AARP SOLUTIONS FORUM

LONG-TERM CARE REFORM: TRANSITIONING TO HOME AND COMMUNITY-BASED SERVICES

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SUSAN REINHARD: It's really great to see so many people who have such an active history in long-term care. And I mean that, history. There are some of us who have been doing this for quite some time. But – and to see the networking. So we're sorry to stop the networking, but you came here for a reason.

For those of you who I haven't met personally, I'm Susan Reinhard. I'm the senior vice president of the AARP Public Policy Institute and I direct a wonderful group of staff members who I'm going to introduce a few of them in a moment. It's really great to see you. Some of you I saw this morning. This is turning out to be the long-term care day in Washington which, again, those in the field just think is fabulous. We haven't had a full long-term care day in Washington for a while.

The Brookings Institute had a forum this morning and I did a little sneak preview of the report that we're going to be discussing today since I had a captive audience there including Mark McClellan, who got a copy of it. But this is the official solutions forum. I just want to say a few words about this. This particular AARP solutions forum is intended to discuss policy options to promote home- and community-based care for people, particularly for older adults and younger persons with physical disabilities.

But I just wanted to mention, it's our third AARP solutions forum, something that the public policy institute has developed in collaboration with many of our colleagues within AARP as a way to bring together thought leaders, policy-makers who are thought leaders, and stakeholders together to consider options for solving some of the most pressing issues that face all of us as we age and for people of all ages in the United States.

Previous forums have included ways to encourage private retirement savings and options for containing the rise in healthcare costs. That was just – that was on the day – that last one was the day when the electricity went out. (Laughter.) So that was a particular challenge, but we did pull that off.

On Monday we're going to host another AARP solutions forum so, please, anyone who sees any staff members of AARP, give them a hug because this has been, you know, back to back around a weekend is a little bit tough. That one is going to be focusing on policy options for fiscal stability and economic security. And in the fall, we're going to have another. We're going to continue this work on solutions forums on key aspects of healthcare reform, the foreclosure crisis, and several other issues.

So I want to first acknowledge those who made this particular solutions forum possible beginning with Enid Kassner, who is in an appropriately red suit. (Laughter.) Isn't that great? (Applause.) Enid is the director of the public policy institute independent living and long-term care team. Rick Deutsch, who has been wandering around – there he is – is the public policy institute – (applause) – director of

communications and outreach. And I really have to give Rick credit for conceiving of this idea of how to bring people together and have these kinds of very rich discussions. So I do want to publicly thank him.

And there are a lot of other public policy institute members here who have been involved, particularly Rita Chula (ph), who is probably not in the room. She's the one who says, go and eat, now sit down – (laughter) – really terrific. I tease here because she, in her former life she has a bachelor's degree in computer science and she is a former vice principal. So every once in a while we talk about how we have to have "time outs," you know. (Laughter.) She's just terrific.

So I want to also tell you how the day is going to proceed, or this afternoon is going to proceed. First, I'm going to present the findings – oh, there she is; there's Rita. Thank you. I want to present the findings of the public policy institute report, which we are releasing officially today, although people who have been working on this have been working on it for quite some time very diligently and it's called, "A Balancing Act: State Long-term Care Reform." It shows the progress and, in many cases, the lack of progress that individual states are making to refocus Medicaid to provide more home and community-based services for older people and, again, younger people with physical disabilities. It also discusses national trends. So we're going to focus on both in this panel.

Then I'm going to moderate this panel that includes leaders from two of the states that we found particularly interesting. You know, we talk a lot about the top four states that have more than 50 percent of their Medicaid dollars going to home- and community-based care and I'll say some more about that. And then there's another group of three, I'll call them, that spend more than 40 percent. And then there are these two states that are right there, right at the edge tickling that 38 and 39 percent. (Chuckles.) So you don't often hear about Idaho and maybe a little bit more about North Carolina, but we're very interested in having them share with us how they're doing it, and then a national expert who will be talking about her reactions to this. And I'll introduce them in a moment.

And then we'd like to engage you in discussion. So this is intended to be as informal as you possibly can make a discussion in a room full of 150 or 175 people, especially when it's being videotaped. So I do want you to know that it's videotaped. There will be video clips and a full transcript of these proceedings available on the public policy or the AARP website next week. So let me start with the report.

Well, maybe I will introduce our panelists first. How would that be, because you should know who they are before I get going. First – I'm going to start over here – Leslie Clement is the Medicaid administrator for the Idaho Department of Health and Welfare, where she has been intricately involved in significant reform policies. Prior to her current role, Leslie served as Governor Kempthorne's long-term care policy advisor during his chairmanship of the National Governors Association. And we were reflecting that was where I first met Leslie, she was pretty active as the Medicaid director under

Kempthorne, as you can imagine. She is no stranger to the national audiences and we're very pleased that she has accepted our invitation today.

North Carolina is the other state so let me just turn to them. You know, first of all, to see an aging director – (laughter) – and a Medicaid official from the same state, sitting here together, eating together, breaking bread. This is great! So they are forging relationships as we speak.

Dennis Streets is the director of North Carolina's division of aging and adult services. He has devoted his career towards working in the field of aging and adult services and has also an interesting background in the private sector, which I'm sure he brings into this work that he does. He was the executive director of the Evergreens, Inc,, a non-profit long-term care organization, as well as being a professional relations representative with BlueCross BlueShield of North Carolina. So I guess you know how to craft messages. That's a good thing.

And Tara Larson, to his left, is the chief clinical operations officer of the division of medical assistance for the North Carolina Department of Human and Human Services. Tara has over 28 years of experience in the healthcare field. She has both research and policy expertise which includes quality management within the public sector, consumer-directed support, and healthcare issues in Medicaid. And she has served as a practitioner, a clinician, and an administrator at both the state and local level. So she brings all of those talents together.

And here to be our national respondent here is Donna Folkemer, a very good friend and colleague for many years. She serves as the health group director at the National Conference of State Legislature. She manages NCL's forum for state health-policy leadership and oversees the work of forum staff on the health chairs project, which is a very interesting way she brings all of the health chairs from all of the different seats together. And it's really quite an opportunity to share what's going on across states. She has worked in state health-policy positions for over 30 years, has experience in the Medicaid program in D.C., and you can finish reading more about all of their bios in a moment.

But first let me then turn to our report, which you have in front of you and I'm sure you have digested along with your food because it's such a short report. (Laughter.) I want to acknowledge the coauthors again, Enid Kassner – and they're not all here in this room, so I will read them, but please stand when I read it: Wendy Fox-Grage is here. I think many of you know her. (Applause.) Ari Hauser – there's Ari Hauser. Great. He's getting his Ph.D. in statistics, very serious. Jeane Accius is not here and Barbara Coleman and Dan Mill, who are the consultants to this project I believe also aren't here. Is that right? So please, when you see them in the future, thank them for the great work that they did.

We did this – oh, I should also acknowledge our national advisory committee. They're truly experts in the data they gave – our help in the data we used, the

methodology we employed, and the very topic of this report. I'm not sure that any of them are here except for Donna, who is one. Brian Burwell, Lisa Alecxih, Bob Mollica, Charlene Harrington, and Charlie Reed. Are any of them here? But you all know them. If you're in this field, you've heard those names so, again, we thank them for their help.

We very humbly believe that this report is groundbreaking. We say that with quite a bit of enthusiasm and sincerity because it is the first time we report Medicaid long-term spending and the number of older people and adults with physical disability served with the Medicaid long-term care dollars.

We pulled these populations out from the hole. So normally, when you see these statistics on balancing – and we can talk about whether you call it balancing or re-balancing and how you want to define that, but – this is a sophisticated group so I'm going to sort of pass by that. But we – usually you see that with all populations in long-term care. We pulled out older adults and younger people with physical disabilities from those with mental retardation and developmental disabilities. So in the bureaucratic world, we say MRDD, you know. You all know what that is.

We pull them out and looked at that again for each state. And each state has a two-page summary which took a great deal of work and the people who did that work are in the room; I didn't do it so I acknowledge them on that work. But we did it because we believed it would help us better understand what's going on in states. It is – we believe that the people, the populations who we're serving, those with MRDD, have really shown the way. There's more progress in that population than there is for our older adults. And so we think that this kind of scrutiny could be beneficial to all.

I want to draw your attention to four key findings in our report and so when you go home and read it, make sure you look for those four key findings. There's lots more there, but these are the top ones. First, you could look at this as the glass as half empty or the glass as half full. Now, the half empty – maybe it's a quarter empty; I'm not sure – but the part that's sort of empty is that for adults with physical – I mean, again, older adults and those with physical disability, we still have 75 percent of the dollars going to nursing homes, to institutions.

Now, that's really not a good thing. That means only 25 percent is going to home- and community-based care. So across the country, only one in four Medicaid dollars is spent on home-care options, which includes assisted living, adult foster care, other kinds of residential care. We know from AARP's surveys and other surveys from around the country for years that this is not the preference of consumers. I don't think I have to persuade anyone in this room to believe that that is so. And, actually, this is an improvement over the years. It's not as if we've been standing still. But, really, still, only 25 percent going to home- and community-based care.

So that's the kind of downside of the news. The good side of the news is that when you look at the numbers of people served, we have made progress because, you know, every dollar spent on home- and community-based care gets you more service.

You can serve more people for every one of those dollars. So every shift helps in terms of the numbers served.

The nation has made considerable progress. There's been about a 40-percent increase in the numbers of people served over five years. From 1999 to 2004, the number of home- and community-based participants increased in 43 states. There's only seven where it did not increase. Actually, it declined in seven states.

But another interesting part of this is that roughly half and half, half the states have seen a decline in nursing-home use and half have seen an increase in nursing-home use, at the same time. So that's kind of interesting, too. So that's the first point.

The second one is, we can do better. Almost two-thirds of the states spend less than the national average, which is 25 percent of their Medicaid long-term care dollars, for home- and community-based services. And only one – I should say, one in five, 20 percent of the states, spend less than 10 percent, less than 10 percent. We have states, you'll see, it's 1 percent, 2 percent. It's really not a good situation when you really look at that across the states.

So that leads us to the next finding, which is, again, good news, that balancing is doable. We are impressed by the success achieved for the population of MRDD, people with development disabilities. I've noted that, for an older adult, it's 75 percent is going to institutional care. In the developmental-disabilities arena, it's only 39 percent. So 75 percent versus 39 percent with DD. So the MRDD population has achieved a 60/40 balance, meaning 60 percent in home care and 40 percent in institutional care.

We haven't achieved that. We have 25/75 for older adults, really tipping the scales in the complete opposite direction for that population. But the progress that's made in balancing services to people with developmental disabilities is quite optimistic. We feel very good about that. And I don't mean to say that 60/40 balance for people with developmental disabilities should be the end, either. There are states that have – are spending 98 to 100 percent of their dollars in the community for people with developmental disabilities: Michigan, New Hampshire, Oregon. It's doable. That's the point.

We didn't think that was doable years ago. I think even 10 or 15 years ago, we didn't think it was so doable to shift even to where we are now. It is doable and the states that are up here will tell us more about how to do that. There are a handful of states. I've mentioned four that are over 50 percent: Washington, Oregon, Alaska, New Mexico. Those are the ones you often hear about. And then there's three more that are over 40 percent: California, Minnesota, Texas, and then these two: North Carolina and Idaho. So they are showing the way.

The other thing is, when you look at a state like Washington, I was just discussing this morning, it's not, again, the percent; it's also the people. So in Washington, 54 percent of their dollars are spent on home- and community-based care. That means that

more than 70 percent of the people are receiving services in home- and community-based care. So that – it can be done.

Fourth, and finally, my point is, it's about the pace of change. And it's something we were talking about earlier when I first came to AARP about a year ago. You know, how are we doing? Someone once asked me that about a – it was the Pew Foundation. So how we doing? What's going on and how fast is – are we going fast enough? That was her question. So that kind of got me into this.

The proportion of long-term care Medicaid spending is going up in home- and community-based services about a percent a year. And Brian Burwell has been telling us this for years, that the he analyzes the – (inaudible) – status. This isn't a surprise, except when you really think about it. So what does that mean? One percent a year and, of course, it's not 1 percent in every state; it's on average. So 1 percent a year. How long would it take us to get to 50/50, assuming that is even the right balance? Just assume for a moment that's what you want. So our staff looked at that and we have a nice little chart in here for you that I hope you spread all over the country; it would be great. Feel free to use this. And it would mean that it would take us to 2020, 12 more years, to make a 50/50 balance, still not even approaching where those with developmental disabilities are.

So we'd like to see that accelerate. We think we could kick that up a notch or two and the people in this room, we hope, are those that can help us do that. So some next steps – first, we do think we should be accelerating this, that people should have choices. And that idea of increasing access within Medicaid we consider part of phase one in something that is also in your packet. It is called the long-term care framework or framework for long-term care reform, which is part of a bigger document that AARP has been developing on a vision for ensuring health and economic security for all. So this is one part of a larger vision that AARP has been working on for quite some time. And we're just releasing this particular document today. But, again, this is only phase one. There are other phases that we talk about within that document and many different ways of achieving that vision.

Second, we need to reduce the barriers to balancing. We think that change – this pace could be quickened by – supported by federal and state policies that do a couple of things. And I know we're running short on time so I'm not going to adopt all of them, but I am going to show a few, one of which is the adopting nursing home diversion programs.

This is something that is capturing more of the attention. I think some of our folks on the panel will talk about it. The U.S. Administration on Aging has grants out there. I believe a second wave of grants is perhaps available. And CMS, the Centers for Medicare and Medicaid Services, has a grant out for hospital discharge planning that could be very helpful in this regard. So there is federal action. There are opportunities here. We need more and more of that.

Eliminating waiting lists for home- and community-based care – I think one of our panelists may address that, offering a range of residential options. Supporting family care-givers – AARP is – I am personally totally committed to this idea of supporting family care-givers, to have more of a patient- and family-centered care going on.

And I think I'll just mention one more and that is exploring, offering states financial incentives to accelerate the pace of change, in other words, increase FMAP to those states that are showing some progress and really push even harder, reward them, look at what they're doing and see how we can really focus, target on those states that are moving furthest as quickly as we can.

So those are just a few points, hopefully the major points, of the report that we have before you. And now I'm going to turn to our panel to ask them to comment to us. So I think I'm going to start with Idaho. Here we are, Idaho. So when you look, you can flip if you want, if you have it in front of you, to look at what Idaho has been doing. What struck us – after we did all of this analysis, we had no preconceived ideas, we pulled it out and we said, wow!

What's going on with Idaho? (Laughter.) It's not a state that you often hear about, you know, and I had met Leslie before and she's really terrific, but what are they doing? They have tripled the number of people served in home- and community-based services while the numbers of people you're serving in nursing homes has remained almost flat. So our question, obviously, is how did you do this? How did you move along this pace of change?

LESLIE CLEMENT: Well, I first have to say that I'm absolutely delighted. It's seldom that Idaho ends up in the top 10 of anything. (Laughter.) So this is a pleasure and I had to make sure that I got on the plane and flew across the country for this. So this is exciting.

There's some real – there's a couple of real simple reasons why we've had the success that we've had. One is, I think it's interesting that the states that are at the forefront of home- and community-based services are Western states, for the most part. And I don't think you can underestimate kind of what that means in terms of the people that are out there. And they are very independently minded. They are very opposed to institutional care. So that helps with the mindset and the framework.

The other thing that we did in Idaho was really simple and that is, we never instituted a waiting list. And I know that I – you know, my partners in the advocacy world speak across the country and say that folks are literally astounded that we've done that. But we think that's the right decision. You put a waiting list in place, you create a barrier, and because of the entitlement in nursing homes, they slip right into the nursing home. So we didn't ever want that to happen.

We have done a few things recently that have helped. We have forged partnership with our folks on the aging side, although we administer the waiver itself.

We partnered on the ADRC grant and we created a program called "Aging Connections." And that really is a very proactive effort on our part not only to say, hey, if you are at the point of needing long-term care, the home- and community-based alternative is a good alternative for you and help expedite the eligibility process, but also those that may be able to live independently and not have Medicaid. So it can – it provides us with an avenue of being proactive.

MS. REINHARD: You just said something about people who aren't on Medicaid. Can you say a little bit more because this report is about Medicaid because that's the data we're looking at? But we know we need to do more than that.

MS. CLEMENT: Well, I think under Idaho's modernization effort, what we said is, you know, Medicaid is just a part of the overall system. And you can't ignore that, you know, if we wait until everybody gets on Medicaid, your opportunities are less than if you expand and look beyond that. So the Aging Connections program really is a great opportunity for us to inform Baby Boomers, to inform people before they hit a crisis about what are some options.

What can they do to take control of their own lives and their own destiny and make informed choices, because I think one of the things that we've seen, I guess, as we all – and I know there's a mix of ages in this audience – but more and more of the Baby Boomers are experiencing things that are happening with their aging parents. So we're learning individually what that means. And I think it's an opportunity for all of us to start saying, okay, so you've got some time here. What do you want to do? And I haven't met anybody who says, I want to go to a nursing home. (Laughter.) That is not anyone's first choice and I think we need to build to that.

MS. REINHARD: So it sounds – if you have no waiting list and you're starting to let people know they have options, then maybe you're at the balance you should be at in Idaho. Or do you think you should be moving more?

MS. CLEMENT: Obviously, opportunity for improvement. I think that one of the biggest barriers in our rebalancing effort has to do with costs. The fact of the matter is that, you know, nursing homes are an entitlement and their full costs are recognized. So when we negotiate our rates with a nursing home, it's based on everything. And it's on a prospective-payment basis. And all of those infrastructure costs are there. When we go to our assisted-living providers, when we go to our family homes – we have certified family homes in Idaho – all we can pay for are the direct service components. We can't pay for that room and board. We can't pay for that recreation. We can't pay for all of those things that are a part of what you see in nursing homes.

So that's a huge barrier and we're at the table right now with assisted living providers who are saying, we're not sure we can take anymore Medicaid folks because you don't pay us enough. And they're saying, you don't help us pay for the lobby, you don't help us pay for the whole meal preparation and purchasing stuff. So the imbalance there – there's a real reason why home- and community-based services in Medicaid cost

substantially less and that's because those costs are not recognized and we have to address that.

The other thing we have to address is we have to address the federal law. It was so excited in the Deficit Reduction Act when they said we're going to have home- and community-based services be a part of our state plan. Great, we don't have to go through all that administrative bureaucracy, doing waiver application, and proving they're cost-effective. We know they're cost-effective. Put them in the state plan. Well, they put them in the state plan and they didn't align it with our current waiver eligibility. So and they dropped services. So when we looked at it, what that would mean for Idaho – instead of a step forward, it would make us drop one-quarter of the people that were on our waivers to put them in the state plan home- and community-based services program. So we need Congress to fix that and that would be a big change.

MS. REINHARD: Okay, well, great, thanks. Let me turn to North Carolina for a moment and we'll come back to you, Leslie, so don't get too comfortable. (Chuckles.) So now, if you have it in front of you, you can flip to North Carolina if you really like – if you're really data-driven – kind of you can look at this. And also, North Carolina has been holding relatively constant the numbers of people in North Carolina and has made significant progress in increasing the percentage, dollars, as well as the number of people served. So I thought I'd start with you, Dennis, to just give us a little background because North Carolina has been doing this bit by bit by bit, but constantly moving forward. So how's that happening?

DENNIS W. STREETS: Thank you, thank you, Susan. Welcome, from North Carolina. I wanted to start with saying that it is a work-in-progress. And I think it's important to give a little bit of a historical note here and we've provided you, as a handout in your materials, a lot more than we're going to have time to talk about this afternoon but it included a reference to some general statutes.

Dr. Ellen Winston was actually the first, I think, the first U.S. commissioner of welfare and before then – that was in 1963 – before then, she was actually the commissioner of welfare in North Carolina back in 1944 and we were fortunate that she was a North Carolina native. So she returned to North Carolina and was actually head of our Governor's Advisory Council on Aging between 1977 and 1984 and it was during that time that you'll notice in the materials, that our General Assembly, in 1979, put forth a statement of principles and then in 1981, a long-term care policy.

And that has served as sort of the backdrop, the foundation, the platform for, I think, how we proceeded, incrementally, for sure. Such things as recognizing, back in 1979, that older people should be able to live as normal a life as possible, the importance of transportation, the importance of service coordination, the importance of providing access to information on all services, the importance of when you're planning, that you do it with, in addition to for, the older population, and that the state should aid older people to help themselves and also encourage families into caring of their older members.

If you go on to 81, again, those – that same sort of recognition and this statement that the General Assembly further finds that the public interest would best be served by a broad array of long-term care services that support persons who need such services in the home if – excuse me – or in the community and that the General Assembly finds that as long-term care options become more available, the relative need for institutional care will stabilize or decline relative to the growing aging population, still recognizing, though, that the nursing homes, the institutional side, was a critical component of the long-term care continuum. It was though that kind of recognition back in 1979 and 1981 that again, I think we've been able to build on.

We did try to play off the idea of the balancing and showed you in the materials three scales. The first is sort of our current status and a large part of that is in fact in the late '70s, North Carolina did adopt at the federal, really, requirement a certificate of need on nursing homes. And then, in 1987, the federal law was repealed. But North Carolina kept that statute in place and has kept that certificate of need for nursing homes.

And today, I think that has – relative to the nation, we have a lower bed count in nursing homes. And we also have a higher acuity level for our population. You can look at incontinence; you can look at dementia; you can look at impairment visually and number of medications – all higher than certainly the nation.

At the same time, we've worked in partnership, the aging and the Medicaid sides and others, in terms of offering the Medicaid waiver for a number of years. And Tara will talk more about that as well as personal care service as a major, both in the community and also with assisted living. We are also fortunate in North Carolina in having the general assembly strongly support our home and community care services for the non-Medicaid, that near-poor population. And we serve a very socially and economically needy population. More than half of what we call our home and community care block grant funds are Older Americans Act, but also a little bit of Social Services block grant and state appropriations. More than half of that block grant are state appropriations.

We also feel very strongly about the family caregiver support and so what we've been able to do not only with the Family Caregiver Support Program but also Alzheimer's support and otherwise supporting family caregivers. And then the advocacy of our senior groups, our senior Tarheel legislature – I see Mary Bethel from our State chapter of AARP – and the recognition, the importance of, again, having the communication and collaboration among all the agencies who have some hand in long-term care.

As you would move forward, you'll see that we've – through all the acronyms that our listed in the 2nd graphic here – as we begin to balance a little bit more, we've seized on the opportunities made available through the administration on aging and CMS and others to try to use, infuse into North Carolina some of these aging and disability resource connections: the support for the nursing home transition, chronic disease self-management and so on. And then, as we would move ahead in hopes of actually again

moving that balance, that scale forward is to look at other things such as Project 2020 which is an initiative of – it's in some ways outlined in the New Order Americans Act under choices for independence but the National Council – excuse me – the National Association of State Units on Aging – Martha Roherty is here – and the National Association of Area Agencies on Aging putting forth the importance of, again, looking at the near-poor population in a way that will try to divert, as you were saying, before they are on Medicaid and the options are more limited. I'd like to come back to that at some point.

MS. REINHARD: Okay good. So Tara what have you been doing?

MS. LARSON: Whatever Dennis wants us to. (Laughter.) Actually one of the points that when I joined the Medicaid agency it was to grow our community services and it was a very – it was one of our first goals that we wanted to achieve. And it was the adoption as a Medicaid agency the philosophy of person-centeredness, family focus. And that was a very different philosophy that our agency had operated under for many, many years.

I had the pleasure of actually managing our MRDD waiver for many, many years and we were not even a bleep on the radar screen at the Medicaid agency when we came to being. I mean we were a very small part of that budget and that budget is now in the top six expenditures of our Medicaid budget, which, if you're in the Medicaid you're going "oh," if you're on the advocacy and in the program and clinical side you're going "yes!" (Laughter.) You know, so that balance.

And now that I'm on the Medicaid side, it's like, okay, which hat am I wearing today? But I think it's important from the Medicaid standpoint to recognize philosophically that it is a culture change. It is a huge culture change. And to recognize that it's very – I say easy to ride a wave or to ride a service definition. We have to do that in partnership with our advocacy groups, with our stakeholders, with our families and our consumers, and also with the industry and with all our partners because it is not – if we don't have everybody at the table, you're going to make someone upset. And to act like the economics and politics are not part of that culture change will actually backfire and will slow the process down, as you try to grow the infrastructure and you try to grow different parts of the budget.

We recognize that our waiver, our HCBS waiver, and for people who are aging, hasn't really been changed in about 20 years. It's been tweaked; you know, allowables went up and service definitions may have gotten tweaked. And so we are undergoing now a total redesign of our waiver, looking at adding many, many different kinds of services. We've just finished our road-show, a town hall across our state – in many different parts of our states to listen to families and consumers about what would it take for you to live with dignity and age in place, in your choice, your residence of choice. And I think that's important because, you know, we were talking earlier, Dennis and I were talking – it's okay, and I say that with quotations, to fall in a nursing home; it's not

okay to fall at home because that means you need more supervision and you got to go to a nursing home.

Something's wrong with that. It's about what do you do with health safety, what do you do about choice, what about my dignity to make that choice and to have risk. And so that's – it's a culture change as well as a programmatic change. You know, writing service definitions, we all can help write the definitions. The Medicaid agency, our job is to make sure that yes, we meet all the CMS guidelines, but we have to partner with our clinical and our programmatic partners.

You know, Dennis's folks are the aging experts. Of course, we have people in our agency as well who are the experts, but we within our department – and we actually have a huge department with North Carolina Health and Human Services that have all the various disability and social services and human services agencies under one umbrella – but partnering with Dennis to actually help us design a waiver that meets the long-term plan for people who are aging in North Carolina. We are a funder of those services. We are part of the process, but it needs to correlate with the overall aging plan and not just you either Medicaid and you have everything, or you don't have Medicaid and you have nothing. So how does it fit, and how do we leverage each other's dollars in order to build an infrastructure that's going to serve our families as a whole, and our citizens as a whole?

MS. REINHARD: Thank you, Tara. I'm thinking where's Martha? There she is. So you know, Martha is now the executive director of the National Association of State Units on Aging, a Medicaid expert and now aging expert, so this must be music to your ears.

(Laughter.)

We'll come back to you as well, North Carolina, but I would really like to turn to Donna, as a national expert here. And she thinks a lot about states and I've talked with her a lot about long-term care over the years. She had a sneak preview of the report, so she's had a little time to digest it. What do you think?

MS. FOLKEMER: Well, I'll talk about the report. I first wanted to start out by saying anybody who knows me knows that I used to get up and talk about policy and what's going on. I've realized that – lately, that I do have a lot of experience in this area, and so I really want to start by saying well, we're talking about people here. And I want to say that what all of us hope we can do as we grow older is grow older well, and be able to make our own decisions. My mother's 95 and my father's 91, and my mother-in-law is 94 and my father-in-law's 90, and they're people who I absolutely admire and respect because they're telling me about aging and how it works. And the way they do it is – they've been lucky, of course – but they're optimistic, they're looking to the future, they're thinking about how to solve problems from the perspective of strengths rather than deficits, and they would never for a single minute think anybody should decide anything about their care, especially not their kids.

(Laughter.)

So I really, you know, think about that, having been in this field for 34 years and kind of, you know – you kind of think about what you do at work and then you kind of think about how does that connect to real life out there, and it's only recently occurred to me that, wow, these are very, very old people and they are doing just exactly the way we all – aging just the way all of us ought to.

MS. REINHARD: Well, congratulations.

MS. FOLKEMER: (Chuckles.) It's great.

I think I wanted to, yeah, step back a little bit. I did want to mention the report. I was on the advisory group and I think that probably most of you haven't looked at it yet. I think that one of the things important about it, is it's going to serve as a real important reference guide for a lot of us. We get a lot of questions at NCSL. You know, who has the money – (inaudible) – person? Who's doing nursing home transition and who has these various little grants – and they are in various places, you know, on the CMS website and other places. But I think this report does a good job of putting some of those things in one place, and in a format that's going to be very useful to folks that are trying to look up information. So I want to congratulate AARP for that.

I think – speaking for the National Conference of State Legislators, and I think there are two important things to say. The one would you definitely expect me to say: The National Conference of State Legislators would absolutely say that if we're going to do significant major reform quickly, we're going to have some more federal money devoted to this activity. You know, the creativity that's been at the state level continues. There continues to be a lot of creativity at the state level, as well as creative thinking, you know, at the federal level and among all the groups that are out there working together. But we're going to – you know, states are constrained, Medicaid – people think of Medicaid as an entitlement, yet Medicaid is subject to state budget processes. So states are working within certain constraints. If we look at Medicaid or other state funding sources, and they're certainly working within constraints. You should think about state tax sources. So you'd expect me to say that.

But the other point I want to make – and again, no surprise, I think, to anybody – there is strong bipartisan support for strengthening community-based care, for giving more controlled consumers, for giving more options and choice to consumers, to changing the system in that way. So there's strong bipartisan support for that, which doesn't mean at all that it's easy to do. But you know, there are a lot of issues out there on which there is not bipartisan support. There are a lot of issues out there, even in the healthcare arena, where there are – perhaps especially in the healthcare arena where there's not bipartisan support. So I think that's important to keep in mind and think about.

The other question Susan asked me about was how to legislators come to us, how does the issue of long-term care come to us at the National Conference of State Legislators. And the answer to that is you name it, it comes to us that way. I was – we often get calls from legislators, sometimes their staff saying some of my constituents are caregivers, they're having trouble; I'm a policy-maker, I need to do something about that. What can I do? We have people come to us and say our Medicaid budgets are going crazy – and we think a lot of that is because we're spending too much money on the wrong things – and what can we do about that. Again, these are all questions that have challenging and not sort of a magic-bullet answer and not a single answer.

So what we try to do at the National Conference of State Legislators is let states know about what other states are doing. Again, this report helps us in that regard, but you know, people will say does anybody have a broad-based 1115 waiver on this; oh yes, Vermont has such a thing, you know. (Laughter.) Has anybody thought about this from a county level and a per-person payment? Oh yes, Wisconsin Family Care. You know, so you could talk about some of these things. You can find out where people are starting and where they're going.

I think the most important thing we do at NCSL is stay in touch with legislators, try to communicate with them on a regular basis. For the folks that are interested in pursuing this issue, I brought with me a note I got today. I got a request from a staffer in a state, and he – we sent him a bunch of materials and then he sent me a note today, saying I want to tell you about three laws that we passed; one of them is a caregiver law, one of them is a law setting up a long-term care taskforce. I want to thank you for your help; I want to tell you what we've done and I want to stay in touch on these things. I want to stay in touch and get your help, and continue to tell you what we're doing as we go down the road.

So I mean, many of you in your jobs do this, too. I think that – I guess just the point that I'm making here is that we sometimes hear from people who say well, we think state legislators don't understand this topic, don't care about it, you know, don't talk about it. I think the message really is that they do. It's as challenging for them as it is for many of us.

I was also reflecting, going back to when my friend Susie Bostek (sp) and I, back in 1980, 1981, we're working on the channeling project – the really old people in this room know the channeling project – (laughter) – and we thought, you know, some fundamental – I think we thought that, at that point, through our hard work some fundamental reform was around the corner. So we're still, you know – (laughter) – this is an activity, you know, of sort of how we think about long-term services and supports, how we think about aging itself and the transitions within aging, and long-term care services and support fitting into that. You know, this is very much an incremental process.

So let's see if there's anything else I wanted to say. I think that's it for now, thank you.

MS. REINHARD: Well, let me just mention that Donna and CSL in general are entering into a collaboration with AARP. Elaine Ryan, our vice president of government relations and advocacy, has been working with Donna. Maybe you want to say a few words about what you'll be doing?

MS. FOLKEMER: Well, I think, you know, Elaine and I and others are still thinking this through. But I think that the idea here is that we often do have legislators in the states who are interested in long-term care, who are interested in being leaders, and how do we take some of this work that I mentioned, you know, where we're sharing best practices, where we're trying to respond to questions on an individual basis. How do we – I use some of that experience to try to support legislators as they kick some of the best ideas to scale, as they say. And so that's really what we're thinking about and certainly, AARP's focus on community-based care is – you know, certainly is consistent, then, with this bipartisan support that I mentioned, that occurs through NCSL.

MS. REINHARD: So stay tuned. I think we'll have a press release on that any moment here.

Before I turn to all of you to see how you would like to engage with this group, I just want to turn back to the states for a moment and sort of throw out a few questions, and you can pick out whichever one you want. I'll put it that way. One is, is there anything you wanted to say that you didn't get to say; there's that. And then two is if you could have one federal action to support your work, you have some – you know, a lot of people here are inside-the-Beltway people. (Chuckles.) It may be in Congress or on the Hill, or in federal agencies or think-tank people that talk to a lot of other people, so you have a pretty good audience here. What would that be? What one federal action would you be looking for? So anything you would like to say at this point?

MS. LARSON: I'll take that one on.

MS. REINHARD: Go ahead, Tara, okay.

MS. LARSON: I think I would recommend, as Leslie was referencing earlier, making the process simpler. In the hotel room this morning, I was actually looking – we're in the process of, like, rewriting our CAP-DA (ph) waiver, which is our elderly waiver. We're also doing our MRDD waiver. That was a 275-page application that I was reviewing. By the time – and again, part of it's because we have added all these services and a lot of it is a very big process, but there's all these – you know, the cost neutrality and the quality measures, and all that it takes to do a service on the state plan, may be three, four, five pages. So it's a much more elaborate process and I know I am oversimplifying that. But the whole process, I think, if it could be easier and less administratively burdensome because when you want to add something, it's – you're going to get both sides, so I would – not only with the funding piece or how you can actually calculate your costs. So that would be – I don't know if that's all you would like.

MS. REINHARD: Okay, that's very straightforward. Dennis?

MR. STREETS: Mine won't be as – mine's a little more global, and that is that I would hope that we would see a continued support or attention to some major, I think, acts that will make a tremendous difference. One is already authorized, and that's the lifespan respite care act, and so the funding for that, I think, is critical. One that's under consideration is the elder justice act and I think that, for a number of our folks who are at high risk – and where we're trying to make a difference to Adult Protective Services – is critical.

And the third area I've already mentioned briefly, and that's Project 20/20. And I really do think it's a very smart investment. It's a large investment, potentially; I think we're looking at billions rather than millions of dollars. But at a critical juncture where, again, for persons who are really in that nursing-home look-alike or on the verge of nursing home, where we can intervene through critical counseling and information before discharge, or along with discharge from a hospital, also with critical home and community care services; chronic care management, both self-management and general management and then also, again, helping divert people, when possible, from the nursing homes. Those three areas, I think, are critical.

MS. REINHARD: Okay. Dennis, you had mentioned to me – I wanted to make sure you had an opportunity to talk about it – about those – remember those Medicaid regulations that are now under moratorium, particularly case management? Dennis had said something to me and I thought you might want to share it, about how that might have affected you.

MR. STREETS: Well, I think it goes back to the notion of how important it is to see this as a state-federal partnership. And in North Carolina, part of the reason why we look good on the community side is that we do have a large assisted-living industry and where personal-care services enable. But also, that can range from people in two beds up to, you know, hundreds of beds. So one of the things that our general assembly did in 1998 was to allow us to do a demonstration similar to the Medicaid waiver for nursing homes, but this time for assisted living, and we call it the special assistance in-home option. And so we are able to pay 75 percent of what you would pay if the person went into assisted living.

And we've been able to grow that program so that it's now available in 91 counties, but the success of that program depends on targeted case management, is our social workers being able to go in and do a very good assessment to work with the families on a strong service plan, and then work with them on the budgeting and the monitoring of that plan. And it has been very cost-effective in North Carolina. We've looked at a savings per individual of something like 8,500, considering all costs per individual. And so targeted case management has been critical; I was pleased to see the moratorium and I would hope we would see it continue.

MS. REINHARD: It's a sigh of relief. (Chuckles.) Leslie, anything you want to add?

MS. CLEMENT: This is just too simple, but it is about the money; it's always about the money. So you look at the services you have out there and you say why are some services used more than others; it's about the money. So you really have to attack that, and the whole funding issue is enormously important to address and to balance. So we can do some good things, and I was thinking – you mentioned SCHIP at one point and I thought, you know, a lot of these strategies for increasing coverage to kids could be equally applied to our home and community-based services, including simplifying and expediting eligibility processes, looking at effective marketing, looking at opportunities where you can make those connections with community partners. You know, there are very different populations, but they're very similar issues in terms of really getting people into the right services early.

And you know, I guess I would just re-emphasize the intent of Medicaid, I think, is there as a safety net for vulnerable individuals. And what we've found in long-term care is those costs are so catastrophic and the needs are so great that the populations are not quite the same; they are middle-class populations that are suddenly finding themselves on Medicaid. And that's, I don't believe, the intent of the program. And I think the more that we can think proactively and do things, in terms of encouraging long-term care insurance, make it something that's affordable and has good coverage. And Idaho did institute, implement long-term care partnerships. In fact, one of my staff was back here recently as part of the Centers for Healthcare Strategies, learning how you market that option for individuals. How do you promote that? So a lot of what we do in the Medicaid area is very bureaucratic and cumbersome and difficult. We were chatting over lunch about it seems pretty silly to blame it on your MMIS system, but the fact is that is a huge undertaking and it creates problems. So we have to expedite things. We have to become more efficient with the tools that we have at hand.

MS. REINHARD: All right. Donna, anything else?

MS. FOLKEMER: Well, I didn't – NCSL was very active during the time these regs were being discussed and was active on the Hill in pushing the moratorium. Joy Wilson, my colleague who handles federal affairs, worked on that. So it certainly is our position that the flexibility for states, and in this case particularly the case management issue, is an important one to stay on top of. Again, flexibility is kind of the – it's certainly what we think is important, and I think that's the important point there.

I did want to say something else on a different subject. We have put together a long-term care legislation database that's on our website. And you'll have to either try to find it on our website, which is a challenge, I'll tell you that – (laughter) – or give me a call and I'll tell you where it is. I don't really want to sort of go through the whole URL here, but we tried to pull together legislation from the states basically starting in the 21st century, so 2000, 2001 going forward. And we're going to try to keep that up to date. Much of the legislation is mentioned in the AARP report, and then you find if you go into

our database, you'll be able to link to that if you want to read it. So I wanted to mention that.

MS. REINHARD: All right, great. Well, we'd like to turn it over to you. And I have constant questions I could ask these folks, but we think you might want to engage in some dialogue too. Now, I believe there are two microphones. There's one over here. Where's the other one? We have one over there. So we'll – here's a question right there.

Q: Hi, my name is Chuck Kaufmann and I am formerly the mid-Atlantic director of the National Aging in Place Council. And I want to second what Leslie just said. I think that the insurance companies have not stepped up to the plate, that there is – you're fighting a battle at the bottom of the heap. The insurance companies could easily, with marketing, take over and really make affordable long-term care products hooked to life insurance. I just handed one of the AARP young ladies a plan that I have been thinking about for a long time. But long-term care insurance can pay the bill, and the larger part of the bill; there will always be need for a Medicaid net, safety net, but I advocate privatization and more affordable long-term care products hooked to insurance perhaps, not life insurance, but that's where I am today.

MS. REINHARD: Anyone disagree? (Laughter.) I think you've got a home run there. All right, let me take one from the back too so we can mix it up. On the right side?

Q: Howard Glicken with the Urban Institute doing a book on long-term care. And at the risk of being politically incorrect, I'd like to ask you all about the woodwork effect – (chuckles) – and whether you actually are seeing people coming onto the program who you didn't expect to see and whether it's putting pressures on your budgets?

MS. REINHARD: Leslie, let's start with you since you don't have a waiting list. (Chuckles.)

MS. CLEMENT: Oh, boy. Yeah, we have a woodwork effect, absolutely. Our level of care determination in terms of what it takes to qualify based on function is pretty low. But you know what, I think that's the right thing to do. You get people who may not be as frail as those who are really actually in the nursing home, and you keep them in the homes, and you provide those services and support, and I think it pays off in the long run. So I tend to think of the woodwork effect as prevention.

MS. REINHARD: There you go, re-conceptualize that. (Laughter.) North Carolina?

MS. LARSON: There's no doubt about the woodworking effect, and I agree. I think our eligibility, income, spouse of one, we apply the same financial eligibility as an institutional setting on our waiver. I agree, it's part of being able to divert admissions. One of the things that we have to do is work with our nursing home industry, and we did

this in our ICFMR world. We actually went in and taught them how they could become HCBS waiver providers rather than just residential providers. So when you started moving that, then we actually saw them being part of the recruitment and the outreach for people to actually access the waivers, and so – because it becomes a revenue stream. It's a revenue stream, whether, again, it goes back to the money. If you build it, they will come. So the woodworking effect is there. I don't think that's a bad thing.

The other piece that you have to take into account with the woodworking effect for the waiver is you've got to make sure that primary health care is there as well, and because in the nursing home, you are going to get taken care of, your physician is going to be available, you're going to have nursing staff, and we have to recognize that the primary care has got to be there as well.

And so we have been working on our community care of North Carolina and assigning populations, as well as our 646 Medicare waiver that we are in the process of trying to obtain. So woodworking effect is a big part of the overall plan and you've got to recognize it and factor it in. And you need to project, being able to cost-model, and project out because if you just look at existing utilization, you will be way, way under budget.

MS. REINHARD: Dennis?

MR. STREETS: This is a little bit of an aside. Under our home and community care block grant, which is the non, if you will, largely non-Medicaid old Americans Act program type of programs, of course if you're 60 and older, you're eligible. But what we've tried to do, and what we've learned of course, is that we're targeting the most socio-economically needy. And we have now in excess of 11,500 on waitlist, and that's a conservative figure, for such services as home-delivered meals and then our maid services.

With basically flat funding, we're finding that we're able to serve fewer people than more, and that's certainly true now with the cost of food and fuel. So I think what we're seeing is the importance of trying to go ahead and target and reach those who are most at risk, and that will remain a principle sort of focus. When I was talking about this SA in-home program, or special assistance in home program, I would say in some cases our assessment of these people who are in the community is more rigorous than those who might be placed in a facility.

MS. REINHARD: Okay, where's the next one? Okay, how about up here? Carol? Mike is coming. Can you say your name and where you're from? I should have said that earlier.

Q: Hi, I'm Carol O'Shaughnessy from the National Health Policy Forum. We have very strict regulations for nursing homes. As states are moving more quickly, some are moving more quickly than others into home and community-based services, regulation of homecare services, quality of homecare services is a problem in some of the

states. Can you tell us what your quality measures are for home care and where do we need to go further on that?

MS. REINHARD: Do you want to, Leslie?

MS. CLEMENT: Well, this is what I think we need to do. I think some of the nursing home regulations are overly rigorous to somewhat of an absurd degree, not focusing on outcomes, not necessarily focusing on whether the care improves over time, but really on the bricks and mortar. So I hear from our nursing home industry all the time that just the regulations are really onerous. On the other side, our home and community-based waiver services were rolled out with very little quality assurance, but I think, at least I'm feeling more confident in Idaho, that we're doing a pretty good job at this point.

And part of that was prompted by the GAO report and the fact that CMS said, hey, you've got to have all these things in place, but I think that's a good thing because especially in a state like ours where you've got people remotely located and it's hard to kind of get there and make sure, you want to be confident that in small homes where individuals are receiving care that they're safe and that their care is good. So we are doing more and more in terms of bringing on staff whose sole responsibility in the home and community-based service world is on quality assurance.

MS. REINHARD: All right. Do you want to add anything, Tara?

MS. LARSON: I was going to focus on the outcomes piece because I think there is a difference. I know our state has typically looked at process outcomes. Do you have this policy in place? Do you have, do you meet this licensing requirement? Did you complete the background check, those kinds, and there's a process. And they definitely have to be there, but then there's the other piece on the personal outcomes. Did I make progress? Did I remain happy? And how do you measure that and the whole rights issue? And we are probably somewhere in the middle, definitely more on the process side.

We have instituted some outcome measures that we are looking at in the healthcare world through our community care where we are looking at, by getting service, by getting assigned a primary care physician, is your asthma better? Are hospital admissions down? So we're looking at the personal outcomes as a result of the interventions that are being provided. And we want to leverage that and go more onto our waivers. It's not there yet; that is, when I mentioned earlier about CMS's application on the waivers, I think they with, and we would agree, have put a lot more emphasis on the quality measures and the quality indicators where it was more a very small part of an application before. So I think you're going to see a lot more growing in that area.

MS. REINHARD: I think there's some CMS folks in the room, I won't point them out, who are probably very happy to hear of all the work that they've done, that you're actually thinking that's okay. (Laughter.)

MS. FOLKEMER: I wanted to raise something. I mean, I don't have the answer to this, so all of you researchers and thinkers in the audience can figure this out, but I think that when you're doing long-term services and support, they are a part of a person's broader life. And that life includes whatever chronic conditions they have, whatever acute episodes come as a result of those chronic conditions. And they probably are going to have several, and they're going to have acute episodes and they're going to have a period when they need long-term services and support and then some other kind of acute episode or close to it.

I think that they, when you think about long-term services and supports, the quality question we ought to be thinking about is how do you think about those services and how they contribute to the greater health care, to the support of the person, and rather than thinking about home and community-based care as sort of separate quality measures. So again, I know a lot of you have thought about that, but I think we may have thought about, let's think about quality measures for these services, and we need to sort of figure out a way to think about quality measures as it relates to a person's life course there, including their chronic conditions, their acute episodes that come from those chronic conditions, their changing chronic conditions, and so forth. So all of you can figure that out. (Laughter.)

MS. CLEMENT: Can I just make one –

MS. REINHARD: Magnus, you've got the answer? (Chuckles.)

MS. CLEMENT: Can I make one comment? I can't resist – (chuckles) – because primary care is a crisis in the United States right now. We don't have enough primary care doctors. And so I've been involved in another larger, broader healthcare reform discussion and it really is a serious issue right now. But at the forefront of what is most concerning is that physicians are no longer taking Medicare clients. And so we need to be really careful in terms of things that happen, again money, money, money, but with the payment reductions that have been recently taking place in the Medicare area, that's a very serious concern because if you say, we want to combine the social part with the medical part, and we do. They're integrated. They're important. They've got to be all together, and then you make a change in the Medicare program where you reduce physician payments and they won't see their Medicare patients anymore, we have a very serious problem.

MS. REINHARD: Well, we know a lot about Medicare and the recent legislative battles around that, so, but I think Dennis would like to add something.

MR. STREETS: I'll just – I just wanted to weigh a little bit in, again, mostly thinking about the non-Medicaid, but although I think a number of these things would apply to both areas. I think consumer-directed care can be a help in this area. We have strong service standards in our area agencies on ageing, and the stewardship of those funds and the public trust is critical. I go back to the Elder Justice Act, and support for Ron Budsmen (ph) and for adult protective services can be important.

We have in our assisted living area, I think we're one of the first states to do it, is an adult care home quality improvement program where we're going in, a consultation kind of program, focused on Medicare nursing management initially, but also looking at person-centered care through a look at performance outcome measures, going back to the clients, the outcomes that you're trying to realize, the whole idea of, again, quality of life as well as care, and the promotion of livable and senior-friendly communities, keeping people out and engaged, visible. And the chronic disease self-management is another area, so I would agree with all of that that has been said too.

MS. REINHARD: How's that, Carol?

MS. FOLKEMER: Good. (Laughter.)

MS. REINHARD: Great, and a question back here? Deborah?

Q: Deborah Lipson with Mathematica Policy Research. Susan, since you began the conversation by comparing what was going with the MRDD world with ageing disabilities, I can't help but ask this question.

MS. REINHARD: Well, good.

Q: Much of their success has been due to a conscientious strategy to deinstitutionalize and close down those beds and facilities. Should that be a very conscious goal and strategy for those who are aged and physically disabled as well?

MS. REINHARD: Okay, it looks like Tara is going to bite off on that one.

MS. LARSON: That's because I – we were fortunate enough to get a money-follows-the-person grant. And when we started working with our stakeholders in developing the grant, the first thing with the nursing home industry was does that mean you're going to shut some beds down? You're going to close some beds? In our state, we do have a 10 percent reduction on our MRDD beds, and we have made a conscious decision not to grow our ICFMR beds anymore, except in rare situations, and it's a very elaborate process. So I think it will have to be a policy decision.

I think, again, CMS has provided us some leadership in this area by saying less than four beds in the MFP process, and that we can use. We can back down and use CMS and say, well, you know, CMS told us we couldn't do it, you know? (Laughter.) We've got to have those four beds or less or you can't. So I think it is going to have to be an actual policy decision. And I think that will have – that's going to be – as Dennis and I say frequently, that's a pay grade way above my head. (Laughter.) But I think it will have to happen.

MS. REINHARD: Leslie, you wanted to?

MS. CLEMENT: I think our experience in Idaho with the MRDD is pretty amazing. And I was looking at some numbers this morning, and I think that we're about 80 percent home and community-based compared to 20 percent in institutions. And there, we have one state institution and, you know, the goal there is to pretty much get as many people out as possible in the next two years, and there's not very many. I think 90 total.

But there are some very seriously disabled individuals, particularly with behavioral issues that also have criminal histories. And those are the toughest people to manage in a community. We're really struggling with that. In fact, the whole mental health and mental health DD combination is just probably the single most challenging issue that we have. I think on the whether you can do the same thing that you did there on the ageing side, I would probably say I don't think to the degree because I think you've got some very high medical issues that is not quite the same in that population. So there's probably a good reason why they're not in the same waiver because they don't have the same needs, and they don't have the same issues.

MS. REINHARD: Okay.

MS. FOLKEMER: I guess a couple of points on that. If you look at both Susan's report and some of the recent work done by Loewen Group I think, perhaps on the work you've done, what you see is that essentially the number of nursing home beds in this country has been pretty stable for many years; well, I don't know about many years. You wouldn't know that better than me. And the proportion of older people of all ages, and especially the people 85 and older in nursing homes has gone down dramatically, something about 21 – there were going down from 21 percent to 14 percent in people 85 and over between 1985 and 2004, that's the Loewen Group work. So what you're seeing then is that nursing homes are certainly not a growth industry.

So then the question would be how do you think about sorting things out so that we move more quickly to more community services? Then you get into what kinds of things work best? I think in the real world, we have moved much more now toward incentive kinds of approaches, certainly the folks putting together the Vermont system, which say that's what they had in mind to do, to basically say we're going to change a little bit how we do our level of care things.

We're going to make community care more available, and then we're going to see what happens. And preliminary stuff shows, preliminary data shows there that the proportion of people who are able to access the very services or choose to access them more, use them, whether it's choice or not, has changed. So I mean, I think that gets down to the question of what works in the real world? And I think, again, some of you who are evaluators can think about that, but that would be my thought on that.

MS. REINHARD: I just want to note that on page seven of the "Building a Sustainable Future," we indicate that within phase one, stop paying for excess nursing home beds, which is an option that we have included. When I was at Rutgers Center for

State Health Policy providing technical assistance through a grand firm CMS, we produced a whole lot of information actually on what states were currently doing to right-size nursing homes. So if you are interested, that is on the hcbs.org website.

And then shortly after that, I had a meeting just as I was coming and came to AARP, and we did a webcast with our AARP state offices who were really interested in this topic. So I think it's fair to say, Deborah, there's a great deal of interest in how do you get the infrastructure to fit the vision and where are people actually going. The details of that get to be a little difficult how you incent and how you support in sort of right-sizing that nursing home industry, but AARP is on record as wanting to have that as one of the options that we consider and how we do it.

MS. LARSON: I would add too, in North Carolina our nursing home association are very active partners. They're at the table being a part of the discussion so that it's not some behind-the-doors, behind-the-scenes activity that's going on. And they are taking a leadership role in helping to shape that process and work with their industry. And they're valuable, valuable players at the table.

MS. CLEMENT: Just one comment that happened in Idaho over the last two years is actually there was a separate assisted living facility association and then the nursing home association, and they combined. So we'll see what happens to that. (Laughter.) I think they're torn apart at times, but yeah.

MS. REINHARD: We have about five more minutes, so we have time for some more questions. How about right in front? We haven't gone here for a bit. Am I ignoring that you were sitting next to somebody? Oh, Mike Chief will be next then, sorry about that. No, you go ahead. (Off mike.) No, that's all right. We're going to give it to you and then Mike.

Q: Sue Ellen Galbraith with Anchor. And we're a national organization of providers of supports to people with disabilities but began on the so-called MRDD side. And just first is a comment, one of the things, the question back here about what happened with the MRDD world. I think history will show us that there were several reasons, and at least three of the four that I can remember were because of family advocacy work, the closures of large institutions, in states where there were major federal litigation, some of which went to the Supreme Court, and states that had a strong sense of civil rights in general. That was three of the four; I can't remember the fourth one.

But I think whether we talk about MRDD or the ageing side, keep in mind, when we talk about the institutions for MRDD, people were quote, "coming back to the community." So when we talk about Medicaid, home and community-based, no room and board housing, we talk about people ageing in place or coming from a nursing home, there's maybe a housing issue there. But for all of you, I know that you recognize two of the biggest barriers to home and community-based supports for many people: the issue of housing and the issue and finding direct support professionals, direct care workers, paraprofessionals, personal assistants, whatever words you want to use, in general across

the country. We're talking about paid caregivers, whether they're family or independent contractors, or through agencies such as ours.

To the proactive side, though, on all of this, we keep putting the pressure in this nation on Medicaid to take care of long-term care in this country. And I know that's the focus of this report, but let's, as coming back to your point, Leslie, and some others, and there is work from Congress on that DRA issue – (laughter) – some of the flaws. But until this country takes on this issue and addresses it and doesn't say, well, here are all the faults of Medicaid and we're going to cost-contain it and now you get $1.25, go out and purchase it on your own, we're not going to be able to address this issue because Medicaid will never receive that federal level or the state level, the attention and the money. Talk to a member of Congress about what Medicaid is and he automatically talks to you as if it's a Medicare program.

MS. REINHARD: Thank you for that, and that's why I do want to point out this is – (applause) – that this is phase one. What you're talking about, we have more like in phase three, but I think you have wide agreement.

Q: It's an election year.

MS. REINHARD: It's an election year. (Laughter.) There you go. There you go. Mike, I promised.

Q: First to Leslie's point about assisted living providers struggling, some free resources that my organization offers under –

MS. REINHARD: Can you say where you're from?

Q: NCB Capital Impact. The Robert Wood Johnson program funded the Coming Home program with us for about 10 years, and it's a whole package of tools that combine housing financing tools with Medicaid and private financing from people to create affordable assisted living by helping push down the development costs using things like low-income tax credits and home funds from out from HUD and from state coffers to push down those costs. And that's all free; Robert Wood Johnson paid for it, Google Coming Home and come pull it down because it's for free.

The second is a real question for the panel. My background is in developmental disabilities, and when I left the State Developmental Disabilities Director's Association, we were just starting to work on the concept of supports waivers, which included everything but residential, had a much lower cap on spending, and really they were targeted in the initial states like Colorado driven by litigation around addressing waiting lists. And they were intended to support families and give them just enough to keep the individual at home. And I wondered why, perhaps from Dennis and Tara and Martha, with the state unison on ageing, why we haven't seen that trend in ageing and physical disability as much?

MS. REINHARD: I'm going to start with Tara.

MS. LARSON: Actually, North Carolina is in the process of submitting its support waiver on MRDD as we speak, as a matter of fact. And you're right, I think it's evolving. I think for us it would be a matter of educating our public on what a support waiver actually is and cannot do and they look at it as more of a comprehensive waiver. I mean, we're finding that even in our MRDD world. We have – and for those of you who don't know, in our MRDD world, our average is much higher. And when you start talking about a $15,000 cap, in our ageing population waiver families would die for $15,000, and in the MRDD world that's just chump change. So I think it's a matter of really working with our agencies and our folks and letting them explain. I would love to see that in our ageing world because that's one of the things we're going to do, Dennis and I have been working on, is adding respite under our DRA auction, our 1915-I option, so that we can maybe accomplish some of the same sort of activities under our fee for service arena instead of having to go the waiver. And I think the respite for caregivers is going to be a huge part of our state's options.

MS. REINHARD: Martha, did you want to say anything?

Q: No.

MS. REINHARD: No, that's okay. Well, I think we actually have run out of time. Does – everyone got 2:00? Oops, wait a minute, there's one – can you stand for one wiggle moment here, someone who's jumping out of her skin?

Q: Sally Atwood, president of the community of people living with – (off mike) – disabilities. Could somebody just set me on Florida? Now that I am a member of the AARP, I know they published an article in the last term about persons not having the opportunity to live at home anymore, that they were being forced to commute back into the nursing homes?

MS. REINHARD: Can anybody? Can anybody address this from AARP?

Q: I don't know if it was in MRDD or the agency.

MS. REINHARD: I think – I'm not seeing anyone that looks like they have an answer, so if we could talk afterwards, I'll give you my card and we'll talk? Yes. Thank you. I want you to all please acknowledge the incredible expertise up here. (Applause.) And I want to acknowledge the incredible expertise out there, and really, thank you for coming and spending the afternoon with us. I think the food was great, so maybe we'll do it again. (Laughter.) Thank you.

(END)