowicz: Shall I go ahead now?

Roger Auerbach: Why don't you continue.

Sara Galantowicz: OK. I want to talk a little bit about how the PES was developed so I can answer the question of what I have been doing for the last two and a half years. We developed the PES using a combination of both quantitative and qualitative methods. We had a work group. Some members of the work group are actually on this call right now including Roger who provided technical assistance and oversight. Really their job was initially to help identify what the priority areas were for the survey. We looked at related instruments. We then drafted some items to operationalize those identified priority areas. We did cognitive testing which is our Phase I testing and then field testing. I will talk a little bit more about all of those things.

First to our work group. Members of the work group were state staff who worked with various different waivers, CMS regional and central office staff, disability group representatives and experts in survey methodology and disability research. They were initially; this work group was initially formed to assist in the development of the protocol. I assume most people on this call are familiar with the protocol for regional office reviews. This project really grew out of the protocol once the protocol had been articulated and how quality waivers would be assessed, and then the recommendation was to develop this tool that states could use themselves to monitor quality.

Again, they had to identify the priority areas that were relevant to program quality and as the project went on they reviewed our testing results and gave us feedback and guidance as to what we were finding.

Drafting the items. Medstat actually drafted the items to specify, sort of fill out the domains, and we looked at some existing tools to identify some additional items. Some of the surveys that we looked at are the CAHPS tools, the Consumer Assessment for Health Plans. We looked at the Core Indicators project to consumer interview and the Healthcare Satisfaction Measure, but we felt that this survey was a positive addition to the field by being sort of a waiver-specific survey developed under this workgroup.

Our guidelines for developing items are that they had to be actionable by state and they had to be by purview of the waiver program. This had to be really practicable, usable data. That is another reason so we get away from satisfaction items. We were really faced with a trade off between the simplicity of the question to enhance accessibility and the depth or the complexity of what we can add. You will see, if you look at the survey, we chose to err on the side of accessibility and simplicity. There are a lot of yes/no questions in this survey for a reason because they are the most accessible to be answered by the largest number of people. We may have lost some of the nuances in the process, but we have hopefully opened it up to as many participants as possible.

Finally, we really were directed to avoid some standard satisfaction items for two reasons. They are not really useful for quality improvement because you want to know the factors that are driving satisfaction. Are you happy, yes/no doesn't tell you if people in no are not happy what might be the drivers of that unhappiness. There are so many confounding factors that are sort of outside the purview of the waiver program, particularly all the correlative disability, low-income, unemployment, depression that can affect satisfaction items that aren't necessarily going to be amenable to a quality improvement project. So we instead really focused on satisfaction, I mean on experience with services and unmet needs.

The first thing we did after we had drafted the items, we did some cognitive pre-testing. Just real briefly cognitive testing is a way to help researchers understand how questions are understood and how those answers are derived. It is amazing that the question you think you are asking is not the question that other people are hearing and that can really affect your results so we do cognitive testing to reduce any potential measurement error. We make changes to the sentence structure, terminology, the way items are ordered.

To do the cognitive testing, we did in-depth interviews using probes to sort of figure out what the respondents were thinking about when they heard our questions. We'd ask them a question and then we would ask them additional questions. What were you thinking about? What does this term mean? Give me an example. We also did some behavioral observations to look for items which may be unclear based on body language that might be misinterpreted or just even potentially offensive.

We did a total of 40 cognitive pretests in five states across 11 waivers. These interviews went anywhere from 20 minutes to 2 hours so they really allowed us to get in depth. It was a very iterative process. Every time we would do a few interviews, we would come back and make changes to the instrument based on what we learned so we could then try out some new questions or try out some new learning and see how that resonated with our respondents.

What did we learn? We learned that this type of testing is extremely useful. We made a lot of changes through this process that enhanced the comprehension, specificity, appropriateness of the items. I already mentioned that when we asked about people being hurt, we heard about hurt feelings. When we asked about problems, meaning problems with staffing, we heard about people who needed help hanging up their curtains so that we learned a lot about the need to be specific and clear in the questioning.

Another thing we learned is that one size does not fit all. I didn't mention earlier that our initial charge from the work group was to create a single cross-disability instrument and it became very clear during the cognitive testing that there are significant differences between populations in terms of not only cognition and comprehension issues, but in terms of services received and things that are important. So we began the process of developing the separate instruments that were linked by the common priority areas but the questions, the wording and the focus were more specific to the population.

As I have alluded to already, we learned that simplicity and consistency are absolutely key. With yes/no response patterns everywhere we tried to get away from jargon and abstract terms as much as possible and we really tried to limit hypothetical questions. Abstract terms and hypothetical questions are particularly challenging for people with cognitive impairments. So we have tried to make this as concrete and current as possible. Then again, what we learned in the cognitive testing formed the basis for our field test documents.

The second phase of testing was field testing. Sort of in contrast to the very detailed small number of cognitive tests, field testing is a large population-based testing. We worked with three states, Mississippi, Arkansas and Ohio. Those three states drew themselves and interviewed a random sample of anywhere from 200 to 400 waiver participants. The reason we do field testing is we wanted to sort of look at the logistics of implementing. It is one thing for me to drive to a few people in a state and sit down and have in-depth conversations, but what happens when a state needs to interview 400 people and we have looked at all the logistics around scheduling, travel and so forth? Field testing also lets us look for problems with individual items. When you have data on 400 people it gives you an idea which questions are working and which are not. It also gave us some data on variability.

We produced a special field test version of the survey that allowed interviewers to track any problems that they encountered. We also captured that data on problems electronically. Problems could be did they have to repeat a question? Did they find that they had to rephrase a question? Did they feel when they asked the question that the item just was not understood by the respondent or did they have any indication that the response that was given was not a valid response? That could be through observation or through additional information that they learned.

What we learned on field testing that we used the data on the problems and particularly on skip pattern violations to delete or modify items as well as simplify skip logic. Skip patterns it turns out are difficult for a lot of people including even myself who developed the survey sometimes have problems following the skip patterns. So we really simplified the skip logic whenever we could.

Consistent with other surveys of this type, when we had the satisfaction items that were on the survey did tend to show fairly low variability. We got feedback from interviewers and we looked at the other data to see what percentage of the respondents could understand and respond appropriately. Again, the decision was to make this instrument strictly for waiver participants so we needed to evaluate what percentage of waiver participants could appropriately respond. Our estimate is that about 95% of the people that were interviewed using the elderly disabled instrument were able to understand and offer meaningful responses. About 80% of the MRDD respondents were able to respond. We will need more testing, particularly on the MRDD side to really feel that those numbers are solid.

We did a little bit of factor analysis because when you do survey research you do factor analysis. But the survey is not designed to produce sort of scales or composite measures; it is really designed to produce the individual performance indicators that will guide where states might need to get more involved in quality improvements. So the factors were not strong because that was not the intent of the instrument to group things together.

Finally, we did a little bit of interviewer reliability and found good reliability between different interviewers.

That is sort of in a nutshell what the instrument is and how it was developed. There are certainly lots of logistics that go around fielding a survey like this. We have produced a tool, but there is a lot more that goes into actually conducting a participant survey and using the data. Some of the issues, and these were even alluded to in the questions, is sampling. How do you select the interviewers? How do you train the interviewers? How do you actually go about scheduling the interviews, in person interviews, for all these waiver participants? How do you analyze results? Then how do you ultimately use the data for quality activities? The good news is that there are a lot of resources available to assist you in this process. A lot of the things on the last slide that I just read are addressed in the User's Guides that you received. There are discussions of sampling and there is training materials that covers all these issues. The User's Guides will also be available ultimately in accessible formats that can be used with text readers and so forth.

There is also assistance. States can request technical assistance on fielding the PES through the National Quality Contractor. CMS has more information on that. Finally, Maureen will be talking about the Work Book for Improving Quality in Home and Community-based Services and Supports that will really give you an idea on how these data, these performance indicators can be used to enhance program quality.

The last slide has my name, my phone number and email address. I am more than happy to handle any questions that don't get addressed today or provide some of the huge volumes of information about this survey that I have to anyone who wants to follow up. Or anyone who is interested in learning more about the software, helping test the software or the brain injury instrument. So with that, I guess Gentry will open it up to questions again.

Roger Auerbach: Great, Sara. Thank you very much. Gentry, let's see if we have any more questions for Sara.

Gentry: All right. Let's do. Once again ladies and gentlemen, if you have any questions or comments at this time, please press the "*" followed by the "1" on your touchtone telephone. As a reminder, if you are using speaker equipment to lift that handset before pressing the numbers. Sara, it looks like we do have two questions. The first one comes from the line of Loretta Hicks. Please go ahead with your question.

Loretta Hicks: Yes, Sara, I have several questions. You used consumer input in developing the survey you said?

Sara Galantowicz: We did not have consumers on our work group. We had representatives of disability groups. Then during the cognitive testing process when we would interview consumers using the tool, we asked them for their input on questions that they wanted to see changed or additional questions that they thought we were missing. It is difficult to sort of anticipate all the areas that might be important, so they had a lot of consumer input during that cognitive testing phase.

Loretta Hicks: What about ordering of questions?

Sara Galantowicz: We did do a lot of changes in ordering the questions sort of based on the other feedback or reactions we got to the way the questions were asked. One example in the ADL and the IADL section initially, the very last question has to do with bathroom use even though that logically belongs up with the other ADLs and that is because the feedback we got, since that is such a personal area, that you didn't want someone to be sort of caught up in the whole bathroom issue and not being paying attention to the remaining questions in that section.

Loretta Hicks: I am a consumer and an MSSW and my reaction to it was that it is discouraging to have those questions at the beginning of the survey. So that is my input. I worked on the Koss Multi-Site Study as a consumer advisory panel representative. We helped develop the curriculum, I mean the protocol. So that is my input. I will email you about several of the other things that I ran across.

Sara Galantowicz: OK. When you say your reaction was discouraging to have the ADL and the IADL questions first?

Loretta Hicks: Yes. When I was reading through them, it was, knowing that some of the people are going to respond yes, yes, yes, yes, yes to these, I felt like the feeling is going to be very discouraging to people as they answer these questions. By the time they get to Dignity and Respect they are going to really go, "Yeah, where is the dignity and respect?" So that is my reaction to it.

Then another point I would make is under Employment. I would include volunteer activities and possibly hobbies because not everybody has a job. I am talking about the Elderly Disabled version because that is what I can speak to.

Sara Galantowicz: Right. Actually, in the User's Guide and in the training for interviewers, we defined 'work' incredibly broadly. Work does not mean paid employment; it means both paid employment, volunteer activities, day programs, school, training classes, any kind of structured activity that the person engages in. So it is the very short word 'work' in the question, but in the training of how that question would actually be administered, it is a broader definition that we are looking at.

Loretta Hicks: Then using the word 'respectfully' under number four and it is used somewhere else. I wasn't sure whether people would know what that, I mean some people do know what 'respectfully' means, but some people might not. I am looking for it.

The other thing I wanted to suggest, in talking about interviewers, we used in our study consumer interviewers and we are writing a paper about it right now about the multi-site studies use of consumer interviewers. I would highly recommend it. I supervised consumer interviewers at any time about 8-10 consumer interviewers in our study and they were outstanding in terms of rapport with clients.

Sara Galantowicz: That is a good point. We are actually using some consumer interviewers in New York with our brain injury instrument so it will be interesting to see what their experience is. But I look forward to getting any detailed comments that you have. Please email them to me because we appreciate all the input.

Loretta Hicks: Sure. Thank you.

Roger Auerbach: Thanks so much Loretta. Gentry, do we have any more?

Gentry: Yes, Sir. Yes we do. Our next question comes from the line, we actually have two more. Our next question will come from the line of Sara O'Brien. Please go ahead with your question.

Sara O'Brien: Hello. I had to join in late because I had come from another meeting. I don't think I got all the tools and the things you sent out over the Internet. I had some problems with memory on our server. How do I get a hold of the User Guide? I work with the Head and Spinal Cord Injury Waiver and the Mental Retardation Waiver.

Sara Galantowicz: So you are looking for the User's Guide for the MRDD instrument or for both?

Sara O'Brien: For both.

Sara Galantowicz: If you can just email me at the email address listed on the last slide I will email back all the materials to you.

Sara O'Brien: That is what I don't have is your email.

Sara Galantowicz: Oh you don't? Oh, sorry. My email address first name is sara.galantowicz@medstat.com.

Sara O'Brien: OK. Thank you very much.

Gentry: Sara, do we have time for another question?

Sara Galantowicz: Sure.

Gentry: That will come from the line of Nancy Hall. Please go ahead.

Nancy Hall: Hi. This is really great. I am really charged up about this. If you have anything for follow up? Do you have anything coming up to do follow up and check to see who has the RN369, etc?

Sara Galantowicz: I am sorry. Follow up around?

Nancy Hall: Around when we get around these places. They want to move, get them into the community on follow up to see where they are three months, six months, nine months, a year?

Sara Galantowicz: We have some; those questions aren't necessarily included in this instrument but that is something that the state could make as a focus when they use the survey. One of the ways this survey can be used is sort of a longitudinal tool that you can look at people. You can interview them after they enter the waiver. You can look at them a year later and see how their responses might have changed. We do and our Brain Injury Instrument does include some questions looking at how people themselves perceive their progress after entering the waiver program. So it could definitely be, it could also be the focus of a quality improvement project that comes out of using this survey is deciding that there needs to be more follow up on people's experience.

Nancy Hall: Great. Thank you.

Sara Galantowicz: You are welcome.

Gentry: Thank you, Nancy. Sara, there are no further questions so if you would, please continue.

Sara Galantowicz: That is it. Thank you everybody.

Roger Auerbach: OK. Thanks so much, Sara. We really appreciate your presentation. Lots of questions and you were really revving the motors to get so much information out to people out on the call in such a short period of time because we want to be able to hear from Maureen Booth. Maureen is going to talk about the Work Book for Improving the Quality of Home and Community-based Services and Supports.

Maureen is a director of quality improvement program area at the Muskie School of Public Service at the University of Southern Maine in Portland, Maine. In that capacity, Maureen has provided technical assistance to the state of Maine and the New England states on the design of quality management systems for managed care programs serving Medicaid and the duly eligible population. More recently, Maureen directed the development of the Work Book, which she will talk about, for use by states in the design of a quality management system for home and community-based services.

For the past ten years Maureen has also been a Fellow at the National Academy for State Health Policy where she has been working with the Centers for Medicare and Medicaid Services on the design of quality oversight systems for both the Medicare and Medicaid programs. Maureen serves as principle staff to the Performance Measurement Partnership Project, a program to guide national policy on performance measurement for Medicaid and the State Children’s Health Insurance Program. Maureen received her Master’s degree from Cornell University and her Bachelor’s from St. Peter’s College.

Maureen, if you would.

Maureen Booth: OK. Hi everyone. I feel like we should all stand up and stretch for a moment before we begin. Sara is a very hard act to follow. The Participant Experience Survey is a very tangible product and tool. The challenge in design of the Work Book was to organize what for many is a very amorphous process into a practical guide for states to improve the quality and care of their home and community-based services.

My main goal today is to provide an overview of the Work Book for Improving the Quality of Home and Community-based Services so that you can hopefully see its potential to your work. I also want to whet your appetite for the release of the Work Book which we are anticipating this summer. There are currently some CD-ROM versions of the unapproved draft of the Work Book that are available and if people are interested you can email me and we can try to get a copy to you.

At the end of this discussion I am hoping that Susie Bosstick or someone else from CMS can talk more specifically about when they expect to have the release of the final Work Book and how people can get copies.

Unlike Sarah, I don’t plan to go through all the slides, which you have received. They are given to you so that you can review for yourself the content of the Work Book. Given the brief time that we have, I would like to focus on why the Work Book and how it came to be, the format of the Work Book, the organizational framework for the Work Book, and if we have time give you some examples from the chapters on getting started and conducting a preliminary assessment.

Before turning to the slides, I have been asked to address an issue that frequently comes up. Many people, when they hear about the Work Book ask why CMS needed yet another guide to quality. In the last two years, there have been several publications focusing on the quality of home and community-based care. First there was the protocol which I think at the time was called the HCFA protocol, which provided detailed interpretation of how CMS reviews a state's compliance with the six waiver assurances. The understanding at the time was that the CMS regional office reviews the protocol during waiver site visits to assess a state's compliance.

Shortly after the publication of the HICVA Protocol, the American Public Human Services Association published the *Guide to States*, which gives very concrete illustrations on how a state can meet the requirements of the protocol. Finally, as Thomas Hamilton spoke about during the last CMS audio conference, the *Quality Matrix and Framework* was published which describes the quality outcomes states should look for from their home and community-based programs.

Each of these documents identifies what is important to measure and monitor. The Work Book that we are talking about today provides tools and methods for how to measure and what to do with the findings. Now we are going to turn to the first slide.

In terms of the Work Book and why it was developed. There are really six purposes to that Work Book. Our first purpose was to apply the QI techniques, which are so broadly used in other settings of care to the home and community-based program and in the process to distinguish what a state does to meet its compliance requirements from quality improvement activities.

We also wanted to show ways that a state could design an internal structure for its quality improvement function knowing that very often these home and community-based waiver programs don't have any focal point for quality within the program itself.

We want to demonstrate how existing data, as well as new data not now collected, can be used to identify priorities for quality improvement. We wanted to walk through a process for designing and implementing a QI project and show the importance of focusing a state's time and resources on topics that are of the greatest urgency and where the impact can be the greatest.

Developing the Work Book, my colleague at Muskie, Julie Fralich and I, interviewed eight states to learn their approaches and challenges to improving home and community-based services. Many of these interviews stressed the struggle states face in finding and using data to inform their decisions. The Work Book acknowledges the difficulty in obtaining reliable and timely data while at the same time it provides a way for all states to begin the QI process regardless of the level of data it may have right now. The Work Book also shows how to organize data in ways that are constructive in understanding quality problems.

If you skip now over in your slides to, it is on page 3 in mine, called the QI Roadmap. Depending on how people printed out their slides, this might be a very, very tiny slide that you cannot read. Hopefully you are able to follow me. The Roadmap shows how the Work Book itself is organized. On the left side of the diagram are the titles for the Work Book's nine chapters. On the right side are the products that come out of the activities described in each chapter.

We know that states are at very different places with respect to their quality improvement activities. If you are new to the QI process, you will want to read the Work Book from start to finish to get a good sense of what you are in for and what it will take to make more serious effort to improve quality. If you have started your quality improvement effort but are stalled on how to determine priorities, you may want to go to Chapter 3, QI Priority Selection. Likewise, if you are looking to identify measures that you can routinely collect for monitoring priority areas, you may go to Chapter 5, Measure Selection.

Each chapter is a self-contained chapter while building off the knowledge base of previous chapters. The format of each chapter describes a component of the QI process, the tasks that make up each component, references and resources that a state can turn to to learn more about a topic, case examples from our fictional state, Any State, USA, which presents an account of a state's effort to design and implement a QI system.

Finally, within the Work Book, there are worksheets that a state can use and modify to document its QI activities. The case example illustrates how these worksheets can be filled out.

The other slides you have summarize the major topics that are covered in each of the nine chapters. I think I would like to open this up for questions now, but before I do I wanted to briefly refer to the slide entitled, “Compliance versus Quality Improvement.” On the left side we see under “Compliance” that for most of us compliance means meeting the basic requirements that are believed to lead to good care. These are typically prospective standards that are put into place long before services are actually rendered. They tend to be more regulatory in nature. Under the Quality Improvement Process, one is looking for the impact of services on the quality of life, functioning and health of the participant. It tends to be a retrospective analysis about what actually happened and in order to be most effective needs to be collaborative in nature. Collaborative with the providers and others who are influencing the care that is being provided to that participant.

Roger before, because I understand that we are under some time constraints, Gentry I would like to open this up for questions to see if anyone has any and otherwise we can then move on to the contents of each individual chapter.

Gentry: Very good. Thank you. Once again ladies and gentlemen, if there are any questions or comments at this time, please press the “*” followed by the “1” on your touchtone telephone. OK. Ladies and gentlemen, we always do look forward to any questions or comments that you do have, so if we do have any please press the “*” followed by the “1” on your touchtone telephone. As a reminder if you are using speaker equipment lift the handset before pressing the numbers. All right. Well there doesn’t appear to be any questions at this time so please continue.

Maureen Booth: OK. Let’s go on then and look within your slides to the one entitled “Getting Started.” We really focused a lot of time and energy on this particular activity because it really serves as the infrastructure for the quality improvement process. First even just defining the scope of the quality improvement function. Many states do not now have a separate function within their waiver program and the question to them is whether or not each single waiver program or home and community-based program should have its own quality improvement function or if that function should span multiple waivers or if it should be a consolidated centralized function that crosses all of long-term care.

The second part of “Getting Started” is to develop an internal organization for the QI function. Here the question for some states will be whether or not it is a discrete function or one that is combined with compliance activities and there are clearly some pros and cons to doing that. The advantage is for states that have scarce resources to be able to make maximum use of those existing resources, but it does begin to confuse the question of whether or not this is a regulatory or a collaborative activity.

Another issue that needs to be addressed during this phase is whether or not activities are delegated, either delegated to your contractors or to a external body and if so, what specific activities need to be delegated and how do those get delegated? Do they get delegated through your contractual arrangements with your assessment agencies or your care coordinator agencies or is it directly to your providers?

Who makes up the QI team? Here we felt it was very important to bring in other personnel from state agencies who can be helpful to you throughout the QI process and either collecting, interpreting or analyzing data. Very often we found in our interviews with states that they had not made close contacts with the Medicaid office personnel who are responsible for the Claims Management Systems. So we are limited in terms of being able to use that data in their quality improvement efforts.

The third part of "Getting Started" is how to engage external stakeholders and the process for bringing them into the quality improvement function and to benefit from both their experience and their expertise.

After the "Getting Started" phase of the Work Book, we talk about the preliminary assessment. In this chapter we try not to make it difficult for states that already do not have very much data and are looking to begin the process of quality improvement and to think of how one can go about gathering what you already know about home and community-based services both in terms of the information that you are collecting for either program or through the Medicaid claims data, through survey data such as what Sara just described. Then what the data says about participant quality of life, functional independence and the health of the participant. We did find that oftentimes it is just in the organization of the data that states really struggle. How they can take what seems to be very diffused information and organize it in a way that they can use for decision-making purposes.

We demonstrate and show in the Work Book brainstorming techniques that states can use with their external stakeholders and internal stakeholders so that on a more anecdotal level we can talk about quality concerns. Also identifying data gaps that can be addressed in the future.

The next chapter of the Work Book talks about selecting a topic for a QI project. This will be somewhat constrained by the data that one had during the preliminary assessment. But we begin with talking about the criteria for selecting a QI project, areas where you can have the greatest impact. The group process techniques that one can use for ranking the options for selecting a QI project and once a topic is identified, developing a QI project workgroup that includes both internal and external stakeholders that can help both steer and implement the QI project. The explicit statement of what outcomes one anticipates for the QI project that everyone understands you are working to achieve.

The next phase of the quality improvement process is the identification of barriers and actions to achieving whatever desired outcomes you have identified for the QI project. Here we feel it is important to bring in multiple perspectives that understand the barriers to achieving your desired consumer outcomes and to understand whether or not a problem is related to particular populations or is it confined to certain geographic areas or certain specific providers? Or is it a more systemic barrier that could be addressed through policy changes in your program and/or are there resource barriers, either at the state or at the provider level? We then describe a process that states can use to identify feasible actions to overcome barriers.

The next phase of the quality improvement process is the use of Quality Indicators so that you will know if your QI project is actually working. We provide several sources for quality indicators and Sara's survey indicates as well that there are multiple indicators that you can use just from the survey instrument alone. We described data that can be used to calculate the quality indicators, focusing on the survey data; Medicaid claims data, program data such as incident reports, chart reviews, assessments. All of these have their place in calculating and selecting quality indicators.

We finally talk about benchmarks for evaluating performance and how one can either use national benchmarks or simply use as your benchmark improvement over baseline.

The next chapter talks about the QI work plan that lays out in much more specific detail how one goes about conducting a QI project and to ask some very basic questions about whether or not the intervention is realistic and are the roles clear and doable by the participants that you have brought into the process? We provide some guidance on assessing whether or not resources are sufficient to be effective and what additional data you may need to monitor the progress over time and how and when and where to collect the data that might be needed to monitor that progress.

The next phase is Implementation and Monitoring. Oftentimes projects get started and they just take a life of their own without going periodically back to assess whether or not the progress is occurring as you had anticipated. This chapter also addresses how a state can communicate their QI results to both internal and external audiences and what needs to happen periodically to do mid-course corrections and as I described here, know when to hold up and know when to fold up to figure out towards the end of the project whether or not certain modifications are needed, whether or not you want to extend the duration of the QI project. Oftentimes it takes longer than we expect to achieve the outcomes that we were looking for.

If you want to no longer think of it as a QI project but institutionalize it so that it becomes part of your permanent program or what criteria you want to use when deciding to terminate a QI project, perhaps prematurely.

The final chapter of the Work Book describes the process for moving from a QI project to a QI program. This is where things become more complex. You are trying to both sustain the progress you have already made to you want to be engaging the stakeholders on a regular basis so that they understand what progress is going on, where the difficulties are and where the challenges are. You want to broaden the quality indicators to new areas so that you are not always looking at the same areas at the problems, but have a broader sense of what is going on across the entire area of your waiver program. More routine data collection will be necessary in order to calculate and monitor those indicators. Periodically you are going to be selecting new priorities that will shift your efforts. You want to design targeted QI interventions and continuously monitor the results of those so it becomes part of your own culture within the waiver program and does not get confined to a single project but becomes your way of looking at the program across the board.

That concludes my formal presentation but I would very much like to open this up for any questions that you may have and also would encourage Susie Bosstick to give us some more information about the likelihood of the Work Book coming out in final form this summer and how people will be notified and able to receive copies.

Roger Auerbach: Thanks so much, Maureen. Gentry, can we ask people to get on the line and ask questions?

Gentry: We certainly can. Once again ladies and gentlemen, if you have a question or a comment at this time, please press the "*" followed by the "1" on your touchtone telephone. We do encourage Susie Bosstick, if you are online, if you would press the "*" followed by the "1" on your phone.

We have quite a few people polling up right now. First question will come from the line of Deb Parker-Wolfenden. Please go ahead with your question.

Deb Parker-Wolfenden: Yes, thank you. I was particularly...

Gentry: Ma'am?

Deb Parker-Wolfenden: Yes?

Gentry: If you can, if you are on a speakerphone, if you could lift your handset while asking the question?

Deb Parker-Wolfenden: I have.

Gentry: OK. Thank you.

Deb Parker Wolfenden: Excuse me. Perhaps Maureen just began to touch on the question that I was having, but as I was listening to this wonderful overview of this product, Maureen, the thought struck me in terms of the types of if you will support and training and perhaps even technical assistance as being planned to help providers integrate the data that they are getting into improving the quality of their programs versus seeing it as not productive information.

Right now my observations of how the system is engaging or I should say folding out, is that sometimes there is a tendency, because many times I think that providers might not be necessarily included in the initial discussions around what makes for a quality, what makes a performance indicator, what makes a quality indicator in a person's life and then they are shown the information and asked to use it in their programs to improve the quality and to offset a tendency perhaps to become defensive and to not see it as productive. What kind of support and technical assistance is going to be available to the providers?

Maureen Booth: Well, I think that that is something that will happen on a state-by-state basis. As part of this project, there is no formal technical assistance, although we are trying to work through regional office meetings to give them further details on the Work Book and how it can be used, but I think that individual states and the message that we tried to get across in the Work Book is the importance of bringing the provider community into the process early on so that you don't run into the problem that you are just describing, Deb, and having a indicator or having a QI project that really has no relevance to the providers that will be doing the bulk of the work and will be needed in order to move towards improvement. I think generally in the area of home and community-based care we do have this problem of accountability and we are hoping that through a more inclusive process early on there can be a better understanding upfront how to take advantage of the different provider communities and others that might influence the outcome of a project.

Deb Parker-Wolfenden: Thank you.

Gentry: OK, does that answer your question, Ms. Parker-Wolfenden?

Deb Parker-Wolfenden: Yes it does. Thank you.

Gentry: Great. Our next question will come from the line of Mike Loughlin. Please go ahead with your question.

Gay Jeffries: This is Gay Jeffries instead of Mike Loughlin, but I do have a question related to if you plan to offer any formal technical assistance or any workshops if CMS plans to do this or if they have got any contracts with anybody to do this related to this particular project?

Maureen Booth: I would encourage Susie Bosstick, if she is there, to maybe speak directly to this, but we definitely see the need for individual technical assistance and are working with some of CMS contractors to see how, once the Work Book comes out, we can join forces and provide some direct technical assistance to work with states to make it happen.

Gentry: Ma'am, does that answer your question?

Gay Jeffries: Yes it does.

Gentry: All right. Very good. What I am afraid of, Ma'am is I think that Ms. Bosstick may actually be in the room with somebody and her name is not actually showing up as a queued participant. So Ms. Bosstick, if you are in the room with somebody if you would just press "*0" on your phone and that will signal me that you are with somebody else. Otherwise we are going to take the next question from the line of Beth Kidder. Please go ahead with your question.

Beth Kidder: Yes. Can we know how to get a hold of you? Is there an email or a phone number or a website?

Maureen Booth: Yes, and I apologize. I am just realizing now that on the cover slide I don't have my email address so let me give that to you. It is maureenb@usm.maine.edu.

Roger Auerbach: Could you do that once again, Maureen for people who are slow writers like myself?

Maureen Booth: Sure. Maureenb@usm.maine.edu. I don't know Roger if as part of this conference there is a participant list that will be going out to everyone and if so as part of that my email and telephone number could be included.

Roger Auerbach: Well, not normally, but we are going to give a contact name for people if they haven't received all the PowerPoints, if they haven't received all the materials that we hoped were sent out to everybody prior to the call. We are going to give a name and an email address at the end of the call and we can send your name and Sara's name out and email addresses and phone numbers with that information too.

Maureen Booth: That would be great. Thanks.

Roger Auerbach: Gentry, do we have anybody else on the line?

Gentry: We do. We have one additional question and that comes from the line of Loretta Hicks. Please go ahead with your question.

Loretta Hicks: Hi. I have been looking into consumer satisfaction surveys and under the evaluation center HSRI, the one that I was able to find information about on the website was Larry Fricks and the Georgia Evaluation Satisfaction Team's Guest. Are you familiar with that?

Maureen Booth: I can’t say that I am. Sara, if you are still on the line if you are familiar with that?

Sara Galantowicz: No, that doesn’t sound familiar.

Loretta Hicks: It was developed in 1994 by consumers in Georgia and it is appropriate for small, going into a facilities that are small, on a small scale. It is being phased out. It is going into a private; it has been a non-profit for several years but people are going to, consumers are going to start working out of their homes because the state has contracted with a large provider to do a statewide, 10,000 face-to-face surveys. I was wondering, actually I had seen the South Carolina Choice that was in the, one of the handouts that you had emailed us for this presentation. In the second email.

Roger Auerbach: Actually that wasn’t from us, Loretta, but I got that same one too from the mailing list I think of the Open Door Forums in CMS.

Loretta Hicks: Oh, so I got confused with that other call. But it looks very impressive to me and I know that South Carolina, through another consumer I know, I know Larry Fricks. He is the Consumer Advocate for Georgia and he was the initiator of the Guest Program and I know another person who is a consumer leader who was in South Carolina. They took the Guest Program and there was a lot of buy-in as I understand it in South Carolina into bringing that model into South Carolina and I was impressed with South Carolina Choice that I had seen and so that is why I inquired into it. I was wondering about a state taking on Guest as an initial project. Would that be a mistake? Would you want to start with a large project that statewide is 10,000, surveying everybody in the state or would it be better to start with technical assistance from these consumers at Guest who have been doing this since 1994 and have actually disseminated a project to both Louisiana and South Carolina and are willing to do that to other states. What would your opinion be?

Maureen Booth: I am feeling somewhat awkward not being familiar with the documents that you are referring to.

Loretta Hicks: It is referred to in the Evaluation Center at HSRI in 2001 by Clifton Chao under Consumer Satisfaction Surveys.

Maureen Booth: What the Work Book tries to do is to distinguish between the data collection effort, which in this case would be a survey administration, from what one actually does with the data. So I don’t feel that I would be qualified to help in deciding whether or not to move forward with a large survey enterprise. But rather what you would do with the information once you receive it. That is where the Work Book would be most helpful to you. I don’t know if you, Sara, you have questions or comments on the specifics of the survey and the value of going out with something as large as what is being proposed?

Sara Galantowicz: Again, I am also not familiar with the survey being referenced, but just to address a comment that you made earlier. If you want to look at your whole waiver population, it doesn't necessarily mean that you need to interview the entire waiver population so getting population-based data, you can draw simple random sample and interview 10% or some smaller number so that shouldn't in itself be considered daunting. But as to whether it is better to start with a very focused group or to look at the population as a whole, that is really something the state has to decide and how they are going to use the information and where they are going to take the project and what is valuable to them in terms of what they know about their waiver.

Loretta Hicks: OK. Thank you.

Gentry: OK. Ladies and gentlemen, we actually have one additional question and it does come from the line of Susan Bosstick. Please go ahead.

Susie Bosstick: Hello everybody. This is Susie Bosstick from CMS and I just wanted to comment on two issues that came up in the call. First of all we are currently sending both the PES survey and the Work Book through the clearance process here at CMS and while it is difficult for me to tell you exactly how long that process will last, we are working to get those documents out to the states as quickly as we can.

Then the second issue about technical assistance. As Sara mentioned, there will be technical assistance available for the PES through our National Quality Contractor and the same type of technical assistance will be available to states that are interested in using the Quality Work Book. When we send out both of these documents to the states, we will have instructions and a transmittal letter about how you can access that technical assistance. Thank you.

Gentry: And thank you, Susie. At this time ladies and gentlemen we have no further questions nor comments. Please go ahead.

Roger Auerbach: Let me, Maureen, we are getting close to time, but I am looking at the Quality Framework that Thomas Hamilton presented a couple of weeks ago and specifically the functions of Design, Discovery, Remediation and Improvement. How does the Work Book that you have developed, how does that relate in the Quality Improvement Programs to what Thomas presented in terms of discovering, remediating and then sort of feeding that back into a quality improvement process? Is there a relationship between what you are talking about and developing a quality improvement program and that improvement process that Thomas was talking about?

Susie Bosstick: Absolutely. What we have tried to do is dissect those four core concepts into a process that a state then can loop back and continually modify and refine its quality improvement program as well as its waiver program so that the two, one is an abbreviated expression and the other, the Work Book, is a more detailed explanation of how one exactly goes about doing that.

Roger Auerbach: I hoped that that was the answer. Great. Gentry, are there any more questions?

Gentry: Sorry about that. I need to take myself off ‘mute’ when I speak. At this time, no we don’t, Mr. Auerbach.

Roger Auerbach: OK. Great. Then I would like to just close by saying on behalf of the National Technical Assistance Community Living Collaborative and the Rutgers Center for State Health Policy and our partners at the Independent Living Research Utilization, thank you to all the people who participated on the call today. Very good questions, lively discussion and really great presentations by Sara Galantowicz of the Medstat Group and Maureen Booth from the Muskie School for Public Service at the University of Southern Maine.

If any of the people on the phone, participants, have any questions or any more thoughts about topics in the area of quality assurance and quality improvement, I would ask you to send those ideas or questions to Nirvana Huhtala, and I will give you her email address. It is nhuhtala@cshp.rutgers.edu. Again nhuhtala@cshp.rutgers.edu. Again I would like to thank everybody for participating today and again especially to Sara and Maureen for their excellent presentations. Thank you all very much.

Gentry: Ladies and gentlemen, this does conclude our conference call for today. Thank you for your participation and have a great day.