Webinar
June 30, 2009
Center for Personal Assistance Services

Lewis Kraus: Hello and good afternoon, good morning. Welcome to the Center for Personal Assistance Services Webinar. I'm Lewis Kraus, director of training and dissemination for the center. Today's presentation, "Do Noninstitutional Long-Term Care Services Reduce Medicaid Spending?", is the first in a series of Webinars hosted by the center that will focus on issues around all aspects of personal assistance services.

First a little information on how this Webinar's software works. The Webinar will be audio with slides. For those of you who want or need captions to support the audio, you can select the closed captioning button (the "CC" button) at the top of your screen. The presentation will take about 30 minutes and then we will open the floor to questions at about 15 minutes before the hour. Please uncheck your audio. That's the microphone button at the bottom left of your window. It should be gray, not yellow.

Because of the size of the group we are going to only take written questions at the end. You can write to us in that chat window on the left-hand side of your screen. It will probably be best to send messages to the moderators. You can do that by pulling down the menu choice where it says, "send to all rooms" change that to "send to moderators." If you have an issue during the talk, send a message to me or to the moderators through that chat window. When it is question time, send those through the chat window as well. We will read them out loud for everyone to see and hear.

The Center for Personal Assistance Services is funded by the National Institute on Disability and Rehabilitation Research in the U.S. Department of Education. It is a five-year research and training center established at the University of California San Francisco. The first center was

established in 2003. And we are now in the current funding cycle, which began in fall of 2008. The goal of the PAS Center is to improve the access, quality and cost of PAS for people with disabilities to live independently, comfortably and safely in the community and to function in society, including employment.

The Center is conducting research in the following five areas: Need for PAS; home and community based services; workers and caregivers, that is the PAS workforce; economics and workplace PAS; and emergency preparedness.

The center has many major collaborators. It is based at the University of California San Francisco. Charlene Harrington is the principal investigator. Other collaborators on the Center are InfoUse of Berkeley, California; Topeka Independent Living in Topeka, Kansas; PHI, formally known as the Paraprofessional Healthcare Institute in New York; Research Triangle Institute in Washington D.C.; and Burton Black Institute in Syracuse, New York and Washington D.C.

Today's talk is being given by Steve Kaye. Dr. Kaye is associate professor in the Institute for Health and Aging and the Department of Social and Behavioral Sciences at the University of California San Francisco. He is co-principal investigator at the Center for Personal Assistance Services. He is also co-director of U.C. San Francisco Disability Statistics Center. Steve's research focuses on access to health care and long-term care among people with disabilities, employment of people with disabilities, and usage of assistive and information technologies among people with disabilities.

I'm going to turn it over to Dr. Steve Kaye for today's talk.

Dr. Stephen Kaye: Thank you, Lewis.

This presentation is based on some work that I did with my colleagues Mitch LaPlante and Charlene Harrington of the Center for Personal Assistance Services, and that work was

funded by the National Institute on Disability and Rehabilitation Research. I have to say, I'm delighted there are 200 people participating in this Webinar. When we were planning it we thought maybe there would be 30 people, or maybe 50 if we were lucky. We were a little taken aback when we got something like 450 requests via e-mail off the center Web site for copies of the article. I think people are kind of interested in this.

Here's my take on what the problem is. This is a chart showing Medicaid long-term care expenditures between 1988 and 2005. The blue line at the top of the screen represents the total long-term care expenditures, which basically went up steadily from 1988 all the way to 2002 and then leveled off. This is after I have adjusted for inflation in medical care costs, which is a really big adjustment. Even after that adjustment there is a huge growth in long-term care spending. This is something that pretty much everybody knows. But, if you look at the red line, it's kind of flat going across the screen. That's the institutional expenditures, on nursing homes and ICF/MRs.

On the other hand if you look at the yellow line at the bottom of the screen representing HCBS expenditures, you'll see that it is going steadily up through the entire period and it is pretty much parallel to the blue line at the top for total expenditures. A policymaker looking at this might say, "Well, the reason we had such a huge growth in long-term care spending is because of all these home and community based services programs that have been added on." So they might think that, if we left it all to nursing homes, spending would be flat. I don't think that. But that is a kind of typical thing that happens: The expansion of home and community based services is what gets blamed for the expansion of long-term care spending overall.

There was some previous research that our center did on the costs of home and community based services. An article that colleagues of mine did--Martin Kitchener, Terence Ng, Nancy

Miller and Charlene Harrington--found that home and community based services save quite a bit of money. They found that if you add up all public expenditures on HCBS--not just Medicaid expenditures, but also Medicare and other public expenditures--per participant you would save $44,000 each year, if a person were getting home and community based services instead of institutional services, which is pretty impressive.

Here is a chart you are seeing for the first time anywhere, and what it shows is the distribution, in red towards the right of the screen, of monthly costs of nursing home services. On the left side of the screen, the distribution in blue is home and community based service expenditures. This is not just Medicaid--it is any payer at all. There is a huge difference between the two. This line where I'm putting the pointer right now represents $3,000 a month. Nearly all of the nursing home expenditures are above that. Here is $3,500. That is pretty much the lowest you can get for a monthly cost of a nursing home--$3,500 a month. Almost all of the HCBS expenditures are much less than that, in fact, I think 8 percent of them are above $3,500 a month. More than half are less than $1,000 a month. More than two-thirds less than $2,000 a month. So, there really is a huge difference in per person costs between home and community based services and nursing home expenditures. So, that is one line of research.

Another line of research is that home and community based services programs themselves don't really cost very much. Mitch LaPlante and Charlene Harrington and I had a paper that came out in 2007 that estimated the cost of what was called MiCASSA and is now called the Community Choice Act, which is a mandatory Medicaid home and community based services benefit. In 1997 the congressional budget office came up with an estimate for MiCASSA which was a huge amount of money per year. That is one of the reasons MiCASSA never got anywhere. We estimated that, instead of their cost in

current dollars of 13 to 25 billion dollars per year, it would only cost one tenth of that: 1.4 billion to 3.7 billion dollars a year, which by today's spending levels is a drop in the bucket. So, we did that research.

And the reaction was, "That's very nice, but...." The first but is that individual cost savings don't necessarily mean program savings. The individual is different from the aggregate cost of the whole program. Policymakers want to know and program people always want to know how big is the so-called "woodwork effect." Which is an offensive term, frankly: What comes out of the woodwork? Cockroaches. People with disabilities do not wish to be referred that way. It tends to imply that this is a bad thing. People who present themselves for services when you have an HCBS program who would not have presented themselves for services if you just had a nursing home. That's somehow bad. It's only really bad if there are people who don't need the services.

Policymakers always want to know: "How big is this woodwork effect? "How many more people want to be served?" "Does it break the budget if you have an HCBS program and more people sign up for it?" That is the first but.

The second but is: Policymakers said, "It's not enough to show that a program is affordable. You need to show it is cost neutral.” That's what Congress wants. Or you need to show there's actual savings in it. There are state program people who really want to be able to show their legislators that, if they increased HCBS, there would be a savings.

We wondered what the actual experiences of states were. Do states with thriving Home and Community Based Service programs actually control their long-term care costs better than other states that don't have such programs? Our approach has been to examine annual state Medicaid expenditures for all types of long-term care services paid for under Medicaid: Nursing homes; institutions for people will intellectual and developmental disabilities, know as ICF/MRs; the home health benefit under Medicaid; the personal

care plan, which is an optional Medicaid benefit; and HCBS Waiver programs. The source of that was data that is available from CMS, which is collected by Brian Burwell of Thompson Reuters, formerly Medstat. It's basically the data that everybody uses in analyzing Medicaid expenditures.

What we did was separate out cost for people who have intellectual and development disabilities from costs for all other kinds of disabilities. I will show you why we wanted to do that in a moment. Having done that, we combine states with similar spending patterns over a period of ten years, 1995 to 2005. We combined states with similar spending patterns to examine their trends over time. For details of the analysis, please look in our *Health Affairs* article, a citation for which you got in the e-mail advertising this Webinar.

So, here's why we wanted to separately treat services for people with intellectual and development disabilities from services from people with other types of disabilities. At the top is the trend from 1988 to 2005 in nursing home expenditures. Through most of the period it was going up, even after adjusting for inflation; only beginning in 2002 or 2003 did it start going down. In contrast, the red line is expenditures for ICF/MR, which started going down after 1990, and actually by 2005 it's quite a bit lower, after adjusting for inflation, than it was at the beginning, in 1988. The point being that there were already cost savings through getting people out of ICF/MRs that started happening around 1990, but cost savings in nursing homes for whatever reason didn't begin until much more recently.

Here is a graph showing home and community based services expenditure in various types of programs. The blue line at the top is for Waivers for people with intellectual and developmental disabilities. This is from 1995 through 2005, and beginning just after 1996 there's a huge increase that continues through most of the years in spending on the so-called MR/DD Waivers. In contrast, personal care

services, most of which go to people without intellectual and developmental disabilities, did not start increasing until about 2001 and thereafter. Waivers for people with other kinds of disabilities were going up, but nowhere nearly as dramatically as MR/DD Waivers. So we want to talk about two different waves of deinstitutionalization--that's Mitch LaPlante's phrase--where people with MR/DD were beginning to be deinstitutionalized in the early 1990's, but the push to rebalance expenditures for people with other types of disabilities did not happen until more recently.

The proportion of long-term care expenditures that went to Home and Community Based Services is much different for people with intellectual and developmental disabilities. It starts going up again after 1996 and reaches a majority, 60%, by 2005. So 60% of MR/DD expenditures goes to HCBS by 2005. That's compared to less than 30% for people with other kinds of disabilities by 2005.

I'm going to be talking about four different types of expenditures. This gets complicated, so I made a diagram, a two-by-two matrix. The two columns refer to the different populations served. The left column is for everybody who does not have an intellectual or developmental disability. The right column is for people with MR/DD. The top row is institutional services for that population. The bottom row is noninstitutional services for that population.

First I'm going to talk about people with all other types of disabilities than intellectual and developmental disabilities, and I'm going to divide it into institutional, which is nursing homes, and noninstitutional, by which I mean all the Waivers except those Waivers explicitly targeted toward MR/DD, the Medicaid optional personal care plan, most of which we presume go to people without MR/DD, and the home health benefit. Later I'm going to talk about MR/DD. Right now I'm talking about these two types of expenditures on the non-MR/DD population.

This is a map of the states showing the percent of

long-term care expenditures that were spent on Home Community Based Services for people other than those with MR/DD. The lowest is Tennessee, at only 1%. In Tennessee only 1% of long-term care expenditures goes to Home and Community Based Services. In contrast, Oregon has 54% going to Home and Community Based Services. Alaska, 53%. Washington, 50%. New Mexico, 52%. There are other states like California, Idaho, Texas, Kansas, Minnesota, North Carolina, and Vermont that are high on the proportion of expenditures going to HCBS. And there are a bunch of other states in the South, some in the Midwest, Pennsylvania, some in the Great Plains, Utah, that spend very little, 10% or less of their long-term care expenditures, on Home and Community Based Services. There is a huge variation from state to state.

So we can divide the states into two equally sized groups. One of which we call the high-HCBS states, the states that spent more than the average amount on Home and Community Based Services. That was in 2005. Those states have much higher levels of expenditures on Home and Community Based Services than the low-HCBS states. The low-HCBS states start out at about $13 per capita and increase only modestly during the 10-year period, as compared to the high-HCBS states that start out at about $25 per capita and go up to double that amount, $50 per capita. There's a big difference between the low-HCBS states and high-HCBS states.

If we compare nursing home expenditures (again, this is the non-MR/DD population) between the low-HCBS states and the high, in low-HCBS states nursing home expenditures are a bit higher and they go up through most of the period, or go up from 1997 until 2001, after adjusting for inflation, and then they go back down and level out. At the end of the period it is about the same as it was in the beginning, after adjusting for inflation. In contrast to that, the high-HCBS states, states that are spending relatively large amounts of money or HCBS, there's a fairly significant decline in nursing home expenditures over the period, from about $111 per capita down

to a low of about $95 per capita in 2005.

If we add up the institutional (nursing home) and noninstitutional expenditures to get the total long-term care expenditures over the entire period, we see pretty much the same thing for the high-HCBS states in red and the low-HCBS states in blue, except that during the middle of the period the low-HCBS states are actually higher, but at the beginning and the end they are about the same. This is pretty good evidence, I would say, that HCBS does not break the bank. There is really no difference in the amount of cost containment that states got, regardless of the extent of their HCBS expenditures.

What I'm going to do now is further classify the states. The low-HCBS states were the ones with less than the median proportion of spending on HCBS in 2005. I told you the high HCBS states were all the other states equal to or greater than the median. I'm going to divide the high HCBS states in two groups. There are expanding HCBS states, in which the inflation adjusted HCBS spending more than doubled between 1995 and 2005, and then there are the established HCBS states that are all the others. In other words, their spending did not double during that period.

Comparing these three types of states, the brown line, which is near the top and is relatively flat, is for the established HCBS states. They were spending quite a bit as early as 1995, and in 2005 they were spending a little bit more. In contrast, the low-HCBS states, as we already saw, are pretty low throughout. But the expanding HCBS states started out as low as the low-HCBS states, just over $10 per capita, and they increased very dramatically over the period. They are even higher at the end of the period than the established HCBS states. These three different types of states are very different in their HCBS spending patterns.

So that is how we classify the states, and here are the states as classified. The established HCBS states are in green. There is Oregon, always a pacesetter, as is New York,

and there are several other states scattered around the country. Yellow states, which are playing catch-up, are the expanding HCBS states. The red states are lower HCBS states and again, they are the states in the South, some in the Midwest, some Great Plains.

I already showed you the HCBS expenditures for the three types of states. Here are the nursing home expenditures for the three types of states. And for the established HCBS states, there was a pretty significant decline in nursing home expenditures over the period, from just under $140 per capita to below $120 per capita. That is a big decline, especially when you notice the low-HCBS states, as we saw already, grew in their nursing home expenditures over the period. The expanding HCBS states also saw their nursing home expenditures decline, but not as dramatically as the established states.

Here is what happens when you add together institutional and noninstitutional. You see that, for established HCBS states, there was a decline in total long-term care expenditures, and a large one, over the period. In contrast, in low HCBS states there was an increase in total long-term care expenditures, but you see that for expanding HCBS states, there was an increase in long-term care expenditures that was even bigger than that for the low-HCBS states. It looks like if you have an already well-established HCBS program, you do pretty well at containing your long-term care costs. In fact, controlling for inflation you get a decline. If you are in the process of expanding your HCBS programs, you actually are spending more money. Maybe there is an initial period when you're spending more money on HCBS.

Let's look at the other side, which is expenditures for people with intellectual and developmental disabilities. On the institutional side we are talking about ICF/MRs, or institutions for people with intellectual and developmental disabilities, and on the noninstitutional side we are talking about Waivers for the specific MR/DD population.

And here again is the map of the states. You know, it's different from the expenditures on the non-MR/DD population, but it still has certain similarities with it. Once again, Oregon is the highest, 100%, tied with Alaska. Neither of them spend any money at all on ICF/MRs. There are no ICF/MRs in two states. In contrast, in Mississippi, only 14% of their long-term care expenditures on the MR/DD population go to Home and Community Based Service Waivers. Again, a lot of southern states and some midwestern states are very low in their HCBS spending. On the other hand, Vermont is at 99%, New Hampshire 98%, Rhode Island 98%, so some of the New England states are doing pretty well here too.

If we look at total long-term care expenditures, although this is a different classification of states for MR/DD than non-MR/DD, we see exactly the same thing. It does not make any difference if you are a high-HCBS or a low-HCBS state, your spending pattern is almost identical. Again, HCBS does not break the bank.

Again I have done a classification. The same kind of thing as before only using MR/DD data. The green is established HCBS states: Oregon, Washington, and New England states and some Great Plains states, Rocky Mountain states. Yellow are expanding HCBS states and red is again the low-HCBS states. Interestingly, some of those are in the West: California, for example, did very well in non-MR/DD expenditures but not so well in MR/DD expenditures in terms of proportion of HCBS spending.

Here are the HCBS expenditures according to type of state. For expanding HCBS states, they were already very high at the beginning of the period, in 1995, almost $50 per capita. And they rose by quite a bit, until they flattened out in about 2001 or so, and stabilized at $70 per capita, which is quite a bit. The low HCBS states are a big contrast: Although they did grow quite a bit in their expenditures over the period, it's very low, from $15 per capita (compared to $50) before growing to about $36 per capita. So it is more than

doubling, but it's still not all that high. The expanding HCBS states started low but they are heading toward the level of the established HCBS states by the end of the period.

That is HCBS expenditures. Here's the institutional expenditures, ICF/MRs. The low-HCBS states are still spending a huge amount of money on ICF/MRs, more than $40 at the beginning of the period, about $36 per capita at the end of the period. Still quite a bit. In contrast, both groups of high-HCBS states are spending much less. The established states really show a dramatic decline in institutional expenditures, from more than $25 per capita at the beginning of the period dropping down to $10 by 2002 then leveling off. Expanding HCBS states are steady for a while. Then they start to show a bigger drop towards the end of the period.

Here are the total long-term care expenditures in the three types of states. Established HCBS states show an increase at the beginning of the period and then, beginning in 1998, they level off and are steady, after adjusting for inflation. And they are the only group of states that manages to control their MR/DD long-term care spending. Low-HCBS states grow steadily throughout the period. Once again, the expanding HCBS are growing in their total cost and growing faster than the low HCBS states.

Once again, if you have an established HCBS program, you are able to contain your costs. If you are expanding your HCBS programs you see a period of cost growth, and if you are a low-HCBS state you see steady growth, and you probably see that steady growth on and on.

So we wondered what happens when states all of a sudden decide to start a new program or to rapidly expand an existing program. What happens to the expenditures, to the expenditures in the program and also to the expenditures on the institutional side? Can we see a kind of commensurate drop in spending on institutional costs when there's an expansion in HCBS costs? What we did was to examine states that introduced new or greatly expanded Home and Community

Based Services in the late 1990's. We picked the late 1990's first because there were a lot of states that expanded the programs in those years and second because we had several years of data to follow them up after that and see what happened to their long-term care spending.

There were nine states that rapidly expanded their non-MR/DD programs in the late 1990's, and then basically stopped and did not do any more major expansion. So a rapid increase and then fairly steady. We found 15 states we used as a comparison: states that did not expand their programs and held their expenditures on home and community services fairly steady. On the MR/DD side, we found 11 states that rapidly expanded their HCBS programs during the late 1990's. We did not find any comparison states. All states are trying to do something to increase Home and Community Based Services for the MR/DD population and decrease ICF/MRs.

If we a align the states so that their expenditures line up with the period of time when they expanded their programs, there is a year zero, the before-growth year, before they started to expand the programs. All the nine states took two years to expand their HCBS offerings whether it was a Waiver they started up or a new personal care plan, they took two years to do that and in those two years they basically doubled their per capita HCBS expenditure, so it's a pretty dramatic increase. And then after that, their expenditures flattened out. That is how we selected the states--they had a growth period and flattened out.

What happened to their nursing home expenditures during this period? They were flat until after three years following the expansion, and then they started to decline rather dramatically.

If you look at the total cost, adding together the HCBS costs and nursing home costs, the total costs rise. They rise during the two-year period when they are actually expanding the program and continue to rise a little bit more for the subsequent three years, and then start dropping.

They dropped to a level that is lower, slightly, than the comparison states that did nothing. So this suggests that, if you have an established HCBS program, after about five years or so you will start seeing at least cost neutrality. After four years you will see cost neutrality and then maybe, after five or six years, you will see some cost savings. It is the experience of states that they actually save money, compared to other states that have done nothing, when they expand their HCBS programs. That's the non-MR/DD side.

Now let's look at the MR/DD side again. A rapid increase, almost doubling in HCBS expenditures, in these 11 states during a two-year period and then a flattening out of expenditures. In this case ICF/MR expenditures start declining immediately as they start expanding the program and then they level out.

There is a difference between non-MR/DD long-term care and MR/DD long-term care. In dealing with ICF/MRs, what states tried to do was move people out of these institutions and into community settings. So they switched them from ICF/MRs on to Waiver programs. There was a much more immediate savings in the MR/DD side. Which isn't really the case with nursing homes and Home and Community Based Services for people without intellectual and developmental disabilities. In that case, it is not really about transitioning people out of nursing homes, although that is a goal, it is about diverting people, providing them services so they do not need to go into a nursing home a year or two years from now. There is a bit of a delay in realized savings.

The total costs go up during the first two years and level out. Remember, all the other states on the MR/DD side saw lots of expansion in their costs after controlling for inflation. These 11 states did not see an expansion in their costs a couple of years after they expanded their program. This is quite an accomplishment for these states.

In conclusion, it is quite clear, I think, that HCBS programs do not break the budget. There is nearly identical

spending for low- and for high-HCBS states, which confirms the cost neutrality these programs are supposed to have. In applying for a Waiver, they are supposed to guarantee there is cost neutrality. There really is cost neutrality, which I think is important to demonstrate.

And it appears that states with well-established HCBS programs did contain their costs better than states with low HCBS programs. But, I'm not saying that institutional savings are automatic. I'm saying states can, when they try, reduce their overall long-term care expenditures by increasing HCBS programs and doing something about reducing nursing home expenditures.

It appears that Home and Community Based Services increase short-term spending when you start up a new program, but probably involve long-term cost cuts. An important fact here is that, as you expand HCBS programs, you serve a lot more people, the so-called "woodwork effect"--more people who need services are being served and the cost is lower or maybe equal to what it would have been in nursing homes, but you are serving more people. Isn't that the goal of a public program, to be cost effective and serve more people for the same amount of money? That is a good thing about HCBS. It may save money. It will not break the bank and you serve a lot more people. I think it is undoubtedly a good thing.

And now I would like to turn things over to Lewis who will moderate the discussion.

Lewis Kraus: Thanks very much, Steve. That was an excellent presentation. And now for everyone, if you would like to ask a question, you can type it into your chat window and we will then ask these questions to Steve by audio so everyone can see it, and that is the way we will work this. Mainly because of how many people there are. I realize it may be better to be speaking these questions, but I think this will work best.

We do have our first question. And that is from Christy of Dale Macintosh Center in Orange County, California, who says:

With the California budget crisis, our legislators see the costs of HCBS programs like IHSS increasing rather than seeing savings of people not being in institutions. We know the savings, can we call on you to put the charts to use in a presentations to show them how it saves our state?

Dr. Stephen Kaye: Well, I have tried doing some of this. I won't mention names. I had a conversation not so long ago with a California official who was one of those people who said this is all very nice, but I cannot convince the legislature to increase HCBS programs if they know there will be a short-term expense to it. What I want you to show, this person said, was we have already gone through the sort of "woodwork effect." Now we will get immediate cost savings. That is very hard to sell. I mean, what politicians want is cost savings now, especially right now with the budget crisis. Not cost savings three or five years from now. It gets tricky. Even to say there will be a little bit of added expenditure. There is work on federal level to help states pay for the initial few years of building HCBS infrastructure. That does not so much apply to California as other states like Mississippi or Tennessee, which do not have an HCBS infrastructure.

Lewis Kraus: Second question is from Jody Anthony. Jody asks: How much of the decreased costs in a home and community based setting is attributable to uncompensated care by friends and family?

Dr. Stephen Kaye: A great deal of it is. Something like 85 percent of personal assistance services that people get at home are provided by family members and friends. In California, we have a program in which some can be paid for through IHSS. That may go away soon. I hope it does not. Most states do not have such a program, so family-provided PAS is uncompensated. In a sense that's bad. In a sense it is good because I think there are some family members who prefer to do it without being paid. I think it is a complex issue. Yes, you're right. I think it is largely the fact

there's a lot of uncompensated services being provided here.

Lewis Kraus: Next question is from Tanya: I live in Pennsylvania. How do I get more HCBS help for my mom who is suffering from mild dementia and is a fall precaution.

Dr. Stephen Kaye: Our PAS center Web site, www.pascenter.org, has links to resources in every state. I don't know specifically what goes on in Pennsylvania. I know Pennsylvania is a somewhat problematic state, but at least you will find resources on our Web site.

Lewis Kraus: Let me add to that, at the center's Web site on the left-hand side you will see "State information." If you click on state information you can choose your state and you can find a whole list of information by state, including the state agencies that provide PAS That might be the best way for you to get that information, Tanya.

Next question from Travis Hoffman: Have these numbers been presented to senator Baucus and the finance committee including CCA in health care reform?

Dr. Stephen Kaye: Short answer is yes. Mostly Senator Harkin, but it goes to senator Baucus. They know about this work.

Lewis Kraus: The next question is from Pocatello, Idaho: Was the $44,000 savings amount on HCBS over a lifetime span or a specific amount per year?

Dr. Stephen Kaye: It was per year. Sorry I did not say that.

Lewis Kraus: Martha asks: In institutional care housing, food, utilities health care are included. How are these costs included in HCBS costs?

Dr. Stephen Kaye: Those costs are not included in HCBS. That's one reason there is such a dramatic difference between HCBS cost and nursing home cost. Room and board is included in nursing homes. There is the fact that most people who are in nursing homes have to do this huge amount of spend-down in order to get coverage, so they basically have no income anymore. Some of that income can be preserved in Home and

Community Based Services and the person pays for room and board themselves. That is one of the reasons the cost is so much less.

Lewis Kraus: The next question is from Alisa, she asks: I wonder if your analysis looked at states in which waiting lists exist for MR/DD and non-MR/DD. In California there's an entitlement to services for MR/DD population and IHSS for all eligible people, both MR/DD and non. This not the case in other states which means there is probably a larger population of people who are underserved. How would this affect the cost analysis?

Dr. Stephen Kaye: Our center has done work comparing states, and identifying states with waiting lists. or at least with Medicaid administrators who will admit they have a waiting list. In some cases they are actually prohibited by law from having a waiting list, you're supposed to serve everybody, and they are not doing that. That does clearly affect costs. But the states that are expanding their HCBS programs are probably not the states that are. The reason they are expanding their programs is because they want to serve people in HCBS. I suspect it is the low-HCBS states that are the ones with the big waiting lists.

Lewis Kraus: Filo asks: What is the nursing home lobby's response to lower spending using HCBS?

Dr. Stephen Kaye: Well, they hate it. They do what they can do attack our findings. But they remain a powerful lobbying group at the state and federal level. I don't know what else I can say.

Lewis Kraus: All right. Moving on, Christine asks: Are distinct family caregiver's support program included in your HCBS programs in doing your analysis?

Dr. Stephen Kaye: I don't know the answer to that. I would suspect it is no. Well, are there Medicaid funded family caregiver support programs? If so, I would think they would be included. But I don't know.

Lewis Kraus: The next question on the list here is from

Patrice. This sounds like another question like we had before about things you have about trying to get your dad's program some help in Texas. I think your best bet will be go to PAS Center Web Center Web site and look at the state information page for Texas. Maybe you will get your answer there. We will try to limit the questions here to Steve's talk.

Floyd Harper asks: Would the integrated care initiative with special needs plans be picked up or missed in this or followup analysis? This relates to Medicaid Medicare dual eligibles under SMP?

Dr. Stephen Kaye: Sorry, Floyd, I don't know the answer to that question.

Lewis Kraus: Travis Hoffman asks: Is this PowerPoint available?

Yes. It will be available at PAS center Web site. This Webinar will be archived there.

Martha asks: Don't your findings demonstrate that established programs contain cost growth rather than containing total costs?

Dr. Stephen Kaye: Well, yes, in the sense that everything I've shown is adjusted for inflation. So, they're containing the growth better. But, if you just take as a given that inflation in medical care cost happens, then I think you would probably agree that, at least in some cases, we are actually seeing cost savings. So there is actually a decline in costs after adjusting for inflation, at least in some cases. In some cases, it is the cost growth that is being better contained. So I agree with you in part.

Lewis Kraus: We are at the hour now. We have a few questions left to do. I think we will just try and take as many as we can and go through them and see where we can get to.

Sarah makes a comment: There are programs especially FDS that will permit payment of family caregivers.

Dr. Stephen Kaye: Yes. But I have actually been doing

some analysis of this recently. I think it is still quite rare. There are programs in some states. In California, we have quite a lot of family caregivers being paid. But I think on the national level it is still quite rare.

Lewis Kraus: Michelle adds to that in her comment that says: Our consumer directed services office has family members as paid caregivers and it's funded through Medicaid. Missouri has such a program for personal care services.

Lots of people are answering this question.

Christine also says most of them are state programs except for the national family support program. I'm not sure that is funded with Medicaid dollars. Maybe that is another type of analysis.

Vicky is asking: Will we be able to print out this session that will include the graphs used? It might be beneficial to others.

I believe you will be able to print that out, Vicky. If not, just write to us. We will do something with that.

Vera Johnson asks: Does your research indicate that HCBS Waiver costs will increase for MR/DD Waivers?

Dr. Stephen Kaye: I don't know why the MR/DD costs have gone up in every category. I think it's because there are more people being served, but I have not analyzed that. I don't know whether I would expect that to continue or not.

Lewis Kraus: Bobby also weighs in on the question from before: She says, with regard to the question about family members, Medicaid-paid consumer-directed personal assistance programs are included.

Toby says: What will you be researching next?

Dr. Stephen Kaye: Right now, with the same colleagues, Mitch and Charlene, I'm doing another paper for *Health Affairs* which is basically a broad picture of long-term care services, including personal assistance services, in the United States. I'm looking at expenditure data and demographics. That's how I know who the principal caregivers in the family are and how many people get paid help.

Lewis Kraus: The next question is from Floyd. He asks a similar question: Do contracts of managed care companies for HCBS diversion programs get included in these number? Florida has a long-term care community diversion program. Would those dollars be reflected in this analysis?

Dr. Stephen Kaye: I think so. I did not come up with these numbers. They are aggregate cost numbers provided by states to CMS and then collated by Brian Burwell and company. I believe that in almost all states, almost every home and community-based service is included. There are states in which there are managed care expenses that cannot be distinguished between institutional and noninstitutional, and so on are included.

Lewis Kraus: That is the end of our questions. I just want to thank Steve Kaye for a very interesting presentation. I hope you all enjoyed it. Thank you all for attending. Please provide feedback on this Webinar by answering the four questions at the link on your screen. It should take no more than two minutes of your time. Please watch for the next Webinar which will be announced on our PAS center Web site via e-mail. We appreciate your time and hope you have enjoyed this. We look forward to speaking with you at our next session. Have a good rest of your day.

Dr. Stephen Kaye: Thank you everyone for attending.