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# Community Living Exchange

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# Nursing Home Transition Audio Conference Transcript

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**Robert Mollica**

**National Academy for State Health Policy**
**Date: June 19, 2002**

**Audio Transcript: Nursing Home Transition**

Bob Mollica: Welcome to this audio conference on Nursing Home Transition Issues. My name is Bob Mollica and I am with the National Academy for State Health Policy in Portland, Maine. I will be your moderator for this afternoon. The audio conference is funded by a grant from CMS to provide technical assistance to real choice systems change grantees. The call has been organized by the Rutgers Center for State Health Policy and the National Academy for State Health Policy in collaboration with the ILRU which is our other technical assistance exchange partner. This call is one component of our plan to work with nursing facility transition grantees and we welcome your feedback on other activities as well as topics for future audio conferences.

Before I introduce our two guests, I wanted to mention another opportunity to learn about nursing home transition programs. The National Academy for State Health Policy will hold a one-day, pre-conference that will be part of our annual health policy conference and it will be held on Sunday, August 4 in Philadelphia. You will be receiving more information about this conference shortly.

In a few minutes, you will be able to ask questions of our two guests or make comments by pressing the "1" and the "4" key on your phone. If your question has been answered

or you decide not to ask your question, press the "#" sign and you can drop out of the queue. Now let us turn to our guests.

And now to our guests. Mary Clarkson is with the Division of Benefits Coverage and Payment at the Disabled and Elderly Health Programs Group at the Center for Medicare and Medicaid Services. Mary has been working with states on 1915C waivers since 1985 and was very involved in the preparation of the recent state Medicaid Director's Letter dealing with transition issues.

Steve Eiken is the project manager for nursing home transition at the Medstat. Steve has conducted site visits and prepared several case studies of states that received early grants from both CMS and ASPE to develop relocation programs. Welcome to both of you.

Let's start with Mary. The Transition Cost Letter is a very welcome initiative and I know states have been pushing for this for a long time. Could you start by explaining what it does generally?

Mary Clarkson: Certainly. The Transitions Letter, which was sent out on May 9, is the latest in a series of letters that we have been putting out in order to clarify our policy. As you know, the Americans with Disabilities Act was interpreted by the Supreme Court in the Olmstead Decision to encourage states to provide services to people with disabilities in the most integrated setting appropriate to their needs. Now, from the

Olmstead Initiative, we have the New Freedom Initiative, which has given us both the impetus and the means to assist states in making the program work.

When a person is institutionalized, we had received calls from both beneficiaries, advocates and states for years saying it is almost impossible for that person to save enough money to start up a home upon discharge from a facility. Many states allow people to keep only $35 a month and it would take many, many months for you to save up enough money at that rate. A couple of years ago when we began the Nursing Home Transition Grants, we wanted to find out, if we were to allow states to pay for some of these one-time expenses, what would happen? They were quite successful. For that reason, we found some ways we could actually make this available as a home and community-based waiver service. Now this is only a waiver service; I have to make that plain. It is not available under the state plan. As an approved home and community-based waiver service, states can now provide the resources to enable an individual to set up an apartment or a house, get the necessary furnishings and get started in life in the community.

Bob Mollica: How would states implement it?

Mary Clarkson: So far we have only one state that I know of that has actually requested a transitions service amendment to their waiver. They would go about it the same way they would go about amending any waiver. That is:

- ✧ Define the service,

- ✧ If they are going to put any limits on the service tell us what those limits are,
- ✧ Identify providers (provider types),
- ✧ Cost it out, and
- ✧ Provide it in a cost-neutral fashion.

Bob Mollica: OK. Is there a limited period of time before leaving a nursing home that these expenses can be incurred?

Mary Clarkson: Actually, we have not set a time limit. However, because this is a service that involves bringing a person from an institution and into the community, and because the person is only considered to be enrolled in the waiver when the person leaves the institution, the amount of time that would be spent by a state in expending these types of funds would necessarily be limited.

Bob Mollica: How might the waiver be worded? Are you looking for general descriptions of what might be covered or should the waiver be very specific?

Mary Clarkson: That is up to the state. States could be very, very specific if they wanted to come up with a list of things they wanted to cover. The advantage of that is that you know exactly what it is you are paying for. You have a very good idea of what your financial exposure would be. Or, you could be somewhat more general. The advantage of that is, of course, you have far more room for creativity and flexibility. But

the downside of being much more general is that you open yourself up to other people's interpretation of what this benefit should be.

Bob Mollica: The letter listed a few things that can and cannot be covered. Could you describe what those are?

Mary Clarkson: Certainly. As far as things that could be covered, I think the one that would probably attract people's attention most is coverage of security deposits to obtain a lease on an apartment or a home. We would also allow payment for the essential furnishings, moving expenses, set-up fees and deposits for utility services, telephone, and electric service. You could cover other services that would be necessary to make the home livable such as getting rid of pests, allergy control, and one-time cleaning expenses. Could some of these things be furnished as other benefits? Yes. We have always allowed under home modifications and chore services some of the services such as pest control. But, if a state wanted to put them into one package of services to support deinstitutionalization, that would be an option that we would make available to the state.

Bob Mollica: OK. If people on the call have questions, whom should they call?

Mary Clarkson: They could call either Mary Jean Duckett at 410-786-3294 or me at 410-786-5918.

Bob Mollica: OK, thank you. We will be getting back to you with more questions later. Steve, you have been spending quite a bit of time now looking at states that have experience and a track record. How have the transition programs that you have visited been structured?

Steve Eiken: They have had the three common elements that we usually think about with nursing home transitions. There is someone providing case management or service coordination that is, someone who works directly with the person to organize how to complete the transition. There is a way of identifying who will be served because usually these are small programs with less than $1 million in funding, drawing solely on the federal grant so far. So you have got to narrow the pool from the thousands of people that may want to move. Also there has been funding for one-time expenses much as Mary Clarkson was talking about.

Medstat has visited seven of the twelve states that received nursing home transition grants between 1998 and 2000. There are still two more states that we are planning to visit. We are writing case studies on each of the nine states. None of those reports are ready for public release yet. We had planned to have the first two out by August 4 before the pre-conference that NASHP is hosting.

Bob Mollica: Terrific. As states start to plan the development of these programs, what are the most important things to do early in the planning process?

Steve Eiken: I think first, the most important thing to do is to make sure home and community-based services and housing are going to be available for people or at least to find ways to make that available. In most of the programs we have reviewed, most people who have left nursing homes have gone with home and community-based service waivers. Some of those waivers have waiting lists and that creates a tension within the state about whether people leaving a nursing home should go to the top of the list or not. That is controversial but that is something each state needs to consider. If someone is has to wait for services, several months or a year, it can make the activity counterproductive.

Housing has been a large barrier too. I would encourage working either at the state or local level or both, working with housing agencies upfront, to make landlords and public housing complexes more comfortable serving people who have left nursing homes. There is frequently a mindset that someone in a nursing home is more disabled than someone in the community. They should be in a nursing home and they shouldn't be in my building. That is not a universal mindset by any means, but it does happen and it is good to have that communication upfront.

Another thing I would recommend is, before starting the project, to communicate with all the potential players to they are aware of it beforehand. Local agencies are or local states staff who are doing the coordination, the people managing home and community-based services, the nursing homes themselves all need to know about it in advance because it can facilitate entry into the nursing home. Those are the three main agencies that

definitely need to know about it and if there is additional outreach that states can do to other stakeholders, that would help as well.

Bob Mollica: How could states that you have looked at been working with nursing homes? Have they been allies or opponents or both?

Steve Eiken: Both at times. There has really been a wide range of response. To some degree, it has been somewhat connected to occupancy rates. Nursing homes in areas with higher occupancy rates have tended to have more cooperative. Nursing homes with lower occupancy rates, say 60-70% have tended to be more resistant. It is not always the case, but that is usually how it works. Some nursing homes have even suggested people, both from allies and opponents, who are challenging to serve in the community either due to a history of substance abuse, criminal activity in some rare cases, to just needing a level of services or a type of services that may not be available in that community. Sometimes nursing homes suggest great people and are wonderful allies. They make referrals for people who moved to a community with great success.

Bob Mollica: When nursing homes refer the tougher people to assist in relocation, how have the programs responded?

Steve Eiken: Usually the programs do respond. Most of the local coordinators worked for Independent Living Centers or organization with a similar independent living philosophy. The thinking has typically been whoever needs help, we will help them.

They have usually worked to help these people to move into the community and often have done so successfully. There have been some rare occasions when it has not worked well. There is at least one example I can think of right now of someone who sold the furnishings that were purchased with the transition funds and as best that local organization knows, that person is now homeless. That is that person's choice, but the local folks did not consider that as a desirable outcome.

Bob Mollica: I can imagine. As people leave nursing homes, Mary described some of the things that could be covered and couldn't be covered. What have you found have been the most common things and do you have any sense of how much these things have cost so that a state might anticipate how to budget for them in their waiver amendment?

Steve Eiken: The most common items have been housing deposits or the first month's rent and furniture. Probably furnishings more broadly because it is the house wares that someone would need. Cooking supplies, sometimes even toiletries may be necessary. Basically I hear the word 'Wal-Mart' a lot. (Laughs) It is that kind of thing. I am in Arkansas right now so everyone with me is laughing because Wal-Mart is a big part of the scenery down here.

Usually the transition services cost around $1,000-2,000 per person. Some people don't need any services and some people need five figures worth. The most expensive transition services have been home modifications which are often defined as a different waiver service. There are some less common examples that show the flexibility of these

programs. In one case someone, had an accessible van, but lived in a nursing home. The project paid for registration fees so that that person could keep that van and operate it once he or she left for the community.

Some states had actually paid for trial days in the community where they can move to either an assisted living facility or public transitional housing where they can try out living in the community for a few days. The project can pay for the personal assistance services during those few days while the person gets a feel for what life would be like in that community and make some adjustments in their expectations if necessary or come away thinking this is great. I really want to do this and I am ready to move.

Bob Mollica: Have you seen instances where there might be a delay between when the person actually moves and when they can be enrolled as a waiver client or beneficiary and the use of transition funds to cover the interim?

Steve Eiken: Yes. We have seen examples of that. Often, and it varies so much depending on the state's processes for completing assessments. This is one reason why it is important to communicate with the local waiver staff so they know it's coming, and they can adjust their work schedule to get the assessments completed more quickly.

Another factor in this is the local people who determine Medicaid financial eligibility. The sooner those two folks know someone is leaving a nursing home, the better. It can take several weeks to determine the Medicaid financial and waiver eligibility once a

person moves to the community. Most states have tried to expedite that process rather than pay for the services in the interim although I have seen examples of both.

Bob Mollica: OK. So you would suggest that states keep a flexible definition of the benefit rather than a really specific one?

Steve Eiken: That would be my suggestion. Just because you don't know exactly what an individual might need but states might want some oversight to make sure that the services or items covered are appropriate because there is always that tension.

Bob Mollica: What kinds of monitoring and oversight have you found?

Steve Eiken: Several states have actually approved each transition service. A local agency would fill out a one-page form, usually a rather simple one, outlining each service or each item that they are going to purchase or each service that they plan to provide for a person that is part of the transition plan and fax it or email it to the state to get approval. It's a common tension where local agencies typically don't want a separate approval process. They want a lump sum that they can spend. It is hard to do that with a waiver service because Medicaid pays for it. Local agencies do not want prior approval. I think it is still good for the state agency to have prior approval so they can document how funds are being spent. It gives them information about other services they may want to cover.

Bob Mollica: Thank you very much. Let's turn now to our audience and see if they have any questions. A reminder, if you want to ask a question just press "14" on your phone and if you want to drop out of the queue just press the "#" sign. Dante, are there any people online?

Dante: First we have a question coming from Randall Blume of New Jersey.

Bob Mollica: Go ahead.

Randall Blume: Yes, I wondered what the CMS position was on giving priority on the waiting list to people coming out of nursing homes?

Bob Mollica: Mary, do you have a response?

Mary Clarkson: Yes I do. Randall, CMS has not taken a position on waiting lists. We believe that it is a state matter to decide who is going to receive services and in what order. At this time we have not attempted to take any positions whatsoever on waiting lists. You are, of course, subject to all Medicaid requirements as far as timeliness is concerned, but beyond that we have not taken specific position about waiting lists or how they should be allocated.

Bob Mollica: OK.

Randall Blume: Thank you.

Sandy Barrett: Bob, this is Sandy Barrett. How are you? I wanted to ask Mary if the transitions services could include the case management that would occur in helping the nursing home resident apply for waiver services, help them identify appropriate accessible, available housing, the kinds of things that case management might offer?

Mary Clarkson: At this point we have not envisioned case management as a transition service, however, we have permitted Medicaid case management either as a state plan service or as a home and community-based waiver service for the last 180 days of a person's institutional stay. In addition to that, the state also has the administrative capability of assisting an individual at any time to apply for any Medicaid service for which that individual might qualify.

Sandy Barrett: Thanks.

Bob Mollica: Are there any other questions pending?

Dante: We do have a question coming from Todd Ringlestein of New Hampshire.

Todd Ringlestein: Hi folks. We have a couple of questions. One is, "What is the type of person who typically has come from a nursing home into the community?" What is the average age?

Steve Eiken: Most people have been under 65. If I were to guess at a median age right now I would say in the 50's. So far, these have been rather small programs with the exception of New Jersey which had a state-funded initiative for a couple of years before they received the federal grant. The most common local coordinators have been independent living centers. I think they either because of state targeting or because of the natural focus of Independent Living Centers, they tend to serve younger people with disabilities, more people under age 60 or 65. I don't think that necessarily is an indicator of who is more appropriate or likely to leave an institution. I always ask local coordinators what are the characteristics of someone who is likely to leave a nursing home? The common thing that they mention is the resident's attitude. That seems to trump functional status, age, and gender. That has been the primary factor. That and the local housing supply have been the primary factors determining the ease of which someone can move into the community.

Bob Mollica: Steve, earlier you had said that the role of the care coordinator is to identify people who might be served. I know there has been a lot of controversy about whether you use a set of criteria or you just go and ask people and work with them. How were the states finding that? Would they say that just asking people if they are interested in moving or relocating is a better approach than coming up with a specific set of criteria?

Steve Eiken: I think most of the states I work with have operated on a referral basis. Making information widely available and waiting for residents, nursing homes or family

members or someone to call and to request assistance. I think some local areas have had success just going into nursing homes and talking to people and finding people who want assistance. In other local areas, coordinators have not been successful and have been kicked out of nursing homes or nursing homes have put a lot of pressure on the state agency regarding that. I don't want to recommend not going into nursing homes, but I think most states in these small programs have had plenty of people to relying on for referrals.

Bob Mollica: If there are participants who would like to comment on these responses or ask further questions, please feel free to log in and do so.

Mary Clarkson: Bob, I would like to add one thing to what was just discussed. Although the nursing facility transition grants were specifically targeted at helping people leave nursing homes, the transition services that are being made available under home and community-based waivers are not limited to people in nursing homes. They can also be used for people who are in intermediate care facilities for persons with mental retardation.

Bob Mollica: Thanks.

Dante: We do have another question coming from the phone lines. Our next question is from Mary Jo Iwan of Nebraska.

Bob Mollica: Yes, hi Mary Jo.

Mary Jo Iwan: Hi Bob and Mary. Thanks a lot for taking the call and also for having this conference. One of the things we are interested in is why in the memo TV sets were excluded as not considered essential furnishings? I know that when we had a nursing home transition grant it was so important to so many people to have a working television and it really cut down on their isolation. Especially with the weather that we have, so many people can't get out that often and it really gave them a connection to the world outside so they just weren't as isolated as they had been.

Bob Mollica: Mary?

Mary Clarkson: Congratulations on asking a question that really doesn't have a good answer. The TV sets, cable TV, that sort of thing were put in because there remains a concern - there always has been a concern with home and community-based waivers - that we would be paying for services and for things for which there was actually not a medical need. Since this is advice to states, if a state actually wanted to write to us and specifically discuss an item such as televisions or cable TV, pointing out reasons, such as: we think this should be covered because it would help break up a person's isolation; we think this should be covered because in our state, Nebraska, every time I look at the Weather Channel there is a tornado alert on somewhere. If you were using it for those purposes, all I can say is that we would entertain that and certainly give some very serious thought to whether or not we had acted properly.

Mary Clarkson: I think you also have to understand that any time we come up with a clarification in policy that is as revolutionary as this one, it is not uncommon for us to take the more conservative approach at the beginning and, as things begin to play out, to modify our approach. I would encourage you to let us know.

Bob Mollica: I think that is a tribute to the flexibility that lies behind the development of this policy as well. Is there another question waiting?

Dante: Yes, our next question is coming from Judy Roy of Alabama.

Bob Mollica: Go ahead, Judy.

Dante: Judy has just removed herself from the queue. Our next question is coming from Jackie Dunaway of Massachusetts.

Bob Mollica: Hi Jackie.

Jackie Dunaway: We have two questions actually. One is, this may be a question for Steve. We were interested in seeing some of the materials developed by the earlier projects. We understand New Jersey developed some educational programs for making presentations to the nursing facilities. Vermont developed a screening device, an assessment tool and also some of the projects were using quality of life and satisfaction measures. Are those available centrally or do we need to contact each individual state?

Steve Eiken: You can contact me. My email is steve.eiken@medstat.com or you can call me at 202-719-7815 and I can contact the state and see what they have or make copies of what I have. I have copies of some of those materials but not all of them. Or I can email you URLs like Michigan. Their Independent Living Centers created an assessment tool that is available online so I could email that to you. I think that might be easier than contacting each state although I don't have a library of things I can send, but I can make copies.

Jackie Dunaway: OK. That would be helpful.

Bob Mollica: If you want another resource, you can certainly call the technical assistance exchange and we can try to track those things down as well if you find some things that aren't available through Steve.

Jackie Dunaway: OK. Go ahead Maryanne.

Maryanne Brennan: There was another question too as to whether or not there had been any issues coming up around confidentiality with the people that are selected for the project when you are working as an interagency effort? I don't know if people have run into that at all.

Jackie Dunaway: It has been a major headache for us and it is keeping agency lawyers real busy trying to word agreements that will be acceptable to elder affairs, mental retardation and human services agencies and the nursing facilities. We have a true interagency effort, but it is giving us a real headache and we anticipate more problems when the new HIPA regulations come out in April 2003 or become effective, so we wondered what people's experience was and how they solved those problems.

Steve Eiken: The only problems I have heard about were in Wisconsin. They had planned to use the Nursing Home Minimum Data Set, the MDS Data, to identify nursing homes residents under age 65 and to give the names of those people to Independent Living Centers so they would have a list of folks to talk to. They were not allowed to do that for data privacy reasons.

Jackie Dunaway: Our issue is similar. We were trying to get the MMQ, the Management Questionnaire data from the nursing facilities and actually, the Division of Medical Assistance (Medicaid agency) maintains that data. We are having trouble accessing that as well.

Steve Eiken: It may vary by state. I am not really sure what the variance is. Vermont may be a good state to look at because Vermont actually did use MDS data to identify people. They had had some pre-set criteria for who they thought would be appropriate for nursing home discharge and sent that information to their local agencies which were area agencies on aging and home health agencies.

Bob Mollica: Is that because the Vermont agency that was doing the program had the data in-house or did they have to get it from Medicaid?

Steve Eiken: They may have had that in-house. I don't think they were the Medicaid agency.

Bob Mollica: No, I believe it was the Department of Aging and Disabilities (that operated the program). In Massachusetts it may be different when they are asking for information to be shared across agencies.

Steve Eiken: One cautionary note with data, Vermont's experience was that the MDS data really wasn't helpful. It goes back to the main criteria. It is really hard to measure the resident or the family member's attitudes with assessments. The local agencies found the MDS data was too predictive. By the time local agencies received the MDS data, people had left the nursing home already or the people who had remained in the nursing home were not likely to leave the nursing home or didn't want to or had other complications that made leaving the nursing home difficult.

Jackie Dunaway: That is an interesting example.

Bob Mollica: If there are any listeners who have any experience with confidentiality and how you write a consent form that would address the problem, we would love to hear it. Dante, do we have any further questions?

Dante: Our next question is coming from Gayle Propson of Wisconsin.

Bob Mollica: Hi Gayle.

Gayle Propsom: My question is for Mary. When someone asked about at what point or how soon the transition services could be provided before a person moves from a nursing home, you mentioned that the person isn't actually on the waiver until they are out of the nursing home. Does that mean that these transition services can't be actually put in place until that time? We have had nursing home transition grants and many of the things that need to be taken care of for the transition have to happen before the person leaves the nursing home.

Mary Clarkson: I am really glad you asked that because it is going to give me the chance to clarify something that I think has become a misperception in a number of places. We recognize that there are a number of services that must be started before a person is deinstitutionalized. Actually, the work has to start before the person comes out of an institution. Securing an agency or a provider has to start ahead of time. This is why we even put in that 180-day criterion for case management. But in addition to that, things like home modifications can't happen in the period of time it takes for the person to leave the nursing home and get home. That would be a record for any contractor. We would consider the service to be a waiver service when the person enters that waiver, and that is when FFP becomes available. So the key is you consider the service complete

when the person leaves the nursing home. You just don't send us the waiver bill for somebody who has not yet gone on the waiver.

Gayle Propsom: The service can actually occur before that but we don't submit to the bill to the waiver program until the person is on the waiver?

Mary Clarkson: Right.

Kris Baldwin: Bob, Kris Baldwin here and Arkansas has a question.

Bob Mollica: OK.

Kris Baldwin: This is a question for Mary. Mary, does CMS have a problem with releasing any of the MDS information? Prior to my working with the Division of Aging and Adult Services, I worked with some folks in Medicaid here who had told me at one time that MDS information could not be released, that CMS was not comfortable releasing MDS information. Is that true?

Mary Clarkson: There are some very, very stringent criteria that surround the release of that information. Of course Medicaid has had privacy rules in addition to the MDS rules that have been in effect for years. This is all complicated of course by the fact that HIPAA came along and really surprised a lot of people both by the transaction codes and also with the privacy part. Now we think that we may have taken some major steps

towards states and providers living under HIPAA when it comes to the transaction codes. We are still working on the privacy part. I have to tell you we have some people who are working very hard on that, but I don't have a final answer for you on the extent to which those regulations will apply. Fortunately, they haven't been issued yet.

Dante: We do have more questions coming from the phones.

Bob Mollica: OK, let's go.

Dante: Our next question is coming from Dann Milne of Colorado.

Dann Milne: Bob, actually it is a comment about the gentleman's question from New Hampshire. We had a deinstitutionalization project here in '97 and '98 and the age range of our clients was from 35 years to 99 years with the average age being 71. The months in the nursing facility ranged from 0 to over 50. Both of those findings in our project were surprising to us, but gave us insight into the diversity of that population that could be gotten out of nursing homes. Trying to narrowly target on age ranges and people that are only in nursing homes very short periods of time, proved not good strategies for us.

Bob Mollica: That is very interesting. Colorado has one of the early experiences and has done a good job of documenting their experience. Dante, we are ready for another one.

Dante: OK. Our next question is coming from Phyllis Culp of Kentucky.

Phyllis Culp: Thank you. Is there any experience with using the nursing home ombudsman as a referral source?

Steve Eiken: There has been very little experience with that. Just this week in Arkansas someone mentioned that some ombudsman were concerned about losing some sense of objectivity with the nursing homes and the fact that being a referral source might interfere with their role as ombudsman. There have been some referrals from ombudsmen across the states, but that has not been a large source of referrals.

Phyllis Culp: Thank you.

Dante: Thank you. Our next question is coming from Linda Kendall of Georgia.

Linda Kendall: Hello. I was wondering, this is kind of related to the referral pattern. I know that Steve made an earlier comment that there are plenty of people came through referrals. I am wondering about how those referrals are being pooled or collected. I know that our Medicaid director in Georgia is really looking toward the steering committee for the nursing home transition grant to make a recommendation about the long-term sustainable place that we should collect those referrals. I imagine whether it is nursing homes themselves or consumers or CILs, I know that in our current transition grant it is really the CILs collecting those names. But in order to get the whole

system working together, I am wondering are there other things in place to serve as a long-term repository for those referrals?

Steve Eiken: Two states come to mind and there are probably others that have done this as well. Arkansas and Wisconsin have kept databases. I think Arkansas use a central intake. They had a 1-800 number and a Website to collect referrals. I think Wisconsin may have had a centralized intake as well. But they at least had a centralized database where they can store information about all the people referred. As the program matures, local folks will get referrals. It is somewhat common for a local coordinator to be in a nursing home working with someone. Another resident in that nursing home will see what is going on and will ask for help as well. It's important to have central repositories to emphasize the communication. I think it is better to have state-level data at the state level. That is just a personal bias of mine. Sometimes it is going to be challenging when the local organizations are so busy doing the work, may be the worst at doing the paperwork and passing on all the referral sources since they are so busy working with people. They may only pass on referrals that they are working on. So there are some data integrity issues that may arise.

Bob Mollica: Is this a data reporting issue or a referral process to get somebody who is referred for relocation assigned to somebody that can then help them?

Steve Eiken: I am talking about more from a data reporting issue. From a referral issue, I haven't seen a lot of problems with getting referrals to the right people. If there is a

central intake, just an email or a fax to the local folks has typically done the trick. The local folks tend to do a good job of keeping track of their referrals when they come just to the local level.

Bob Mollica: Anything further, Linda?

Linda Kendall: No. I think it sounds like it is kind of a both-end answer which is probably right. I am always concerned that we are missing something or someone or not getting the systems in place if there is no kind of coordinated approach, and yet I wouldn't want to see it become just bureaucratic. I certainly agree that the CILs are particularly effective at identifying people as they are already in a facility speaking with someone else. I think if we want nursing facilities or others to begin identifying people themselves they need to really need to know what number, whether it is local or statewide, to contact in order to make sure that we move the process along as quickly as possible for people.

Steve Eiken: I agree with that. The success of this has varied from local area to local area, but several coordinators in different states at the local level have had success, sometimes even before they start working, just going to the nursing homes in their area, introducing themselves to the nursing home discharge planner and sometimes the director of nursing or the physical therapists and explaining who they are, what they are doing, assuring them they are not part of the state division of licensing and coming to make their

lives difficult, but to make their lives better. That has worked in more than one state and it has really been effective at a local level with local coordinators doing it.

Linda Kendall: OK thanks, that's it.

Dante: We do have another question coming from Judy Roy of Alabama.

Judy Roy: I have a couple of questions. The first one has to do with a consumer needing durable medical equipment, particularly a power chair while they are still in the nursing home. Can this equipment be purchased for them?

Bob Mollica: Mary, do you know the answer to that?

Mary Clarkson: The current answer is if it is a waiver service and we are going to look at it the same way we look at all waiver services. That is a little bit more of a complicated question. We may have different answers right now for people who are on Medicare because of the PPS that is going into nursing homes than we do for people that are solely on Medicaid. We are actually trying to tackle that issue right now. We are kind of hoping that issue may be the next in the series of letters that we have been putting out -- something that addresses assistive technology and training a person to use that while they are still in nursing homes. As of now, we do not have a specific policy for starting this ahead of time.

However, if a person is in an ICF/MR, we have a slightly different answer. A person in an ICF/MR is entitled to, and must receive, active treatment which is directed towards the needs of the person. If de-institutionalization is identified in that person's plan as one of the goals of the active treatment, then the ICF/MR could buy the chair, and train the person in using it.

Judy Roy: My second question is, are we supposed to have received a copy of the letter also or would it have just gone to the state agencies?

Mary Clarkson: These were sent out to all of the Medicaid agencies but you can get it by going to the CMS Website.

Dante: Mr. Mollica, we do have two follow-up questions.

Bob Mollica: OK.

Dante: The first one is coming from Todd Ringlestein of New Hampshire. Go ahead.

Todd Ringlestein: First thanks, Colorado, for following up on my first question. My second question is related to our project that is dealing with the seriously mentally ill and helping folks get out of the nursing home. I am wondering if there are specific examples of how other participants have been able to overcome tight housing markets to find places for transitioning residents?

Steve Eiken: There are. They vary a lot from local levels and I hate to always say this, but there hasn't been a lot of widespread, statewide systemic changes that have freed up the housing market for more folks. Michigan, just as an example, has taken an interesting approach. They have funded some start up grants for local communities to form community coalitions solely to look at accessible housing and they haven't targeted the housing. They may be now but from what I recall from a couple of years ago they are not specifically targeting housing to people leaving nursing homes but the more accessible housing there is in the market, the more there is for people leaving nursing homes. A lot of local coordinators have had success working with individual public housing complexes and individual landlords. I think someone in New Jersey explained that one landlord was particularly willing to work with them because he realized that it was a steady rent check that they were getting because of the SSI. The person was getting case management on an ongoing basis. After the first person moved into the building, this particular landlord was more willing to accept people with disabilities and people on Medicaid waivers in his building because he saw that they could live and succeed in his building. I think the most common approach has been a dialogue with the housing agencies or with assisted living facilities.

Dante: Todd, did you have another question?

Todd Ringlestein: No, but I will say that we are experiencing that now. We are at the table with housing folks and I don't know how it is like in other parts of the country but the housing market here is absolutely incredible. The costs are just sky high and finding

an apartment or a home is one of our major barriers. This is actually the discussion that our collaborators are trying to address -- just getting and finding a home and a place for people. I suspect that is a nationwide problem.

Steve Eiken: That is my suspicion too. In most states it has been the number one challenge for people leaving nursing homes. Another interesting approach just for building a network, New Jersey paid for their local coordinators to go to training provided by I think it was the Supportive Housing Association, by a housing organization. The training was about housing policies in general, kind of an introduction to supportive housing. It not only provided training on housing issues, but also provided a networking opportunity because most of the attendees were people working with particular public housing complexes or working with people with Section 8 vouchers.

Todd Ringlestein: Good idea.

Bob Mollica: OK. Is there another question?

Dante: Thank you. We do have another follow-up question coming from Randall Blume of New Jersey.

Randall Blume: Hi Bob. Thanks for the opportunity. In the response to Wisconsin about when FFP would kick in, the response was when the person enrolls in the waiver.

What if the person never enrolls in the waiver? Either they hange their mind at the last minute, or they die? When does FFP kick in if at all?

Mary Clarkson: When a person is going to enroll in the waiver, we are talking about a waiver service so we would not be able to provide FFP for the service costs unless someone enrolled in the waiver. Some of the transition costs are expenses that could be refunded and you would expect to see refunded such as security deposits. As for other things, I would encourage you to write to us so that we could formally clear the answer to that through our general counsel: Whether or not, and the extent to which, we might be able to consider it a Medicaid administrative expense. I couldn't give you a definitive answer on that yet because we just haven't reached that conclusion yet. But I really would encourage you to write to us. Send me an email, mclarkson@cms.hhs.gov and we will run that one up the flagpole.

Randall Blume: Thank you.

Dante: Mr. Mollica, we do have two further questions.

Bob Mollica: OK.

Dante: Our first question is coming from Gloria Masaric of Alaska.

Bob Mollica: Welcome, Gloria.

Gloria Masaric: Hi Bob. Thanks for putting this together. I have a couple of questions that hopefully are some clarification. We are just starting so I really appreciate hearing from everyone else. I am talking about the Nursing Facility Transition Grant services because our state has not pursued transition services under the waivers. In our initial meetings with nursing homes here, we of course are receiving mixed response. Some of the things that we want to ask about are what might be covered. The social workers are asking things, which is so remote, like will the transition grant cover things like airline tickets to bring family members in to learn how to care for a family member going back out to the bush? Another question would be, can this transition money be used for temporary housing as our clients are applying for their HUD applications for housing assistance?

Also, there are two other things. One of which is dental care which is pretty limited under our Medicaid state plan services and sometimes when people are having procedures, they need dental care before they can be released because of the increased risk of infection. That was a question that was posed to us.

Mary Clarkson: Because you are talking about the specifics of your nursing home transition grant, I would encourage you to contact your project officer and discuss those things because it would really have an awful lot to do with how you wrote your grant. In addition, I might also point out that dental services are one of the services that you can provide under a home and community-based waiver.

Gloria Masaric: Right. Our state does not at this time.

Mary Clarkson: Right. As you are looking to modernize and update, that might be one of the things you might want to consider.

Gloria Masaric: OK.

Steve Eiken: Now although I can't really address Alaska with your grant in particular, I have heard of a few occasions where a nursing home transition grant fund paid for housing while a person was waiting for a permanent placement.

Gloria Masaric: Housing is a part of our grant, but it is not that specific. It is some of the same issues you all have talked about in terms of trying to secure vouchers that are specific to a nursing facility transition or to waiver clients so that they could access housing more quickly. But this is a little different than that. I will take that to a project officer. Thank you.

Dante: We do have one last question coming from Sally Birchfield of West Virginia.

Sally Birchfield: Hi and thank you very much for including us in this call. We just are really getting going in terms of our project, but I am wondering if anyone has information on how you are providing information out to the nursing home residents in

order for them to make informed choices and specifically any mechanisms that you have got or ways that we can pay for perhaps, augmentative communication devices. We are hearing the voices of those who have voices, but a lot of the persons in nursing homes perhaps do not have a voice or maybe do not have the skills or have not been taught to use an augmentative communication device. Is anyone addressing that or techniques thereof or how do we pay for those specifically for some of the consumers?

Steve Eiken: I don't have any examples from the grantees we visited.

Sally Birchfield: OK.

Steve Eiken: As far as getting the information out to nursing home residents, it has been newsletters with advocacy organizations, brochures in nursing homes have been common, brochures in other areas of the community to reach family members. Both have been the main means of communication.

Bob Mollica: I recall somebody also commenting that they made requests of the activities director or other person in the nursing home to be able to address residents in one of their community activities or community meetings.

Steve Eiken: Yes, there have been some presentations to residents themselves.

Sally Birchfield: We have been starting on that frame too. What we have come up against is quite a few people actually who perhaps don't have the ability to communicate in a written form or verbally and are not trained yet on augcom devices nor are the staff. We are just trying to address that need because some of those people have voices and choices.

Steve Eiken: I think it is a significant need. Unfortunately I don't have any examples of people trying to address that yet.

Sally Birchfield: Would that be something that we could include as perhaps a device that would be purchasable through the sort of the pre-transitional kinds of services if someone is looking at moving out?

Mary Clarkson: Are you talking about your 1915(c) waiver or under the grant?

Sally Birchfield: Well, I am speaking under the grant, currently.

Mary Clarkson: Under the grant you want to talk to your project officer.

Sally Birchfield: OK. Thank you very much.

Dante: Our next question is coming from Rebecca McMillen of New Jersey.

Rebecca McMillen: I am well, thank you. I just wanted to address the folks in New Hampshire about the Supportive Housing Association that we deal with very closely here within the state of New Jersey. I do have numbers or an email address. They might be able to give you some really good ideas about how to access housing and make it more available. We have been working with them and sent a lot of our staff to some programs and have been very successful with them. The Website is www.shanj.org and they might be able to really give you some good information.

Dante: We do have a follow-up question coming from Mary Jo Iwan of Nebraska.

Mary Jo Iwan: I just wanted to mention that if people needed information on approaching people in nursing homes, we did do extensive marketing research on how to approach the residents, how to approach nursing homes, how to approach physicians, family members and all of that. If there is information that people need on that we would be happy to send it to them.

Bob Mollica: Mary, perhaps if you could send it to me, I could email it to the people that are on the call.

Mary Jo Iwan: Thanks Bob, that would be great.

Bob Mollica: Do you have the email address? The email address is rmollica@nashp.org. I have just received an email from Richard Petty at ILRU who

reminds us that there is a report of a project funded by the Robert Wood Johnson Foundation to Alpha One which is an Independent Living Center here in Portland, Maine. The study deals with the success of moving people of different ages into the community. If people are interested in that, let me know. I think I have a copy, if I don't I will get one and forward it to people. Are there any more questions out there?

Dante: We do have another follow-up question from Judy Roy from Alabama.

Judy Roy: I had a couple. Alabama, talk about being so broke. I have had a recurring problem with other programs in terms of putting up money for utility deposits or security deposits and the whole question about whether that money remains with consumers after the waiting time required for the deposit is over, in other places, does that remain with the consumer or has there been any attempt to return that money to Medicaid?

Steve Eiken: I haven't heard any examples. I haven't heard of states pursuing and getting reimbursed and I haven't heard of people keeping the security deposits once they have moved so I don't know how states have handled it.

Judy Roy: Something would have to happen to the money. I am just kind of curious which way it would go. Would it revert to the consumer or would it revert to the state?

Mary Clarkson: It would revert to the Medicaid agency.

Judy Roy: I think it would revert to the state.

Mary Clarkson: It would revert to the Medicaid agency and the Medicaid agency would treat it as it would any other refund or over payment where you keep your half and you send us our half.

Judy Roy: Ok. So it wouldn't automatically go to the consumer. It would automatically go back to the state.

Mary Clarkson: If it does go to the consumer, the consumer should forward it to the state.

Judy Roy: OK.

Mary Clarkson: Just as they would in any other payment that came erroneously to them.

Judy Roy: OK. So that would be considered erroneous if it did come to the consumer.

Mary Clarkson: Yes because the state is making the payments, the state, under the Medicaid program, the state would get any refund.

Judy Roy: I understand that. I just want to be clear on it because different programs handle it different ways and I wasn't sure how Medicaid was doing it.

Mary Clarkson: I understand that.

Judy Roy: The other question I had was, and I am not sure who asked this before, about reaching people in the nursing homes. I haven't had any trouble just going in and talking with people. Actually I had a consumer in one nursing home who has been referring other people to me hand over fist who has finally said that she is interested in transitioning. But I am running into a problem with staff who say that they want to talk with the family members of the consumer prior to allowing me to talk to the consumer regardless of whether that family member is a guardian or not. Has anyone else run into that?

Steve Eiken: I'm sorry. That was a question about a requirement to talk to the family member before talking to the...

Judy Roy: People were saying I won't let you talk to the consumer until I have talked to the family member for their approval, but the family member is not necessarily the guardian of the consumer.

Steve Eiken: And the nursing homes are saying that?

Judy Roy: Yes.

Mary Clarkson: Sounds like quite a tremendous violation of confidentiality.

Steve Eiken: Actually, I have heard in the first few states that we visited there were among examples of nursing home resistance was talk to the family member first and other things. One thing that has worked somewhat consistently is to remind the nursing home that if the resident themselves is inviting that person, inviting the coordinator into the nursing home, that the nursing home has to let the coordinator in. At least three or four states that I have visited have said that is where the local coordinators have said that has worked.

Judy Roy: I'm sorry, I didn't catch that.

Steve Eiken: I was wording it awkwardly but there have been examples of nursing homes refusing local coordinators to enter the nursing home and talk to a particular resident. If the coordinator is invited by the resident, if the resident wants that support service and they know the coordinator is coming, the nursing home has to let the coordinator in.

Judy Roy: OK. It has just been a question. I have been talking to staff and they have mentioned this person or that person and then said I am not willing for you to talk to them

as a possibility until I talk to the family first. Should we report that? Should we report to somebody if that happens?

Mary Clarkson: Nursing homes have to understand that confidentiality requirements apply across the board. They are not waived just because the state is going to do something or is contemplating something that the nursing home doesn't care for.

Bob Mollica: Sounds like something that it is covered under the Resident Rights Provisions too.

Judy Roy: Well I am just trying to find a workable way to do this so that I can continue to have access into the nursing homes to talk with people.

Steve Eiken: This is interesting because the staff, it is not the resident calling for assistance, it is the staff saying they have someone in mind.

Judy Roy: Right. But they are saying I am not going to even ask the consumer how they feel about it until I talk to the family. So far I haven't had a situation where that family member was a guardian which would be different. If they said this person is the guardian so it has to go that way then. That is a little bit different from just the family members, not the guardian but I am still going to ask the family first whether we should even pursue this with the consumer.

Steve Eiken: I would really encourage the nursing home to talk to the consumer themselves. I am kind of surprised that they mentioned someone to you and then say we don't want you to talk to them yet. It seems kind of silly that they mentioned it in the first place.

Judy Roy: I think I am sort of increasing their world view of what is possible and then maybe they are turning around and realizing this might be a problem and so they are snapping back to their comfort zone. I just haven't known really whether to sort of force my way in. Obviously not physically, but just make an issue out of I am allowed to talk to the consumer. The consumer is allowed to talk to me or whether to just wait and see what happens after they talk to the family member. I don't know who in a nursing home might be interested until they talk with the staff unless I have some sort of inside contacts. Usually just in the course of conversations the social workers will say to me we have this situation. They are real quick with that if they are referring somebody who they see as a problem, but I have never had anybody say you have to talk to the family member of this person who has a history of behavior problems before you can talk to the consumer. But if I don't perceive the consumer as being a behavior problem, then they seem to throw up this other thing about the family has to approve it first. I have just challenged them on the families, not the guardians, and they just said well I feel more comfortable if I ask the family first. So just from a working perspective I wasn't sure if anybody else had found a gentle way to say the consumer has the right to talk to me regardless. I don't want to antagonize the whole nursing home arena until I have to.

Steve Eiken: Yeah. I don't know how. I think a lot of the Independent Living Centers or the other local coordinators have found gentle ways to say this. I wish I knew. I can't really say what words they have used or how they have done it. They have just told me that they say the resident has the right to speak to me and it is their choice and it is not the family member's choice.

Judy Roy: I have said that and then they say yeah, but I would still feel better if I talk to the family first. So I guess it is just a question of building trust with the staff person to say you are not going to send everything into a tailspin if I just talk to this consumer and maybe making them feel safe enough to take that risk as opposed to... I am used to them seeing me as a resource, not as a threat. With some people you are going to be able to do that and some people you are just not going to be able to do that.

Bob Mollica: I think in six months we will contact you and you can tell us what has worked.

Judy Roy: OK.

Dante: We do have one last follow-up question right now in the queue, Sir.

Bob Mollica: Ok, we will take one more.

Dante: That is coming from Gloria Masaric of Alaska.

Gloria Masaric: Thank you. I had just one other question. I have heard a number of people mention that they are using the CILs as a place for referrals. I have talked to one state that is actually using Independent Living Center as the contractor or the staff to the nursing facility transition grant. In our state I guess I would wonder how common this is and I would also add that our State Independent Living Council put an ad out in all the newspapers when we got this grant and has actually attempted to go into nursing homes to talk to residents and has been restricted by some nursing home administrators from cruising the halls, so to speak. I guess I am just wondering what state's experiences are around the Independent Living Centers?

Steve Eiken: About half of the states I have been to have used Independent Living Centers in the grant or other local organizations. Some states have used area agencies on aging. Some states have used their own state staff at the local level. New Jersey is one example of this. They have counselors throughout the state and some other home health agencies have been used. A lot of Independent Living Centers have experience with nursing home transitions. I think that is one reason why they have been used frequently. Some of them would do this work anyway and the project makes it easier to do. They see this as part of their mission.

One of the challenges as a program grows is that a lot of Independent Living Centers are smaller organizations so they may not have the capacity to serve a large number of people like New Jersey. They use state staff. They have provided counseling services to

an average of 1,500 people a year for the past two state fiscal years. It would be very hard for them to do that using Independent Living Centers because it would become a very big part of those programs after that. I think generally speaking they have done a really good job when they have been the primary organization for these small programs.

Actually, one Independent Living Center in Arkansas I just visited yesterday started with a support group and one nursing home that was willing to work with them. They just formed a support group of people that wanted to move out into the community using a kind of a peer support model. As that group became more successful, they started support groups in other nursing homes. They were able to work in partnership with the nursing homes as well. That has been one of the more successful examples I have heard of independent living centers finding people instead of waiting for referrals.

Steve Eiken: I think that this points up a lot of differences. There is a difference between which organizations have experience and the capacity to work with nursing homes and residents to help them move versus what has been successful regardless of who does it in working with nursing homes and getting the cooperation. On the organization end of it, I think that a lot of the earlier experience has been with Independent Living Centers because it is part of their mission and as Dann mentioned from Colorado that as these programs broaden their focus on the residents that they might want to approach and serve, it opens it up for aging and other organizations to start to have a role in this as well.

Bob Mollica: Well, we have come close to the end of our time and it is clear there are lots more issues working with nursing homes being among them that we need to deal with so I would really love to hear from you about any suggestions you have for future audio conferences like this or other activities that we might undertake. You have our email address so send those thoughts along.

Before we end though, I would like to turn to Steve and Mary to see if they have any final thoughts. Steve?

Steve Eiken: I would just like to thank you all for joining the conference call and thank you Bob for the opportunity. It has been close to a year now that we have been visiting these states and this is one of the first opportunities we have had to really let other states know what we have seen. I really appreciate the opportunity and thank you all for all your questions.

Bob Mollica: Thank you for joining us and we look forward to getting the case studies and helping you disseminate them. Mary?

Mary Clarkson: Thank you very much. I too would like to thank you all for taking the time and trouble to participate. You know we stand on the threshold of a tremendous opportunity here. It is a tremendous change that we see coming about and it is really for all of us here at CMS and for me personally we feel that this is a privilege to take part in it as your partners.

Bob Mollica: Thank you and thank you all for joining us and we look forward to having more of these types of events for you. Good day.

Dante: Ladies and gentlemen, thank you very much for your participation. This does conclude today's conference call. You may disconnect your lines at this time and have a wonderful day.