Cash and Counseling: Part of the Long-Term Care Answer?
July 29, 2005

[1] kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

[START RECORDING]

ED HOWARD: … engaged today, trying to tie up business before the August recess. I want to welcome you to this briefing that is designed to examine one of the most carefully run and thoroughly evaluated long-term care demonstrations, I think, ever in the United States—Cash and Counseling, more fully Cash and Counseling Demonstration and Evaluation.

Cash and Counseling is clearly nonpartisan in origin. It started in a Democratic administration and carried forward in a Republican administration; a public/private partnership in the truest sense involving a private foundation and government agencies at both the federal and state level. We are starting to get useful results back from this demonstration. That is what brings us here today, to see what lessons Cash and Counseling might hold for the larger question, how to meet the very large and growing needs of Americans for long-term care.

Our partner today in the program is The Robert Wood Johnson Foundation, America's largest philanthropy devoted to solely health and health care. I want to thank Risa Lavisso-Mourey the presi- [No Audio]…today Dr. Jim Knickman, who is the vice president in the research and evaluation team at the Foundation, who has been involved with Cash and Counseling from its inception—in fact had a hand in its inception. Jim, thanks for coming.

JAMES KNICKMAN, Ph.D.: I would like to extend a welcome

to you from the Robert Wood Johnson Foundation, one of the co-sponsors of this briefing and, as Ed mentioned, one of the co-sponsors with ASPE [misspelled?] of the Cash and Counseling Demonstration that will be the focus of today's discussion.

Robert Wood Johnson Foundation is a Princeton-based philanthropy with a mission to improve health and health care of all Americans. We are fortunate to have this nine billion dollars in assets that allow us to support and encourage a range of activities across the country to encourage innovation and improvement in the health care sector.

Our approach is to identify a limited number of well-defined issues or problems or challenges in the health sector and then to devise strategies for addressing these strategies. We try to harness a range of assets when we address these issues, not just our financial assets but also partners, leading thinkers and the ability to convene and to motivate. Cash and Counseling has been, we think, a successful example of this approach. We have partnered with ASPE ever since our interest started in this idea and we have partnered with leading thinkers at the University of Maryland, Boston College, and Mathematical Policy Research and some others to direct this initiative. Probably most importantly, we partnered with our first round of grantee states: Florida, Arkansas, and New Jersey, who have worked tirelessly to give this innovated concept a field trial. I would like to thank each of these

partners for getting us to where we are today.

Let me turn quickly to my job today, which is to be a little bit of a historian since I have been around from the start and just sort of mention the roots of Cash and Counseling and the history of how we got to this point. Yet simply the idea of providing cash benefits or near-cash benefits instead of service benefits grows from the concept of consumer direction, consumer-directed care and patient-centered care. The notion of why not respect a preferences of individuals who needs services; why not harness the informal networks of individuals to find creative solutions to finding caregivers? For me personally this idea came watching my Aunt Charlotte in Brooklyn, New York, receive services from home care agencies that in the late ‘80s and early ‘90s were even at that time costing 10 or 12 dollars an hour. She was never satisfied with her worker. I noticed all the caring people who lived in her apartment building who were working at jobs that paid substantially less than 10 dollars an hour and would have been happy to take care of my Aunt Charlotte if they could have. I wasn’t the only one thinking this way. Robin Stone and Pam Doughty at ASPE also were thinking about these ideas as many others around the country, you know good ideas, I think, come to people at the same time.

Over time, our foundation and ASPE really decided to experiment more formally with the idea to see if one could try

it. Why the elaborate demonstration? And this is an elaborate demonstration. But we were convinced that we would need hard evidence to convince anybody to adopt this idea broadly. That is because we would be giving individuals a fair amount of control over what to do with direct Medicaid dollars. We figured without good evidence that the money would be used wisely and effectively this would never take off. We were unsure about the take up for this initiative. Would frail people be willing to do this? We were unsure about the capabilities of frail people to manage the way they need to in this program. We were unsure about the possibility of fraud, that families would take this money or informal people would take this money and not deliver services. We were unsure about whether the program could be managed at any level, the federal level or the state level. So we thought all of this required a careful test.

So here we are many years later, I guess about 10 years later, when we have some clear evidence about the program's potential and about some of the difficulties of doing this program. We are really pleased to be able to bring some of these ideas to you.

Interestingly, I think Cash and Counseling is an idea that has spread more quickly than the evidence has developed. It has a lot of proponents out there and I think it is because it is a logical idea that looks more and more logical as you do

it. But I am pleased that now we have evidence to say exactly what are the pros and cons of this.

In closing, again I want to note my pleasure and the Foundation's pleasure of having worked with ASPE over the years on this program and more recently with the Administration on Aging as we have gone through a second-stage replication. As Ed mentioned, there is a lot of talk about public/private partnerships around this town. I think this is one that has really worked and it has been stimulating and fun to be involved in all along the way.

Thank you very much.

ED HOWARD: Thank you, Jim. Let me just do a couple of logistically housekeeping items that those of you who have been to briefings in which the Alliance has been involved, will have heard before but you should take a good look at the materials. We have made effort, with the help of our speakers and others, to assembly things that would be useful to you as the next steps in learning about this topic. They will also let you know some more extensive biographical information than you will get from me in the short time that I'll use to introduce our speakers.

There is a webcast of this briefing that will be available on Kaisernetwork.org by the close of business today. And a transcript of the briefing within a few days. We will try to send you an e-mail about that so that you will know that if

[1] kaisernetwork.org makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

you want to use it, it is available. And at the appropriate time, there are microphones to which you can repare to ask a question and there is a green card where you can write the question, as well as a blue form that we want you to fill out before you leave to give us some comments about how we can improve these briefings for your better understanding.

Before I introduce Kevin Mahoney, our first speaker, I just want to say one thing personal thing about this topic. We are now one day short of the fortieth anniversary of the Medicaid program, a program that has accomplished a great deal including care for fragile elders and people with disabilities. Now I wasn't working on these issues when Medicaid law was enacted but on the tenth anniversary of Medicaid's enactment back in 1975, I was on the staff of the House Aging Committee where Claude Pepper was trying to open up more home and community based care for vulnerable groups. Mr. Pepper would be pleased that people were trying to use innovative thinking like that involved in the Cash and Counseling Demonstration to pursue that same goal. I think he would be especially pleased that Florida was one of the states in the original demonstration. That is enough of that. I think we have assembled people who know a lot about this topic and we want to give them the chance to talk. So let's start.

We are going to lead off today's discussion with one of the country's top long-term care experts, Kevin Mahoney. Kevin

is on the facility of Boston College Graduate School of Social Work. He has been national program director of the Cash and Counseling Demonstration Program that we are here to talk about. Obviously, he is our most important speaker because if you will look at the biographical information, we printed his twice as big as we printed anybody else's. [Laughter]

Kevin, welcome back to the Alliance. And thanks for joining us.

KEVIN MAHONEY, Ph.D.: Thank you. Today in most states whether you are elderly or a younger person with disabilities, if you are on Medicaid, you rarely have the say over who helps you, what time of the day they come for such even basic things as a bath or helping you get up. Never mind what they are going to do but for years people in disability community were saying if I had more control over my services, my life would be a lot better and I think I could do it for the same amount of money.

The Cash and Counseling Demonstration and Evaluation was really set up as a policy driven, a major social experiment to test those claims of the disability community. Today we actually have the privilege for the first time presenting the results from the whole demonstration.

Before I get into a brief overview of the results, I would like to give you a thumbnail sketch of the history and the model. This really in my mind, four things that are sort of unique about the Cash and Counseling Demonstration and

Evaluation. First is its scale. This involved approximately over 6700 people across three states. Second thing that is unique is this was a powerful social experiment with randomization. The third thing is it is really one of the more ultimate forms of consumer direction, one where the consumer really gets to manage an individualized budget very broadly. They are not just purchasing workers but assisted devices, home modifications, any thing that really meets their personal assistant needs. The fourth thing that is unique is it cut across populations from elderly to children, and all the various disability groups.

From day one, it was partnership between the Robert Wood Johnson Foundation and the ASPE and the Administration on Aging as our most recent co-sponsor. It could not have been done without week in and week out oversight from the Center for Medicare and Medicaid Services. This was run under 11-15 waivers. I had the privilege of being the national program director for this effort. I am at Boston College and Mathematical Policy Research has been responsible for the quantitative evaluation.

The three sites as you heard were Arkansas, Florida, and New Jersey. In all three states involved the elderly, all three adults with disabilities but Florida took it even further and they were a thousand children with developmental disabilities. I might even note that just an understanding of

the findings, in fact in Florida over 90% of the adults, non-elderly adults with disabilities were also from the developmental disabilities waiver program.

This was an alternate to Medicaid personal care benefit, the option personal care in Arkansas and New Jersey. It was an alternate to three different 19-15C home and community service waivers in Florida.

What I would like to do is – I tried to get the model down to five steps. Just so, you can follow as you think about the results. Basically, in these states, the consumer answered the program home committee service program much as they always did and got the same assessment in care plan. Then a dollar value was assigned to that individual's care plan so you could see the equity that it was the dollar value for that is them paying back individual an would have gotten in that state. In step three, the consumer often with their family, and if they wanted, if they felt they couldn't manage this entirely on their own, they could appoint a representative but these people received the information to make the choice if they wanted to manage the individualize budget, have those responsibilities and opportunities or if they wanted to stay in the traditional system. Step four, the consumer with their counselor or support broker develop a plan for how to use this cash allowance. It wasn't a pure sending out the cash. The heads had developed a plan and the litmus test was how does it tie back to meet my

personal assistance needs. They could workers even in two of the states, they could even hire spouses. In Florida parents of children. Assisted devices, home modifications. Step five; people weren't left on their own. Some of the supportive services that we learned in focus groups of people's desire was number one, physical management service, which is a bulk, check right in tax paying service that virtually everyone wanted. And then the counseling or supports broker help the people do all of the back up plan, the training, that type of thing.

So now I can fly on to those states with the original – I am getting ahead of myself, but as of last October with funding from the Robert Wood Johnson Foundation and ASPE and the Administration on Aging, we have moved and added eleven new states and actually in January, the Retirement Research Foundation funded Illinois to join. So there are altogether fifteen states.

I am going to apologize for rushing but two things: one, all of powerpoints and slides are in your packets in more detail and secondly, we are going to have a hopefully questions and answer session and Randy Brown from Mathematica will be here also to help in answering your more particular questions. I will give you a second set of T, you can see we have arrayed by Arkansas, Florida, and New Jersey. T represents the treatment group, which got to manage the individualized budgets, C is the control group stayed with the traditional

system.

The point of this first slide is one of the biggest effects of Cash and Counseling was the increase on access to services. Maybe one way just to highlight it and we could focus on it later, is if you look at the far left, like under Arkansas when we interviewed people, when Mathematica interviewed people nine months after they started in the demonstration and said did you get any personal care services in the last two weeks. For the non-elderly adults, 95% of the treatment groups said yes but only about two thirds of the people in the traditional system said we got any services of any personal care services in the last two weeks. As you can see, its across the board the increase in access, Arkansas just happens to be the most dramatic but it really shows up in New Jersey strongly as well. But that also as you will see later has effects because it is the traditional program isn't delivering the services; they aren't spending any money on them.

When you look at some of the measures of quality the consumers were much more – just look at the consistency of those findings. Look at the size of the differences, the people were much more apt to be satisfied. There was a whole range of satisfaction measured but just saws in one. As far as when you get to reduction in unmet needs, again just at the consistency but basically, unmet needs were reduced by 10 – 40% below their

incidence in the control group.

Now as Jim mentioned – Okay clearly there were no major incidences of fraud and abuse but our goals went beyond that. it was a question what would the effects be on various health outcomes: contractures, falls, bedsores. Let me just say and here is a typical one that I presented. Basically out of the – of all of the measures of which I think there was 77 different ones of health outcomes, either the treatment group did just as well or they did better if they managed their own benefits. In about a third of the comparisons, treatment group had significantly less likely to experience health problem differences and the differences were sizable. They were in the 20 to 50% of the control group means.

Very satisfied – this is measure of overall satisfaction with life. It is important to note the size of the benefits in states like Arkansas were only in maybe the high three hundreds a month and you have these kinds of effects on overall life satisfaction 25 to 90% more likely than control groups report themselves as very satisfied.

These effects carry over very dramatically with caregivers. This is one we just selected to show effects on them being very satisfied with overall care; but you will see in your packets a lot more slides. There was less emotion, physical, and psychological stress. And hopefully, you might think in the long run this might lead to less consumer burnout.

One of the slides – some of them are in your packets but I wont delve on unpaid workers – but basically in two of states, New Jersey and Florida, consumers when they had the choice of how much to pay people paid their workers about a dollar an hour more than the agencies do. The workers report – the directly hired workers were much more likely to be satisfied with their wages and benefits than people in the agencies. Over 90% felt that they were fully prepared for the job.

Now I go onto to effects on costs. This is divided into three parts. It is sort of like what are the effects on personal care costs, what were the effects on all your other Medicaid costs and then what was the net result, how did it effect Medicaid overall. The first one deals with the effects on the personal care costs results. They were significant higher for the treatment group in each state. In Arkansas and New Jersey, as you have seen earlier, this is mainly because the control group received substantially less care than was offered us. In Florida it was mainly because children and adults with developmental disabilities got larger benefit increases immediately after they were assigned to the treatment groups and before the program really goy underway.

Effects on non-personal care costs, the other Medicaid costs were moderately lower for the treatment groups in each age group in all three states and the best, of course, most dramatic example is that Arkansas were compared to the control

group, the treatment groups had 40% fewer admissions to nursing facilities in the second year.

Overall, in Arkansas that by the end of the second year there really was no significant differences in the costs between the treatment and control, reductions in the nursing facilities and other waiver costs offset the increase in personal care costs. In New Jersey and Florida, costs were up to eight to twelve percent but the states really during the demonstration period, I think learned some very important lessons about how to control those costs so that states can look forward to a way managing this I believe without it having to cost the state anymore. Certainly any higher costs in Arkansas and in New Jersey are due to the failure of the traditional system. Policy implications – and you will certainly hear more of this today – but we believe you can increase access to care and certainly improves quality dramatically. The caregiver's benefit – and states may be concerned about costs but we think there are some implementation lessons on how to control them.

The next thing we would really like to do is to show a short, maybe three or four minute video clip. This is of Tanya Dickens and her mother, Rhoda Sloan. Tanya was really one of the early clients in Florida's consumer directed care program, which is what they called their Cash and Counseling program. The thing that I will note just so you can watch with Rhoda

Sloan, the mother, I first learned of these people when Rhoda wrote to us about the dramatic impact the Cash and Counseling had on the life of her daughter. But this has sort of lead Rhoda on where she has now become sort of a theater counselor in Florida's counseling program. She is actually volunteering about 25 hours a week herself but without more ado, this is Tanya's story.

[START VIDEO]

RHODA SLOAN: When our children are born with a disability, the dream of their future is taken away. The control of this program gives that dream back to us to be able to help our children become more independent and determine.

Tanya was born April the sixth 1971. She is mentally retarded. So we just for many years, we searched for why and then it became not important why it happened. We just had to do whatever we needed to do to get Tanya to the point where she needs to be. I had heard about this consumer directed care. Tanya and I went out to the meetings to hear about it. The major benefit for consumer directed care that I felt at the time was being in control, being able to access the services to help Tanya become more independent.

CATHY THACKER: I am Cathy Thacker and I am Tanya's companion.

RHODA SLOAN: We meet Cathy at a parents group meeting that Tanya and I had attended. So we talked to Tanya and asked

her what she thought and she said yeah. We called Cathy, we interviewed her and we hired her. The difference in being able to hire this person we want to be able to hire is to be able to write the job description, instruct that person as to how you want them to do that job. She has clipped her coupons so she wants to go to the drugstore today.

CATHY THACKER: Okay.

RHODA SLOAN: Maybe after work. – My husband, Cathy and I sat down and we developed a plan to get Tanya out in the community and to show her what was out there and what could be available to her.

CATHY THACKER: Tanya what do you say to your mom?

RHODA SLOAN: Bye honey, have a nice day. – Cathy would take her out, going to a type of business and ask them if Tanya could shadow one of their workers to see what a job consisted of.

CATHY THACKER: Tanya showed an interest in the animals so we went over to PetLand and we asked if we could shadow there. And that is how it began. In the beginning, I basically – she didn't know how to do anything. So, we had to train her and a lot of the work that I did myself but now Tanya does most of the classes by herself. I don't even help her. Don't you like the money you get for working here?

TANYA SLOAN: Yeah.

CATHY THACKER: What all do you do with your money?

TANYA SLOAN: Buy stuff.

CATHY THACKER: Like what? What do we buy when we go to the store?

TANYA SLOAN: Buy stuff.

CATHY THACKER: Like what?

TANYA SLOAN: Anything.

RHODA SLOAN: Another benefit of the consumer directed care program, in fact Cathy has been able to introduce her to other individuals that are maybe a little bit more independent than Tanya.

To know what consumer directed care has been able to do for Tanya, you have to know how Tanya was four years ago. She did not have her own feel of her home. She did not know how to unlock the door. I would have to comb her hair. She couldn't comb her own hair. Tanya didn't fix herself anything to eat so her life was totally different before consumer directed care program. We all need help. We just all need different kinds of help. And I know that one day Tanya will be living in an apartment probably with a roommate with the right kind of services and help. Tanya will be able to live independently.

[STOP VIDEO]

ED HOWARD: That is terrific. Thank you very much Kevin and thank you Tanya as well.

You are going to hear now from Bill [Inaudible]. Bill is the director of New Jersey's division of disability

services. New Jersey of course being on of the original Cash and Counseling states. Bill has been in charge all that time of course. In fact, he has been doing disability and aging services work at a very high level for thirty years or so. He is among other things the president-elect of the National Association of Head Injury Administering. Bill, thank you for being with us.

WILLIAM DITTO: Thank you very much. I am the oldest and longest surviving project director from the original Cash and Counseling demonstration and I am living proof you can do these programs in the states and survive. We have been actively running this program for almost six years in New Jersey and I have a couple of quick messages I want to give you before I focus in on my other comments.

First of all, the program works. It works very well. It does not work for everyone and it is important to remember that. This is not a panacea. It is not a solution. It is an approach that makes sense for some people under some circumstances. It supports and enhances but does not replace family care giving. We found that people know what they want but they need help to get it organized.

WE found that this program can serve all people regardless of the nature of their disability. This is an important message because when we started out most people believed that this was program only for younger disabled

people. It would not work with the elderly, it would not work with people with traumatic brain injury, and it would not work with people who have cognitive disabilities. It would only work with a population of people who can manage, direct, and control their own lives completely. That is not true. It works for everyone. They need assistance, they may need a representative, they may need to some help but they are perfectly capable of managing and using this program if they want to.

It is a value driven program. What is important is that the individual and what is important to the individual is what drives their choices in the program. And it is one of the features that I find most attractive about it. Just like you yourself have certain things that are quite important to you and other things that you could care less about, consumer directed services allow people to fashion their services around their values. Most importantly one size does not fit all in the long-term care system.

Why are states interested in this program? The reason the people are interested is the growth of the population in both the aging and disability with a large number people wanting home and community based services and support, not wishing to enter long term nursing facilities and we need to be prepared for that. The system is not capable of addressing these needs in the future.

We have already in many parts of the country worked for

shortages – people are gone – so we need to begin to think about how we interest a non-traditional population. Certainly, the themes of increasing personal responsibility and empowerment are rampart – we believe that this approach allows for increased personal responsibility. It was amazing to us in New Jersey how many people had no idea what a personal care services under the Medicaid program and when they found out those dollar amounts, they took ownership and was [Inaudible] – we found that our consumers are prudent purchasers. They make much better of resources than we do often times at the state government level. We purchase services in bulk and using standardized rates and other kinds of formulas, our consumers are negotiators they take time to figure out what the best price for something is and they are unwilling to pay a price that they don't think is fair.

We had many problems in New Jersey with consumer satisfaction. This program helps to address that by giving the consumers the control of the resource and the ability to make their own decisions.

And last but not least, the program provides a very significant support to informal caregivers. I cannot tell you how many people have said to us were it not for this program my mother or my father, my aunt or my uncle would have had to go into a nursing facility because I simply couldn't bear the full responsibility for their caregiving and now I have the support

I need.

What is some of the lessons that were learned by Arkansas, Florida, and New Jersey in doing this? Well, as I said earlier on, the program works and people like it. I haven't already showed you some of the statistics. I live this day in and day out so I hear it first hand from the people that are enrolled in. Cash and Counseling is not for everyone. Fragile isolated elderly people are not good candidates for this kind of a service delivery system. They benefit from the traditional care models that we have for so long used. And those models are very important for them. It is for people who are not satisfied and not happy with the service system that we have offered them and have a better idea about how they could manage it.

I mentioned before the session counseling supports informal caregiving. And I do want you all to remember today when you leave here to use the term Cash and Counseling, please do not say cash and carry. [Laughter] Throughout the country, we have people saying cash and carry and I have had to say on many occasions in many public venues that we are neither a lumberyard nor a liquor store. [Laughter] We are not cash and carry.

People get the services they need when they need them and they are prudent purchasers. When you are a 24-year-old young man paralyzed from the neck down, you do not want to go

to bed at five in the afternoon. Most traditional care agencies are unable to provide workers beyond five or six o'clock meaning that many younger disabled people have been forced to spend an inornata amount of time in bed simply to get the services that they need. Equipment, supplies, and devices can help increase independence and function. We have marveled at how resourceful people have been in locating devices and even simple things like microwave ovens that have made a tremendous amount of difference in their ability to function independently.

I think long range research into Cash and Counseling will prove to us that many peoples need for help from other people decreases over time as their environments become better equipped and they are able to do things. We had typically in New Jersey certified homemaker, home health aides, supervised by registered professional nurses for whom we have reimbursed with Medicaid 15.50 a hour, how to doing things like food shopping when we gave people control of an individual budget and let them make their own decision. They were doing their own food shopping. They were using $7.50 to take a taxi to get to the food market and they were doing their own food shopping. They hadn't been incapable of do the food shopping; they just didn't have another alternate.

Most folks in the Cash and Counseling program actually understand their allotments. Over time when we looked at

people's accounts, we find that people do not spend nearly what we appropriate to them on a monthly basis. That is because a lot of people particularly in the elderly population have what I call the rainy day mentality where they believe they need to keep a little to the side there in case they run into some sort of difficulty. Again, I think long-range analysis of data will show that these programs do in fact meet the desired goal of providing personal care service and do not cost more than the traditional system.

An important point that I want to make and I feel the need to make everywhere I go. Traditional home care agencies are still a very important element and we do not in Cash and Counseling program negatively impact on them. When we started this demonstration there was a great deal of tension between the traditional home care agency providers and the people who were doing Cash and Counseling. We value, appreciate, and respect the contributions that home care agencies make. We know that they are the perfect agency for many people and we know that their services are very crucial. What this does in essence to reduce the burden on traditional agencies by enabling them to deploy their work force more appropriately and allowing people who can locate and hire their own workers to do so. But we are actually conserving an important resource for home care agencies.

Now a couple of issues in Cash and Counseling

specifically around federal waivers: As you heard Kevin say the initial and original three Cash and Counseling states, all used 11-15 waiver, Section 11-15 waivers in order to implement the demonstration. The 11-15 waiver route is a complicated route for states to take. There is a tremendous amount of documentation that is required. There are concerns around budget neutrality, which is contrasted with cost effectiveness in the home and community based waivers. For states who wanted to cash out a personal care assistant state plan benefit, the 11-15 waivers is basically the route that needed to be used.

The 19-15C waivers do not reach the large number of elderly and disabled people who receive state plan personal care services. It is interesting to note that of the twelve new Cash and Counseling demonstration states, which you saw on that map that Kevin showed, none of them are currently planning to include state plan personal care assistant recipients within their project. This is troubling to me as a state program administrator of one of the original demonstrations because our overall goal was to make this service delivery option available to all Medicaid recipients who rely on PAC services whether they are in a home and community based waiver or whether they are getting those services under regular state plan.

And last but not least, the faces of CNC, I just want to share with you very briefly. On your left is a lady by the name of Dorothy Miner and I have her permission to use her name

so I not — she is a real person and I know her. She is 67 years old. She has a variety of health problems including arthritis, asthma, diabetes, heart disease, and a herniated disk. She has had a lumbar spinal fusion and she also has carpal tunnel syndrome. She was a teacher and an administrator for about fourteen years. She is very competent. She is very much in control of her own life and she is very active with her church. In fact, her pastor at church has been very instrumental in helping her to locate workers. When she had traditional personal care services in our state, she had basically no control over who came into her home and frankly she reports that most of the aides were very disrespectful and frequently failed to show up. This ties back to what Kevin was saying about services not being delivered. We have a problem where people just don't show up for the job. So what she did is to hire her granddaughter and I just want to quote — give you a little quote from Dorothy Miner because this really tickles me. "The personal preference program allowed me to control who came into work for me and what they did. I will fire my children or grandchildren [Laughter] if they don't do the job they are expected to. If I didn't then what is the use of this program. I could have just stayed with the agency. My granddaughter has been a blessing to me and has been a wonderful caregiver, however, when school ends for the summer she likes to her five children, my great grandchildren, to my house. This creates

both work and agitation for me. Its stress that I don't need in my life. So, I told my granddaughter if this were a regular job, you wouldn't be toting your kids along with you. [Laughter] So, you can't do it here. So I fired her for the summer but I will hire her back in the fall." [Laughter]

On the other far side of the screen on your right is Lisa Manchearni [misspelled?] who is forty-three years old. She is seen here with her mother who is a retired registered nurse. Lisa has Frederic's ataxia, which is a progressive, degenerative neuromuscular disease and she requires pretty much total care. She is not ambulatory. She is unable to feed herself, visually impaired, has respiratory problems, slurred speech, and uses an augmentative communication device when she does speak. However, she is completely alert and oriented and makes all of her own decisions. And I can assure you of that because she sends me very frequent e-mails to complain about things she is not happy about. She doesn't complain about Cash and Counseling of course but she complains about other things. There was no question in her mind about participating in this program. In fact when the enrollment interviewer went to see her at home, she said just show me where to sign, I really don't need any further information on viewing this program come hell or high water. She uses almost all of her cash grant, which by the way is about $2431 to employ people. She has about eight or nine employees. Now why does she have some many

employees? Because she requires some much care, she wants to make sure that she has a supply of caregivers available in the event that something happens.

She advertises actively in local newspapers to recruit new workers when she needs them. She is very active in the disability and advocacy community and serves on a number of advisory boards in our state. And I am sorry that she is not with us today because if she were here she would tell you how vital and how important this program is. She would also tell you that she really thinks that we should do this under the Medicare program as well as the Medicaid program. With I will stop.

KEVIN MAHONEY, Ph.D.: Claude Pepper would like her.

[Laughter]

ED HOWARD: Thanks very much, Bill. Now you heard Jim and Kevin talk about ASPE. Well, here is ASPE. ASPE stands for the Assistant Secretary for Planning and Evaluation and he is our final speaker. That is Michael O'Grady, assistant secretary at HHS and in charge of planning and evaluation. Mike has served in key Congressional staff positions. He has been a senior staff member at MedPak and other advisory agencies. He first spoke at an Alliance event while he was at the Congressional Research Service, so welcome back Mike. Thank you.

MICHAEL O'GRADY, Ph.D.: Thank you, thank you very much.

I will try and move perhaps a little quicker through some of my slides here because you have already heard – being the last guy out, you see what other people have already said so I will try and move relatively quickly. But there is a number of things I did want to talk and kind of set a policy context because what we really do see here is we see a very encouraging program that we would like to be able to build on in many ways.

So again, as you have seen, this is a very nice public/private partnership that has worked quite well. They sometimes do, they sometimes don't, they are sometimes kind of shot, you know, trying to shift costs onto each other. This one has worked particularly well kind of bringing the strength of both what the public sector does well and what the private sector does well to really do this. I would think if I were going to make a prediction that over the next few years as you see tighter and tighter budgets in both public and private, that this notion of how you team up, how you partner to work out something is going to be – you will see more and more of it.

Now certainly this falls into a policy context in two major areas. Certainly the Medicaid modernization notion. How you think about Medicaid, where it is headed, the pressures it will be under. Now part of that but also standing out on its own is thinking about long-term care. Long-term care and how it affects the Medicaid program both in terms of the disabled

population and the elderly population is I think a bit of a sleeping giant. We know about Social Security. We know about Medicare. We have trustee reports that come out every year but the underlying demographics of much of what drives that of solvency; long-term financial viability is exactly the same in terms of long-term care.

So this is a policy that is in that realm that you want as a policy person where it is clear enough that you know that you have got a problem but it is not about to overwhelm you. So, you still have some time. So it is not about to crush you, at the same time it is clear it is not going to go away by itself. So when you start thinking about what you are going to do about, the idea of coming up with innovations, thinking about tools you can bring to bear, this is exactly what you want to see. This is sort of a new innovative way to deal with an old problem. That if you keep going with the same formula, it is probably only going to get worse and worse.

This is also a very nice example of where you go in, you take an idea, you develop it, you smarten up about the way you do it, that you do a proper evaluation. Far too many public programs, private too, but where you think you want it into an innovation, no one does the proper sort of measurement to see what the real effect was. So you say we heard great stories, we have, well you know. It is hard to take something from a program of $50 million in one state and roll it up to scale and

talk about a national roll out unless you have got some real hard facts. Any of us who have dealt OMBs, CDO, at some point you are going to hit an actuality in your life and they are going to say, I need to see a number that shows that this was something more than people felt good about it. Really what did it do?

This is certainly a very good idea in – this is a very good example of a kind of value of research and how that research can play an integral part in terms of informing policy development.

Now in terms of thinking about LTCRG, long-term care reform goals and really how Cash and Counseling fits into that, the idea of encouraging independence. I think you have heard a consistent message here about these are folks, don't be patronizing, help them to be more independent, give them the tools they need to be able to live their lives the way they need to.

Sustaining natural supports, we have this ongoing situation for decades. We have informal caregivers, the pressure it puts on families. This is a way to bridge some of those prior problems of thinking about getting the right sort of people and not undercutting the kind of family and friends support that you see out there in the community, actually supporting them.

Assuring assistance to dependable home care, again, I

should skip over that because you have already heard that. I would be the third, fourth guy to tell you that too. Exactly how this can help in that area.

Overcoming the institutional bias, you have heard about it before. Medicaid certainly the way it was originally designed and we hit this with any major program. If you lay out a design of what you think is an appropriate policy in 1965, you know you have got to come back. These policies often, especially if they are laid out very specifically in stature, are hard to be self-adjusting, things change, the world is different. How you so sort of have that notion? It is true that in 1965, a program designed with a major focus towards a nursing home facility that made perfect sense in 1965. We need more flexibility. We need to be able to think about how you hit the right policy for the right person.

In terms of setting predictable budgets, absolutely, there is no free lunch. Everybody lives under a certain amount of how much money there is to bring to bear. We would all like it if you could stand – so this is a program that is able to bring services to people and do it in a cost effective way and think about exactly what you are spending on. You have already heard that enough from other people but again the idea that an individual facing a day to day is in a position that should be hundreds of miles away to decide what they really need and how to get it in the best way.

[Inaudible]. We are committed to improving home care [Inaudible] those of you who don't know the president has a new freedom initiative. This has to with a respond to a certain degree homestead ruling. [Inaudible] it creates sort of an environment folks can live in. Have a CMS initiative quality, which [Inaudible] from Congress. The GAO in terms of thinking about how you really make sure the people are getting [Inaudible] also we are trying to improve quality. We are trying to improve access at the same time there is the reality of being careful with the taxpayer's dollars. There is a [Inaudible]. You want to make sure you are saving that money for the people who are really in the greatest need. So, you have to really be sure that you are not – you know you are protecting your base of the people in the greatest need.

Certainly long-term care [Inaudible]. They have to be thinking about what you are doing and be smart about it. And targeting all other long-term care financing, we know – I am also a member of the Secretary's new commission for the Medicaid Commission. Certainly one of the areas of hurdle discussion is this idea of more moderate and high income people who are protecting assets when – to trigger spend down and to be able to use very scarce Medicaid dollars that are needed for the sort of beneficiaries you saw in those pictures and you have heard about. It is not really; this only for middle income people that they run into real serious problems, not so they

can leave a home to their children and not have to – they will ask their fellow taxpayers in their state to pay for their care. So protect assets – so it is.

We need to think about this. We are back to my point about the demographics. We right now have the baby boomers that are in their peak earning years. We need to look for those people that more moderate income, how we protect the Medicaid dollars by helping them to figure out some ways, whether that is long-term care insurance, whether they have savings accounts, whether that is tax – whatever those happen to be, you want those folks who are in a position to pre-funded their own care to be able to do it so you protect the money for just the kind of people we are talking about today.

In terms of cost containment and how you need to be careful about this at the same time you are supporting the program goals. I would make a point here that you need to be careful in terms of are you really digging down and being sophisticated in terms of how you think about savings and what you are spending. Too many times, we have seen the sort of smoking mirrors that appear to be savings; they are short term and what I would call a loose rate. If we have something where we save on the front end and therefore we trigger more nursing home care later, we trigger more hospitalization later; we have not really saved any money. So part of this as you saw the way that Kevin laid it out in terms of what we are doing. We are

making an investment in people that then pay off for us later in terms of reducing that kind of care that more expensive sort of care that they are not dying for. They are not interested in getting. They had rather stay in their own home. They had rather be able to control their own lives.

So, it is in terms of – it is trying to meet the disability needs and reducing nursing home costs that is the same notion. It is one of the few things that we have in terms of most of our public policies are very, very tough trade offs. This is a chance to have a bit of win, win, where you really are meeting the needs or improving the quality at the same time you are doing it in a more cost effective way.

Budget neutrality there is as mentioned before by Bill, you know, we have a situation where these are going forward under waivers. They have certain constraints. This is budget neutral by design. To a certain degree knowing that you have those charges to get going in, you can be smarter about the way you design and be sure of what is going on. There was a concern that was brought up before, where there be abuse. Thank goodness, the evaluation coming back has not shown that as a major problem. At the same time as this program rolls into more states and I think what is taking up to scale, again that is something to be careful about but its certainly the good – the yearly reports are good and we are pretty comfortable with that. But those protections will be built in, no doubt about

it. Almost no one chooses cash. As you have heard before about how these people are being very careful, they are going through their – we are not seeing some of the things we were concerned about. And it certainly is where we are in a situation where we are doing everything to prevent fraud. And it certainly is – we are in a situation where we are doing everything to prevent fraud but, again, that will be ongoing.

Moving beyond the experimental and the demonstration phase, certainly this is not – this is a typical government base and I think state government base to a certain degree, a new idea comes in. there is always people who are true believers and there is always, as I say everybody gets an acerbity at one point in their life. It is sort of a professional skeptic so the idea of putting a demonstration, trying it in a few different places that are willing to try it, having the sort of vigorous experimental design that we are talking about here, that is how you start to try to figure out what works and what doesn't. Not only would you – and sometimes it a middle ground. It certainly is that idea, midcourse corrections, how do you get ready rather than going to the whole nation all at once. What we are seeing is a very careful design here. Starting with a few states, expanding in the second round to more and then seeing where to take it from there.

We certainly are – Okay. I will skip this. I am running

out of time. In conclusion, I mean I think that is a great. This is wrapping up right at the time – you know we have seen these kind of results right at a time when we are talking about the ADA anniversary coming up. We see an improvement in quality. We are seeing a cost effective way of us doing it so again that rarity that we have where we can improve quality at the same time that we are being more careful with the taxpayer's money and certainly we are doing everything we can and with our state partners and with our private sector partners, to be able to continue to move in this area. And that we don't want to be over bureaucratic we don't things to be – we certainly don't want to be in the way of being able to provide this sort of quality care in the most cost effective way possible. Thank you.

ED HOWARD: Thanks very much Mike. Now we get to the part of the program where you get a chance to ask tough questions. Consider yourself auditors for the afternoon. Acuities in response to the assistant secretary's comments. Either the green cards which you can hold up and some one will take from you and bring it forward or by lining up at the microphone. I would ask you to be sequent in your questions and identify yourself and your affiliation if you would.

I think we actually need to acknowledge two people. One the Emeraldus Greed or however one pronounces that in the back of the podium is Pam Doughty, who is one of the most respected

health researchers in the area of long-term care. She has been around for a long time and knows where all the old policy bodies are buried. [Laughter] So you can't put anything past her and we are happy to have her involved and how –

MICHAEL O'GRADY, Ph.D.: We call that extensive expertise.

[Laughter]

ED HOWARD: And also, we have, as Kevin noted, Randy Brown is with us I am we move to open this discussion up. Randy is the vice president and director for health research at Mathematica. He is a senior and much respected health services researcher who is leading the evaluation team for their Cash and Counseling project that is yielding the kinds of results that Mike and the other speakers have alluded to. We are very happy to have him on tap for the Q&A.

Randy, do you want to respond in same way to what you have heard or let us know where you are coming from on the evaluation? Very briefly.

I will kick it off with questions here a bit. I have to tell you I have been doing evaluations and demonstration programs for twenty-eight years and these are the biggest most positive effects that I have ever seen. My colleagues are all jealous because we are usually the guys that are telling people that their clever programs that they so carefully designed and implemented does not work worth a lick at all. It is sort of

like telling a mother that their baby is ugly. [Laughter] It doesn't make you real popular. I have actually been booed at HMOs national convention when they didn't like the results I was presenting on Medicare HMOs about ten years ago. But the results that you saw today are very positive and very robust. So, we are not expecting to get booed. There are weak findings that are sometimes sited as evidence that a program works like showing that people who opted to participate did better than people that chose not too leaving you wondering if there are other differences between the two groups that are responsible for the better outcomes.

This is a randomized design. Everybody in both the treatment and the control groups wanted to participate and they were randomly assigned. Not only is the design strong but the results hold up across all three states and across all age groups. Kids, young adults, older adults and when there was an exception, there was a clear reason for it. For example, Florida elderly adults, it was the only group with little or no favorable effects on satisfaction on unmet needs but this was the group where only 40% of the people in treatment group actually got an allowance to manage. Similarly though one exception for the carrier of favorable results was in New Jersey, elderly adults; no favorable effects on their quality of life like there was in the other states or for younger adults in New Jersey but again this was the only subgroup where

the caregivers in the treatment group actually provided more hours of care than the control group did so they didn't get or at least the primary caregivers didn't get the relief that the other groups did and so there wasn't these favorable effects on their life.

So, we are happy to take your questions now. I can't promise that I or the other panel members will be able to answer all of them but we will try. We ought to be able to. I have gotten some many reviewers comments that I can't believe that you can think of anything that they haven't already asked me [laughter] but let's find out.

Let's get started. Yes?

HOWARD BEDLAND: Howard Bedland [misspelled?] with the National Council on the Aging. We have been long standing proponents of Cash and Counseling and consumer direction recently finished up a three-year project with the National Association of State [Inaudible] Aging trying to get consumer direction into the mainstream of senior services, not only Medicaid but there is other applications as well since the older Americans Act designed a website, www.consumerdirection.org that has a lot of additional information and surveys that I think are very relative. That was also funded by RWJ, thank you again.

My question has to do with how this all is relative to federal legislation. Are there barriers that we need to be

looking at possibility within the context of Medicaid reform that may inhibit these programs from becoming more wide spread and permanent? I was very pleased for example to see a separate handout from Kevin clarifying the definition of personal care. I think Bill has been working on this issue for some time the limitation that hands on one-on-one assistance is clearly covered but it's unclear whether equipment and goods and services are covered. We have been kind of frustration that hasn't been clarified. I wondered if you could comment on that. And, generally, if there are other barriers that the federal government could be looking at to promote this kind of an option.

ED HOWARD: Anyone wants to take a crack at that? Let me say to our speakers as well, that as briefly as you can answer them and be responsive would be appreciated because as you see we have a number of questions to be asked.

KEVIN MAHONEY, Ph.D: I will try first then if Bill could chime in. Basically the 11-15, I suppose to be simple can be very onerous. I mean Arkansas now despite the results that you saw is in their third time of now trying to renew that waiver. So you have states for instance New Jersey who has written to centers of Medicare and Medicaid service saying isn't there some way but there could be a clarification of the personal care benefit that it just have to be hands on service but could be any range of things in a care plan that was

approved by the state. Some might say well why cant 19-15C waivers do it. At ten of our twelve new states really did feel sort of – they weren't willing to go through all of the time or hassle of getting an 11-15. So, they are going for these 19-15C but there they can only deal with people that are nursing facility eligible and there are a number of restrictions like you can't – whereas most of the consumers wanted the physical management service to manage the whole benefit. They certainly like getting ten percent of the benefit in cash for miscellaneous expenditures. You just can't do that under a 19-15C, at least as far as we have figured out so far.

WILLIAM DITTO: I think Kevin basically sums it up. You just need to be aware and believe me I – CMS has worked with us and has been very helpful in many regards but there is nothing in statue and there is nothing in regulation that really defines personal care as the assistance of another individual. It is only in the guidance that CMS has issued to the states that describes the service categories that this issue comes up so it is not really a statutory or even a regulatory change that could make this happen. It is really an issue of CMS issuing guidance to the states with a somewhat different description. Of course, in writing to them, I did propose language, which I thought, was excellent for this purpose [laughter]. It is for having for anyone who wants it. Okay.

MICHAEL O'GRADY, Ph.D.: Yeah, just real quickly. In

terms of thinking about the waivers, thinking about what we tried to do in this administration to make that a more – a less bureaucratic, a more available option, I think that we tried to do the heavy lifting here but we certainly know that there is more to do there. It certainly helps matters to have the sort of track record that we are talking about here. That this becomes you know not a totally unique thing that is just coming in and out of the door. You have seen it before, you know what it is. And it is that balance between wanting to be as flexible as possible and at the same meeting the sort of data and the various things you need to be sure that the program – to properly manage the program. But I think we are continuing to try and think about different ways this better. And for other innovations, just to be flexible enough, I think it is a reality that is recognized that it is – that programs like Medicaid are not one size fit all programs, both in terms of populations in different states and we will use them differently. We will keep working at it but I wouldn't – but we are certainly not there yet.

ANTHONY CRUSERO: My name is Anthony Crusero [Misspelled?]. I work with measuring the budget. In addition to my day job of being one of these sort of accrual types that you mentioned before, my wife and I own a small business, photography business that she runs, and we have a single employee and that is a good woman who comes and works in our

home for about thirty hours a week. I have spent a disproportionate amount of my time on the weekends figuring out her payroll when it comes to federal deductions, state deductions, federal unemployment tax, state unemployment tax, not to mention the fact that I have felt obligated morally and from a business perspective to provide her with health insurance, which took me quite a bit of time since I couldn't get a group plan and I had to help hold her hand when she bought an individual plan, are making contributions for HSHA and there is lots of things to consider. When I tried to procure these payroll and essentially human resource services in the marketplace, it is very cost ineffective and inefficient for one person because they want to charge you minimum $1500 a month to process a what amounts to just one payroll a month or one payroll every two weeks.

So my question for you is in your cost accounting when you said Okay, this is a basket of services or cash, does your cost accounting include helping this person who is receiving the cash navigate this payroll problem which I am sure, I know from personal experiences is not easy.

One other thing since I only get one opportunity to speak. There is mention in one of the handouts that there was a blimp, a cost increase of ten to fifteen percent I think in New Jersey but then you said let's get those costs under control. I don't know if this has anything to do with payroll, maybe not,

but if you could maybe mention that as well too. But the main question is about how do you help them with payroll and human resources.

MICHAEL O'GRADY, Ph.D.: The cost comparisons that we did, did control – did include the cost of physical intermediaries and bookkeepers that provided those services. So, that was reflected in there.

ANTHONY CRUSERO: But the point is that they are there –

KEVIN MAHONEY, Ph.D.: But basically that every state provided was there is bookkeeping, check writing tax paying service and after the description you just gave, no wonder 99% of the people wanted that service.

ANTHONY CRUSERO: Yeah.

WILLIAM DITTO: In calculating the service in New Jersey, what we did was to take the approved clinical hours that somebody would have received under the personal care program by doing a standardized assessment. Then converting that into a dollar amount by using our existing Medicaid reimbursement rates. Once we had done that, we then removed ten percent from the top of that amount before declaring that to be the cash allowance that the individual had to work with. That ten percent that we took off the top was used to buy the physical intermediary service for them and the counseling component so that we could maintain the budget neutrality that

is required under an 11-15 waiver and that is highly desirable to states in terms of operating their Medicaid programs. Nobody in New Jersey was interested in managing the cash and doing the payroll themselves, despite the fact that we held that out to them as an option and provides them with retraining and all sorts of things. Everybody wanted to use the physical management service for the very reason that the last gentlemen brought up. The complexity of doing this and the difficulty of doing it on a consistent basis.

KEVIN MAHONEY, Ph.D.: I should also that your question about whether there were some economies that could be gained in those services. Arkansas discovered that there was more efficient ways to pay for those services over time and that enabled them to reduce their costs.

ED HOWARD: If I could ask a follow up question asking the forbearance of the people at the microphones that someone put on a card that has to do with how much this costs. The range of cost in the states that were evaluated now compares to people who weren't in the experiment. I know all of that is in the materials and several people have alluded to it but some numbers might be helpful for people to get a good grasp.

KEVIN MAHONEY, Ph.D.: The median allowance was about three – a little over three hundred dollars a month in Arkansas, in Florida it was over a thousand dollars a month and New Jersey was somewhere in the middle around eight hundred.

So, that is kind of that ballpark of their benefit level.

SARAH WINN: Sarah Winn [misspelled?] with *Professional Quarterly.* You had mentioned that people are interested in having this program in Medicare. Is there going to be any sort of push to do any kind of pilot project with that? Or any other legislative action?

MICHAEL O'GRADY, Ph.D.: Well, it's certainly, I mean when you see a program like this it has a – you are pretty happy with the results so far. It is certainly worth discussing. Howard brought it up, that is a good point. We have the same sort of cost problems in Medicare that we do in Medicaid so certainly in terms of considering, thinking about how it fits in the current program. We have been a little with the drug benefit the last few months, which may explain some things of – some of Bill's frustration over slow waiver, ABI and things like that.

So we would like to kind of make sure that that program is up and running and efficient before we take on too much new. But I can see no reason why you would not want to put an idea like this on the table.

JAMES KNICKMAN, Ph.D.: I might say that words are not directly involved. My understanding is that there is to be a small demonstration under section 648 looking at this in the home health area.

WILLIAM DITTO: Right. That was part of the MMA. He

ED HOWARD: Very quickly, circling back to this tax preparation question. Some one had asked are people in this program exempt from paying Social Security taxes and VICA and other kinds of unemployment compensation taxes?

WILLIAM DITTO: No, they are not. [Laughter] There is only one instance that I am aware of in which the circumstances are a little different and that is in spouse-to-spouse employment. If you hire a spouse, there is a slightly different mechanism in terms of deductions. I believe it is on the Medicare side. Other than that, one of our big requirements in New Jersey and I believe in all of the states, was these people are employees, whether they are your next door neighbor, whether it is your sister, whether it is your relative, these folks are employees. They need to be treated as employees. In New Jersey, for instance, we require workman's compensation coverage so everyone that is in our program either has to have a worker's comp policy or access to worker's comp coverage for all the people that work for them. That does vary from state to state.

It is very, very important that we not create a system in which the worker is disadvantaged because these people are going to need to retire or go on disability themselves potentially at some point. We certainly don't want to set up a cottage industry where people do not have the appropriate protections. So all of those things, all of the tax laws in New

Jersey and the federal tax laws are observed fully in the program.

ED HOWARD: I might point out there is some material in your packets from the Service Employees Union which has been active in making sure that some of the things that Bill was talking about actually occur in some states.

Yes, go ahead in the back.

STEVE MOSES: I am Steve Moses with the Center for Long-term care Reform. This is a very attractive model so I am wondering why we don't see more of it in the private sector economy. As it affects Medicaid since it is so attractive, have you seen any evidence of the so called woodwork factor, people coming out of the woodwork to take advantage of it. Are you concerned that it may encourage the practice of Medicaid planning? You know kind of artificial manipulation to qualify for Medicaid. Would it have a chilling effect on private long-term care insurance purchases that would enable people to get this kind of service funded through a third party payer other than government?

ED HOWARD: A wide range of questions. Anybody want to take a piece of it anyway? Kevin?

KEVIN MAHONEY, Ph.D.: I will do the first and then Randy would speak of the second. This has been to my knowledge, extremely interesting to people. I have spoken the last number of years at the private long-term care insurance conference.

The very information that we present today on greater satisfaction reductions and unmet needs, costs can be kept under control. Have been extremely interesting there. We have even done some research with managed care organizations on their potential interest when they are involved with long-term care.

RANDY BROWN: It is very attractive for, as Bill said though, for the minority of people that are most interested in it. The take the break was about six to ten percent for adults in a three state range between six and ten percent except for kids. It was about 16% for children in Florida. So, it is not this huge outpouring of interest in that it is going to attract a lot of people. It also – Arkansas was the only place, the only one of the three states that allowed people that weren't already getting services or were already assessed for services to start getting them as they came on to Cash and Counseling.

There it looked like the main reason that people in the control group weren't able to get – weren't getting services was because they weren't able to. That was part of the reason why Arkansas wanted to do Cash and Counseling to start with was because they knew there were people, particularly in rural areas that didn't have access to home care services. So, that was not unexpected that there would be some people getting services that weren't otherwise able to. But it wasn't the woodwork effect; it was that the demand was always there. It's

just that people couldn't get them because the services weren't in the areas that they lived.

MICHAEL O'GRADY, Ph.D.: In terms of the third part about having to do with the long-term care insurance. Our research shows in looking at long-term care insurance, and certainly as I mentioned, we're pushing down hard on the idea of getting the boomers to think about their own long-term care needs and not waiting and assuming that Medicaid or the false assumption that Medicare will cover it for them and however they can do that. What we have seen so far in terms of long-term, the target population for current versions of long-term care tend to be in much higher income levels. I think we would and this is not clearly a high-income population. So I think in terms of long term policy of thinking about savings versions, long-term care insurance, different things that you might do there. I think we would like be in a situation where we thought that long-term care insurance had penetrated so far into the moderate, middle income people that we would even have to worry about that because those are people – when you think about higher income people, they will probably never spend down into Medicaid and when you think of really lower income people, they are in a big assets protecting situation. It is those people in between, those moderate income people, the guy making fifty thousand dollars a year that if he wasn't you know he would probably make twenty five in retirement and if he has something

serious happen, he or she will spend down. so its that sort of person who is in a situation through either savings or insurance or home equity conversion or different options like that. Those are the sort of people that you would like to see focusing more on their long-term care needs rather than this self-population we are talking about now.

ED HOWARD: Is there private long-term care insurance that will allow this kind of flexibility? Or when you explained this program did they say yippe skippy let's write that policy.

KEVIN MAHONEY, Ph.D.: There are policies developed along that principle, yes.

ANDREA RICHARDSON: Hi, Andrea Richardson from GAL. I was curious to know if you did any analyses looking at individuals who were in their last year of life to see how they maybe utilitized this program differently from other people. I am particularly interested in individuals who don't qualify for hospice under Medicare.

JAMES KNICKSON, Ph.D.: We did not do specific analysis for people in the last year of life. But there are only about six to ten percent of the people that died during the first year in the program. So, sample sizes would not allowed us to really do much with that.

KEVIN MAHONEY, Ph.D.: The only thing I would add and I might like to say more later, we are going to have basically the data from the Cash and Counseling demonstration as a public

status take and we have an interactive website that I would like say more of because we know there is much to mind that we haven't been able to do yet.

TOM MILLER: Tom Miller with the Joint Economic Committee. I want to take a stab at reaching for a general, a broader level of application and generality here. Cash and Counseling seems to have worked pretty well for a particular set of services for a particular type public program beneficiary. One way of looking at it is that you couldn't help but to show improvement from the status quo program services in their current that otherwise were not performing very well for those that it was suppose to assist. But another way of looking at this is that it worked well even for individuals who are often mistakenly thought of being less able to fend for themselves and make decisions that help direct their care.

So, what are the real creative possibilities for extending what we have learned here to other types of health care services. It has been mentioned in terms of Medicare, even conventional Medicaid insurance, not just for the disabled or the long-term care, for veterans' health care, for where we are moving in private health insurance. What does this tell us about whether moving away from kind of a top down defined benefits sometimes patronizing structure in which we kind of hand those services out as to where we might actually be able to go. If it works here, where should it work elsewhere in our

health care system?

JAMES KNICKSON, Ph.D.: I can start. I mean we already know of numbers of groups, for instance SAMSON, you have had mentioned private long-term care insurance, you have mentioned the demonstration over in Medicare. So there are many places where I suspect that you could think does this apply. When I had the chance to testify before Energy and commerce health subcommittee, I am more cautious here, you know and sort of saying look this demonstration took place with basically non-medical services, the types of services people provide for their own family members. It is clearly a matter of choice. They had the option to stay in the traditional system. They could return at any time. These are long-term care chronic services, easier to predict what the budget would be. So my only thought is much is in the Medicaid area where this is lead to a new demonstration. I think that is helpful thinking.

WILLIAM DITTO: I think you brought up a number of very good points, Tom. I have to say that my responsibilities are caught the whole portfolio of what HHS does. We are seeing a real analogy situation to what I think of even outside of – you know the pension policy. We looked at what happened with the those [Inaudible] plans, steel employees who had on paper a beautiful benefit package, you know defined benefit package. In reality when that company went under, they had nothing. Well they had PDDC, I shouldn’t say nothing but its like falling

back if your bank account goes out, you have your FDIC insurances sort of stuff, you know pennies on the dollar. And that sort of situation versus something they really own. And part of what you see here is this idea of rather than this sort of paternalistic notion of I know better than you do, you are seeing this option being put on the table. I think it is also clear – you know there are some people who really just want someone else to take care of it. So it is how do you bring the right set of tools. This is not a one-size fit all situation and you really do want people who can do and want to do this stuff for themselves, as I think we saw in that video. It clearly changed that young woman's life because she actually took the responsibility, became an owner of this, was an employer, and moved forward on it so I think this whole notion of thinking about how people really use this stuff and is this again something you want to move out to other states, want to move out to other populations. As long as it keeps working, I don't know why you wouldn't.

KEVIN MAHONEY, Ph.D.: Certainly there is there is an issue of numbers of new states wanting to look at this model and with Robert Wood Johnson Foundation funding, Minnesota, one of the demonstration states is also applying this to their administration on aging funding.

MICHAEL O'GRADY, Ph.D.: Just a quick response. I think it is an excellent question. I want to give two concrete

examples where I think you could consider. First of all it is on end of life hospice care. I mean you could imagine there are a lot of people who get hospice who could use different types of things within that hospice benefit than is covered. Like there is very little personal assistance covered in hospice yet some people that is they could use as opposed to the sitting nurses and some of the equipment that is offered. So that is one example where I think there is logic at work.

The other is again almost anybody who is in a situation where they are bedridden and require a lot of medical equipment. It is amazingly complex what get covered by the average insurance policy in terms of hospital beds or mattresses or equipment. Boy there could be lots of cashing out of that option and people could more efficiently decide whether they need the bed or they needed the wheelchair or what they needed. So I think there is a lot of what you said to be pursued.

ED HOWARD: I have a couple of questions that has to do with the cost of this program. Not necessarily the dollar figures, one of which says simply and addresses it to Kevin, how exactly can states control their expenses? And someone else without specifying who they want to have answer it, simply says how can it be budget neutral? You are delivering all of these services, that last part.

KEVIN MAHONEY, Ph.D.: Randy – well I suppose I start

out as how it not be budget neutral. You know basically these are the Medicaid services that individual would have been receiving in that state already, that is the bases of the individualized budget so it was designed to be budget neutral. And basically by design the costs for the fiscal management service support brokerage was designed to be out of the same pot of money that use to cover care management and administration and the states are even finding that there are some savings that are possible on the administrative side. So I would twist the question around, you know there are numbers of things that really made – in summary slides today, it's the traditional system in your particular state is one that isn't delivering the services that are prescribed in the care plan, then that is a threat to the problem. At least that is the start to the answer.

RANDY BROWN: I just want to say that it should be remembered that this was tested in a period when there were pretty significant shortages of low wage labor. So, the labor markets were tough. So to get workers in the traditional, I think the budget neutrality is going to very much – I think there will be cost savings if we are in an economic where there was excess low wage labor because I think those control sample people would have gotten a lot more services, would have cost more, and you would have seen real cost savings. So I think that is important. Also on the table is a very controversial

about throwing the table anyway, is in some high costs states where the Medicaid home benefit is very expensive and the hours of care are very high, I can imagine at some point saying to some recipients who are getting fifty, sixty, seventy hours of care a week that would you like eighty percent of that in cash as opposed to 98 or 95%, so I think there is a lot of room for potential cost savings as this concept evolves and as it is applied to other types of services.

MICHAEL O'GRADY, Ph.D.: The states are worried a lot about this budget neutrality because they had to so there was a discount rate applied, a discount packet was applied when they figured out what was in the dollar value of the baseline care plan two of the three states applied a factor to that to reduce, to reflect the normal difference between is in a care plan and what people actually got. So there were a lot of attempts always keep an eye on what the cost per month was. Also remember you don't have to pay agency overhead costs so there is more money to go around when you do a Cash and Counseling. And finally, there are the offsetting costs and other Medicaid services that help offset some of the costs so the bottom line for Medicaid is what really matters.

JAMES KNICKSON, Ph.D.: the data showed a better-cost picture in year two in Arkansas than in year one. You have any sense of what is going on in year three.

WILLIAM DITTO: We are just starting to look at that

and it looks like maybe its divided up into people that were already getting services at the time they joined versus the new people who works for the continuing folks. Continues on about the same level of reduction as in the second year.

JOANNE BULK: Hi, Joanne Bulk with the AFL-CIO and perhaps not surprisingly I would like to hear more about the worker's side of this. We heard I guess in one of the presentations that workers on average in the control group had a dollar more per hour than in the treatment group. I would like to hear more about wages and benefits generally. Were they more or less likely to have health insurance than agency workers? Why are we hearing that in New Jersey they are employees and so would qualify for worker's comp if injured on the job? Is that typical in other demonstration states? I guess I would also like to know would they qualify or how would they get training if they need for example on how to safely lift a consumer if they are mobility impaired?

ED HOWARD: I would just add to that maybe if you know it, information about those answer in the twelve new states would be useful too.

JAMES KNICKSON, Ph.D.: I will just start off to say that in New Jersey if the workers needed training, an individual would be enabled to use their cash allowance to provide that training for the individual and some people have opted to do that. Generally most of the people that were

employed in New Jersey did receive at least a dollar more an hour than counterparts in agency service. We offered through the fiscal management or fiscal intermediary service a health insurance brokerage piece so that if consumers wanted to they are able to assist in locating health insurance.

Now one of the things that we found that there was, that there are a lot of people that were doing this work that might have had health insurance through another family member. So, what they were more interested or might be in something like dental insurance. So they would say to the consumer, what I really want is dental insurance and so that would be what would be brokered. Some people said increase my wages and I will take care of the health insurance part on my own. Just give me more per hour and I will settle that problem for myself.

One of the nice things I think that we found in New Jersey is that people were getting sort of customized employment packages based on their circumstances. They were negotiating with the consumer around what is suitable and appropriate for them rather than just getting whatever the standard agency benefit packages. So I think in that sense it was good. We also did as you correctly observed we want to make sure that worker's comp was in place and other kinds of things. We also have a non-occupational temporary disability program in the state of New Jersey that covers you if you get injured away

from the job and can't be working. We want to make sure the people under our program have that coverage as well. So, they are not disadvantaged in any way as opposed to agency workers.

Frankly because the consumer has very low overhead, they can pay better wages than agencies would pay and they generally tend to do that. They also tend to structure what they pay based on the type of service that they need. The person – they use a diversity of people. The person who does the cleaning and the food shopping might get minimum wage or a little bit better. The person that they depend upon for the personal care might get eleven, twelve, thirteen bucks an hour because they are concerned that that person remain with them and also that they are on time and that they show up for work regularly. So this sort of diversification of punctation is something else that was very attractive to us because I have a very hard time issuing $15.50 for a certified homemaker/home health aide who provides by a registered professional nurse to be sitting in a laundromat watching laundry going around in the drum that. That could be done by somebody else at a more economical level.

KEVIN MAHONEY, Ph.D.: It is also true that unfortunately the agency workers don't get many fringe benefits either. A lot of them are part time and only about 20% of the paid workers from agencies that we interviewed in any of the states said they were getting fringe benefits.

WILLIAM DITTO: You will find in your packets a longer version of these powerpoints that really discuss these issues a bit more.

JANE TILLEY: This is Jane Tilley from the Alzheimer's Association. I am more interested in what the states learned about how to deal with people with progressive dementia. I can understand how somebody with developmental disabilities who has an intact family to help them manage the services could do it. I can see a lot of potential benefits for those for people with dementia but I am wondering what lessons you learned about how to deal with that population or were they screened out of the demonstrations?

RANDY BROWN: They were not screened out. There wasn't any screening on health conditions because people could have representatives that would act in their stead. We don't have results broken out by whether somebody had Alzheimer's or not. Those diagnoses and claims are often not very good and so I cant say particularly what would happen with that population.

We do know that the developmental disable population, the results were just as favorable for them as they were for the aged and the physically disabled younger adults.

WILLIAM DITTO: As Randy has said the use of representatives became very crucial for people with dementing illnesses. Well actually for lots of people. It made it possible for people to make use of the program. The other

interesting thing particularly with Alzheimer's and related dementias is that people were not getting the kind of service that they needed under the traditional system. We were getting them four or five hours of homemaker/home health aide a day. It wasn't really cutting it for them because actually they were up all night because they had to worry about somebody wandering away. Well a lot of families in the program when they had the cash allowance actually purchased companion services rather than personal care service per say because they could get more hours using a companion and the service gave them more freedom, gave them a chance to sleep in many instances, which they have. People also used technology. People used part of their allowance for wander guard systems and other kinds of things that made it possible for the individual to remain at home safely using assisted technology so these were very important developments and we were very consciousness at the onset of the demonstration how we did not want to limit this. We didn't want to say you have to fit a particular profile in order to come into the program. If you can't do this generally for the long-term care population then it is not a very successful program in my mind because it becomes a boutique program that only a few selected chosen people can go into. So, we have looked all along to adapt the program in a way in New Jersey that makes it possible for anyone who wants to participate to participate. They just need to a different set of supports in order to do

it.

ED HOWARD: Bill, that reminds me of a card question that we got that recalls something I think you said in your presentation which is this program is not for everyone and in particularly not for frail elders. And I wonder if you want to address in the context of what you just said.

WILLIAM DITTO: If I didn't say it before, I should have said it but you know you get a little nervous when you are making these presentations. When I say that comment, I meant to refer to isolated frail elderly people. I am talking about folks without social support system. People who do not have relatives, people who do not have neighbors they know. People who do not live in a supportive community are not appropriate candidates for the program because they don't have a representative. They don't have someone to help them in managing the program and actually in some regards we counsel those folks away from this alternate, not that it took very much to convince them but simply because of the fact that in the traditional agency programs, they would have gotten the regular nurse supervision and other kind of things that they would not be getting under the Cash and Counseling model so I don't want to ever have anyone think that I was saying frail elderly are not appropriate, highly appropriate but they need a social support system if they are very isolated then this is probably not a good choice for them.

MICHAEL O'GRADY, Ph.D.: Actually this is a question I was hoping we would get. But just for example, in Arkansas 73 – 74% of all of people who signed up for Cash and Counseling were elderly, now that is reflective of the personal care population in that state. But take a look at those slides and just see, this works for the elderly.

LIZ SAVAGE: Liz Savage from the AARP of the United States. All of us in the disability community are very supportive and enthusiastic about increasing consumer control and this is a very impressive project. I would like to follow up on some of the comments made about what services are appropriate to be considered? Like for example, it is obvious that personal care related services are successful in this program. But many of us have concerns about providing people with significant disabilities a lump sum to purchase very costly equipment, durable medical equipment, like power wheelchairs and other high, very costly types of assisted technology that are different than some of them that have been cited by the panel. So my question is specifically if you could provide more detail on what services would be considered appropriate in your view.

WILLIAM DITTO: Everyone is looking at me. I guess there are a couple of things to this. First of all, when people are using a cash benefit like this, it is important to make certain that they understand that they have the ability to

request consultation and evaluation services before they even make a purchase. We have had this a lot with home modifications to be perfectly honest. We have people that say I want to use part of my money to build a ramp. They have got ten steps. If they built that ramp the ramp would be at this angle, it would be totally useable and unsafe. What we have had the counselors say to them is, folks, you need to get an evaluation of what is the appropriate solution. You have identified the problem. You can't get in and out of the house. Now what is the appropriate solution for that problem? Maybe the ramp is not the answer. So a lot of this – a very crucial element of the program is having trained counselors that are able to sit down with people and help them figure out these things. I wouldn't want to give somebody a large sum of money to buy an electric wheelchair without making sure that they had had a proper consultation and proper discussion of what the options are before they negotiate that purchase. But I think there are a lot of times where you need to really have good solid counseling as a basis for decision making in the program. As I said earlier on in my presentation, there are two parts to the program. One is the cash part, which we tend to focus on a lot. The other important element is the counseling element, which is very crucial to whether or not people will make good use of their cash allowances. So, that has to be there and has to be present. It is not just the case of sending someone a check and saying,

"take care of it." It is a case of sending somebody a check and sending somebody a person that says now with this check how can I work with it.

MICHAEL O'GRADY, Ph.D.: Bill, who are the counselors?

WILLIAM DITTO: Well, in New Jersey we have used a set of human service agencies through out the state and we provided them with a training course at state expense that we developed in conjunction with the Rikers University School of Social Work to train people to do this kind of work and the biggest part of the training is to get people away from being case managers to being we call them consultants. We thought counseling was a term that suggested a deficient model so in New Jersey we call them consultants because we say this isn't a person who make decisions for you or worries about the outcomes. This is a person that comes in and gives you advice and helps you reach an informed decision about what it is that you want to do. So there are all sorts of people. There were social workers, there were nurses, rehab counselors, untrained people. We had folks from independent living centers; they were some of our best counselors that we had in the whole state so a wide variety of people.

ED HOWARD: as we go to what I think will be the last question, I want to remind you to dig out those blue evaluation forms and fill them out before you leave. Yes, go right ahead.

LORI GALBERGUM: Mine is a two-part question. My name

is Lori Galbergum [misspelled?] I am with the National Mental Health Association. In a program based primarily directed at those with developmental and physical disabilities as well as older adults but I know that there were individuals with mental illness with the program and if they had any special issues or outcomes that were any how different than other individuals. The second part of my question is with giving somebody a cash allowance were there examples where people reached that allowance and then what happened once they reached that threshold you know as far as needing additional services. Thank you.

WILLIAM DITTO: I can answer the second part for you. We require every person that comes into the program to develop a cash management plan that details the use of that money and it has to balance, like the amount at the top at the top of the cash management plan after they plan all of the services and things that they want to buy and save for, has to balance up at the end. The fiscal management service does not make any payments on behalf of the individual that do not comport with that plan. Now they can come back to us every single month and change the plan anyway they want to to suit their needs. But it is virtually in New Jersey impossible to overspend your allowance. You have to live within the budget that we provide you with because we are not authorizing payment for anything isn't contained within that plan. So, that takes care of it.

Unfortunately, in New Jersey, we do not cover individuals with mental illness absent a secondary physical condition under our personal care program so we have not had any direct experience with that.

MICHAEL O'GRADY, Ph.D.: And certainly when people's needs change they can be a reassessment which can lead to a larger or smaller care plan. If I take the first part of your question, you know, yes we have just started some analysis of different subgroups, including those for instance with mental health problems. I would be glad to speak more about it but that is sort of a work in progress but it gives me a chance to sort of say an interactive website has been developed by the national program office of Cash and Counseling and the website will provide sort of a unique opportunity to explore this data from the original three states of Arkansas, New Jersey, and Florida. It should allow researchers and policy makers as well as federal and state administrators to have immediate answers to some of the more descriptive analysis types of questions. We still have a small number, I think, of spots on August 3rd we are actually doing a series of rather small briefings for Congressional staff, federal agencies, interested national and state organizations, sort of showing off how this public use data could be available.

Lori, could you stand up? This is Lori Simon [Inaudible] with the University of Maryland at College Park. I

think you would be really rather pleased to see in September or October when this becomes available but these small briefings are to help make sure this meet your needs.

FEMALE SPEAKER: [Inaudible]

ED HOWARD: In case some of you in the back didn't hear that I think she said August 3rd and if you want to pursue that, that you should see her directly before we leave.

I believe we are at the end of our time. This has been an incredibly informative session as far as I am concerned. I want to thank you for asking good questions to flush out some of the details of this. I want to thank the Robert Wood Johnson Foundation for partnering in this program and for making sure that this program happened in the first place. I want to ask you to join me in thanking our panel for an incredibly useful discussion.

[Applause]

[END RECORDING]