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Promoting Quality in Home and Community-Based Services Audio Conference Transcript

Roger Auerbach

This document was prepared by Roger Auerbach of Auerbach Consulting, Inc.

Prepared for:



Susan C. Reinhard & Marlene A. Walsh



Robert Mollica

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Roger Auerbach

Auerbach Consulting, Inc. May 6, 2003

Promoting Quality in Home and Community-Based Services

Gentery: Welcome to the conference call entitled *Promoting Quality in Home and Community-Based Services*. I would now like to turn the conference over to Mr. Roger Auerbach with Rutgers Center for State Health Policy. Please go ahead, Sir.

Roger Auerbach: Thank you so much, Gentery. Good afternoon everyone and good morning to our colleagues in Alaska and Hawaii. Welcome to this audio conference on promoting quality in home and community-based services. As Gentery said, my name is Roger Auerbach. I work with the Community Living Exchange Collaborative at the Rutgers Center for State Health Policy and 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 Resources 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 about what CMS requires for quality in community-based services, about promising practices and quality assurance and quality improvement and overall CMS goals for quality services. We hope you will let us know

if you need more information on other topics in the area of quality assurance and quality improvement.

Many of you already know that we are sponsoring another audio conference on quality on May 21. That audio conference will explore the recently released participant experience survey, formerly known as The Consumer Experience Survey. Sara Galantowicz of Medstat, who played a major role in its development, will be our presenter.

Now to today's conference on promoting quality in home and community-based services. We will begin our conference with presentations by two national leaders at the Disabled and Elderly Health Programs Group, Thomas Hamilton and Glenn Stanton. During their presentation, participants will be in a listen-only mode however there will be a number of times during the presentation that Mr. Hamilton and Mr. Stanton will ask for questions and Gentery will come on the line and explain to all of you again how to ask questions. We are looking for a free-flow, an exchange of information and encourage your participation in the question period.

It is now my distinct pleasure to introduce Thomas Hamilton and Glenn Stanton. Thomas Hamilton is the director of The Disabled and Elderly Health Programs Group within the Centers for Medicare and Medicaid Services. The group is responsible for Medicaid state plan services for adults and similar services that account for about \$140 billion in Medicaid expenditures per year. As well as responsible for home and community-based waiver services under 1915C of the Social Security Act, Medicaid Managed Care Programs for adults, health coverage for workers

with disabilities and long-term care research and demonstration programs for adults under Section 1115 of the Social Security Act.

Under Mr. Hamilton's leadership, the Disabled and Elderly Health Programs Group has placed special emphasis on working effectively with states to improve their Medicaid programs. In the past few years, the group has established a national technical assistance program to promote colleague-to-colleague technical assistance among states, establish a new CMS website for promising practices in community-based services, created special templates for easier approval of waivers that promote the ability of elderly or people with disabilities to direct their own services and awarded \$125 million in Real Choice Systems Change Grants to states.

For 21 years prior to joining the Federal Government, Mr. Hamilton was one of the principle architects of the Wisconsin Long-Term Care system. During his tenure in Wisconsin, he designed and managed innovative programs for integrated health services, managed care involving Medicare and Medicaid, long-term care, home and community-based services, income maintenance programs and employment initiatives for people with disabilities. He also administered the state's SSI supplement program, the state's Katy Beckett Program and quality assurance programs for community services.

Among his accomplishments was the design and management of Wisconsin's Community

Options Program, a program that provides community alternatives to nursing homes for more
than 20,000 individuals of all ages. Mr. Hamilton also helped sponsor the development of two

PACE Programs in Wisconsin and then used that experience to develop a combined

Medicare/Medicaid integrated managed care initiative known as the Wisconsin Partnership Program.

A native of the Commonwealth of Massachusetts, Mr. Hamilton received a Bachelor's degree in 1973 from Brandeis University in Waltham and conducted graduate studies at the University of Wisconsin.

Glenn Stanton is currently the deputy director for the Disabled and Elderly Health Programs

Group. He has 20 years of service within the public healthcare sector, at the county, state and
federal levels, much of that time devoted to assisting persons with disabilities. His experiences
have included managing the direct provision of supports and services as well as policy
development and oversight. In his current role as deputy director at CMS, he provides leadership
and organizational management for highly-skilled staff devoted to issues related to Medicaid
state plans and waiver services directed to older adults and persons with disabilities. He began
this position in January of 2001.

From 1993 until coming to CMS in January of 2001, he was a director for the Bureau of Quality Management and Service Innovation within the Michigan Department of Community Health.

During that time he was responsible for the development and dissemination of innovative service and support models for persons with disabilities, including consumer-directed services and the development of person-centered planning practice guidelines for persons with mental illness and developmental disabilities. He also was responsible for the quality management system for Michigan's Medicaid Specialty Services and Supports Waiver.

Prior to joining the State of Michigan, Mr. Stanton served as the executive director of a three-county community mental health service program in Michigan. This agency managed and provided direct services and supports to persons with mental illness, developmental disabilities or substance abuse conditions.

Clearly we have two national leaders at CMS who are well grounded with lots and lots of years working at the state and local level. Without any further introduction, it is my pleasure now to introduce Thomas Hamilton who will begin the presentation. Thomas?

Thomas Hamilton: Thank you Roger and thank you to everyone at the Technical Assistance Exchange Collaborative for getting us organized and creating this opportunity. Thanks for that long introduction. I think the main take-home seems to be that I always had trouble sitting still and Glenn seems to have that trouble as well.

I think my job here is to first establish some context for what seems to be happening and why we should be paying attention to quality in the home and community-based waiver realm. The most important context I think is to recognize that this is an emerging field, that there are unique aspects to home and community-based services, particularly in the area of quality assurance and quality improvement. It is the kind of field that really requires our close collaboration between states, between individuals with disabilities, elderly and the Federal Government and providers to figure out a way in which we can best approach quality in as a holistic and person-centered way as possible.

Fortunately, the home and community-based waivers came out of a history of collaboration, really led first by states that identified a severe bias towards institutionalization in the Medicaid program and then conducted experiments, often with state-only funds, to develop packages of home and community-based services that could serve as an adequate substitute for institutional services. Then prevailing upon Congress to pass in 1981 the Home and Community-Based Waiver Legislation that allowed states to get some federal financial help as well as using state-only dollars to make these services available.

In the early days of the home and community-based waivers, states were required to submit a plan for quality assurance and quality improvement, but there were no particular details. That remains today in terms of detailed expectations. What we find is that states have a very strong global expectation to assure the health and welfare of individuals who participate in the waiver. This is worth spending a moment to reflect on. If you compare the home and community-based waivers to quality in regular Medicaid state plan services, the expectation for states in the home and community-based waivers is actually higher. In state plan services, states are required to assure the quality of the service, but we all know that some people succumb to falling through the gaps in between services. In the home and community-based waivers, each state by law is required to check off an assurance that says, "We the state will assure the health and welfare of individuals together with that individual." That leaves room for adequate risk taking and liability, but those agreements with the individual need to be worked out so that that overall assurance can be met.

However beneath that global assurance, there really have been very little in the way of specific expectations with regard to what needs to be in a state system for assuring quality or improving processes so that problems in quality can be prevented.

Another part of the context that is worth appreciating is that these waivers, these home and community-based programs started out quite small, but in many states they have become a very large part of the system and in some states they have become the predominant system for assuring support in services for people who have quite substantial health or long-term care conditions or disabilities. That is especially true in the developmental disabilities arena, but also increasingly true in some states for the elderly and people with physical disabilities.

What that means is that as home and community-based waivers have grown considerably, the expectations have begun to change. Increasingly we find that we collectively are expected to have a firmer notion of what quality is, how quality shows up, what ought to be part of the state quality assurance- quality improvement system and also what CMS should be doing.

Most recently, there will becoming out a General Accounting Office study on quality oversight conducted by CMS. We have this in draft form right now. I will confide in you that this draft is fairly critical of CMS from the perspective of saying there seem not to be specific expectations with regard to state quality assurance systems that CMS has put forth or indeed has not put forth. Secondly that CMS has very little information about what happens with regard to quality. And thirdly that there seems to be an absence of adequate monitoring and review and follow up to remedy problems that may occur in the quality arena.

So I share that with you as a piece of emerging information if you will. We expect that that draft would be finalized in, certainly this year, possibly in less than a month. We are using that information from the General Accounting Office as part of our own self-assessment with regard to what we ought to be doing. It is not new information to us per se, because we have been working together with the state associations for some time recognizing that the home and community-based waivers have grown considerably, that we really need to do more collectively. So I welcome this opportunity to engage in a dialog with some of you with regard to how we are thinking about approaching these particular issues and some of the things that we have most recently done to try to move this field along and move our national conversation forward so that we can continue to invent good approaches to this issue.

Certainly with regard to quality assurance, it would be fairly easy to rely on many of the old standbys, the traditional ways of approaching quality. I think generally the stand-by approach, the default setting with regard to quality assurance, if you will, in most state and federal systems is survey, insert or inspection, certification and sanction. That is a practice of going out and looking at systems through and after-the-fact annual inspection and identifying problems combined with a set of enforcement capabilities such as sanctions to insist that problems get corrected.

I think actually one of the big dangers that we face is that if we do not invent broader and more appropriate ways of approaching quality in the community-based services arena, the default setting, the approach that systems in crisis tend to adopt, is the straightforward monitoring

inspection and sanction approach. Not to say that monitoring and inspections or sanctions are unimportant. I personally believe that in every effective working quality assurance system, monitoring is quite important and it is important to make sure that when all else fails, there is strong enforcement capability.

But to build an entire system around monitoring, inspection and sanctions I think loses the larger point, particularly with regard to home and community-based services where so much of what is quality in home and community-based services really comes from the design of the program in its entirety, its ability to operate in a person-centered way to afford people choices of services and more control over services so that the individual participating in the program is a coproducer in many ways of quality. If we take that much broader view about quality, then that demands a somewhat different approach to ensuring quality in the first place.

So these represent some of our challenges I think to first recognize that home and community-based waivers are not the small pilot programs that they were 20 years ago, but instead are a mainstay of the system and in some cases represent the major system. That we have a responsibility, thereby, to ensure that the systems are effective, not only for participant safeguards, but for ensuring quality in its broadest view.

So if we accept that responsibility both at the federal level and at the state level and the local provider and the individual level, we all have roles to play with regard to quality. We might ask, from a CMS perspective, what exactly is the federal role? Well, certainly the federal role is not to do quality assurance itself because the states run the home and community-based waivers.

The federal role is really to ensure that the states have effective systems in place to assure quality. So when we go out from the federal perspective to look at what is happening in the home and community-based waivers, our first and foremost responsibility is to gather information about the state quality assurance and quality improvement system and ask is that system working? If it isn't, then our job is to work with the state to try to make sure that the necessary improvements are made.

One of the things that we first decided that we needed to do was gather more information because the General Accounting Office has been correct that CMS has had very little information with regard to the state quality assurance systems. So we engage with a few key partnering organizations, the National Association of State Units on Aging, the National Association of State Directors of Developmental Disability Services, and Health Services Research Institute and the Medstat Corporation. The four of us, four parts of the team, got together and organized a survey of states. I am pleased to say that 100% of the states responded to our questionnaires. We guaranteed anonymity. Our main purpose was first to get a baseline. Where are states now in their quality assurance systems? What are the issues and what approaches are states taking? In particular, what promising practices and good things are happening? The kinds of things that tend to come to CMS's attention tend to be the problems. Where are there breakdowns? So we get a very skewed impression if we just wait for things to come to us with regard to what is happening. So it was quite important for us to be a little more assertive and go out in an organized way and get a response from everyone. We expect that we will be putting forward some of the information that we garnered through that quality inventory process with our key state association partners.

As part of that exercise, we found it necessary to construct an overall approach to quality just to organize the information. This gave rise to something that we have called the Quality Framework. I know that Roger had sent out the slides that may give you a loose sense of some of the things that we are talking about and there is a pictorial in those slides. It is labeled "A Quality of Framework." I will spend a little time really focusing on that framework and after the framework pause and see if we have stimulated any conversation, questions, comments, ideas that you might like to offer and spend a few moments engaging in that dialog.

In the Quality Framework, this framework doesn't represent requirement per se. It simply represents a way of looking at quality assurance and quality improvement systems. I emphasize the word 'systems' because many people go out and they start thinking about quality and we found that instantly people tend to gravitate to try and figure out what measures there should be for quality and doing a lot of research and validation of individual measures. But what we also found is there seemed to be often no over-arching system that gave meaning and coherence to what the state was doing. That is why we started trying to organize what we were seeing into what became the Quality Framework.

I would suggest that there are really two different dimensions to the Quality Framework. The first is a set of four functions: Design, Discovery, Remedy and Systems Improvement. Basically what we are suggesting there is that in any system you will find those four functions one way or another. With regard to quality itself, a determinant of quality really starts with how well the home and community-based waiver is designed. Is the service package, for example, adequate to

meet the needs of the particular population who will be served in the waiver? If it turns out that most of the people in the home and community-based waivers need a vital service that simply is not included, then quality will be jeopardized.

Similarly, our participant safeguards in place make sure that if something untoward happens that people are protected. The first question that we might ask of any system is, "Is quality built into the upfront design of the system? Is the system overall designed for quality?" The second question we might ask is, "Regardless of what theory that the Federal Government or the states might have with regard to how good our program is, or our system, do we have a discovery function in place, a monitoring and a discovering function, by which we could find out what is really happening out there?" So we have a great theory about quality, we think we have a good design, but is it really showing up in the real world? If things go wrong, do we have the ability to get that information in real time, quickly enough, to mount an adequate response?

That moves us to the third function, which is, do we have an adequate response and remedy system? If ill-advised things happen, unintended consequences, bad things, can we get that information quickly and actually act on the information that we get for an adequate response?

Lastly, if we see a pattern of individual problems that we may have all remedied, can we identify that pattern and look back to our design and have a process of systems improvement to ask how might we redesign the system so that we can prevent these problems from occurring in the future?

So this has been a way of simply looking at four functions in a quality assurance and quality improvement system. We might ask with regard to each of those four functions, what are some of the priority areas that we ought to inquire about? So if we are thinking about design, what aspects of the system are really important that we ought to focus on and ask, "Does quality show up?"

So we identified, together with the state association, seven areas that seem to be important in the state systems that people were concerned about. For example, participant access. How do people learn about services, come into the service system and get connected with services? So if somebody has a dire need for long-term support for example, do they know where to go? Can they get an eligibility determination process quickly? Once they are determined to be eligible, do you find a long lag time between eligibility and actual connection with services? After services are authorized, do they really show up? If it turns out that we may have a great design for quality, for services, if you will, that are theoretically available, but people are left languishing, waiting for individual services and only three or four of the needed seven services for a particular individual actually show up, then that may cause quality problems. So that is an example of design questions in the priority area of access.

Moving to an example of discovery systems. Another priority area is participant safeguards. So we might ask, "Does the state have an effective method of incident management?" That goes beyond simply incident reporting and certainly that is important. Does the state have in place a mechanism and protocols for people to report when major and unusual incidents occur. But

more than that, do they have a way to respond to those incidents so that they can be managed and responded to.

So those are examples of just applying a couple of functions to some of the seven areas. The seven areas that we identified with the state associations were Participant Access; secondly, Participant-Centered Service Planning and Delivery; thirdly, Provider Capacity; fourthly, Participant Safeguards; fifth, Participant Rights and Responsibilities; sixth, Participant Outcomes and Satisfaction and seventh, System Performance.

So we could spend more time later if you would like delving into those different areas. It seemed to be important overall that we have some overall framework to begin to look at systems and ask does the state have a system in place that can address these different functions in these priority areas? Again, this is not per se a requirement, but it is to say that this is a useful approach to looking at systems in general and analyzing a state system. Our job is to really work with states to try to figure out how you can put into place in each of these areas effective techniques that could assure quality.

I have used the term 'quality improvement' a number of times. What we mean by that is that we are not simply looking at monitoring and inspection, but we are really trying to build in processes by which you can gather information, step back and look at the design of the system and make the improvements necessary. If you notice in the managed care world, about a year ago CMS issued some regulations for managed care and quality improvement is a significant aspect of that particular approach in managed care to assuring quality.

I am going to pause here, Gentery, and see if we have stimulated any questions or comments.

Gentery: Very good. Thank you, Sir. Ladies and gentlemen, we will begin a question and

answer session. If you do have a question, please press the "*" followed by the "1" on your

touchtone telephone. You will hear a three-tone prompt acknowledging your selections and your

questions will be polled in the order they are received. If you want to decline from the polling

process, please press the "*" followed by the "2". As a reminder, if you are using speaker

equipment today, you must lift the handset before pressing the numbers. One moment please for

the first question.

Mr. Hamilton, there doesn't appear to be any questions at this time. Please continue.

Thomas Hamilton:

OK.

Gentery:

I apologize, Sir. We do have one question. It will come from the line of Dee

O'Connor. Please go ahead.

Dee O'Connor:

Hi Tom, this is Dee.

Thomas Hamilton:

Hi Dee.

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Dee O'Connor: When you were talking through the Quality Framework, Thomas, and started talking about the design aspects of it, the example you used was if a service is needed by participants and it is not available, then quality is jeopardized. I wanted to probe a little bit more on that. For example, if a state offered a program that was primarily a waiver offering personal assistant services. What some participants, maybe many participants needed was something like an emergency response system that wasn't a part of the design of that system, does that somehow argue for a quality problem in the service that was actually designed or the program, if the state has designs? In theory, people might need a wide range of things but states are often in the position of designing more targeted programs.

Thomas Hamilton: Yes, and I want to be careful about my statement. I would not regard the fact that somebody needs a service per se, to mean that quality may be jeopardized, but rather there is a threshold and if it is a vital service, that at some point I would suggest that you do cross over that line and say we have a quality problem. The particular example you used, if you have an individual who is in a wheelchair who requires a personal care worker to help them get up out of bed in the morning and bathe and eating, things of that nature, and there is a real breakdown in the system such that there is not a real personal assistance service available, then in many cases I think that really is a breakdown in quality. So it really depends on the nature of the service, what it is used for. As opposed to, for example, there being problems in a supported employment service that an individual may go for sometime without any real jeopardy and that may be a lesser issue of quality than say the failure to have a decent emergency backup system.

I mentioned earlier that CMS has not promulgated very specific expectations for states other than the law requires states to fulfill this very global health and welfare assurance. One of the things we had been doing is working with states on some of those key techniques. In some areas where it has been voluntary so far, such as the Independence Plus Waivers, you can see areas where we have begun to identify particular techniques. An emergency backup for personal assistance services in the Independence Plus Waivers is one of those. So for the Independence Plus Waivers, having an emergency backup system is a requirement if the state is going to use that.

We have not extended that requirement to all waivers. But I think if you look at the finding of the General Accounting Office in the general sense that waivers are a major part of the system now, a prudent person would make the logical connection between some of the things that we have been talking about that are voluntary right now and the prospect that they might be required in the future. What we concentrated on in the Independence Plus Waiver template, the voluntary template, is a number of things that we felt were particularly important for as part of the state responsibility to surround an individual who will be self-directing their own services with certain support systems to protect their own health and welfare and assure quality. So one of those requirements is, in the Independence Plus Waiver, is to have an emergency backup for personal assistance services.

Another requirement is to have a criminal background check available as people are hiring workers. A third requirement for example, is that the state have a major and unusual incident management system in place. You can see the lines along which we have been thinking and working with states. But again, back to your original point. It is not always the case that the

absence of the service is going to jeopardize health and welfare. But the absence of some of the most vital services may indeed do so and that can be a problem in quality for the state.

Dee O'Connor: Thank you.

Gentery: Thank you, Ma'am. Our next question comes from the line of Linda Shendaria. Please go ahead with your question.

Linda Shendaria: Tom, the question that we had is we have implemented our quality assurance process so we have our baseline data. A challenge that we have in maintaining the QA system is looking at the QA questions for the aged population with physical disabilities, to really look at their satisfaction. We have not been able to find a resource. We have looked at the CMS protocols and also at Medstat to see if we could find some examples to use with the elderly population. We were wondering if you knew of any resources or any state that has been successful with that?

Thomas Hamilton: We have got two enterprises underway. One we have been asking the same very question you have been asking for our Promising Practices website. We are very interested in some of the things that various states have done. When you look across the entire country, there is a tremendous amount of very good stuff happening. It is not all happening in one state. So if you look at one state you might see a lot of problems, but if you look nationally and somebody has got something going in one area and we are trying to collect those examples.

So we will be pursuing that question and trying to get information up on our website under the Promising Practices arena.

Secondly, you will certainly want to turn in to the TA Exchange Collaboratives conference call in two weeks and I think Roger will be back later to give you more information on that particular call on which the participant experience survey that we have been developing with states will be discussed and so we are trying to develop some of these tools.

You are asking an even broader question which is, how can we collectively work together to fashion the kinds of tools that states can find useful? We are willing to make investments in that area and when the discussion with Susie Bosstick and others happens in a couple of weeks with regard to the participant experience survey, I think you will get a good example of that where we have tried to refine questions that would be suitable for the population that you are describing and actually try to automate it and make it easy for states to use. With a caveat being that states really need a whole set of tools in their toolbox and satisfaction surveys, I think, are quite useful but most satisfaction surveys find that the great preponderance of people in home and community-based waivers are satisfied or very pleased to be getting the services and if you find that 96% of the folks are pleased, that is great and that is important. It is very helpful in working with your legislatures as an overall indicator of the value of what you are doing.

On the other hand, when you are a manager of one of these programs and you are interested in systems improvement, that 4% who may be dissatisfied isn't enough variance to really give you useful information. So there are many other techniques such as focus groups, such as having a

system in place where somebody can go out and actually talk to an individual in their own home, their own environment, and other ways of getting information that will be very important as well.

Linda Shendaria: Thank you.

Gentery: Thank you, Ma'am. Once again, ladies and gentlemen, we do look forward to any questions or comments that you may have, so once again please press the "*" followed by the "1" at this time.

Mr. Hamilton, there doesn't appear to be any further questions or comments. Please continue.

Thomas Hamilton: OK. Thank you and thanks for the comments and questions.

As we look at these different areas and take the General Accounting Office study seriously, we will be in the market for ideas of evidence-based, time-tested, actual, useful techniques that states have been finding helpful in getting a sense of what is happening in the program and developing these response systems and systems improvement techniques.

When we get done sort of fashioning the Framework, the way of organizing information about systems, I also looked at this and said well you know, this framework applies not just to states. It applies to CMS as well. We ought to be asking ourselves at CMS what is our design for quality? Secondly, do we have the capacity to actually monitor and discover in real time important information about what is happening in the home and community-based waivers. Even more

importantly, do we at CMS have the ability to work with states to remedy problems that are happening out there in the field? As one state developmental disabilities director said to me, "You know, the more we improve our capacity for discovery, the more things we discover." So it is very important that we actually be able to use the information and do something with it. That means we need to go back to design questions and figure out how do we design our system to make sure that we have those kinds of capabilities in the system? We notice from many of the CMS reviews that it would be problems identified in a home and community-based waiver. Everybody agreed that there were problems, and major problems.

The difficulty came to be when we struggled to work with the state to figure out how to resolve those problems. Simply more monitoring wasn't going to solve the problem. In many cases, the problems came from program management challenges that are inherent in the service delivery of home and community-based waivers. For example, if the main problem is that personal assistant workers are not available or are not showing up, the service is theoretically available under the state design, but the follow-through, the recruitment, the retention, the support for direct service workers are not there. Not just the emergency backup systems, but the original basic service is inadequate. That means that the response to a quality problem comes right back to the very beginning of program management. How is the waiver program designed and operated? Is there capability there at the state level and at the provider level? Are there good systems in place for making sure that direct service workers are available and supported?

So that got us into figuring out how we could actually help from a CMS perspective. One of the things that we did was make sure that quality assurance systems and quality improvement was

part of the Real Choice Systems Change Grants. So far we have allocated out to states \$125 million for a three-year systems improvement for home and community-based services. We explicitly built in examples of how these dollars might be used for improving state capacity for quality in the system. A number of states decided to come in with applications that use Real Choice Systems Change dollars for that purpose. I am glad to report that there is another round of the Systems Change Grants coming that hopefully will be on our website sometime in May. So states will have additional opportunities, not just in the quality arena, but in a number of highly-important, problematic areas for home and community-based services to make applications to get resources that will support the infrastructure you would need to improve systems or expand them.

So the Real Choice Systems Change Grants have been I think a very welcome addition to this added capacity. Lastly, we mobilized some resources to contract with HSRI to back us up in providing technical assistance to states. Mainly as a backup to some of the CMS reviews when the CMS reviewers go out and if they identify problems that then require some work in improving the program itself, HSRI staff are able to contract out with experts in the field to go out and work with the state on particular systems like Dale Dangrmon who has been going out and working on Incident Management Systems with states. Very particular kinds of very involved things where states benefit from having the expertise.

We are also trying to foster state-to-state help. The fourth item that we put in place was to use part of the Real Choice Systems Change Grants for the Technical Assistance Exchange Collaborative. So Roger and Susan Reinhart and over at ILRU, Richard Petty and those folks,

have been working and mobilizing experts not just in the quality area, obviously, but in all areas that states might benefit from some assistance. Of course, one way that states can help themselves is from importing some of the expertise from another state. That may be your best source of information. In each state they have solved different problems. Through those kinds of state-fostered exchanges, then a tremendous degree of progress can occur.

So those are some of the things that we have been trying to put in place as well as continue along the line of developing particular indicators that might be used in state quality assurance systems. So we are continuing to percolate with very precise, trying to work with states on developing precise measures of quality. But we just haven't made that a primary focus because it seemed like what first seemed to be missing or inadequately developed, was the larger system of quality assurance and quality improvement.

Susie Bosstick has also worked with folks in Maine and the National Association of State Health Policy to develop some additional tools for a quality workbook that talks about how techniques of quality improvement might be used in the context of our quality framework. So those things will be available and will be on the Web at least sometime this summer of 2003.

Then I did mention earlier the promising practices that is on our website. I would encourage you to periodically scroll through those items on our website. It is World Wide Web.cms.hhs.gov.

Then you can just put some slashes after that and type in "New Freedom". That will tell you things that are happening in our New Freedom arena but you can also type in "Promising Practices" and that will take you to our section in which we are sort of randomly collecting

examples of things that we think are promising. We are not really qualified, I don't think, to identify best practices. I don't know who really is qualified to appoint best practices, but certainly we can all pitch in and identify things that seem to be quite promising.

Then we have been trying to develop two-page write ups with the Medstat group to provide information on what different states are doing and provide information about how you can contact people in different states who can give you more details. That ranges from very particular and focused techniques to quality assurance and also to some of the larger design issues that we think are worth entertaining from a very broad view of quality.

Some of those are some of the things that we have proposed in the President's 2004 budget.

Some of you have heard me talk about those so far so I will just mention them in cursory fashion and then if people have any questions, then I can go into more depth. In the President's 2004

New Freedom Budget for HHS, there were five major initiatives proposed. The most farreaching was the money-following-the-person initiative that would provide \$1.75 billion over five years. That is \$350 million a year for states to come in with a plan and the Federal

Government would pay 100% of the cost of a community-based package of services for people who had transitioned from Medicaid-certified institutions for twelve months on the proviso that three things happen. One, the state agreed to have continuity of service at the end of those twelve months, the state would agree to put the person in a regular waiver program or provide a package of state plan services that will allow a person who had moved to the community to continue living in the community.

Secondly, the state would agree in the interim to rebalance its long-term support system to reduce reliance on institutions and improve community services and fourthly the state would try to build in techniques of the state's own design to put into place some of the principles of the money following the person. This may be a good example of where quality connects up with program design. The quality of life for a lot of people is limited by the fact that in Medicaid, states and the Federal Government tend to organize budgets by provider type. Budget a certain amount for nursing facilities, for example, a certain amount for ICFMR. A certain amount for the home and community-based waiver. A certain amount for home health; and the problem arises when people need changes or they want to express their preference to live in a different setting, but the money won't move with the individual. So not only is money following the person a good design principle in general, it also speaks to the question of quality because if money can really follow the person effectively, then the person's quality of life can be improved. That is to say, to the extent that money follows the person and enables a better match between the individual's needs and preferences, and the service system can be more responsive and flexible to adjust the mix of services across settings over time or as needs change, and then we have got better quality in the system. So I think that is an important initiative. It is before Congress; whether or not Congress is able to pull this one out of the many things that Congress has on its plate, will depend a great deal on whether or not they hear from folks that this is an important item. So if it were enacted then think it could be an important part of the larger quality picture as well as service picture.

Then another item in that package is of the President's New Freedom Budget for 2004 is the System's Change Grants. Again, I mentioned that in May we expect another \$40 million to be

available out in a solicitation on our website. The President's 2004 Budget would propose an additional \$40 million, another installment in 2004. So again that is before Congress and we will wait and see what Congress does.

There are also in that President's New Freedom 2004 budget some major demonstrations. Services such as respite, would be available for at ten-year period. I won't go into details on those per se other than to say that through those mechanisms of added financial participation from the Federal Government, if states then are able to use that in a way to round out the service package to make them responsive to what people need, then overall quality itself will be improved as well.

I am going to pause there and see if there are any questions or comments so far.

Gentery: OK. Thank you, Mr. Hamilton. 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. If you would like to decline from the polling process, please press the "*" followed by the "2".

All right, Sir, there doesn't appear to be any comments or questions at this time. Please continue.

Thomas Hamilton: OK. Well I will just wrap up in terms of some of the things that we are thinking of by way of full disclosure and also an invitation to get involved with us and give us

your ideas and thoughts. Again, my approach has been to try to, before acting, get as much information as possible and engineer a sort of national conversation about quality and then figure out as much together as we can. What are the important priority areas and approaches that we ought to pursue? I think the General Accounting Office report will give some structure to this as well. Fortunately we had that quality inventory and have a lot of these conversations in place and we will be then looking forward to taking it to the next level when we will be asking what are more specific expectations? It really ought to be part of any state quality assurance, quality improvement plan and when CMS goes out to fulfill its statutory responsibilities under Section 1915F of the Social Security Act to monitor the home and community-based waivers, when that happens what are the most important things for CMS to be doing and recognizing that in any large system we will identify substantial problems and sometimes less substantial problems, but problems nonetheless. What should be the design of our work together to try to make sure that we have got a systems improvement approach in place? I emphasize that because if we fail to really make progress, to develop more specific expectations and have these systems in place, then I think any reasonable person looking down the road would foresee some major crises in a system and a crisis environment is not the best environment for federal requirements to be engineered. The danger is of course, that what we would end up with is something that relies almost exclusively on fairly heavy federal monitoring and sanction processes. So those processes need to be part of any system but the question before us is can we design a larger and better quality assurance/quality improvement process that makes better use of quality improvement techniques so we can anticipate problems and keep the attention focused on responding to problems and improving systems rather than on the monitoring per se?

So that is a big part of our agenda and we will be trying to engineer some more national conversations on that topic. Probably some national conversations and conference calls such as this, but especially through the state associations that have made a lot of progress thinking deeply about these issues. So we will be trying to take that state experience and ask what is appropriate to show up in a federal system?

That is our basic agenda and I would ask that you take these kinds of challenges back and try to work on having good conversations about the quality topic at the state level so we can have a process that proceeds from the field up if you will, as much as possible, and that we can get informed by your thinking and the thinking of the individuals who have a disability or elderly who rely on this service system so we can have the best and the most responsive approach possible.

That pretty much concludes, there are more things that are in your overheads and there are references to some of the websites from which you can get more information, not just the CMS website but the home and community-based services website. The World Wide Web.hcbs.org is also in the developmental disabilities arena and a good website called the Quality Mall and that is really worth taking a peak at. Then we have had different conferences in which we have focused on quality and some of that information from those conferences is available on the website as well.

So that pretty much concludes what I have prepared to talk about. I am willing to talk about anything that you want to discuss so if that stimulated any further thought on your part, this a good opportunity to engage.

Gentery: Thank you, Sir. Once again ladies and gentlemen, if you have a question or a comment please press the "*" followed by the "1" on your touchtone telephone. As a reminder, if you are using speaker equipment you must pick up the handset before pressing the numbers.

Very good. Our first question will come from the line of Maureen Booth. Please go ahead. What is your question?

Maureen Booth: Hi Thomas, this is Maureen Booth. I wonder whether or not you could talk a little bit about how the CMS philosophy, as you have described it in the area of quality assessment and improvement, is trickling down to the CMS regional offices who play a very substantial role in reviewing state home and community-based waiver programs?

Thomas Hamilton: Thanks, Maureen, and for those of you who don't know Maureen, Maureen is one of the authors of the quality workbook that I mentioned earlier and I am sure as that rolls out you will be hearing more from Maureen. I just met today and yesterday with the Associate Regional Administrators for Medicaid and we discussed quality and framework and these particular approaches. They recognize that we are in an emerging field. We have had differences in how the regions have approached the waiver reviews, but I have to say to the extent that there are variations between regions in that approach, it is entirely due to the fact that

here at Central Office we have not provided adequate overall guidance in a framework. We did work pretty hard through an initiative that Susie Bosstick and Mary Jean Duckett engineered with a review protocol for the regions. That went into place almost a year and a half ago to try to standardize some of the approaches to quality reviews on the part of the regions. That particular protocol and the current reviews that are being conducted are being conducted from what is in place in the way of both understanding and requirements right now. Since that was done, since that protocol was done, we have been learning from our experience with it and from some of the limitations and have had many more conversations with that state associations. That is what has gotten us more into a broader perspective to develop this quality framework. Let's not just look at what current requirements are, but let's step back and ask ourselves what are the elements of an effectively working quality assurance, quality improvement system and for states that are doing this well, how have they organized it and what seems to be working? So we are in the process of rethinking how we are approaching quality and we will be engaging much more with the regions on that question and we will be examining with them how we are conducting the quality reviews and ensuring not only that we have a consistent approach between the regions, but a good approach and one that really looks at the question of how well the state systems are designed and operating and it gives us a firmer basis I think to move forward.

So we are engaging in a conversation not only with states but also amongst ourselves to figure out how we address this.

Gentery: Miss Booth, does that answer your question?

Maureen Booth: Yes it does.

Gentery: Very good. Thank you. Our next question comes from the line of Linda Shendaria. Please go ahead with your question.

Linda Shendaria: Yes, could you tell me how much funding you are anticipating for the next round of Real Choice and Nursing Home Transition Grants?

Thomas Hamilton: The next round of the Real Choice Systems Change Grants will be \$40 million. In 2003 that is what you can expect to see on the website. While this will be a competitive solicitation, so I am not at liberty to talk about the particular funding categories, other than to say that in the past we have had a funding category specifically devoted to nursing facility transition itself and we think we learned a tremendous amount from that four-year consistent effort and probably will not have such a narrowly defined category in the future, but we will have other categories in which nursing facility transitions would be an appropriate, an important activity. So \$40 million for 2003 and then the President's Budget proposes an additional \$40 million for 2004.

I will add that we also have coming to a website very near me I guess, the CMS website, an additional solicitation that is not funded with as much money. It is a \$6 million solicitation in which we hope to engage with some states to improve techniques for recruitment and retention of direct service workers. As you know, in addition to family and friends, the direct service

workers represent the backbone of the long-term support system. Many states have identified or experienced significant problems with the recruitment and retention of direct service workers. So we are looking at a variety of techniques that states have used when trying to organize this information and do a coherent sort of program. So this solicitation won't have as much money in it, but hopefully for the fewer states that will participate with us, will be a good vehicle for testing out various techniques to improve recruitment or retention from which we can learn bill promising practices and then possibly take that to new heights.

One of the techniques we are interested in promoting is the use of health coverage as a recruitment and retention device. As you know, we have got this twin problem of shortage of direct service workers, but also having direct service workers working in the healthcare industry who themselves don't have health coverage so the question is if health coverage is available how can that be used effectively to better recruit workers? So that is an example of some of the techniques that we have been looking at with various states. So that is an additional solicitation that will be on our website very soon.

I will also mention, while we are talking about grants and things of that nature, that we have on our website the Medicaid Infrastructure Grants for the Ticket to Work for the Medicaid buy-in programs to help states design methods by which individuals with disabilities who go to work, who might otherwise lose their Medicaid coverage or who don't have Medicaid coverage right now, would be able to purchase Medicaid coverage and have the continuity of health coverage that they really need to be able to obtain and sustain work. We already are funding 40 states

right now, so there is an opportunity for some states that don't participate with us to get some additional help in that area. Those grants are about \$500,000 per state per year.

Gentery: Ms. Shendaria, does that answer your question?

Linda Shendaria: Yes, thank you very much.

Gentery: All right. Thank you. Once again, ladies and gentlemen, as usual we always look forward to any questions or comments that you may have so if you would please press the "*" followed by the "1" on your touchtone telephone. As a reminder, if you are using speaker equipment you will want to lift the handset before pressing the numbers.

Sir, there doesn't appear to be any questions at this time. Please continue.

Roger Auerbach: Thomas, this is Roger Auerbach. Maybe I can take the prerogative of the moderator's position here and ask you one. On the Quality Framework that you discussed before, you have identified the four functions and seven focus areas. I was wondering, those focus areas would lend themselves to further refinement by some kind of performance indicators. Is that something that you have in your plans on actually sort of drilling down even further and coming up with some potential performance indicators for states to use?

Thomas Hamilton: That would be. That requires an investment in time to come up with the particular measures and a lot of conversation. So we are very interested in ideas for measures,

particularly if states have implemented measures and tested them out and have some experience. That would inform our processes tremendously. I caution, however, that part of the reason we backed off to the framework itself is we discovered that some of the major problems were really coming from the absence of some of these functions. So for example, a state just didn't have any process by which to find out what was happening in the real world. So it had no discovery function, no monitoring. Or it had some sort of monitoring but the monitoring was limited to an occasional survey of participants and all kinds of problems were occurring but they don't show up in a participant satisfaction survey.

It seemed important to us, and especially from the perspective of linking up with the Real Choice Systems Change Grants, if you are talking about building state infrastructure, we needed to especially concentrate to make sure that the framework was in place, that the state had basic capacity. You can develop all kinds of discreet measures all over the place, but if you have got no way to implement those measures, nobody is gathering information, then any measure that you concoct that requires that information be gathered, won't be feasible. So these are really pretty basic kinds of questions.

Let me give you another example in the Discovery and Design area combined. We had a waiver review in which a state had been serious about its discovery function, particularly with regard to incident management and reporting. So the state said not only are we going to have an incident management system, but we are going to make sure that we take action on that information if there are serious problems. So they designed their incident management reporting to go directly to the DA's office. This was going to be serious.

The problem was that very few of the incidents that arose were prosecutable in the nature of the problem. They were basic problems in service delivery and things of that nature and they needed a program response, not hauling someone off to court. The problem in the design came to be that when all these incidents were reported to the DA's office, the information became confidential. So none of the information from the Incident Reporting System could be reported to program managers who ran the program. So those program manager, by the design of the system, were deprived of a very important and useful body of information, a body of feedback about what was happening in their waiver. So those are the kinds of things that got us back to this question of the first thing to do is to look at how a system is designed and ask is it designed for quality?

So yes, we are interested in measures and Glenn Stanton has been able to get released from his policy meeting and join us as well. I have basically, Glenn, gone through the overheads and a framework and some of the things we are doing and we are just wrapping up on the questions and Roger just had a question of whether or not we were still interested in the outcome measures and we are still interested in proceeding, but also to make sure that the basic system is there.

Roger Auerbach: Thomas, you also mentioned something in the slides about data and that you were going to do some data collection and analysis that states were using. How is that going to factor in? How is that going to help states in their process of achieving better quality?

Glenn Stanton: I assume, Roger, that what you are referring to is the Data Readiness...

Thomas Hamilton: Aaah, Glenn, there you are. Welcome.

Roger Auerbach: Actually it was a slide that talked about collection and analysis of state data for long-term care, state planning data for systems change, but I know that there has been conversation over the course of years about having states look more at the data that they are collecting and look for the need to collect more data to inform their system improvement.

Glenn Stanton: Let me clarify what is in the slides and then get to the more specific data question. The collection and analysis of state data for long-term care is really under the heading of tools for CMS, and we needed to have the ability to have information from waiver applications, essentially, that described the program, that described the persons who were being enrolled, the services eligible and we have been building that over the last couple of years and are now using it on a fairly regular basis to answer some basic management questions like how many enrollees, what kinds of services are being covered in what place in different states, responding to both individual state questions as well as some broader issues. So this was really trying to build some data from the applications from the 372s and some other sources that would give us the ability to see what is going on across the country.

The State Data Readiness Project is actually an interesting one in that that was seven states who are currently using data as part of their quality management systems and there have been a number of interviews with those specific states and out of that is going to come a series or a single document, I am not sure which, which are promising practices or examples of how states have been collecting and utilizing real data to make improvements in their overall quality

management systems. I think that is going to be the first step towards sharing information about states like Texas, like Michigan, that are collecting information, looking at it from a performance measurement standpoint and then feeding it back into systems improvement.

Roger Auerbach: And that was listed in your Technical Assistance and Resources slide.

Glenn Stanton: That is correct.

Roger Auerbach: OK. Thanks. Well that is going to be pretty exciting and that is going to be available you hope this summer.

Glenn Stanton: Yes. That is another project that Susie Bosstick has been the point person on.

Roger Auerbach: Great.

Thomas Hamilton: Again, it ties back to the Framework. If you look at that monitoring and discovery function, we have already had on the call today a number of examples of ways of getting information that states use. Linda Shendaria earlier mentioned satisfaction surveys. We talked about incident management systems and I talked earlier about some states having very good systems of sending people out to visit people in their own homes as well as other states using focus groups where they bring folks in together and help them interact and sometimes

when they reinforce each other then you get information that you don't get from people when you are visiting in their own homes even.

So those have been techniques. Now we have ended up on another technique which is to say some of these techniques are pretty labor intensive, focus groups, sending people out to their own homes. To what extent can administrative data be used to analyze what is going on in a system? So for example, a state that says we have got a great design for a waiver. We have case management. We individualized every one of our services and people get exactly what they need. A program manager, if they have got a good information system, would just run some reports to say well, let's take a look and see what people are actually getting. If it turns out that just about everyone's only getting three of the available seven services that everyone is basically getting the same thing, then that is a feedback source of information that tells you well maybe things aren't quite as individualized as one might think. That is a small example, but the question that we have posed is to what extent could systems be developed of an information management nature that gives state program managers useful information in real time that they can use to find out what is going on out there in the real world.

So the same thing applies to us, of course. To what extent do we at CMS have information that is happening and can we get any of that information back to states? You haven't seen this, but we are sort of working and asking how can we put together information about things that are happening in states that state program managers would find useful? We know, for example, that there has been a tremendous amount of progress made in building community systems. We do see reliance on institutional forms of service. Each state has information about what is

happening in its state, but it really doesn't have good information about what is happening in

neighboring states or other examples. So we can put that together and share that with states.

So we have got a number of projects here to try to gradually over time, nothing rash and nothing

fast, but we do hope to be able to marshal some of that administrative data and make it more

available to states.

Roger Auerbach:

That would be great. Gentery, do you have anybody waiting in the queue

to ask questions?

Gentery: No we don't, but I do want to remind everyone if you do have a question or a

comment press the "*" followed by a "1" at this time.

Male: So far, Linda Shendaria gets our frequent questioner award.

Roger Auerbach:

She does, she does.

Glenn Stanton:

Roger, you have a group of awards there to give out.

Roger Auerbach:

I do, but we will have to send them electronically.

Gentery:

Gentlemen, we don't have any questions at this time.

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Roger Auerbach: Glenn, is there anything that, I know you were unfortunately were involved with another meeting. I know that you wanted to be with us. Is there anything that you would like to highlight? I know that you didn't listen to most of the conversation, but is there anything as you think about this subject area that you want people to take home with them?

Glenn Stanton: With respect to Thomas and to others who participated in the call, I really am sure that there have been great minds and discussions here and I don't need to repeat anything. I just think that the important part for us is that quality because of the context, because of the number of individuals who are trying to live full lives in the community, us knowing that the systems are not just, not just trying to identify and correct problems under the old Quality Assurance Model or under the Simple Remediation of Individual Problems Model is important still, but really where we would like to see the system evolve to is one in which we are having a continuous dialog, a continuous set of activities to improve not just individual lives but collectively how the systems are designed and implemented. Hopefully that is where we will get to over the next few years.

Gentery: Gentlemen, if I may interrupt you. We do have a question from Linda Shendario. Please go ahead, Ma'am.

Linda Shendario: Well, since I got an award, I have one more question for you. Some of the Tag Letters have been talking about the client has to use the Medicaid Waiver Service per month and then it had some discussion as to whether it needs to be yearly, quarterly. We were

wondering if you could clarify if a determination has been made that the client has to use the

service, waiver service monthly? Thank you.

Roger Auerbach: Funny you should mention that. We were just talking about that today.

That is the current requirement that has been a long-standing policy. We have, as you know, I

mentioned we have engaged with a technical advisory group with state folks on that question to

see if there might be a better way of approaching it and we are still in process internally here to

try and figure out if we can take the suggestions from the state technical advisory group and be

able to respond to that. So I am still hopeful on that front, but there hasn't been a final

determination.

Linda Shenlandia:

Thank you.

Gentery:

OK, gentlemen, we have no further questions.

Roger Auerbach: Then what I would like to do now everyone is to thank Thomas Hamilton

and Glenn Stanton for their time and their information today. It was, I think, incredibly helpful

and informative to know what CMS is doing and what they are thinking about in the area of

quality assurance and quality improvement.

I want to ask participants if they have any further questions, anymore thoughts about topics we

might cover in the area of quality to please send them along to us. I am going to give you an

email address for Heather Allen, the project director at the Center for State Health Policy. Her

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email is hallen@cshp.rutgers.edu. So any comments, questions, or thoughts about quality please

send them to Heather.

I would also like to remind you as I did when we started the conference that we were sponsoring

another audio conference on quality on May 21 on the Participant Experience Survey. We talked

a little bit about that today, but we will have at least a full hour of opportunities for questions

with Sara Galantowicz of Medstat who played a major role in the development of the Participant

Experience Survey. So we will be sending out announcements about that audio conference and

registration within the week for sure. Again, I would like to thank Thomas and Glenn very much

for their helpful information and sharing their time with us.

On behalf of the Rutgers Center for State Health Policy and the Independent Living Research

Utilization Technical Assistance Exchange is funded by the Centers for Medicare and Medicaid

Services, I would like to thank you all for participating and I wish you a good day.

Participants:

Thank you.

Gentery: Ladies and gentlemen, this concludes our conference call entitled "Promoting"

Quality in Home and Community-Based Services. Thank you for your participation. You may

now disconnect.

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