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ACHIEVING BETTER CHRONIC CARE AT LOWER COSTS

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LUNCHEON PANEL: NEW OPPORTUNITIES IN IMPROVING CARE FOR OLDER ADULTS:

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PROCEEDINGS

DR. McCLELLAN: All right, good afternoon. I hope everyone's had a chance to at least grab a lunch box. I want to thank you all for accommodating a very crowded venue. This -- we actually have somewhat higher attendance than we expected with both in here, we have a full room and a full overflow room and a lot of people watching on the web. I think that's a testament to the quality of the participants we have and the discussion, so I do want to get right back to that now.

So if I could ask our lunch discussants to come up to the front and have a seat, after we cut their lunches short as well.

We're going to spend this next hour -- or a little bit less than an hour talking about some of the new opportunities in improving care for older adults. And just put this into the context of the rest of the morning. You've heard already today about some programs that are underway. Some projects actually reform care and address some of these very important gaps in quality and opportunities for cost savings and most importantly, for improving the lives of older Americans with significant health impairments, significant functional impairments. You've heard about some of the ideas for better ways of measuring what we really want this care to deliver and thereby making it easier for regulations and policies to support that.

For the rest of the day, we're going to try and take more of a forward look in putting these different ideas together. And I'm very pleased to have with me a number of people who are in unique positions to make a difference and are making a difference in taking these steps forward.

So, we're going to hear from some distinguished leaders in government, from academia, from the nonprofit sector, each of whom are involved in public efforts, private efforts to improve care quality, care experience, and efficiency of care on behalf of older adults.

So, this will help us lay out a path forward and understand where we can go in terms of improving our overall healthcare system, which as you've heard today we're not going to be able to achieve without addressing these fundamentally important issues.

So, we're going to hear from Mary Naylor of the University of Pennsylvania. She's the Marian Ware professor in gerontology and the director of the New Courtland Center for Transitions in Health at the University of Pennsylvania School of Nursing.

We're going to hear from Katie Maslow of the Alzheimer's Association, who is the director of policy development there. Her work focuses on improving access and quality of care and long-term services for people with Alzheimer's disease and other dementias as well as a big emphasis -- I know from working with her -- on support for family caregivers of people with these conditions.

And we've also have the special privilege of having two very busy leaders from the federal government here with us, Richard Frank, my former colleague way back when who is now at the Department of Health and Human Services. He is the Margaret Morris professor of health economics at Harvard in the Department of Healthcare Policy at Harvard Medical School. And he is on leave -- is that -- I'm sure there's a technical Harvard term for this, to serve as the deputy assistant secretary for planning and evaluation at HHS, where he directs the Office of Aging, Long-Term Care, and Disability.

And also, my good friend Carolyn Clancy, the director of the Agency for Healthcare Research and Quality. She's also served as the Agency's acting director, previously director of ARC Center for Outcomes and Effectiveness Research and has a life and career long enduring commitment to and has had impacts on quality of care, health IT, comparative effectiveness research, and a range of other important topics for getting to a better healthcare system. And we've also been working together as co-chairs of the Quality Alliance Steering Committee.

Before turning to all these groups, I just want to give you a reminder. You heard a couple of times this morning about the recently launched Long-Term Care Quality Alliance, that's one of these opportunities looking forward. And after today's event, at 3:15, right here after we re-set up and you have a chance for another break, you all are invited to stick around for a reception and to hear a bit more about the LTQA, its practical activities, how you can get involved, how it intends to work together to address some of these issues that we're talking about today, particularly focusing on some of the measurement issues and developing public/private support for implementing and expanding programs that work.

So with that, let me turn to Mary. Can you tell us something new that's going on to help us achieve some of the goals that we've been talking about morning?

MS. NAYLOR: I certainly will. But I want to start with a little story.

Tomorrow, I'm going to be attending the funeral of my 101-year-old aunt. And about a week ago, I was having a conversation with her and she's asking me about what I was doing. And she said, you know, life is very short and you ought to pay a little bit more attention to a higher quality of life than you currently have.

So -- and I think that that's largely what many of older adults in this country are seeking and striving for is to have a very high quality of life. And I thought it was also great wisdom on her part.

So, I have been extraordinarily energized by the conversation this morning. And it feeds, I think, very much into an initiative that Mark has already talked about, the Long-Term Quality Alliance. And Mark actually was the chair of a steering committee that worked for quite a number of months, maybe over a year, to really lead to this point in our time.

And as I listened to this conversation today, I thought that the work that we are about to move and advance is very consistent with so much of what has been described here. This alliance is a member organization. It will be -- the partners in the alliance will be the leaders of the organization, representatives of organizations who are responsible for assuring the high quality of life that my aunt really enjoyed and the environment in which she lived for the last five or six years.

And it will be an organization guided by an extraordinarily richly diverse group of individuals. Leaders in the delivery of long-term services and support, policymakers, researchers, scholars, thought leaders who’ve been thinking a great deal about it, consumer and family caregiver advocates, and a range of others who are coming together with one common mission that in spite of a great deal of the barriers you heard about today, we think that there’s a tremendous opportunity to substantially accelerate quality improvement for the group of individuals that we talk about here. Those individuals often not represented here, but who wake up every day confronting very basic challenges in things that we all take for granted.

And we sense a sense of urgency about this. This is not an agenda that we want to be talking about 5 years from now or 10 years from now without having a sense that we have capitalized on this great group, the members and the leaders on the board to really advance important areas and goals.

And so let me just talk briefly about a few of these and how we propose to address them. The first is that we really want to work toward advancing measures and quality measurement in for the people that we serve and the family caregivers. The kinds of measures that are aligned with their preferences, with their needs, with their values. So, this notion of person and family caregiver, care manager-centered care is extraordinarily important to us.

Secondly, we want to promote measures in areas where we think we have great promise to affect change in the short-term around improvements in care coordination, care transitions. You heard about this all morning long, the opportunity to think about measures that will assist us in avoiding very costly hospitalizations among this group that are very, very vulnerable to poor outcomes when they occur, et cetera.

And, finally, I think what's really exciting here is, we really see ourselves trying to position the member organizations with the best available evidence. And yet, yes, it's imperfect. But we do have a great deal of evidence about how to make things better, how to improve the quality of lives, how to improve the function and cognition of these individuals, how to address the family caregiver's needs, and so we really want to position all of the member organization with some of the knowledge, some of the tools, the resources that they need to quickly be able to accelerate improvement in these measures that we are about.

We certainly want to take advantage of every opportunity we have with the demos that we hope to support, the pilots that we hope to support, in order to help position policymakers with the knowledge and skills that they need to change the incentives -- the quality and financial incentives that will really, really advance quality improvement for this population.

And as I listen today, I think another agenda has surfaced for us that I think will be very important. And that is about promoting public awareness. We do need to create an alliance with those that we serve to see them as our partners in this effort. And so to create the kind of awareness that will support what I think is needed, and that's culture change in this country around how we deliver and -- services to this population.

So, I see tremendous opportunity. And I wanted to highlight a couple of things related to the nature of evidence. Our team, as you heard a little bit about, has been involved for over 20 years in trying to promote the better interface between the medical and social support world, between hospitals and home, and now increasingly, between the acute and long-term care sector.

There is a great deal that we know about how to improve the world for these individuals. We've also -- I was moved by Carol's statement as researchers have been working very much in partnership with the deliverers of these services. So, have partnered with -- and with the support, again, of many foundations here in this -- represented here today have tried to figure our how to build a roadmap to translation to develop the tools to promote dissemination, et cetera. So, I think we do have a great foundation upon which we can move.

Within our own school of nursing we've been able to establish a pace program that was established 10 years ago. We had to work through a number of barriers, but from that we have numbers of lessons learned about how to improve and deliver care to this population.

We have a study going on right now that is assessing health and quality of life changes of older adults as they enter the long-term care system. This is through their voice and it is longitudinal over time. We're tracking what's important to them, what happens to them when they're hospitalized, and how that influences their care and their outcomes. And I think will be the grist of really helping us to define not just the quality measures, but how to improve quality.

So, I see us really well-positioned with the support of everyone in this room, the overflow room, and at the end of the Webcast, to really move quality improvement for this population. And I look forward to working with all of you in the future to do this.

DR. McCLELLAN: Great. Mary, thank you very much.

I'd like to turn to Katie.

MS. MASLOW: Thank you. Thank you for inviting me.

I'm going to talk just briefly about Alzheimer's disease and other dementias and some of the problems in care for these people that I think could be reduced by initiatives that we've been talking about today. And in particular, I'm going to just talk about performance measures, family caregiver support, and coordination of care for people with these conditions.

So, as many of you know, there are about 5 million people with Alzheimer's and other dementias in the U.S. now. These people are very, very high users of home- and community-based services, long-term care services. They constitute half of nursing home residents, almost half of assisted living residents, half of adult day program participants, a quarter of Medicare home health service receivers, a third of Medicaid home and community-based services clients. So, huge -- people with Alzheimer's and other dementias are -- need long-term care, they are likely to need it for a very long time. So they're an important component, I think, of the people that we're talking about.

I was a little bit jarred this morning when I arrived and got the chart book that we got that doesn't have -- it doesn't say Alzheimer's, it doesn't say dementia, and it doesn't say cognitive impairment. And I think that's because it's from MEPS, and MEPS has other functions and doesn't pick up these people. But anyway, they are a very large component of the people that we're talking about today.

And what most people don't realize is they're also a very, very great users of medical services. So, people with Alzheimer's and other dementias are three times more likely to be hospitalized than other older people. We just got data from the new CMS Chronic Condition Warehouse, they are three times more likely than other older people to go into the emergency room. And those same data show -- and I think this really fits with what we've been talking about -- that they are half as likely as other older people to have physician visits. So, you know, that could be part of the reason that they're ending up in the hospital.

As these people, others said, bounce back and forth, I think that's a good term. They bounce back and forth between various long-term care settings and services and providers: acute care, post-acute care. They are -- as you can imagine, they are -- it's very difficult for people with dementia to do these kinds of transitions. It's very hard for the patients. It results in poor short-term and long-term outcomes, health outcomes. And the brunt of this kind of bouncing back and forth ends up on the family caregiver, because we don't have a coordinated system of care.

We could go on and on with this. I just -- you get the point. And those of you who have taken someone with Alzheimer's or another dementia into a hospital or ER know the difficulties that I'm talking about.

So, over the past 20 years or so, I'd say we've made a lot of progress in long-term care, in home- and community-based services. There are more services, they are more appropriate for people with Alzheimer's and other dementias, there's a lot of good work on training, there's not enough funding. Kathy Greenlee said this earlier, others of you know this very well.

So, one thing that happens because of this bouncing back and forth between the community, the home, the residential care facility, and acute care is that some of the good work that's being done in the home by home health agencies and other home- and community-based providers and by families is lost. And Julie Bynum described this, what happens to a person in the hospital -- -- so the person -- this person goes into the hospital and the good work that has been done by residential care and community care providers can be lost in a couple of days, resulting in poor, short-term and, as I said, long-term outcomes.

So, three exciting things in terms of improving care. One is in addition to the programs that Chad Boult talked about and others have talked about today, there have been maybe 7 or 8 research and demonstration projects conducted over the past 10 years or so specifically on coordination of care for people with dementia, coordinating, as Mary said, the acute care, medical care side and the social care, the home care side. These studies have statistically significant positive outcomes for the person, for the family. They greatly improve the care and the quality of life of these people. It's very difficult to put them in place in our fragmented system, and it's impossible to maintain them with the payment structure that we have now. So, they can't be maintained, but they are there as examples of what can be done.

Family care giving. We have now, really with the support of the Administration on Aging, a set of family caregiver information and support programs that are shown to be -- they are evidence-based, randomized, control trials showing positive outcomes. The Administration on Aging is trying to move these from research to practice into the community, and the availability of these programs would make a tremendous difference, I think, for family caregivers -- not just caregivers of people with dementia but caregivers of all people who needs these kinds of services and support. So, that's exciting, and it should be part of anything we're doing going forward.

And then, just lastly, performance measures. We're not doing well. Greg Pawlson said there are 3,000 measures on your -- on -- there are 4 for dementia. Two are British measures that have not been used in the U.S. One comes from NCQA, it's about tricyclic antidepressants; and then there is one from AMDA about pain in nursing homes. That's great, but it's not much. Four is better than zero.

So right now the National Quality Forum has a project in place to try to develop the kind of measures that I think Julie Bynum was talking about, that Greg was talking about, that would cross different settings, deal with Alzheimer's and dementia, measure care for those people but across the different institutions, medical and community care. So, that's really an exciting situation.

So, just one last thing. The alliance that you can hear about later on, I'm sure you can imagine, from what Mary said, how excited I am and the Alzheimer's Association is about the development of this alliance and it's coming together, the idea of care that's efficient, that's a measure for which there are good measures that can cross settings, and the focus on the person but also on the family are extremely exciting.

DR. McCLELLAN: Thank you very much.

Richard.

MR. FRANK: Thank you. I'm delighted to be here, and as Mark mentioned --

SPEAKER: Can't hear you.

MR. FRANK: Is this better?

SPEAKER: Yeah.

MR. FRANK: Okay. As Mark mentioned, I'm relatively new to Washington and I haven't quite yet been socialized, and I apologized in advance for that, but the number of cameras that are in this room sort of highlights that I'm someplace different than Harvard, and it also allows me to channel my sort of role model for healthy aging, which is my grandmother, who taught me how to rock climb and ice climb, and she was in her 70s when she did that, and so she's a great --

The other thing it reminds me of that my grandmother told me was never give cameras a profile shot, and so I'd appreciate it if you'd take of that.

SPEAKER: You're next.

MR. FRANK: All right. I want to make a couple of observations about some work that we've been doing at ASPE where we've been looking at some data on people with chronic conditions, have been thinking a bit about what it means, and then have tried to put it in a context of reform in some of the innovations that are so much the subject of this meeting.

The discussions today all start with the observation that the people most in need of coordination are those with multiple chronic conditions, and doing a better job with these populations leads us to the Holy Grail of health care, which is better quality and potentially lower expenditures. And the recent evidence, particularly from the Medicare coordinated care demonstrations, sort of points us in the direction of targeting, that our success in doing this has a lot to do with how good we are at targeting our interventions, and so this chart book that you've all received today is really the first of two works that we're putting out at ASPE with the Luen Group, and it starts to go behind the numbers on spending for people with chronic conditions in this country, and what it does is it starts to pull things apart by stratifying on the basis of functional impairments. And the tables in this book highlight a couple of really important points related to the idea of targeting and coordination, and let me just take a few of those off for your, and then I'll move into what we're thinking about that this means.

The first is that if you look at just the average amount of spending for people -- elderly people with chronic conditions, it comes to about $5,800 a year in 2006. Now if you pull that number apart and you look at people who have both chronic conditions and functional impairments, their spending goes up to $11,200, okay? So, immediately you see the importance of or the perhaps misleading data that can be done from too much averaging. So, if you start to pull this apart and you start to think about where do you really want to target, certainly functional impairments become very important, and this has been known and discussed, but I think we're starting to really sort of put some precision on the numbers.

Now, what's interesting is that the ratio of the amount of spending by people with both chronic conditions and functional impairments to those with only functional impairments remains the same, more or less, as you increase the number of chronic conditions. So, there is this continuous gap that grows, that moves together, as you go up the number of chronic conditions distribution.

Now, if you look at, for example, the 5 percent of people who have the highest level of spending so that the 95th percentile and above of spending among people over 65, those with both chronic conditions and functional impairments account for 61 percent of that group. So, there is an opportunity here to target that we think is very important.

Now, one of the questions is what exactly is going on here and what do we do about it. And so clearly functional impairments make accessing health care harder. It can interfere with self-management. And since about 80 percent of people who get help with ADLs and IADLs get that help from family members and friends, it is those people who wind up doing the care coordination, for the most part, and very often they're not well prepared to do so. And so these facts start to come together in how we start to think about targeting.

The links between health care and long-term services and support are generally either weak or nonexistent, and so the disconnects, you know, come across a lot of dimensions. They're cultural; they're organizational; they're economic. And I think the work that's been talked about here today that is now really dominating the literature really points us to the elements that have to go into coordinated care -- long-term services and support, both formal and informal; chronic care treatment strategies; and palliative care. And most people with functional impairments rely first on their informal caregivers and then on the health care provider, okay? And the implication of this in part is that the health care is, on one hand paid for by Medicare and/or private insurance but typically is disconnected from any kind of payment for long-term services and support and, certainly a prevalence of long-term care insurance in these populations is very low.

Now, Medicaid, which is very often a focal point for discussions here, you know, is the main payer for long-term services and supports in this country, but actually only about 10 percent or less of the people that we're worried about here actually touch Medicaid. And so what we have is a financial decoupling. We don't have a set of financial mechanisms that provide a point of leverage that cuts across both the long-term services and supports and health care arena, so policymaking is at something of a disadvantage. So, for most people, we don't have a good money tool for kind of encouraging the kinds of coordinated care that we're talking about.

Now, I think health reform starts to offer some new opportunities here, and it offers it at both the sort of micro and macro level, and I think that as we think about both levels, we need to think a lot more carefully about how we make the good ideas that are developing in the field, particularly in the research community, operational and sort of implementable. But you look into the health reform bills as they are, and you see sort of kernels of all sorts of important and interesting things.

For example, the Independence at Home Act offers sort of an organizational -- one organizational strategy and one payment strategy for getting organized care to some of the most vulnerable people that we're worried about here.

The Class Act offers a different set of opportunities. It offers a new, flexible source of funding that can be used to overcome some of the obstacles that caring for people with chronic conditions and functional impairments present. Now, the Class Act can be used to get help with self-management and facilitate contact with professionals. And, in addition, it can be also -- what it does is it directs more and more attention to the quality and the nature of the direct care work force, and inside the Class Act is a real effort to look at the supply of direct care workers but also to worry about the quality of those direct care workers. And, as I said earlier, it is, to a large extent, under a Class Act type of financing system. That is a point of leverage where you can up the skill levels that will allow you to do more on the coordination front.

So, in deed, health reform, the Class Act, and many of the sort of detailed provisions that propose a variety of innovations are ways that we can make some progress, but I don't think we should limit ourselves to that. There are lots of promising models for care coordination for individuals, particularly those who are duly eligible for Medicare and Medicaid; and, really, when you read the literature, and particularly for someone like me who has not spent their entire career working on issues around delivering services to elders, one sees how quickly people go to the duly eligibles and I think we need to sort of start to look beyond that because, as I said, only 9 percent or so of elders wind up touching Medicaid. And so, really, the points of leverage for solving the problem to most of the people who suffer from multiple chronic conditions and functional impairments is somewhere else, and so Class Act, innovative financing systems like the Independent at Home Act present some opportunities to make some progress on this, and it is really going after that piece of the pie that represents the hardest work in some sense and, you know, in a sense I understand why we haven't gone there as quickly, because that's really where the hard work is.

Thanks very much.

DR. McCLELLAN: Thanks, Richard. I'm sure we're going to come back to these issues again.

Carol?

MS. CLANCY: Thank you and good afternoon, everyone.

I want to congratulate Mark and his colleagues and my colleague, Deb Parham, whose enthusiasm for this work knows no bounds. She's been fabulously helpful to me -- as well as Mary -- on the turnout here today. I walked in and people were saying oh, my gosh, the overflow room is overflowing and I don't know where we're going to go next and --

But then as I thought about it for a minute, I'm not actually that surprised. Not to take a thing away from the Brookings team, but this is an issue that I would guess most of us in this room are watching on the web are about 1 degree away from at most. It is certainly defining my family's experiences recently as we struggle to figure out. I am the patient navigator from 500 miles away for my father in trying to figure out how is it that we can get all the services and so forth that he needs, which are both medical and social; and then there's stuff that we don't actually know which box it goes in. He's not touched by Medicaid or he doesn't touch Medicaid, whichever is the right way to say that.

So, Mary, I would actually reinforce your point about public awareness, because one of my interesting challenges is trying to explain this to my siblings. I'm from a very large family. I'm the only one in health care. And their expectations for what is success here, well, they need work. That's all I'm going to say. They keep thinking we're going to have a cure any minute, and for a variety of reasons that won't be happening.

But it's actually quite illuminating to me that a sort of byproduct of the dramatic increases in life expectancy that we saw in the 20th century is that people kind of think we can cure everything, right? The right pill; we'll get a vaccine for this; and so forth. In fact, one of my siblings asked me at one point very dramatically, does Dad have cancer? And I thought oh, boy, we have a long way to go. And I said no, in many ways his life would be easier if he had cancer. We could go to war on a specific condition. And instead, like many other people Richard was describing and have been discussed this morning, he has multiple chronic illnesses. Thankfully, a very healthy wife, which helps a great deal.

So, I know that -- and I got from Deb some very careful notes of our discussions this morning.

What I want to talk to you a little bit about is some of the work that ARQ is supporting right now in addition to our being terribly proud of being one of the funders of the Guided Care work. My whole life for the past year and a half has been about the Recovery Act or ERA. I often say that I have not had a lonely moment since about Thanksgiving of 2008, because the phone started ringing with people working fast and furiously on that legislation.

I think, as many of you know, we had a huge opportunity this past year to invest in patient-centered outcomes research formerly known as comparative effectiveness research. Now, ARQ has been doing this work for four or five years, and I must say that our initial focus was pretty clinical. Organized by conditions, most of the conditions are those areas that are causing the biggest challenges for people served by Medicare, Medicaid, and SCHIP, which is pretty much the whole country when you think about it. But this year we started to get much more deliberate in terms of thinking about what is comparative effectiveness research. So, both the Federal Coordinating Council and the Institute of Medicine Committee that was mandated by the Congress on which Mark served expanded the definition to include care delivery interventions.

Now, this is both exciting and very relevant to today's discussion. It's also incredibly challenging. We know what a pill is. We don't always know if someone's taking the pill, but we actually know what it is. It's pretty standardized. For much of care delivery, we're going to actually have to come up with a vocabulary, much less clear definitions of what it is that we're talking about, and we're going to need to learn how to describe the context in which these interventions are deployed in a way that so far the literature has not been overflowing with. I think we're more than up to the task. I think it's very exciting.

So, I will tell you that right now we have published solicitations on research to optimize prevention in health care management in people with multiple chronic illnesses. That closed the other day, or last week, and we're also putting out data that people can use for additional research analyses and so forth. In fact, a substantial portion of the $400 million allocated to the Secretary of Health and Human Services will be invested in data and infrastructure. So, the lovely analysis that Katie just presented about looking at the chronic disease warehouse data I think will be much, much easier, and multiple data sources, particularly from CMS, will be linked. There's going to be investments in registries, distributed data networks, and so forth.

Many people see health IT as a very important part of the solution, and it's hard to disagree. The VA is doing some very exciting work with their Healthy Vet program, and we, too, are funding some projects, including one on Active Aging, which is all about supporting individuals and enhancing community-based care through health IT. Notice how that rolled right off my tongue. The ultimate goal is to help extend independence and functioning and reduce unnecessary health care utilization by older adults and using the IT to put the family and caregivers at the center of a more expanded and efficient network of different providers and people providing services. I can't tell you how excited I am to be part of the long-term quality alliance, so I hope if your schedules permit that you will be able to stick around later -- and really, really excited that Mary Naylor has agreed to chair this very exciting board and group of people who I know will have very diverse opinions on many topics.

Let me just about some near-future activities. One, I think many of you are aware that the Patient Safety and Quality Improvement Act was passed in 2005. It's a fairly complicated piece of legislation, so it took us a bit of time to finalize the regulation for creating patient safety organizations in addition to being able to certify patient safety organizations, which create a protected space for providers working together to identify errors, near misses, and causes and also to evaluate whether what they're doing makes a difference at all. The law also gave the Secretary the discretion to require that these PSOs use common formats for reporting.

Now, the idea is that these PSOs can report de-identified data to ARQ, and then we're required to report it to the Congress in our National Healthcare Quality Report so that although the space in which providers are working together is protected, indeed the lessons learned could be shared more broadly through that strategy. But if people weren't using the same definitions of patient safety events, what we would have would be a mess in short order.

So, the last Secretary was very enthused about doing that, and we have recently released the second refined version of these common formats. Not yet for long-term care, but it's on our very, very near horizon to actually get to that, because there are lots and lots of safety issues, and it's very, very hard to even identify all of the safety issues in the realm of long-term care and support services.

I think some of you may also know that the meaningful use regulations that will provide support and additional incentives for the adoption of health IT for Medicare and Medicaid were recently released. That would be December 30th. And that version actually includes measures around transitions in care in the out-years. David Blumenthal was very clear that we're not doing this one year at a time and then starting all over again, that we need to think about every year's reg as in building on a trajectory, so transitions in care is very much part of that map moving forward.

There's clearly been a huge amount of excitement around the Patient Center and Medical Home, sometimes so much excitement it's not clear that we're all talking about the same thing, but that's okay. Lots and lots of states and communities and funders supporting work in this area. I think there's a huge opportunity here to think about how that could be operationalized in this arena of long-term support services. My father doesn't really need a primary care doc whose a quarterback in the same way that I might value and appreciate that. He needs much more than that. But there aren't a whole lot of good models for how that works.

And I know that very well, because early in my career I had the privilege of working with a colleague in Richmond who started and just figured it out on his own a physician-led home health team. And going out and covering that service was really quite revealing. My personal favorite experience was going to somebody's house -- this was for a gentleman on oxygen, and they had a sign out front that said No Smoking. It was misspelled. So, I almost started to smile, and then I realized it actually didn't matter if it was misspelled, because it did the trick. Nobody with a lit match was going to cross the threshold. There was someone sitting right there to make sure that that didn't happen.

So, I think that as we advance in our biomedical science to try to figure out how do we get to a place where we all get to live a really long time and then die very quickly and peacefully, which I think is what most of us want for ourselves -- to get to 101 or whatever it is -- yes -- and just --

SPEAKER: Died in her sleep.

MS. CLANCY: Exactly. Turn out the lights and there you go. It's going to be a while till we get there. But I think we should remember that although the need is great I think the resilience and the opportunities are phenomenal as well.

So, let me just stop here, and again, I'm really thrilled part of this.

DR. McCLELLAN: Well, thank you, Carol, and some great comments.

I actually really appreciate the comments from all of you. Clearly, there's a lot going on and a lot of opportunities to make progress on the issues that we've talked about today.

I would just like to open this up now to the audience. We've got a little bit of time for questions about any of the topics that our speakers have raised. They've put a lot of future opportunities on the table and would like to see if there are any questions or comments about any of it.

Let me start right here.

SPEAKER: Are there models for education on the lowest common denominator health care provider in community colleges or in technical schools around the country?

SPEAKER: The educational programs your talking about expanding out this team support as we've been talking about today?

SPEAKER: No, we're talking about putting a burden on a lot of health care providers, and the question is how are we educating them, where are we educating them, why are we educating, who's paying for it?

SPEAKER: I can take that one. There are actually some demonstration programs. Right now the Department of -- and I assume that you're talking particularly about direct care workers and things. There's an effort right now focused on nursing home direct care workers and home health direct care workers on trying to sort of build them into things that the Department of Labor runs, known as apprenticeship programs, and there are ways of sort of in a sense creating job ladders, creating sort of a -- more of a professionalization so that in order to stabilize the work force, provide better training, and things like that, and I think there are a number of efforts like that. That's the one that we're most directly involved in right now, and in the health reform legislations, there are things that encourage us to go that way further.

DR. McCLELLAN: You -- here. Mm-hmm.

DR. POPLIN: Hi, I'm Dr. Caroline Poplin. I'm the internist. I want to tell a story about my father who passed away in 2003. He led a very healthy life. He played tennis. We ate the right stuff. But his parents died in their 50s of a heart attack and a stroke, and it all caught up with him at 70. He had all the multiple chronic conditions -- diabetes, hypertension, depression -- and he fractured his hip and he had a bypass and lots of other surgeries, and his last six months were horrible. He was in and out of the Beth Israel in Boston and the Brigham, the modern American medical MEC. They had all -- all the other records were electronic. He saw five or six physicians a day, usually different ones. Great. They had the records, but nobody read them. The cardiologist read the cardiology notes; the renal people read the renal notes. We couldn't get in touch with anyone.

My sister is a physician, too. We had constantly shifting teams of interns and residents who didn't know what was going on. His internist came in at 6:00 in the morning, checked his heart and lungs, scribbled a note and left. No one who knew this patient was talking to the doctors who were caring for him, who were constantly changing. That's where you need an internist. You need a physician, not a nurse, not a paraprofessional, not -- my mother was fine, taking care of him at home, but this is a serious problem.

DR. McCLELLAN: So how can we get a internist, a physician effectively supported to address that kind of coordination?

DR. POPLIN: Well, I know you have a philosophy, and I respect that. But I think that there are -- there's a pretty compelling body of evidence that suggests that you need a team for the care that your dad or at least the thousands of patients that we've enrolled in our multiple clinical trials for the last 20 years who have very similar pictures to the one you've described. People with multiple chronic conditions coming in and out of the hospitals who have often care complicated by cognitive impairment, we have a trial going on now a great deal of support to the Alzheimer's Association, The National Institute of Ageing. Their needs are very complex, and they do need excellent medical management, but they need overall care management, because the issues that bring people in and out of the hospital are not just about sometimes the progression of diseases, they're about the lack of knowledge the cultural differences, the poor communication that you described.

And so we have you know five clinical trials showing us consistently that a nurse led team based model that really helps people navigate these very different difficult situations and that are designed to interrupt the trajectory. I mean, we are accepting that every hospitalization needs to take place, and we know that for the long term care population 25 to 40 percent of them are avoidable if we interrupt the trajectory, if we make the investment in people, and in their family care givers to substantially have a long-term impact. And so our studies have shown the capacity to reduce readmissions for one year post discharge, and save people from the tremendous human burden associated with it.

I'm not suggesting it's the only model, and it really does rely on excellent collaboration between the nurse and all of the physicians involved in the care, and the social workers, and everyone else who can bring some knowledge and expertise to make things happen.

DR. McCLELLAN: And how does this work out from the physician's standpoint? What's their experience with this program, and how --

DR. POPLIN:XXX?XXX They love it. I mean, primary care physicians, when the nurse picks up someone an acute illness the first -- she contacts all the physicians. This time the hospitalization might have been for heart failure, but two months ago it was likely for something else so that she or he contacts all the physicians, including the primary care physician. Goes to the first visit with the patient to the primary care physician, and helps them to understand what took place during that hospitalization, and works in partnership with these physicians. And that's how things happen.

It is -- we're engaged right now, a couple of us, in looking at team-based models of care and how important they are for the high-risk population. And the evidence is pretty compelling. If we're going to change the way we address the needs of a long-term or a very high-risk chronically ill population it's going to require engagement of all the players, including direct care providers, patient's family caregivers as members of the team to make it happen. The evidence is there.

DR. McCLELLAN: Go to the question in the back.

MS. ROW: Yes, I'm Connie Row. I'm executive director of the American Academy of Home Care Physicians and we want to say thank you so much to Dr. Frank and to all of you who have mentioned the Independence at Home Act. And others of you know Dr. Peter Bowling. By the way, Doctor, can I say I believe Mary Naylor does as well, and thank you Dr. McClellan for having mentioned it in the L.A. Times article.

Our question is really this, this set of ideas is one intervention absolutely that we believe in. This is home-based primary care for a targeted high-risk population, it meets all of the things that everybody has been talking about. But like lots of other ideas -- and by the way, there's new evidence from the VA that shows that there's savings not just -- Dr. Frank knows this, not just in the VA, but in the Medicare population as well. And everybody is now talking about needing to have both quality improvement and cost savings matched together. But we're now at a different transition. The Independence at Home, despite all odds, managed to make it into both House and Senate Health Reform bills, in some form or another, and so did some of the other ideas. But now all of that is on freeze, or at least so it would appear to many of us on the outside.

So, the question that I guess I have speaking for perhaps others in this room is, how can we make sure that these good ideas keep going, no matter what? And in an environment that we know is as politically complex as any that any of us have ever seen. And yet we know the direction that so many of us want to pursue, how can we work together to make this happen no matter what?

DR. McCLELLAN: Very good question. Carolyn?

MS. CLANCY: I think one of the huge challenges here -- and I'm thrilled that you were able to come today, is how do you identify models that are revlicable and scalable? And even if magic happens, and tonight at midnight it all comes together and the bill is signed tomorrow that doesn't in anyway substitute for the kind of collaboration represented and hopefully led by the Long Term Quality Alliance, and many others. You know Peter Bowling didn't know -- didn't have a protocol guide of how to do this when he started out. He probably does a whole lot of things differently, and frankly I think one of the areas we need much better information in the geriatrics literature is full of this, is how do you target the right interventions to people based on need.

I was very surprised with Peter's initial population that about a third of the patients did not have incredibly intense medical need. What they had was pretty much cognitive impairments. So, actually getting physically home to a physician's office was not going to happen unless somebody went to get the, and for a variety of reasons it was easier in that case to go to them. But I don't think we've characterized the population at a functional level in the way that Richard Frank emphasized well enough to know how to do that. I know the Innovations Clearinghouse was mentioned this morning, this is a site that ARC sponsors, and it provides sort of a hug for communities who've practiced. And I've been sort of amazed by the various groups that have come together. Greg Pawlson is on our Editorial Board for that.

So, no matter how you cut it the challenges in this arena are not all that different than the rest of the health care system, where we've got some very, very promising results and we really don't have a clue as to how scalable they are or not, consistent with Atul Gwande's article in the New Yorker where he called for an extension service. Now, that is also in the legislation and I think that maybe an idea whose time has come here. Because I think this is an area where for years and years we've been kind of sort of figuring it out on the ground, very experiential, but without ever sort of refining out knowledge and getting smarter, and frankly spreading what really works.

DR. McCLELLAN: If I could just add to that a little bit and take a moderator privilege here. The steps that we've talked about today that have identified a number of ways to reform the way that care is delivered for this very challenging population, it was mentioned on the last panel, do you really want to see those spread around? Information and education is important, and we've heard about a few steps to do that.

But also the financing and regulatory changes to go along with it are important, and certainly some elements of the Legislation that is in process somewhere in Congress right now could help with addressing that. But I would like to emphasize that you heard today about a number of steps that are being taken in term to financing reforms and other reforms anyway, regardless of the legislation being passed.

I can tell you from the CMS standpoint the agency actually has quite broad authority to change payments so long as a couple of conditions are met. Number one, you don't take anything way from beneficiaries; and number two, you've got a reasonable expectation, and then can show that it actually does work to improve quality and lower cost. Would that be easier if there was new federal funding for a major renovation center and if Congress gave a strong directive to the Secretary of HHS, you know, the Secretary shall do this?

Now, sure, that would help, but there is a potential for doing this sort of thing now. Carol talked about these special needs plan that she had set up. It did actually get those different financing strings from Medicaid and Medicare to come together. It was a lot of, you know -- to continue your shower metaphor, it's kind of like build your own plumbing from, you know, like, one building over to the next to get that hot and cold water to come out together. But it can be done. And hopefully, in the future, it's not going to be so hard, but there certainly seem to be a lot of opportunities to do it now.

And I wonder if anyone else on the panel has some suggestions about putting these different pieces together, the evidence on what works in a pilot from a pilot standpoint, the financing, the regulation, those pieces that do seem to be -- does seem to be possible to add those up to make some changes. Maybe not as easy as it should be, but it does seem possible.

SPEAKER: With some of our work in translation, we've engaged local payers to -- who also have the same kind of incentives -- Independence, Blue Cross, and others -- to support -- and now this work as service delivery. So, I think that you have to look within your own community to the kind of people you bring together around an accountable care organization to say we have common mission, we have common goals, how can we work to achieve this. And there's been a really very positive response in that regard, so.

DR. McCLELLAN: I think the LTQA wants to focus on getting more measures available, and then putting together these different parties to try to help make this happen --

SPEAKER: Exactly.

DR. McCLELLAN: -- as well, so it does seem --

SPEAKER: I think that what you said is encouraging. We might --

SPEAKER: (inaudible)

SPEAKER: We might lose now and there are still things in place, but I think that there are people who believe in these kinds of payment and system change initiatives. We have failed to communicate that to the public, and I think that that's clear in what's happening right now, and that the awareness issues that both of you raise are really important here, so.

DR. McCLELLAN: Well, so why is that so hard? I mean, just from hearing the comments that people have made, that Carolyn's made, it's -- everyone in this room I think is at most one degree away from a very tough challenge with someone that they care deeply about.

SPEAKER: Right.

DR. McCLELLAN: Who's having the kinds of problems that we're talking about today? I mean, we're not just talking about one in six Americans that are touched by this. Just about everyone is. And yet it does seem to be a real awareness gap. What -- why is that?

SPEAKER: I'm not sure it's awareness at a personal level; I mean anyone who's experienced this knows exactly what the problems are. But often the people experience it are very vulnerable themselves. So, someone with cognitive impairment is often being cared for a spouse who has multiple chronic conditions. And so you're asking people who have very little energy to get mobilized, and begin a movement. And I think we really need to push that, I mean I think that there needs to be much more public attention in the ways you build campaigns for people to understand they're not in it along. This is not their experience; it is a shared common ground. And I don't know that we've done that kind of work.

Katie, certainly with the Alzheimer's Association a sense of the issues from your prospective?

MS. MASLOW: Yes, I agree that we haven't, and the conversation earlier about Congress saying so what shall we do? Okay. So, we have ideas about what to do. I don't think that we disagree very much about those ideas. But I don't think we're conveying them in as clear a -- when people experience these pilot programs or demonstration programs there's no question that they're happy that they -- there's no question about the outcomes. So, I don't know. There's Chad, you ever -- Guided Care where --

DR. McCLELLAN: Are there comments on this?

MS. MASLOW: How are we going to communicate this? These -- Mary has randomized clinical trials of this nurse-based transition model published in JAMA 10 years, 15 years ago?

MS. NAYLOR: Twenty, I was 12.

MS. MASLOW: Twenty?

DR. McCLELLAN: If it's been 20, Carolyn, that's about the right timeframe, so people should start --

MS. CLANCY: It's time to go, right, exactly.

DR. McCLELLAN: Chad, did you want to comment on this?

MR. BOULT: It's just this, David Reuben put me on this a couple of years ago, the enormous challenge of translation and taking something that works in a research setting and all the things you have to consider, the -- all the factors that determine what is diffusible and what isn't, and what tools do you have to produce to allow others to adopt the innovation whatever it happens to be. And then how do you get it known? How do you adjust or how do you influence the public policies that determine payment and eligibility criteria? There's just an enormous number of determinates of whether something can actually be translated. And I think we're all kind of at the beginning stages of -- on a learning curve about how to do this.

SPEAKER: Yes, I guess, you know, the other point I would make is we also have some sobering not successes here. I'm thinking of geriatric assessment units, right? And the issue there wasn't is it a good idea, but we're talking about a multifactorial intervention, which appeared to work in one randomized trial, and people were just deliriously excited, and then every time it was replicated this issue of how the patients were selected was really, really tricky. That's why the expanded definition of comparative -- sorry, patients-entered outcomes research was very exciting to me, because it will allow us to begin to build and test better methods for understanding that.

Congress can only legislate so much. They can legislate certain components. They can certainly provide resources. I'm talking any year, any season okay? The rest we really have to figure out how to do, which is why the LTQA is going to be very, very important.

DR. McCLELLAN: Time for one last comment, maybe there in the back?

MS. FADER: Thank you, Mark. Judy Fader from Georgetown, The Center for American Progress, and proud to be a member of the board of that Long-Term Care Quality Alliance. Thank you so much, Mary and others.

A couple of comments. I've been in and out today, and I have heard many of the comments with respect to the pending legislation. And I -- Mark, when you were the most optimistic person in the room we got a little bit of a problem. I think this will be -- I say thank you for your optimism. And the rest of the people in the room, get a grip because we need to make it happen.

So, but I -- the other thing that I wanted to say with respect to getting a grip, I see -- think of Chad not as a -- I don't think of him as a representative of CMS, although I'm happy to. And Mark, I think we can't see you always in that role. And I think that it's interesting that we have ASPY here, and ARC here, and the Administrative -- the Office on Aging, and that we don't have CMS at the table. Now, we know we are in the room on the panels, and I think we all know that it is -- as we have said collectively, it has got to be the engine of this reform. So, I think it's wonderful to see all the parts of HHS working together, and that part needs to be there, too, and very much energized. And I think that I'm optimistically -- we'll have reform and, therefore, we will have the additional tools. But I think that what Mark tried to do when he was at CMS and needs to continue is using all of the tools that we've got.

And finally, I would say that the people in this room need to be -- well, not quite finally -- cheerleaders for that reform. So, that's where I was chiding Chad early today when he was a little bit -- I think you were a little dubious about the pilots, Chad. And (inaudible) essentially we got a make it go. And the people in the room and the organizations and groups that people are affiliated with I think have a tremendous capacity to do that.

And now finally, I don't know if anybody in the room -- is here in the room from the Partnership for Women and Families. But the Partnership for Women and Families with support from Atlantic Philanthropies is mounting a campaign for consumer awareness of and participation in more effective delivery of patient-centered quality care. So, I think that we've got a mechanism to achieve -- accomplish some of the greater understanding and awareness that happens beyond the episode, where we're all so overwhelmed by the care needs of family member that we don't have time for a broader movement and to get that movement going, and so that's that.

DR. McCLELLAN: Do you want to say, or maybe Bruce or someone can say, another word about the partnerships efforts in this regard? Unfortunately, Debra couldn't be here today. Yes, go --

MS. FADER: Well, there's -- here you go.

DR. McCLELLAN: Yes.

SPEAKER: Thank you, Judy. And I didn't even have to pay her for that remark. The National Partnership in conjunction with Atlantic Philanthropies is beginning a campaign for better care. And the idea behind this campaign is to really create a patient movement for some of the very things we're talking about today. In order -- in other words, what we're doing is creating a consumer coalition made up of more than 50 consumer organizations that are essentially coming together to work both at the legislative end, but also look programmatically and through the regulatory process at what can be done to improve chronic care for patients and family caregivers.

DR. McCLELLAN: Great, thank you. And I think that's a nice note to end this panel on. I'd like to thank all of our panelists for a very stimulating discussion.

And we're going to move right on to our last panel of the meeting, which is going to try to put all of this work together. So, thank you all very much for sticking with it.