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INTERNATIONAL LONGEVITY CENTER

The Caregiving Project for Older Americans

**Developing National In-Home Caregiver Training
Standards: A Consensus Conference**

**The International Longevity Center and the
Schmieding Center for Senior Health and
Education**

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The Caregiving Project for Older Americans Conference

[START TAPE 1]

MR. EVERETTE DENNIS, Ph.D.: Before we get to substance, there are always logistics and technology rules. So let me say, first, that all of the microphones in the room are, indeed, live. And they will be live through the day. The proceedings are being recorded. So if one presentation strikes you as particularly inept, don't say so unless you want everybody to know. So that's a starter.

Secondly, the Harvard Club, which we are a part of here today, has a rule banning cell phones except in the territory we control; which is this room and the hallway outside. Otherwise, cell phones are verboten in these places. This is part of the 19th century; not the 21st century. So we need to know that.

And, finally, restrooms are down the hall to the right and please come and go. There are refreshments outside. Please help yourself to those.

Again, good morning. I'm Ev Dennis of the International Longevity Center and I want to, especially, welcome everyone to this gathering of eagles in the field of caregiving. We're honored to be host to this project with our colleagues from The Schmieding Center in Springdale, Arkansas and we're very, very happy that all of you are here.

My role is simply to open the proceedings this morning and to make a few introductions. Also, to acknowledge the wonderful support that has made this meeting possible coming from The Schmieding Foundation, whose representatives are here; the Amgen Foundation; the MetLife Foundation; and the Pfizer Foundation. We are extremely grateful for this support that makes this meeting possible today.

The meeting has been greatly informed and helped immensely by our colleague and senior advisor, Gail Gibson Hunt, a doyen in the field of caregiving, who is with us today and will be part of these proceedings.

Before we ask the members of the expert panel to introduce themselves, I'd like to acknowledge two members of our National Advisory Committee for this project. One being Dr. John Finnegan of the University of Minnesota; the other being

Humphrey Taylor, a member of our board and the chairman of the Harris Poll.

I'd also like to recognize Dr. George Maddox, the chairman of the program advisory committee of the International Longevity Center, which, of course, as you know, is based at Duke University in Durham, North Carolina. We are thrilled to have all these folks here.

Also, to acknowledge the presence of Dr. Mike Magee from Pfizer who will be our speaker this evening. He will be with us this morning. Mike is right back there.

Let me introduce them. The Co-Chairs of this meeting this morning: fresh from the Charlie Rose show last night, Dr. Robert Butler and our colleague, Dr. Larry Wright from The Schmieding Center.

They are going to get us moving along the track here on this important and timely topic that we're so happy to be part of and to be involved with here. Also, we greatly appreciate all of your presence and involvement here today.

I think Drs. Butler and Wright are going to ask each of the members of the expert panel to introduce themselves first. I'll do that. Beginning with Dr. Marie Bernard, over here. We can kind of go around the table and then I'll turn it over to the chiefs.

DR. MARIE BERNARD: I'm Marie Bernard. I'm the Chairman of the Reynolds Department of Geriatric Medicine at University of Oklahoma College of Medicine.

MR. JEREMY BOAL: Good morning. My name is Jeremy Boal. I'm the Executive Director of the Mount Sinai Visiting Doctors Program; a program that takes care of homebound persons, mostly older persons, throughout Manhattan.

MR. JOHN CREWS: I'm John Crews. I'm with the Centers for Disease Control in Atlanta.

MR. STEVE DAWSON: I'm Steve Dawson. I'm President of PHI which is in the South Bronx. We pursue quality care through quality job strategy in long-term care.

MS. LYNN FRISS-FEINBERG: I'm Lynn Friss-Feinberg [phonetic] with the National Center on Caregiving at the Family Caregiver Alliance in San Francisco. And we are celebrating our

thirtieth anniversary this year in supporting families caring for relatives with adult onset cognitive impairments.

- MS. CLAUDIA FINE: I'm Claudia Fine. I'm the Chief Professional Officer for Senior Bridge. We're a company that provides complex, chronic care in the homes with an integrated model of homecare and professional care management.
- MS. MARY JO GIBSON: I'm Mary Jo Gibson. I'm a Senior Policy Advisor with AARP's Public Policy Institute in Washington. I work on long-term care policy and policy on independent living.
- MR. RICK GREENE: Good morning. My name is Rick Greene. I'm with the Administration on Aging and I oversee the National Family Care Reverse Support Program.
- MS. LINDA EMANUEL: I'm Linda Emanuel. I'm the Director of the Bueller Center on Aging, Health and Society at Northwestern School of Medicine.
- MR. ROBERT KANE: I'm Bob Kane. I'm usually referred to as the other Kane. I'm here because I'm helping to organize caregiving for my mother.
- MS. SANDY TIMMERMAN: I'm Sandy Timmerman. I am Director of the MetLife Mature Market Institute. We do a lot of research in the caregiving area, particularly related to working caregivers and also consumer education.
- MS. JEANETTE TAKAMURA: Jeanette Takamura [phonetic], Dean of the School of Social Work at Columbia University.
- MS. DIANE MEIER, M.D.: Diane Meier [phonetic]. I'm a geriatrician at Mount Sinai, a palliative care Doctor and I direct the Center to advanced palliative care.
- DR. CLAUDIA BEVERLY, Ph.D.: I'm Claudia Beverly. I'm a nurse and I am Associate Director of the Reynolds Institute on Ageing in Arkansas and, also, Director of the Hartford Center for Geriatric Nursing Excellence.
- MS. CAROL LEVINE: Good morning. I'm Carol Levine. I direct the Families and Health Care Project at United Hospital Fund here in New York.
- MR. HUMPHREY TAYLOR: I'm Humphrey Taylor. I'm from the Harris Poll, as you heard. I am the least knowledgeable person sitting around this table, seriously, on caregiving. But I

am a professional voyeur, so I look forward to learning from you all.

MR. JOHN FINNEGAN: I won't even try to follow that. John Finnegan, Dean of the School of Public Health, University of Minnesota.

MS. GAIL GIBSON HUNT: Gail Hunt, head of the National Alliance for Caregiving in Washington.

DR. DENNIS: Doctor Butler.

DR. ROBERT BUTLER: Am I now supposed to speak?

DR. DENNIS: Yes.

DR. BUTLER: Okay. Good morning. Number one, I want to thank all of the experts that are here. I want to, especially, thank Gail Hunt because she's come and spent time with us and helped us to think through what we think of as a very, very important project.

And I can't help but be a little auto-biographical from my days in practice between 1963 -- before Medicare -- before Medicaid -- and 1975, in Washington, DC when I actually made home visits; sat around kitchen tables and talked to older people and learned an enormous amount.

All through that time, we did not have even what we have today. And so often, I would be worried about the second patient; that is to say, the caregiver being burdened, being stressed and not being able to cope. It was a very central part of my experience and practice.

And so we have to realize four big issues. Number one, how do we address the issue of needed certification; either by a state by state basis or a national basis. How do we construct curriculum?

Second, in regard to the family caregivers -- with respect to palliative home caregivers -- and how do we deal with certain domains which are very special, like the issues of AIDS or dementia, stroke, the other specific problems that need our help.

Third, we have to deal with the reality of career development. The thought that we have to find means of retention of, often, wonderful people; who work very hard lifting patients and exposing themselves to great and often

harsh conditions. And yet, as you know, often, poorly paid and, often, without benefits. Can we find a way working with community colleges or other venues to give a shot for a dignified growth of the field?

And finally, do these people need some kind of a national organization. The boomers are very much at risk, in my opinion. I think we have about ten thousand new boomers every day. They are already experiencing issues with their parents. They will have to start thinking about the issues that will affect them. They're a generation at risk.

We have a Presidential campaign coming up next year. We are certainly going to have health as one of the great, critical, political issues, as I see it. I hope there will be discussions of long-term care and we need a well-trained, effective workforce if we're going to really have an effective long-term care.

Tonight, you will get to hear something about the potential role of technology in assisting the caregivers and families from Dr. Mike Magee. I think you should look forward to that very much.

Let me just conclude by saying that the purpose for you all to be here is to really speak up and interact. Give us advice; give us counsel; move us forward, especially, around training and curriculum. We want your recommendations. We want your help.

Let me turn it over to my better colleague because we've known each other forever. He was trained in the East in Geriatrics. He made a terrible mistake returning back to Arkansas.

Of course, his dad happened to practice medicine in a little town you may have heard of called Hope, Arkansas. His dad had a nurse that happened later to eventually be the mother of a president. So you are sitting next to an historic figure here.

And he's really been a terrific friend. They have worked very hard with a remarkable, older man named Lawrence Schmieding [phonetic], now 85, who bore the caregiving responsibilities. At the end of that, he said to himself, if a person with my means had as much trouble of being able to provide a decent homecare and health for my brother, what do

ordinary people do?

A great and humane individual who would have loved to have been here today but can't. In any event, Larry Wright -- Dr. Wright -- has been a terrific colleague as we've tried to think our way through -- to work our way through this very important national topic.

Larry Wright.

DR. LARRY WRIGHT: Thank you, Dr. Butler. Good morning and I want to add my welcome to all of you, the experts and our special guests. Thank you so much for giving your time today to be a part of this and I look forward to your contribution and participation in the discussion.

I'm very self-conscious and acutely aware of the incredible work, experience and expertise that's represented at this table and very much humbled by that and appreciative of what is brought to the table today. I look very much forward to the kind of solutions that a group like this can result in collectively.

Without any further delay, let me just start by telling you just one word in self-disclosure about who we are at this meeting center.

We're a non-profit, regional center on aging in Northwest Arkansas; a program at the Reynolds Institute on Ageing at the University of Arkansas Medical Sciences. Broadly speaking, our program is education and clinical care.

The clinical care is in partnership with a very progressive community hospital in the Northwest Hill system; which is, arguably, among the most progressive community hospitals in the country in terms of geriatric care, employing seven fellowship trained geriatricians in the area that is not an urban area. We are very proud of being part of that.

And for our education program, our pre-emptive education theme, because of Lawrence Schmieding and his interest, has been in developing caregiver training for home caregiving.

And then of course, in this project, the Caregiving Project for Older Americans, we're so delighted and pleased to be in partnership with IOC. I count it a great gift and blessing to have this working relationship with Bob Butler, Ev Dennis and Ken Knapp, who you'll hear from this morning. And all the

staff at IOC and the wonderful work that they do in addressing the challenges of an ageing society.

Well, at the outset, let me just say, it's obvious to everybody in this room that there is a caregiving crisis in America. The elements of that are pretty obvious and one is driven simply by the progressive ageing demographics of our country as the ageing baby boomers hit their retirement.

As you know, will be swelling the ranks of the retired and over-age, by their definition, of over 65 by two-fold over the next ten to twenty-five years. And that has incredible implications for health care and long-term care. I think we can all agree.

It leads to a very compelling question. And that is, how will we care for our elders, who will number twice as many as we have now, living twenty to thirty years longer than ever before with more chronic diseases and with a changing family dynamic.

As all of us know, the overwhelming burden of caregiving in the home has been the families. The contribution of family caregivers, in terms of simply the cost-savings to this country, is obviously numbered in the near billions of dollars. And yet, it is a very fragile balance and the American family, delivering this caregiving, is under a great deal of stress.

We know there is a growing shortage of both paid and unpaid caregivers in this country. We think that the most critical part of this crisis is the growing number of older adults in home settings. We're not the only ones who think this.

It's not a well-kept secret; although, solutions have come forth that have been written into law. As recently as fifteen months ago, December '05 at the Wellness Conference on Ageing, which met two of the most prominent issues coming forth in the recommendations from that conference, for surrounding caregiving workforce in a home-centered long-term care system.

That conference, as many of you know, pulls in thousands of delegates, leaders and older adults, themselves, who are probably better informed than the American public about these issues and challenges of an aging society. And they are given the mission in a few days to bring forth fifty

recommendations.

Well, five of the top ten and seven of the top twenty recommendations address these two issues. I just want to run down them quickly to give you a flavor of this.

The number two ranked recommendation out of the White House Conference, and that's after, by the way, number one was simply renewing, preserving the Older Americans Act. As far as a specific recommendation, otherwise, the leading one was coordinated long-term strategy.

Number six was prepared health care workforce. Number seven, non-institutional long-term care. Number nine, capacity of the geriatric workforce. Number ten, coordination of aging in place. Very pertinent to this conference. Number thirteen, strategy for informal caregivers. And then, number twenty, designs for livable communities. Very relevant topics closely related to the issue of caregiving that we're going to be addressing today.

If we look at America's long-term care system, I want to make a few opening statements that I don't think are very controversial. It is: our long-term care system has been institution centered. It's widely regarded as broken.

One expression of that is the very low rating in terms of consumer satisfaction. And by consumer, I would mean here, older adults, patients, and their families. I think we have to acknowledge that there are an inadequate number of beds to meet future needs even if we were satisfied with an institution center long-term care system.

So over the next ten to fifteen years, the cohort of the older population in which frailty, disability and dependency is highest -- that over 85 group -- is going to go from 5 million to 20.9 million. There's no way, even if we wanted to, unless we were going to build a whole lot more nursing homes -- that would be an answer.

I think it's safe to say that there's a growing consensus for a transition of our long-term care system to a more integrated, home-centered system of long-term care.

Every meeting that I go to, I'm impressed; not with just the meeting but the discussions in the hallway in between sessions that there is an implicit understanding that this is the way that America has to move.

Well, let's just talk about what are the caregiving needs of the non-institutionalized, frail elders in long-term care -- those who are living in a home setting. They're, mostly, related to functional decline or impaired activities of daily living -- Not so much, although certainly, it is included here -- not so much skilled nursing needs or medical problems; Though they certainly have many chronic diseases.

Twenty-six percent of older adults are frail, by the definition from the Urban Institute, of one or two limitations in ADLs. And 6.1 percent, that's roughly 2 million, people have severe disabilities; three or more ADL limitations.

Well, as far as looking at what the big challenges are for transforming the current long-term care system into something that is a more desirable future system. We believe that addressing this workforce shortage is critical.

One of our National Advisors, who was initially planning to be here but is unable to be, Val Halamandaris of the National Association of Hospice and Home Care, made a statement here at IOC last fall at the Agement [phonetic] Academy. He said that he could take any small collection of experts, certainly such as a group we have here today, and go in a small room for a few hours and design a more rational long-term care system the new have. That wouldn't be the problem.

But he said, you can do that but without the basic workforce, you couldn't implement it. And so perhaps our biggest challenge is creating, growing, and retaining this workforce. There's an inadequate number of available workers and we believe that there's inadequate formal training both for paid and unpaid caregivers.

This is nothing you'll find in a paper. This is my, kind of, down and dirty overview of the long-term care system in America. And it's not meant to be comprehensive; so much as a scheme that would help a person understand where the frontline worker relates to the rest of the system. This scheme highlights, to the left, the institutional base long-term care system in pink. Everything to the right, in purple and blue, is more home-based. You could pick this apart in a few ways.

Assisted living isn't mentioned in here, and I intentionally left that out, because we could argue about whether that is

home-based or institution because in different places it will be different things.

Some assisted livings employ their own people and do their own training; making them a little more institutional. And others clearly represent a home setting. But in any case, if you look across this scheme, at the bottom on the left side, certainly an institutional based, long-term care -- the frontline worker -- that C in the CNA means certified and that typically means they've been.

There certainly is a national standard for training and a national requirement for training and certification for that person to go to work in a nursing home. The purple, on the right side in the home-based, is the part of this system that is regulated.

So we're talking about home health care agencies which are Medicare certified and, certainly, require that their front line workers be certified and have training. And those, whose work in the home, are being reimbursed by Medicaid, similarly, would have requirements, though they vary from state to state.

In blue, this aspect of home-care delivery and these front line workers -- you see the family caregiver and the friends and volunteers -- the unpaid part of the workforce which I've already acknowledged as giving the lion's share of care in the home. And then the paid in-home caregiver in the light blue, we might call independent providers.

In the right, lower-most corner, though, this would be paid in-home caregivers possibly working for home-care agencies not home health care agencies but home-care agencies.

In many, many states, this really requires no formal training. I know, in many of the places that we've talked to and many of these caregivers, though they're more or less billed as trained, that training may have just been that they were given a workbook. Saying, if you find any problems that aren't answered there, there's a nurse on call two counties away who you can get by phone to answer your questions.

It hardly represents training. It's partly reflecting a huge variability in what exists out there in terms of training and standards.

If we have a bias at this meeting center and this certainly

is open for discussion. We want to hear from the experts today. It's in what kind of caregiver training is needed for older adults in America living at home. It needs to be specifically designed for older adults and for the home setting.

In terms of the geriatric focus, this simply acknowledges what most of us working in geriatrics (nurses, social workers, geriatricians) understand implicitly and that there is very important age specific changes and vulnerabilities that are physical, mental, social, and otherwise, that are very important and unique.

And then we believe that the home setting is very different from the institutional setting. It's unstructured; it's less equipped; it's less organized. There aren't policies and procedures there. And it's unsupervised and as much as the supervision, it's simply the ready access to available nursing consultation. This is a glaring omission.

And most of you in this room know, there is a progressive trend and I think progressive in both senses of that word, trend toward consumer directed care. Well, if we're going to have people, especially older people -- vulnerable older people -- given that independence of directing exactly what people do and calling someone who's not trained, to do certain instrumentation and other procedures in the home -- we hope that that frontline worker has a lot more than experience only type preparation for that work.

Well, who are the current home caregivers? This is known well to all of you. We've already acknowledged that families are doing most of it. Most of it is being done by women in this country. Friends and volunteers are a very important but a small piece of this also.

I'm sorry about this. This should be paid caregivers of which there are roughly three types. The independent provider would be one. But there's also, obviously, the government reimbursed Medicare/Medicaid worker and then those working with private home care agencies.

One common denominator is that, fortunately, these are, by and large, very caring people. But also arguably, mostly untrained to meet the unique needs of older adults.

So who will provide caregiving? We know that there are

changes and Gail Hunt will be talking about family caregiving. But there are certainly changes in the American family which will be threatening the number of available family caregivers: divorce, more women employed in the workforce, fewer adult children and more and more family caregivers who are involved, but at a distance because they are scattered around the country and very hard to be in proximity to give hands-on care.

There are paid caregivers as we've described, volunteer caregivers. It's hard to think of volunteer caregivers being a huge piece of the answer systemically; but certainly there is an important role for faith-based and other non-profit organizations to enter here and be a contributing part of the solution.

Well, the Caregiving Project for Older Adults with Humphrey Taylor's organization's assistance, just conducted a telephone poll survey which to me that one of the most important findings is this whole factoid; and that is, families and older adults who are hiring paid in-home caregivers for older adults, 78% believe that these caregivers are formally trained.

It is very hard to get exactly what the reality -- what the number really is -- but it's much closer to being just the opposite -- 25%. And some people would say far lower than that in terms of who are really formally trained.

So we know that there is a perception out there -- it's almost like the perception of the American public that Medicare is going to take care of long-term care -- you believe when someone says I'm prepared to do this; I've done this before. Whatever, you want to believe they've been formally trained and the reality is that they usually have not.

Well, that is an opener, an overview. We'll proceed. Any opening comments before we get into the first presentation? In which we're going to actively elicit your discussion. I want to -- the next part of the program, Dr. Roland** and I want to share with you a formal effort to canvas the country for training curriculae for this home caregiver workforce. And I want to share with you, the results of that.

Actually, this expert panel -- this is in the binders that everybody in the room has. The expert panel should've

received this in the last week or a little bit earlier than that.

Let me just go into this and then I'll introduce Beth Vaughan-Wrobel to share with you the findings.

The current situation, we believe, is that there is no consensus for training standards, nationally, for in-home paid caregivers equivalent to those that exist for institutional long-term care.

There certainly are no mandatory standards of certification for independent in-home paid caregivers. As we just mentioned in the Harris Center active slide, the majority of families hiring paid in-home caregivers erroneously believe that they're getting people who are formally trained.

There was also a CBS poll just out last month. You probably saw this. It indicated that 16% of Americans are currently caring for an older adult in the home and an additional 5% have done so. Sixty-four percent of Americans are concerned about this or very concerned about having to take care of an older adult at home.

Did I mention the Harris Center active poll? Additional information from that is that 8% of Americans have used or paid for a hired in-home caregiver in the last twelve months. That, coupled with the CBS poll, would indicate 50% of those are caring for an older adult in the home.

Again, 78% believe that those people were formally trained. Only 8% of that survey who are hiring these paid in-home caregivers for older adults in the home, acknowledge that they were sure that the people they had hired were not formally trained. Very interesting, I think.

So there's a perception of training in-home caregivers and then there's reality. There's a 78% public perception and we know that it's a much smaller percentage. It's a very hard number to get to.

Unless one of our experts is aware of a hard number that you can find, there are some really occasional guesstimates. Twenty-five percent, I'm really comfortable with but there's a lot of indicators that it could be as low as 10%.

What we've done is conducted this four-month national search for curricula, available to in-home caregivers for older

adults. I just want to introduce those who, primarily, did this work. Two of our nurses educators, Valerie Alsbrook. Valerie is the coordinator of our training program at the Schmieding Center. Sherry White is our coordinator of education and they did the lion's share of the work you're going to hear about, under the direction of Beth Vaughan-Wrobel.

Beth is the Associate Director of the Schmieding Center for Senior Health and Education. She has been the Education Director since our opening in 1999. She has a long career in nursing education and has been the heart and soul of the caregiver training program and most of the work that has gone on at the Schmieding Center in the last eight years. I'm very pleased to introduce Beth Vaughan-Wrobel.

MS. VAUGHAN-WROBEL: Thank you, Dr. Wright. Well, it was interesting that when we started this in 1999, Mr. Schmieding gave us the money to proceed with the project. He said, "Go out and teach people, so old people won't have to go in the nursing home."

That's what we were supposed to do. In 1999, we looked for a curriculum. Why were we going to re-create the wheel? We could not find one in 1999. We took the Federal and State guidelines and created our own. Then when the IOC got involved in this project, Dr. Butler said, "Are there other curriculum out there?" And we said, "Well, you know, in 1999 there wasn't."

We started the new project of looking for what's out there. It's pretty amazing, the growth in the last six or seven years, in the interest in caregiver training.

The question that we posed to ourselves and that we looked at was: What curricula are used to train paid and unpaid individuals caring for older adults in the home?

The methodology that we used is that we reviewed the literature. We made personal phone calls and emails factored into trying to get all this information. We looked, you have the paper in front of you -- some of you have read it and some of you have not -- but there are 131 references that we looked at in the literature. We searched everything that we could find on caregiver training.

We made 165 calls for curriculum through email, fax, postage,

web pages and actually we got 48 returned packs. Could have been by phone, by email -- some people called. That's a 30% return. People are interested in this topic and we thought that that was very good.

We also made 68 personal phone calls and we talked to every one around this table. We followed up on the guideline of the people that you recommended that we talk to. In all, we did make 68 individual phone calls talking to people around the country.

We did search all 50 states. We tried to find information about what was going on in all 50 states, as we looked at what curriculum was being used for training caregivers.

Now, what we were particularly interested in is not all kinds of caregivers. We wanted training specific for caregivers of older adults, not across their lifespan but we're interested in older adults. That was the focus.

The second focus was the in-home setting; not institutional settings. We found lots of caregiver curriculum. When we started looking for specifics for older adults and for in-home, it was not so easy. We found lots of caregiver training for older adults in institutions but not for the home setting.

When you find our findings and you say we only have so many and we know a lot more out there in the country, yes, but the specific things that we were looking for were older adults in the home.

The third one was a curriculum. Lots of materials are out there for training. Lots of reference materials; good books; good DVDs. Nothing wrong with any of it but are they a curriculum?

And when we talked about a curriculum, we were very specific as to what we were looking for. Did they have goals and objectives? Did they have topics and content?

Just telling me that you need to do a bed-bath does not tell me how to do the bed-bath. A lot of guidelines are out there but specifically, if you want consistency and to set standards, there's a way of doing it; whatever the way is that you select.

The strategies for teaching and learning, do you tell people

how they are to teach this content? Is it to be returned demonstration? Just lecture? Interactive learning? What type of strategies are you to use.

And, also, who is to teach the content and any evaluation. If there is not a way for the program, for the learners to learn and be tested to see if they can actually do the skills before they go out there in a setting where they are by themselves, we felt that evaluation component was very important.

You can also go to the paper. We did write the paper with IOC staff as a discussion paper to stimulate thought for the panel and to give us input to look at these things. The algorithm of how we selected the criteria and how we eliminated some. Very good curriculum but not specific to the criteria that we were looking for.

The last item on this slide is, we did not look at quality. Quality was not an issue. We were looking for availability of the curriculum in the country today.

Some of the major findings that we found were that few curricula were actually available that were specific to in-home training for caregivers of older adults. What we found is -- we found six.

Now we have received a few, three or four, since our cutoff date that we haven't really been able to look at yet and see if they had all the components of the curriculum -- on older adults and focused on in-home but there are probably more out there than this.

This kind of gives you an idea of what we found and what we looked at. This table is in the discussion paper. It does compare, across the top, all the states, what we found that were for paid caregivers that we felt met the criteria. We found three that were for families or volunteers that we felt met the criteria.

This table is just showing you the top of it. We also looked at course materials, teaching methods and content. We took examples of them and showed you so that you could see what we have looked at. Just to kind of see if those components were in the documents. We also brought the six that we had selected.

I'm not supposed to say selected because they truly self-

selected. If they met the criteria, they were put into the group. So they're in the back for anyone who would like to see them.

The paid curricula, we divided them into the two -- paid caregiver training curricula. Meeting the criteria were three. The CNA for today is out of Milwaukee. It was developed in 2005 and it has 105 hours. This is all in that table if you want to look at it a little bit later.

It's done by the Stonewell Association and it was originally developed for a home caregiving agency for the training of their personnel. In the meantime, they have put that into a franchise and it is available for franchise.

This is out of Wisconsin and upon completion of this, their graduates can take the CNA exam from the State of Wisconsin. That was one of them that we selected.

The other one that met the criteria -- that again did end up in the group -- was the Elder Stay-At-Home from Springdale. We started this development in 1999, actually, completed the development and testing of it in 2001. It does meet the federal and state guidelines for CNA testing but the focus is on home. When they complete the 115 hours of our curriculum, they can take the CNA exam in the State of Arkansas.

The third one was Personal Care Attendant training program. This was developed by Mary Karpinski [phonetic,] out of her company Healing Arts Communication, in 2001. It's a thirty hour. So you can see the range. In the first one is 105 hours; ours is 115; and the last one is a 30 hours. There's quite a range and it was developed in 2004.

Then we look at the family and find here caregiver programs and we chose the American Red Cross. That was one that surfaced. Everybody that we talked to around this room -- around this table -- referred us to the American Red Cross curriculum.

It is nine modules. One hour a piece. There really is no evaluation in this one but we decided that maybe for families that was not quite as important as it was for paid caregivers. We went ahead and put it into the findings.

The second one that we found was Caring to Help Others. It comes from New Jersey. It was sponsored by a pharmaceutical company and had several organizations that helped develop

this curriculum. It is for volunteers. It's three levels and the hours vary upon the level.

Again, there is some evaluation in this one. Nothing that they have to do hands on. The questions at the end of the chapter, at least the developers did consider that trying to have some kind of an evaluation was important.

And the third one that we found was the National Caregivers Training Program. Again, this is Maryann Kapinski's Healing Arts Communication. It is an 18 hour and was developed in 2001. It focuses on the physical skills needed by families caring for a loved one in the home.

Those are the programs that we found. Again, it's not exhaustive but it does give a picture to what's out there. And if you notice, these were all developed in 2000 and forward. It is becoming much more of an issue for people and curricula are being developed.

There were many curricula out there. The main focus of those was across the lifespan. They were excellent curricula and they were curricula. But they did focus across the lifespan and we were looking specifically for older adults.

Another major finding is that as we look at all these curricula -- all these caregiver materials and programs that they vary, definitely, in content; the amount of content that was presented. We found it from 1 hour to 200 hours.

We found them just focusing on the physical skills, focusing on the psychological skills, just focusing on what the caregivers should learn about the business of being a caregiver.

We found that there was a great variance there.

As we looked at the literature, we came up -- and this is something that we found. It's not something that we found that somebody else had said. As we looked at this literature, we found two models. One was a comprehensive approach to caregiving. And this is like caring for all ages in all settings. In some papers, we did find the term "universal care worker". So that is one approach.

The second approach was the specialized approach to caregiving. This was the one that we looked at and we advocated the fact that caring for specific populations have

different needs.

Caring for a young person with a mental disability is much different than caring for an older adult who has a dementia. A lot of the things that we found were that an older adult was put with caregiving with someone with a disability. And it's to be discussed whether that's a good issue or not. The two models of comprehensive approach -- we'll give some examples of these in another presentation a little bit later.

Another finding that we found, as we looked through all this literature, is that the terminology is very, very, confusing. It's inconsistent and it certainly adds to the difficulty of a family of deciding who they are really trying to hire or use as a caregiver.

These are just some of the terms and certainly they are not an exhaustive list. When you look at these names -- these job titles -- and you wonder what in the world do all these people do. And some of them do the same thing. They're just titled differently. It's even hard for professionals to get a grasp of all of these names unless you really work in the field.

Another finding was that there are no consistent national standards for training caregivers of older adults and particularly for in-home. Now we do have some regulations for in-home care and those vary by state, but really no standards for someone who is not involved with a regulatory agency.

DR. DENNIS: Thanks Beth. And just summing this up, I want to acknowledge, as Beth did, that this was not a definitive or exhaustive study of an academic paper but I think it does give us an overview or a big picture glimpse of the current caregiving landscape.

In the few conclusions that we make, there's no consistency of the education materials, the format, the teaching methods, the demonstration skills. There's not an optimal standardization of training that we think would ensure the American public of competency among this workforce.

There is, as we acknowledged at the outset, a consensus growing fast, a shift that favors a more home-centered system of long-term care. To accomplish that we feel like one of the biggest obstacles is the shortage of well-trained home

caregivers.

That should be a workforce that has superior caregiver training because the studies show that the degree of disability and dependency of people residing in their homes and requiring care is very similar to those who are in institutions requiring care.

Jeremy, among the medical profession, I think, it's kind of like if you're working in intensive care, you're doing real medicine. If you're out in the hospital elsewhere maybe not so much. If you're in a nursing home, certainly not as much. And if you're in a home, you don't really need that much.

We would maintain that you actually need every bit as much and maybe more to work in the home. Especially since these caregivers are unsupervised and working in an unstructured environment.

So our conclusions leads us to the question, is a special curriculum needed for training in-home caregivers for older adults?

Those of us working in geriatrics, certainly, believe there are unique health and safety challenges working with older adults -- different from other age groups, as we've already mentioned.

We do believe it calls for information skills, attitudes and approaches that these caregivers should have. It adds training complexity to be delivering this kind of care in the home for the reasons we've also already mentioned.

And just reminding you that we are asking these paraprofessionals to often make very vital decisions out there on their own about an elder's care without the supervision and consultation that they need. And again, I would say that this worker is certainly not to be a CNA- but a CNA+.

Families and older adults are unprepared to evaluate what kind of caregiving options they have. There are certainly information resources out there that the family's often don't access immediately or have a hard time finding sometimes despite great efforts by many organizations to provide that.

And there's this presumption of training that even when a person's hired through an agency, often is very misleading.

And the public doesn't really understand and value the importance of professional training. Often, again, we have to mention the confusing titles.

These are six recommendations that are in your paper. We toyed with the idea of not presenting them as part of this presentation and I am self-conscious about the fact that this is really what we're asking you to come to. We're not presuming to have the answer for you.

So we're throwing these out as possible recommendations because we might not have the exact thing that you would prefer as a recommendation. I hope that the issues brought up by each one of these can be addressed.

The notion of having a more universal recognized title for this kind of in-home professional caregiver would be a big advantage, we believe -- Geriatric home caregivers.

We want to accomplish the fact that this person is trained specifically in the care of an older adult and specifically in the home setting but there may be another term that works just as well.

We do believe that there needs to be uniformed standards for training. It could be accomplished by creating a national standard for curriculum. And then a certification process would certainly be helpful.

Promoting career ladder -- you'll hear about more in a separate presentation today. And then, continuing education with respect to anyone else delivering any aspect of the care to older adults. Then accreditation of training curricula or programs.

Questions to set for discussion are, which Dr. Butler will be moderating, let me just run through a few. They are in your handouts.

Do we need a national model for training in-home caregivers of older adults? How about the family/volunteer caregivers? And does one size fit all? Or do we need different levels of training for different categories of caregivers? And how does public policy influence the supply of well-trained in-home caregivers? Are there public policy changes that could improve recruitment and retention? And maybe to just launch it, Bob, I think this might be the first question.

DR. BUTLER: Well, I don't want people to be constrained by these questions. So we have about forty-five minutes to open up, to have a frank discussion. I want to, first, thank my colleagues for their presentations. I look forward to working with you. Yes? Robert Kane [phonetic]

DR. ROBERT KANE: I would like to challenge a couple of the notions that we're doing here. The first one is, this ingrained belief among academics that confuse education with immunization. That the idea of some recent exposure to some kind of educational material, however packaged, somehow abused the recipient that comes - that some mechanism will immunize them to the vicissitudes of the real world.

It seems rather naïve. A belief in continuing education seems rather naïve because it doesn't work for doctors; it doesn't work much for nurses or the low level people. It's importing a model which has seen dismal failure across the education spectrum for people who are getting large doses.

If you look at your retention rates of information for medical students, I think the estimates are somewhere between 7 and 10%. And that's with four-plus years of exposure. So, perhaps, 10% of that -- 10% could be possibly useful.

You're talking here about hours of training. And I think it creates -- it may do more harm than good by creating the illusion that these people are really prepared.

What we know about education and performance is that environment trumps training. If we're really going to think more creatively about to prepare and support this workforce that we desperately need; and are going to need even more in the future.

I would suggest that we think about it in a different kind of a way. That we think about it -- entirely put a structure out there, an information structure that would, in fact, help these people to make relevant observations or respond appropriately, provide oversight, give them direction and guidance rather than try and sort of create this intellectual pate du foie of shoving down their throats, in a brief moment in time, some big bolus of information that supposedly is not going to turn to fat in their livers. I just think we're thinking in much too traditional ways about this.

DR. DENNIS: Bob, you're always full of ideas. Let me just move

around the room a little bit. Steve?

STEVE: Well, I take Dr. Kane's point as only one element of the much larger picture of how to strengthen this caregiving workforce. But I do think training is certainly going to be an important element of it. And certainly, what Beth and the rest of the staff has done is a real service in terms of surveying the field and understanding what's out there. I think, similarly, in terms of questioning the frame - you developed a territory that is looking at elder specific. IT's looking at the private for-pay only. You're looking at a national frame and you're looking at something that's really a curriculum based answer. Trying to make a standard based curriculum.

I think that makes a lot of sense as a business strategy. You are creating a very specific framework that is sort of defensible. It's very, very targeted and therefore, it's not surprising that you found relatively limited answers or curricula to a very limited territory.

But if you try to scale up in terms of policy, I think that that narrowness begins to shear the wrong way. Particularly for the worker prospective, I think in terms of creating public policy, we want something that cuts across the long-term care sector in terms of being valuable to the worker.

You want something that is both public and private because the world that we experience, we do a lot of work in a number of states on curriculum. We work with a number of stakeholders in states in terms of developing these standards that agencies, many agencies, not all, both public and private -- workers go from public to private -- to have a single certification for only private, I think, it sort of reinforces the status -- looking only at elders, looking at reinforcing the silos.

We all know that, in terms of long-term care, it's state by state. We have 50 long-term care systems in this country, at least. Creating certification issues and licensing issues, particularly, is a state by state issue.

So the work that PHI's been doing is much more state by state. Is much more trying to create training that is based on competencies rather than curriculum. That competencies - while I definitely agree that there are special needs of particular populations -- there is, in fact, a great set of

competencies across long-term care for workers. And that what is helpful is to figure out what are core competencies across the board.

And then, what can you train, in terms of specialization -- particularly adaptive skills of problem solving and communication et cetera. If someone finds themselves in a different setting they have the skills to know how to adapt.

I'm concerned about the basic frame of being a good business strategy but not so much a great public policy strategy, so that we can give workers credentials that are valuable across settings -- that are valuable across agencies providing systems.

DR. BUTLER: Does that include institutional and non-institutional?

STEVE: I think so. I think there's just a real concern that -- I mean, PHI grew out of home-care. We run a 1000 worker home-care agency. We train 500 people a year. We came out of home-care but we also do a lot of work in nursing homecare.

We tried for years to keep my mother-in-law in her home and that tore up the family enough that we finally had to help her find a good residential setting.

I think it's a mistake to say that even though it's true that all of long-term care is shifting more toward home communities and we want that. It's still really important to have institutional settings.

CNA is still not good enough for residential care. We need to make sure that we raise the standards of all workers in all settings because we're going to need all those settings. And we shouldn't try to reinforce the --

DR. KANE: I think it was first quality in terms of, I assume, codifying. In terms of, I imagine, the whole way of how you manage the worker at home in terms of case management.

MS. VAUGHAN-WROBEL: Well, I just want to basically agree with the first comment. Because I think the issue here is not whether you can train someone to the point that they can function independently. Since nobody in health care functions independently they -- the very fact that people who have limited training, which I agree we need to look at the training and raise the bar -- are functioning alone with

people who have complex care needs. Doesn't make sense as a system.

So, again, I think that the training is important but I think looking at the structure around the training that provides - not just the information and the competencies - but the ongoing support is critical. I don't think you can look at training without that.

DR. BUTLER: Thank you. Dr. Boal [phonetic].

DR. BOAL: You know, Bob, I was thinking about this. I somewhat agree with Bob. I'm not in disagreement with other people. But it occurs to me that, possibly, one of the most important things that we can do is make the country and families aware or what their elders should be able to expect in the way of quality of care.

And I say that because so often, what happens is when people are being cared for they feel so much as if they are at the mercy of the individual who is caring for them. And they often times feel that they have no right whatsoever to complain about the quality of care.

And thinking about a special friend of mine, right now, who is in the process of dying, she has breast cancer that has metastasized. She's now receiving respite care. She's in the same city that my sister lived in and my sister passed away, also, from breast cancer.

And when my sister was dying, I actually had to intervene with the people who came to help care for her because they were giving her terrible care. The friend who's dying, who is a physician herself, said she is experiencing exactly the same thing. And she was not willing to go farther than she already had to assert her rights.

So although she's in Seattle and I'm in New York, I said to her, I will get on the phone and I will make them do their job, if necessary.

So I do believe that while we spend time training people and measuring the outcomes, that perhaps they will be able to achieve through educational programs just as important will be conveying to the public that there are certain minimum standards that we ought to have in relation to the care that we are given. And I think we particularly need to make sure that the message gets through to those individuals who may be

vulnerable.

DR. BUTLER: Lynn. I'm sorry -- I mean -- please.

DR. EMANUEL: Linda. The points that have been made, I think are very important and I would, actually, strongly agree with Robert Kane. And I think we have some solutions pretty well right-off the bat that fall out of your presentation and the collective comments so far. We have the unpaid versus the paid caregiver.

And I think we have an option to think about a policy that would put together what we already have which is the Medical Family Leave Act with our Medicare/Medicaid programs. Because we've got a population of people who have some limited and little used options to stay home when there's someone ill in the family.

We can build on that; expand on that and layer in with it training programs that would allow people in the family to become paid givers that are legitimate and policy supporting. We could then, even, provide those that fall off their current employment ladder to get on another employment ladder.

We could have better care; monitorable care that we have tabs on. We could require standards for. We could hook into some kind of virtual. We'll hear about technology later. Some kind of virtual mechanism for monitoring standards. And we could mitigate some of the economic devastation that comes with chronic illness as well.

All by building on the Family Medical Leave Act and connecting it with our existing Medicare/Medicaid. I think, that by going along those kind of policy lines it comes out of the data you've already provided us. We have a way of saying, yes, Bob Kane is right.

The curriculum is not going to solve it and a nursing course is not going to solve it but if you combine that with some sort of virtual college that's hooked to policy and that looks properly at the full economic picture, that goes along with the health issues, we could build something that is actually amazingly viable given that we've got something like a five-fold increase in the debilitated population coming down the pike.

DR. BUTLER: Makes things easier --

DR. EMANUEL: I'm sorry?

DR. BUTLER: Go ahead. Complete.

DR. EMANUEL: No, that's fine. I'm finished.

DR. BUTLER: Just wanted to make it easier for the transcriber, Dr. Linda Emanuel. And now Carol Levine.

CAROL LEVINE: Well, I think that there's -- I have a lot of reactions but specifically to Linda's comment. The Family Medical Leave Act is medical leave without pay. I would not have been able to take leave - Family Medical Leave Act for 17 years to take care of my husband.

DR. EMANUEL: That's why it needs to be built on.

MS. LEVINE: The other thing is, I didn't want to. I wanted to have a life that was not solely devoted to caring -- total care for a totally disabled man with cognitive problems. I wanted to have a life.

So I had hired people to help me do that. And I think what is missing from -- what I haven't heard -- I don't know that it's not there but is what this is all about is managing the relationship between the family or the consumer, the patient and the paid caregivers -- whether they're independent or agency. And that's where the system breaks down -- that relationship.

And I don't know of any training for family or for paid in-home caregivers that really works on that relationship which is where the problems that Janette was talking about come about. Where either people feel intimidated and I don't want to upset this person. Or they fire them immediately and they're out of there. And they call -- the daughter gets the call. Your mother fired the latest homecare aid. Why? Because she doesn't like the idea of being dependent.

It's the expectations of what each of these essential partners can do should be doing and how to work out the problems that arise. That seems to me, much more important after you've learned the basic skills -- the basic competencies which, I agree, have to be learned, probably, in that kind of curriculum and then how do you work that out.

I don't know if that's something Jeremy's team works with but in my seventeen years of experience that's what made it work

when I had workers that I could negotiate with. They would tell me what I needed to know. I could tell them what they needed to know. And we worked it out. The Family Medical Leave Act, California's at least paid something but it's not going to take care of these long-term years and years and years of needing care. That's enough.

DR. BUTLER: Dr. Jeremy Boal [phonetic]

DR. JEREMY BOAL: I just wanted to back it up a little bit and focus on the issue of competencies because I think as providers, who have been in the field for years, when we reach a point where we have a very good relationship with the family and the caregiver and when we're all communicating very well, the patient gets the kind of care they need.

It's very hard to get to that point unless the circumstances are really ideal. Before we do anything else, we still need to develop a set of core competencies for everybody. We need a set of core competencies for the paid caregivers. We need a set of core competencies for the family members who work with paid caregivers in terms of how to work with paid caregivers. If we can develop that, we have a hub that we can then build on in terms of policy and in terms of everything else.

When I was in the field seeing patients, after ten years of working with caregivers, I still didn't have an idea of what the core competencies were for those paid caregivers. I had a pretty good idea but what I viewed as core competencies could be very different from my colleague who had different experiences.

There still was nothing to turn to for us to be able to say to the family, this is what you should expect. For the paid caregiver to be able to turn to -- to say this is what I'm supposed to do. So I still think that is a -- whether we imbue that through traditional training or through other mechanisms -- is, I think, the first issue.

The second issue is what are those core competencies and can we agree on them.

DR. BUTLER: Marie Bernard.

MS. BERNARD: I would just insert that as we're thinking about these issues, we should also think about what that caregiving group is likely to be as time evolves. We have an ageing

population that is becoming more diverse. We also have a caregiving population that's becoming more diverse. There will be issues.

We've talked several times about communication. There are issues that will result as a result of caregivers who have very different backgrounds than the care receiver. That needs to be part of those competencies that we're addressing.

DR. BUTLER: Steve.

STEVE: Just briefly, for Dr. Wrobel. That the National Clearinghouse and the Direct Care workforces collected a number of different efforts across the country that focused on core competencies of direct care workers and that's been developed and published and is also being worked with at the US Department of Labor. There's a lot of work that's being done on that, in terms of looking at what those core competencies are.

DR. BUTLER: I think you've been trying to say something down there. Mary Jo Gibson.

MS. MARY JO GIBSON: Yes. Just on the issue of what the core competencies may mean. I wonder if those could include -- I don't know how you try and base a competency in communication and interacting with patients and families, care recipients with dignity. But to enhance their feelings of privacy and dignity and their own competencies.

But that is, I think, a paragon that's really important. It's not just the quality of care; it's the quality of life. Certainly, from my personal experience and experiences of a lot of caregivers that I've spoken with, breakdowns often occur, as Carol was suggesting, around these issues of major communication barriers.

I don't know how that is addressed in curriculum. I don't know how that is taught. I'm just putting it out there as a big problem.

Another being, two, the lack of back-up support. That happens very frequently when a caregiver -- the usual paid caregiver does not show up, it's a nightmare for family members in the workforce, particularly in many instances but it relates to the whole issue of what that environment can be that's supports both the family member and the paid caregiver in the home.

DR. BUTLER: Gloria Fine.

MS. FINE: I have to say, Wow. First of all, there are so many issues here but for me, the first one has to do with taking the elephant out of the room and acknowledging the fact that we're dealing with a certain element of ageism here and a lack of understanding in our society that there are certain needs that people deserve when they're old and sick.

And that it doesn't mean that their life -- it's not that they're patients -- they're people. So these core competencies have to do with developing the training to teach people how to work with people.

At Senior Ridge, I've been frequently quoted as saying, "You know, this is brain surgery." What we expect of a caregiver is brain surgery. It is really hard, hard work. And it is sophisticated work. And yet we're paying people \$7.00 an hour who come very difficult backgrounds; who have very little education and sophistication. And they're going into these very difficult situations.

What we've done at Senior Bridge is to work around the problem because that's all we can do. Nobody's going to pay \$40.00 an hour for the kind of person that needs to be there to take care of mom in the way that they've fantasized that mom should be cared for.

So what we do, is we provide the support around that person. I don't think that's an answer long term. I think that it's a very, very complicated problem.

One more thing, the regulations in states really don't address the fact that people are living with clinically complicated issues at home.

Dr. Boal, as you know, people are blind and need to put drops in their eyes and they live at home. We can't have a caregiver do that. It is against state regulations. Someone has to pay for an LPN to the tune of \$35.00 an hour to put drops in someone's eyes, if the family wants to outsource so they can have a life. These are major, major problems on all levels. It's beyond training.

DR. BUTLER: Greg Greene.

MR. RICK GREENE: I want to get back to the caregiver training programs that were identified. Then I would like to follow

up on this, also.

Under the National Family Support Caregiver Program, we did award a series of grants out for the development and evaluation of caregiver training programs. There are a few that you may not have had an opportunity to look at.

One was the Powerful Tools for Caregivers which was originally developed by Legacy Health Care out in Portland, Oregon. The grantee was Mather Lifeways [phonetic]. This is a program -- I think part of the confusion is terminology right now. We're talking about caregivers and caregivers.

In ageing and in caregiving, we refer to the family caregiver as the caregiver and we refer to the paraprofessional coming into the home -- well, as not a caregiver but a paid employee. Depending on who you spoke to and how you phrased the question, that might have elicited some of the responses.

Another program that you might want to look at is called Caring at Life's End and it was developed by the Hospice of the Florida Sun Coast. It's a phenomenal program. They actually have done some trained trainers around the country. It can be implemented within the states.

The third program, I think you may have touched base with them but I'm not sure because it doesn't seem to be identified, is the Area Agency of Ageing. It's based in Cincinnati. They actually had an in-home caregiver training program that went into the home, assessed the family caregiver and taught him or her the skills needed to care for their loved one.

Those are three of them. Before I came to AOA, I ran Caregiver Services for the State of New Jersey for close to thirty years. Thanks to all of you who came to Atlantic City because casino monies were used to nurture caregiving programs.

One of the programs we did use was a program developed by the Rosalyn Carter Institute called Caring for You, Caring for Me. What we did is we modified the way they had originally implemented it. And again, we offered it around the state and it was evaluated by Rutgers University and that evaluation -- I can tell you where you can get that one.

State by state, I agree the certification of rules are different. I ran the Homemaker Home Health Worker

certification program for New Jersey. We wound up supplementing the training for Home Health Aids that was required at the time by -- at that time it was HIFFA.

Many of the states have also developed specialized training programs for in-home, adult day, nursing home personnel. You may want to survey the state health departments who are -- I can help you survey the state units of age and that might generate some other additional programs.

I think, switching back to some of the other comments, I think one of the areas that we have to focus is educating the family caregiver. What to expect when an aide comes into the home. Especially, if the aide is a private pay and not affiliated with an agency. What his or her expectations should be of the aid; what to look for in hiring the aide; what supervision and what are the responsibilities of both the aide and family caregiver. We can learn some of this from the Cash In Counseling Demonstration. Thank you.

DR. BUTLER: Lynn? I haven't heard from you. Lynn Feinberg.

MS. LYNN FEINBERG: Yes. Thank you. I'm sitting here thinking. I feel like I've been in these meetings before and you have all labored long and hard about some of the issues that we're grappling with today. I'm really struggling with the terminology issue.

I'd be interested to see what Steve -- your perception of the term caregiving which doesn't always work very well, as we know, for family members that are caring for an older spouse or parent. It gets very confusing when we confuse the paraprofessional workforce with family care issues. It's very confusing. I would hate to see this very important project go down that road that can, in some ways, divide us more than bring us together.

I think the most important take-away, I believe, is that families are doing the mainstay of long-term care in the home today for older people. Paid care is rare and uncommon.

That's not to say, of course, that we need to do a better job recruiting and retaining direct care workers and certainly we do. It really is families that are doing the bulk of the work, unaided and only at the very, very end of the home care journey do they seek out paid help.

The communication issue is really the key. I would agree

with Dr. Kane. I think that this is a larger issue in terms of chronic care management that really need to grapple with in terms of long-term care.

Continuing education training has not been successful, certainly, in the physician community. I say that as a social worker. If we could think out of the box and perhaps think in terms of public policy of some opportunities of chronic care demonstrations that might get at some of the issues that we need to look at in terms of direct care and training. That might be a way to go.

DR. BUTLER: We haven't heard about end of life care, Dr. Diane Martin. And palliative care.

DR. DIANE Meier: Yes, let's call it Palliative care because palliative care is not restricted to end-of-life care. Palliative care is medical care or health care focused on the relief of suffering and support for quality of life at any stage of a serious or chronic illness.

As I have been saying to reporters all over the country -- Elizabeth Edwards' metastasized cancer is not a death sentence. It means she's going to live with cancer as a chronic disease. She's not going to be cured but she can live for a very long time with breast cancer metastatic to bone. Yet, everyone seems to believe she's terminally ill. She's not. That is true for many, many cancer survivors as well as most older adults. They have multiple, chronic illnesses and they live for a very long time with major functional needs as well as palliative care needs. The two are the same.

If we're going to talk about training, competencies and support of environments, and I agree strongly with Bob Kane that the training is something that we can say we did it but it doesn't have much, if any, influence on quality of care.

The work environment -- how the work environment is structured, how the respect for the paid caregivers as well as the clients is established up front. When you're in a real workplace, you know what your rights and responsibilities are. You have a position description. You know where to go if you have a problem. There are methods in place for resolving disagreements or uncertainties. None of that exists in the paid home-giver environment.

When I was hiring help for my parents, it never occurred to me because I didn't have any resources, that there should be a clear, written description of what the expectations were on the people we were hiring. Were they going to do dishes? Were they going to do laundry? Were they going to do grocery shopping? We never talked about it. Were they going to fill the medi-sups?

All that sort of thing. Technical assistance is what we call it at the Center of Advanced Palliative Care. With the human support -- that front-line support whether they're doctors in the hospital or paid caregivers in the home -- have to have in order to continue to do this work. It's much more about the structure of the environment and the supportiveness and the rules that apply to all parties and are agreed upon upfront than it is a certificate if I got trained.

So all the caregivers -- the paid caregivers caring for my parents -- all got their certificates because otherwise we couldn't collect on the long-term care insurance. They couldn't afford to get the training for the certificates so I paid for it.

The training was, I'm sure it met the check list, but it was irrelevant to the work that they were doing for my parents. Most of the good people, I know from my work as a geriatrician, don't have that certificate because they can't afford the \$3000.00 to get it.

DR. BUTLER: This part of our discussion -- we have about five more minutes. I'd love to hear John Crews say a word about the CDC.

MR. JOHN CREWS: Well, I'm not going to talk about that. Actually, I always try to have the role that Bob Kane does to say something provocative enough that it controls some of the discussion. I don't think that I can trump that.

I do have some random comments. I have become a super expert in caregiving for those people who are not my friends around this table, I have a 26 year old daughter who has cerebral palsy and I keep trying to get her to go off to graduate school.

But then, my mother-in-law, who is from south Arkansas, moved in with us about a month ago. She has a broken hip. We kind of know caregiving, big time. I have some random thoughts

and if you can fashion them into some kind of whole, I challenge you to do so.

Number one, I would just urge you guys not to have this kind of exclusion criteria of just looking at ageing and not looking at disability because I think that the disability community has much to say to the community that are comments about control, who's the boss in these situations. There is much to be learned. I would not exclude that by any means.

I think the other thing that I would just observe is that there is in our discussion and the examples -- is the human experience of receipt of caregiving. There is a distinction between disability and health.

Many people do have substantial complex health needs that need to be addressed. Many people just need assistance with ADL. It's not really a health issue. It's a disability issue. That can be addressed differently from a medical model. I think we just need to think about that.

The other thing that occurs to me in terms of the core skills is that, I think, there is a core set of knowledge or a core set of behaviors. I don't know what those are but if; in fact, part of the training of an attendant is to say, if you're going to wash somebody, would you use warm water? If that's part of the training -- it doesn't just occur to you to turn on the faucet and get some cold water and start washing somebody's face. Many times you're in that.

That's where you have to begin. You have to cover things that seem fairly reasonable to the meanest intelligence. Let me give you a specific example, yesterday morning -- I won't give you all my stories. I'll save those for some drinks but -- I left my home yesterday morning. At 9:00, my daughter's attendant showed up. At 9:30 my mother-in-law showed up. They're all getting paid. And these two people -- one of them weighs over 300 pounds -- they are eating us out of house and home.

As I think about that interaction, my daughter has a very rich life, very involved in the community. My mother-in-law sleeps a lot and watches Wheel of Fortune; which I did not know was still syndicated. I've learned lots of things about not being overly critical of my mother-in-law but there is a commonality in this care giving and there are differences.

You know, the bathing is fairly common; getting a meal on the table and the courtesy is fairly common; the control is fairly common. But there are differences and we need to sort those things out and not say these are independent experiences. There's a Venn diagram. There's commonness and there's differences. We need to recognize all of that.

The other thing that I had not heard about is what's in it for me? We pay her \$10.00 an hour for attendant care. If I don't make \$10.00 an hour, what's in it for me? Am I going to get 110 hours of training; spend three weeks doing that; pay some tuition and then make \$10.00 an hour?

I don't have the money to front it. I don't have the time to front it. Somebody's got to pay that. We've got to think about career ladder. I don't know what ladder. It's maybe a step-stool. There's not very far you can go in these things that I'm aware of.

Now the other thing, Diane is talking about what the person's going to do. It's what you're going to do. If you're hiring these people personally, then you got to go W-2 -- W-2 and withholding and pay workers' compensation? I do pay. When we were having private pay, I'd sit down once a week and I'm doing all this and I got sued \$100,000 by one of Kate's aides. A \$100,000 lawsuit against me.

If I didn't have worker's comp, I'd have a \$100,000 less. People get into these relationships -- they need help, they call a neighbor up and they say, I need somebody to help me. They hire them.

There are broad assumptions made about what they're going to do; what the interaction is going to be. It kind of fizzles; takes different trajectories; and that's probably what happens in most of the cases of caregiving. It's not that the agency's too expensive. People try to work that out.

But you assume -- the person who's doing the hiring -- you assume major liabilities by having an employee. If you're hiring more than, what is it? A hundred hours a year? You have to file -- you have to do W-2 and all that. And many people don't.

The final comment is this, what I love are people like Linda who think big picture integrating all these policies and I think we need to take these specific experiences and really

try to figure this out into some kind of national well-integrated policy. I can't do that. I can't get my mind around that.

I think we do understand a lot of the elements that are probably relationships, funding sources, public policies that can be integrated in ways that are not, and certainly if we've got the numbers, that they be boomers like me coming down the pike. There's great pressure to do something.

DR. BUTLER: All right. We're right up against the coffee break. One more comment from Humphrey Taylor.

MR. TAYLOR: I have a hobby horse; which is I go to a lot of conversations where nobody talks about what is happening in the rest of the world. Guess what? I'm from the rest of the world. I have a brother in England who has a wife who is bedridden with Pick's disease and he has twenty-four hours/seven days a week care from aides, who look to me, to be pretty good. Caregivers with a pretty good idea what their training is -- paid for fully by government. I hope that part of this project that we really will look at the best practices in the rest of the world. Though many of them may not be politically achievable here.

The second point I have is that this is an incredibly difficult set of problems and we should always remember Voltaire who said that the perfect see the enemy in the good and if we can make improvements, that's wonderful without necessarily solving all the problems I've heard mentioned here today.

DR. BUTLER: [...?]

FEMALE VOICE: I wanted to just put my two cents in, too. You know, I'm really responsive to everything that is said and I began to think about the gatekeepers. That we really have to look at the agencies that are providing these caregivers and really get them on board because they are, in fact, the ones who are influencing the people who are out in our homes.

And I also want to comment that, I guess, we have to start somewhere and I appreciate what you said because this whole issue of societal need to get more caregivers, to pay them better, to elevate the position, to get a better public policy, is something we all want desperately.

I think we're also committed around the table. It would be

important, I think, to kind of hone in on the training piece for what component it may be today. And really say let's start somewhere. Maybe we start with the agencies that are providing homecare workers and not think so much about the workers who we, as family members, are going to hire. If we can try to contain ourselves a little bit today, then we'll have some building blocks and that's what I wanted to say.

DR. BUTLER: I can't quite identify you because the light. Someone is furiously raising their hand at the back of the room. Identify yourself.

MARGARET BARAN: I'm Margaret [Baran]. I'm from San Francisco. I run a very large publicly-funded home-care agency and I'm on the mayor's advisory council for long-term care.

What I just want to say, from the worker perspective, I think it's important to remember that all the training, communication training, relationship training, is critical if you want to retain the workers. My workers, who have to go into extremely difficult clients -- they're not particularly nice people, a lot of them -- very difficult, very challenging conditions. -- will not stay in this field or at that job or in that client's home if they don't feel comfortable that they have the skills to manage the situation.

We do have supervision at my agency. I have case management but you're not in the home with them. It's critical, that we have learned anyway, if you are going to retain these workers, that they have to know what they're doing and that they can handle these incredibly difficult situations.

Without training, they don't feel it. It's not to say that they will retain all of it or not but we've just seen a large difference in terms of people staying in this field. We need them to stay in the field otherwise we're totally down the creek.

DR. BUTLER: Thank you. Well, you've done exactly what I was hoping you would do. You were critical. You came up with the obvious complexities of the situation. We plan to be very responsive to that but at the moment we get a coffee break and I would like you to be back by 11:15. You can bring your coffee with you or whatever and we will reengage. Thank you very much for your participation.

[END TAPE 1]

[START 089_936-TAPE 2.MP3]

[Background noise]

EVERETTE E. DENNIS, PHD: It's my great pleasure to introduce our senior advisor for our project, Gail Gibson Hunt, President and CEO of the National Alliance for Caregiving who will now speak to us.

Do you want me to get out of the way of this?

MS. GAIL GIBSON HUNT: No, I think if you sit down-

DR. DENNIS: [Interposing] Okay. Okay.

MS. GIBSON HUNT: -everybody should be able to see.

DR. DENNIS: Alright.

MS. GIBSON HUNT: Yeah. And I just mentioned that my last name got left off that, but that's okay.

DR. DENNIS: Oh.

MS. GIBSON HUNT: Because my dad would be really proud. He always thinks that's cool. And always says be sure to give the middle name.

So I'm going to talk about the interface between family caregiving and paid caregiving. And let me just say I was little confused right before the break about who's the specific group that we should be targeting today.

And the kind of personality I am, I was, sort of, looking at the end result. What is it that we want to come out with? And so I have been clarified by the Schmieding Center people on what is the target population we're really focusing on for training.

And it's the paid caregiver who is working in the home who does not work for a home health agency. It's basically the person that the family member has gone through the newspaper, or word of mouth, or whatever and has found. And that person is doing the paid caregiving in the home. So if we can, kind of, keep that in mind as the person that we're thinking about. I think that'll, kind of, clarify it for-it certainly did for me anyway.

MALE VOICE 1: Freelancers?

MS. GIBSON HUNT: Freelancers is one way to think about it, yeah.

So just very briefly about the Alliance, we do national research around family caregiving, actually, a lot of national research. We work on national policy issues. We develop programs to reach out to caregivers through what Carol Levine [phonetic] was calling gatekeepers, like librarians, and financial planners, and OTs and pharmacists. We work on public awareness of caregiving issues, a lot of media work and work on the Hill.

We've most recently become very involved working to strengthen the state and local caregiving coalitions. And there are about 70 of them around the country to really create them—strengthen them into a virtual network that will—and we're training them in advocacy so that they can begin to advocate as a very powerful voice for family caregivers.

And then lastly, I do a lot of international caregiving work. And specifically participate with other caregiving countries; countries that have caregiving organizations in an international alliance of caregiver groups. And the Alliance is a coalition of about 45 national groups that have come together around the issues of caregiving.

So in talking about the interface here between family caregivers and what I'm going to call direct care workers, training needs, obviously, is one place where you can see the relationship between the two groups coming together. And increasingly it's seen as both needing similar training in particular aspects.

And United Hospital Fund, for example—where Carol Levine works—a couple of years ago came out with a study that showed the lack of training needs that family caregivers have as well. We've heard a lot about the lack of training that the direct care workers have. But the family caregivers also don't have this.

And as Lynn Feinberg [phonetic] reminds us—and I'm just going to say it again—the vast majority of the work—the long term care work in this country—is done by families without paid help. So those family members are doing precisely the same kinds of transfer, dealing with nutritional issues, doing wound care, all of the things that nurses actually used to do

when the person, for example, is sent home from the hospital. Those are being done by family members, as well as in some instances, direct care workers.

Susan Reinhardt [phonetic]—who's a nurse out of Rutgers—testified just a week or so ago before the National Commission for Quality Long-Term Care. And was talking about the fact that nurses, social workers and other professionals need to be brought together to identify potential strategies to support family care givers across all settings, especially transitioned from hospital to home.

And especially as we're having more Money Follows the Person, which is a federal program that's being pushed by the Administration to really have money go with the person, and therefore—in whatever the setting the person is—therefore, the money is now going to be going home rather than to the institution.

So another question is along these same lines, I thought I'd mention that the Rosalind Carter institute has really decided to change its whole focus from what it had been in the past. Its dropping this group they called the NQCC. They have decided to create a quality care network that's really going to be looking at—and has already started looking at—evidence-based interventions that involve the family caregiver, as well as professional and direct service workers.

The first component they're looking at is the pulling together. They are having—NCI (National Cancer Institute) has done this for them—to examine training to see which populations have the best outcomes. So they're looking at evidenced-based training, specifically across both direct service workers and family care givers to see which populations are most affected. And then they're really looking at how changes have been made—systems changes being made.

And then also there is—just brand new, in the last couple of weeks—some real interest by Congress in this. Is there some interface of training needs between family care givers and direct service workers? Although I will say that when Congress is talking about this or CMS they're not limiting it to people who are outside agencies. In other words, they would be including direct service workers who are part of agencies, so just to make that distinction.

And obviously, some of the places where there's overlap in training would be things like personal care skills, transferring, nutritional needs; those kinds of things that really is reflected in the American Red Cross training program.

And then also stress management, that's typically not thought. That's something that comes up in almost all the programs for family caregivers. But it is something that certainly could apply to direct care workers as well.

Talking about assessment of skills and abilities, this is another area—am I doing that?

MALE VOICE 2: No, it's me. I'm sorry.

MS. GIBSON HUNT: Oh. I was, like, look, nobody's moving and this is happening.

MALE VOICE 2: My fault.

MS. GIBSON HUNT: Oh, okay. I thought I was bumping something, sorry.

On assessment of skills and abilities, not all direct care workers are going to be equally able to do all the tasks that are required to care for this person. And there really needs to be assessment.

And we're seeing assessment coming up in quite a few states. But it's directed to the family caregiver. So their states are being interested. In some states—Minnesota as an example—they have moved ahead with an assessment for family caregivers. I think there's one that's in New Jersey; in some parts of New Jersey. As well, there's one in California. So there are states that are interested in assessing the skills and abilities of the family caregiver, just not assuming that the person is capable of doing everything.

And centers for Medicare and Medicaid services—CMS—at some level is also exploring assessment for family caregivers as is the VA. The VA is beginning to develop assessment tools for family caregivers, too. And the idea is not just what does this person—in the case of the family caregiver—not just what does this person—what skills and abilities do they have, but do they have needs themselves? Are there things that they need for support services?

And actually, that has brought up a question that came up in Chicago at the American Society on Aging meeting that was characterized as; is the family always the best person to provide the care? So that's clearly at the intersection of this discussion we're having of direct care workers and family caregivers. Is should we be looking at; is the family caregiver always the best person to be providing the care for that individual care recipient?

We've touched on, a little bit already in our discussion, the communication issues in diversity. And the, sort of, mismatch between the formal organizational structures; the way that even the home health system is in place versus the tasks expected of the family. As well as the family's expectations of what should they reasonably expect of this person that's come into their home? What should they be able to expect?

And like, John Crews [phonetic] was talking last night, as well as his stories today. Should we expect the care workers to be cleaning up after themselves? Should we have reasonable expectations of their being able to do some tasks that support the family more broadly; maybe some cleaning, maybe some cooking? Or should they just be focused on sitting there for eight hours while his mother-in-law sleeps, or watches "Wheel of Fortune," or "Jeopardy," or whatever it was she watches"? Reruns of "Law and Order," that's my favorite.

So there is that mismatch. And there have been a number of studies actually done on discrepancies between staff and family perceptions of appropriate tasks. And a lot of these have been done in facilities that the barriers to communication, really, staff—not just in facilities, but in the home—have time pressures that perhaps the family does not recognize or doesn't know how to deal with. Families are hesitant to make suggestions or criticize for fear of retaliation when they're not there.

And there are differences in, sort of, ethnic and socioeconomic groups. And that's been touched on, too, that as both the families grow older and become more diverse, and the paid workforce becomes more diverse, there's more difficulty sometime in communicating between the two groups, because of cultural issues.

One solution that was offered by Pillemer, but it was with nursing home staff, but its, kind of, an interesting idea, was training programs for both the paid staff and the family caregivers in what they called active and empathic listening. It would maybe be nice to have that.

I'm not sure that given what we've heard, we're at an earlier stage. Maybe we could tack that on, sort of, later on as a part of what you get as a booster shot after you've already been immunized in Bob Kane's [phonetic] concept.

And then there are studies that have shown that you can have stress management, for example, for Latino family caregivers that might also be adapted, say stress management to Latino paid direct care workers.

In terms of care coordination, that's really the intersection where both the family caregiver and the direct care worker are trying to execute this plan of care. So the questions that come up here, I think, are who's responsible for what in the home?

And who is really overseeing the care? The family member, certainly, is overseeing the care for the older person. But then sometimes there is a supervisor or someone that is also supposed to be overseeing the direct care worker.

And then we've got the relationship of the Doc, the care manager, the nurse who may be working with the family caregiver and the direct support worker. And that whole thing about how they work together to carry out the plan of care, and look for smooth transitions and create smooth transitions is really a nightmare of an issue.

And then lastly, the relationship of the family caregiver and the direct care worker, and how those two get along in terms of coordinating. I thought this was, kind of, interesting along the lines—not directly dealing with training—but it is a very interesting idea here. And this is blurring the lines between the family caregiver and the direct care worker.

And some of the things that we're finding here having to do with this is the numbers of direct care workers who are also family caregivers in their real lives. So they're out there doing that. And there was an informal survey that was done of Home Instead employees. And they said that 60% of the people who are Home Instead employees who go into the home—

home care workers—were also family care givers at home. So that's, kind of, a blurring of the line. It's not quite so clear.

And then under consumer direction, which has been mentioned recently, we are beginning to move much more into the area of paying family caregivers. So it's no longer family caregivers and paid caregivers, because some of the family caregivers are now paid caregivers. And 15 states have now some version of Cash and Counseling, under which family caregivers can be paid to provide services; the niece, or the granddaughter, or the son, can be paid under Medicaid to provide services for the care recipient.

And that brings up questions of; is this person now a direct service worker? A sort of, blurring the line between what they were—just the family caregiver—are they now a direct service worker? Should they be required to have certain training? Should it be the same kind of training we're talking about? Should somebody be monitoring them to see that they're providing services?

And then we also understand, in some states, where they actually had paid—California's one example—where they've had paid caregiving for quite a few years, not just under Cash and Counseling.

The SEIU is requiring these family caregivers to become a part of a union. And the concept here, I think, is that they have a career as this. That's why they're in the union and they're paying union dues, because this is a career, when in fact, these people are doing this job because they're family. This is a family member. I'm caring for my mother.

And when my mother dies or something happens, I'm not going to do this anymore. This is not a career. But I'm just, sort of, mentioning this, because it really is an interesting blurring of the lines issue.

And it's also been suggested—and some work has been done in the EU actually around this—about we could boost the supply of family caregivers by recruiting them into getting them to become paid caregivers. So you wait 'til the family caregiver no longer does this job—doesn't feel that they have to do this job—like Bob here, we could take him. He was a family caregiver. And now he doesn't have to do it anymore, so we'll recruit him to be a paid caregiver on an ongoing

basis.

BOB: \$10 an hour.

MS. GIBSON HUNT: At \$10 an hour, exactly.

MALE VOICE 3: Seven.

MS. GIBSON HUNT: Only seven for you. That's right.

MALE VOICE 3: He's not experienced enough.

MS. GIBSON HUNT: That's right. He doesn't have enough of that experience.

But the idea here is that it's really creating some interesting philosophical issues, I guess, as well as economic issues. Because the whole reason the EU got into this was they saw it as a macroeconomic issue.

How do we get these people who have been out of the workforce for a number of years back into the workforce? Oh, we could just train them a little bit more and morph them into paid direct service workers, because that's what they were doing before for their family member.

So lastly, I had already put this up—a word about terminology—before we even got into the discussion. And I'll just say—and other people around the table have been very involved in this issue as well.

The family caregiving field has worked for quite a few years to get the term family caregiver with the word "family" at the front to refer to any people who have this, sort of, emotional attachment. Whether you're related directly by blood, or whether it's a neighbor, or a friend, or a partner, or whatever. That's the family caregiver. And they really prefer that the word "caregiver" not be used by anybody else.

So Docs use that all the time, which seems extraordinarily inappropriate, actually. I mean there are lots of terms for doctors and all that. But the doctors and nurses refer to themselves as caregivers. And of course, so do all the other people; the people that come into the home and all the different aides. They call themselves caregivers. And it's really gotten to be very confusing.

So if there were a way to identify these other groups, especially the people who are in-home, because that's used

all the time; the in-home caregiver or the formal caregiver or something. All of those terms create some difficulties for the family caregiver.

If we could find a word and push it out. And get people to agree on it. And it doesn't have the word "caregiver" in it. That would be great. That's why I used direct care worker.

But you know, we could call 'em whatever. But just so they're not called caregivers. 'Cause terminology is becoming an increasingly difficult issue, as we've even seen here just this morning. So thank you, very much.

DR. DENNIS: Thank you, Gail. I think you've added to the complexity.

MS. GIBSON HUNT: Sorry.

DR. DENNIS: You know, the International Longevity Center actually has centers in five developed countries and poor developing countries. And Humphrey [phonetic] earlier mentioned the national system that provides total comprehensive funding for the care of his sister?

HUMPHREY: Sister-in-law.

DR. DENNIS: Sister-in-law. One of the interesting things we discovered, in the transcultural sense, was Germany under their long-term care system, will pay family members for the provision of care.

Japan, which adopted essentially the same system as the Germans, won't do that. It's a cultural difference, so it just to add further to the complexity in terms of cultural issues.

The floor is open for discussion; Marie Bernard [phonetic].

MS. MARIE BERNARD: Very nice presentation. And I would like to add to the discussion about terminology. Some of the things we were talking about prior to the break and was brought to the attention of a couple of us during the break, terminology with regards to teaching. The provocative statements from Dr. Kane.

I think as we go through this day we're going to be thinking about what should be done, what should be developed in terms of expectations for training of direct care workers or whatever term we decide upon. And I think we also need to

think about what this term "training" really means.

It has been used to be synonymous with imparting a body of knowledge to individuals, which may not translate into different behaviors. And I think that the term is meant to be a more comprehensive term than that.

Certainly, ultimately, what we intend is to bring about behavioral change that will lead to better outcomes for the care of older individuals residing in their home. It is a many-stage process, however. There has to be a perceived need. And I think we all agree that there is a need here.

There needs to be some basic knowledge. How extensive that knowledge needs to be, will have to be determined depending upon what services that individual's expected to provide.

Then there needs to be an application of that knowledge. And that's where the gap often exists in many educational programs, a la the defunding of the Geriatric Education Centers, et cetera. Because we're able to demonstrate to Congress that that knowledge that was imparted was being applied.

There needs to be a check to determine that that's been appropriately applied and then some reinforcement of that. And so those all things that we need to be thinking about when we're thinking about direct care workers or however we want to define them. And I just want to put that into our nexus.

DR. DENNIS: Yes, Mary Jo [phonetic].

MARY JO: Yes, on the, kind of, international comparisons. In Germany, free training is provided for family caregivers. In the process of trying to find out more about, kind of, the content—if there's a standardized content and so forth—but one of the interesting points, I thought, was its relatively low take-up, is the term used. Many family caregivers, you know, had not taken advantage of their free training.

And I'm not clear on all of the barriers. But one, I think, is probably pretty obvious. Is that it's hard to leave home when you're a family caregiver to get the training, even if you have good respite provisions, which they do have in Germany, at least public benefits for respite.

But I learned that the latest reaction is to now offer

training to family caregivers in the home. I don't know who would be providing it. But it raises the broader issue, kind of, that we were just discussing of where this training would take place.

It's not necessarily all in a classroom, right? From the review that was presented this morning. And I don't know, kind of, you know, where? What settings we're talking about? If there is anything that could feasibly be provided in the home, which of course, would seem to be ideal; expense, no doubt. So I'll just stop there. But the, kind of, the setting of that training raises other issues.

DR. DENNIS: Bob Kane [phonetic] and then Claudia [phonetic], Beverly [phonetic].

MR. BOB KANE: I want to, sort of, try to tie in what we did before and after the break, because I think that there's an overarching central issue here. John Crews was, sort of, talking about his experience as the father of a child with disability.

I'm sitting here, sort of, thinking; if we weren't quite so; A, fixated. If we had broadened this meeting to people of the disability community, we would be hearing a very different story about the need for training, about the expectations of people.

And basically, they would have said take this curriculum and shove it. They are very empowered. They know what they want. They feel confident to direct those people to do what needs to be done. Bob's [phonetic] shaking his head. I mean, there's a fairly rich body of information out there now from folks like ADAPT and other groups that certainly have a very different life view than the one we're espousing.

And I find it a little bit ironic that we are behaving in such a, what I would consider, an ageist fashion. I think if we try and put this into a more neutral framework, we would say that the knowledge and the skill of the client/family dyad may vary, in terms of who owns that skill and knowledge. Basically, is a countervailing force to the need for training in the-whatever that worker term is going to be over there on the right-hand side-the homegrown or whatever we're going to call them.

If you think about this there's, sort of, a dynamic

equilibrium. I mean, if you have people who know what they want and are able to convey that, they can either ask for, demand, or instruct. And all of those models exist in the disabled community.

The workers to perform those tasks. And if the workers don't perform those tasks, then presumably some negotiation or replacement is made. And this is the model of the personal care attendant. And this is the way it works.

We have somehow taken older people and reduced them to vulnerable, frail, elderly, incapable of making decisions. We have somehow decided that family members don't have this capacity. And that instead we are going to try and create an alternative paradigm here, which is, sort of, the trained home person. Where they're going to come in and that's going to, sort of, rebalance this imbalanced situation.

I don't find much [unintelligible] basis for that. I think if you look at the little bit of work that's been done; the evaluations of the Cash and Counsel program, which worked with a Medicaid person. And this is not the upper-middle class people that the private folks are hiring. But the people who have, you know, generally less education.

The leading project was done in Arkansas. And the results were pretty persuasive. I mean, basically, you know, the folks who hired their own folks, you know—it wasn't super sized—but it was pretty good. Basically did as well or better as the folks who, you know, went through the more traditional methods.

The program in California that's been going for, you know, a long time that was just recently evaluated, which basically, was a precursor to Cash and Counseling showed exactly the same results.

And so we're, sort of, working on developing an answer to a problem we haven't quite defined yet. I mean, it seems to me that, you know, we ought to go back and, sort of, ask some more basic questions. I mean, what kind of assistance is needed?

Should the assistance, as I think was hinted at earlier, be tailored at the consumer or the provider? You know, do we need better education of, you know, the people—you know, the family members—if we think that older people can't hold their

own, which I'm not prepared to concede yet. You know, should we be providing, you know, more information and training? I mean, maybe we should certify the older people and let them [unintelligible] age.

I mean, I just don't think we're thinking very creatively in the way we've approached this question. And we, sort of, started with this old-fashioned, fixed educational model, which as I said, I don't think is the way to go.

DR. DENNIS: I very much respect what you're saying, Bob. But I'd be interested in Mary Jo's view, because the older people I saw treated over the years were frequently women who were very vulnerable, not empowered, were disabled, certainly. But were not able to really fend for themselves and to direct the care at all.

So I think there's a very serious need for significant attention drawn to that group of people, which is not inconsiderable in size. Dr. Beverly?

DR. BEVERLY: There's several things that I wanted to talk about. And one; whatever we call this individual, and as we were talking about would this individual participate in cooking or cleaning the house or whatever. And I think that if we look across the board.

And it's been interesting to me how many times I've been in a home where individuals are receiving care from multiple agencies. It may be through the area agency, provider group, and somebody's coming in to do housekeeping. And then somebody's coming in to do personal care. Then you have home health coming in to do something else.

So from a policy perspective, I think the challenge is for us to really look at what we need. How can we bring in the precious resources we have in the country? And meet the needs. And not have these multiple people coming in, if you will.

I also think about the cost. And I agree with you wholeheartedly, John, about families become employers. And they become employers at a really critical time and a very emotional time. And yet they're learning how to fill out all the forms and so forth.

And then if someone calls in, then they have to call their list and see, you know, how they can replace 'em and so

forth. So families have accepted another burden if they are being the direct employer. And I think also the ones they are employing most often are ones that don't have healthcare. That are very vulnerable themselves.

The other thing that I want to add to Gail, I know that Susan Reinhardt, along with Dr. Heather Young [phonetic] and some others have really been addressing the nursing delegation piece. And that there are several states who are finally looking at this from a policy perspective.

And incorporating delegation into the Nurse Practice Act, which I think is a good step forward. It's for a lot of nurses is, kind of, scary. Because it means, oh, I'm not in control. But yet they really are. And they have better, if you will, the more oversight they get less. And they have these hands and eyes that are out there helping 'em do things that perhaps they didn't before.

And then I think last, I would talk about cost. And I know in Arkansas, if you hire someone 24/7 in-home that that almost doubles what the individual would be paying in nursing homes. And so for many families that cost is not easily attained.

And you know, so I think that long term care insurance, if it's a good policy. And we're seeing more purchasing long term care insurance. I think we're going to see some help along that way. But I think that there are still few people who can afford that 24/7 kind of work.

So I think, in part, you know, just looking broadly, what is it that we really want that individual to be able to do? How do they interface? And I think it's very critical that families understand what they're getting into to the best that we can help them understand. And I don't think that's all set up.

And I do want to brag. Our Cash and Counseling, that Herb Sanderson [phonetic] in Arkansas led, has really done a very good job of getting families and making an impact on helping them stay at home. Then helping them put an infrastructure in place where they would be successful.

DR. DENNIS: Dr. Boal [phonetic]?

DR. BOAL: I just wanted to follow up on Dr. Kane's comment. And I think, you know, with all due respect to your viewpoint on

this and also to the experiences you've had as a caregiver. I do want to respectfully disagree with the notion that we are disempowering the patients and their caregivers by trying to develop and advance the cause of competent paid caregivers into the home.

The people in this room, including myself, are not the typical caregivers. We're more educated. We're more affluent. We have more social supports. The majority of the caregivers that we interact within our program are single parents who have their own parent that they're caring for who cannot advocate at all for themselves. Is typically somebody with moderate to severe dementia, multiple comorbidities. Typically also has their own children and a job.

And what they need is they need a high-quality competent person to walk into the home. And say I can take care of your loved one while you're at work and while you're dealing with your child. You know, I need to know what the preferences are here. But I'm going to help.

And the family members are not necessarily in a position where they can, you know, take more of an active role, as they might be able to in the disability community. And I don't want to lose that. I think we may be overweighting the experience and the ability of the caregivers based on who we have in the room today.

DR. DENNIS: Steve?

STEVE: Yeah, I would have to agree. I think so much of the conversation ends up pitting family caregivers against paid caregivers, saying elders are different from people with disabilities. Everyone needs more support.

Everyone needs better training. I certainly agree that most of the training in the country for paid caregivers is very poor. And that's the problem. Training isn't the problem. Its bad training is the problem.

There's a lot of advance that has been done in terms of the type of adaptive skills that we talked about in terms of how to supervise, how to communicate, how to problem solve. Those are all such essential elements of training. And there's really good examples of that.

I think, unfortunately, the narrow frame of this initial research precluded a lot of very good curricula out there

that happened to fall out of the definition in terms of that it just serves people also with disabilities or for publicly funded programs, et cetera.

And these are not drones, Dr. Kane. These are individuals who really do, Gail, want to provide care. So I think that while we call them direct care workers—and I think it's helpful to make the distinctions—most of the workers that we work with directly really do see themselves as providing care.

So if you take away that concept of the paid caregiver and saying you're not here to give this care, you're here to give us services and support. I think we lose a lot of the reason why paid caregivers are willing to do this work despite very poor pay, no health insurance, and really other poor working conditions. The only reason why they are willing to do this work is that they want to provide care.

So I think the family members can determine what they want to be called. I think it's hard to tell other people what they should be called.

DR. DENNIS: Sandra Timmerman [phonetic]?

MS. SANDRA TIMMERMAN: I'd like to, sort of, talk about different types of paid caregivers at home. Because as I think about the softer side—people who are non-medically trained who are caring for those with Alzheimer's—it's a whole different situation than someone who is doing physical care for someone. And I realize at some point, those two blur.

But we really, in my view, need to look at those intangibles in training. Those who deal with people with Alzheimer's have to rise above the situation in ways that we can't even imagine. And how can someone who's at home with a person who fires them every day or treats them with disrespect, really do their job unless they're able to have some support from their employer; the agency, perhaps, who hires them, or some network, whether its online, or even being able to talk to a family member, I suppose.

But I think that the word "training" as someone said, may not be the right word in this case. Because I see this curriculum in, sort of, the psychological, the attitudinal, the, sort of, softer side and then some of the more physical types of work that people have to do.

And I'd almost like a clarity today to help us think through what this project is about. Are we talking about anyone who is paid who comes through an agency?

Or is it broader? Is it someone who's trained; who maybe took a course at a community college and then goes out to a home? Can we eliminate from this the people who are hiring family members who don't have the certificate?

I'd like a little bit of clarity so our discussion can focus more, because like others, I'm thinking of this in multiple levels. And as I said before, I think we've got to start somewhere.

I think having someone who's in the home who's aware of these issues and who has had some training is better than somebody in the home who hasn't. And so, you know, we're working on that premise. But help me define it a little more.

DR. DENNIS: Well, we didn't want to define it too much, because we didn't want to foreclose the borders [phonetic] so to speak. I mean, we really want the kind of discussion we're now having in the broadest sense; caregiving in there. How do we approach it from many different perspectives? Dr. Emanuel [phonetic]?

DR. EMANUEL: It seems to me that we're really moving in the right direction now. I loved Gail's discussion and the notion of paying family caregivers from Medicaid and the fact that the EU has looked at this from a macroeconomic perspective.

I think we should learn more from Gail and anybody else who's an expert on those programs. Because we need to know how successful they were. We need to know whether we can learn from them.

Because what we're moving towards in this discussion is the recognition that we need to build a supportive infrastructure for an extremely diverse job, an extremely diverse population. And so how do we do that?

There's one element I wanted to also add to the mix, which is the notion that we've been exploring in another context for a decade now, which is the notion of a virtual college.

So we do these Immunization Education Programs that I bet Bob would call 'em. We give people a two-and-a-half-day immersion course. Many of them do find it transforming. It

is immunization in many ways. It's effect immunization. But we recognize that it's only so much.

And so we have put in place various other programs that keep in touch with people. We're developing them all the time. We're developing right now a Rent a Mentor program. We're developing a program for--well, we had it for a long time; a program for a development workshop that follows on [phonetic].

We follow people. We track them. We try and stay in touch with them. And again, back to the technology idea that we could actually track people who enter the home if they wear a little monitor, which makes them feel like they're in a public setting and in a setting where there are colleagues and so on.

And if we start getting really creative about where we are and where we're trying to go, I think we could create a national program with a policy attached that we could advocate for. But towards that end, I just wanted to add the notion of a virtual college for caregiving training and follow up.

DR. DENNIS: Alright. [Inaudible]

MR. JOHN CREWS: Yeah, I may be a little unsafe to make a comment. You know, so I may have to be reseated later.

DR. DENNIS: For the record, it's John.

MR. CREWS: Yeah, I'm sorry.

DR. DENNIS: Okay.

MR. CREWS: Let me just add some, kind of, again, they're, kind of, random thoughts. If you asked me and my wife, Nancy; if you said we want to give you some training so that you can do a better job in your caregiving responsibility.

What I would say is if you really want to do something for me, get somebody in the house so I can go out and have dinner with my wife. I mean that's more valuable to me than the delivery of some knowledge, unless I'm darn sure that there's good training.

So I think in just terms of this hierarchy of need, training's not high on my list, but getting some help is.

DR. DENNIS: Respite.

MR. CREWS: And try to nurture some other things.

DR. DENNIS: Respite is very high in priority.

MR. CREWS: Yeah, I guess so, yeah. Now I think the big piece living this is recruitment, not training, is a huge issue for us. Now let me give you an example, if you run the shortest ad in the Atlanta Journal Constitution for one day, if you try to get an [unintelligible], its \$400-

FEMALE VOICE: [Interposing] Oh, wow.

MR. CREWS: -for one day.

FEMALE VOICE: That's crazy.

MR. CREWS: And I would bet in the last eight months, we've probably spent as a family between \$3,000 and \$4,000 advertising for folk. And we get, like, 10,000 resumes, you know, some from the State Pen. I mean, just very despicable creatures, you know, who are applying. So this recruitment is a huge issue and pales in comparison to the training thing.

The other thing I would say in this train, and I want to be very sensitive to this, and not overstate it or understate it, families are expert in disability. They know their disability, 'cause they've got [unintelligible] one. They're not trying to serve everybody with CP, everybody with dementia, all that. They've got that family member. And they know that inside and out. And they can respond to that pretty well.

And so there is some filling in that families need. And that's where that needs to be targeted, not to sit in a classroom or whatever the mechanism is. And I tend to believe, as I said earlier, I think these are just, kind of, values issues of respect.

Another issue that we have not talked about is conflict. And my wife's a social worker. You know, families learn conflict. They learn the boundaries of what can be said and what cannot be said. Some families yell at each other. Some families don't yell at each other. I mean, they just learn those things.

If you're bringing people in with different cultural

backgrounds, different economic backgrounds, their notion of conflict may be real different from what's normative for another family. And so some of that might get played out in some pretty abusive ways, you know, in the bathroom and so forth. So we need to think about that.

The other thing I want to say, I think, 'cause I really do believe that there is a commonality in all of this that we can learn from the disability community and the aging community. I don't want to, again, not to overstate and not to understate it, but there's a cohort of fact here.

You know, all of us, all of the baby boomers in this room will be different consumers of services from our parents. 'Cause we're the ones who are getting called up from across the country and beating somebody up, you know.

And we're very comfortable in those directive roles. Well, I bet you, as we age, we will be probably much stronger advocates, much more confident, in terms of managing that. And we just have to recognize that that will change.

DR. DENNIS: Claudia Fine [phonetic].

MS. CLAUDIA FINE: Another word about terminology. The word "training," is that really the word we want to use? 'Cause I think that when we speak about training, I start to think about drones. And one of my colleagues says that you train dogs, you don't train people. Aren't we really talking about developing people and educating people?

And I think, you know, you may not need training. But I think, with all due respect, you probably do need educating about what-

MR. CREWS: [Interposing] Yeah, that's what my wife says.

MS. FINE: -about what this process is. First of all use Craigs list. That would help. It would save you money.

FEMALE VOICE: That's great.

MS. FINE: So you do need to, sort of, like, you know, education about this wonderful world of aging and chronic illness. And then you can go out to dinner with your wife. So that's one piece.

The other piece is in-I do agree with a very small part of what you said. And that is that part of what we need to

educate our caregivers about is to know who the client is. They need to be educated about assessment.

And there's going to be a difference between the frail, vulnerable, elderly person who can't advocate and the elderly person who has multiple ADL deficits who, you know, is competent and intact. And needs a certain level of interaction. And so that's another aspect of educating our caregivers.

And ultimately, I think, I'm not sure we can really educate a caregiver to meet all the needs of any one aging individual or disabled individual over time, because nobody is the same over time.

And so the caregiver with the skills to deal with the resistant, agitated, early dementia patient, they're going to need different skills. And they may actually need to be a different person with different, you know, desires about caregiving.

'Cause I do agree with you that these people go into it because they want to care. And also with the person who needs to be able to transfer and have, you know, very strong nursing-based, clinical skills.

DR. DENNIS: Mary Jo [unintelligible].

MARY JO: Well, I was just going to say that I do think that clearly the aging community can learn from the disability community and I'm quite sure vice versa as well. And that I don't want to see us draw a sharp line between the two communities in the way we approach, kind of, frail elders, kind of, versus people with disabilities who can make all, you know, competent decisions, as some would characterize it.

Hopefully, there would be some way to bring the two sets of, kind of, issues together in whatever, kind of, educational perceptive we're trying to develop. Because I mean, there is no doubt, to my mind, that many family caregivers—I've been one too and I well remember.

And to this day, I worry about issues of safety and not being able to lift properly. And I'm quite sure that's a fairly common or at least I'd find a way that wouldn't hurt my back so much. From your very simplest level of physical competency all the way up to the more complicated kinds of communication skills and interactions with people with

dementia.

I know that's a tall order. And I don't what we'd call it. But I think there's certainly a need, to my mind, for that kind of education for both direct care workers and for family caregivers.

DR. DENNIS: Mary Jo, while you're speaking as senior policy advisor to AARP, are there any policy initiatives within AARP with regard to caregiving, explicit?

MARY JO: Well, we have a good deal of public policy on caregiving and there are-

DR. DENNIS: [Interposing] But are you advancing any particular policies within congress or government related to long term care and-

MARY JO: [Interposing] There are several legislative proposals that some of my colleagues in federal affairs are working on with various caregiver folks around the table currently. That I mean, the specifics of which, I'm not going to get into here.

DR. DENNIS: Oh, okay.

MARY JO: But you know, indeed, it's an area of major interest. And many states are also working on, you know, state caregiving initiatives. And Frank Bailey [phonetic] is my colleague from AARP, may want to comment further on.

MR. FRANK BAILEY: Well, there are a number of state initiatives around the area, but a lot of which are around the quality issues as well, however.

And so in case you didn't hear, there are a number of state initiatives around caregiving and quality in caregiving. And then there's also a number of states initiatives around funding for caregiving, including the Cash and Counseling approach.

DR. DENNIS: Thank you. Carol Levine?

MS. CAROL LEVINE: Well, I have a number of disconnected. I think I'm catching John Crews's random thoughts.

MALE VOICE 3: You could be immunized by that.

MS. LEVINE: I could be immunized, right. I guess I would

consider myself an empowered caregiver of the type that Bob was talking about. I've also been called, by many professionals, untrainable, in the sense that I resisted being forced into a mode that was not appropriate for me, as a person, as a caregiver and other ways.

So I think that what I'm trying to say is that training or education, whatever you want to call it, has to take account of the fact that the family member has a very different emotional relationship with the person receiving care. And that's part of the equation.

And it's not learning to move someone, learning to move someone, learning to move someone. It's learning to move someone. It's learning to move your husband. It's learning to move your mother.

And they're really different experiences, especially if husband or mother complain and say why are you hurting me? It's different for a direct care worker who understands that's part of the job. It's different for the family member.

And that emotional component is so seldom recognized. Or if it's recognized, if like I say, this is something I just can't do. Then you're considered noncompliant, unwilling to learn. And just, you know, the bad wife or the bad daughter.

And so there is something that's really important about understanding that, yes I can learn to do all those nasty things and did. But that I have to be helped along in a different way from someone whose job it is to do this.

This was not, you know, the way I started out my marriage to do these things. And that's missing totally. And it's very upsetting. And it's very humiliating to be treated that way and you are.

I once had a nurse come to the house after my husband had minor surgery on his back and had this great gaping wound. And she said now this is what you do, you take this stick and you dig around. I said, actually, no, this is what you do. You're the nurse. You do it. And she wrote down, wife refuses to do this. But anyway, that happens and if you don't have a fairly strong sense of yourself, you can really be pushed down.

I was saying that one of the best experiences I had in

education was being in a recreation session where all of us family members were shown how to use a wheelchair. We sat in the wheelchair. We were pushed around. We got the idea of what it felt like. And then we learned how to turn corners. Those are things that you really need to know, you know?

And so I guess my message is, part of the reason caregivers don't come to these things; I know that. I don't need that. What I need is something else here. And they want to be very selective about what they think they need. And you don't often get that chance.

So I sometimes go out on the street. And I want to stop people and say, if you want to do the corner and there's no curb cut, this is what you do, you turn around. You do it this way. But those are the things that are valuable and important and don't often get those real, honest to God, on-the-ground, this is what I need to know.

So those are, kind of, random thoughts, but I guess the most important thing is it's the emotional component that has to be acknowledged and it isn't. That's it.

DR. DENNIS: Very quick, Humphrey. You want to make the last comment?

HUMPHREY: I'm going to hold it in the interest of staying on schedule.

DR. DENNIS: Alright. Then we will go to lunch.

STEVE: Could I just?

DR. DENNIS: Something very important, Steve?

STEVE: Yeah, I think so. Just in terms of if we agree that at least part of the solution, certainly not the total solution, but part the solution is to have a stable, well trained workforce and since the workforce are individuals, then I think we cannot only look at the question from what consumers need, although that's where we start.

But we also have to ask, what do workers need? What do these paid direct care workers need in order to want to show up, want to answer the ad, want to go onto the next job?

And so I think it's really important to have the conversation reframed somewhat. In terms of, if this is the frame that you presented us, one element is training, one element is

credentials. Then I think we need to agree that there's a range of other elements of a quality job, in terms of wages and benefits and supervision.

And that training is one of them. Workers want training. Workers want to have some help in terms of knowing what to do when they face a particular situation.

So I would like as we go into after lunch to make sure we're not only looking at this from what the consumers need, but also what the workers need in order to have a stable, qualified workforce available to those of us who need care.

Mostly 'cause I don't want to carry them home, I would direct you to this on the table, in terms of, there's a lot of work that's been done in terms of determining what are those essential elements of a quality job.

DR. DENNIS: Thank you. And we do need that balance. I want to thank Gail again for leading us off. The buffet is right down the hall in the President's Room.

MALE VOICE 4: It's not a buffet. It's actually a served lunch. I think it's a served lunch.

MALE VOICE 5: It's a served lunch, yeah.

DR. DENNIS: But you have to go down to the President's Room.

MALE VOICE 5: That's right.

DR. DENNIS: Yeah, that's what I'm saying. You have to go to the President's Room and you will be served lunch. And you should be back, if you would, at 12:50.

MALE VOICE 5: Well, we could go for, like, maybe ten minutes longer than that.

DR. DENNIS: Alright. You can come back at 1:00.

[END 089_936-TAPE 2.MP3]

[START TAPE 3]

DR. BUTLER: Does this seem hopeless? Is this absolutely hopeless? I know what I could do, I could call on Carol Levin and I could call on Dr. Wrobel? If nothing else works, you humiliate people.

Good afternoon. We should proceed, but I do want to point

out that there are a number of publications of various groups on the one table here, and other publications in the outer hall for those who might be interested, and you are, of course, welcome.

And now we move into the presentation. We are a little late. We are quite late, actually. Models for Training Paid In-home Caregivers of Older Adults. Beth Vaughan-Wrobel, Valerie Alsbrook, Sherry White. Where are you guys?

DR. BETH VAUGHAN-WROBEL: I am going to do the talk.

DR. BUTLER: You are going to do the presentation? Okay. Beth will do the presentation and then we will open it for discussion. Beth?

DR. VAUGHAN-WROBEL: Thank you. I did talk about one of our findings that we found in the original work was that we found two models. And the models are going to open up the, the comments that I have already heard so many of you say, and allow us to talk a little bit more about, if we went this way what kind of models are out there and what we would select. And we talked about the comprehensive model approach to caregiving and that is an approach to caregiving across the lifespan. Sort of like the universal worker. Some of the skills are core. There is no question about that. But how you apply them to different age groups is different. At least we believe that is the truth.

And the specialized approach to caregiving is what we would advocate in the fact that yes, older adults I do believe, we do believe are different than any other age group. Caring for an older adult, people have not been use to doing that. And if you just think about the number of older adults that have been hitting our population in the United States in the next 20, 30 years, we are going to have a very large group of older adults. And they are going to need care of some kind.

So, we feel that specialization is an approach that would help the caregivers of older adults learn how to handle the problems that older adults have. Not that the core content couldn't be somewhat the same, but the approach of handling an older adult in a home setting would be where we would particularly like to see this go as we talk about caregiving of older adults.

We also looked at two approaches to training. And of course,

we talked about the curriculum and we happen to believe that it's more than just references. It's more than just guidelines. It's more than just DVD's for the paid caregiver. Maybe not so much for the family caregiver. They certainly cannot go through a training or an educational program. And we certainly don't have a market on what goes into that. That's what we were hoping that the group here would be able to share. And I heard some excellent comments this morning about some things I am going to take back to Arkansas to look at engaging the families. We do and I am going to talk about our program in just a little bit.

The other approach is, is that things that we found is there are a lot of excellent books out there, DVD's that have caregiver content on them. More for reference materials, than for learning how do you care for someone in a home setting, particularly an older adult.

We talked about the comprehensive approach to caregiving. And it emphasized across the lifespan, individuals across the lifespan, in multiple settings. And Moseby is just one that we selected. The Washington State's curriculum is an excellent curriculum. And it looks at it across the lifespan. And it is a curriculum. But this has all the components, but it doesn't focus on homecare, which we believe it is more than just caring for someone in an institutional setting.

And we will talk just a few seconds about what ours is and how we approached it. And it is specific to care of older adults. This could have been any of the three that we found. And maybe some more that we will be finding. Several people have suggested that there are other curriculum that missed. We know that. We didn't, we don't think ours is exhaustive in any way, but, the search that we did. But for ours, it is three levels that represents the three books, and we also found that, and it is for population specific older adults. And it is for in-home, an in-home setting.

It is three levels. And the first level is elder pal. And I am going to talk a little bit more about career laddering a little bit, and someone said how do you do that with these kind of workers. Well, I think it is possible that there is an opportunity for a career ladder, which I will talk about in a minute.

But we do elder pal. It is twenty-five hours. And it's work, helping caregiver and that's the term we use, someone with minimal assistance with ADLs. In ours they do have to test out as an exam and in competency. So that we know that at least at one point in their training that they could carry out this field.

FEMALE VOICE: Is this about family and?

DR. VAUGHAN-WROBEL: No, thank you. This is not family caregiving at all. This is the paid in-home caregiver that we have, that we work with.

FEMALE VOICE: Are you going to sort of speak to the kind of competencies that elder pals have?

DR. VAUGHAN-WROBEL: Yes. An example would be for an elder pal they learn about assisting with the bed bath, could be a shower, could be a bed bath, transferring, assisting, some with eating. It's sort of if you want to look at it, it's like a companion, but it's more than just sitting there and watching someone. It is actually assisting someone with ADLs.

When you get to the personal care assistant, that is the working with someone like with a total bed bath, so that they build on each other. They don't stand alone. The second one cannot happen without the first one. And it is also twenty-five hours. And that covers a PCA, which is the like the normal, we follow the state and federal guidelines for training of PCAs, and between those two you get all the skills that are required in our state.

The third level is the home care assistant. And that is fifty hours, matches a hundred hours of our training. And in this one, they do things like unconscious patient lift, Heimlich procedure, things that are more advanced that if for someone who was totally bedridden, could not get up, or very minimal could get up. So that they are more, what we call the advanced level. They also get a little bit of long term care, because we are approved by the State of Arkansas so that our graduates can write the CNA exam. So, they have to have some long term care institutional content for them to pass that exam. But it is only at this level and it is not to a total focus at this level.

In the State of Arkansas, in the last year, they have now

mandated to have 15 hours of a dementia, and Alzheimer's course. And it is 15 hours for all CNAs. In our program we are abiding by that rule and have a module for the dementia. So, that that is where our 115 hours occurs.

Now, we also, when we put this together, when we were looking we decided to develop a set of DVDs to go along with the skills that occur in the training. And we also do, took the content, particularly of elder pal, and created a family care giver training program. So, we used the DVDs for the training of the paid in-home care givers, but they also can be used for families, to use as a reference at home, or for the training. And so we do an eight hour to ten hour family caregiver training workshop about once every couple of months, and bring families in. And they do come in. We are working to get that online, so that they won't have to come in, because we also have the problem they can't always come, because they are in the caregiving role. But if the family member decides they would like to come, we try to work with some of our caregivers and let them come, get someone to care for their loved ones, so that they could come into classes or to caregiver family caregiver workshop.

They graduate with 115 hours. We do call them the geriatric home caregiver. It was pointed out that grammatically that may not be correct. The title is not an issue. The title is trying to find a title that indicates that they are in-home and not institutional care. That's all it is. And that just happens to be what we call them.

Just to give you a little bit more information, because somebody said how do you find these people. Do you have to advertise in the newspaper for \$400 and yes, in northwest Arkansas that use to be the case. And I went through the caregiving just like the rest of you, and my husband died ten years ago. And when I was looking for a caregiver I couldn't find a caregiver. And I asked the home health agency how do I find somebody to help me 24-7. They gave me a list, single spaced with all these names on it. And I said, okay, how were these people trained to help me with Joe. And they said, oh, they are just good hearted people that want to do this. And so, they took their names down. And that's what they were giving out to those of us that were in need of caregivers. And Mr. Schmieding had the same kind of a problem.

Now, in Northwest Arkansas you will not find that list

anywhere. The people that, but you can always advertise and get them, and hire them that way. But if you want to get a trained caregiver that we call Schmieding certified, then they call us and we send them the directory. And this directory lists the people that we have trained at the three levels that we have trained them. We also, we send the family how to interview, information on how to interview, how to hire, how to do taxes, how to do security checks. We do not do the security checks ourselves, but the family members we help them in learning how to do that. And we try to give them all the tools that they need to be able to go into that unfamiliar territory that they are fixing to go into. And it is updated every time we graduate a class, and we graduate a class a month of elder pal, and every two months of PCA, and about every three months of HCA. And our graduates are about 100 a year individuals, and about 300 graduations, because you have to build on it.

Then once they have completed and they go through the CNA, then they are fine. That means they can do the CNA, they can come onto our list. Anybody can be on our list. We have people call us and say, well, I have been a CNA for fifteen years and I have worked in caregiving, and I know I can do this. I want to be on your list. And we say, no, you have at least got to go through one part of our program, elder pal, to be on our list. And once they do, more than likely they go through all three, because yes, they may have been doing it for twenty years, but they don't know how to do it properly. And so, they, we have good testimony that they like the training.

And then, we also require twelve hours of continuing education annually to stay on our list. You can't just go through the training and be on that list forever and a day. And we would be proponents for, if we decide to do standards of training and all that, there is continuing education. It may not be the answer to everything, but it certainly helps keep people abreast of what's happening. And we go off over all kinds of topics, fire code, fire things, safety. We go through the diseases, Alzheimer's, how you care, I mean, all kinds of topics. And we provide that CE then for the caregivers that come.

One of the things just to tell you is, is that this is not Medicare-Medicaid supportive. These people pay out of their pockets. We make the fee very reasonable. We happen to be

very fortunate in that we are supported by Mr. Smeedy, and he would not turn away a person who wanted to come through and get this training. So, they get all the training at \$75 per class, and with that they get a book, the notebook that they get is back there. We do use the Mosby textbook to go with ours. It takes more than just what we have got. But we have the DVD. We use the textbook and we have our own notebook that goes through this field.

It's very hands on. Yes, there is lecture and content given, but it's the practice in the home setting, because we have a lab that looks like a lab, looks like a home. It's got all the assistive devices that anyone would ever need in a home setting. And so that they can feel more secure when they go out into a home on their own.

We do support -- for the caregivers if they want them and we are always there to help answer questions and they do come back to us. And for us in Northwest Arkansas, that's what we would love to see the rest of the country have is, is that we have seen a difference in the care provided by independent contractors in the home.

DR. BUTLER: Thank you, Beth.

DR. VAUGHAN-WROBEL: So, questions, I forgot my questions. Should the training of in-home caregivers of older adults specialize, use a specialized model?

DR. BUTLER: I think also, a point that Steve has made at the very last moments before we went to lunch, that we really have to think about the providers themselves and how they are treated, and how they are paid, and the benefits they have, and the dignity that they should have. The floor is open.

MALE VOICE: I am just curious, you have trained a number of people now, is that right? Do you have any data to suggest that the outcomes of care of people who have received care from your trainees is different from the outcomes of care for people who have, using caregivers who haven't had that training?

DR. VAUGHAN-WROBEL: We have done the surveys of the caregivers themselves, as well as, the persons who hired them. And the persons who hired them are very pleased. And we have lots of testimony on that.

MALE VOICE: We can find people who are pleased with, anywhere. I

mean, my question is, do you have any outcomes and any real data?

DR. VAUGHAN-WROBEL: No. We do not.

MALE VOICE: Those are, we are making this big case that accreditation is terribly important to quality. You are in the best position in the country, presumably to actually empirically test whether trained people significantly change the pattern of quality over untrained people.

DR. VAUGHAN-WROBEL: Yes, and that is on our agenda to do. Have we done it? No.

MALE VOICE: You mentioned that the cost to the trainee is \$75. What is the total cost to the program including whatever subsidies?

DR. VAUGHAN-WROBEL: About \$250 per person.

MALE VOICE: \$250?

DR. VAUGHAN-WROBEL: Yes.

MALE VOICE: Okay.

DR. VAUGHAN-WROBEL: But that's minimal. But, yes, that includes building, textbooks, personnel and everything.

FEMALE VOICE: One question and one comment on the question that you have up there. The comment on the question that you have up there about specialized model. Seems to me that we have many examples where it's pretty clear that what we need is a core curriculum, and then we need layers of specialized training for different categories of populations. And that would fit very well with the layering model that you already have, and could be very easily done. And it's already being done by you in some sense, because you have that extra layer for dementia training. So, that seems to me very nice answer that we could put up there in response to your question.

The question I had for you is what about risk liability? Is that something that you prepare for in any way?

DR. VAUGHAN-WROBEL: We do not place people. We are not a placement agency at all.

FEMALE VOICE: But you have a list.

DR. VAUGHAN-WROBEL: But we have a list. And it's very clear that

that is not, that's, disclaimer is on that. We do talk about that with families, and make them aware of liability issues. Our graduates don't carry liability insurance. They can't afford it. They can't even afford their own. So, what we think is, and what we are working on is pulling these groups together and I am currently investigating right now group insurance for them.

You know, we talk about, Steve talked about caring for the workers. Well, how are we going to care for the workers if we don't help them with getting some of those benefits that we all enjoy and they do not. And so, we are looking at that. And one of the things we think we could all ban together with some of these people that don't have those, we might get some decent costs for them.

DR. BUTLER: Dr. George Maddox?

DR. GEORGE Maddox: Bob Christian is a good one. There is something, organizations don't regularly do which is to demonstrate that what they have done works in some sense, demonstration that something works. The next question you would ask is does that mean that that would be the only thing that would work. I think one of the most basic observations has been made about understanding organizations is to understand that there is no one size of organization response that fits all circumstances.

Two key elements make that so. One is the capacity to align what you are doing with your understanding of the perceived needs, the sources, values of a community. Add to that leadership. In fact, to get people, the key people to buy into it. Which would lead to the observation no one size is likely to fit all in any solution to any kind of major problem.

So, I think and I haven't heard anybody suggest that Arkansas now wants to say go and do likewise. It is rather, a model that says as we understand our alignment of what we are trying to do with our perception, and there are good indications they are beginning to ask that question. What evidence do we have that we are, in fact, doing the right thing. That's the great tragedy of many organizations having demonstrated in the short run that they appear to be doing good. They don't ask the question, again.

So, I'm expecting Arkansas to continue to ask that question,

because the need for alignment will shift, as a matter of fact, over time. Several people have mentioned we are coming into a new era with this very large number of boomers and so on. We'll wait to see what the implications of that is going to be. And your response may change in response to that.

So, leadership, understanding context and alignment become critical issues. So, what Arkansas has done is to put up a model of here is what we are doing. We will evaluate it. You do what you are doing and we'll evaluate, we may discover both of us are doing equally well, or neither.

DR. VAUGHAN-WROBEL: That's very true.

DR. BUTLER: Jeremy?

Dr. BOAL: First of all, I wanted to congratulate you on the work you have done, which from my perspective is extraordinary. I also wanted to think a little bit out loud about this issue of looking at outcomes, and how much we need to see, convince ourselves that this is a worthy effort. So, I don't think anybody would say that in order to test the value of medical school training we would put patients in a setting where they were taken care of by physicians versus people who weren't trained. And in this case, I don't think we need to do that either.

The alternative, though, is to look at outcomes such as consumer demand. And I suspect that if you ask consumers whether they would rather have somebody off of your list, as compared with some, a random person that a neighbor recommended my suspicion is there would be high demand. So, you may be able to find outcomes that you can demonstrate very quickly to people that need convincing in this room and elsewhere that this approach is a worthwhile effort.

FEMALE VOICE: Just again, I think this is great. What I do think it does is it sort of brings the private caregiver up to the standards of what I would assume an agency caregiver, at least in New York, would have. But I do think that there are some things that because they caregivers are working independently, and going into the home that isn't addressed by the curriculum. Things that have to do with elder abuse, ethics, and I think these things have to be addressed not just because people, the caregiver needs to understand what their limitations and responsibilities are, but I think the consumer will be more likely to accept the help that they

need knowing that there is some kind of minimal safeguard to having a stranger in their home.

So, I would just encourage you to add that into your curriculum.

DR. VAUGHAN-WROBEL: Well, let me just respond to one thing.

FEMALE VOICE: Sure.

DR. VAUGHAN-WROBEL: This is not to say this is the thing. This is up to stimulate the discussion. And some of the things I heard this morning I am already taking back to add, because one of the things we might look at in a standard curriculum or whatever format we want to look at is that it's not only the training of the caregiver, but it's also training of the family. I mean, I had not thought, we had not thought about that.

Now, we do family caregiver training and we do support groups and all of that to help families. But, what I was hearing here is that there is more to it than just, we do the ethics. We do all of that kind of stuff. It's not only hard skills. But, there is, so a recommendation might come if we do this, that it have two components. It not only be for the caregiver, but for the care, the family.

MALE VOICE: One of our big concerns, the reason we drill down on the independent providers, is that it's so glaringly a gap in that they are outside of the system. You know, and if they are going to call themselves whatever, whatever term they want to use, advertise themselves to families as we do this, somehow they need to be held to a standard as well. That's really the emphasis.

DR. VAUGHAN-WROBEL: Absolutely.

FEMALE VOICE: One thought, too, about your continuing education. It seems to me that questions will come up periodically for any caregiver in a home and you say you are doing twelve hours. So, it also would be a good thing in my view to be able to have more interaction with the caregivers, whether it's online or paid caregivers, whether they have an opportunity to really share among themselves. And I wondering, you know, what your plans are in that particular area to really allow from each other as well as to be taught. That's number one.

And then, I don't know whether this is a problem in Arkansas, but I think about literacy. We talked about the diverse cultures. And it seems to me that that's where the communication gap really lies. Is there any way to allow the caregivers in this program who are not proficient in English to have a component where they would be able to learn English or at least to begin to start.

DR. VAUGHAN-WROBEL: That we have talked about that, and we do have someone on our faculty who teaches, who has Spanish background. One of the things that when we looked around the country and all the curriculum we found that's most glaringly absent in ours is cultural diversity. And if you look at the chart, that's not there, because that's not something that we in Northwest Arkansas experience as much, because we don't have that much cultural diversity.

So, definitely, we are going back and add that into our curriculum as something that we need to look at.

FEMALE VOICE: Can you talk about the continuing education piece, what that entails?

DR. VAUGHAN-WROBEL: Basically, it's a one hour presentation, whether it's a new skill that they are suppose, to be learned or a new topic that's presented by people other than our faculty, and our faculty.

They come in monthly. We offer them monthly at two different times. We offer support to the caregivers. Our caregiver students come back to our faculty a lot with need for skill training in another area. So that the faculty are there to help them if there are care recipient needs and skills refresher. We have a lot of times that they will come back and say, well, I need to refresh this skill, because my new care receiver needs blank.

FEMALE VOICE: I mean, I don't mean to hog the microphone, but I also think that one of the dilemmas of being a caregiver is that you are home alone and you don't really have your colleagues. And I would think that you would want to build into that continuing education some way to make people feel that they are part of a bigger whole.

DR. VAUGHAN-WROBEL: One of the things that we are working on with elder stay home which is the name of our curriculum is that we are going to go online. And we will have care coaches.

And the care coaches will be available and we'll be able to answer within, I can't remember the exact number of hours, within twenty-four hours or more recently if they want to call in. They can do that.

So, we are trying to address those issues and you are right, there has got to be looked at how do we support these people who are out there more independently. And we are just, we are trying to look at that and needing suggestions and hoping that the group can help us with some.

DR. BUTLER: We have Ev Dennis and Bob Kane, and then John.

Dr. Dennis: A question really and that is the project here grew out of an earlier work on looking at Arkansas as a model for aging services, and given the fact that Arkansas has a very high percentage of older people in its population, the largest percentage per capita of geriatric physicians, the largest percentage of geriatric nurses, etc. And then has also everything from this very wealthy area of Northwest Arkansas where these folks are from to the very poor area of the Delta of Arkansas. But I am wondering for the group really, what are the differences that factor into a curriculum, if there is to be a national model, if there can't be a national model, what are the fundamental differences in the United States between states, regions, etc. based on either ethnicity or economic conditions, or degrees of disability. I am not sure what those factors are that why there couldn't be some kind of national model with certain variance built onto it.

And then, another question related to a very important issue to me here is the whole question of status conferral, which to some extent training confers status, but money confers status. And how does this, maybe that's for a later session, how this becomes something worthwhile.

DR. BUTLER: That's terrific. You want to respond to that? Either one of you?

DR. VAUGHAN-WROBEL: Well, I am going to talk about the career ladder, which, in a minute. That might help you with the.

DR. BUTLER: Steve, do you have anything to say on the status issue?

MALE VOICE: Having credential that is required by public authority at the state level can be connected to wages. I

think in a particular region, I think we are talking about it last night that in a particular region if you get a brand as Schmieding has done, then that becomes market value in the open market place. So, I think you either have to have a branded capacity that has value for the worker in the market broadly, or something that is more regulated in the public sphere and both, and training credential can relate to both and support both.

DR. VAUGHAN-WROBEL: I was just going to talk to Steve last night. I talked to him about the salary, and the Schmieding graduates are drawing a larger salary than people who are not trained. And the people in Northwest Arkansas are willing to pay that, because they know what they are getting. Some of our graduates are going into the \$14 and \$15 an hour, because they are trained and they have access to getting help if they need it.

DR. BUTLER: That's better than doing hamburgers at the Burger King.

DR. VAUGHAN-WROBEL: And it helps, it helps, yes.

DR. BUTLER: Bob?

MR. KANE: I wanted to take this opportunity to respectfully disagree with my colleague Jeremy. First of all, this is an area that cries out for empirical work. There is nothing unethical about testing it. We are not talking about depriving people of care. We are asking what is the marginal benefit of going through this curriculum program, as opposed to hiring people who, the way we hire them now. I think it's a perfectly valid empirical test.

We have done tests more dramatic in the area of medicine. We have certainly compared the level of training and its effect on outcomes and found in many cases that it was not in the expected direction. That, in fact, more training does not produce better care.

We have certainly shown that nurse practitioners can provide primary care that's equivalent to what physicians, interns provide. I think that there is a danger here to become so enthusiastic about a belief system that we put aside this highly evidence based empiricism that really ought to drive what we are doing. And my sense is that we are designing a curriculum before we even know that a curriculum is the

right, I mean, we sort of assume the answer and now we are working on polishing it, before we have even really explored whether that's really the right answer.

I would be very excited to see a test between an information driven system that would take relatively untrained people, put them in the community, and support them with computerized information system, using PDAs and modems against a 120 hour training program to see which one had the greatest effect on improving the outcomes of care for frail, older people.

I think that there are more ways to achieve the end that we are seeking that what we are considering and I do despair that we sort of started with an answer and are working desperately to find a question that it fits. And I think we need to be cautious about not going down that trail too hard.

DR. BUTLER: John Finnegan and then Linda Emanuel.

MR. FINNEGAN: Well, I think Bob addressed a key issue. I was concerned about if you think of evaluation say if you wanted to look at patient outcomes on one side of the four square versus consumer satisfaction on the other side. And you have high and low, and high and low. If the consumer satisfaction is going to be more important a variable to you, then you basically would be saying that if we score well in the low patient outcomes, but high satisfaction sell, then that's as good as or better than scoring in the low satisfaction versus high outcomes sell. And I think from the standpoint of the patient and the health of the patient, we probably would not agree that that's a benefit.

But, to go beyond that, and to get to, back to a couple of other things. In my listening to this, and this is not my field. Mine is more in the communication realm, social marketing. It's in interventions and campaigns and so on. In listening to this, what's intriguing to me is that in a way you are trying to define a market, if you will, I am sorry to use the business language, but that may help in the social marketing framework. You are trying to define both the demand and the supply part of the market. The demand is ill formed at this point, except that everybody knows they are not happy. Everybody knows they are on the Titanic, and nobody is satisfied with rearranging the deck chairs. Okay.

So, part of it is about, is about that issue. It's trying to form that demand out there and to move it from what I would

call a low involvement market of basically dissatisfied and ambivalent to a market where it's very clear what the demand is and what the consumer wants. And that the consumer isn't some facet willing to go out and get it and many of the people around this table will therefore, supply it.

And I think what the language I would use is a little different from Bob, but I think the concepts are basically the same, which is that where we are right now is that we still have this really low involvement market and we are coming up with the answer to the low involvement market before we have got the level of demand. So, I think that's part of the issue is we are already trying to figure out what the supply is and the consumer hasn't really powerfully, anyway, made clear what that demand is, other than just mere dissatisfaction.

The other thing, if I could just add really quickly, and I didn't have anything to say this morning, so I'll take my extra time. And this is just real quickly, this is not a one time or even a couple of meeting kind of question. I think this is really an issue about strategic planning and operations. And so, if you are familiar with some of that literature on the strategic planning side, which is sort of what this meeting is about, you are really trying to define the vision, the mission, and the strategies.

On the other end of it, you are trying to describe the operations, which is the structure, the process, and the outcomes, if you will, and the means by which you are going to measure it. And I think part of the unease that some of us have is that maybe we are plunging into the operations part before we have fully articulated what the vision, the mission, and the strategies is all about. So, I'll stop there.

DR. BUTLER: Linda and then Darryl, and then John.

MS. EMANUEL: Just a quick follow up to Bob's comment about the empirical data. The empirical data in evaluating the impact of an educational program can be thought of in six steps. We call it the Dixon six. You can evaluate attitude, knowledge, skills, and then behavior change, then the outcomes for the people who get the care, and then the societal norms. And evaluating the first three are pretty easy. Still, hard, but pretty easy. Evaluating the last three are unbelievably

difficult, because there are so many other things impacting the real world. So, even if you do get a negative finding, that doesn't mean that your curriculum was no good, or that your educational intervention was no good.

So, we do have to be careful about that. But, I think going back to the point about what do we want.

MALE VOICE: But, I mean, this is part, isn't this though part of the discussion about the perfect being the enemy of the good. I mean, everyone agrees.

MS. EMANUEL: No, actually, I want to go somewhere else. I agree with that point, but I wanted to go somewhere else with it, because I wanted to go to your point about where are we going with all this, because I think one can think of a curriculum in terms of what are we going to do to change the care experience and its impact on that. But a curriculum does other things as well. A curriculum in a field where there are no defacto standards creates defacto standards. And we know that about curricula. And so, I think it is important to go back and figure out what we want and is the curriculum the approach to that. Because it may well be, even if we don't have Bob's data, with all due respect for the role of data.

DR. BUTLER: Carol?

FEMALE VOICE: Yes, I'm, evaluation is out of my line of work, but aren't there some relatively straightforward things you can look at like how long do the workers stay with patient, as opposed to agency in and out. We are particularly concerned with transitions, and hospital, and short term nursing home, and back and forth, which is always a bad thing, from my perspective. How often do the people go into either one of those situations. You know, some of it's going to be unavoidable. These are old people with lots of problems, but is there some way you can measure that against some other standard that's in the community, without actually doing major, big research studies. And maybe there are certain things like diabetes control that are health specific outcomes that you could look at. It seems to me those are not so complicated to set up that would at least give you some information, if not exactly what you need.

MALE VOICE: Well, I am either, I still have random thoughts, and probably some are predictable. Just the one comment is I

don't think that satisfaction is a good measure. I mean, I know it's a measure, but you know, if you are walking you might be satisfied with a UGO. But, you know, so it's kind of a relative thing.

But, the comment that is predictable is I just would urge you to not exclude people with disabilities, and the experience of PAS in this. I just think that it can enrich what we are trying to accomplish for older people. Personal Attendant Services, I am sorry. And then I think about from the point of view, this is a point of view issue, if from the point of view somebody who wants to do work in caregiving, if somebody came to you guys and said really what I want to do is work with young people with disabilities. They would, I think, probably turned away, or they would see that as not the market place.

So, I think in terms of the choice of people who are interested in doing caregiving, kinds of work for pay, they should be able to engage these topics as well, and not be turned away.

One little red flag that went up that I just think is that unless you, you have been down this road is in Georgia, at any rate, if you have two employees, not full time, if you have two people working for you that you are paying for, you have to take out a worker's comp policy. Cost of that is about \$1000. You have to pay that annually. So, if you have got two people coming in to take care of grandma, you either have a liability of being uninsured and violating the state law, if you are the employer, or you got to shell out a \$1000 upfront. So, that's a \$1000 on top of \$13, \$14, \$15 an hour. It becomes, you know, for middle class families, at any rate, it's an issue. And it's a genuine issue. And people say, I need somebody to help me. I am going to hire them off the street. We don't want to go through agencies now, because of that liability. And people just will, they can get themselves into a bind unwittingly. I don't think it occurs that often.

The other thing, I just think there is a science about all of this, and I, I am just trying to figure out, trying to discover what that science is. And I know we are not going to get to this, be able to understand all the dimensions of

this great variability of populations that we are talking about. But, I think there needs to be some more rigorous investigation of the needs of providers to sit down with people who are paid folks, and say, what did you need to know, when did you discover that you needed to know that, how did you go about learning that, and get some information. And that doesn't have to be population based. You can go out and ask some people. Steve probably has the answer.

And then the other piece of this equation in this assumed did is ask some of the consumers. You know, what is it that you want. Do you want somebody who can do your meds. Give me an example, you know, since I am doing my examples today. My view is that the attendants that work for my daughter do the things that my daughter cannot do. Well, the dog needed a bath yesterday, because she got into some dirt. Okay. Now, if my daughter were able she would wash the dog. Well, the aide wasn't cool, didn't think it was cool to wash the dog. So, who washed the dog? My wife washed the dog after working eight hours. So, instead of making less work, it made more work. Now, that's not a big deal, but that's again, at the end of another day there is more work to be done, instead of less work to be done.

So, I think just there needs to be some investigation, some body of knowledge, some empirical data that we could, this is easy to do. I mean, these don't have to be huge studies to be able to investigate that. And then there are data, other data sources that we could develop and prepare to gather as part of a successful.

DR. BUTLER: Dr. Meier and then Steve.

DR. MEIER: I want to bring the discussion back to a sort of a 30,000 foot level, which is not too edit this curriculum or to suggest how it should be evaluated, because it's premature to evaluate it, because it's still evolving. And evaluation won't occur until there is enough of a market and demand for rigorous research that someone will fund it. And at the stage it's at now, no one would fund this project.

DR. BUTLER: I was going to say, Rick, would you --

DR. MEIER: So, all of these recommendations are great, but the NIH will not fund this.

DR. BUTLER: NIH will not fund it. I doubt if AOA will fund it.

DR. MEIER: In any case.

MALE VOICE: But there are very cheap ways they can do it themselves.

DR. MEIER: Well, but we need to have a model developed that we like, and agree on before we study it. But, there are other reasons to develop a curriculum that Linda was alluding to. And those reasons have to do with aims to influence policy. And so for, example, as an analogy, the field of palliative care, which didn't exist in this country ten years ago, now has specialty board certification status, ACGME, fellowship training status, mandatory undergraduate medical school, exposure. Where did it start? It started with RWJ funding a curriculum development for physicians and nurses. Basically, we made it up. Okay.

We didn't subject it to rigorous RCT evaluation. But it created a field, because it created legitimacy, identity, and a perception, a perception, which is very powerful in the policy world that there is a problem here and there is a response to it that professionals can avail themselves of. And it lead with many other major foundation investments, in a very short period of time, to a pretty substantial social change and that I think shortly will also lead to policy change in terms of payment and models of care, and accreditation models for hospitals. And home care needs are not certified home health agency, home care. But the home care we are talking about needs to go through a ten to fifteen year strategic process just like that, if we are going to be even have a prayer of responding with quality care to the demands that are going to be put on the population.

So, I see this meeting and this curriculum as one of the means of the bottom up, top down strategy that's going to be necessary to bring some attention to this component of health care, which is basically been completely ignored. I would also argue that you don't wait for the demand, you create the demand through social marketing.

There wasn't a lot of doctors pounding on the door looking for education in palliative medicine, because they don't know what they need. We told them what they needed and we marketed aggressively and now they want it. And that's how you do it. That's what social marketing is about. I mean,

the public doesn't know what it should have. We have to create some expectations out there.

MALE VOICE: That's low involvement versus high involvement marketing.

DR. MEIER: Right, exactly. But that's what we need.

DR. BUTLER: Steve?

STEVE DAWSON: As to John's question in terms of outcomes for the workforce. There is a, in fact, a pretty large body now of data, Chris Langston is here from Atlantic, and Robert Wood Johnson co-funded a Better Jobs Better Care program over the last four years, which had both applied research and demonstration projects over five states, and much outcomes in terms of work force outcomes, of lower turn over, job satisfaction, increase in wages and benefits. So, I think there is a, and you can find that at BJBC.org.

In terms of the, back to the question in terms of the type of curriculum model, from a worker prospective, I think trying to, building on what Linda suggested that there, that you have a framework here which does have sort of an initial core that is less specialized and then you become a little more specialized as you go along. I would say that the more core, the more generalized you can start with the better, that would allow someone to have a credential and a training base for a wider range of clients than just simply elders. And then allow the specialization to come up so that later, because certainly there are distinctions in setting and by client, but, the more you have like, we are working with in Pennsylvania and Washington State, where the first level is 75 hours that's much more personal care, lot more in terms of the communications, problem solving, team building type of skills necessary that you would find in any setting. That to the worker would have greater value in terms of portability if it were recognized by a state in terms of licensing for agency use.

And so, I think that it's important to sort of focus as much as possible on what's generalizable across settings before you go to specialization. And that you focus on little less on curricula, which I think is just to have a single standard of curriculum frightens me for any setting, and certainly, nationally. But there could be much more agreement on what are the core competencies, what are the best practices in

terms of adult centered learning, and training. Those are the elements that you could really create some standards around and gain a lot of agreement across settings, and across advocates, and less tie to a specific curriculum.

We have had a curriculum in New York for fifteen years now, which we never published because we are always changing. And because we always want to improve, our clients are changing, our worker population is changing. So, be careful in terms of coming up with a standard that is tied to a particular curriculum as distinct from tied to competencies.

DR. BUTLER: Linda, I think you had your hand up?

FEMALE VOICE: Just very briefly, there is also been a, there is a large body of research on what families prefer when they hire workers to help them in the home. And the two top issues for families in virtually every study is reliable and trustworthy help. And the one question I wanted to ask Beth is, for many family members the reason why they want to hire outside of an agency is because oftentimes there is the four hour limit where you have to hire a worker for four hours, which is a huge barrier.

So, I wonder after you do the training, do you work with the direct care workers to help maybe match with families that need care in the home?

DR. VAUGHAN-WROBEL: No, we cannot do that, because we are not a placement agency. We can, we just give them the list and we say these are graduates. That's about all we can do, because there is a state regulation. But we have found is, is that the families, and long term care insurance and you look at what the costs when it goes through an agency. And you can half that and you double your amount of time of a caregiver, normally, if you do it independently.

Now, knowing that they are not bonded and they are not liability, families are willing to take that, because they get twice the amount of time. But it takes, because of the cost of the agency.

Now, some of our graduates go to work for agencies, and we have had them in the care agencies, particularly, not home health agencies, but care agencies. And they come back to us and they decide they are going to go independent then, because they don't particularly care for the help they are

getting from the agencies. So, some, I mean, when you really look at it some of these home care agencies that are evolving, maybe not in New York, and maybe not in California where you have a lot of, some of us out there in the boonies, they are evolving and they are needing help on training their care givers to go into the home.

Now, we chose to focus on trying to look at the in-home care giver, but that's not, I don't want to eliminate the thought of the caregiver that's part of the home care agency.

MALE VOICE: I just have one other follow up question to that. Have you considered becoming an agency in order to manage the costs for the worker, so that it wasn't as expensive as them using an outside agency? They would get the certification. They would get the, you would have the higher quality and some incremental costs to the client, who is hiring.

DR. VAUGHAN-WROBEL: We have tried, and we would very much, I don't know very much, but yes, we looked into that. But, in the State of Arkansas the regulations will not allow us to become, we have to be a home health agency to do that. And there are only so many home health agencies per county in the State of Arkansas, and those are all filled. I would have to buy another agency.

So, to answer your question, we looked into it.

DR. BUTLER: Yes?

FEMALE VOICE: Well, being a home health agency among other things, and actually going through very much this process of being a care manager, wanting care for my clients, and being frustrated by home care agencies in New York, and other places, I completely, you know, agree with your dilemma. I actually elected to hire privately. In fact, if I am not mistaken, Diane, I think I advised you about hiring privately at different points. But, and I think it gets back to the policy issues about what state regulations require from agencies who are, you know, because families do want sometimes help with the liability issues. They need that, they want it off their plate. They have other things that they have to do with their lives other than managing a caregiver.

That's not to say that, I mean, there has to be some mid ground. And it's expensive to do this. It costs a lot of

money. That's why you elected not to do it, because it's very expensive to run an agency.

The other thing that I wanted to add that even with, you know, all of the training and I would say that our basic training is pretty much consistent with what you have, and then we have like the sort of more touchy, feely, social stuff that we add to that, too. But, what I say in my role as a marketer is that a trained caregiver is a caregiver is a caregiver. And that what differentiates, you know, certainly what we do is that in many situations you need much more than that. You need a decision maker. You need an assessor. You need analysis. And to have an independent person out there with a very complex situation is high risk and liability.

DR. BUTLER: Okay. Ten minute break. Lets see how good we are getting back in ten minutes.

[BREAK]

DR. BUTLER: All right. The next presentation is the issue of career ladder development. And the presentation is by Beth and by Ken Knapp. Ken Knapp is an economist at the International Longevity Center.

DR. VAUGHAN-WROBEL: Just another idea, as we look at this workforce. And of course, as we have talked in the past, how did we get these caregivers and retain them in the workforce. And as we begin to talk about this and as the caregiver project started, one of the things we said is well, maybe there could be a career ladder, an opportunity for these people to move from just doing caregiving to specialized caregiving. Or someone suggested that it come through maybe going up the ladder for an academic.

So, one of the things that we talked about is that we would look at, we needed to look at, or at least give some consideration to a career path that would build and retain these caregivers. And we are talking about the paid in-home caregivers. And whatever we end up and call these people, if we go through the recommendations whether they are assistants, or whatever, we just call them caregivers. And so that's what we are talking about, though. Is that they are looking for opportunities to increase their wages. They are looking for opportunities for advancement through a wider work settings, or more advanced in their work settings, and some personal satisfaction, and some stability.

What we have found as we have worked with caregivers, is they really want to be part of a group. They want some recognition for what they do, and their self-esteem needs to be built. And what we have tried to do in our workplace is to do just that. We do call them professional. We recognize them. We give them the name badges. We do the things that we hope then that will increase their self-esteem.

One of the things that we looked at was a career ladder. Now, there are two ways that we have been, if you can look at this, as an academic or technical training, or specialty in home caregiver training. Some of the people that we bring in and train will not ever be interested in going to college, nor would they be eligible for college. They would never, or an academic setting. So, I am going to talk a little bit about the career ladder as we see it for the specialty training. And then Ken is going to talk about it and the academic and the technical training.

And I told you that we had three levels. And we look at that as a career ladder. We recruit for the first level, and then we recruit them on for the second and for the third level. And so, as they go through they become more specialized in the training, in the care of an older adult in the home. Some from just, you remember I said that it was kind of like a companion, more than just a companion, but in your head you might think about that. And then more specialized and more specialized as they go up the ladder.

For Arkansas, the dementia training module is a 15 hour defined amount of training that they must have before they can become an CNA. And we highly recommend our graduate to go on and become a CNA. It gives them more opportunity. Some of the long term care insurance agencies say if they are a CNA, they will hire them for the long term care, even though they are independent.

So, or if they wanted to go to work in an agency, another type of agency having that credential, that testing and that credential, is an important rung up the ladder. So, we have and that's the way we talk about it with them.

And the terms we use is the geriatric home care giver. We think that identifies the population they are working with. It is at home and it is a caregiver role that they are doing.

The specialty training column, we are in the process of

developing modules that are very, that are on various topics so that once they may have a client that they want to have more information about, and they want to come back and have some formal certification in further dementia care, the restorative care, the disabilities for older adults. Everybody knows that the population of those with disabilities is growing older, too. And in our area, people have begun to address how do you have someone with a disability that's growing older. How do we care for those persons.

Palliative care, chronic disease modules, specific, if they were working with someone with diabetes and felt that they needed to come back and get some more information specifically to help that caregiver. So, what we see is, and it may just continue on. And it goes a lot with what Steve says, is that there are core competencies. And that you maybe can build on them.

Now, we elected to identify specifically for older adults, but it doesn't mean that the opportunity may not be that we identify core competencies, and we use the career ladder for specialization on up the, as far as working with older adults. So, it's something to think about. It is the way that we are going to, we are progressing in working with our caregivers. And we are trying to get them into an organization, a group of people coming together for the sharing and then hopefully, we will be able to help them with some benefits, so that we can help them as, to feel the self-esteem and proud of what they do, as caregivers in-home.

Ken?

DR. KNAPP: Okay. Thank you, Dr. Vaughan-Wrobel. MetLife Foundation has provided major support for our community college, caregiver training initiative. The purpose of the initiative is to encourage the development of caregiver training programs at community colleges. We want to encourage both newly implemented programs in under served areas, which can be modest in design, and enhancements to programs that already exist.

Community colleges hold a great deal of promise for the recruitment of people into the caregiving field and for the training of both professional home care workers and family caregivers. Up to twelve grants of \$25,000 will be awarded

to community colleges who implement new programs or build upon existing ones. We expect to issue a request for proposals on this in the next week or so. Under the RFP, we are requiring that training programs to be implemented by fall 2007. And selections of grantees will be made in June.

Before I move on to how community colleges can strengthen the career ladder, I just want to go quickly over some factors that will influence the selection of grantees under the initiative. Trainees should receive certification at a minimum certificate issued by the college to recognize satisfactory completion of training. Hours of training should go beyond the 75 hour federal minimum. Training for a family caregivers must be included in the program. Trainees must receive instruction on care for older people, not necessarily exclusively, but the care for older people has to be included. And training for care in home settings must be provided. The organizational capacity and strength of local partnerships will also be a major factor in the selection process.

Okay, now, there are several reasons that community colleges can strengthen the career ladder of professional caregivers. Sixty percent of all new registered nurses receive associate degrees at two year institutions. And allied health programs, especially registered nursing, are the fastest growing curricula among community colleges. Many nurses start out as professional caregivers. So, if you have got a community college offering a nursing program, also doing some caregiver training, there is an obvious career ladder there. And the community orientation of community colleges, their experience working with local employers, workforce development agencies, triple A's, that strengthens the career ladder. And community colleges have in-house job placement and job counseling programs that help students find jobs.

So, I think we can open up the floor to discuss some questions, and feel free to come up with your own questions. One, to what extent do community colleges currently provide caregiver training? Two, what are the main challenges community colleges have faced in offering professional caregiver training. And three, what, excuse me, should a career ladder include more than advancement to technical or college education. And lastly, what examples are there of promising programs to strengthen the career ladder for professional caregivers.

DR. BUTLER: The floor is open. Looks like Dean Takamura would like to say something.

DEAN TAKAMURA: Kenneth, I am just curious. Is the RFP out already?

DR. KNAPP: No. We expect the next week or so.

DEAN TAKAMURA: Okay. And then when are you going to request the responses to the RFP by?

DR. KNAPP: By.

DEAN TAKAMURA: June, is that true?

DR. KNAPP: That's right. Well, we are going to make the selection in June. It's like mid-May is when we get the.

DEAN TAKAMURA: And did you want the courses taught in the fall?

DR. KNAPP: Yes.

DEAN TAKAMURA: I think you are going to run into an impossible deadline. I mean, candidly speaking, most faculty go on vacation during the summer. And unless they get ad comp, additional compensation or whatever, they are not going to produce something that will be as strong as if you gave them more time. That's one thing.

The other thing is having been involved in curriculum development, I mean, if you really want a good product, I think it's going to be really hard. And again, unless you have community colleges that already have something online, but my sense is that you really do want to influence the content, so it's superb as opposed to just taking something off the shelf. I am really concerned about that time table.

FEMALE VOICE: I am wondering who will teach these courses and do you have something built in about the qualifications or the variety of people who will, community colleges will recruit to teach, because that's always a problem.

DR. KNAPP: Well, it's open. We'll see what the applications say. There are community colleges that do already provide caregiver training. There are some that work in partnership with training agencies in the area. So, it just depends on how they want to do it. And I know that, the implementation deadline is tight, very tight.

We expect that we'll get a lot, we have actually just based on a press release we sent out in January on this, we have gotten fifty or more community colleges to express interest, to want to know more about it. So, I think there is interest out there. You know, if you have got community colleges that are providing caregiver training now, what we are going to ask under the RFP is that they build upon it, sort of justify the how they are going to spend the \$25,000 by creating special modules or what have you.

But, we are also going to recognize a community college that decides to offer a couple courses for family caregivers in very under served area. So, if there is a program that doesn't exist, there is a need from some training in that area, that's something that we would consider.

FEMALE VOICE: Two suggestions. I would really strongly recommend that you have a consultant available to them that provides, at least, a baseline of understanding about what you mean when you say curriculum. And what you mean when you say learning outcomes, if you will, or performance outcomes, because notions of curriculum are all over the map. And for a lot of people, you know, curriculum is not anything like what they, what it actually really should be.

The second thing is, I would really strongly recommend that you take a look at funding several community colleges that in particular would attract students who are from minority groups. And part of the reason I say that is as we move forward in the decades ahead, it's very likely that our caregivers are going to actually be coming from those minority groups. So, I think it would be good to have a long track record of training, and perhaps improving training programs for caregivers.

DR. BUTLER: Gail?

Ms. HUNT: Yes, I would just from the little I know about the way community colleges are structured, and provide their programs, this could be viewed as a one shot deal, one time only, you know. Lets, I get the money and then we do this program. And also, if you can still build into your RFP something about sustainability.

DR. KNAPP: There will be a statement about that.

Ms. HUNT: They are not just, but they have to make a commitment

to not just take the \$25,000 and then that's it. So, that was one point.

The other point is the issue of outreach. Some of them probably do an outstanding job already, and would have no difficulty getting direct care workers to come in to take the program. But, others may actually need assistance, but also need to have a really well thought out plan for how they are going to reach out, especially if they are going to like reach out to the minority community or something.

So, I would really put some emphasis in the RFP on how they are going to do outreach to get the students in.

DR. KNAPP: Right.

DR. BUTLER: Sandra?

Ms. Timmerman: Yes, I also thought that many community colleges have gerontology certificates and I would think that that would be important to ask in the RFP if there are gerontology courses offered or a certificate program in gerontology, which would show commitment on the part of the community college to serving this population.

I think the other piece would be their connection with say the area agency on aging or some aging organizations that they can, you know, already show that they are doing work with them.

And my third point and I know this is not about home care agencies, but I still hope that you might consider this kind of training to be feeders to home care agencies as well, because you know, part of me feels that the consumer is protected by the homecare agency in a way that they are not protected by independent caregivers. And as time goes on, people may be looking for a combination of both. And this kind of program would get support from not only the area agency on aging and the non profits, but if you get your business involved in it as well, I think you are going to get a much better support in community for it through these local homecare agencies.

DR. KNAPP: Well, absolutely. And as I mentioned, the strength of local partnerships, track record of working with employers in the area, homecare agencies, triple A's, workforce development agencies, hospitals, nursing programs, that's going to be a strong component in the selection process.

Definitely.

DR. BUTLER: Marie?

Ms BERNARD: I recognize that right now the focus is on community colleges, but looking at the broader question about a career ladder, as you do your next iterations of this. You might think about also focusing on vocational technical schools, depending upon the region of the country that you are looking at. Votechs may be even more widely available than community colleges, and a lot of LPNs are trained in that setting. And thus, that would be another place in which you could do some outreach.

DR. BUTLER: Claudia?

Ms. FINE: A couple of things, not necessarily on what you just talked about, the RFA and so forth, but I have been surprised, if you will, over the last couple of years in talking to a lot of direct care workers in different settings. And you know, I was always of the impression that all of them wanted to go ahead and continue in their education in some way or another. What I am finding is that there are really a small percent that have that will. And for that small percent that has the will, it is very difficult, because most of them are from home settings that have not gone the academic route, if you will. And have not had the support. And also, they are struggling with having to work full time, because they are trying to support their family or families. And so, you know, to have the freedom to go to school, much less the support of whether it's their employer or others, I think, is something we need to address as we encourage individuals to go throughout. Because I don't think many of them could be successful in doing it by themselves, because they don't have the support at home, and most often have not had the support from their employers.

So, I think that we really need to at the same time look at a structure that will help them to be successful as they wish to continue, especially in the formal route.

DR. BUTLER: Steve?

Mr. DAWSON: Just briefly, the Department of Labor, US Department of Labor has had several years of challenge grants to community colleges, about 250 million dollars, not strictly for healthcare at all, but similar encouragement to develop

particular curricula around job development for different sectors including healthcare. So, you might want to really check to see what lessons they have.

And also, Robert Wood Johnson just issued an RFP on selected sites that is more health related, and do, it's a, related to at work learning, but requires community college engagement. So you might work with them to just see what their learnings are.

And I would just reinforce Dr. Muer's point that I would hope you could convince your funder to give you another year here to give you a time line that would allow you to develop some of these relationships, and give the community colleges time to really think through a high quality program, the type of relationships, type of sustainability issues, etc. that you are seeking here. I think you are talking about RFP that goes out in early April that has to come back by mid-May, then seems like there is very little time.

DR. BUTLER: Rick?

Mr. GREENE: I hope when you look at the grant applications that come in, you give serious consideration for a rural project. That's one of the major difficulties that we are encountering right now is providing care to rural caregivers. And there is also, as you are aware, you know, shortages in manpower amongst the few agencies that may be available there.

Another thought that you, that we had had a grant at one time from public health service to train older persons to become homemaker, home health aids. That might be a market that you might want to consider also. And there are also some programs in New Jersey that were going into the high schools, and working out arrangements with the high schools so that the students could come, be trained, be placed, and get high school credit as well as ultimately certification.

The other random thought I am getting like John, is another thing that might be useful is a public awareness campaign, sort of modeled after the Johnson & Johnson Foundation, campaign on nurses. That really revitalized a lot of the schools of nursing, and increased enrollment.

Mr. TAYLOR: I was a bit involved with the J&J program, and there is only one little problem, which costs many millions of dollars. The, a couple of questions if I may.

MALE VOICE: I am sorry, what did you just say?

Mr. TAYLOR: I am saying the J&J program, which is wonderful, costs tens of millions of dollars, I think. So, I am not sure that we have those resources.

Two questions. One is, is \$25,000 enough to get a community college to do this. And the second question is, what do we know, if anything, about the potential demand from students. This is really a follow up to Claudia's question. Is there, if the courses are there and the doors are opened, will they come.

DR. KNAPP: What was that second question, again, I am sorry?

Mr. TAYLOR: Well, I am sorry. First question is \$25,000 enough. Second question is, okay. They take the grants, they open their doors, they provide the courses, what do we know about the demand from potential students for those courses, if we open the doors, will they come?

DR. KNAPP: Okay. Yes, I do think \$25,000 is enough for, to attract just based on this press release. We have gotten fifty, at least fifty community colleges to ask us more about it. So, there is definitely interest out there. Now, they can't build from scratch a brand new complex program, but they can build upon their existing program. And they can create modest programs in underserved rural areas, for example. And we are going to consider all of that.

And the second, if you build it will they come. Well, we are going, we are going to ask applicants to make, to have a statement about local needs, enrollment, total enrollment in the community colleges, and the population that would be served by their program.

FEMALE VOICE: Also, there are curriculum out there, so they don't have to go and develop them themselves. If they are interested, they can, like the Washington. There are some other very good curriculum that are out there. And if they take it and do it across the lifespan, but focus on older adults they can do that without even having to develop.

FEMALE VOICE: See, but I think that's where you need somebody to provide the consultations so that they will go to those immediately, but also know where they can make the adjustments for their particular community.

Ms. KARPINSKI: My question was the training exceeds a 75 hour federal minimum. Where do you, what is the 75 hour federal minimum that I am not aware of?

DR. KNAPP: Well, if you are a home care agency that's sending people out to provide care for people getting Medicaid, or Medicare, there is a certain level of training they have to have for that. They have got to be, in order for the homecare agency to get paid from Medicare.

Pardon?

FEMALE VOICE: The home health aides?

DR. KNAPP: For home health aids. But that, see that, I sort of hesitated putting that up and discussing that. And I didn't want to sort of get into all the little details of the RFP. I was more interested in talking about community colleges as building career ladder. What role they could have on that.

Now, the 75 hours would not apply to a community college that was offering, for example, a modest program, a couple training courses for family caregivers in an under served area. So, that would just, just something we would look at for community colleges that already had caregiver training programs in place. You know, other things equal, the one that had more hours of training does better in the selection process.

FEMALE VOICE: I just wanted to ask about the whole, the companion training and maybe I am more tuned into this because my husband had Alzheimer's disease. And what I needed was a companion more than a certified home health aide. And that kind of training is really informal care, in a sense. People in homecare know this perhaps better, but my unit does market surveys of homecare, private homecare, paid homecare by individuals, as well as, companion care. And we find fewer and fewer homecare agencies actually making private pay homecare available through the agency. More so, the sort of companion care, which sometimes is not covered under long term care insurance. More and more it is being covered because there is such a shortage. And I do think the distinction is interesting, because there might be more people who would come in to be these companions, but they still need some basic level of understanding, particularly for people with dementia.

So, I am trying to, you know, sort of level set you and say, is the training going to also help those people who really just want to be a companion and still can understand and may not need to do the heavy lifting, so to speak.

MALE VOICE: Companion is such a good thing, function, but I know Claudia has thoughts on that subject.

FEMALE VOICE: I couldn't agree with you more. But, I actually think that on some level that it requires, you know, not more, but a different skill set, and there needs to be a module, if you will, that includes companion skills. And you could have it almost, you know, you could have companion alone. Companion, you know, home care worker alone, or you could have a sort of continuum, which is very often what's needed.

FEMALE VOICE: What will happen over time.

FEMALE VOICE: Exactly. Sometimes, you know, at Senior Bridge, we will start with somebody who is a companion and then, but we will want that person trained or certified in caregiving techniques, because the needs are going to increase.

MALE VOICE: Things may have changed a lot since my practice, but the churches use to provide family visitors who really had a different, total different skill set. They were terrific companions.

FEMALE VOICE: Although, to get somebody in your house twelve hours a day while you are working, it's hard to get a volunteer to do that. You really need a professional. And those people are so critical for certain illnesses that I wouldn't downplay that. That is really a very important part of the care continuum.

MALE VOICE: I think Sandra, you are illustrating the extraordinary complexity of the vast needs we are going to have as we move along in this century. But, to the degree to which we are talking about health oriented and the opportunity for people to grow and develop a career, I don't think the companion skill set is quite where we would be going. I think that's a very different skill set.

FEMALE VOICE: Although, it's not, companion is the word for it. It's a home health aide. They are called companions, but it's different terminology. I think Claudia, you would know better. They are professional caregivers.

FEMALE VOICE: Yes, I respectfully disagree.

FEMALE VOICE: It's not what you are thinking. Companion is the wrong word.

FEMALE VOICE: It's not a housekeeper. It's what actually you were looking for. And that person needed to have a certain amount of sophistication and knowledge and was very much going to need to understand the next steps. It's, you can't separate out these skills from homecare for an aging population.

FEMALE VOICE: And I just want to say, I was using Home Instead and I am familiar with their work because they actually received an award from the American Society on Aging for their curriculum for dementia care. And people go through a training to be certified to do this. And they have someone they can call, because issues come up all the time. These are professional caregivers, and you pay good money for them. They are not companions like family visitors.

FEMALE VOICE: And to reinforce, at our, we have something called a specialty companion, which is what we really use. We don't have like so many just regular companions. And we actually charge more for them than our home health aides, because it's much more, you know, you just need much more training.

FEMALE VOICE: And just, I am sorry to keep going back and forth, but in our market surveys of homecare aides, and home companions, that is a legitimate class of people and there are schedules within the home health agencies for these people. And they are screened. And they have supervisors and so, it's really important because I know the terminology varies from state to state, but I think when the training is taking place, the curriculum needs to understand the distinctions of these two, because it's really a non medical model. They cannot administer drugs, and things of that sort. But they can call the agency and it might be that the agency would bring somebody in a couple of hours to do the medical, but this person is there the rest of the time. And the agency manages it.

And I think this independent, from an independent caregiver point of view, that's something to think about as well.

DR. KNAPP: I just want to say that I have no doubt that the responses we get to the RFP are going to represent a variety

of program designs, and local partnerships. And we are not, the RFP that we are writing up is going to allow for flexibility and innovation. We are not prescribing X number of courses that specifically address any particular thing. So, I just want to clarify that. And I just wonder if we could go back just to the, one of the main questions here, which is what, how much is known about experience of community colleges providing caregiver training, and where do community colleges in the opinion of the experts assembled fit in and strength career ladder for caregivers.

FEMALE VOICE: We have with our personal care attendant training program, we have contacted hundreds of community colleges. And we haven't found anyone who has caregiver training. The obstacle that we face is getting them to understand the need for caregiver training. And we have worked with some vocational technical schools that have offered caregiver training, and we are working with the community college in our community.

But it's interesting when we, well, this is what we have run into is if we go through workforce development or if we go through continuing education, they want to bypass it through the nursing department first. When it gets through the nursing department, it gets slammed down, because the nurses feel that we are lowering the standard of care by not having all, every person be a certified nurse's aide.

So, they kind of feel like it's lowering standard of care, and then we have to explain to them that you know, this has been a worker that has been invisible in our health care system for years and years. And we have allowed people with no training to walk into the home of our elderly and disabled. So, we seem to get through to those people when one of them has had some caregiving experience. Then they totally understand it. And then you know, they are willing to work with us that way.

We are now working with a community college to put our program online. And they approached us. And the person who approached me is from Work Force Development. And I said, are you going to put, have our program go through your nursing department, and he said are you nuts. They would, they would you know ban it totally. They would not be for it, because you know, our healthcare education model has been CNA, LPN, RN. And one of the things that we have tried to

say is that the CNA is not really the entry level into homecare. It's really this worker that we are talking about.

So, you know, that's kind of the challenge that we have been up against with the nursing departments. And what was the other thing I was going to say? Well, I am just going to say what I was going to say earlier. Partly what concerns me is that we have ten years before we are going to have almost 21 million people who are going to need care. And we don't have a lot of time to, this is going to come really fast. And so, in my opinion I think we really need to start training the people in our churches. We need to start training our neighbors. We really need to start training people in our community, because we are not going to have nurses. So, that was the point I was going to say before, is that the focus has been on the nursing shortage, and it's been really the nursing shortage in the nursing homes, and it's been in the hospitals.

And nobody seems to, except this group here, seems to be looking at the shortage that's going to be happening in the home, where we have almost 90% of all homecare is done by family caregivers or somebody hired. So, my concern is that if we put so much restriction and I, you know, I truly believe we do need some kind of skills. They do need some skills. None of us here would want to be in a hospital receiving a bed bath or having somebody taking vital signs from someone who had no training. And yet, we have quicker and sicker discharges and we have people who are going into the home with absolutely no skills at all. And we are expecting family members and these direct care workers to provide really nursing care that nurses provided in the home. And it's really an unsafe situation.

But my concern is that like in Canada, for instance, they are training people in the Philippines to take care of their elders. And you know, putting them through nursing home. So, when we start to make the curriculum so difficult and you know, I mean, in questioning the 75 hours in some ways, and you are saying it's a federal requirement. But, who is going to, who are going to be our caregivers in the future. And they are going to be coming from minority groups. They are going to be people with English as second language.

So, you know, that's why our curriculum is written on a fifth grade reading level, but even you know, the community

colleges are perfect in that they can offer some English colleges to help, English classes to help these people, but you know. Those are the kinds of people that are going to be going into this kind of training. They are not going to have a high school diploma. So, we have to make the training available to those people, or we just not going to have the caregivers in the future, which is really just right around the corner.

DR. BUTLER: I think your sense of urgency is exactly what appealed to us and identified this as a major crisis. We really do have to move on it now. I think Jeannette wants to say something.

FEMALE VOICE: Yes, Bob, very quickly. I am going to join John's club of non sequitur speakers, if you will. But I do believe that if you are going to focus in on any educational institution, probably it is the community college and or it's the high school continuing education program. One of those two.

I also would agree with Marianne that there will be some institutional barriers. In 1988 or 1989, we introduced a full scale frontal program of initiatives to make the entire state of Hawaii cognizant of the long term care needs of a growing aging population. And so, I think what I am going to suggest to you is that it's really going to take more than issuing an RFP to have any certainty that you are going to get some results. And that's why I initially raised the concerns that I did.

What we put into place is a two year every week program called LTC, Lets Take Charge, on television. And we put it on TV and every what is it, twenty minute program had three segments. One of it was just introducing people to concepts surrounding aging and long term care so that there wouldn't be a mystique. The second had to do with actually showing people things that they could do in the home if they were caregivers.

So, we demonstrated for example how you could put a belt around someone and use the belt to actually lift them. Good techniques of lifting and bath techniques of lifting. Showed them all the assistive devices that people have no notion were actually out there and available to them. And then we entertained all kinds of questions about long term care. And

we ran this television program literally every week for two weeks to create a climate within the state that would make long term care part of the fabric of every day life.

And it really took that kind of massive informational effort to then introduce a caregiver training program at one of the community colleges. It ran, but it had great difficulty in finding students. And it was through a nursing department, as a matter of fact.

In addition to that, we put online a multi lingual telephone access line for caregivers. First one in the country. So, that anyone with any questions about long term care no matter what language they spoke, could call in. And we are getting calls from all over the country at that time. Even with all of that, ten years later, we discovered that, in fact, we would have had to continue the effort in order to keep long term care in people's radars, and keep them thinking that this was a priority issue.

So, I just think that, I am not quite sure what your expectations should be, but my fear is that your expectations may be too high for this first set of RFPs. And I could be, I hope I am really wrong.

DR. KNAPP: I hope you are wrong, too. I just, again, I want to say, that just based on a press release that we issued in January, we got over fifty community colleges contacting us wanting to know more information. When is the RFP going to come out. So, I am hopeful.

DR. BUTLER: Well, we should move on. But I do want to reecho Marianne's point. I do think what drove us was the sense of urgency about this caregiving issue. And of course, if we had all the resources of the world we might agree we ought to carry on a big awareness campaign and do many, many things. So, what we have tried to offer today was at least our beginning effort to present to you a start. And we know that it's not complete and it's not the final edition. This may be just half of the first edition.

And you have all been, as far as I am concerned, just great in being critical, being analytic, and presenting to us your various ideas. So, now, that I think becomes not a bad segway into something that's going to be even more problematic and that is the whole idea of setting standards and accreditation of training. How reasonable is that. How possible is it at

this early stage.

And at this point, I'll turn it over to my friend Larry Wright.

DR. WRIGHT: Well, the topic as we framed it is the idea of setting standards and that could be acknowledged through an accreditation process for training programs and certification process for the caregivers, or the direct care workers themselves.

Just as a reminder of what a good definition might be from someone who is an authority from the National Commission on Accrediting, William Seldon. Accrediting is the process whereby an organization recognizes a program of study as having that certain predetermined qualifications or standards. So, the purpose as we see it here would be to establish a minimum substandards, raise the excellence of training, provide assurance of acceptable level of performance, and raise the level of awareness, professionalism, and compensation hopefully of those who successfully complete the program and become certified.

So, the obvious questions are simply, are accreditation and certification important to raising the standards for in-home care of the elderly. And also, the companion question might be, should continuing education be required. And will this help bring the independent in-home caregiver into the system. And as I mentioned earlier, I think one of the big reason we focused on this independent provider is that it's such a glaring outside of the system piece of delivery that's going to have to be called on more and more in a growing workforce, at least in the short term.

Floor is open. Yes?

MALE VOICE: One question I am sure you have grappled with already is how would we, this is already a shadowy world.

DR. WRIGHT: The grey market.

MALE VOICE: The grey market. And accreditation and certification implies a certain amount of policing of this shadowy world. And have you thought at all about the downstream impact of making a requirement on people who are already at the margins, and does that, is it enforceable in any way? Or is this really an effort that won't lead anywhere other than to create more people who are feeling marginalized. I guess

that's my question.

FEMALE VOICE: Well, my response to that is that no, you wouldn't police it, but it would give those of us who need to hire and if we desire to have a certified person, then we could find them. It's not a mandatory kind of a thing. It's a credential that the families then would be able to have some assurance that the person they are hiring has some skills that they have learned, that they are recognized by a body whatever that body would be. So, I see a little bit differently than policing or making sure that everybody had it.

It's more for those of us that need it, if that's what we want. Then we would be able to find that and hopefully, the people would want to do that.

DR. WRIGHT: But obviously the family retains the right to hire anybody they want to.

DR. BUTLER: Claudia?

Ms. FINE: I just had a kind of ah-ha, and I saw that this is not so different from the sort of history of geriatric care management, because you really don't need to be anything other than as we call them a wannabe to be a care manager and that's been true. I took care of my aunt. And now I am going to hang out a shingle.

And there, the National Association started with people who just hung out shingles and then there were people with Ph.D.s. So, you know, over the years the association recognized that the consumer needs to be protected and so, the, you know, we set standards of who can be in the association. And I think maybe one of the questions that needs to, or ideas might be that you want to set a standard about who take the course. So that you already are, and of course, then you have the conflict of if you are trying to get everybody to be a caregiver, because you are frantic, and you need lots of bodies to take care of people is that sort of, sort of counterintuitive.

On the other hand, if you are looking to ensure some sense of quality and protectiveness of the population, perhaps setting some kind of initial standard about who is trained might help a little bit.

MALE VOICE: Well, I think one of the things at PHI is, one of the

many things is some of their studies showing that part of building retention and sustainability of the workforce is accomplished by requiring training. You know, people rise to that, and realize they are getting into something that they can value and hold on to. And I am paraphrasing that.

DR. BUTLER: Steve?

Mr. Dawson: Sure, I think there are a number of states now that are moving toward certification of the personal care level, sort of below the home health aide, non clinical services. And Washington State, for example, will have a referendum in November requiring 85 hours of training for individuals. So, I think that on the public payer side there is going to be more and more movement toward this. I would assume that will impact the grey market private pay side. What I am not clear in terms of your recommendation is how you could create enough of a brand on this, on a national level, if it were not a public requirement, public policy requirement of provider agencies. I mean, if you are only trying to create a credential for the individual worker, I am not sure who pays for the training. I am not sure what value that has except, again, I think it makes a lot of sense in a region where you get a brand. You get a quality training program. You produce quality candidates. They provide a higher level of care. There is an experience in the community and then you have a brand. And then people start paying for that value.

I think that makes sense. I think in terms of a national approach to that, though, I don't quite see the business model. What I do see is sort of moving on the public side and creating minimum standards there, that would hopefully inform the private market more, not the other way around.

DR. WRIGHT: State by state?

MALE VOICE: Well, you know, absolutely. I think what we do have in the country is only the 75 hour requirement for clinical level of home care, and nursing home care that is paid for by Medicare. And that's still minimal. For the personal care that's still paid by a combination of state and federal dollars through Medicaid, there is no federal requirements, and so it's a state by state. Some states have nothing. Some states have 40 hours. Some states have more.

It is really a state by state process. And that's where when

we talk about the international comparisons, it's really tough. I mean, this is not Japan. This is United States where each state is very strong in its own licensing requirements. So, I think you have to pursue a state by state strategy. I think you probably have to start from the public side and hope that that move into the private, rather than the other way around.

DR. BUTLER: Steve, what's your thought about the SAIU that Dennis Rivera and the unions began to move in?

MALE VOICE: Well, SAIU is very strong in certain states, and where they have saturation, meaning a large percentage of employers organized or public programs organized. And they are able to have enormous influence. And I would say that SAIU is the only entity that is really succeeded in raising wages and providing benefits if you look across the country.

MALE VOICE: What's going to be their interest? Accreditation or not?

MALE VOICE: I think increasingly this referendum that I referred to in Washington State is an SAIU Local 775 initiative. So, but that is still going to be primarily public agencies, public authorities, or home care agencies. There is no interest in organized labor to try to organize the grey market. It's unorganizable. But certainly, SAIU and somewhat ASMI are increasingly focused on the home care, and particularly this home attendant level or personal care level of worker. They have organized, created home care authorities in California, Oregon, Washington, Michigan, Massachusetts. There is probably four or five more in the works. So, they have a very strong role, and they have a pretty strong belief in training as part of their way of creating a higher value.

FEMALE VOICE: This is probably a bad idea, Bob. Jeanette Takamura. This is probably not a terrific idea, but I am going to put it on the table. You know, one of the things that concerns me in many of these discussions and I am as passionate about long term care as anyone else in the room, is we still lack a financing mechanism to, a financing mechanism to cover the cost of care. So, even when we think about trying to entice workers into the field, we are looking at doing that in an environment in which there aren't ready dollars. And in an environment in which there are other

industries that appear to be sometimes more attractive.

So, I guess I am thinking that maybe it's inevitable that we go the public policy route of licensing caregivers, you know, the caregivers that we are talking about. But, I wonder whether the skirmishes in the trenches at the state level are really necessary at this point. I mean, I am wondering if there is an intermediate step that can be taken, and perhaps it's too late already.

You know, senior centers have for a very long time been in a sense accredited if you will through the National Council on Aging. And it's a little bit of a softer approach. It doesn't require people to go into battle with competing paraprofessional or professional groups. I am just thinking about the licensing of social workers in New York State, which began with an idea that would it, we would end up with a good outcome. And then the war became must more than people realized that they would have to take on.

So, given the fact that we are really short of time in many respects, and we have got to get this work underway quickly, I guess I am wondering would it be possible to go with an intermediate step that permits people to understand that there is certification by some body that is recognized as holding some standards in place, but not necessarily going the full distance of having the legislature go through all the hairy details. Because frankly, if you could find a body at a national level who could do that, then you are probably able to approximate a national standard more than if you go state by state from one legislature to another.

So, just a thought.

MALE VOICE: Linda and I at lunch, would you care to talk about your policy thoughts on more long term care basis? You were a little more optimistic about money, I think, than I was. Maybe not.

FEMALE VOICE: I am not sure that I have any specific comments right not, Bob. I certainly feel strongly that nothing is going to work until we have the economics figured out clear and crystallized into a policy that we want to promote. Everybody knows that the bottom line is money. Everybody knows that the way to get people to do things is put the money in the right place. And I remain extremely worried that we have had a lot of conversation about content and

need, and clinical situations, and domestic situations, and not enough about money.

So, it's a plea, as much as it is anything else, to figure out the economics of the workforce, the economics of the family, and the policy economics for the nation. I keep on taking the very 60,000 foot view, if you will. We have got a situation where as a nation we have got a massive asset transfer going on that somebody somewhere must have a really good fix on, but we who care about it most of all haven't put it on the table for enough discussion.

So, why is the nation committed to the form of asset transfer that's going on. So, we have got 40% of people spending down to poverty, when there is a life threatening illness going on. We don't know anything about who is coming up after the person has died, out of that poverty. And we don't know what the correlates are of people coming out of that poverty slide. We don't know for whom it's a trap. We don't know for whom it's a slide. We don't know how long recovery takes. We don't know enough about what the opportunity lost is for individuals who get involved in caring, and whether what we are proposing about training them is really going to be a substitute for opportunity lost.

There is enough opportunity lost. So, it just feels to me that we don't know what we are doing, and that's a very uncomfortable feeling, because nobody that I know of knows more than this group does. So, maybe there are people in policy and economics that we should have at the table. But we have got people in economics at the table who are very prominent. So, my guess is that maybe we do know all there is know, and that's a sickening feeling.

DR. BUTLER: It gives me a chance to say that.

MALE VOICE: Sounds really optimistic.

DR. BUTLER: This is only, this gives me a chance to say that this is just the first of our meetings. You know, we in here, we are in this for the long haul. Humphrey, how come a rich nation like Great Britain can take care of their sister-in-law, and this poor nation can't.

MALE VOICE: Well, I mean, I think the short answer is two fold. Number one that we have a system, a critical system in this country which has actually given greater power to vested

interests, rich vested interests, which they have used to block many what I would describe as progressive and desirable policies. And under parliamentary systems, and countries which don't allow lobbyists the same power and influence in terms of cash and packs and all that kind of stuff, it's much, much easier.

Secondly, I think that Europe and Canada and Japan and other countries have much more of a what's good for society as opposed to what's good for the individual. The United States is more than any other country probably what's good for the individual. And if you will.

DR. BUTLER: Do we have a consensus on that?

MALE VOICE: Let me just say one other point, one other point, which is that, I actually find that in surveys Americans tend to think that people who are poor are poor because they were lazy and didn't try, and didn't work. And in most other countries, there is much greater sense that they were unlucky.

FEMALE VOICE: There is also a sense, I think, that caregiving, what's the big deal. You know, well, anybody can do it. Like, women do it. And it's not a valued skill.

MALE VOICE: Like teaching.

FEMALE VOICE: Like teaching, like, and that has, I think, makes it hard for people when they come up against the system for the first time, and say, what, this is impossible. I can't do this. And there is a sense of and you find that throughout the system. What's so hard about this. Why can't you do this. Why do you need help doing this. And in the correct terminology, just take personal responsibility for it. You save your money and you can pay for it, and don't expect to get any help for it.

So, you are coming up against all these really ingrained societal attitudes. And I think effects, you know, why would people want to go into this as a job, if not a career, because they don't, you know, if the society doesn't value what this contribution is.

So, I don't have a solution to that, except that the more people who have experienced it can you know testify to the complexity of doing it, and the complexity of managing the different kinds of care that you need. And we have only

talked about a little bit of that. That does seem to seep down.

Policy makers who have had that experience themselves, they say, oh, yes, right, wow, what is going on here. So, but it's going to take too long to make the whole world get that. But, it's basic, I think.

DR. BUTLER: Bob?

MR. KANE: We are on the verge of actually asking an interesting question, which we want to avoid if we possibly can. I mean, it seems to me that there are a series of contaminated questions here. If we start at the bottom, which is how can we improve giving care to and then we can decide whether it's people with disabilities, frail older people, whatever subgroup you want to fit into that. Then you get into a fairly complex policy analysis that we have been struggling with.

The UK has historically taken a very different approach to delivery of this care, and it's not quite as nice as Humphrey might have you believe. Not everybody gets the care. His sister-in-law does. There is a huge class distinction between, my guess is his sister-in-law is getting care, because she probably is not in class five.

MALE VOICE: She is not in class five, but I am not sure that's the reason.

MALE VOICE: I mean, there are a lot of other things that are going on. If you want to get into the real policy issues of this, you need to go way down and look at, for example, follow the money. People don't realize right now that for Medicaid, for most people receiving long term care today, particularly in the community, more Medicaid dollars are spent on them for medical care than are spent on them for long term care. So, if you want to capture money, if you start out with the premise that we probably aren't going to pour a large amount of new money into the system, that you are going to have to redistribute the money, you have got to find where your policy levers. Your policy levers for long term care are largely in the medical industry. Virtually everybody in this country, with perhaps a few exceptions, would admit that we are a very inefficient medical system in this country.

We are overpaying for what we are doing. David Cutler might disagree, but most people would take that position. And so, I mean, there is sort of a resource pool there that one could begin to look at in terms of how to tap it. Now, the question is how do you tap that.

Well, one of the ways you tap it is by making an argument for economic efficiency. That, in fact, if you gave certain kinds of care, you could prevent some of these catastrophic events that run up large bills. And so, you know get into an investment model. That would require some empirical data, which they have taken off the table as being unnecessary. But, it might be helpful, if in fact, you want to make a policy case, that in fact, you got better results by doing things differently.

Then you get into an image problem. Right now the image of long term care, and caregiving is that it essentially is a socially necessary service, but not necessarily a very effective one.

[END TAPE 3]

[START TAPE 4]

Or we actually have empirical information, we might be in a position to actually make a different kind of case that long term care is worth investing in, and then we would ask the question, which components of long term care and which approaches to delivering long term care are most effective. I mean, this would take us down a rather different approach perhaps than starting out by saying our first step is to certify a group of home health workers.

So, if this is the first of a series of meetings, I guess I would hope that the meetings would take a somewhat broader perspective about, because I think we all share a common desire to want to develop a system that has better long term care.

We would all agree that long term care is an undervalued politically impotent area. There is some interesting contrast, because the other fact that you might want to look at is the fact that per recipient Medicaid in this country spends three times as much on younger persons with disability as they do on older persons with disabilities. I think you might want to ask yourself, what's the difference? And I'll

give you a clue. It begins with an A and it stands for advocacy.

The younger disabled population have had much stronger advocates. Basically, I mean, older people have advocates for a couple of years. There are very few people who are doing that. I'll put in a plug that we have started an organization called Professionals with Personal Experience in Chronic Care, which is really designed to find people in the business who have had this experience, recognize the problems, who are more likely to become the sustained advocates than the average lay person.

MALE VOICE: Bob, I am curious as to whether you have seen any, you look with any optimism on the political impotency of the long term care issue maybe changing as we baby-boomers have been only addressing our aging process by denial. But, becoming caregivers of our elderly parents we have to get realistic and now there is an issue that has an audience out there that could resonate. Do you have any optimism?

MALE VOICE: Well, I think it's an audience that hopefully could be organized, but the way the discussion is going now, I mean, as I track what's happening in states, it's all about costs and nothing about what you are buying. Every state legislature where I have, and we work with a number of them, I mean, it starts out by looking at the price of everything and the value of nothing.

MALE VOICE: See, I agree with you, but when I talk to my patients and we talk to the people coming through our center, it's just the opposite.

MALE VOICE: But they have not yet been, I mean, the question is, can you organize these people during this relatively brief period when they are at risk or their parents are at risk, to become a sustained rallying force. You compare the, we don't have a single strong elderly advocacy group that's pushing the long term care agenda.

MALE VOICE: If we did.

MALE VOICE: With all due respect, it's not on the top of their list by any means.

MALE VOICE: If AARP made it advocacy over this issue, number one, don't you think the fact that basically baby-boomers are looking at the care and the options their parents are

getting, and saying, may be too late to do anything about this now, but as I am getting older this is unacceptable. Is that an audience that could translate into some political capital?

DR. BUTLER: Mary Joe wants to say something.

MARY JO GIBSON: I always have to respond to Bob. And my colleague Frank may want to, as well. As many of you may know, AARP recently launched a major campaign effort called Divided We Fail, in which it's a really quite serious campaign. And partners are SAIU, and the Business Roundtable. On the agenda is long term care. I would not say that it is the number one, and I would also put forth the argument that healthcare reform is to many people in this country a very serious issue. And that is absolutely a front and center in terms of AARP's advocacy. And long term care is a companion along with that, and right in there. And it's a question along with financial security.

But, more resources are being put into this effort than I have seen in my twenty-five year aging in place career with AARP. Our board is, in deed, serious and it's the focal point of a coordinated multi year campaign, looking at strategic choices and opportunities depending upon the political environment at the time.

So, I did have to make some kind of rejoinder, and Frank, would you like to?

MALE VOICE: You did a great job.

FEMALE VOICE: Thank you.

FEMALE VOICE: I may be an optimist, but I feel that the climate is right for national health insurance, for a whole lot of reasons. When business is saying that costs are high for them, hospitals are concerned about the costs of people coming into emergency rooms, and really can't get reimbursement for them. I mean, when I heard George Will say that it's time for national health insurance, I thought that's quite interesting.

MALE VOICE: You didn't have a heart attack?

FEMALE VOICE: I was very surprised. But, you know, things could really change on the macro level. I am an optimist and then long term care might follow, because it would be part of the

mix. Today I think we are more tactical and you have got a proposal that you are going to, you know, instead of looking at the big important issues that I would love us all to deal with at some point. But we also can take a baby step by making this work.

And so, I don't want to forget the bigger picture, but I think that we ought to think about how we can approach it from both levels.

MALE VOICE: The six questions there, which I am not going to answer, but address. But the question of what pushes an issue up or down the chart in terms of public opinion and therefore, the pressure on politicians, a lot of it has to do a much with the media as with reality. And that when crime was falling year after year after year, most people in this country thought that crime was getting worse year after year after year, because the media showed them nothing but crime stories on their local television stations.

When drug consumption was going down, concern about drugs was going up because the media focused on drugs. So, a key, not the only key, to getting long term care higher up on the political agenda is the media. And I am glad to see we have a section at the back which deals with that in terms of at least some media coverage, while coming out of the activities of the ARC.

FEMALE VOICE: I think there is another thing to bear in mind. Bob, it's me again, Jeannette. Oh, go ahead.

FEMALE VOICE: Yes, I was just going to say there has been an enormous amount of media attention to the issue of caregiving over the past five years. Just an explosion and that's at every, that's on the newspaper. That's on radio and certainly, on television. What I understand from talking to people in Washington is the political will is not there. It's not that the media isn't, it's the political will. And they all say basically along the lines of AARP, the first agenda item is going to be access to healthcare. That's what the country is focused on now, including divided we fall.

Then, once that's dealt with, however long that takes, then there will be some focus on things like fixing Medicaid, and Medicare, which are huge economic issues that the country is facing. And then long term care down here.

So, there is not, there is just not the political will to deal with this issue, and I would agree with Sandy. I think if we take that issue on, we could be here until the cows come home, and you wouldn't get your, basically the tactical part that we need to deal with. So, I would suggest we focus on that.

FEMALE VOICE: I think there is a question of the tipping point here. Frankly, back when I was doing state and federal work, we always looked at, you know, incumbency protection. We may be thinking about our families, and we may be thinking about our communities, but you got to just embrace the idea that policy makers think about whether they are going to be an incumbent or not.

So, how does this issue play out if we need to ask for a tax? It's not going to happen. But, all the other instruments for financing long term care don't seem to be very effective. So, I think one thing we need to bear in mind is, what will the incumbents think will protect them as well. I am not sure what the answer is.

DR. BUTLER: It may be time to wrap up, but what I would kind of like to do is if, is to say that when we first identified the caregiving issue as a crisis, everyone said it's too big a topic. And now that this day is over, it's not big enough. Apparently, we have got to deal with the economics. We have to deal with science studies, scientific studies. We have to do all sorts of things.

And I would like to suggest at this point that, in fact, this is just our beginning, our first salvo. We realize that there is a lot more that we need to do. I, myself, and I am sure joined by Larry, extremely grateful, because everybody has been very frank and very open, and have given us tons of ideas. And we are going to write them all up and issue a report, which you will get, which will give you a sense of what we have been able to absorb and integrate.

We certainly have taken seriously the fact that we really do need to the degree possible to undertake studies of outcomes. We take very seriously the fact that we don't want to have a fixed curriculum. We want to have something that's open and porous, and available for growth. We want to build upon this.

While we are in the world of geriatrics, we recognize, too,

the advantages of life span development. But, we also know there is special interests in terms of children, when it comes to specialized care, special interest with regard to end of life care, or palliative medicine. So, it may be that we need to have some degree of specialization while being sensitive to the reality of the lifespan, itself.

We have heard a lot of I think valuable discussion of consumer issues, and provider issues. And the importance of provider issues, I think, cannot be under estimated, because in my experience, at least, these are people with great hearts who work very hard under very difficult circumstances, and to the degree to which we can be helpful in giving to them dignity, and decent pay, and benefits, so much the better. Although, I realize that runs us right smack into the economic issue, because, of course, the more we do to make the caregivers life more humane and decent and dignified, the more costs has got to go up insofar as being able to pay them. And I well recognize that.

Some day we may be able to move ahead, I think, in the whole issue of healthcare. I was very much struck by the General Motors and its increasing realization that they can't compete with the European and Japanese cars, because they have to charge \$1500 more dollars for an automobile. So, I actually think that the planets may come into alignment around not only the pressures that come from consumers, but perhaps even from corporations. We may find it attractive to resolve the issue of healthcare.

Now, I would like to give each of you, should you wish, a chance to say one more thing. And I want to give my friend Larry, and Beth a shot at being able to make any summary remarks they want to make. But, first, around the room, anything anyone feels compelled to say.

MALE VOICE: This will be my final comment. I do think that there are a variety of problems that we face that seem impracticable. And it occurs to me that we have got a fairly smart group of people here who spent seven hours now and we don't have the model to understand the complexity of this. And it seems to me that maybe one of the avenues is to better map, if you will, some of these dimensions of caregiving, where the costs occur, where the consequences occur, where the potentials are for cost savings, and if we could do that, or someone could kind of lay that out. Then, it's easier for

others to identify where potential interventions or changes in policy might reside. And so that the problems, in fact, do not seem so intractable. That when people from the outside kind of approach these things, it is this amalgam of irrational policies and human needs, and without laying that out for people in some kind of understandable way, no one knows where to begin to engage the problem.

So, I think maybe an effort at some level to try to understand this problem. Lay it out in some of its dimensional ways, and where opportunities are for reform. Then as people begin to raise these questions, we can direct them in the right way so that they are not floundering trying to find an appropriate avenue to resolve the problem.

Mr. TAYLOR: I would just like to congratulate you, Bob, and Larry, and Beth, and Ken for the optimism of describing this as a consensus conference.

DR. BUTLER: Can we take a poll? I have to remind us all that a little over a hundred and twenty years ago there were people who called themselves doctors, who were practicing without any curricula until a certain major event occurred due to the Rockefeller Foundation that resulted in the Flexure Report.

So, I wouldn't say that the history demonstrates that you can't begin by thinking of curricula reform. And that you don't have to have it fully tested. We have never really tested medical schools in any real sense. And we certainly have not tested the failures of medicine in terms of having a broader understanding of social behavior and other factors, and then only addressing the medical model.

So, we have to start somewhere. So, we thought this was a reasonable way to start. You have been terrific. You have been very valuable. And now, Larry and Beth?

DR. WRIGHT: I want to be sure we haven't.

DR. BUTLER: You don't want to mess up the consensus?

DR. WRIGHT: That's right. I think there might be consensus out there. And I gather there were a few that might be about to say something.

DR. VAUGHAN-WROBEL: Thank you.

DR. WRIGHT: I want to add my thanks to everyone taking this time,

and the frankness of all the discussion. We were certainly from this meeting center very self-conscious about coming forward and boldly saying what our, you know, from our little angel and our little perception of the world. We understand that that doesn't, definitive enough, and it also is presumption to think that our answer, in the context of our community is the answer for the country. But we do, and it has caused us to understand a problem, one part of a problem. And it's part of a much larger problem, but that it needs to start being addressed.

I look with real awe at the kind of work that many of the organizations represented here certainly, PHI and Gail's organization, NIC and so many others, have done. Realize this has been over a number of years, quite a few years. And it's like, it's much like the last White House Conference on Aging. A number of us were there in 1981. It's the same issues in over 25 years, and many of the same recommendations and solutions. And you say, good golly, you know, we must still have the same, wasn't it Winston Churchill who said you can always count on the Americans to do the right thing after they have exhausted every other possibility.

And it seems like we are in a long term trajectory to do that. But, having said all that, I am optimistic, because I do think that as I believe Humphrey said earlier, that you know, as daunting as this task is, it's not an excuse for doing nothing. I mean, we must start in the right direction, and hope that we build on that. And I certainly hope people of the stature of Bob Kane don't think that people don't recognize the importance of empirical information. It's just here is a problem that I share Marianne Karpinsky's sense of urgency about this. We are going to look back and wonder why we didn't do the obvious a few years from now.

DR. BUTLER: All right. We have reception at 5:30. But not here. It's at the Century Club, which is around the corner. You have a little chance to walk. And it's on 43rd Street, also roughly the same side of the street as the Harbor Club. So, we'll see you there.

[END TRANSCRIPT]