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# Discussion Paper

## Community Living Exchange

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Respite Grantee  
Audio Conference Transcript

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**Susan C. Reinhard**

**Rutgers Center for State Health Policy  
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**Respite Audio Conference**

Susan Reinhard: How about we get started. This is very informal so some of you have already heard who is on the line and others have not, so let me just start. This is Susan Reinhard and I am co-director of Rutgers's Center for State Health Policy. I direct the Community Living Exchange Collaborative at Rutgers. With me at Rutgers, although she is physically not with me, is Nirvana Huhtala. You see her name a lot. She is communicating with you and helping not only staffing in this area, but Nirvana herself has been a family caregiver. Somebody supporting a sister and who is very interested in this topic and will be doing some real substantive work in respite with us.

Also on the line is Deidra Abbott from CMS. She will be our first speaker. Deidra, who is with you there now?

Deidra Abbott: With me is one of our project officers, Fred Harris.

Susan Reinhard: Great. We are expecting Cathy Cope shortly. Richard Petty, who is with ILRU, sharing in the technical assistance work is on the line and has friends from Arkansas on the line. Want to say hi Richard?

Richard Petty: Hi everyone. I am sitting in for Darrell Jones `who is returning from Phoenix today.

Susan Reinhard: Oh, that is great.

Richard Petty: But Darryl will be with you on other calls.

Susan Reinhard: Great. Let me just go down; did I interrupt somebody?

Nirvana Huhtala: I'm sorry. Susan, I just wanted to remind you and everyone on the call that the call will be recorded.

Susan Reinhard: Thank you. That is great because there are some people that could not join us and really wanted to be able to listen in. So let me just run down the states that I heard were on the call. New York? Are you there? New York? I thought I heard New York was on.

Male: Maureen was.

Female: Did I hear Doreen Sharp?

Susan Reinhard: Doreen, are you there? New York? Well maybe New York will come back. I am certain I heard them.

Nirvana Huhtala: Maybe they are on mute.

Susan Reinhard: They could be, which is very courteous. Is anyone from Ohio on? I didn't hear them. Rhode Island, are you there? Nope. I think that Sharon will be joining; no, yes, Sharon will be joining us. California? I heard Kathy.

Kathy Kelly: And Jane Laciste at the California Department of Mental Health.

Susan Reinhard: Great. Arizona? Or Arkansas, I am sorry, Arkansas? Bruce is on, Bruce Whitten.

Bruce Whitten: Yes, we are here.

Susan Reinhard: Bruce is going to be telling us particularly about his grant and you have some other folks from your state with you?

Bruce Whitten: Yes.

Susan Reinhard: And who are they?

Bruce Whitten: David Deere is the contractor for the grant.

Susan Reinhard: Great. Oregon is on the line.

Janet Strauss: Yes, Janet Strauss.

Susan Reinhard: Is Michigan on? I didn't hear anyone from Michigan. Alabama? Maryland?

Alicia Steinberg: Hi, Alicia Steinberg.

Annette Snyder: And Annette Snyder.

Susan Reinhard: OK. And did someone just join us?

Doreen Sharp: Yes, this is New York. I am sorry I cut you off.

Susan Reinhard: *(Laughs.)* There you are. We knew you were there. Is that Doreen?

Doreen Sharp: Yes it is.

Susan Reinhard: Hi. Do you have anyone with you?

Doreen Sharp: Yes, I have Priscilla Ferry and Margaret Willard.

Susan Reinhard: Great. Thank you Priscilla and Margaret. Did I miss anyone else? OK.

Well this call, as Nirvana has, in case anyone didn't hear this, this call is being recorded but it is very informal. Anyone else just join us?

Lori Irish: Yes, this is Lori Irish from Michigan.

Susan Reinhard: And Audrey Kraft, who will be here in just a moment.

Susan Reinhard: Great. We are really glad. We have almost all the states on. We are just missing a hand full. We were just saying that this phone call is being recorded but it is meant to be quite informal. We are recording it at the request of grantees that couldn't make the call and also for our own note taking because we would like to summarize some of the information and maybe an issue brief or something that could be helpful.

The question that first came up, we did our calls, and as most of you know, we did group calls and we had a breakfast meeting for those that were able to attend the CMS conference in Baltimore in March. We have been asking what are you up to and how can we be of help? We have heard from you about you'd like some help in literature reviews and survey construction and analysis of what data is out there, what states are doing, best practices. Those are some of the areas you have asked for help.

But one of the most thoughtful discussions we have had was over this breakfast meeting and the question came up, "What is the policymaking nexus for respite at CMS?" And, "What is 'respite'?" Respite is easier to define what it is not than what it is. Given those questions, which I have kind of bounced around with both Rhode Island and California as well as Maryland before this call, and Arkansas. It is kind of difficult to provide technical assistance if we don't have a more common ground for what it is you are trying to do and where you think you might be going in these feasibility studies. Sort of what is the next step.

So we reached out to Deidra Abbott, who is the, I forget your formal title Deidra. Policy guru, I guess. You are the technical director of the Division of Benefits, Coverage and Payment for the Disabled and Elderly Health Programs Group at CMS. But you are also, is it the policy lead? Is that the correct terminology?

Deidra Abbott: That is the terminology I use, Susan. So tomorrow that could change.

Susan Reinhard: (*Laughs.*) The policy lead for respite and we talked with both Deidra and Kathy about putting together this call so that we could hear from CMS what their thoughts are on this sort of a national focus from CMS's perspective on respite. So Deidra is going to get us started.

Deidra Abbott: Great. Thank you, Susan. Thank you all. I am very happy to have an opportunity to talk with everyone today. Perhaps more importantly to hear what is working or at

least some of the direction that you all are thinking about and then to entertain any questions that everyone may have in terms of the demonstration and CMS perspective.

I just wanted to start by giving a little bit of background and hopefully sharing, I think with most of you, information that you already know, but I think it does help hopefully, in at least establishing the framework under which CMS is looking at these respite grants.

As all of you know, there is no recognition of respite as a covered Medicaid service. In Section 1905, they (unclear) Social Security Act and Section 1905 of the Act is where you will find, in the Act, all of the mandatory Medicaid coverable services under the general Medicaid State Plan Program as well as optional services.

Where you do find respite in the Social Security Act is listed in Section 1915C4B of the Act. This section, however, is the Home and Community-based Services Waiver section of the statute, an optional program. So that is the only specific place in the Social Security Act where you will find the reference to respite as a coverable service. Again, it is only listed here as an optional service that states can provide under their optional Home and Community-based Services Waiver program.

The HCBS program implementation, at least in terms of how we look at respite, is very general and fairly broad. We really consider respite for the HCBS Waiver program as a service that is furnished on a short-term basis. Usually by short-term, we are looking at 30 days or less. The service, to think of it as a service that is provided because of the absence or need for relief of the person normally providing care to a Medicaid-eligible participant.

In terms of specifics, or at least the parameters around respite, HCBS Waiver program, is fairly broad in terms of what we look at and with considerable flexibility for states. CMS does recognize that there are multiple locations where the respite can be provided. For instance, individuals may receive respite in their own homes or the home or residence of a family member. We recognize that a state may provide respite in a foster care setting. We recognize that respite may be provided in a Medicaid-certified facility such as an ICFMR, a hospital, a nursing facility. We also recognize that there may be respite locations in a given state that are residential setting separate from an individual residence such as a group home or a licensed respite care facility. So again, recognition on the part of CMS that there are a number of specific locations that a state can use or may use in terms of providing locations for respite care.

CMS also recognizes, again looking at respite, that there needs to be some exceptions in terms of the payment that can be made for FFP regarding room and board. So we have said that if respite is provided in an institutional; I'm sorry. If respite is provided in a facility that is approved by the state that is not a private residence, which would include an institutional setting, that room and board can be claimed for that service. That is an exception for the general HCBS Waiver Programs.

One thing I thought was very interesting to share with the group is just to give you a sense of the number of states that currently have HCBS Waiver Programs that do provide respite services. At this point, and I did a very quick search of this prior to the call, but it looks as if we have

approximately 175 state programs currently in operation that offer respite. That is 175 out of approximately 280 existing programs. So well more than 50%, actually I think it is closer to 60% of the state programs currently in operation do also respite care services. Respite is the most frequently covered waiver service in the programs that are in existence today.

But even though CMS does allow for respite in HCBS Waiver programs, there is recognition on the part of this administration and rightly so, that this focus on respite is incredibly limited. We need to consider the value of expanding respite coverage under Medicaid. So as a part of that recognition, the President's budget, I think as all of you are aware, in both 2004 and 2005, submitted proposals to fund respite demonstrations for caregivers of both adults and children, which at least the 2004 demonstration, excuse me, budget proposals leading to the 2004 grant awards, which all of you are benefiting from, for feasibility studies that we hope will lay the groundwork for a larger and future initiative.

Now again, as I have mentioned, the President has proposed in his 2005 budget to also include demonstrations for caregivers for both adults and children. Obviously we have no idea what is going to happen in terms of that recommendations. We are optimistic though and hope that it will be adopted by Congress. But kind of stay tuned and keep our fingers crossed.

In terms of CMS expectations without having the benefit of these demonstration programs, we really I think are at a crossroads in terms of respite. We obviously know that there is value in having respite coverage, which again is in keeping with the administration's recognition and hope for doing some expansion of respite. But at the same time, we really have not had an extensive evaluation of the existing respite programs, how well they work, how well they don't work, what works, what doesn't work, what is missing, what is needed, as well as the fact that where do we go from here? Again, as I have stated, respite under Medicaid is limited to the HCBS Waiver program. What is the value therefore in having respite as an optional state plan service that can be provided under a state's general Medicaid program?

Again, what there would work? What wouldn't work? Does that look or should look different from waiver programs, excuse me, for a respite under a waiver program. That is where we are looking to you all in terms of the feasibility studies that you are working on. We are really grappling to try to figure out what is the best approach that needs to be taken in terms of respite and perhaps more importantly, the future direction that CMS needs to move towards in terms of respite.

One of the questions that I have heard from a number of states from consumers and from advocates is when you are looking at these feasibility studies, what is the expectation? Is it the intent that these feasibility studies should be limited to waiver services or respite as a waiver service? Or respite as a state plan service or a combination? We, I can honestly say, really are looking to you all to establish those parameters. The grant was made so that there is incredible flexibility so that states can do one or the other or a combination thereof. I think the issue, however, for you all to consider will be the sustainability. I say that because you know at this point that respite is not available as a Medicaid-covered optional state plan service. So the question I think for you all to consider if that is the route that you will take, what happens then after the point where money is no longer available and you need to or at least are looking for

future Medicaid funding for that service? Will, without some change in legislation from the federal perspective, obviously the money will not be able to be there to support a state plan service. So I think those are some of the questions that you all need to consider.

I just sort of rambled on a little bit and I would like to stop to at least maybe get your reaction and your thoughts.

Susan Reinhard: That was really, really good. Thank you for reviewing all of that. I just have one follow-up question. I am sure grantees also have questions but I just want to be clear about what you said. The 2004 and 2005 proposals for the demos, did those demos envision moving towards an optional state plan service or they were also very broad?

Deidra Abbott: They were also very broad. Actually that is a good question, Susan. I am sorry I didn't address that. They were fairly broad. However, ultimately, the hope is that we would be able to use those as a basis for arguments towards the need for moving towards the state plan service.

Susan Reinhard: OK, thank you. Any questions for Deidra?

Bruce Whitten: Yes, I have a question from Bruce Whitten in Arkansas.

Deidra Abbott: Hi Bruce.

Bruce Whitten: Temporary Child Care Act back in the 80's; it funded at least a dozen years of respite feasibility studies. Have you all not interacted with that agency, the Administration for Children and Families? The respite care problem has been studied to death.

Deidra Abbott: Right, right. Bruce, I am aware of that. I have to say though, unfortunately as an agency, CMS has not looked into those feasibility studies.

Susan Reinhard: Bruce, can you say a little bit more about that? These are feasibility studies where?

Bruce Whitten: Yeah, they were at the Administration for Children and Families is what it used to be called.

Susan Reinhard: You are saying; how long ago were the studies?

Bruce Whitten: Well, back, I think was passed in '86 and it went on through the late 90's.

Deidra Abbott: Bruce, my guess is, and I am speaking on behalf of the administration so that may be a dangerous thing for me to do, but my guess is that some of the issues that we would be looking at is what is the cost fertilization in terms of the population? Is it really an apples-to-apples comparison? Are the individuals that will be covered under those demonstrations Medicaid recipients? Maybe they are. That I don't know, but what I do know is that we are very interested in looking at the coverable population for Medicaid purposes.



Bruce Whitten: Well, all I can speak from is our experience and we ran a program under the Temporary Childcare Act for nine years at a level of \$200,000 a year. The recipients that we had were mostly Medicaid-eligible recipients.

Susan Reinhard: OK.

Bruce Whitten: Mostly SSI or TEFRA.

Susan Reinhard: Bruce, isn't that the program that you guys then transferred over for the most; or am I?

Bruce Whitten: Our present program is modeled after that program that we ran.

Susan Reinhard: Bruce, this is probably a good segue for you to talk more about that program and then we can return to Q&A's for both of you. Can you tell us; you are saying you had a history of nine years ago developing this respite program for children and you have now segued it into a Medicaid waiver program?

Bruce Whitten: Right. It was very flexible with a minimum of paperwork and now there is a maximum of paperwork. We did some things that probably were unwise. We didn't do criminal background checks. The philosophy was if the parents were satisfied with the caregiver, then we were satisfied.

Susan Reinhard: But now you do?

Bruce Whitten: Well, the Feds insisted on it and of course there are some parents, you know, are not necessarily responsible. At any rate, we have two waivers; one through the MRDD population and one for the physically disabled. It is a small program. There are 150 slots for the physically disabled and only 100 for the MRDD because there is another Home and Community-based Services Waiver, another much bigger one that is run by the Division of Developmental Disabilities Services, which covers not only respite but many other services and they are all; you can get much more respite out of that program. But they work through providers that are licensed by the state whereas our program is; again, it is left up to the individual families to select their caregiver.

The criteria, requirements for the caregiver are very general. They must be 18 years of age or older, U.S. citizen, free from evidence of abuse or fraud, conviction involving crime, must be able to read and write. Most importantly, be able to perform the central job functions required, which will vary depending on the type and severity of the client's disability.

We only have \$280,000 budgeted for, like I said, 275 slots plus five emergency slots. In the first year of the program, which ended last September, we only spent \$155,000 of that and that is part of why we are doing our study now to see how we can increase participation. Many people objected to the requirements insisted on by our State Board of Nursing that a caregiver must be

certified by a registered nurse. Many parents had a hard time finding a registered nurse to certify them so that was a big reason why the full amount was not spent.

In the second year of the program, we have loosened that up based on the State Board of Nursing's advice that only if nursing duties are involved must a registered nurse sign. In many cases, nursing is more care taking than it is nursing duties so we have increased participation this year with that ruling.

Susan Reinhard: When was that ruling?

Bruce Whitten: It was only about three or four months ago.

Susan Reinhard: OK. I know that Herb Sanderson has been trying to work on this issue in general for private duty nursing of children, which is outside the respite program but I think does affect you.

Bruce Whitten: Right.

Susan Reinhard: I also know that Rhode Island is interested in that topic.

Bruce, can I just ask you a follow-up question? The \$280,000, is that total funds? Is that state and federal?

Bruce Whitten: Yes. It is only \$70,000 state.

Susan Reinhard: OK. Any questions for Bruce?

Kathy: I actually have a question. Why is there certification required for by a nurse for a respite provider when in the Cash and Counseling Program I don't think that; is that required in Cash and Counseling in Arkansas?

Bruce Whitten: I am not familiar with the Cash and Counseling Program. It was insisted upon by our Medicaid policy section when we were setting up the procedures in concert with the State Board of Nursing that this be done. So...

Susan Reinhard: Was that Kathy?

Kathy: Yes.

Susan Reinhard: OK.

David Deere: I think the difference in those two is the Cash and Counseling, this is making some assumptions.

Susan Reinhard: Could you just say who you are?

David Deere: This is David Deere from Arkansas.

Susan Reinhard: OK.

David Deere: One assumption I am making is in Cash and Counseling, the individual hires the and pays the caregiver. With this one, it is actually the state paying them so you have liability on the state's part. Would that be part of it, Bruce?

Bruce Whitten: It is Medicaid who pays them, not the state.

David Deere: Well right, but it is through the state auspices.

Bruce Whitten: Right, it is through the state audit.

Susan Reinhard: Part of the issue with Arkansas, I have been in communication directly with the Arkansas Board of Nursing and their attorneys and Herb Sanderson. It has to do with children. They don't have a lot of comfort with children. They have more comfort with adults with physical disabilities and then a little bit more, a little less so older adults, which mirrors the country, the boards of nursing, and then children are what they get most worried about since some of it is our biases on the parts of the board of nursing and then when the Medicaid agency reinforces that it is very difficult. But I do think this is an issue that other states, as I said, Rhode Island, Sheldon Levy in Rhode Island has been working with Sharon Kernan there in trying to address almost the exact same issues.

I don't know if there are other states that have that concern?

Kathy Kelly: This is Kathy Kelly. I would have to go back to, there is in the regional centers for kids that serves, primarily kids and not exclusively. There is a respite program and I don't know what the stipulations are for the provider community, but it is a consumer-directed model so that is why I am curious why? Every state is obviously a little bit different.

Susan Reinhard: Right.

Kathy Kelly: I realize it is the difference between children and disabled adults, but there is also a difference between kids, persons that are cognitively impaired older adults. Each has surrogate decision makers involved. I was just curious why there wasn't a kind of more of a parallel in policy.

Susan Reinhard: One of the other questions I had for you, Bruce, is you talked about another HCBS DD waiver that includes respite and many other services. So this waiver is only respite, but could be for a very similar child and family member. How do you make the distinction in which waiver that person is placed?

Bruce Whitten: Well, there is a long waiting list for the big waiver, which is called Augmented; what is it called? I can't think of the name. ACS is the acronym for it, but there is a long waiting list so many of our clients on our respite waiver are on the waiting list for the big

waiver. When they are approved for the larger waiver, then they are immediately ineligible for the respite waiver.

Susan Reinhard: OK. Great. Any other questions for Bruce? How about for Deidra?

Sharon Kernan: I had a question for Deidra. This is Sharon Kernan from Rhode Island.

Susan Reinhard: Hi Sharon.

Sharon Kernan: Hi. Deidra, you are from CMS, correct?

Deidra Abbott: Yes I am.

Sharon Kernan: OK. I want to try to clarify what you said so I am sure I understand it. It sounds like you said there are 175 state waiver programs that provide respite.

Deidra Abbott: Right. About 175.

Sharon Kernan: And they haven't been evaluated.

Deidra Abbott: Right.

Sharon Kernan: And CMS is interested in understanding more about respite and considering the value of expanding respite.

Deidra Abbott: Absolutely.

Sharon Kernan: And you have give out these feasibility demonstration grants to states to help you understand it better.

Deidra Abbott: To help us understand it better. To help us understand what currently exists that works, that doesn't work. But again, Sharon, just to kind of go beyond that and help us to get a better handle on what types of expansion that we need to consider in the future, in future initiatives.

Sharon Kernan: Right. So as we move forward in our state to work on this, we could consider having a new waiver that would be more expansive than what we have now, which is limited to children who are MRDD.

Deidra Abbott: Uh huh.

Sharon Kernan: Or we could consider the feasibility of adding respite as a state plan service if that became an allowed benefit.

Deidra Abbott: Correct.

Sharon Kernan: But if we wanted to explore or develop it as a state plan service, we don't know if CMS would support that in the future.

Deidra Abbott: That is, I mean it is kind of a catch-22, absolutely right.

Sharon Kernan: So I guess I am a little confused as to how we are supposed to demonstrate to you the value of doing that when if we did do it, we couldn't really do it and if we tried to do it in some way, we might have to stop it, which would be very detrimental to families. So I guess I am a little, need a little more guidance or something.

Deidra Abbott: Right, right. That is a good point, Sharon, and you are absolutely right because if the possibility would be if you went down that road, you would not conceivably have future funding.

One of the things maybe you could think about, and this is just off the top of my head, is look to your state to see if you would have adequate (unclear) that would at least be able to sustain the program for a limited number of, a limited period of time beyond the grant period.

Sharon Kernan: Did you say, "adequate resources"? We had a little technical glitch.

Deidra Abbott: I'm sorry. I heard a hissing as well. Yes. No, and I know that I can't speak for your state. I know that that too is a problem for many states because the additional funding is just not available.

Sharon Kernan: Right. Well that would be certainly an issue in our state.

Deidra Abbott: Yes. So the bottom line I guess, unfortunately, because I do think it woefully limits what can and cannot be done under this grant program, is that the most logical approach, I think, in terms of sustainability and future funding for you all is going to be looking at the existing; I should say either your existing waiver programs or new future waiver programs.

Sharon Kernan: Right. OK. Well that is what we are thinking too, but I just wanted to...

Deidra Abbott: It really is unfair because it is a severe limitation and I don't think it is going to give us or you a really good sense as to kind of expanding the benefit, but thinking of it in practical terms and working in the environment that we have, that we are facing at this point, that is probably the most logical approach.

Susan Reinhard: This is Susan. I just want to have a follow up to that. Sharon, if Deidra had said to you in response, "Well, we are about 99% sure that the state demos are going to go forward and that the goal is to have a state, an optional state plan service, what would you do differently in the feasibility study you are doing now?"

Deidra Abbott: That is a good question.

Sharon Kernan: Probably we would be, I think if you have respite as a state plan service, it seems to me it would be a thornier issue of how you would limit it. Everything that is part of Medicaid, as I understand it...

Deidra Abbott: Limitation would be an issue under state plan services.

Sharon Kernan: Whereas if it is in a waiver, it is a little easier to control it, as I understand it.

Deidra Abbott: Yes. But Sharon though, on the other hand, you are absolutely right. Just by virtue of the nature of state plan services, there are very few exceptions that would allow you to place severe limitations on the service. But I think I am going back to the comment that was made if these demonstration programs were to be picked up by Congress and the funding was made available, my guess is that it would be an opportunity for the states to think outside of the box. Perhaps you would not be limited to the broadness and expansiveness of a traditional state plan service.

Sharon Kernan: So we could be presenting our thinking on how we could limit it in terms of (unclear) the Fed and the hours and the allocation...

Deidra Abbott: Right, right. Even the target group possibly.

Susan Reinhard: Deidra, is Cathy with you?

Deidra Abbott: No, she still (unclear.)

Susan Reinhard: Something that you are saying triggered targeted case management.

Deidra Abbott: Absolutely.

Susan Reinhard: Targeted case management is different than other state plan services. You can limit.

Deidra Abbott: Correct.

Susan Reinhard: So that might be something we should share with everyone, what that is about and just thinking. I think the challenge for the feasibility studies for those states, and it sounds like Sharon, you may be one of them, that wants to explore the potential of well, would it be a good thing to have an optional state service, which would be way down the road. You would have to have a, Deidra, correct me if I am wrong here, but I think you would have to have a demonstration project that runs five to ten years and is evaluated. That report is given to Congress who then has to change the law.

Deidra Abbott: That is right. Susan, you are absolutely right. The funding time period I believe that had been proposed this time around is (unclear) is a ten-year period.

Susan Reinhard: So what we are talking about is truly, as Deidra said, this is a time that CMS was offering them opportunity for states who were extraordinarily interested in this topic of respite care, which all of you are, to help them figure out is this something that should be considered down the road, an optional state plan service.

One of the things I was trying to do, and I didn't finish doing it, is what is the last optional plan service that Congress voted on? Is that personal care, attendant service? I really don't know the answer.

Deidra Abbott: Oh, you know Susan, I thought it was some of the breast cancer.

Susan Reinhard: Oh right, that's right. We did talk about that.

Deidra Abbott: Right.

Susan Reinhard: But in terms of long-term care.

Deidra Abbott: In terms of long-term care?

Susan Reinhard: Or long-term supportive services.

Deidra Abbott: Yeah, I think it was personal care.

Susan Reinhard: It was probably personal care. I don't remember how, maybe the 80's that was? I am trying to remember.

Deidra Abbott: That sounds about right. It has been a while.

Susan Reinhard: Now that really revolutionized in many states the ability for people to stay at home. The majority of states have it. There are still states that are pushing for it. Richard, I don't know if you want to jump in here. I know that ILRU has explored this issue as well and that might be, this might be a similar situation to that where the index person, if you want to say it, is the family.

In fact, I think Tom raised this matter in Oregon. Mike in Oregon raised it at the breakfast meeting that in the case of respite, to what extent, I am veering off a little bit, but I think it is important for the feasibility studies. To what extent are we focused on the person with a disability, regardless of age, who is receiving support from a family member and the assessment procedures, etc. are focused on that recipient, that beneficiary? Or to what extent, maybe it is and/or, are we focused on the caregiver and the assessment is on the caregiver?

I know Kathy Kelly and her colleagues at her organization have done a lot of thinking about caregiver assessment and whether that is something that should be included or could be included at feasibility studies?

Deidra Abbott: Susan, that is a good point. I think it probably has to be because when you really think about respite, even though the ultimate benefit is to the participant, it is, some may argue, it is a benefit to the caregiver as well. So I do think you have to consider the value then that is, that the service does offer to the caregiver and take that into consideration. But I would suggest, however, that the primary emphasis would still need to be on the value of that service to the benefit because you are looking at potentially a Medicaid service that is provided to a Medicaid-eligible participant.

Susan Reinhard: Right.

Kathy Kelly: Can I, this is Kathy Kelly. Can I follow up for just a moment with this?

Susan Reinhard: Sure.

Kathy Kelly: Then what is actually the definition of “respite”? Because if there is these services that are being provided in the home or in an out-of-home placement, of primary benefit to the care recipient, then isn’t that a personal care service or some other supportive service to them? Because respite then becomes, if you don’t consider expansion of the eligibility in terms of the ongoing primary caregiver, then why call it respite?

Deidra Abbott: Unfortunately, Kathy, we do not have a definition of “respite”. Obviously not in statute. It is not in the regs. It is not in any of our policies. The only place you will find anything close to a definition is in the HCBS Waiver application. Then there really isn’t much there. What is there is what I shared with you earlier, where we say that the service is provided on a short-term basis to the beneficiary because of the absence or need for relief for the caregiver. So even in the definition, it has both the recipient as well as to the caregiver.

Susan Reinhard: Interesting.

Fred Harris: Or some states have also come up with their own individual definition within these varied feasibility grants that we are going through right now for ’03 and ’04.

Susan Reinhard: Yes. Is that you, Fred?

Fred Harris: That is me, Fred Harris.

Deidra Abbott: What you will find in some of the existing HCBS programs is very, I think much so, getting back to your point where the respite service that is provided does have some elements of personal care or homemaker. So sometimes you will even have the same provider serving multiple functions.

Susan Reinhard: That is right.

Sheldon Levy: Can I ask a question of Deidra? This is Sheldon Levy from Rhode Island.

Susan Reinhard: Hi Sheldon.



Sheldon Levy: Hi, how are you?

I was wondering if CMS has or plans to do a cost/benefit analysis of respite care, specifically for children? What I had in mind by that, what my thoughts were about that had to do with well you know, provide respite care for a disabled child and they go into some place or are with some people outside the home. And that has a certain cost to it. But there are certain benefits to the child and the family for having had that respite experience and that benefit may be, for example, less medical care that the family goes through because there is less stress in the family or there are less days missed at work because the parent doesn't have to be with the child as much and there is a certain cost to that. Those kinds of things are things that aren't directly, the child being placed in a respite situation, but have benefits outside of that and the cost of the service compared to what kind of financial and other benefits there might be to the family and the child. Have you done that or are you planning on doing that?

Deidra Abbott: Sheldon, we have not done such an analysis and to be very honest, have not talked about that per se, at this point. Although I could very easily see that as a logical next step in terms of the feasibility studies and/or if we received funding from Congress through the demonstration programs. Again, I can see that as being the logical next step.

Sheldon Levy: But it is not anything that is planned or missed in the pipeline in any way?

Deidra Abbott: Not at this point, no.

Susan Reinhard: Would that be that Sheldon is referring to; Sheldon, maybe I should ask you this. Is that something you would envision a state would do or that that would have to be a national analysis?

Sheldon Levy: Well, states could do it. It could be done locally. But I think a national analysis would be helpful just from the public policy perspective, especially at the state level when we are making policy decisions about services for children with special healthcare needs, we think of it in terms of cost/benefit. That is while it costs a certain amount of money to provide this service or expand existing services, but there is a financial benefit for doing that. In other words, if we have less expansive services to more kids, that in fact might cost the state less rather than more in the long run. So that, for example, if a family is less stressed because there is more respite available, then there might be less, as I mentioned, healthcare utilization on the parts of other family members, siblings, parents, aunts and uncles, because we know from other areas of research in health services that one benefit in one area may lead to a benefit in another.

In other words, it might be in someone else's budget, not in ours. But the overall benefit to the state in terms of outpouring of money is positive, even though it may cost our budget more. It might decrease somebody else's budget. That is the kind of analysis that can be done on the state level or it can be done on the national level.

Deidra Abbott: Sheldon, I can really see that type of analysis being done and needed at a national level if again, down the road, future initiatives we were ever to get to the point where Congress would seriously consider expanding the statute to allow for an optional respite service.

Kathy Kelly: This is Kathy Kelly again because I want to follow up again. I am sorry to be...

Susan Reinhard: No, please do Kathy.

Kathy Kelly: And this actually goes to Sheldon's point about looking at cost/benefit because you wouldn't be able to determine stress within the family without doing an assessment on the caregiver, at least in some minimal data set, to be able to determine that. So my question comes back to, which I think that is actually the direction we are going. Looking at if you are going to provide respite, then the benefit probably actually accrues more on the side of the primary caregiver or the consolation of the care giving constellation rather than to the care recipient themselves. That is kind of; it is a benefit to them, but respite in and of itself by definition has to have a primary benefit to somebody who is providing care because your definition of absence or need for relief to caregiver implies that the benefit accrues to that individual person.

So the follow-up question that I have that kind of lies underneath all of this is while it may not be defined in the HCBS application, the definition is probably that broad. Operationally, do you have a sense of what the determination of absence or need for relief to caregiver is? That is kind of where we are stymied is how is that actually even determined if you have 180 programs, 175 state programs, that are saying they are providing respite, then how do they determine that?

Deidra Abbott: That is a good question. I, to be honest, am not sure. But one of the things that I think we can do on our part in order to get that kind of information to you is just kind of have a quick discussion with some of our states to get a sense of the parameters that they look at in making determinations as to who needs respite? What I guess are the triggers for a respite?

Kathy Kelly: Right.

Deidra Abbott: Yeah, why don't we, I can commit to having us do that for you.

Kathy Kelly: I think that would be helpful because if this is truly going to kind of follow the care recipient or unless, and that was sort of my second question, and it kind of gets at Sheldon's question about the cost/benefit analysis. Is there, in terms of developing these feasibility studies, should we be looking at expanding some sense of eligibility or data collection criteria to include the family caregiver?

Susan Reinhard: Actually Kathy, I feel strongly we should but I think CMS does have to give us that direction because your first argument about well, it is almost total logical. There has to be a benefit to the caregiver. How do we measure that or shouldn't we be measuring the benefit? Maybe it is just a qualitative or the outcome is that the person is able to stay in their natural, supportive environment.

Deidra Abbott: Right. Because the caregiver received the relief that they needed in order to continue providing the care.

Susan Reinhard: Right. But nonetheless, you would think you would still want to have some measures of that if you are, even from a quality perspective. How does the state know whether they are truly providing respite if you can't define it? You have got to be able to define it, measure it and a quality improvement framework should be able to have oversight of that. So therefore it seems to me you need some measures of how the recipient of the respite is responding to that service that is really for, designed to make the environment more supportive to the participant.

Kathy Kelly: I guess I am sort of looking for some general guidance that when we go forward and we propose this because we have been involved in doing respite programs but our primary client is the family caregiver so we collect all sorts of information on them to look at what are the outcomes over the long term. In this it is kind of (unclear). It is a little bit tricky and so I am kind of wondering what is the guidance in terms of suggesting that we collect a minimum dataset of assessment information to look at outcomes if you are providing respite.

Deidra Abbott: That is a very good point. Why don't we make an effort on our part to touch base with states to see if, obviously I can't imagine that the states have not already addressed some of these issues and I think they are going to be the best resources so why don't we go back to them and see what they have been able to come up with and share that information with you?

Susan Reinhard: Deidra, you are talking about those states that are currently providing respite under waivers?

Deidra Abbott: Correct.

Susan Reinhard: For both adults and children?

Deidra Abbott: Correct.

Richard Petty: This is Richard Petty at ILRU and always a little hesitant to advance slippery slope arguments but I think one of the things we probably would want to be careful in any shift of focus from the primary recipient of the service is the danger of shifting quality measures and assessments from the quality of the service and the benefit from the primary recipient to someone else. There, it seems would be some danger of losing focus in that kind of effort. Certainly there are benefits to the person who is providing a service for someone, and we shouldn't ignore those, but it would, I think it would make a lot of people in the community pretty uncomfortable to see the kind of shift that we are thinking about.

Susan Reinhard: I don't think we are talking about a shift. We are talking about both.

Richard Petty: Which is fine to talk about both. I would like to trust that we are all talking about both.

Kathy Kelly: No, I actually talking about an “either/or”. I am talking about both. But you know, from our kind of reconnaissance of what is going on across state programs, there is actually almost no information asked about the family care giving constellation, in terms of the needs of that, to support the person in the home.

Richard Petty: It is a good discussion to have in terms of any service that is provided, whether it is personal assistance service or others. In terms of what are the other benefits that accrue to the community and others who are involved, so it is not a bad discussion to have at all. But I think there is a question of emphasis and one that I would urge some caution about.

Sheldon Levy: In terms of talking about children, there is...

Susan Reinhard: Could you just identify yourself?

Sheldon Levy: This is Sheldon Levy again.

Susan Reinhard: OK.

Sheldon Levy: From Rhode Island. I would agree what you said, but in terms of children there is no, it is unreasonable not to look at the impact of respite care beyond just the child because in fact it is an entire system that benefits from it and it is not to take away from the benefits to the child, and that obviously needs to be evaluated. But the focus hopefully needs to be on the family and I don't think it is one or the other, at least in terms of children. Maybe there is perhaps less of a need for doing that with an adult who is having respite care and their family but even there I would agree that it would be an important to see the impact on the family as well.

Richard Petty: I think we are in agreement on that.

David Deere: This is David Deere. What I would think we would want to do is to look at the impact on the family, but also then look at how that impacts their ability as a caregiver for the consumer.

Susan Reinhard: That is right. I think...

David Deere: We wouldn't just look at the family absent how that impacts the consumer.

Sheldon Levy: Right. Absolutely. That is actually what I am saying.

David Deere: Right.

Kathy Kelly: It strikes me that most of the time when the family is asked a question, it is posed in a way to determine the elasticity of services that are going to be provided to the care recipient. In other words, how much can the family provide before formal services will kick in?

That is actually the kind of the narrow band of information that is available. How much care does the family provide? In very few places is there ever the question of what are the needs of the family caregiver in order to support the family, in order to support that person remaining in the home, regardless of whether it is a child or a if it is an adult.

There are specific kinds of measures obviously, stress, burden, depression, health. All these are the kinds of things that I am not particularly suggesting either/or or any of those be used. But in tandem, they are an assessment of the family system along with the information that is on the beneficiary.

Susan Reinhard: So Kathy, this is part of your feasibility study?

Kathy Kelly: Well, I'll tell you, this is the kind of the, to me is sort of the, one of the nuts of the issue is who is the beneficiary and how are you constructing it? Because it does make a difference in terms of not so much about looking prospectively about how many people would be in need of respite services and kind of doing that kind of forecasting, but actually trying to determine where the eligibility would lie. Is it on functional disability of the individual? That is not always an indicator of stress on the family.

Susan Reinhard: I know. You know I have written papers about that. (*Laughs.*)

Kathy Kelly: I know. But that is what I am saying. That is kind of when you start to, when you look at sort of the general population, number of AADL's and IADL's and that kind of stuff, you can sort of figure out people do need some help above and beyond maybe what they are already getting. But when you start to look at some more global eligibilities, then it gets down to what is happening with the caregiver? That does make a difference in terms of trying to kind of move forward.

Susan Reinhard: It is really a capacity issue of the caregiver. I think you were using "elasticity" but Deidra, Fred, CMS in general I think what I am hearing and what I also believe is that if you are only assessing the need for respite based on let's say the ADL's; this is something we have been talking for older adults in particular. This discussion has come up. Their ADL needs. So like the more ADL needs, the more eligible you might say, the family caregiver is for services doesn't make a whole lot of sense because it depends on how the family caregiver is doing.

Kathy Kelly: Right. You are absolutely right.

Susan Reinhard: You can certainly measure the ADLs, but you really have to measure the needs of the family caregiver. It is not a matter of 1-2-3-4-5 ADL needs. It is really how is the situation going?

Fred Harris: And it seems to be; this is Fred Harris. It seems to me taking all this in, we are here in May and as we go forward with this, probably even in five or six months, we may even have more insight into many of the concerns that have been voiced on this telephone call. I

personally see this as a multi-pronged thing. I figured all of those focus on the recipient or participants.

To me, if a caregiver is tired, ill, pressured, call it what you will, after many weeks of taking care of his charge or her charge and now needs some kind of relief, that has got to be a benefit albeit whether it is direct or indirect on the actual recipient his or herself because whether it is human or an inanimate object, when something starts wearing or getting worn out, it is time for a replacement. This respite for the caregiver I think can, in many circumstances, which are not necessarily black and white, but they vary. It is certainly going to benefit the caregiver. It is going to benefit the recipient participant. It is going to benefit (unclear) this situation all or certainly most of the participant's immediate members of the family. It will free up other children in the house, which there very well may be, to spend more time with their parents.

What we have to find out, and I think many of the questions that you are coming up with are wonderful and really valid at this time, but we are just too soon into it and we will have to flesh a lot of this out and to see how the several states who are involved in this now are doing and what their input is, some of which came out in this call. I think is really a good thing as we proceed down the road.

Susan Reinhard: I agree. And so the commitment that we can make to you guys is looking at some of the states currently under the HCBS waiver program that are providing respite, what triggers do they use to determine when Medicaid waiver recipient needs respite? So we will commit to get that information. It is a good point, a very good point.

Bruce Whitten: I don't mean, this is Bruce Whitten again, to sound like a broken record, but again, I would strongly recommend that someone contact whoever might be listening from the Administration for Children and Families. This issue was studied to death for twelve years with state demonstration projects and university studies of the issue. For the 11 years that we have run this program, and on our application, we go through (unclear) and everything, but we ask the parent to just give a paragraph of why they need respite. The doctor who is on our eligibility committee says he learns more about reading that paragraph that the parents write about why they need respite care to reduce the stress in their lives and he can, from looking at the assessment of the ADL.

Susan Reinhard: Bruce, do you weigh the paragraph more than the assessment of the ADLs or is it a combination?

Bruce Whitten: It is subjective. We have a three-member board. They each rank respite, the need for respite on a scale from one to four. We average out the results. It is as good as we could come up with, but it is highly subjective of course.

Susan Reinhard: Deidra, let me just be clear about what we are saying here. What you are saying is CMS is committing to turn to turn to those states that have existing waivers, which we know are many. Kathy Kelly, by the way, had turned to Charlene Harrington, also in California of course, who has a very rich database on these services and that she ran data just for adults, A&D waivers, should say, with respite services and came up with, for example, Florida having;

not Florida, I'm sorry. Yeah, Florida, their Age and Disabled Waiver, they are spending \$11 million right now. Arkansas, no Alaska, I'm sorry. Alaska is \$4.7 million so (unclear) we can send this to you, the data that has already been launched.

Deidra Abbott: Please, that would be great.

Susan Reinhard: So I don't know if you want to have some of the states with the bigger waivers or whether that matters. I know New Jersey had their respite services, both state and what Medicaid waiver services studied by Mina Silberberg, and we can send you those reports.

Unknown: Susan, I am thinking it may be more telling to kind of do a combination. Both those states that have high expenditures but also those that have relatively low expenditures to see if there is a difference in how they make the determination.

Susan Reinhard: We can put together another call with folks on the phone and folks that couldn't have made it. Kathy, I know that this would obviously be very interesting to you to hear this. But is what you are asking, that CMS, Deidra and Fred and Kathy, perhaps with our help, Deidra, we can talk how you want to do this. That they would come back and say, "Here are examples from five or six states on how they make the determination of absence of relief to the caregiver."

Kathy Kelly: That is right. When, what would be the trigger for...

Susan Reinhard: What is the trigger?

Kathy Kelly: Right. I think that "trigger" is the word I keep using, but...

Susan Reinhard: OK. So what you are asking for is at least for now, what is happening? To your point, Bruce, sort of what is out there in the field right now? I know it has been studied for children for years and I don't know if folks at CMS have access to those studies. But we are asking right now in the waiver, and I think we should do DD, MRDD. We should do A&D waivers, sort of a cross section. How exactly are they operationalizing this?

Now Kathy, once you had that, how will that be helpful to you?

Kathy Kelly: Well, I think it would be helpful to see how much information, if any, is being collected on the family caregiver. I mean that would be enormously helpful. It may, I just think it interesting that we have a fair amount of programs that are already providing this and so again, coming from the guidance from CMS, are we going to break out of the box, so to speak? If there is no information, or very little information, are we going to suggest that actually in terms of chronic care, that chronic care be viewed in a family systems approach or is that not going to be amenable? Should we color more within the lines?

Susan Reinhard: Deidra, do you hear what she is saying?

Deidra Abbott: Absolutely.

Susan Reinhard: Another point I wanted to raise, Sharon you are still on the phone?

Sharon Kernan: Yes.

Susan Reinhard: Oh good. Sharon and I talked earlier this week and I have actually shared that discussion with Kathy on my cell phone on the train getting interrupted. It was the need for some grantees to survey or the desire of some grantees to survey their current beneficiaries. Sharon, my question to you is would that be helpful to know how other states are assessing the need for respite services or the trigger, as Kathy had summarized it? Is that what I am trying to get to?

Sharon Kernan: I think the survey that I mentioned to you; our thoughts on that matter were to have a survey of the current beneficiaries, which in our state is about 400 families.

Susan Reinhard: Is it more about satisfaction of services?

Sharon Kernan: Yeah, satisfaction, availability, yeah. How satisfied are they? What else would they like to see? But certainly we would also like to know what other states have done, if they have done any similar types of efforts to assess satisfaction and also what they have done to try to address quantification of unmet need and what people would like, etc.

Susan Reinhard: All right. Is there anyone on the phone, especially folks from Maryland? I know you have done some provide surveys, but does anyone on the phone, have you conducted any such survey of satisfaction?

Annette Snyder: This is Annette in Baltimore. Not for respite services, but the thing we are looking to do, because our respite programs are so fragmented and varied here is to just do a provider survey to understand what the various providers are requiring of their vendors or the people who provide respite services. The family part of that would be to understand families (unclear) to acquire those services. We are understanding that there is a shortage of quality providers is one of the main barriers our families are facing.

Susan Reinhard: OK. Well great. I have one last question. That is on our call; I don't know now whether it was a month or two ago about how we might be of help. There was a suggestion, Kathy it might have been you who suggested that we have a list serve and so I would like to raise that with folks on the phone now, now that we have more questions rather than answers, but a lot of good dialog. Would that be useful to you?

Unknown: I think it would be a good idea.

Susan Reinhard: OK. So Nirvana will set one up?

Nirvana Huhtala: Sure, I can set it up.

Susan Reinhard: OK. Folks at CMS would probably like to be a part of that?



Deidra Abbott: Yes, please. Thank you.

Susan Reinhard: Great, great. Any other questions that anyone wants to raise or issues they want to raise?

Unknown: Just would like to underscore the point made by the gentleman from Arkansas who had indicated that there had been all this research done by the Agency for Children, Youth and Families. It still exists, by the way. I was just down there a couple of months ago.

Susan Reinhard: Oh good.

Unknown: I told them to talk to CMS about something we were doing with therapeutic childcare, but that is another story. I would underscore that someone from your agency should call them, talk to them or get on some kind of communication with them about the information they have about the impact of the kinds of things that were done for a number of years and the research that was done. Otherwise it is wasted in terms of public policy.

Susan Reinhard: Yes.

Unknown: If you don't do that, you are going to be making a very serious mistake.

Unknown: I would definitely agree. Is there any way you can help us kind of target someone to talk to?

Susan Reinhard: Do you have a name that you have been talking to?

Unknown: The gentleman?

Susan Reinhard: Uh huh.

Unknown: The gentleman from Arkansas was the one who said that...

Susan Reinhard: No, no, I mean does anyone have the name of somebody...

Unknown: Not on me but I recently spoke to the Deputy Commissioner.

Susan Reinhard: Great.

Unknown: I can give whoever that name, if you...

Susan Reinhard: All right.

Unknown: That would be great.

Unknown: Who shall I give that name to?

Deidra Abbott: Why don't you share it with me, please, if you don't mind? Deidra Abbott.

Unknown: How can I get a hold of you, Deidra?

Deidra Abbott: Let me give you my email address.

Unknown: All right.

Deidra Abbott: It is [dabbott@cms.hhs.gov](mailto:dabbott@cms.hhs.gov).

Unknown: I have the name downstairs. I just don't have it with me. I will send you her name and I will cc a copy to here and she knows who I am because we talked about her talking to you about another issue so perhaps you can talk about both issues if you get her on the phone.

Deidra Abbott: That would be good. Thank you so much.

Unknown: You are very welcome.

Susan Reinhard: Who was that?

Annette Snyder: This is Annette in Baltimore. We had sent in five questions and I think...

Susan Reinhard: I was just going to raise that. There were five questions that Tom sent along with the folks on the phone and Fred, my assumption is you are going to answer them?

Annette Snyder: I think three of the questions have been somewhat addressed by our discussion today because we had the same question about we are addressing the individual with the disability or the caregiver so that helps us a lot because the question regarding state plan versus Medicaid service, we have addressed from. Two of our questions had to do with the target population and just how others were defining that. Is that more financial eligibility criteria that you are using or a categorical one in terms of the type of the disability?

Unknown: Annette, I am working, I think specifically we use the term "severe disability"?

Annette Snyder: Yes.

Unknown: I am sorry. I didn't hear you.

Annette Snyder: Yes, that was one of our questions because that term "severe" came up later in (unclear) than earlier.

Unknown: Right, right. I can tell you, at least from the CMS perspective, we are not limiting your ability to target. It truly is wide open. Why we made the reference to "severe" is we were trying to make the distinction that we are really looking at children who have long-term care

needs. So by using that word we were hoping that at least made that determination much clearer. If it didn't... (*Laughs.*)

Annette Snyder: It did, it is just that we didn't have that word in our initial deliberations. I think we have actually come up with a target group at this point, which is different from our original thinking because we were going to take a really broad, more across agencies and have children with different kinds of disabilities but I think now we have decided on the severely mentally disabled child.

Unknown: OK. And you are OK with that approach?

Annette Snyder: If that fits what CMS is thinking on target population, yes.

Unknown: It does. Again, we were really just trying to make the distinction that what we were looking to in terms of the demonstration with that, these really should be children targeted. The program should be targeted towards children who have long-term care needs.

Bruce Whitten: If she is looking at only the mentally disabled, she is losing a lot of physically disabled children now.

Unknown: She is, but I think it is really their call to make if that is the target group that they want to focus on.

Bruce Whitten: Well true, but.

Annette Snyder: The point was to pick a target group that we could do a comprehensive evaluation and demonstration with with the idea of expanding it to other groups of children later.

Unknown: Again Annette, that really is your, within your purview to make that determination.

Susan Reinhard: But CMS folks here are saying that your update to the version of the 2005 New Freedom Initiatives is CMS accomplishments. That is where I think it was noticed that the Respite for Children Program is now described as "respite services to children, to caregivers of children with severe disabilities."

Annette Snyder: Correct.

Susan Reinhard: You mean that intentionally and the folks from Maryland are OK with that?

Unknown: Yes.

Susan Reinhard: Does anyone else on the phone, especially those who are respite for children, any questions about that? OK.

Anything else from you guys from Maryland?

Unknown: Annette, would it still be helpful if we tried to put some of this in writing for you?

Annette Snyder: I am sure it would since all of us aren't here to listen. My understanding of the other three points we had though, which we have discussed today, is that there is a lot of latitude that we have in terms of how we include the caregiver in our definition of respite and in the process that we use for the demonstration.

Unknown: Correct. And we can just verify that in writing for you.

Susan Reinhard: You know, I am glad you raised that again because one thing we did not talk about but it is in the grant proposal is it can be non-Medicaid services too. You could be including state-funding sources as well, other state funding.

Unknown: OK.

Susan Reinhard: I just wanted; CMS, you are still OK with that, right?

Unknown: Right, thank you Susan. That is a good point.

Unknown: We have one more question. The children didn't have to be currently Medicaid eligible or SSI eligible? They could be outside of those target groups.

Susan Reinhard: All right, but the state would be funding them, not on Medicaid dollars. Is that correct CMS?

Unknown: Yes, that is correct.

Unknown: Even if we were fashioning it as a Medicaid waiver-type program with maybe an extended income eligibility?

Unknown: If it is fashioned as a Medicaid; let me back up. I think what Susan's point was that was in determining the funding source, you can use a number of different sources available to you such as state funding. Susan, is that...?

Susan Reinhard: Yes, yes. But I think now Maryland folks are saying, "But could you have children in the target population that are not SSI eligible currently?" They are not currently Medicaid eligible. In a waiver context, I assume you can make it 300% of SSI?

Unknown: Yes. By virtue of the fact that they are on the waiver, they therefore would become Medicaid eligible.

Annette Snyder: It could be a waiver that we don't currently have?

Susan Reinhard: Right, but you'd be doing the feasibility study to have such a waiver.

Annette Snyder: Yes.

Sharon Kernan: Could I clarify? This means that we could; this is Sharon in Rhode Island. We could propose that we would have a waiver that would have higher income limits?

Susan Reinhard: That is right.

Sharon Kernan: Than currently exist, but we can't, could we propose a program that would have a combination of the target population would theoretically include children who aren't going to be eligible for Medicaid under a waiver or anything else and somehow we design a program that had a waiver, Medicaid funding and also state funding?

Susan Reinhard: That is right, but basically that wouldn't be a waiver. But it could be seamless. It could be consistent.

Sharon Kernan: I don't think we are going to do that. I just want to clarify.

Annette Snyder: I think that; this is Annette in Baltimore. I think if part of what we were thinking, that we wanted to include the category of children, that all those children would be part of the program but dependent on their status, their caregiver status, the recipient status, they might receive funding from one source or another, even contribute more that would be seamless to them in terms of they are eligible for the program. It is just how the funding, how can you get paid for them?

Unknown: That would be the difference. Yes, you could do that as well.

Susan Reinhard: Great.

Jane Laciste: This is Jane Laciste in California. I have to sign off. I have another call at 1:15.

Susan Reinhard: Thank you. I thank everyone. Did you have a last-minute question?

Jane Laciste: No.

Susan Reinhard: Well thank you for joining us.

Jane Laciste: Thank you.

Susan Reinhard: I think everybody probably needs to leave. Is there anything immediate? CMS, do you want to add anything?

Unknown: No, just again thank you all for the opportunity to talk with you this afternoon. I think it has been a good call. Lots of good issues were raised.

Susan Reinhard: Me too and we really appreciate your time on this and for all of you to join us today on a pretty busy day. So thank you.