UNITED STATES OF AMERICA

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DEPARTMENT OF HEALTH AND HUMAN SERVICES

AGENCY FOR HEALTHCARE RESEARCH AND QUALITY

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CITIZEN'S HEALTHCARE WORKING GROUP

PUBLIC MEETING

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Wednesday, August 17, 2005

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The meeting was held at the Conference Center at Harvard Institute of Medicine Room 138 77th Avenue Louis Pasteur, Boston, Massachusetts, at 1:00 p.m.

MEMBERS PRESENT:

MR. RANDALL L. JOHNSON, Chair
MS. CATHERINE G. McLAUGHLIN, Vice Chair
DR. FRANK J. BAUMEISTER, JR., Member
MS. DOROTHY A. BAZOS, Member
MS. MONTYE S. CONLAN, Member
MR. RICHARD G. FRANK, Member
MR. JOSEPH HANSEN, Member
MS. THERESE A. HUGHES, Member
MS. ROSARIO PEREZ, Member
DR. AARON SHIRLEY, Member
MS. DEBORAH R. STEHR, Member
MS. CHRISTINE L. WRIGHT, Member

STAFF PRESENT:

MR. GEORGE GROB, Executive Director
MS. JILL BERNSTEIN, Research Director
MS. JESSICA FEDERER, Program Analyst
MR. ANDY ROCK, Senior Program Analyst
MS. CONNIE CHIC SMITH, Communications Director
MS. CAROLINE TAPLIN, Senior Program Analyst
MS. RACHEL TYREE, Program Analyst

OTHER PARTICIPANTS:

MR. LARRY PATTON, Designated Federal Official
MS. NANCY REAGAN, Associate of Joseph Hansen

AGENDA PAGE

P-R-O-C-E-E-D-I-N-G-S

8:39 a.m.

CHAIR JOHNSON: We'd like to welcome the Working Group back to another session, and start our meeting by just thanking Richard for your hospitality, as you've put together an excellent series of discussions yesterday, in terms of our meeting, and then also in also in our forum last night.

Already I've had a few comments today that have expressed and commendation for that. So thank you very much.

I'd like to invite your attention to our agenda as we start. This morning, we'll start with a focus on mental health care, and since we've started at 8:40 or so, we'll just extend our time for an extra ten minutes.

Following that, we'll have some comments regarding state, county and local initiatives. Later on in the morning, we'll have a discussion about end of life. It will start at around 11:25 or so and probably go through about 12:40.

We'll take a break for lunch and then

following that we'll come back and talk about Leapfrog and Bridges to Excellence. Just a word for you as panelists.

Our process has been to take about 10 to 12 minutes for your presentation, and have you decided who you would like to go first on that?

You did, okay. Then we'll go right down the line. So we'd ask that you take only 12 minutes. The richness of our sessions has been the dialogue that we're able to have with you as panelists.

So we'll start with you and then each person, and if in fact you're getting a tad lengthy, I'll just put my card up like that. That will be a signal to kind of wrap up if you would.

Dr. Elizabeth Childs, M.D., was named the Commissioner of the Department of Mental Health Care in June, 2003. Prior to that, she was the Chief and Director of Psychiatry at Carney Hospital in Dorchester, Massachusetts. She's held appointments at the Massachusetts Institute of Technology, Harvard University, and the University of Cincinnati.

Our working group has your bio. So we are

not going to be extensive in explaining more about that, but just a brief summary.

Dr. Deborah Nelson is a licensed psychologist and co-founder of Beacon Health Strategies, an NCQA and URAC accredited managed behavioral health organization serving over a million private and public sector enrollees. Welcome.

I think most of us know who URAC and NCQA are, but right in the matter of qualifying on a quality basis, and we're interested in your thoughts regarding that.

Dr. Toby Fisher has experience owning and operating a small business, and selling a variety of services for a business consulting firm, working in the field of mental health care for several agencies and in several positions.

So this is our panel. Again, welcome, and we're looking forward to your discussion.

DR. CHILDS: Thank you very much for having me here, Mr. Chairman and Vice Chair McLaughlin, and respected members of the Working Group. I very much appreciate and I'm honored to be

here.

As you know, my name is Elizabeth Childs. People call me "Beth," and I am the Commissioner of Mental Health in Massachusetts. But I am also a board-certified child, adolescent, and adult psychiatrist. Most of my career, prior to my commissioner role, was spent in actual practice, and I still actually do practice. I have a small practice in my home.

I'm thrilled to be here with my colleagues, Dr. Nelson and Toby Fisher. I think you have made an excellent choice in having them on this panel.

I'm going to start by talking about mental health in the Commonwealth of Massachusetts. Mental health is a very significant public health problem across the country, and we will talk about what we do in Massachusetts.

We believe that mental health is an essential part of health care. In Massachusetts, the Department of Mental Health is the state mental health authority, and through that authority promotes mental

health through early intervention, treatment, education, policy and regulation, so that all residents, all residents of the Commonwealth may live full and productive lives.

You'll notice mental illness is not listed in there. It's because our consumers were clear that we should talk about mental health, and not mental illness.

Our mission is to assure and provide access to services and supports to meet mental health needs of individuals of all ages -- mental health, mental illness affects everyone -- enabling them to live, work and participate in their communities.

Mental health is a vibrant and important value to our communities. Without it, our communities suffer and the fabric of those communities suffers. We also do not settle for not having -- for people not being able to live and work and participate. Symptom reduction is an important first step, but it's not an adequate step.

We accomplish our mission by establishing standards to ensure effective and culturally competent

care to promote recovery. We believe that most individuals with mental illness can recover, that recovery is a process and everybody is at different points along that continuum. But the ultimate goal is recovery. It's much more than simply rehabilitation.

The Department of Mental Health promotes self-determination, protects human rights and supports mental health training and research. This critical mission is accomplished by working in partnership with other state agencies, individuals, families, providers and communities.

This effort to eradicate mental illness and to more effectively address the needs of people who have mental illness cannot be done by any state agency alone. It truly is a partnership between the state mental health authority, the providers, our consumers, our family members, and our communities, who we ask and have found that many of our clients are actually excellent employees in our communities, excellent neighbors.

Our value proposition for Massachusetts is that we will be a value to the Commonwealth. I feel

that it will be time for me to retire when I hear somebody walking down the street and they say "I live in Massachusetts, and Massachusetts is a great place to live, because it has an excellent mental health system."

I think it is true that if you have an excellent mental health system, it adds value to the places where you live. We believe that we get to that value proposition by three basic principles. One of them is excellence, which speaks to taking evidence-based practices, best practices and putting them into practice.

That is both in the clinical realm and in the administrative and business realm. We also believe we can get there by cost-effectiveness. Efficiency doesn't only refer, however, to dollars. It also refers to our human resources.

We do have limited numbers of trained professional staff to work with our clients. It's very essential that every one of those staff maximizes the value and efficacy of their interactions with clients.

Lastly, innovation and creativity. This is really to speak to the importance of allowing creativity in the marketplace. Of course, we don't want experimentation. I'm not talking about reckless experimentation, but the practice, the standard practices of today were at one time innovative.

An innovation occurs because people in practice listen to what families and patients tell them. So if you have a client who comes to you and says "I know, doc. This is not how we usually do it. But I believe that for me, this would make a big difference."

If based on a body of knowledge and expertise and experience you really believe that trying something different would make a difference in that person's life, we need to make sure that our system allows that innovation and creativity to exist and flourish.

In Massachusetts, we have undertaken a strategic planning process. Part of that strategic planning process was to look at our national context. In the national context, I want to highlight two

important reports about mental health.

One of them you are probably very familiar with. It's the report of the President's New Freedom Commission on Mental Health. We wholeheartedly in Massachusetts adopt those six basic principles. We have tried to weave them through our approach to mental illness in Massachusetts.

We had a chance in Massachusetts, which is poised on the brink of an opportunity to really do something better in Massachusetts and transform our system.

This occurred two years ago, when the Executive Office of Health and Human Services, to which the Department of Mental Health belongs, was reorganized. In that reorganization, the agency of Medicaid, the single state agency of Medicaid was elevated so that now, the Secretary of Health and Human Services is the head of the single state agency of Medicaid.

In that role, the Secretary can have the authority to delegate programmatic responsibility of the Medicaid programs to agencies that have the

expertise to align services.

In Massachusetts, the Secretary delegated the programmatic oversight and administration of the Medicaid behavioral health programs to the Commissioner of the Department of Mental Health, and charged the Commissioner and the Department with aligning those two systems of care.

The Executive Office of Health and Human Services functions as a single enterprise. We recognize that it is important for mental health to not be in its own silo, but to be closely integrated with physical services, youth services, our social welfare system, our child welfare system.

As we reorganized, the Executive Office of Health and Human Services was reorganized into three separate offices. The Office of Health is where the Department of Mental Health resides. We feel that's a very important statement about mental health care.

Finally, the other aspect of mental health, however, was that it doesn't only reside in the Office of Health. It is critical to the stability of other agencies. It is critical to the success of

our criminal justice agencies and our corrections agencies and court systems.

The mandate in our statute is that the Department of Mental Health shall be cognizant of all matters affecting the mental health of the citizens of the Commonwealth. The broad mandate and responsibility requires that the Department think about every aspect of mental health, whether it be publicly funded or privately funded.

Our strategic planning process came up with our own six principles in Massachusetts, which we feel are important to transform the mental health system here. It is no accident that number one is that all services are consumer-centered and family-driven. Massachusetts is a leader in the national consumer movement. The change in our system is to listen to what consumers say will help them, and to adopt this strategy, to incorporate peers, peer-run programs, both in terms of peer counseling and peer-run other support services.

Number two, you've already heard me say this. Resiliency of recovery are the ultimate goals.

Three, quality improvement principles are embedded in everything we do. My charge to our system is that if what you're doing is not improving quality, either clinical, administrative, business quality, then I want to know why you're doing it. It has to be an overarching framework and a philosophy under which we operate.

Fourth Services should be local. We know the value of access and timely access. Although Massachusetts is a relatively small state compared to the rest of the country, it is a burden and a hardship to a family member to have to travel two hours to have dinner with their loved one who might be in a mental health program.

It's very important that these key services be available to families and consumers. It also is important to not pull the services away from the community supports that a person has. So we don't want to pull somebody out of their school system and move them three hours away. We don't want to pull them away from their church or from their community group or from their families or extended family

network.

We want to make sure that we can keep the person where they grew up and understand the culture of their community.

The fifth principle is that we add value to our local communities. There is a recognition that in war-devastated countries, the first thing you should put in place is health care and schools. Mental health care is an essential part of health care, and it must be a part of any community-building and structure and longevity.

It's an acknowledgment that as a mental health system, we are responsible to work with our partners in social services and other health and human service agencies to assure their success.

Can you imagine an education system without mental health services? Can you imagine a child welfare system without mental health interventions for post-traumatic stress disorder or for depressed mothers or alcoholic parents or domestically-abused parents.

You cannot pull mental health out of all

these important fabrics of all of those interactions on a day-to-day basis.

The Secretary charged us with coordinating mental health services, recognizing this across all the Health and Human Services agencies. We pay particular attention to very vulnerable populations, those children and adolescents, those who are homeless, and we focus on community care.

The belief is, and evidence supports, that most individuals with appropriate services and supports can live in the community. The days of long-term institutionalization fortunately are receding into our memories.

We have still have a way to go here. We have to strengthen our community-based system of care significantly, and at this point, our technical ability is not so good that we don't need some in-patient care. In fact, we absolutely do.

But in-patient care, I believe, is one component of a strong community-based system of care. The goal is always to get somebody back in the community.

The Department of Mental Health provides the clinical rehabilitation support services necessary to achieve that. We sometimes provide them, we sometimes purchase them. We integrate public and private resources. Again, this is not a fully state funded initiative, and our relationship with Medicaid is important.

In order to have a true continuum of community-based system of care, you must think about every aspect of a person's life, and it is important that they be integrated.

So this graphic really speaks to having in-patient care for those people who really need that level of support. But our goal, as you think about it, is to use all of the other boxes and use the in-patient care as little as possible.

We've got residential options -- case management, care coordination, flexible supports, to really allow somebody the help that they need to survive in the community. Perhaps it's somebody to help them manage money. Perhaps it is somebody to make sure that they get transported from their home to

appointments.

PACT teams, Programs for Assertive Community Treatment are multi-disciplinary teams. It is in evidence they're effective. It has been rolled out nationally, beginning in Wisconsin. We have 11 PACT teams in Massachusetts. We clearly could do more in that arena.

These teams have helped us successfully close one institution of 255 people that were discharged from that institution. It is now closed. Their re-hospitalization rate has been 17 percent, which we feel is quite low for that group of people with serious emotional concerns.

Many of our clients have substance abuse disorders as well as mental illness, and the importance of integrating those services is critical to their success and their recovery.

Clubhouses are one model that works to get people into employment and transitions people from the most supportive levels of employment to the most independent levels of employment.

In Massachusetts, among the Executive

Office of Health and Human Services agencies, the Department of Mental Health has the highest employment rate. We employ 17 percent of our clients, and our goal is to continue to employ more.

It's a surprise. People don't expect that we would have the highest rate, when you think about comparing us to the Department of Mental Retardation, the Department of Transitional Assistance. But we do, because our clients make excellent employees when they get the support and the services they need.

Employment, as I said, is a necessary step to recovery and self-sufficiency. It is not realistic to believe that somebody can fully recover if they don't have a roof over their heads.

It would be very hard for us to get up in the morning to get to where we need to be, to be here to talk to you, if we had to deal with not having a place to sleep at night, not having a place to cook our food, not having clean clothes to wear.

I'm not going to go through all the things we do. We serve 26,000 individuals through our Department of Mental Health programs. We serve over

900,000 individuals through Medicaid. The demographics are that 78 percent of the DMH clients are on Medicaid, and 24 percent are on Medicare, and 12 are uninsured.

We have three lead initiatives in Massachusetts. The first one is to unify the two systems of care. The Medicaid acute mental health system is Medicaid funded, with medical necessity criteria, and the other is the DMH continuing care system. Melding those two cultures is very challenging.

One is based on medical necessity and the insurance-type model; the other is based on an eligibility criteria based on diagnostic groupings and rehabilitative needs. The goal obviously is to incorporate all of these aspects.

Again, this is why I'm speaking to the goal, to incorporate all of these principles into one mental health program. You meld those two systems of care by several mechanisms. System redesign, system reprocurement, regulatory change, waiver changes and contractual improvements.

It is an important aspect that is often forgotten. You can exert influence sometimes to make things happen. Collaboration among patients and public dialogue are essential, and we have been going around regionally, talking with multiple stakeholders about the programs.

Our second initiative is to have an outstanding community care system, to close some of our in-patient long term multiple beds, but to replace those beds with a state of the art excellent facility, to replace antiquated, outdated facilities that do not foster recovery.

Our last initiative is to create a comprehensive quality improvement plan across the entire system of care, using data to make decisions, having quality improvement from the ground up, so that everybody involved works towards quality management, and to embrace innovation and creativity and measurement.

Lastly, I would speak to stigma. The President's New Freedom Commission identifies stigma as the major barrier to treatment. Mental illness is

a public health problem that requires a public health approach.

We have had significant efforts around stigma to increase awareness, to educate, and to explain to people and the public that mental illnesses are treatable and curable, and people do recover.

In 1997, we launched a Changing Minds campaign, in collaboration with the Massachusetts Association of Mental Health. Today, our latest work has been supported by a federal SAMHSA grant, the Eliminating Barriers Initiative, and utilizing a national anti-stigma campaign approach.

It is publicly the single most important aspect of helping people get the actual kind of health care that they need, and that is to eradicate stigma around mental illness. Thank you very much.

CHAIR JOHNSON: Deborah.

MS. NELSON: I need a little help.

CHAIR JOHNSON: Technical assistance arriving.

(Pause.)

MS. NELSON: Good morning, everyone.

Thank you very much for inviting me here to speak with you today. My name is Deborah Nelson and as Randall has already introduced, I have a somewhat unique perspective in that I'm co-founder and vice president of a women-owned Northeast-based regional managed mental health care organization.

We serve, as you mentioned, over a million members and we are fully accredited and if there are questions about that, I'll be glad to answer those later.

CHAIR JOHNSON: Deborah, can we ask you to move a little closer to the mike?

MS. NELSON: Move a little closer? Okay, sure. I mentioned that we're in a somewhat unique position, in that we work with both private sector plans, such as Blue Cross of Rhode Island as well as public sector plans, such as the Neighborhood Health Plan of Massachusetts, Neighborhood of Rhode Island and Hudson Health Plan in New York, as well as the state of Maine. So there's that balancing of the public and private sector approach.

I was asked to say a little bit about what

an MBHO is, and as you can see, organizations like ours do for mental health what a Kaiser or Blue Cross does for overall health.

That is, we contract with doctors and hospitals; we set rates; we make sure there are good quality providers in the system. We actively assist members in getting access to services, and we do quality improvement to improve things, and we pay claims for those services.

The aim is to bring, as you know, a specialized focus on mental health, to get the right service to the right member at the right time, and to recognize the unique challenges of mental health and substance abuse. Public sector entities and health plans often hire MBHOs such as ours, to assist them with the goals of balancing costs, quality and access.

We find -- let's see. Prevalence figures obviously tell us that with mental health issues, there's a huge gap between those who have need and those who are getting access to the services.

The issues in mental health and substance abuse are not as straightforward to treat as in the

medical surgical arena. To overstate that just a little bit, treating a broken arm is, I think, a lot easier than addressing some of the issues that some of our members present with.

Many doctors in the medical arena know when a member is getting better, and that's not always the case in the mental health world.

People come into mental health treatment through two avenues. One is being seen and evaluated by a mental health or substance abuse specialist. But the other avenue is that over half of Americans are treated in primary care or come to primary care for help with their mental health problems.

While this is handled well in some cases, the literature is actually quite replete with examples that mental health conditions are under-diagnosed, misdiagnosed, or under-treated in the primary care arena, and this is an area that I think we can do something about as we seek to improve health care.

The reason is that pediatricians and internists and others are often not trained to spot these issues and to deal with them. They're very

busy, and they fear that to ask about it is to open up a Pandora's Box. Yet when half of the people go to primary care to get services, we've got to somehow address the issues there.

Because to the adult child with an elder parent who is depressed, to have that mixed up with a urinary tract infection is a big deal and a big problem.

Nationally, health plans do not pay much attention, I believe, to mental health and substance abuse issues. I think it's often a sidebar or an afterthought. The reason I think primarily is that it is only about four percent of the commercial dollar premium, and about ten percent of the Medicaid health care dollars.

This relatively low spending on mental health and substance abuse leads sometimes, I think, to entities not promoting it as a primary focus of their work, making again identification and treatment issues rather tricky.

A small number of individuals do account for quite a lot of the cost, and they do receive

sometimes inappropriate care. We find that -- I'm sad to say it -- but that historically, less true now, but historically there would be a lot of services thrown at someone or at a problem, with the prevailing observation that those services are not always particularly effective in ameliorating whatever issues the person was struggling with.

In order to ensure adequate attention and treatment for the complexity of issues that those with mental health and substance abuse problems present with, Beth talked about this, but there's an enormous and I still think unmet need to coordinate among the various systems that interface with the members, such as the medical system, foster care, juvenile justice, housing, transportation. All those areas touch the lives of our members.

I think that one success of managed care is that we and some of our colleagues in the field have done a good job beginning to close the gaps in service delivery and connect the dots, if you will, among the various needs that a member presents with.

We know that once mental health and

substance abuse needs are identified, they are not always treated appropriately. I've listed some of the reasons here. Beth spoke about evidence-based treatment and providers differing widely in their training and ability to assess things. So I think I'll skip over that one at this point.

It is important to say that I think in forward thinking managed care systems, we seek not to over-treat nor under-treat, but to use the evidence-based practices to really deliver the very best that we know how to do for a member.

There has been a tendency to purchase services based on price, rather than on quality. For instance, there are some examples of managed behavioral health organizations bidding low in order to get business, but not being able to subsequently deliver on the quality that consumers deserve.

I think that to the extent that this went on and perhaps even still goes on, it gives some of managed care a justifiable black eye. So it's something I think we need to avoid in terms of making sure that the proportion of dollars available for

mental health and substance abuse care, relative to the total amount of health care dollars, is an adequate amount to ensure a fair benefit, because I don't think that there are bargain basement values available. There are no bargains in health care and I think mental health needs to be funded appropriately.

In the interest of time, I think I will skip over the last couple of bullets. We can talk more about those later if there's an interest in it. But the last bullet speaks to, I think, managed care and some of our colleagues in state agencies have done a very good job creating many alternatives to the old in-patient versus out-patient models that were historically available.

Challenges. I've touched on some of those already. Here are some additional ones. There are, I think, you know, local and national program -- local and national problems in availability of certain services in the mental health and substance abuse world.

For instance, there is a scarcity of psychiatrists, particularly child psychiatrists

nationally. They are a front line of defense for the children of our nation and this is a problem that many, including our own organization, working in concert with others, are seeking to address through a variety of very creative approaches which I'll mention at the end a little bit.

I did bring an article, which some of you might find interesting, citing some of the innovative approaches about child M.D.'s being in short supply and what people have done to address that, and some of the work we've actually done is cited there.

Beth talked at length about stigma. I think I will pass over that, again in the interest of time.

Talk a little bit about identification. I think you know that a main barrier in access to mental health and substance abuse services is the familiar, the old refrain of let's make it really tough for somebody to get care. Let's put up lots of hurdles for them.

I think that forward-thinking managed care organizations have not done that, or they have really

sought to get the right care, the right service for the right member at the right time.

Parity has helped with that. I still think there's a way to go on some of those issues. There's more we can say.

I do want to spend a moment talking about linguistic and cultural barriers that are particularly relevant to some of the public sector enrollees, but it certainly crosses over to the private sector as well.

I think you all are familiar with the linguistic, cultural and other barriers that exist in medical care, seeking medical treatment. But I think those barriers are even more compounded in the mental health and substance abuse world.

We know that people from different cultures manifest their mental health and substance abuse issues differently from others, and if a clinician is not sensitive to a consumer's unique background, that clinician is much more likely to ignore symptoms that a person presents with, and to be less likely to understand the consumer's fears and

needs and concerns. The Surgeon General has pointed that out, I think, quite well, that we have a way to go in that area.

Because the implications of misdiagnosis and mistreatment are of course profound. A couple of examples. African-American youth are more frequently referred to the juvenile justice system than to the mental health system for behavior problems.

ADHD, attention deficit disorder with hyperactivity is less often treated by medication in minority groups than in white populations. Finally, Latino youth have a higher rate of -- actually the highest rate of suicide by the research, and yet are less likely to be identified by their providers as having problems with such profound depression.

So I think there's more we can do as we're crafting a better system for tomorrow.

A quick moment on other barriers to access affecting those primarily served in public sector plans. There are barriers like transportation and child care; Beth touched on that. I'll note there are some Medicaid plans doing a terrific job with this,

such as Hudson in New York and the Neighborhood Health Plans in Massachusetts and Rhode Island, where they specialize in focusing not just on the mental health and substance abuse care, but the other social supports that a person needs to really get what they need, and get the recovery and hope that is warranted for them.

So managed behavioral health organizations are hired by health plans to assist those plans and government agencies who hire them with some of the challenging issues which I've been describing. I want to take just a moment with some examples here, and this will be my last slide and I'll wrap up a little bit.

Part of our job, Beth mentioned this too, is to work collaboratively with providers and others, to keep on the lookout for best practices and evidence-based treatment, and to create some of those best practices.

It's our job, and I think a great deal of innovation is happening, which I hope your working group hears about as you travel the country. Once we

identify those best practices, our role as a managed care plan is to disseminate those, and to really encourage and facilitate the use of those in the care of very vulnerable members such as, for instance, the breakthrough treatments available in depression.

In terms of access, driving improvements in access, recognizing the local and national problems that exist in that area, organizations like ours have worked in conjunction with stakeholders to drive improvements.

I want to give you three quick examples, which I could expand upon later if you're interested. First, we have the ability now to send a mobile mental health specialist out to a doctor's office or a nursing home within an hour of being summoned, in order to get a member at risk very quickly evaluated.

That ability to get someone out mobile has created an enormous improvement in access issues and also care.

Second, we have now the ability and frequently prepay for appointment slots, appointment slots that either can evaluate someone for medication

or for just, you know, what's going on with a vulnerable person. We have psychiatrists and therapists available at different times of day, different days of the week, all around the state to get help to a member when he or she calls us in distress, or when a PCP or a doctor is sitting in her office with a member, kind of wondering what to do with someone in such profound distress.

It's very common for a doctor's office to call us and for us to plug somebody in to an appointment two hours later, to get them the services that will help with the situation.

A third example is a type of service which extends the reach of doctors, where doctors are doing so much of the care of mental health in our nation. How do we extend the reach and support doctors doing that care, and one such service is our decision support and consultation telephone line.

It's an 800 line which is answered rapidly by one of our psychiatrists on staff, who's right there to help a doctor or a nurse with questions about needing consultation, the proper dose for medication

they might want to begin, and basically providing support to both member and primary care.

On that note of primary care, I do believe that MBHOs have made enormous progress in supporting primary care and integrating the medical care. I think much of the concern about fragmentation does not exist when there's full attention paid to reaching across to our medical colleagues.

A couple more quick examples before I wrap up. We currently locate our managed behavioral health care staff on site at the health plans who hire us in several instances. That close side-by-side working relationship really just helps coordinate, where it's appropriate to do so, the care for members that are in need.

Another example is that we actively work to co-locate mental health providers in the offices of primary care providers, in multiple areas around the area that we work. We find that this physical contiguity, while it doesn't ensure that people are going to talk to one another, it makes it a lot more likely that they will do so.

Prevention and intervention. I'm going to skip down in the interest of time a little bit and talk about that just for a moment. We work routinely to screen for mental health issues, trying to find cases earlier before small problems are big.

We work with our health plan partners, for instance, in trying to do health risk assessments, where members, once they enroll in the plan, are quickly screened for issues that may be brewing, co-morbid medical issues of mental health or substance abuse. We get help to them rapidly, get educational material, wellness programs available rapidly to them.

We also do an interesting thing, which you may find surprising, which is we work with providers to find out whether they ask about substance abuse problems, when they are working with a person with a mental health issue.

It may sound surprising, but it's often routinely not done, to ask about substance abuse, and of course, the presence of substance abuse compounds any work that needs to be done.

We also actively disseminate to primary

care practices screening tools and pediatric screening checklists, depression and the like.

My last point, I know that my time's about up, is about ensuring quality. Active and practical quality improvement programs can have direct and meaningful impact on health care indicators that are important to consumers.

One example of that is our after care program, which we recently reported on at the Institute for Health Care Improvement. What we do is actively outreach to members who have just been discharged from an in-patient mental health facility, and we call them.

It's a simple thing, but we call them or we reach them by letter if we can't call them, and we remind them of their appointments within seven days of discharge from the hospital, and again within 30 days, as generally accepted practice.

If they haven't gotten to an appointment, we will make another appointment for them. In those calls, we will find out about barriers, their child care issues, transportation, linguistic, cultural,

other issues. We find that in so doing, we also educate about the importance of after-care and follow through.

It's common sense stuff, but we have found that our seven and 30-day after care rates are among the best in the nation, and in fact for one plan, the very best for a Medicaid plan in the country.

It isn't just about aftercare. Those members are readmitted to in-patient care much less frequently, practically down to zero. They are more satisfied, and of course their functioning is a lot better.

The last point was about close coordination with stakeholders. You know all about that. That's really your aim as part of this health care committee, and it's like mom and apple pie certainly to coordinate with other stakeholders.

You know, I look at our list here and I am struck by a lot of the common sense things that we're doing, that do seem to make a difference in the lives of vulnerable people. We certainly don't have all the answers yet in the managed care world, but I think we

have made enormous strides of late, and I recognize we're all here today, trying to improve things and row in the same direction.

So I thank you for being here today.

CHAIR JOHNSON: Thank you, Deborah. Toby.

MR. FISHER: All right. Let's see if I can do this simply. Prior to coming here, I was not a doctor, okay, and I was --

(Laughter; simultaneous discussion.)

MR. FISHER: So I'm very excited, and Anna will be thrilled.

(Laughter; simultaneous discussion.)

MR. FISHER: Yes. I actually have a Master's in Social Work and a Master's in Business. So I am overeducated and I claim often underpaid. I'm the Executive Director for the National Alliance for the Mentally Ill.

For those that don't know NAMI, I'm the executive director of the state chapter of the NAMI. For those that don't know NAMI, NAMI's a family-based organization made up of family members and people with mental illness and people taking care of folks with

mental illness.

We're a national organization, and for the most part I represent the families and the individuals directly affected by mental illness. What I really want to talk today's presentation to you is the impact of inadequate funding.

I will also tell you that since you are the national platform, you can basically take my presentation. I gave you about a nine-page handout. You can read it on the plane or whenever.

You can basically take my presentation and just change the state's name for virtually every state you go to across the country. It is -- I'm just going to kind of give you the high points of what we really focus on, and again you can see that it's very consistent across the country.

You know, Massachusetts, among other states, Massachusetts has excellent quality services if you can get them. That's the big question -- if you can get them. In Massachusetts, you know, we have our 46,000 individuals with severe and persistent mental illness.

These folks just aren't a little sick; they are very, very sick. They're eligible for DMH services, which is not an entitlement. Of that, 20,000 of them, give or take a couple of hundred, are waiting for services. The numbers have changed slightly in the couple of hundreds over the past five years, but not dramatically. That's a huge priority.

A huge priority to us is the access to medication. You will find, unfortunately, medications for mental illness are enormously expensive. They eat up probably 50 percent of the budget across the country, and in Massachusetts about 50 percent of the budget.

The reality is that, for whatever reason, medications are in my opinion, very expensive. When you work with chronically mentally ill, you don't know why those medications work, for a while it didn't work. So that we advocate strongly that access to medications must be made by the individual practitioner.

The other big priority is housing. You know, particularly with the closure of state hospitals

across the country, in Massachusetts we have had a number of state hospitals close, often to find out they're turned into fancy golf courses and luxury condos, and not what, you know, our family members turn into adequate residential services.

You know, while we don't advocate that state hospitals are the ideal treatment, for a very small population it's still necessary. But for the vast majority, these people are able to live in the community, because of great medications, because of good quality treatment.

What was seen as these hospitals are closing, and these assets are taking sometimes decades to get sorted out, and then the community, the mental health community for which that building served at one time, is given very little, if any, housing.

That varies considerably in Massachusetts, and you'll see a common trend that's common across the country.

Where a lot of the folks are ending up, and you know, I'm sure you folks have been hearing this, you're certainly seeing Department of

Corrections, Commissioners and police officers speaking publicly about that. They're ending up in the jails and the criminal justice system.

Most of these folks are not really dangerous. They're caught up in the system. You know, seven counts of loitering, shoplifting, whatever the case may be. Disorderly. The police will say "Listen, you're going to come in with me." They're psychotic, they're symptomatic, they resist arrest and then they pick up an assault and battery on a police officer. This is very common.

There are a small number of these folks that unfortunately, like people without mental illness, did commit horrific crimes. I would argue many of them, if they had received adequate treatment, would not have committed the crimes.

But the vast majority of those folks, you know, wouldn't be in the jail. Years ago, they would have been in a state hospital, and I don't know if that was terribly better. But today, we have much better options.

So to paint the picture, and this is

across the country, you know, financial outlook since 2000 was horrible for state budgets. It was horrible. It's just now improving. In Massachusetts, we saw a deficit around three billion, about 12 percent of the state budget.

At the same time, and I don't know if this number's increased, but at the same time Medicaid costs were growing at a rate of 13 percent. So you know, this was on top -- in Massachusetts, what you saw during the 90's, was a robust economy. The state of mental health, the Department of Mental Health in Massachusetts was virtually flat-funded.

In other words, there wasn't a dramatic increase in services. There was mostly an increase, contractual increases of whatever the cost of living. For example, the state budget that just recently released is roughly a 3.6 percent increase, of which most of that is salary increases, which are justly deserved.

They're not for contractual increases. They're not for increases in services, and they're not for addressing one of our bigger issues. I gave you

the DMH wait list, which was public information that was very detailed and very organized from 2000. It's a little bit old, but I argue the numbers haven't changed dramatically. They've gone down slightly.

At that time, prior to this commission, that had stopped being tracked. But the state of Massachusetts tracked very closely where all those people were that were waiting for services. These are people who were eligible for services, filled out the paper work, severe and persistently mentally ill, and there were roughly 20,000 of them waiting, you know, sometimes for years.

I just gave you this. The numbers that haven't really changed, and to give you an idea of the types of services, you have adult residential, which is your group homes, those types of programs. You have the child and adolescence programs, case management services, you know, someone who might need someone to help them with their money or their shopping.

You know particularly disturbing is the children and adolescents' wait for services. Again

overall, and this is, I believe, current numbers, there are 46,000 people eligible for services in the state. There are 26,000 receiving them. So the numbers haven't changed much.

The state estimates there are 100,000 children with some emotional disturbances. Of those 100,000 -- those are prevalence estimates -- 3,500 are receiving services. I could tell you where the rest of, a lot of those are. I get the phone calls and they're heartbreaking. They're absolutely heartbreaking.

I have family members who have called me, who have committed their child to DSS who they love very much. DSS being the Department of Social Services, because they were unable to receive the services that their child needed.

So therefore by saying "I'm a bad parent" and committing your child to DSS, the state's obligated to take care of the situation. That does really happen. Those are few and far between and dramatic circumstances. But I have spoken to these parents, and my heart goes out to them.

More often, the phone calls, and we never give that recommendation nor will I ever, but I've spoken to enough parents to understand how much they love their child, to be caught with that Sophie's choice, if you will, because it's a horrible choice, to be that desperate for services, to commit your child.

There was a change to address that, but I think it portrays what I get on the phone on an often daily basis from family members, of them trying to receive services. So again, if you can get the services, they're great. If you can't, you're stuck with a system that can be very bureaucratic and very difficult. And again, you're going to find this across the country. This is not unique to Massachusetts.

We also know that a lot of those people end up, as I said, in the jail system. The Massachusetts Department of Corrections, who now the commission has been public in working. You're seeing a trend where commissioners at DOC are really talking with mental health commissioners across the country.

I think in Massachusetts we have a great commissioner, of DOC and of DMH, who want to do the right thing. I would also say DOC, the Department of Corrections, police authorities, are seeing their budgets being eaten up by mental health people. They find themselves being mental health workers, and again, that will be across the country.

In Massachusetts, the Department of Corrections has 20 percent who have mental health disorders. Now bear in mind, when you're in prison, it's not really cool, if you will, to acknowledge having a mental illness. So many of those folks are undiagnosed.

In the MCI, which is the women's prison, there's 70 percent with an open case. Can you imagine that? Seventy percent of the women in MCI Framingham, the women's prison, have an open mental health case.

So these folks that years ago would have been receiving services, it may have been in the state hospital, are ending up in the Department of Corrections, or homeless. These numbers vary. You know, I believe DMH estimates it's roughly 2,000

people with severe and persistent mental illness across the state. Of those 20,000 people waiting for services.

I've heard estimates as high as 6,000 homeless in Boston, many of whom have some mental health disorder. You really don't need to go far. Just drive down to Pine Street and take a walk in, and these are the folks that years ago, many of which would have been in state hospitals.

Thank God we don't need the state hospitals. Sad, that instead of receiving the care that they need, they're in a homeless shelter or a jail. So that's where a lot of these folks are, and I don't mean to pick on the commissioner or anybody in here, because I think people do good work.

The issue really is inadequate funding at the state and federal level. You know, what NAMI is doing about that, I mean, as family members, we can speak very poignantly about living with this experience, but maybe not very effectively bureaucratically, and not understand some of the policies.

What we understand is our child is lacking services and we're desperate. So what we have done across the country is get to the table, working with various administrations. Some of the changes aren't legislative. A lot of it's sometimes just, you know building a relationship and letting in family members.

I mean, if I had a family member here speak sometimes, or was here in audience, you'd have tears; their stories are so powerful. You know, going back to the state budget and federal budget, we really try to protect base appropriations.

We were lucky. Within the dramatic budget cuts that you had in the early part of this decade, mental health wasn't dramatically cut in Massachusetts, thank God. Because it was flat-funded during the entire 90's. But we really saw a pretty much flat budget while other agencies saw a dramatic decrease, particularly substance abuse and DSS services.

We do support tax or revenue increases. You know, you can't pay for these services. We are watching -- the commissioner alluded to, and this is

going on across the country -- governors go into office and they want to reorganize the government, make it more efficient.

There's a lot of good value to that. There's also -- you have to pay attention. So we often try to pay attention to where the parts move, and obviously looking for increased efficiencies in mental health. You know, mental health, like other parts of health care, is not necessarily an efficient system.

We are not for an inadequate or inefficient system. We're for adequate care, efficient systems. The big one that comes to us at the national and state level is monitoring the Medicaid benefit.

I mean, there are huge changes. For those that know about the IMD exclusion, we in Massachusetts faced losing a hundred and, I think it was 28 million dollars in psychiatric care through a change, if you will, in Medicaid law, which I can talk about afterwards with anybody. Or I'm sure there are other folks who can talk about that.

But there are constantly changes at the federal level, that frankly I have a difficult time understanding, except that it dramatically impacts the care. You're going to see that now with the pharmacy benefit coming up in 2006.

I do want to leave you with some of the best practices that NAMI and I think others and the commissioner and Deborah had alluded to it. There are some great quality types of services, one of which is PFAT or assertive community treatment.

It is a flexible type of wraparound treatment model, that follows some of these very sick folks, some of these folks who might be living under a bridge, who without a little bit of monitoring, might end up doing something horrible or ending up in jail. It's a good program for the very, very sick who are treatment-resistant.

Evidence-based medication practice. It's a big issue. We know the medicine costs a lot of money. We think there should be some quality control around prescribing those, without impacting clinical care.

Supported employment. You know, most of these folks who have chronic mental illness want to be normal. They want to work. They want to do the right thing. They want to have a house. They want to have a relationship. Supportive employment works. I have seen it work over and over again. It takes a long time sometimes, but it works.

Integrated dual diagnosis treatment, that being with substance abuse and mental health. This is some of the inefficiencies of state and federal government. There is often an incentive for agencies not to work together to protect base appropriations, if you will, and this is where we've seen some challenges with dual diagnosis.

So many folks with mental illness have a substance issue or vice-versa. I don't know what came first, the chicken or the egg sometimes, but without integrated care, it's very challenging.

The psycho-educational programs for the family. I will tell you, a lot of these families are taking care of it. I have many families who are taking care of their very sick child because they

can't receive services at home, as the best they can.

In Massachusetts, like other states, sometimes it's all or nothing. In other words, you can get complete services and you get them off the wait list, or you get nothing and you get to keep them at your house, because you're so desperate you don't want them running around homeless. Family psycho-educational provides at least some base of support.

Illness self-management programs. You have seen a good trend on that nationally. I've seen more empowerment and people learning about managing their own symptoms.

So last, but not least, is jail diversion services. I mean, so many of these folks, with a trained police officer, would not be in jail. I have spoken to so many police officers who said "You know, I've dealt with -- I used to deal with state hospitals so many times. I knew how to talk to this person and not put them in jail."

"I've worked in the field for a long time, and only once did I need to use force. I feel pretty confident had I had police training and clinical

training, most of the cases that turned into mental health arrests could have been avoided."

We're finding out there are a couple of pilot programs in Massachusetts, and you know, Memphis, Tennessee has probably one of the gold standards of police diversion training.

So those are the types of programs that we think work. They work in Massachusetts. They work nationally, as you have a national agenda. Hopefully, I was good on time. I think I'm just right on the button. I'm happy to stay longer. You know, I do realize that you're sitting here a day.

For those that aren't in the mental health field, it's like a fire hose being thrown at you. I've tried to give you the broad-based picture, so I can assure you I gave you this report. You can change the state and almost the information's exactly the same.

Long state mental health waits; kids waiting for services; challenges getting medications, which vary. Massachusetts, actually, has a good pharmacy benefit. Some states have been challenging.

You have -- jail diversion is a huge, huge issue and housing or the lack thereof, and the conflicts between federal policies, local policies and local initiatives trying to get these programs integrated. There are often a lot of policy conflicts, if you will.

But those are the four major issues, and I thank you for your time.

CHAIR JOHNSON: Thank you very much, Toby. Deborah, I'd like to open a question to you if I may, and let me just start by thanking all of you for your being here again this morning, and for your dedication to those who have challenges with mental health and substance abuse.

My background personally, academically, though not as advanced as many of my colleagues, is in the area of psychology and social work. Motorola has installed a stigma-free, to use your words, both of you, mental health care program, and has had that in place for well over a decade.

Having said that, some of our issues in delivering that have been care that hasn't been the kind of quality that we would hope for. Of course we

have that in the medical field as well.

In the medical world, what we're focusing on is providing measurement transparency and disclosure of health care outcomes of hospitals and doctors. We're doing, we're focusing on that with a goal of providing a report card, and we have more than 90 members, different stakeholders at different tables talking about that, doctors, NCQA, URAC, physicians, hospitals, consumers, purchasers and so forth.

The idea is to do just exactly that. The mental health care profession has not been at the table. I'm wondering how you, if you'd share a few words, Deborah, regarding the extent to which mental health care professions are ready to have their performance measured in a transparent way, and disclose to the public, just like we're pushing hospitals and they're collaborating with us to do, and doctors as well.

I'm going to ask you to keep your comments to two minutes with each of your responses, because of our limited time.

MS. NELSON: I had to smile a little bit

at the end of your question, the extent to which mental health providers are ready. Being a provider myself, I can probably say with honesty that I think that people are not quite ready. They're not ready as they should be on that.

That said, the science is there in terms of, I think, general, broad agreement of what the indicators of quality and transparency are, in terms of evaluating the structures of mental health, the processes of mental health and the outcomes of mental health.

There have been a number of national efforts afoot, such as Decision Support 2000, which CMS has been fostering, which I've actually been pleased to take part in where, with consumer and various stakeholder input, we've arrived at a course of transparent measures that should tell us something about the quality delivered.

So I think there's broad agreement. A similar effort is taking place at the National Quality Forum, which also brings stakeholders together. They've recently published their behavioral health

indicators. They're there; they exist.

Are they in widespread use? They are not. Are providers quite ready? I would say I think there's still reluctance at being profiled or reported on, for purposes of quality improvement. There's still mistrust that there will be a backlash against a provider.

I mentioned an example of asking providers, "Do you screen for substance abuse?" Not everybody wants someone else looking in, asking that question. Yet if we don't open up the black box of mental health, we can't improve it.

I'm a quality improvement professional, so I believe in the transparency. I applaud the efforts you're doing at Motorola. I'd love to help be a voice at the table if I could help in some way with that.

CHAIR JOHNSON: Thank you very much. Montye.

MS. CONLAN: I have a couple of questions. First of all, I wanted to thank the three of you for coming today and taking your time. I think this is a really important issue.

I thank Dr. Frank for inviting you here and bringing this to our group. Like I said, I have a couple of questions, I guess. Mr. Fisher, maybe I'll start with you.

I come from the state of Florida, and I am hoping -- I'm sending out an SOS to your national alliance. Maybe you can send a rescue mission to us. We've just had a change in our Medicaid formulary. It's the beginning of the fiscal year. Changes in the formulary are nothing new.

What is different is a new policy. The step therapy or what is commonly known as fail first. Well, this has very serious ramifications for those mentally ill patients who have taken years to arrive at the right combination of drugs.

Now, they're removed from -- the drugs are removed from them, and they are expected to fail first at cheaper drugs before they can earn the right to the drugs they've been on. What can we do about this in the interim? This is a real problem that people are dealing with right now.

MR. FISHER: We are dealing with this

issue across the country, in various different things. Florida, a couple of years ago, and what I will do is I will personally call the executive director of Florida. I don't see a name tag there, though. I'm sorry.

MS. CONLAN: My name?

MR. FISHER: There we go. Okay. I'm sure I can look at direct contact information, and I will relay this. What we're seeing across the country is again, 50 percent of your state budgets, pharmacy budgets, are being eaten up by the medications. So they're really looking at psychotropics or mental health medications.

In Florida, Florida, actually going back three or four years ago, was one of the first states that being aggressively targeted. NAMI and a bunch of other groups and the mental health association very successfully fought back and got what's called a carve-out, or a complete exemption of any restrictions on mental health medications.

Well, you know, two or three years later, it's not terribly surprising they're being retargeted.

New Hampshire is another state that actually got a carve-out, and now they're being retargeted.

In Massachusetts, I think we negotiated somewhere in the middle, and we've been living with this deal that isn't a complete exemption, but it isn't a restriction.

So to answer your question, in Florida, you just have to kick and scream, and you have to get at the table. What we find is that a lot of these decisions are held at very senior levels. In Massachusetts, it's required of the commissioner. We got legislation stuck into the budget that mandated that she was in charge of any pharmacy changes. So if anything happens. I know where to find her.

Now she didn't know that, because this was before, right before she started. We knew what we were doing. So we have someone we can go grab and say "Hey, what happened?" Because what happens is they'll have the DUR boards or they'll have these convoluted bureaucratic systems that are hard for us to figure out.

My simple suggestion, two minutes or less,

is kick and scream. I will have the NAMI executive director, NAMI and MAHA and usually the psychiatric association are the lead advocates on the issue, probably because they represent the consumers and there's no financial interest on our part.

All we care about is the care of our children, and the clinicians also understand that while you may save money in the pharmacy line, you'll see a dramatic increase in other lines. I have numerous reports to prove that argument. So I will have the executive director of NAMI follow up.

CHAIR JOHNSON: Thank you. Richard, and then Aaron.

MR. FRANK: I have two questions. I'll ask Beth. I think three or our speakers highlighted the sort of central place that Medicaid has in the modern mental health system. The numbers I've seen have said it's about 28 percent of all the money we spend in the country.

What I was hoping that Beth could tell us a little bit about is how -- in Massachusetts, there are the carve-outs of Medicaid mental health, and it's

run by the mental health commissioner. How are you using that tool, and since that's Toby's constituency, how are you using that tool to move the system?

DR. CHILDS: It used to be that primary funding in the mental health system was through the federal government and state appropriations. Today, much of the funding for the mental health system is through Medicaid.

In Massachusetts, $590 million of service vending are through the Department of Mental Health appropriation. Many of those dollars do generate federal match dollars in Massachusetts. They're used as the state match for a Medicaid dollar match.

$443 million of the publicly-funded mental health system is through the Medicaid system. Those are service dollars. So the challenge is to take and harness that nearly billion dollars' worth of funding to eliminate redundancies between the two systems, and to take every dollar and make sure you're maximizing the value of it for service spending.

The federal block grant for mental health funding used to be a significant part of state

budgets. Today, it is a minuscule part of state budgets. In Massachusetts, in our $625 million budget, the state block grant amounts to about $8 million a year.

What you can use that money for is very prescribed, and the requirement for state match is not technically a match. But the state makes an effort and money, four of that $8 million, is significant.

In Massachusetts, we put up about $200 million plus to get that $8 million in federal money. So that's not a very effective funding stream. So state mental health authorities really have to look to Medicaid.

If we are going to have any way of increasing our spending in mental health, we need to do it in a state and federal partnership, and we need to make sure that we are leveraging every possible aspect of the Medicaid dollar to fund the mental health system.

That's really what this initiative in Massachusetts is about. It's about putting together the Medicaid funding and the state mental health

funding, and trying to leverage and harness that to really create a single system that does not have redundancies and inefficiencies in it, and takes that billion dollars and deploys it to full service funding.

It's interesting that when you look at the data, those individuals in our planning population data, which is really the Center for Mental Health Services epidemiologic data, and it really is quite consistent across the country.

Seven percent of the 9 to 18 year-old population has serious emotional disturbance with extreme dysfunction. That is the most severe group. About 11 percent of the 9 to 18 year-old group have serious emotional disturbance, which we would think of as kids who need services.

The federal data, in the zero to nine age group, is that 2.5 percent of the zero to nine year-old group has serious emotional disturbance. That's pretty striking when you think about the impact of that level of prevalence of illness.

Then in the adult population, we look at

the .98 percent of the adult population which has serious and persistent mental illness with serious dysfunction. When you look at that planning population, not all of those people are served in the state mental health system. But many of them are served in the Medicaid system.

So if you can make those two systems work together, not all of them, but many of them, you can really, I think more effectively, deliver a continuum of care.

When we think about a high performance behavioral health network, we think about high quality, high efficiency and continuousness. I think that one of the major, important differences sometimes between physical health care and mental health care, is the importance of continuousness.

The handoffs have to be extremely seamless for the individual. In a basic way, it's a continuous healing relationship. It's having somebody at your side throughout the course of your illness.

When you do need to make a shift or a change from one provider to another provider, that

that bridge is so well done that the client, the consumer and the family member, doesn't experience a drop or a gap in care.

CHAIR JOHNSON: Okay. We have time for three more questions, and again, we'll ask to make them brief so we can -- and the answers brief as well so we can move on. But Aaron and then Joe and then Catherine.

DR. SHIRLEY: Just very brief. Toby, under the ACT provision, ACT program, you mentioned certain decline in various settings. What are the typical community settings under the ACT provision, the typical setting for where they receive services?

MR. FISHER: That would vary considerably, and probably it would vary considerably. It's really designed to be flexible so that, you know, your mental health -- a chronically disabled person is not -- some might be actually living under the bridge, some might be living at their homes, some might be in a supportive program, or some might be in an independent living situation. It varies with the different model.

The idea of the program is really designed

to -- I mean what you have in the health system is often a cookie-cutter approach, and if you look at the residential programs, they have very standard types of treatment modalities, which is great if you're a state, and you can follow the rules of the program.

This one's really designed to be flexible. So I have a nurse, I'd have some case workers and a doctor, where they have a team that actually can go out to any treatment environment, and that's the beauty of this program.

Because what you'll have is many folks who are very sick, who don't want to follow the rules or aren't able to follow the rules because of their mental illness. They'll be in various settings, and I don't know if the commissioner wants to comment on it. I think -- did I describe it accurately?

DR. CHILDS: Very accurately. The teams actually follow the patient wherever they are. It's a multidisciplinary team. They may be meeting in a storefront. But if the client is living in a supportive housing arrangement and the team needs to go to that client, they go there.

If they're under the bridge, they go under the bridge. Then the team works and meets daily around how are we best going to reach this population and engage them. It's about engaging the hard-to-engage client and is very much part of assertive.

That's where the word "assertive" comes from, assertive community treatment. It's not taking no for an answer, when you know that the client really needs to take their medication, or to stay out of the hospital and keep their job, and the client says "I don't want to take it."

Then the nurse really works hard and says "It's really important. You've got to try to do this," and they go back and back again.

CHAIR JOHNSON: Joe.

MR. HANSEN: Beth, in your presentation, under your initiative number one, you had a slide that had three bullets. It talks about system redesign, reprocurement, regulatory change or waivers, and contractual improvements.

I think you answered most of my question when Richard asked his. But I'm curious about the

contractual improvements in that.

As a follow-up Deborah, you made reference to a providers bidding and really not -- being low bidders, and not being able to provide the services that are in there for the money basically, I think is what your deal was.

Are there any standards or measurements of this, either under Medicaid or under the state or any place else? So it's kind of a two-part deal.

MS. NELSON: The point I had made was that I think purchasers sometimes are tempted by choosing the lowest priced bidder or either selecting a mental health vendor, and I offer strong cautionary notes in doing that.

If you can't fund the benefit adequately to also ensure reasonable access and good quality, then I think we're shooting ourselves in the foot.

MR. HANSEN: Are you thinking of an HMO type of arrangement when you say that?

MS. NELSON: Pardon me?

MR. HANSEN: Are you thinking of an HMO type of arrangement, a compensated type of arrangement

--

MS. NELSON: Yes, an HMO. A state purchaser could offer an HMO too little money to adequately fund the benefit. I understand health care dollars are scarce, but there is a point of no return. I'm not sure how to answer your question, in terms of what is a reasonable amount of dollars.

MR. HANSEN: Well, if the money is public money under Medicaid or something like that, is there any way of measuring the quality of the care that they're getting?

DR. CHILDS: Yes. I think it's really important to speak to our contracting approach. We used to believe that you contract competitively and then you sit on people to make them do the job.

But partnership and getting the people that you are purchasing from to embrace the same principles and to work to the same outcomes is a much more effective way. That's where contractual influence comes in, and getting your providers to deliver the care.

In the state system, of the $590 million

of DMH service spending in Massachusetts, 80 percent of it is contracted out. The state delivers comparatively little care directly.

So I can either work with those vendors that I contract with, and basically sit on them and measure them and say -- or I can bring them to the table, and I can say "These are the principles that are important to us. Can you embrace these two, and can you help us innovatively think about how to make these principles a part of your system?"

So the other thing that happens is on the Medicaid side, almost 100 percent, except for the administrative costs, the 100 percent of the service dollars are contracted, and we purchase.

In Massachusetts, we do that through two mechanisms. One is a direct behavioral health carve-out contract that the state directly contracts with. In Massachusetts, it's Mass Behavioral Health Partnership.

We also do it through four managed care organizations, two of which contract with a specialty organization like Beacon Health Strategies. So in

terms of contractual influence, it's not quite as direct. But we have monthly meetings with the behavioral health directors of Beacon Health Strategies with the commissioner's office, with the direct carve-out.

So we can bring to the table all of those people. Basically, you get people to say "Yes, we can sit on you and we can have these explicated." But why can't we instead say "These were our goals," and then "How can we all think of how to get there?"

Then I think the other thing is you structure the contracts with performance incentives. You set up a contract so it's not just paying for costs. It's paying for performance.

At the end of the day what you want is specialized vendors who have this incredible wealth of knowledge and expertise about how to improve quality, you want them to help you figure out how to make the system better.

If you're paying them because of what they deliver, you're in much better shape.

CHAIR JOHNSON: Catherine.

VICE CHAIR McLAUGHLIN: There's really not enough time, Randy, so --

CHAIR JOHNSON: Go ahead. We'll do okay.

VICE CHAIR McLAUGHLIN: Not to deal with it adequately. So rather than even raise it, I'll ask some of you later, at another time.

CHAIR JOHNSON: Okay. Well, we'd like to thank you as a panel for your input to us, and experience and dedication. We'll try to absorb some of the things you said and proceed with that in our deliberations for the future. Thank you very much.

We'll take a two minute break, so that our panels can change. But we're going to move right into our next panel in about two minutes.

(Whereupon, a short recess was taken.)

CHAIR JOHNSON: We're a little off schedule. We need to move forward and I kind of feel like an ogre with respect to suggesting that. Well, we'd like to welcome you to this next panel, in which we're looking at state, county and local initiatives.

Trish Riley serves as the Director of the Maine Governor's Office of Health Policy and Finance,

leading his effort to develop comprehensive coordinated systems in Maine, and to assure affordable health insurance for Maine citizens.

Trish, we've heard about you in a variety of ways and we're glad you're here. It's all been good, and our colleagues have your bio, so that's about all to say about that.

Vondie Moore Woodbury is from Muskegon, Michigan, and has been the Director of the Muskegon Community Health Project since 1995, where she provided health coverage for 400 uninsured small businesses, undertaking management for 2,000 indigents, and worked with community members on specialized programs. So welcome.

Trish, we're going to let you begin, and as I mentioned in the earlier panel, we're going to ask you to take about 12 minutes for your presentation. When you get to that 12 minutes or so, I'm going to put this up, to kind of signal to you we need to wrap up. But our rich time has been with questions and answers, and as you might sense, from our prior panel, we have a lot of questions we'd like

to ask.

So without further ado, if you would go first, Trish, and then Vondie go next.

MS. RILEY: Good morning. Thank you very much for this invitation. I want to just quickly take you through the Dirigo Health Reform, which is a comprehensive reform passed in 2003, designed to address cost, quality and access, the notion that you can't do one with the other. So it's a tripartite exercise.

Its goal is to over time build a sustainable reform to achieve universal access to health care for all Mainers, by making it more affordable and of high quality.

It started as a voluntary effort, recognizing the limitations of voluntary efforts, under the notion that unless and until we bring down the cost growth, it was inappropriate to talk about mandates. It is a public-private approach.

Each state, of course, has different needs that generate their responses. In Maine, we have a population of 1.3 million. We have 140,000 uninsured,

not unlike the uninsured population. 80 percent in small businesses are self-employed; 75 percent below 300 percent of poverty.

We have the highest rate of uninsured in New England, the lowest rate of employer-sponsored coverage. So that focused us plainly on small business, and we do it frankly as a part of our economic development strategy.

We also were spending over $200 million a year, which is real money in a small state like Maine, on bad debt and charity care, a hidden tax covering people who didn't otherwise have coverage.

Let me just quickly go through the strategies. You have the handouts. Under cost containment, we basically reinvented some old efforts, retooled them. We upgraded our certificate of need program, expanded it to cover physicians when they acted like hospitals and spent significant dollars on capital investment.

We created a budget for capital expenditures and a capital investment fund, and a state health plan to establish health priorities to

govern capital expenditures. We created voluntary expenditure targets for providers, with which hospitals are trying to comply, some significant new transparency, price posting by hospitals and new reporting by insurance companies that was previously unavailable. We created for the first time small group rate regulation, rate regulation in the small group market; convened a hospital study commission to look at the problem of efficient allocation of resources.

We have great variability in Maine. As you can imagine, the whole state has significant variability in its hospital capacities, and that study commission was designed to address those.

Our focus was very much on the hidden tax of bad debt and charity care, costs that are passed to other premium payors. We enhanced public purchasing and we're at work to create a single portal for providers to access eligibility benefits and claims for multiple insurers, to streamline some of the administrative activities.

The second part of the three-part program

is quality improvement. We created core funding for a Maine Quality Forum, an independent organization focused entirely on quality. We created a state health planning process, to make Maine the healthiest state. It's a little bit of hubris here, I guess, but to try to move away from the language of personal responsibility, which so often is blaming, you know, do this, do that, we try to engage people in a discussion about how is it that we can become a healthier state, and why not become the healthiest state?

We have pay for performance initiatives with public purchases, a new all-payor database that's struggling but will give us important information, and a statewide effort about the interconnectivity of electronic medical records, all of the above underway.

The access initiative, I know, is what you're primarily interested in. We created an independent agency with its own board of directors, to keep it somewhat separate from the political environment under which most state government programs run.

It's chaired by a former president of the American Medical Association, Bob McAfee, a truly distinguished fellow, and it's got a big job head of it. We went to bid, and the biggest insurer in Maine responded. It really controls most of the health insurance in the state of Maine.

The program was targeted to the small business, the self-employed and individuals. It creates discounts for employees, recognizing that oftentimes small business would offer coverage, but employees could not afford to pick it up. Insurance rules that require 75% of eligible workers take up coverage oftentimes resulted in small businesses unable to offer coverage.

There was a modest Maine Care expansion, for parents from 150 to 200 percent of poverty, and we created a comprehensive coverage, which is antithetical to where the marketplace is going. The marketplace is going into catastrophic, high deductible plans. We said we wanted real insurance and real coverage.

So it's a comprehensive coverage. 100

percent prevention, no out of pocket costs for well child visits and all the usual preventive services, and no pre-existing condition exclusions. This is the only product in the small group for that, and again, individuals can buy into a small group product in this program.

It has mental health parity extended to the small group market, again, the only product to do so, and the Healthy Me rewards program -- we know that it's important for uninsured people to get a connection with a primary care physician, and get out of the emergency rooms.

You get $25 when you sign up for a primary care physician; $75 when you complete a health risk assessment, to determine your own health needs. It's been popular and successful already in identifying some significant health problems.

We made a determination to use commercial rate reimbursement for providers, not the lower Medicaid rates.

The issue here is can we create affordable health insurance, and since Maine pays more out of

pocket for health insurance than all but five other states, this is particularly of concern to us.

The program has monthly payments and deductibles. It is structured like an insurance program that small business would recognize. In order to get small business to be comfortable with this program, it had to look enough like a small business program.

Monthly payments and deductibles are based on ability to pay up to 300 percent of federal poverty, which is about 55,000 for a family of four, about 27,000 for an individual. It's a tiered discount program.

The marketplace in Maine is rapidly moving to catastrophic plans. So while these deductibles look high, 1,250 and 1,750, they were put in place to respond to a need. The employers said "I have to have to an affordable product." The only way to make the product affordable and comprehensive was to make it a high-ish deductible.

But because we subsidized -- this is still much lower than the $2,500 and $5,000 that are far

more popular in Maine, because of the discounts, the average deductible is about 850 for both plans.

We require employers to pay 60 percent of the employees' share, and we have engaged in a number of system reforms to make our health coverage affordable for everybody, not just those who have no choice.

Just a snapshot here of how the program works. It's a tiered discount. Group A are those people who are eligible for Medicaid, the Maine care program in Maine, who participate in Dirigo as well.

Group B would be those between 100 and 150 percent of poverty, up to Group E, which is between 250 and 300. Group F pays full boat. As you can see, it basically is a program designed to be a comprehensive health insurance program, based on ability to pay.

It's self-financed over the long run through pooled revenues. Member and employer contributions, $53 million in one-time state funds, that becomes the savings offset payment, and Maine Care for those eligible. The savings offset payment

is the vehicle by which we'll sustain the program, and I'll spend a little time on that later.

Anthem reports that Dirigo Choice is the fastest-growing new product in the marketplace in its history. It's very different from the Maine Care expansion. When you open up the doors to an entitlement, you have thousands of people who quickly come on.

This is an insurance product that has to be marketed. But we are very encouraged that 8,100 people have enrolled in the first seven months, and we have a waiting list of 3,000 for sole proprietors and individuals. We had to put a cap on those, because of the fear of the insurance industry for adverse risk.

2,000 Maine businesses, 1,500 sole proprietors, and 650 small businesses have enrolled statewide, and Maine is about small business. So this is an important part of our economic development.

The challenge for us is, of course, linking access expansions to cost constraints. We know that the public health investments that we've launched through the state health plan and the Quality

Forum will take considerable time to make any significant dent into the kinds of levels of chronic illness and problems that we have in the state.

Turning that ship around takes a long time to reap results and focus attention. So what we did was link cost containment with access, and I think we're the only plan to do so. We said that it is important, it is essential to the future of this program to bring down the cost growth of health care.

When and if we do, a portion of those savings will be reinvested through a savings offset payment, an assessment on insurance companies, up to four percent of claims, that will then be reinvested to continue the discount program over time.

So it's absolutely essential that we achieve our cost containment goals, bringing down cost growth, in order to assure access. Yet the access initiative also is part of cost containment, because we know when people are covered, they bring down the hidden tax of bad debt and charity care.

So it's a fairly complicated initiative, and not an easy one. One person's cost containment,

as you well know, is another person's salary. So everybody likes the long term initiative. Quality Forum, a great thing. Public health, a great thing. Making people healthy, a great thing.

The immediate kinds of things that can bring cost constraint to a system like ours, of course, meet with considerable resistance.

We did complete a campaign around these issues of tough choices, and put together a brochure that I can leave for you. But basically it was a one-two-three primer on health care in Maine, and some of the health care costs.

It was designed with every stakeholder at the table, so it was edited about 433,000 times. It, I think, reflects multiple viewpoints as a result.

We contracted with America Speaks to be a neutral facilitator. We then did a random sample selection of Maine citizens, and held a two site interactively connected forum in Maine for a whole day, to talk about choices in health care, would you do A or B?

I think the conclusion from that day is it

was an extraordinary event. People connected by teleconference, sharing results, to educate people. It was real, live citizens spending time in tables of ten, discussing health care in ways that they hadn't before. I think it was an extraordinary educational activity to get people engaged for a whole day.

It was not successful in getting people to actually make the choices. Each time there was a tough choice, there was often a new choice like "Oh, how about single payor?

How about change the paradigm of an insurance-based system?" But it was an extraordinarily interesting experience, and is a base for our state plan and our hearings going forward.

The challenges, of course, as in any health reform, are how to pay for it, and the limits of a voluntary approach, which we knew from the beginning. But we wanted to engage people in a collaborative reform as best we could, and try voluntary initiatives before talking about anything mandatory. We are still committed to that.

As you look at your charts and as I looked

at your charts, there were just a couple of things that jumped up to me about what might be federal roles. Of course, living in a state and in a state that's not a rich state, we of course look to the federal government for help.

States cannot, I think, finance access to the uninsured alone. The need for the deeper pockets of the federal government is real and unequivocal.

So I think roles for the federal government, supporting state initiatives, we wrap our program around Medicaid and CMS continues to have some concerns about how we're doing that, and some kind of federal-state partnerships.

Clearly, what we've seen in our program, a little contrary to our expectations, the vast majority of enrollees are in that B group, the group getting 80 percent subsidies.

The working poor work a couple of jobs and make minimum wage, and don't have the money to pay health care. So we're subsidizing it pretty significantly, and it's expensive.

The other thing I think, and this is

somewhat blasphemous for a state official who spent her life in and around state government, I think there are roles for mandates in Medicare and Medicaid, around four areas.

I do think it would be appropriate, in collaboration with the states, not a top-down mandate, but in collaboration with the states, to determine what Medicare and Medicaid ought to require for consistent data, and how it ought to get that data in a timely fashion. Medicaid data, as everybody knows, is tough to come by in a timely way.

As Cathy McLaughlin knows better than most, people who have tried to do the research know that it just takes a while to get good, credible data.

Standard quality measures for Medicare and Medicaid should be required. I think even though this is a state-federal partnership, I think in these areas, it may be appropriate, and again I'm speaking for myself here, but I think it may be appropriate for the federal government to be explicit.

There are issues of cost. There's constant discussion among providers about the

underpayment by Medicare and Medicaid, and there's constant discussion by people like me about is it underpayment by public payors or overcost by providers. I suspect the truth lies somewhere in the middle.

We need a more neutral review of that question, to get at the issue of what should health care cost and who should pay for it.

Finally, simplifying the eligibility pathways for Medicaid. When we talk about Medicaid reform, we talk about the cost of the program, we talked, as your earlier panel did, about mental health. We talked about the benefit design. But we haven't really talked about the complexity of how you get eligible for Medicaid.

If I had a magic wand that could do anything to Medicaid, I'd say everybody under 200 percent of poverty is eligible. Bing-bing, end of discussion, instead of these silo kind of gap lists.

So I don't know if I've -- I've probably gone over time, but that would be the quick summary, and I look forward to your discussions. Thank you.

CHAIR JOHNSON: Thank you, Trish. I know that you're, what was it, 433,000 editions of your report? Is that what you said?

MS. RILEY: Yes. I think it was probably that many edits.

CHAIR JOHNSON: Yes. That many edits. So I'm sure Catherine and Richard and our Report Committee will feel good that they only have 432,000 left to go for our report.

(Laughter.)

CHAIR JOHNSON: Thank you very much. I'm sure that our group has a lot of questions that we'll want to share with you as we go along.

While we were taking a break, our last panel left two handouts for us. We'll just distribute one to each of our Working Group members.

MS. WOODBURY: That's not it. It's the Muskegon Community Health Project. I could try that, but I don't think it will work very well.

(Pause; simultaneous discussion.)

MS. WOODBURY: Thank you. I want to express, too, my appreciation for the opportunity to

be here and present information about our program in the state of Michigan.

Muskegon is a county of 170,000 people. We're located on the eastern shore of Lake Michigan, almost directly across from Milwaukee, Wisconsin. In 1993, the W.K. Kellogg Foundation approached our community foundation, to test a new model that engaged communities to look at whether, how they could in fact solve access and community-wide coverage problems.

We were one of three counties chosen in Michigan to participate in this model, and the access health program that I'm going to tell you about, evolved out of this model.

I do need to say at the front end that this program, as are all the programs that we've worked on, are community-led. They're done by community members. We have lots of money or we had lots of money to bring in all sorts of experts.

But in fact we found that the best way maybe to do it was to convene our own community and figure out and negotiate with each other what we could and could not do.

Access Health is a community-developed health plan. It is aimed or targeted to small businesses within our community, that were previously without health coverage.

It is a stand-alone 501(c)(3) entity and you'll see, as I get through here, I'll provide more information about this. But I do want to make the point that we directly contract with our local providers.

We started out in looking at the issue of uninsurance in our community by basically mapping out what currently existed, and every community in the country can do this.

In our own community, this is what it looked like. The fastest-growing number, of course, was the working uninsured. That was being fueled by small businesses, the cost of uninsurance in the small business market.

Many small businesses were dumping. In addition, on the next segment of the triangle, with welfare reform we had many people who were disconnecting with the traditional Medicaid program

and then moving up into businesses, working for businesses that did not have coverage.

Let me say about this before I move on also, that I'm going to talk about Access Health. But in the last ten years, we have also in Muskegon County initiated two federally-qualified health centers and a program for indigent uninsured.

As a community, we have to be as close to 100 percent access to care as any community in the country. We've done that by working together and using what resources we have, as well as what the state of Michigan will allow us to do.

Any time you decide you're going to take on something, you have to do a certain amount of discovery. For us, we found that there was a lot of information on uninsured people out there, but not a lot of information about uninsured businesses.

So we took a good amount of time to identify who our target market would be. This is, we surveyed 200 uninsured businesses in Muskegon County and one of the most important pieces or actually what was the most important piece for us is there close to

the bottom.

95 percent of them indicated to us that they did have some money they were going to spend on health coverage. There is a notion out there that many of the uncovered small businesses have no interest in providing anything.

In fact, this tier of small businesses did have an interest, and it was fueled by the 67 percent who indicated that they had a problem with turnover. They were constantly turning their employees and the cost of then rehiring and training these people was cost-prohibitive for them.

So to be able to offer something, they saw it was a very important piece of what they wanted out of our program. I will also indicate or tell you that as we looked at these businesses, the majority of them tended not to be members of the Chamber of Commerce or many of what we think of as mainstream business organizations.

I think child care centers, barber shops, ma and pa grocery stores. The very small types of businesses that we're talking about generally did not

have enough money in the bank to participate in some of those things.

We also looked at the working uninsured, and this actually was a survey of 300 people done by EPIC-MRA as well. Again, we found that if we asked them did they have any money that they could spend, they self-identified that they had anywhere from $35 to 50 a month that they were willing to spend.

We found that there was a high value placed on health coverage within this population. Many of these people had come off of Medicaid, as I mentioned earlier, gone into the work force, and they were used to having health coverage.

In our community, they profiled out as predominantly women under 40 with children, and as you can see, they were foregoing treatment of illness. So we knew that once we started this, we were going to see some costs at the front end of the program.

But at the end of the day, we found we had somewhere between $70 and $100 that were dollars out there in the system that we could tap.

As we moved forward in the identification

of our market, we decided we would take a swipe at 500 local businesses. We've had up to 430 businesses who participate in our program. We also identified that beyond full-time, we also had part-time employees out there. We had many people who were working multiple part-time jobs. They had the financing; they certainly had the money in the bank to be able to participate in something, but there was nothing available for them.

We also, of course, targeted young adults in our community. We don't have a four-year college, but we do have a community college and a business college. So we found that many of these young people were sticking close to home and also were excluded from coverage.

We used the Access Health program as an opportunity, as we sit down with our members, to identify who has children, who may be eligible for either Medicaid or the SCHIP program, and you see there we process about three to five applications per week, predominantly in the SCHIP program, that would stay in the state of Michigan.

The Muskegon Community Health Project right now is ranked as fourth overall in our use of on-line enrollment. If it were per capita, I'm sure we would be first, because we are a relatively small county compared to other areas in Michigan.

I put this slide up because we, while we have a sales staff that sells our product, I wanted to point out to our insurance agency. We also use private insurance brokers, who go out and sell the product. They came to us initially and they said "Hey, how about you pay us commission." We said we don't have money for commission.

They came back and said "You know what? We'll sell it anyway." In fact, this is the tier of businesses that aren't sold within the commercial market. Many times, I know in the national debate, there's been confusion about that, that if you create something that's an alternative, you're going to pull off the commercial market.

That wasn't true. These are businesses. Over 60 percent of them had never participated or bought a thing in the market.

To be eligible for our program, you have to be located in Muskegon County. That makes it a very nice economic development toolbox item. You cannot have had health insurance for the previous 12 months. We certify the businesses eligible here.

So the business cannot have offered for the previous 12 months. The idea was not carve off again what was available within the commercial market, but rather to target in on those businesses that previously had not participated.

The median wage of $11.50 an hour, again, we certify businesses eligible. We tried to stay away from some of the means testing that we normally get into when we talk about any kind of subsidized program.

The reason we did that is we found again, from our survey research, is that these were people -- the people who are working there in these businesses, as well as the businesses themselves, had aversion to government, and did not particularly like being called poor.

So what we wanted to do is try to make

this as mainstream as possible, and that's what we did. You'll see that non-profits are also eligible to participate, which makes it tough in national policy, because any time you want to do something for small businesses, non-profits tend to get carved out of that.

This is our benefit structure. We offer every health service available in Muskegon County, and I can answer questions about that later. Except we do, of course, accept pre-existing conditions. We are one of the most unhealthy counties in the state of Michigan.

So not doing that would not have been helpful. Our exclusions to care is any care received outside of the county. We are a county-based health plan, as well as certain highly specialized catastrophic care. We cover cancer, we cover heart.

These are the sorts of things that frankly we don't do in our community. We are a secondary market. In fact, if we have a member who has one of these needs, we do a referral. They will go to the University of Michigan, they will go to Spectrum, they

will go to one of the higher end hospital systems.

We work with the state of Michigan because these are low-end workers. They fall into a Medicaid spend-down situation, and we still give them the care they need. We just don't shoulder the risk.

In sharing the costs, we use what's called a three-share model. These are called multi-share models across the country. The employer pays 30 percent of the cost; the employee 30 percent of the cost; and the community pays 40 percent of the cost, and this is how it looks.

In our community, to buy our product, it's going to cost you, as an employer, $46 a month. You will do a payroll deduction of another 46 from your employee. Very, very obviously affordable for a number of businesses and the individuals we've identified.

The community care comes from disproportionate share of hospital dollars that the state of Michigan allows us to use, and we have contracts with our individual hospitals that also allow us to use these dollars.

This is our co-payment schedule. We kept it very low-priced in terms of the PCP visits. We knew that we had a high degree of chronic care, chronic need out there. We say to our members we want to see you in the doctor's office within the first six months. We want to figure out what they have and we want to get involved.

We use a generic formulary drug program. If a member needs something other than a generic, than it's a 50-50 cost. If we have a member who cannot afford the 50-50 cost, we also work with them on that.

Reimbursement, for those of you who care, we reimburse our physicians at higher than the Medicaid. As a result of this, 97 percent of all the physicians in Muskegon County participate in our program, as well as both of our health systems. In fact, their network is wider under Access Health than is my commercial coverage.

I mentioned before the financing, the disproportionate share dollars. The way in which that works is we have a contract with Muskegon County under what's called the municipal health facilities

corporations act. That is a law in Michigan that allows counties to set up their own health plans.

The county contracts with us. We do intergovernmental transfers, attach the dish dollars. We are not considered to be insurance.

The profile of our members. I wanted to throw this in here. We have right now actually members who do not -- they really are fairly healthy. Unfortunately, their risk behavior is not so good, and they have awful habits. I'd like to bring the smokers here to Massachusetts, or at least to Boston.

At any rate, for us it's not enough just to create a financing model. As a member of my community-based board said, no matter how much insurance you have, you will never have enough insurance to pay for the total cost.

So one of the things we've had to do is of course focus in on some of the issues that we have embedded within this population. One of the ways we've done that is in my commercial coverage, I get a nice glossy book every quarter. It tells me to lose

weight, watch diabetes, that sort of thing.

In our case, our providers provide a treatment plan that goes over to our case management program. Within our case management program, we work with those members who are at high risk and high utilizers, and help them to connect with community resources.

We work with our community resources, for instance, Curves and some of the programs out there, to negotiate reduced rates for our members. At the bottom, the GVSU, Grand Valley State University, has a nursing school, and we now work with their School of Nursing, with their student nurses, who actually partner up with some of our members to help them in terms of managing their health risks.

We also developed our own software. We started off with third party administrators. We now manage our own claims. By managing our own claims, we were able to save a significant amount of money, and were able to pay our physicians within four to six weeks.

We are able to look at our data within two

weeks, which means that if we have somebody who is out there really utilizing and hitting those ERs, we are able to intervene earlier. So we're able to control utilization much better than you would in a commercial product, or at least what we think of as a commercial product.

Our impact. We serve about 1,500 people a year. That isn't huge, I understand. I'd love to have more money to be able to do more, but of course, as you get into challenges, part of the challenge is how do you get enough money to provide the subsidy that you need.

I've mentioned the 97 percent of all requisitions. We now believe we have 38 percent of market penetration of that tier of small businesses that we identified in our research at the front end, who now participate in our program.

2.3 million is generated annually directly back to health providers. When we began looking at the development of a program like this for our hospitals and our doctors, we were 100 percent at risk. These tended to be slow pay, no pay

individuals. We are now paying them fully for those services.

By doing that, we are creating more capacity within our safety nets for those folks who truly cannot afford anything. We've only had four percent cost inflation since 1999, and that's the whole thing. That isn't annually.

Nationally, there has been national legislation introduced to replicate programs of this type. Multi-shares are springing up across the country. I think as communities begin to look at the role they play in addressing the needs of the uninsured, there are programs now in Jacksonville, Florida and Rockford, Illinois and Huntington, West Virginia. There are programs under development in New Orleans and Galveston and many, many other places.

This is one of those interesting scenarios, where instead of there being a policy that sort of drops down to the communities, communities themselves have taken hold of issues and are now driving policy from the grassroots up.

I am a strong believer in the role of

communities in addressing issues like the uninsured. It certainly has worked in my community. That's how you reach me. I want to thank you for this opportunity again.

CHAIR JOHNSON: Well, thank you very much, both of you. I admire your presentations, because you get in a lot of words per minute. Not only that, they're full of content. So thank you.

MS. WOODBURY: Thank you.

CHAIR JOHNSON: If I can just start the questions, Trish. You're aware that our principle focus or a major difference between this working group and many commissions is that we're intending to listen to the American public. You talked a little bit about your experience.

Can you just share a couple of minutes of lessons learned, that you think would be helpful to us?

MS. RILEY: Well, I think the first lesson is it's very difficult to get to the American public. When you are talking about health reform, I think the experience in Maine, though a small state, is the

same.

You hold a meeting to hear from the public, and you hear from the usual stakeholders. Which is not to say they don't have a legitimate role.

But it's almost always the people who have an economic interest in the system, or are organized consumer advocates, who may not necessarily represent the whole purview of America -- the American people.

So I think that's the first challenge, is how do you get beyond the usual suspects. Not -- again, not to disparage their value. I think the Tough Choices thing gave us that, but it was extremely costly and very difficult.

We did a random sample survey of Maine people, and invited them to come to these forums. I suspect there was still some self-selection there, of the people who were interested. But it was a fairly diverse group of people, with very little information about health care.

I think that's the other challenge, is all of us have opinions, but understanding the health care system and the great black box, is another challenge.

But I do think surveys, the kinds of research about public opinion, if carefully done and carefully constructed, and efforts to really reach into the population and do these focus groups, and to go to sort of natural organizations of people, be it granges, like in Maine, or whatever community organizations there are, and try to get on their agenda.

So that you get a group of people who don't have necessarily an axe to grind or a particular set of issues to bring to you.

CHAIR JOHNSON: Aaron?

DR. SHIRLEY: Could you expand on how the FQHC fits into this overall plan?

MS. WOODBURY: The federally qualified health centers that we have in our community are capable of serving 20,000 uninsured people. Now with our population at Access Health, what we essentially did is we mainstreamed them into private provider offices. The FQHCs themselves, then, continued to work with the remainder of the safety net, in terms of guaranteeing them primary health care.

In Michigan, hospitals are non-profit, meaning that they need to take people. If the people appear, they have to take them. So we are able not only to give them good primary care, but to move them into hospital treatment as well.

Members can, in fact, if they want to, if they don't want to go to a private physician, if they already have a relationship with the federally-qualified health center, can elect to stay with that federally-qualified health center, as their primary care physician, also within our program.

DR. SHIRLEY: I want to bounce one off the wall. There was, on the slide, it said "Non-profits can participate?"

MS. WOODBURY: Yes.

DR. SHIRLEY: Could the FQHC participate? Is there a scenario in which it could participate?

MS. WOODBURY: To elect to purchase the program for their -- if they're located in our county and their median wage falls within our median wage standards, and they have not -- if they have not offered anything in the previous 12 months, yes, they

could. If they meet the standard, yes.

CHAIR JOHNSON: Montye.

MS. CONLAN: Ms. Woodbury, I'm an aquatic instructor, so I was very interested in that benefit.

MS. WOODBURY: Therapy.

MS. CONLAN: Which has a particular definition to me. I assume you're talking about aquatic exercise sort of people?

MS. WOODBURY: Yes, yes.

MS. CONLAN: So I was wondering, do you purchase memberships for people at the pool, or do you sponsor classes, and are these benefits utilized and what's the --

MS. WOODBURY: Yes, they are. I believe the discount we get is something like $7 to go in. It may even be lower. It's either four or seven dollars, and I wish I could remember exactly what it is. But yes, we set it up. They go in for aquatic exercise and they work with the therapists who are there.

MS. CONLAN: Oh, so it is actually there? So you have special classes for different populations?

MS. WOODBURY: Yes. They're already in existence, and we just add our members on to that. What we found, you know, when you set up something like this, you know, for instance, we have a very heavy community. Better than 66 percent of our community is significantly overweight. So people show up with all kinds of joint and pain problems.

Immediately, of course, it's like "I need a new joint," and for our position, it's like "First, you're going to need to lose some weight," and then we're going to see if we can manage some pain, and then we'll make an evaluation about that.

So aqua therapy has actually been a major, major piece of that. In our community, that's quite substantial.

MS. CONLAN: Good. I'm glad to hear that. Yes, it's good for chronic disease management, and also preventative care and I'm just a real advocate of it.

MS. WOODBURY: Yes. It's a wonderful program.

VICE CHAIR McLAUGHLIN: It's always nice

to hear somebody from Michigan, and you had mentioned the University of Michigan, so I'm very appreciative of that, especially in Harvard territory. I'm going to say that Harvard is just the University of Michigan of the east.

MR. HANSEN: Hey. The Red Sox were playing the Tigers last night. It was very quiet where I was.

(Laughter; simultaneous discussion.)

VICE CHAIR McLAUGHLIN: I have a question about state and local, in the sense that as Trish knows I, you know, have been involved in evaluating community initiatives for the past few years, and I'm well aware of a lot of initiatives, including the one that you're doing.

I think that some of -- on this commission, this committee, we are asked to make recommendations to the President and to the Congress, which implies some kind of federal government policy reform, change, something.

At the same time, we were asked to find out about state and local initiatives. So there is

this odd, you know, exchange of saying "Well, why are we listening to state and local initiatives, if we're recommending something to the federal government? What is the interconnection?"

Part of it, I think, is probably what both of you referred to as money, right. So the local initiatives that you talked about, Vondie, incenting the grassroots and bubbling up, the refrain is always "All health care is local." That's certainly true with delivery.

A lot of communities aren't going to have the aquatic, aquatherapy that you already have with therapists. They're not going to have some of the resources and same with Maine. Not every community is going to be the same.

But at the same time, all finance is not local, and you depend on dish dollars, which are state dollars.

So I'm asking you what have we learned from this that you would like us to hear, so that a year from now, when we make recommendations to the President and the Congress, I'm sure you don't want us

just to recommend that every local community do its own thing, because that's the way to go and just leave them alone, because you need the finance?

So what is that balance and that tension?

MS. WOODBURY: From my own perspective, I think it's a blend. I think that in the last ten years, there has been an enormous proliferation of community-based programs that address access and coverage, many of them very successful.

I would hope that you don't dump the babies and the bath water all out. There are enough of us out there, I think, who believe that that single bullet really isn't out there with a lot of -- without a lot of major change in terms of how, a sort of political will to get that done.

My hope is that whatever you recommend includes a blend of the best of communities, that the strong partnership of states and the ability to be innovative and creative. It's very interesting to me that, you know, when people invent things, we think always of business sector.

But in fact, in public policy, communities

across this nation are in the business of invention, and they've done it because they haven't had a whole lot of choices. Deal with what you've got and make it work.

I think out of that there have been some tremendously exciting programs and initiatives. I would hope that you would recommend that the Congress take a closer look at some of those. I think it would fit within a blend. I don't think there's any one silver bullet that solves this problem.

But I do think that it's a meeting of the minds between communities, states and the national government, to figure out what's the best way to do it.

MS. RILEY: I think there's a message about system reform, that you can't do this piecemeal. What we've created in this country is an extraordinarily complicated and fragmented system, riddled with medical error, riddled with inefficiencies, riddled with therefore costs.

We just completed a survey of our members, and it's abundantly clear that people have no idea

what their coverage is, in terms of, you know, the cost of high deductibles and what's covered and what isn't for themselves and their families.

These really cruel realities of families who thought they had a $5,000 deductible, only to find out it's for every member of the family, and they're paying significantly for it.

It's a monstrously complex system, with different standards sort of evolving by payor. I think there has to be some sense of what do we mean by cost containment and constraint? What do we mean by quality standards? It has to be sort of national discussion and a national determination.

The delivery system will always be localized, but the financing, I think, a shared financing is critical. I'm always reminded that there is truth to the notion of states as laboratories.

When you look, there has not been, as you well know, a lot of Congressional action on this issue for a long, long while. But when you look at what's happened, the states truly have been in the vanguard, putting their toe in the water and trying things.

They can't do it by themselves. But when you look at the sort of major reforms, whether you agree with them or not, HIPAA and the health insurance reform laws happened after the majority of the states had already enacted them.

The state children's health insurance program actually happened after the majority of states had enacted them. The patient's bill of rights discussed in Congress happened after states had enacted it.

I think that's an appropriate role for states working with their communities, to experiment. But the need for some simplicity, some standardization and some financing, I think, can't be underestimated.

VICE CHAIR McLAUGHLIN: Do you think the communities and states have experimented enough that we are ready to put together a recommendation to the federal government of okay, the states have already done this? You gave us several examples.

The states have already done this. So now enact it? Or is what you are saying that the

recommendation should be put some resources out there to let the states experiment, and maybe five years from now, we'll be ready for system-wide reform. I'm not sure where you're going there?

MS. RILEY: Well, I think I'm not going for more experimentation. I think, you know, at the risk of being Pollyanna, what we all know is America spends more on health care and gets less. It's got to end, and I think it's time for some solutions, and some serious financing. It's the --

VICE CHAIR McLAUGHLIN: But do we look at different states? I guess what's what I'm asking. Do you think there are things out there that have already demonstrated that they can do it?

MS. RILEY: Yes. There are things called Medicaid and Medicare that have demonstrated it. There are programs like Dirigo that are public-private partnerships. There are community programs, and I think it's hard enough to do this at a state level, and I don't want to underestimate how difficult it is to do a system reform aimed at this. It takes political will and it takes political skill, and it

takes stick-to-it-tiveness.

I think as Americans, we tend to like quick fixes, and it's hard to stay at something for the long haul. So either some sort of initiative that helps states test for the long haul.

But I think we've had -- every ten years we have a rage of experimentation in the states. It started in Massachusetts in the 80's. Well, actually it started in Hawaii, when Hawaii tried to reach everybody pre-ERISA, and in fact has done a pretty good job. Massachusetts, Minnesota Care, Oregon, Washington, Maine now.

I mean each -- there's been so much experimentation, and I think each experiment comes face to face with two realities. One is that you cannot look at access alone. You've got to look at the whole system, and two is states can't finance it alone. Cha-ching is the short answer.

VICE CHAIR McLAUGHLIN: Exactly. That's why I said I think what we tend to hear from local communities and states is basically what I want from the federal government is money.

MS. RILEY: Yes.

VICE CHAIR McLAUGHLIN: That's what we hear.

MS. RILEY: But I don't want --

VICE CHAIR McLAUGHLIN: We want to be able to design our own program, we want to be able to design what fits with us. We want the freedom to do what is right, but we want money from the federal government.

MS. RILEY: We want money, but I don't think you can expect money without some kind of accountability. So standardization of quality, standardization of data requirements, and some help in streamlining this extraordinarily complicated system.

You know, HIPAA tries to move us towards one claims form. Those are important efforts.

MS. WOODBURY: Simply creating another financing model isn't going to do it. At some point, you're always going to keep hitting that wall without some of these other measures, other measures incorporated.

CHAIR JOHNSON: Let me pick up on that, if

I may. I have a couple of questions, and the first one is not necessarily going to get at that subject, but I'd like you to address it, if you would. You talked about different levels of contributions and premiums and so forth.

To what extent in your program have you experienced adverse selections, where you have only the folks who need the coverage purchasing it, and the younger people who don't feel that they do, they don't purchase the coverage?

In the back of my mind, I'm thinking of what's the possibility of having, if not an association health plan, maybe a county health plan with uniform rules, given some of the uniformity that you talked about, Trish? But I'd like to ask you the question, Vondie.

MS. WOODBURY: Well, you know, any time you invent something, you don't know exactly what's going to happen when you jump off that dock. And yes, we did get adverse selection and where we saw it was in sole proprietors.

We believed, not correctly, that if we

simply established this program, that they'd all beat a -- you know, they'd beat a path to our door. Everybody would sign up. In fact, there is some -- there is a need. When you create something new to go out and you have to market and you have to get at your population. It took us a year to figure out we needed a salesman. We put a salesman on the ground.

But if we were looking -- you know, hey, we've done the right thing. This is great. But what we did learn was that of the 17 most expensive cases in our first year, 14 of them were sole proprietors, and what we found there were individuals who would go to a family doctor, and they were paying out of pocket and the doctor would say "Well, you need surgery. Go sign up for the county health plan and they'll pay for it."

So what we've had to do is step back from, and I notice with Dirigo too, you've had to put a ceiling on sole props, is instead work on the development of the broader community and the smaller businesses and the businesses who didn't necessarily beat a path to our door, but those that are just out

there, that you need to go out and reach and bring in.

So you create a healthier pool, and then you can open up again to sole props. We still cover sole props, but we have a limited period of time in which they can come in annually. Otherwise, our enrollment is open for other small businesses. That was probably the worst.

MS. RILEY: For us, because we went with an insurance model, it's fair to say insurance companies are risk-averse. So we spent a great deal of time in program design, to give them the level of confidence that they could take on this plan without killing themselves.

So we built into the program, for better or worse, protections against adverse selection. When you build an insurance model, this is what you do. In a state that has guaranteed issue and it has significant mandates and a strongly-regulated health insurance marketplace, we built into it a morbidity load for the first two years.

We built into it the limits. So from the beginning, we said we'd cover in the first year only

4,400 individuals and sole proprietors. In the second year, the cap goes away completely. But just enough to get the insurance company in, with the confidence that they needed to avoid it.

And we built into the program its own high risk group, internal to the Dirigo project. Already, there are a number of people in it, to manage the care of high risk people who are likely to come in early. At this point, it's much too early to tell.

But our experience in our plans is that to date we have not seen significant adverse selection. But it's very, very early to tell, six or seven months into the experience.

CHAIR JOHNSON: I'd like to follow that up with one more, if I could. We have heard about the description of a fragmented system, different rules here and there. Even some of us have experienced that, different rules which excludes us from this or coordination between Medicare and Medicaid has not been wonderful.

Last night we heard a lot of folks focusing on a single payor system. Share some of your

thoughts regarding a compromise between a single payor system which we don't have, and what we have today, and the compromise might look like a uniform set of rules on a nationwide basis, that health plans could follow.

They would be, maybe for Medicaid and Medicare, there would be uniform rules there, and for health insurance plans, across state lines, there would be uniform rules there, and just asking to explore that with you. That's not a proposal.

But what would be the upsides and the downsides to those kinds of approaches?

MS. RILEY: We actually think Dirigo is the middle road for just that. During the gubernatorial debate, when Governor Baldacci proposed Dirigo, there was an independent candidate who was a supporter of single payor, and single payor has passed referendum in the City of Portland. It's got legs in Maine.

There was also a marketplace proposal. We took the middle road and said "Our goal is universal coverage, but we want to do it through the small

group, build on small groups, keep the notion of employer coverage." It's for better or worse, how we created our system in this country.

So build on it and support employers' capacity to pay for care. That is sort of the Dirigo approach. I think at a national level it is an approach that could work.

Implicit in your statement is the sense of association health plans, and I think those of us who come from states that have strong regulation of insurance markets and believe in them, we worried about association health plans, in that they are a retreat from regulation.

So I think there's always got to be a consumer protection perspective on any kind of simplicity.

The other thing that the Dirigo program does is it does build on Medicaid. Because as we all know, if you're on Medicaid and work, which most of working age people on Medicaid do, if you get a few more hours at work or a pay raise of a dollar, you lose coverage all together.

So it doesn't have an incentive for work in it. We built Dirigo on top of it, as I think you have as well.

MS. WOODBURY: Yes.

MS. RILEY: We built Dirigo on top of it to eliminate the cliff. So if you're on Medicaid you can be in Dirigo. If you get a pay increase or take more hours, you go into the next tier of discounts.

So you have to pay, but you have to pay at a fairly low rate. That's not -- that was intended to sort of build on the Medicaid program. I think that -- any kind of national reform would have to do that.

CHAIR JOHNSON: Other questions, comments? Yes, Montye.

MS. CONLAN: I like what you're saying about the coordination, federal, state, local communities. I was wondering if you think about maybe going down even to a micro level, for this reason.

I work a lot in a volunteer capacity, and since in my community there's been such a lack of services, I just decided to go out and create my own. Aquatic program, exercise programs, and I was going

to ask this to the last panel and they're not here, but I'll say it anyway. A support group which provides some therapeutic and emotional support to chronically ill patients.

Yet I'm out there all by myself. I'm always trying to, you know, partner. I've approached a local HMO. Hey, let's work together. I'll let your members in and maybe you can help me. But there's never any -- and yet I have certified instructors. It's not a question of lack of professionalism.

So have you made any movement towards going down to that level, to partner with volunteer organizations or grassroots organizations?

MS. RILEY: Our plan, because it's an insurance model, it does have an array of therapies and preventive services in it as part of our requirement. Because it is sort of a traditional insurance model, it contracts with local providers as it sees fit.

We do in our state have planning activities, though, as we try to build Maine to be the healthiest state, have a number of initiatives to

support local peer supports and those kind of initiatives to make Maine the healthiest state working.

When we proposed Dirigo, we also tried to use our tobacco money by putting a constitutional amendment in place, to make certain that it was never spent on anything except public health.

We have been absolute in continuing our investment of the tobacco money into local public health infrastructures that are volunteer, the Healthy Maine Communities and initiatives all across the state that are volunteer-driven, and very much directed at those kinds of activities.

As we approach the state health plan, we're trying to create some kind of formalized system that gets resources to those entities without bureaucratizing them. That's going to be an interesting struggle, but it's an important initiative, to build on those community resources.

MS. CONLAN: So do those volunteer groups apply for grants, or how to do they access that?

MS. RILEY: They do everything. I mean

they're phenomenal. They do apply for grants. They are part of the fund for Healthy Maine, which is our tobacco funding. They get some other health fund of some type. A lot of community fund-raising. Maine is still a state of communities where bake sales and local businesses support these kinds of initiatives, and they're very creative and very entrepreneurial, and they would be the first to tell you, and very under-funded.

The way we've approached it is that we have a community really of collaboratives, whether it's diabetes or oral health or a variety of issues that are important, and identify, self-identified by members of our community. Our collaboratives come together, decide how they want to address a need, and then our job as the health project is to help them find the money and the sustainability to bring those things to fruition.

When we started, for instance, we had one operator in the community for low income folks for oral health. Today, we have 20. I think what we've tried to do is to take that volunteer motivation and

their vision for what's necessary in a community, really keeping it as grassroots as possible, and to use that, then, for the ability to build new programs and new capacity within the community.

We do groups like -- we do diabetes support groups, based on the Stanford model. We work very closely with public health, with their smoking cessation program. I mean, the other thing we've done also is to create a single door enrollment structure through the Health Project, where people come to us.

We will screen them to see what they're eligible for. If they have a compelling problem, then we'll see that they get to where they can get that help. That's also helped, in terms of breaking down some of the structures. They don't have to go to a government office to do that. They can come to us.

CHAIR JOHNSON: Well, Vondie and Trish, thank you very much for your comments. Before we close, do you have any final thoughts that you wish you would have had an opportunity to share, but haven't so far, just briefly? Let me start with you, Trish.

MS. RILEY: I would just commend the work that you're about. It's an enormous undertaking, and just beg you to be bold.

CHAIR JOHNSON: Thank you.

MS. WOODBURY: I would certainly echo that. You've got a tremendous burden on your shoulders, but at the same time, I think that the opportunity to even come and present, so that you know what's going on, is very helpful to all of us. It's good to know that something has happened and is happening, and I wish you well on it.

But I would restate, please don't forget communities in your equation. If it's all about government, having run all over this country and talked to many, many communities, sometimes the perception of people isn't that government does it necessarily the best. So some blending of the two, I think, is very important.

CHAIR JOHNSON: Well, thank you very much for your comments. We'll adjourn for ten minutes, and come back for our third panel of the morning.

(Whereupon, a short recess was taken.)

CHAIR JOHNSON: As we begin our third panel for the morning, we're pleased to have Ira Byock, Nicholas Christakis, and Joanne Lynn with us.

Nicholas is a professor of the Department of Health and Peer Policy in the Harvard Medical School, and also in the Department of Sociology at Harvard University. And he is an attending physician, in the palliative medicine program at Massachusetts General Hospital.

Joanne Lynn is a geriatrician and the Director of Washington Home Center for Palliative Care Studies and a senior researcher at Rand.

And Ira is the Director of Palliative Care at Palliative Medicine at Dartmouth University, Dartmouth-Hitchcock Medical Center.

So we're delighted you're here. We'll just briefly mention to you that we'd like to ask you to do speak for up to 12 minutes or so. Our rich time is typically the questions and answers that we have following your presentations.

So when you get to about 11 minutes, I'm going to put this up. That will be kind of a signal

to you and a request that you wrap up your thoughts. But understand that we'll have opportunities in the Q and A period.

Ira, looks like your presentation's on the screen, so why don't we begin with you?

DR. BYOCK: Thank you. Thank you, Randy, and all of you who are serving on this panel, and thanks for including palliative and end of life care in your subject matter.

As my title suggests, we are standing at a time of a real crisis that surrounds the way we care for people, and the way we die in America. The Chinese character for crisis is made up of danger and opportunity.

The dangers are well apparent to those who are seriously ill, themselves or their family members, and are moving through the health care system in America. People who are seriously ill have -- reasonably expect that routine assessment and competent management of pain and other sources of physical distress is simply part of the deal when you go to a reputable medical center or a respected

doctor's office.

That communication about your illness, your treatment options will be clear and complete and honest, and spoken in words that you can understand; that people's preferences for care will be respected when they're spoken by the person or documented in an advance directive or by their legal proxy or close family member.

That because this is a serious illness, care will be coordinated between visits and among the various providers who are contributing to the person's care. That crisis prevention and early crisis management will be a specific portion of every person's individualized patient-centered plan of care.

And of course, that staffing levels for nurses and nurse's aides in our hospitals and nursing homes will at least be at a safe and prudent level, and finally that families will be supported in their care-giving and in their grief.

In fact, however, reasonable as these expectations are, we're constantly reminded that they're not easily met, that those of us who are

clinicians see patients day in and day out are struggling with them, to provide for those reasonable expectations.

The *New York Times* has done a wonderful job recently of highlighting some of the challenges that even people with advanced degrees and real sophistication in advocacy find often feeling adrift in our health care system.

When you look at how people die, the Institute of Medicine really charged us several years ago with these conclusions. Too many people suffer needlessly at the end of life, both from errors of omission and errors of commission; that legal, organizational and economic obstacles conspire to obstruct reliably excellent care at the end of life; that if the education and training of our physicians and other health care professionals fail to provide them with the attitude, knowledge and skills required to care well for the dying person.

Again, just two weeks ago, the *New York Times Magazine* put a human face on this problem, with a stunning article that really captures the confused

and conflicted state of affairs that dying has become in America today.

Our cultural orientation seems to leave no place for the good death. Indeed, I'll assert sort of a conclusion as we go forward, that this is not just my job or our job as clinicians; that it is all our jobs and whatever role we play in society, in our professions, but also in our community life, to find a way to reframe this last chapter of human life in a way that provides constructive, culturally resonant and achievable goals.

That's really the challenge that we have. We'd better get going, because in fact these may be the good old days. Though we're at a stage of crisis, there's no reason to believe that without serious attention it's going to get better. In fact, it may well get worse.

The baby boomers are aging, all 75 million of us, and we want the best care possible. But we're going to stress the system that is already stressed. As we've been growing up, I was born in 1951, we've had smaller families.

We've lived at a distance from our families of origin, and many of us are living in two jobs, some of us in three and four job couples just to make ends meet, pay that damn college tuition, and pay for health care.

Those of us with children are the lucky ones. Many boomers in fact will face old age alone. What's going to happen to them? In fact, we know that nearly half of Americans will at least pass through. Many of us will die in nursing homes today. Something around 30 to 40 percent of people die in nursing homes today.

It's a chilling thought for many Americans. In fact, nursing homes, being in a nursing home often comes close to the top of the list of the things that people worry about most when they look to the future. You know that as well as I do.

Who will care for people in our long-term care? It's hard to get staffing today. Why? Well often because we're not paying a living wage to nurse's aides and home health workers and the like. This federal study was part of a series of studies.

Some of them showed that thousands upon thousands of Americans in nursing homes today are literally malnourished, not because they don't want to eat or are refusing food; not because they can't eat, but because they need help in eating from nurse's aides, who often are tasked with helping 15 or so people at meal time.

It's a national disgrace, and in fact the trends are that it's likely to get worse, because in fact the aides and nursing population is aging right along with us boomers, and not being replenished by young recruits to this profession.

So it's no wonder as the *USA Today* opined on its editorial page a few years ago, that people are thinking about suicide. Kevorkian shown here, speaking to a prospective client. "You have a condition that will cause prolonged suffering?" "Yes. My children are putting me in a nursing home." It's hardly funny.

But in fact, I've lost count of people who said to me "Doc, I'd rather get shot than go into a nursing home." They said it to CBS News a couple of

years ago as well. Eighty-three percent of elderly Americans said that they would stay in their homes if they could. Thirty percent said that they would rather die than go to a nursing home.

Remind me which is it we're interested in? Assisted care or assisted suicide? Again, it's not really funny. My mom sent me this front page of an Orange County edition of the *Los Angeles Times*. She was a resident at Leisure World in Orange County. She called it Wrinkle Village.

This was -- their company was down selling the latest edition of its perennial best-seller, *Final Exit*, a little how-to manual on suicide. Just this lady is asking him a question. Look at the left. It says "Orange County seniors here. Tips on final exit." On the right "Medicare outpatient cost cuts to be sought." You think there's no connection in the public psyche.

So we're at a point of crisis. We've looked at some of the dangers just barely. What are the opportunities? We say, as we go forward, since I only have a few minutes and I know I'm giving you this

sort of view from 60,000 feet.

This is one crisis that needn't exist. This is one crisis that we can solve. I can't solve urban violence or poverty or all sorts of other environmental issues. This one need not exist. There is already plenty of money in the system to take excellent care of people through the end of life. Don't believe otherwise.

We're going to talk about palliative care, and people often say "Well, what's the difference between palliative care and hospice?" In America, palliative care grew from a base of hospice. Hospice started as an alternative, sort of a countercultural model to -- a response to bad dying, mostly in hospitals, often alone, often really in, you know, terrible circumstances.

Palliative care has innovated from that hospice model in America, has matured, and is now on its way to being a full ABMS recognized and certified specialty. It's a team sport. My definition of palliative care is this: It is interdisciplinary care for people with life-threatening illnesses or

injuries, that address their physical, emotional, social and spiritual needs, and improve the quality of their life, like the ill person with his or her family.

It really is that when you get people in a room, it's not just multidisciplinary; it's interdisciplinary, because when they're in the same room, creativity happens, true collaboration happens, and the plan of care is more than the sum of its parts. I can't, again, emphasize that enough.

What we're laden with at the present time in mainstream health care is this sequential either/or model. You know, we'll work for a cure at all costs, until you absolutely refuse to have anything else or until there is literally nothing we can offer, and then we'll send you to hospice, where we say "You're going to love these people. They're going to take great care of you."

But of course you've never met them, and hospice has been divided from cure so it ever more strongly is associated with death. Death remains a hard sell, and it doesn't get easier as people get

sicker. This is the clinical work I do day in and day out. People don't want the deal until they get it. They don't want to give up anything that might be associated with living longer.

When they come to hospice, they do love it. What we're moving toward, many of us are working to integrate palliative care within mainstream health care. I'm not going to talk much about our work at Dartmouth, but it's amazing the receptivity and how well it works.

What I want to talk to you about is a project I've directed for seven years with the Robert Wood Johnson Foundation, that attempted to integrate palliative care within mainstream health care, without this either/or, you know, requirement to give up something.

We've built 22 -- I didn't build them; the grantee's remarkable researchers and clinicians built 22 innovative models, integrating palliative care within the mainstream health care of seriously ill people with cancer, with end stage renal disease, children in tertiary care hospitals.

It went on and on. Rural communities, isolated inner cities. Look at the array of specific services that go into this phrase "palliative care." In a health care system, when you're often feeling lost and overwhelmed even by the information and autonomy you've now been given, having somebody to walk with you and coordinate this care, to provide anticipatory guidance, a term I borrowed from pediatrics, to help you through these inherently difficult but normal stages of life, have been invaluable.

At promotingexcellence.org, and in two of the monographs I've given you, we suggest that when you actually do accurate accounting, what we have found across these 22 programs is that it's not necessary to withhold hospice and palliative care until people are at the brink of death.

In fact, it's counterproductive, that providing access to those services that I just showed improves measurably quality of care, and costs don't rise; they actually fall. How could that be? Because people stay home more often. You don't have to

require them to stay home.

But the area under the curve of hospital use across these programs consistently fell by about a quarter to a third. There are monographs on the Promoting Excellence website to explore. The Blue Cross monograph in the middle there talks about how this looks from private insurers.

There's also a content manual, monographs for clinicians, looking at the application of palliative care within mainstream health care for various disease populations.

I want to -- before I close, I have to say, though, that as hard and as unwanted as dying is, it's not without its value. This time of life should not be considered to be wasted. Alleviation of symptoms and suffering are our first priorities in palliative care, but they are not our ultimate goals.

In fact, this time, as unwanted as it is, has remarkable inherent opportunities, opportunities to communicate with one another sad feelings, the bad news of this diagnosis and the fact that life and relationships will soon end.

To complete affairs. It's not only fiscal and legal affairs, but also to leave nothing important left unsaid between, you know, family. I'm caring for a fellow right now who has two divorces, two stepchildren. He hasn't spoken to either of them, and now he's got esophageal cancer and is dying probably within the next few weeks.

He thought they didn't care, but the first get well card he got was from his stepdaughter from a previous marriage. He realized there's work to be done, things that matter to him, and obviously matter to her.

To resolve previously strained relationships, perhaps between a previous spouse, perhaps between a brother you haven't spoken with for years or with your father, who you haven't spoken to in decades.

To grieve together the impending loss of life and relationship; to review life; to tell one's stories. I encourage people to record those stories, because they become heirlooms for family, being passed on for generations often.

In various ways, to explore that sense of meaning and purpose, which is part of the human experience. Whether somebody is religious or believes in God or not, they have a sense of something that is larger than themselves, to which they are connected, and is a source of meaning.

I teach people frequently. I don't tell them they have to, but I suggest, as I did to this gentleman I just mentioned with esophageal cancer, 48 years old, that before any of his relationships are complete, he may consider the value of saying four things that I learned from people throughout my years.

Please forgive me, I forgive you, because there's not been a perfect relationship in the history of humankind. Even the most close and loving relationships often have histories of misunderstandings, hurt feelings. It's normal. Please forgive me, I forgive you, thank you, and I love you. That's sort of stating the obvious, the "thank you" and "I love you."

Just last week I had a family meeting. The mom just had a stroke. She was in another room.

Family meeting with siblings in their 40's. The son, when I said, talked about the value they might find in saying the four things said "Oh mom knows how much we love her. She knows how much we appreciate her."

My comeback was "Well good. Then it will be really easy for you to get in there and tell her." Because often people die and those things haven't been said and aren't understood.

Families want basically to have the best care possible. They want to know that the person they're losing has gotten the best curative care, but also the best palliative care, care for comfort and quality of life.

They want to feel that their preferences have been followed. They want to know that the person who has died was treated in a dignified manner, that their inherent dignity was reflected in the care they received.

They want a chance to say and do the things that matter most, and say the things that would be left unsaid. Beyond comfort and cleanliness and dignity, they want to have a chance to honor and

celebrate the person in his or her passing, and a chance to grieve together.

So before closing, let me -- we can come back to this, but I think there's a lot of things that public policy can't do. But there are a number of things that public policy can do.

It can ensure adequate staffing and adequate training; foster and encourage innovation; decrease barriers to things like pain prescribing when people are seriously ill. Public policy can eliminate that either/or barrier, that terrible choice that people face.

We can insist on accurate cost accounting and honestly, the cost accounting monograph is dry but it's compelling as to the shell games that often are played. We need to raise consumer and citizen expectations, encourage not only professional but community-based responses, and model in our clinical work, but also in all of our professional work, a cultural maturation that includes a healthy conclusion to life. Thanks very much.

CHAIR JOHNSON: Thank you, Ira. Very

thoughtful comments and we appreciate them, close to many of us in the Working Group. I don't have, and I'm assuming the rest of our group doesn't have your presentation. But we'd like to get it, and each of us do have the two monographs you talked about. We appreciate your distributing those.

DR. BYOCK: That will be taken care of.

CHAIR JOHNSON: Good. Thank you. Okay. Andy, do we have another presentation, or are we just talking about --

MR. ROCK: I think the next presenter does not have --

DR. CHRISTAKIS: Yes. I'm just going to speak from notes. I do realize that precisely the nature of the group I was speaking to, and there was one slide that I'm regretting not bringing, but I'll try to give you a visual --

MR. ROCK: Send it to us here, and we'll put it on the web.

DR. CHRISTAKIS: Yes. So just to refresh your memory, I'm a physician who takes care of people who are dying. I'm a palliative medicine or hospice

doctor. I used to do outpatient care, taking care of people who were dying in the south side of Chicago.

I had a very split practice. A third of my practice was very well-to-do, highly educated, University of Chicago faculty, and the remaining two-thirds were primarily African-American, very poor people who were dying at home.

So I would go to their homes on Saturday afternoons and take care of these two populations. Now, since I've moved to Harvard, the last four years I've been at MGH, doing inpatient consult palliative care, taking care of people who are dying in the hospital.

But most of job consists of doing research. I'd like to give you a little feel today for some findings that I think may be pertinent to the deliberations of this committee, that emerged from the work of a broad group of people, one of whom is at the other end of the table, and some of the work I have done, which I think can maybe help you as you think about some of these problems.

So I'd like to start by giving just a very

quick, what I'd like to call, "report card" on terminal care in the United States. I'm going to highlight five features that we've done some work on, to try to clarify "Well, what is public sentiment regarding the importance of these aspects of a good death?"

For example, being free of pain. What fraction of Americans think being free of pain is an important part of a good death? Well, not surprisingly, 93 percent of Americans think that being free of pain is a very important part of a good death.

What fraction of Americans, might I ask you, do you think achieve this objective? There have been many studies looking at this, but to make a very long story short, about 30 to 50 percent of Americans have a death that's free of pain.

So 40 to 70 percent of Americans, depending on the population and the study and the sample and the era, etc. die in pain, which is ridiculous. It's totally ridiculous. I can tell you that even in my own hospital, even at "Man's Greatest Hospital," MGH, people die in pain, and it's really

unnecessary.

Now I can also tell you, even in the four years that I've been there, things have changed. I personally, anecdotally, have noticed improvements in the care that's given to the dying.

Nevertheless, a substantial fraction of Americans die in pain. Interestingly, not being a burden to family was identified in one of our surveys as being a very important part of a good death. 89 percent of Americans say not burdening family members is an important part of a good death.

Now I think this is almost a quintessentially American virtue. I mean, if you're not going to burden family when you're dying, when are you going to burden your family? But the fact that Americans nevertheless identified this as an important part of their own good death I think is really telling. I'll come back in just a little bit to some work we've done, looking at ameliorating family burden during the process of dying.

So what fraction of Americans is able to achieve the objective of not burdening family? 89

percent say they want not to burden their family as part of a good death. Well, about 45 percent of Americans are able to die without burdening their family.

The majority of Americans impose a significant burden, defined in various ways, on family members while they're dying. Someone quits their job, the family loses all of its life savings in the course of caring for the person who's dying, or other similar burdens.

Having a doctor who listens. Ninety-five percent of Americans say this is a very important part of a good death. Various surveys explore what fraction of Americans has a doctor who listens. Thirty to forty-five percent of Americans have a doctor who, by various metrics, listens to them during the course of their terminal care.

Dying at home. This is actually sort of controversial, but different studies showed different things. I want to pick one number. We can debate it if you're interested. What fraction of Americans views dying at home as an important part of a good

death? Seventy percent of Americans think dying at home is an important part of a good death.

But there's a lot of variation in this, and actually there's debate. It's very sensitive to how you ask the question and what you mean by dying, and which moment in the life.

Nevertheless, more than half of Americans, by whatever metric, think it's very important to die at home, but only 15 percent of Americans die at home.

Finally, knowing what to expect, what a fraction of Americans think knowing what to expect is an important part of a good death, 96 percent think it's very important.

What fraction of Americans actually knows what to expect near the time of their death? About 15 percent know what to expect, have adequate prognostic information in various ways that I would deem adequate.

So being free of pain, not being a burden to family, having a doctor who listens, dying at home and knowing what to expect, virtually most Americans want these things. There are many other things they

want too, by the way.

We could provide you with a paper that James Tulsky, Karen Steinhauser and others and I wrote, on how to define a good death and how this varies across populations within the United States, published in *JAMA*.

That defines this and many other attributes of a good death. Like I just summarized, we're not doing very well in achieving these objectives in our society. Many of these objectives, just as Ira suggested, could be achieved without tremendous expenditures of new resources.

Now I mentioned this business of pain management, most Americans dying in pain. We do know a little bit about what are some of the risk factors for dying in pain, and there's just another huge body of literature as well. I'm going to sort of speak very telegraphically about this.

But one study showed, for example, that the following kinds of things were risk factors for dying in pain. Being a woman increases the probability, after adjusting for other factors, of

dying in pain.

Being older. So the older you are, the less likely you are to have adequate pain treatment near the end of your life, and this could be for a variety of reasons.

Having -- paradoxically -- a good performance status, being in better physical shape near the end of life, is a risk factor for having less adequate treatment of your pain, for various reasons, both on the patient side and on the provider side.

Having a discrepancy -- this is described by the investigators -- a patient-physician discrepancy, in pain severity. That means if the doctor doesn't believe you when you say you're in pain, you're less likely to be adequately treated, in fact, for your pain.

If the cause of your pain is not the cancer, you are more likely to die in pain, and this is actually a point worth highlighting -- only about a third of Americans die of cancer. Most Americans die of things other than cancer, and yet we're much more willing to believe that people are in pain when they

have cancer than when they have non-cancer diseases.

So if you're dying of something other than cancer and you're having as much pain as someone who has cancer, you're much less likely to be believed that you are having that kind of pain. So there are a variety of possible risk factors.

Now I mentioned, I'd like to move on, then, to this business of site of death in the United States. I told you that 15 percent of Americans die at home. Well, what are some of the determinants of whether someone is able to achieve the objective of dying at home?

Research by the SUPPORT investigators and others has looked at this in various ways. Just to summarize, again from sort of fairly broad literature, it seems that patient preferences don't seem to matter in whether you die at home.

That is to say, whether someone really wants to die at home or kind of wants to die at home or really doesn't want to die at home, regardless of their own taste, they'd get one standard widget, you know, whatever the government delivers is what they

get.

So their own tastes seem not to explain a lot of the variation on whether they're able to achieve their desires, okay. So patient preference is seen not to affect what happens to patients in this aspect of care near the end of life.

But there are some other things that do matter. One of the things that matters is the regional bed supply, the number of hospital beds that are per capita in the area where you happen to live.

The more hospital beds there are per capita in the area you happen to live, the lower your chances of dying at home, okay. So it's like if there are hospital beds, there's just this giant sucking sound. This takes the patients away from dying at home and kind of fills them, puts them in hospital beds.

This factor is what we call exogenous to the patient. The patient doesn't influence the number of hospital beds around them. It really shouldn't be a factor that affects whether you realize your own tastes, okay.

Another thing which is a policy lever which does affect whether patients are able to die at home or not is hospice spending. So each additional $10 per beneficiary yields a 2.8 percent decrease in hospital death. That is to say, the more money we spend in the area on hospice care, the more likely you are to be able to die at home.

In fact, there's tremendous variation by geography in a whole host of things. This work was initiated at Dartmouth years ago. A lot of the classic work on end of life care and regional variation has been done by my colleague over on my left [Dr. Lynn].

I'm going to just highlight one finding, a little study that we did, which this is the one slide I wish I had brought, a map of the United States that showed percentage of people -- it's like market penetration for hospice care.

The fraction of people who die in each county, that die while under hospice care, okay. So people die in every county. There are a thousand people that die in this county, a thousand people that

die in this county, a thousand people that die in that county. What fraction of these dead people get hospice care, zero percent, ten percent, 30 percent? And this varies from place to place around the country.

In fact, it does vary tremendously. You can outline the state of Indiana on our map by the lack of use of hospice. It's like two percent or less of the people in almost every county in Indiana who die in that county get hospice care.

On the other hand, there are some counties in Florida where 40 percent of the people who die in that county get hospice care, okay. So tremendous variation, from neighborhood to neighborhood, from place to place around the country, in who gets hospice care, in the market penetration, as it were.

And a variety of things. Researchers have looked at this, including my group, at what explains this variation, and there are a whole host of factors we could discuss if you're interested, having to do with the kinds of patients in those counties, the kinds of doctors, the kinds of health care

institutions and the like.

But the reason this is interesting is that these kinds of small area studies serve several functions. One, it's sort of interrogatory, like why is this occurring? Another is sort of aspirational. Gee, I'm in Indiana. None of my patients is getting hospice care, but right across the border in Kentucky, it's littered with counties where 40 percent of the people get hospice care.

You know, there's not a lot of difference between us and the people next door, you know. Can't we do better? That, in fact, is our objective. So there are a lot of purposes to looking at the smaller area variation.

I was going to outline some of the advantages of hospice care. But there's been a long tradition of research looking at comparing hospice care to non-hospice care at the end of life, debates about the precise philosophy.

I think Ira's definition of hospice care was terrific, or hospice and palliative care. The question is, if we provide this high quality end of

life care to patients, does it matter? When we say "does it matter," what are we measuring exactly?

Are we measuring the patient's satisfaction? Are we measuring the patient's quality of life, whether they're free of pain? Are we measuring are they more likely to die at home if they get hospice care? Are we measuring burden on caregivers if they get hospice care compared to conventional care?

Basically, the answer to all of those things is that patients do better when they get hospice care. They are more likely to die free of pain. They're more likely to achieve their preferences for dying at home. They're more likely to impose less burden on family caregivers and the like.

These are sort of fairly well-documented advantages of hospice-type palliative care at the end of life.

I'm going to close with remarks on two other kinds of studies that I've been engaged in the last ten years. One group of studies has been looking at how illness or death in me, or health care use

delivered to me, affects illness or death or health care use in my spouse, okay. And I'll use my spouse as a proxy for some people who love me.

It doesn't have to be my spouse. But I'm just going to talk about heterosexual married couples for a moment, but these findings could be generalized to non-heterosexual couples, non-married couples, siblings and the like.

We did one study which tested the hypothesis that hospice use by a patient attenuates the adverse impact of bereavement on the health status, and specifically the mortality, of surviving spouses, compared to spouses of patients who died while not using hospice.

What do I mean by that? I mean that we know that if I die, my wife's risk of death increases after my death. The question is if you give me a good death, as compared to a bad death, can you reduce my wife's probability of dying after I die? If you take better care of me, does my wife live longer?

The answer is yes. We did a study looking at 200,000 couples, and using a variety of

sophisticated statistical tools, and we found that if you looked at a group of husbands who had died, and they could die with hospice care or without hospice care, and now they look at what fraction of their wives are dead 18 months later, we found that wives of husbands who died without hospice care, 6.2 percent of them were dead 18 months later. But wives of husbands who got good care at the end of life, 4.9 percent are dead a year later.

So we can save one in 200 women's' lives by taking better care of their husbands, when the husband is dying, okay. So this has implications for caregivers, by taking better care at the end of life.

The other thing that I spent a lot of time looking at over the last ten years has been this topic of prognostication, and there's lots of debates in this area as well, about the ability of doctors to prognosticate, the utility of prognostic information, the permissibility, the tastes, and so forth.

But I'm just going to give you a little kind of, you know, kind of flavor of some of the stuff that interests me.

Here's a testimonial from a patient. Here's what a patient said regarding her care near the end of life, or actually the patient's spouse. She said "The Thursday before my husband died, I thought he was dying, and he thought he was dying. But the doctor was talking about aggressive chemotherapy.

"I asked if this was palliative, and he said that he still hoped for a cure. But my husband died three days later. I was with him at the time of his death, but the room was filled with eight other people, hanging bags of blood and monitoring vital signs.

"It was about as horrifying as anything that could have happened. I don't think the doctors were trying to mislead us. They thought he might be the one case that would have a positive outcome.

"But if I had been told the truth, we could have spent days with the children together, not filled with painful regimens in the hospital."

Now to my eye, the problem in this case, and in so many others like it, is entirely prognostic. In our rush not to abandon patients therapeutically

near the end of life, we typically abandon them prognostically. There is a serious problem, in my opinion, with the state of the art or the state of the science when it comes to formulating prognoses, not communicating them.

I need to stress this distinction. It's often misunderstood. I'm not talking right now about the problem of how doctors tell patients bad news, which is a huge problem. I'm talking about the problem of how doctors, in their own minds, come to formulate well-balanced, scientifically sound prognoses about what's likely to happen.

Because doing this is required to deliver good care at the end of life, in my opinion. Knowing whether the patient before you is going to die or not is really important. I can't tell you how many patients at MGH I'm consulted to see. I go in and I come out and I talk to the junior doctors in training.

I say "Mrs. Jones is dying." They're looking at me "Really?" I'm like "Yes. Mrs. Jones is dying." It's what it looks like. It's amazing to me. You know, this is at our lead hospital. So this is a

problem, okay, helping people to understand and recognize death is part of what I mean when I talk about prognostication.

So just to summarize what I've said. You've seen that the quality of death in America is poor; that this poor quality varies in discernible ways; that improving care of the dying will not be easy; that hospice care is favorably regarded but poorly used. I actually didn't show you data on that.

That numerous barriers to good palliative care exist. Ira highlighted some of those, and that prognostic inaccuracy is a significant problem. So Americans die needlessly badly, and they do so despite the fact that number one, they do not want to.

Number two, we spend $70 billion every year caring for people in the last year of life, and number three, every one of us eventually experiences the outcome we've been talking about, and so we should have some stake in improving this state of affairs. It's not like that marginal group over there has this problem, and we don't have to worry about it.

You would think everyone would have a

political interest in improving the care of the dying in our society. It is fashionable to speak about vulnerable populations in medicine, but it is hard for me to imagine a more vulnerable sector of our society than those who are dying.

I regard the terminally ill as a paradigmatically vulnerable group, deserving of our care, and the best possible research and policy to enhance the quality of their remaining life. Thank you.

CHAIR JOHNSON: Thank you, Nick. Joanne.

DR. LYNN: Would you like to -- while he's coming to put my slide on, I'm just going to do a quick quiz. How many people here expect to die?

(Laughter.)

DR. LYNN: I expect that chuckle and the slow anger.

(Laughter.)

DR. LYNN: How many expect to die? That's easy. No chuckle. How many people here all things considered, would just as soon have cancer? Anyone?

How many, all things considered, would

just as soon have heart or lung disease? Got a few votes for that. Everybody else gets frailty and dementia.

(Laughter.)

DR. LYNN: The hardest thing to get across to people is you don't get a choice of none. It's not really an available option.

(Simultaneous discussion.)

DR. LYNN: So why should this group focus on end of life care? Because it's big, bad and ugly. It is huge. It is probably the case that about a third of the lifetime expenses and most of the avoidable suffering happens in your last phase of life. While you are living with the illnesses, they're usually plural, that will take your life.

It is bad, and people have already spoken to some of just how bad it is. It's unreliable. Everybody knows that. If you hear somebody tell a story about a very good dying, you'll hear the family members saying "Weren't we lucky?"

I am dedicated to the proposition, and you should be too, that American health care doesn't have

to depend on luck to get you out of life in a decent way. It ought to be able to be done every time, over and over again, good, supportive services right through to the end that you can count on.

It's ugly. Nobody else will talk about this. We all want to talk about preventing illness. We all want to talk about cures. We all want to talk about how we're going to reduce costs and shake off disability. By golly, you know, everybody, no matter how much prevention you do, no matter how much good living you do, you still get sick and die.

Mostly now we get sick and die in old age, with illnesses that cause serious long-term illness. The opportunity to fall off a cliff, like a lemming, is just about gone. American medicine and the way we live have made the major success being the opportunity to live longer with a bad disease.

Things that used to kill you at 50, now you get to live with for 30 years and die with slowly. It's a very good thing. I mean, I'm not fond of people dying at 45. But it's a very different thing. This is one of my favorite cartoons. "Do you have

anything that will stop the aging process?" "Sure. Which illness would you like?"

Again, it's the hardest thing for us to come to terms with, is that you do not have the choice of just checking out and evaporating. You're going to have a bad disease. Eighty-three percent of us now die in Medicare; nine out of ten have heart disease, lung disease, cancer, stroke or dementia.

None of those are illnesses that let you off the hook easy. If you want easy, go back to dying of pneumonia at 42. Go back to industrial accident, go back to childbirth fever. If you want easy, it's young. It's not these illnesses.

The big reason we do it badly is we've never been here before. A hundred years ago, look at this. People died in mid-life. They died suddenly. They died with almost no expenses. There was almost no opportunity to be in the health care system.

The big exceptions were tuberculosis and mental illness. What to do with them? Send them off somewhere else. They were not part of the community. We couldn't possibly send away old people that are

sick, now. There are too many of us. They're all of us in the future.

Consider old people with serious chronic illness. The average duration of self-care disability is now probably more than two years. The average duration of needing some help with activities of bringing food in and that sort of thing, managing your checkbook, is now probably pushing four years.

This is a big piece of life, and yet it is not on evening television, it is not in the newspapers, it is not something you talk about. No one has a model for how to live it, because it wasn't here before. We didn't have large numbers of people who got to live a long time in a fragile balance with their physiology and their environment.

Essentially now, the end of life course is a long run on a tightrope, with health care running along underneath propping you up, and death is a combination of a stumble and the failure of a prop. Death is not some cataclysm of lightning that comes in and pulls you from life. It's some trivial thing. It's a little influenza. It's standing downwind of a

pretzel with your bad heart. You get a little too much salt and you're over the hill.

But you couldn't have known a week ahead that this was this person's week to die. You could have told that they were in terribly fragile health. You didn't have reserve in any direction. It's a very different story of coming to the end of life, and it's almost all public.

Eighty-three percent are in Medicare; probably half are in Medicaid; another ten percent are in VA. This is almost entirely a public system with no central vision, no central policy, and no governing judgment as to how it's going to operate.

Medical care is growing like topsy, out of fears of 50 year-old men for heart attacks. You can get 911 service anywhere in the country; you cannot get Meals on Wheels on the weekend. Now if you were talking to the public, and you will get to talk to the public about where their priorities are, I'll bet there are a whole lot more elderly people who would like to have Meals on Wheels on the weekend, and to have a little less opportunity to have emergency

medical services.

But that's where we have put our money, is out of the hopes and fears of people in the 1960's, not the hopes and fears of the population we're now serving.

Nick has already talked some about the ambiguity of prognosis. I want to bring home to you that you cannot do excellent services only for those who promise to die conveniently. If you study this slide a lot, you will realize that the prognosis is uncertain right up to the end of life, that the average heart failure patient has a 50-50 chance to live six months on the day that turns out to be the day ahead of death.

This is not because doctors are being stupid or blind. It is that in fact, it is hard to predict when the stumble and the failure in the prop will occur. So if we were going to take good care of this phase of life, we are going to have to build systems that can stay with some patients for six years, and with others for six days, or even six hours.

But on the whole, what matters will be the ability to stay in there with the person who happens to live a long time. And you will even be able to celebrate that they live a long time. It is a very difficult conversation with a potential hospice patient to effectively be saying that you have to promise to die within two federal holidays.

But it's almost embarrassing to live in hospice for two years. We never put it together to stay with people that long. The severity of the condition and the likelihood that it will stay in place that ought to be characteristics that mark the population, not the promise to die in a timely way, because we can't deliver on that.

Nick's already or Ira's already covered this, so I'll skip right over that slide.

We have organized health care by where it has been provided. So we think in terms of the provider sites: doctors, hospitals, nursing homes, or by the way medical knowledge is organized: disease by disease.

We thought about excellence as excellence

in a crosshatch of diagnosis and setting. This is the best nursing home for dementia care; this is the best hospital for heart surgery; this is the best prenatal delivery system. We've thought about excellence in a crosshatch and we've developed our understanding of health that way.

What we have now is a huge population, us in the future, who have multiple illnesses and need multiple settings, and we don't even have a way to think about excellence. We don't have any way to imagine what good care would be across multiple settings, and having to serve a person who has multiple care needs, who has both hearing deficits and cancer and a stroke, and a fragile heart.

The usual patient coming to the end of life has multiple conditions. So we've been doing some thinking about how you would think about good care. The first idea is if you look at the whole population, that's the whole pie chart, most of us on any given day are pretty healthy.

What do you need from a care system on a day you're healthy? Basically, you need 911 and pap

smears. You need prevention services, and an opportunity to get rapid intervention if you get real sick.

You don't want your doctor calling you at 3:00 this afternoon and saying "Have you exercised?" You want to live your life, and not be made part of the health care system.

And you go along in life, and most of us accumulate a few chronic conditions: hypertension, asthma, hearing problems, vision problems. A lot of us wear glasses. You know, we'd have all been disabled a hundred years or a thousand years ago.

We accumulate these chronic conditions that we can live with as long as we do the upkeep. So mild diabetes, mild hypertension. You just live with them, you take your pills, you manage your diet, and you do your exercise. What you want from the health care system is still prevention and 911.

At some point, almost all of us get a tour through that last little sliver, and that last little sliver is where the costs really add up. That's why there's such a concentration of costs. This is now

walking the tightrope. The costly part of your life is almost all the end of life now.

What is it we want from the health care system then is very different. You do want your doctor to be worried about you at three in the afternoon. You do want you care team to be worried about whether your drug got delivered, whether it's working well, whether you're going to be comfortable going to bed tonight.

Because everything that you can do, once you are very ill, turns on the care system being very reliable. You know, there's no margin for error any more. The care system has to be customized to the things you actually need, and it isn't enough to wait to call 911.

So this is a very sick population, generally getting worse, who will die without being well again, and who will die from progression of recurrent illnesses. This is a piece of life that almost all of us will get to live. Very sick, although in many cases, very comfortable on a day-to-day basis, and living a very rewarding time.

This is not a piece of life to throw away. It is in general possible to live this phase very well. But it will be expensive, and it will challenging and it entails the ongoing relationship of patient, family and care-giving.

When you think about this group, you'd feel overwhelmed. People come at this in so many different ways. How could we possibly even think about all the different family arrangements, the different constellations of illness, of ages, the different care delivery systems.

One of the very strong organizing principles that we have stumbled across is that it appears that the vast majority of us fall along a very small number of trajectories of care needs over the course of the end of life.

The first is typified by solid tumor cancers, though not every cancer behaves this way. There are other diseases that do this. It's typical of lung cancer, colon cancer, a large number of cancers, where people go along for a long time with functional quality of life, really doing pretty well,

although their doctor can hold up a scan and say "Geez, you know, it's all in your liver now or it's all in your bones."

They're still really doing fairly well. Until finally the illness becomes overwhelming, and they take to bed and die.

When I was growing up in West Virginia, people would say "He's failing now." It means you'd better go visit and not put it off. He's really at the end. This is the only image that we talk about in novels, in the movies. The idea that there's a confined piece of time that you can label as dying.

This was the idea behind how we structured hospice, that you could come in and do just the right things, and support the family during a relatively short period of rapid change.

Unfortunately for us who live in demographic reality, it's only about 20 percent of us who get to die like this. It is a little more common to have long-term, sort of in-and-out. These are the revolving door patients, that go in the hospital and get cleared up and come back out.

This is emphysema and heart failure. It is also cirrhosis and renal failure. But the big numbers are in heart and lung disease.

Every time a person gets terribly sick and gets rescued, everybody pats themselves and the patient on the back and says "Glad we got you through that, John," and never tells John that there's going to be one he doesn't make it through.

So we need to be planning ahead for that, and have plans in place. This course requires good disease management: try to have as few exacerbations as possible, try to maintain as much function as possible, and always know how to stop. Is this is a person who's going to be willing to be on a ventilator for the rest of their life? Probably not.

These are the people who have gone through trials of treatment. It ought to be outrageous to be back at the same hospital the second or third time, and not have a plan of care. I have sometimes proposed that, if a person comes back to the same hospital for treatment of the same fatal chronic disease, and no one has broached the issue of a plan

of care, then the hospital ought to get half of the DRG payment.

How long do you think it would take before it became a high priority to talk to people before they left the first time? I think about the end of the week. People just haven't focused on this. We know how to go about this.

Then there's -- and this is a group that has about 25 percent of the people -- then there's those with frailty or dementia. If you manage to avoid the first two, you'll get this no matter what your diagnosis is.

Effectively, this is the way people die in their upper 80's or 90's, and yes, their doctor says they have heart failure, yes, their doctor says they have a stroke. But fundamentally, the problem is dramatic failure to be able to take care of yourself, and no reserve in any direction.

Marginal function of kidneys, marginal function of the heart, marginal function of the brain. Just a little bit of an upset and they're delirious. Half the people who pursue this course have dementia.

Half don't, but they are having a fragile hold on their thinking. So when they're sick, they get confused fairly quickly.

So cognitive failure is a big part of this course. This is the one that requires endurance. This is the one that requires families to take care of people for five years, eight years, ten years, to figure out long-term care. This is the big spend-out of Medicare, and already it's more than 40 percent of us.

To the extent that we are good at stopping cancer and good at stopping heart and lung disease, we will have more of this. That may be a very good thing. I mean, on the whole I'd rather die in my 90's than my 70's, thank you very much.

But it also may be utterly miserable, because this is the one we have done the least thinking about. We have done the least thinking about how to support family caregivers.

Remember that the 94 year-old who needs this care has a daughter who's 70. You know, we're talking about care-giving in granddaughters and great-

granddaughters -- and incidentally it's almost all daughters and women. It's still 70 percent or more of care-giving is given for free by women family members.

It is the biggest single cause of poverty in old age. The woman who takes off work to take care of a family member like this is almost doomed to impoverish herself. This slide is just a breakdown of how many patients are in each trajectory.

We proposed what we called "Medicaring," in which you would create eligibility by thresholds of severity and customize the care to that population. You'd have comprehensive services, you would have a strong focus on continuity. You would look to serve people where they live, which is either at home, assisted living or nursing home. We have to take care of the housing as well.

The coverage probably can't be straight doctor fee for service. It's got to be some kind of capitation or budget for at least part of the services. There can be mixed models. But the one thing that doesn't work is to pay for every time you see a doctor, because a lot of these services are not

heavily doctor-run.

We have to know something about quality and measure and report it, and know what we're getting. This slide is just to illustrate the massive mismatch of what Medicare pays for and what people need. We need to address that.

Medicare did not come down from the mountain with Moses. Medicare was created by people who looked just like us in the early to mid-60's. We could fix it. We just have to get about it.

Paul Bataldin points out that every system gets you the results that it's designed to get, and we have designed a care system around the hopes and fears of 55 year-old men in suits who are scared of heart attacks.

The cases that were presented when we established Medicare were people who could not get a surgical procedure. We did not have before us 90 year-olds who were terrified that they could not be fed, and that is we're now serving.

I put here what we say good care systems should promise, but it almost doesn't matter what's in

the boxes. The point is at the top, we need care systems that can promise anything. A doctor, a nurse, a social worker early in the course of a fatal illness needs to be able to sit down with the patient and family, and say, "We have given thought to how to take care of patients who face what your family member faces, or you yourself face, and we know how to do it. You can count on never having long treatments, always having your symptoms taken care of, no gaps in housing or in care, and no surprises. We'll prepare you for what's likely to be coming, customizing care to your preferences, giving the family a strong role, and most important, the diamond in the middle, it's about living."

It's not primarily about death. It's primarily about living in the shadow of death. We now get to stroll through the valley of the shadow of death for years. It had better be good.

So here's some suggestions -- one of the things we've been working on is how you would customize care to the population, rather than thinking first of provider groups or first of diseases, think

how you would split up the population so as to customize care.

Basically, my current hunch is that there are eight populations we need to have a care system that serves. We need a care system that serves the healthy who are looking to stay well. Second are people with a mild, chronic condition that they can live with very well and for which treatment is preventing or delaying progression.

The third population is moms and babies, reproduction issues, and classic maternal and child care. Fourth are stable, disabled people who have to get on with their life. These are people with profound injuries, mental retardation, all the things that interfere with the ordinary lifestyle, and need some ongoing help, but they aren't particularly up against the end of life.

Fifth are the people who are otherwise okay but acutely ill, who need, you know, the patch that modern medical health care is so good at, and the other three are populations of end of life care: (1.) The population who will have a relatively short

decline near death, for whom symptoms are a big thing, life closure, reliability of their care system; (2.) People with intermittent exacerbations and a rather sudden dying, for whom it's avoiding episodes, having a long life, controlling the treatment, always having a plan in place as to how to do that, and supporting the caregivers; and (3.) The people who will live a long time with fatal illness, for whom it's much more about endurance with the family caregivers providing support, making sure skin stays intact, making sure people are fed. It's a different set of things the care system should have as its virtues.

So my prime candidates for changing policy and practice are things like required continuity. You would never set up a prenatal care system in which people went to a different provider every month. Why is it we think that people who are dying ought to be a bounced around in the care system?

We ought to have 24-7 on call with a plan of care in hand. We ought to be able to get the provider to the home within an hour or two, day or night. We ought to have advanced planning. If you

can't do that, you should not be playing the game. That is the game at the end of life. You should not be allowed to be a provider if you can't do it.

We should value comfort and control. We should report quality. We should enhance relationships, closure and spirituality. This is not primarily about physiology; it's about life. It's about what it means to be a human at the end of our lives, and we need to support the family and the direct caregivers.

We are the only nation in the West and almost the only nation in the world that has no coherent policy about the direct caregivers, and we are going to need them badly. That's what Ira had been saying.

Fundamentally, we need to make it plausible for people to do the right thing and make a living at it, and for those who are doing the wrong thing, to not be able to make a living at doing it. That requires focusing on these populations in a way that we have thus far averted our eyes and tried not to notice. Thanks.

CHAIR JOHNSON: Thank you, Joanne. It's interesting to me that in all of our hearings, that when we're talking about death, our presentation or presenters are as lively as any we've had.

(Laughter.)

CHAIR JOHNSON: Isn't that a paradox? We sense your interest and your focus on this. Andy, if I could, I'd just like to ask you to do something for the Working Group, and that is to get a summary of this part of our discussion out to us as soon as possible, along with copies of this segment -- of this segment along with their presentations, so we can review that.

All right. I have a question and I'm going to ask you the question, first. But I ask that you save your answer until we close the session. The question is if you were in our place, and we are asking --

If we are to ask the American population a series of questions to get a sense of what their recommendations would be, if you were to ask one question of the American population that deals with

this subject, to get them involved and get their feedback, what would that question be to stimulate their input to us as a working group, so that we might develop recommendations to the President and the Congress?

In other words, when we go out to talk with the American public, what is the one question that you might ask people in the community meetings and our website, that they might respond to, that deals with and might move forward the proactive dealing with this subject?

I'd like to ask you for your sentence question at the end of our discussion. But we have a series of others, and why don't we start with you, Chris?

MS. WRIGHT: Thank you so much. It's like wow. I was talking with Dr. Byock before in Sioux Falls, South Dakota, and we started palliative care in a 528-bed hospital system in 1999. Our statistics keep in climbing every year, and the work that we do.

I just want to say for this group, also taking care of the family and caregivers. Every

Christmas we have a remembrance program, and it has grown phenomenally throughout the years, as far as the amount of people that come back to thank us for what they've done, or to have that closure.

To get into my questions as far as where are we now with reimbursement for palliative care? You know, our program right now is there is nothing for the palliative care. It is for the physician taking a look at disease management, pain control and that kind of stuff.

The other thing I was reading about recently is taking a look back at hospice care and changing that six-month qualification. The rest of my background is in oncology. So often, we are delivering chemotherapy up until the last day, to give the pain and reduce the tumor size so they don't have the spinal pain or whatever in that.

Then the gap with closing, and Dr. Christakis talked about this, with -- I would like to hope to say that I'm seeing, because we brought it into our physician training program in South Dakota, our family practice medicine, that we will see a

younger group, younger generation of physicians, and excuse me, there are physicians that are in the room.

But that are more willing to talk about those end of life issues and palliative care and approach that subject with the patient and family.

So I guess the Medicare and hospice questions, or reimbursement.

DR. BYOCK: We just put it aside, and I think this panel ought to attend to it at some point, maybe in a follow-up, but we're still not training that new generation, so that they are likely to be much different than all of us would.

I think we're finding we're still retrofitting new graduates, who haven't been given basic skills in education. They're not born knowing this stuff, and we're really failing as educators.

MS. WRIGHT: And it goes back to the nursing schools also.

DR. BYOCK: Of course.

MS. WRIGHT: And we see it with all the health care workers.

DR. BYOCK: And it tracks back culturally.

We still don't know what a positive outcome would look like. Dr. Christakis talked about a seminal paper that he wrote with Karen Steinhauser and the group, about what a positive outcome would look like. What would a good death be for you, and I've written on what I've termed "Dying well."

You know, what would a positive outcome look like? That's probably going to be my answer, unless somebody sparks something else, because we have -- we're scurrying from the things we fear. The good death is commonly defined by the things we worry about most, rather than anything positive. So culturally and socially, it's as if we're at sea at night in a storm, knowing we need to get the heck out of there, but not having a compass point on which to direct our efforts, and that tracks across all of it.

The $15 million that Robert Wood Johnson devoted to the project that I am just finishing directing, "Promoting Excellence in End of Life Care," was in a sense to build prototypical institutional programs that integrated palliative care in mainstream health care, with the hope that if we could show that

they were practical, feasible and well-accepted, had some quality outcomes and were fiscally responsible, that they would then spark Medicare or, you know, Congress to empanel a population-based regional studies.

Because what we know now it would suggest that we're spending more Medicaid dollars for poorer quality than we could get and should get. However, I think there's a lot of resistance, of course, to changing Medicare at all. Talk about the third rail in politics.

Nobody wants to open up the way we finance and currently pay for services. It's sort of been called Pandora's Box. You never know what it's going to look like when you close on it. So even those of us who have been working in hospice care find that there is resistance from the "industry," quote-unquote, to even look at it.

That's impeding adequate payment for these more innovative models, that integrate palliative care forward. At the moment, those of us who are in academic environments -- I'll speak for myself

personally -- we're really struggling to pay our staff at Dartmouth-Hitchcock Medical Center. Thank goodness for philanthropy, because that's helping most of us get by.

But we're trying to do studies just to prove the cost effectiveness. Again, I can't state it too strongly. The irony is total health care dollars consistently fall with the inclusion of palliative care for people who have serious illness, a limited prognosis at least, and complex needs.

But within that statement, underneath that umbrella, there are winners and losers because of the silos of the current reimbursement structure. So what we need are population-based studies of integrated models, that can provide Medicare with a rational, safe, responsible way to reform payment.

DR. LYNN: I have a quick response to a six month question. I think that that endeavor is not the right policy direction, that when you ask a doctor for the hospice prognosis, you effectively are heard as "Is this person virtually certain to die within six months?"

On average, that means they're only going to live for a few weeks, because by the time you can be virtually certain, the person's desperately ill. We have found that in our quality improvement work, to be much more useful to ask the doctor or whoever knows the patient well, "Is this person sick enough that you would not be surprised if they went on and died in the next year?"

That then finds you those people on the tightrope, and some of them have lived for years, and they'll manage to go a long time before they hit their stumble. But it means that all of that time they'll be in fragile health.

It seems that we have to find ways of reaching out to find that severity of illness criterion, rather than the time frame criteria. It's just a better policy.

CHAIR JOHNSON: Montye.

MS. CONLAN: This question might be -- well, it is a little beyond the scope of what the three of you have been discussing, but I can't resist the opportunity to ask it.

I have multiple sclerosis, and while it's not a fatal disease, there is a degenerative stage that some patients reach. Unfortunately, I found that in my county, there are too many MS'ers that reach that stage, who are abandoned by their families. It just becomes beyond their capacity to provide, you know, the physical care and all of that.

So many of these patients that I'm familiar with are middle-aged, just like myself, but they are admitted to nursing homes. They don't have the support system. Their family has abandoned them. They're in a situation. I feel like, and I am sure that they feel that they're captive with 80 and 90 year-old peers, peers, you know, by virtue of the fact of where they are.

Then that presents a lot of symptoms, in terms of depression, cognitive failure and I think mostly because of their environment. All right. So they get in this environment. They start to get very angry. They get unruly, disruptive.

These nursing homes decide to call me, and they invite me in. They say "Well, you know, these

people need a support group." So here I am going into these nursing homes out of compassion for someone who has the same disease that I have.

Sometimes they can hardly communicate with these MS'ers because they often are not able to talk. What do I do? What's the answer here? Is this a common problem? Do MS'ers get put in those kind of situations?

DR. LYNN: I'm not actually aware in Washington, I guess that we have no one, you know, who is with MS in the nursing home. It's very much a local phenomenon as to how extensive there has been supportive housing.

If you have extensive supportive housing and assisted living, you can find at least a better environment. It may still not be everything a person might want. But it still is better to see and to have somewhat age-related peers and adequate support. It can't always be in a private home. If there's no volunteering help from the family, a private home 24-hour a day is about $150,000 a year and there aren't many communities that will be able to provide it. But

there can be supportive housing in small units, six-bed units that have around-the-clock help and support. A lot of communities are moving that way.

What I think I would find out, though, is that what we desperately need is some locus at which this problem could be noticed and dealt with. We're now working with some groups in Sweden, and one of the most wonderful things is there actually are locations, groups of people who are supposed to address these issues, and to whom you can bring this kind of a problem.

So in the end of life stuff, they're working around three paradigmatic trajectories. They're called "Esther with heart failure," "Esther with colon cancer," and "Esther with dementia." We try to design a care system in which every Esther could count on good care.

That's really powerful. You could have an Esther with MS and no effective family. I think it's also the case that there are an awful lot of cases of good support from the family caregivers, who have kept an awful lot of these families from falling apart.

Again, you don't have any support for family caregivers. We don't support them financially, we don't give them social security, we don't give them health insurance.

So there are a couple of angles, it seems to me, with which we could tackle this issue. We could develop locations that the groups of people are supposed to address it in the support plan for caregivers, and we could look for better housing options.

CHAIR JOHNSON: Thank you. Catherine.

VICE CHAIR McLAUGHLIN: Thanks. Thank you very much for the information. As you look at those of us around this U shape, it will come as no surprise that between us, we are probably indirectly or directly caring for several dozen people, parents in their 80's and 90's.

So we were also looking at each other and the laughter was reflected what we're all going through with our parents, going in and out of hospitals and nursing homes, et cetera. So we're very familiar with this.

I have two questions that relate to that. One, of course, Dr. Lynn is a geriatrician, so it's not surprising that the focus of what you talked about were elderly people and the end of life.

But that's certainly not it, and I wondered if any of you had figures on the age distribution of end of life, because what, as Randy said, we need to go out and talk to the American public about end of life issues, and this is coming shortly after the Terry Schiavo case, which of course caused a lot of concern and a lot of commentary in the public.

And so we would like, I would like some information about, you know, if we talk only about elderly people end of life, who are we leaving out? I mean, what percent are non-elderly, and you know, just to get some figures on that.

Then the second part, although I think all of us sit here and feel more comfortable with the discussion of people in their 80's and 90's and their end of life, for a whole bunch of emotional reasons, as someone who -- my husband and I are dealing with an

85 and 86 and 89 year-old.

I will tell you that two of those three, any kind of discussion that you want us to sacrifice, you want us to give up something to provide health care for younger people.

They really, whenever -- we had some of this last night in our public forum, the use of the word "tradeoff," which is one of the four questions we are mandated to ask the American public about, what tradeoffs are you willing to make.

We find anyway, in our own personal family discussions, this fear that we are going to say "Look, you're costing us too much money you old folks, and you're all on the public dole." Or you can point out that virtually all of them are being cared for through public programs through taxpayer dollars, and their response is "Raise taxes. Don't take it out on us."

So if you could just respond to those two questions, to help us as we -- because we're starting this fall with our community meetings. Help is frame that in some way.

DR. BYOCK: They already make tradeoffs,

you know. I talk to people who want to go for broke. They've got, you know, metastatic breast cancer, widely metastatic, you know, brain mets. There's always something else. The doctors will always offer you something else.

If it's not Herceptin or Taxotere or radiosurgery or whatever. What we forget is that they're already making tradeoffs, because the acceptance of the Herceptin means that we are going to conscript your time and energy to the lab tests, to the imaging studies, to the trips to the medical center, to trips to the office, to the days you don't feel well after whatever treatment.

So what happens is people, and it's culturally not seen. It's not communicated individually or collectively culturally that they're losing some of the most remarkable experiences that I think are part of our human endowment as well, this sense of leaving this life with some peace and resolution, and some sense of meaning and purpose in that last phase of life.

The way people die stays in the memories

of those they leave behind forever. People are still choosing to die badly, I don't think because they actually want to, but it's hard to know what you're getting if you haven't been through it before. But in fact they're not provided with a wholesome alternative.

It's not culturally acceptable to say "Look, you know, you're going to die of this illness. Whether you die this week or two months from now, this illness is going to be the thing that we put on your death certificate. Where do you want to be?"

You know, heaven forbid that you were to die today. What would be left undone? Then when you think about the future, where do you want to be? So it's already making tradeoffs.

There's a lot of other ways we can respond to your first question. But I think it's true that dying happens to adults by and large. It is a Medicare topic. Cancer does claim young people. As I turned over the clinical service to come here, we had, you know, of -- on One West where we are, four of our patients currently are my age or younger.

You know, it does -- but they're middle-aged adults. Seventy-five percent of Americans who die are older than 65. 2.4 million Americans die about each year. 50,000 are children. So that gives you a sense of, you know although I was on a conference call on the way down here. But with Kate Eastman, who had Jason Program in Maine, wonderful work to do to provide palliative care to children.

We are thankfully talking about small numbers, and so Medicare, this is life of --

VICE CHAIR McLAUGHLIN: Nicholas, just one thing. The 25 percent that are less than 65, any idea of how that splits with they die from car accidents, etcetera, so it is right away, versus some of these issues that --

DR. LYNN: Eight percent are on Medicare disability. They have long term illnesses.

VICE CHAIR McLAUGHLIN: Eighty percent of that 20?

DR. LYNN: Eight percent.

VICE CHAIR McLAUGHLIN: Eight percent of the 25 percent.

DR. LYNN: Another eight percent. So you get 83 percent covered by Medicare, because 75 percent are covered because they're elderly, and another eight percent --

VICE CHAIR McLAUGHLIN: Okay, so eight percent are non-elderly on Medicare.

DR. LYNN: Medicare insureds.

VICE CHAIR McLAUGHLIN: On Medicare, got it.

DR. LYNN: And of the rest, it appears that about half have relatively sudden dying, and that they have very small expenses. About half appear to have a serious illness. The non-Medicare population has been studied much less well, because there's not a coherent database. But that's a rough estimate.

DR. BYOCK: And other figures you might just think about. Nick mentioned how many people die at home. It's roughly -- you said 15. I think my figures I've seen is more like 20 percent. About 30, 40 percent of people die in the nursing homes, you know, somewhere between 25 and 40 percent.

About 55 to 60 percent of people die in

hospitals. But fully 20 percent, so a third of those that die in hospitals, die either in an ICU or within a day or two or being in an ICU. So about 20 percent, a fifth of Americans, pass through an ICU just before they die.

DR. CHRISTAKIS: Actually, that's a good point. There's a nice paper by Jack Iwashyna on serial ICU users, and it talks about this.

DR. LYNN: On the tradeoff question, Elliott Fisher has a wonderful set of papers showing that as -- in small geographic areas across the country, as you increase investment in end of life care, you decrease every available measure of quality.

So to underscore Ira's point earlier, this is the one arena in health care in which the more thin application of health care appears to yield better results for the patient.

CHAIR JOHNSON: Okay. We have reached the end of our time. But let me just say this. I'd like to get the four remaining people who have questions, okay.

MR. FRANK: Good chairman.

CHAIR JOHNSON: And here's what I'd like our agenda to be, if it could. We'll take the questions of Richard and Dottie and Rosie and Therese, in that order, and then we're going to adjourn for a couple of minutes and go off the record. But if you would be willing to wait a few minutes until we take care of a couple of internal things, we're going to take our lunch hour and maybe we'll have a chance to dialogue with you a little bit more if you don't, have flights to catch right away. Then we need to get the answers to the three questions.

So let's go, with the four additional questions, but let's try to keep them as concise as possible, and your answers as well, okay. Richard, go first, and then Dottie.

MR. FRANK: Well, you can actually even put off answering the question you know. You could answer it by e-mail if you'd like. Let me put it on the table.

What you've persuaded me of is that actually end of life care is representative of everything that goes wrong in the health care system,

only more so, in that it's just a very good model for all the pathologies of the American health care system.

The difference is that somehow the fissures in decision-making are a little bit clearer. So what I was hoping that we could get from you, and then again you don't have to answer it now, is what -- what are two lessons, would each one of you say, we should take away from what you've learned about end of life, and bring to the general health care system, because I think that it really is an interesting model.

Given the thinking that you've done and some of the things you've put on here, I'd like to sort of get you to step back and say what's generalization, what we can go about fixing.

CHAIR JOHNSON: Could we ask you each to respond to that with just a word -- not a word, a couple of sentences each, to get at least a flavor?

DR. CHRISTAKIS: A few words to start. Let's see, continuity. Communication, care planning. People don't just need clinicians. They need a

concierge. When you have cancer or serious congestive heart failure, you actually need a concierge, because the current system, as configured, is too confusing, and it's very, very, very difficult to navigate and learn.

DR. LYNN: I would encourage a population focus. It's a thing that can be important elsewhere, is to find the population that makes sense and then figure out how to serve that population optimally. Don't make it 200. I have eight. It might be ten or 12, but it's not more than that, that we can handle.

If you start with the needs of the population, and do data-driven reform, you'll end up about right. If you start with the assumptions that the doctors have it right and all evidence is in the New England Journal, you'll have it wrong. Reform starts with the needs of the patients.

DR. BYOCK: No. Just keep going.

CHAIR JOHNSON: Okay. You okay?

MR. FRANK: I'm done.

CHAIR JOHNSON: Okay, thanks. Dottie.

MS. BAZOS: In your report to Richard, I'd

like you to include some kind of discussion about how Medicare and Medicaid play together in this world. I know in New Hampshire, there's been a lot of very, very creative work done around using Medicaid dollars very, very creatively, to support children, out to get care in their homes, and to support care-giving for those children. Also around families who have someone with a developmental disability. We've used Medicaid very, very creatively.

My question is why aren't we thinking about using Medicaid creatively to actually support the services that we need when we're home, for this type of care-giving? So has that been thought of as a model, to at least build on or to incorporate?

We know Medicaid's paying the bulk of nursing homes costs. People don't want to be in nursing homes. Can't we just at least -- is there an opportunity there to --

DR. LYNN: It's very miserably integrated because you have to spend down your personal assets first. So there are actually three players in long-term care.

There's a wonderful program called PACE, which does do dual capitation for Medicare and Medicaid, but you have to have already spent down to be eligible. There are some other waiver programs, and thinking of it in a coherent and integrated fashion has been dramatically missing.

CHAIR JOHNSON: Therese.

MS. HUGHES: Hi. I want to just say a couple of things. First of all, I'm thrilled that you're here. To say that this part of life has fascinated me for years is -- it's an understatement. My mother died when I was much younger, and I started to do hospice work, and did it for years, and felt that a hospice lacked something, which is clearly the palliative care aspect of it. But it was certainly better than what my mother went through at the end of her life.

However, my father just died in the last couple of months, and I'm led to believe that in concert with what you do and propose, in terms of policy and things like that, there must be a very strong education out to families about care and things

like that, and that it's okay to let people die.

Because I've witnessed too many times where that lack of education and I don't think it's all just lack of education. I think some of it are all the messy little ends that come when you say "I forgive you, forgive me," that do and don't get said, that occur at the end of life or don't, that go into it.

But I just think that if there were some type of and perhaps our generation is the one as we go into this, you know, into these ages, that we will be the ones to create some type of a public awareness program specifically, you know, geared towards this sort of thing, that perhaps could combine the palliative care, the hospice care, but also indicators of how to be there, you know. So I thank you so much. Thank you so much.

CHAIR JOHNSON: Reactions, comments?

DR. LYNN: I would just have, as part of that education, educating the family caregiver in clinical awareness, to know how to direct their anger and frustration when the system doesn't work well. It

isn't just therapy, but how we deal with it.

CHAIR JOHNSON: Thank you. Rosie.

MS. PEREZ: I think my question is just what everyone else has asked, but where are we in relation to communities of color? You know, as I walked through my hospice unit, I don't see a lot of Hispanics in the beds. I don't see a lot of African-Americans in those beds.

And, you know, as a Mexican-American eldest daughter, I'm constantly reminded by my parents that, you know, I will be caring for them at home and they will not be going into a nursing home.

But that's, you know, I just kind of feel the outreach and the education, cultural, funding, and regional, where are we with that?

DR. BYOCK: I think we need leadership from within those communities, as well as provocation by the industry and providers. In fact, often people of color and people, Spanish-speaking, primarily people of other ethnicities, non-main ethnicities, and tend to look with suspicion about palliative care and hospice. They think that they're not going to get

the best care possible.

Some of the controversies that Dr. Christakis mentioned about whether you want to die at home or not, that 70-30, 70 percent of the people want to die at home, just about basically turned up on its head when you talk to a number of African-American communities.

In fact, when they become more knowledgeable about what we're actually talking about, it is important to family members to take care and to fulfill their sense of responsibility, and to ensure comfort and honor and celebrate people.

They find that it is quite culturally consonant with, for instance, the Hispanic cultures and the Asian-American cultures. So there's some growing acceptance. But we really need leadership, and it's data. But it's also the telling of stories by prominent people within that community, that this is a wholesome and life-affirming, community-affirming way to care for one another through the end of life.

DR. CHRISTAKIS: Yes. I mean, just very -- just two sentences. The proportions of people

getting hospice care who are of various minority groups are slightly lower than the populations, their representation in the population as a whole.

The question is if that's slightly lower, what is it due to? Is it some structural impediments to getting this kind of care, or is it a question of taste? Actually, it's probably both. But I wouldn't underestimate the taste issue.

So often, when you go and talk to a family and try to encourage them to get hospice care, you find that -- for instance, there's a higher desire for intensive care amongst African-American populations than white populations, and there's a lower desire for hospice care. If that's what people want, that's what they should get, in a way.

But there are other issues. It's a big issue, a complicated issue.

CHAIR JOHNSON: Well, thank you very much. I asked each of you to give us a question to bring to the American public, and Joanne, could we start with you?

DR. LYNN: I thought I would ask if you or

your parents, or somebody you loved, would come to be in your 80's and become frail and old, what is it that you most want from health care, and why can't you get it?

CHAIR JOHNSON: Hang on just a second.

MS. HUGHES: Andy's got it.

CHAIR JOHNSON: Andy's got it. Okay. You ready Andy?

MR. ROCK: Yes.

CHAIR JOHNSON: Okay, thank you. Go ahead.

DR. CHRISTAKIS: Given the fact that we all die, what would a healthy last chapter of life look like for yourself and your family?

CHAIR JOHNSON: Okay.

DR. BYOCK: So I have a similar question. Please state what you think are key aspects of a good death the health care can and should deliver.

CHAIR JOHNSON: You got them, Andy?

MR. ROCK: Yes.

CHAIR JOHNSON: Well, that might imply those are good questions, the fact that you have come very close. Well, we -- I'm just representing our

group. As you can tell, in saying thank you to you. We appreciate your time. This has been a rich discussion. We actually have one minor matter to take care of. We'll excuse you or ask that you adjourn for just a few minutes.

But this will just take a couple of minutes, and then if you'd be available to answer questions informally, that would be great. Okay. Off the record.

(Applause.)

CHAIR JOHNSON: It doesn't pertain to the public at this time, but Therese Hughes of our Working Group has a comment and something that she'd like to share.

MS. HUGHES: I wanted to take this opportunity to thank staff for all the work that they've done, and the reason that I'm doing it now is because staff, some of the staff members are leaving. Some have left, our interns, Rachel's leaving, and we've gotten new staff on board.

I think that, for me when summer ends and school starts, to me it's the most exciting time in

life, because these are where a lot of changes take place, and those changes are, you know, the comings and goings of people.

So in an effort to celebrate also Jessica's birthday, which is at the end of the month, and Rosie's birthday, but you're not staff so you can still participate, I went out last night and I bought 26 cannoli for everybody to have some, but primarily for staff and for a thank you and an appreciation.

However, between, you know, my mother would always say between cup and the lip, there's many a slip. We bought the cannolis back to the hotel and unfortunately, the cannolis were eaten, but not by the individual that went with me and brought them back.

So we are in the process of having the cannolis replaced, and hopefully when we come back from lunch, there will be cannolis here for everybody. But it's in celebration of staff and for the work that they've done.

(Applause.)

MS. HUGHES: The other thing that I wanted to ask is that when we hold our center meetings, not

like this one, a hearing, but just in our regular meetings, since we're a team I would really like to ask that staff join us at the table.

I think that it will build a better team. I think that it will allow us to get perspectives that we may have to go one-on-one or may cut down on, you know, on sidebars and things like that, and I think that it builds a stronger essence of trust, which is, you know, I think critical as we move forward on this really exciting time in our committee.

So I would seriously like to have consideration of that, and hopefully implementation in Portland, Oregon.

CHAIR JOHNSON: Okay. Thank you, Therese. Let's adjourn, and reconvene at 1:30, and if -- I'd like to ask your collaboration in starting right at 1:30, so that people who have flights to catch will be on time when we end.

(Whereupon, at 12:47 p.m., a luncheon recess was taken.)

A F T E R N O O N S E S S I O N

1:36 p.m.

CHAIR JOHNSON: We have one hour left in our discussion and hearing this afternoon. The Hearings Committee decided that we would like to hear, regarding some of the employer initiatives that are designed to provide disclosure of outcomes and quality improvement, and contacted both Leapfrog and Bridges to Excellence, which are two programs that we're going to learn about this afternoon.

Those programs are run individually, not together. But when we contacted people who are working and in leadership of both of those programs, both of them suggested that Jeff Hanson, who is from Verizon in his real world, and actively involved in a number of other organizations, to supplement that real world job, represent both Leapfrog and Bridges to Excellence in our discussion.

Jeff is the Northeast Regional Health Care Manager of Health Benefits Strategy and Design with Verizon Communications. He's, as you can see on the chart, president of Bridges to Excellence and a board of directors member of Leapfrog. A thoughtful person

and Jeff, what we'd like to suggest that you do, since you're representing both of those organizations, take 20 to 25 minutes or so to go through your presentation of both of those organizations, and then we'll open up for questions if that would be okay with you. Thank you.

MR. HANSON: Thanks. Well first of all, thank you for having me here. I guess it is kind one-stop shopping. Suzanne Delbanco could not make it from the Leapfrog Group, so I'm filling in for her. As president of Bridges to Excellence, I was probably the designated driver anyway on that program.

But just as a little bit of an introduction, to give you a flavor of why employers are raising the tenor of their dialogue and their involvement in the health care system, I'll tell you a little bit about Verizon Communications.

We provide health care coverage to nearly 800,000 employees, retirees and their family members, at a cost to the company in excess of $3.2 billion annually. The quality of health care received by our employees, retirees and their covered family members

is subsequently of utmost importance to us, on both a personal and a financial level at the company.

Like many of our country's largest employers, Verizon is committed to ensuring that the people we cover, as well as all the consumers around the country, have access to the highest quality care options at affordable levels.

To that goal, we have taken a leadership role to advance a proactive public policy agenda for health care reform. The widespread deployment of interoperable health information technology, and pay for quality, are two important pieces of our strategy, to advance the quality improvement imperative.

Verizon's CEO Ivan Seidenberg is a member of the President's Commission on Systemic Interoperability, and is exercising a leadership role in advancing health information technology deployment.

We have learned the value of information technology in our industry of telecommunications, and are working with the health care industry to improve their quality and efficiency through use of these tools. Ultimately, a more efficient health care

system will produce long-term value for employers and employees alike.

One of the cornerstones of transforming the health care system, we believe, is provider quality differentiation, transparency of quality data, and the realignment of the provider payment system, based on standardized quality performance indices.

The number of pay for quality or pay for performance programs has increased rapidly over the past two years, and now numbers in excess of 100. Two of more prominent initiatives are Bridges to Excellence, which is an outpatient initiative, and Leapfrog Group, or the Leapfrog incentives and rewards program, which is primarily focused on inpatient and patient safety.

These two initiatives found their genesis in two very high profile reports generated by the Institute of Medicine, "To Err is Human," and "Crossing the Quality Chasm." Literally, these reports grabbed the attention of senior executives at corporations coast to coast, and have been a call to action.

Let me begin today by kind of walking you through the architecture of the Bridges to Excellence program. It's a multi-stakeholder group designed to meet diverse needs. Our mission is to improve the quality of care through rewards and incentives, and encourage providers to deliver optimal care, and encourage patients to seek evidence-based care and self-manage their own conditions, the second point being equally as important as the first point.

Our focus is on the reengineering of provider office practices by adopting better systems of care, and to demonstrate that the reengineering is working through better outcomes for our patients with chronic conditions. The program started with diabetes and cardiovascular diseases, and I will share with you as we go along where we are going from that point.

We are a not-for-profit company with a board and a leadership council. You can see here I serve as president. Dale Whitney of UPS serves as the secretary. Francois de Brantes, who is really the founder of the program and pretty much the architect behind the scenes from General Electric, serves as

treasurer. We have a board of people from various stakeholders across the health care system.

We now have three programs that are operational. The physician office link and portal of the program really focuses on how a physician sets up or architects his or her office to administer care across any number of diseases. That would include the adoption of perhaps hand-held prescription devices, electronic medical records, electronic lab reporting, sophisticated client or patient educational systems.

The second two components are really the two clinical components of the program to date: the diabetes care link and the cardiac care link. We chose these two particular chronic diseases because across the spectrum of most employers, large and small, these two diseases comprise a very significant percentage of the outpatient care spent in the company.

You can see there are designated rewards for the provider, based on them meeting certain standards, and I'll get into a little bit more detail on those, as well as for the consumers getting active

in their own care management.

Our intention going forward is to look at several other areas of chronic care: oncology, low back pain, as well as actually the primary care physician themselves. Once we look at these five areas of care, it will comprise about 60 or 65 percent of the outpatient spend on the company's medical costs in any given year.

We've made some pretty good progress to date. We have pilots in four cities. We have them in Louisville, Cincinnati, right here in Boston, which is our largest pilot, as well as Albany, New York.

In January of -- I'll show you the comparison between January of 2004 and July of 2005. You can see the number of recognized physicians in each of the programs, the employees going to those physicians and the rewards we've paid out to date have been nearly $1.9 million.

There was a significant key to the jump between January of 2004 and July of 2005, and that was May 12th of 2004 here in the Boston market. We delivered the first incentive checks to the providers

from the employers themselves. These are not coming via our health plans or any intermediary third party. The employers are putting in new money into the system to do this.

Once that got the attention of the provider community, we saw the uptick in providers' interest in what the program was about, because I think it really helped build the trust level within the organization, the program and the community.

We have an ongoing rigorous evaluation, as you can imagine. I mean, the employees or the employers and the providers both are very interested in knowing whether there really is any return on our investment and taking a look at quality, and is there really a return to the consumer on that quality.

What we found so far is the doctors who are enrolled in our diabetes care program and who are certified from the NCQA, under the diabetes physician recognition program. Believe me, one thing you all have probably heard of in the past several months is you've done your tour, as a number of doctors in our systems don't do.

But we're seeing efficiency of anywhere from 10 to 15 percent when we look at the costs alone. We are five percent more efficient among those doctors as we're looking at the overall cost of treatment for the diabetic patients across all of their medical expenses.

The physician office link docs are more efficient anywhere from five to ten percent, than doctors who do not meet the standards of the physician office link program through NCQA. What we don't know is are they more efficient over time, or if this is a one-shot savings.

What we believe we're going to find out is that physicians who qualify and who are certified and who meet the rigorous standards of these programs actually mitigate the cost of the patient's care and the quality of outcomes increases over time as you continue to see these certified doctors. So we're very encouraged by some of the initial returns from the program.

For those who are graphically oriented as I am, this is just a graphic view of those savings

that I just spoke about, on both the diabetic program as well as the physician office link program.

The Louisville market, which is our most mature market, is now in its third and final year of the pilot. It has really yielded many lessons that can help you and me as we look at programs like this.

At launch, there were four recognized physicians. Today, there are 36. In a market like Boston, that may not sound like much, but in the Cincinnati-Louisville market, that is a significant piece, considering that this program only covers a handful of very large employers in the market.

The challenge was the physician philosophy was definitely driven regionally. So each market that we go in, even though as an employer we may participate in multiple markets, the philosophy of dealing with the provider community in each one of those markets is markedly different.

Outside of the Norton Health Care System in the Cincinnati-Louisville area, physicians are not recognized or not organized into large practice systems, and they have limited resources to go through

the intensive labor requirement for qualifying for the program.

We've tried to assist them in identifying some resources through outside funding and grants, for them to get resources to help more doctors qualify for the program.

It's a single product market. I think one thing we learned from the Cincinnati-Louisville market is that most doctors who qualify for the diabetes carelink portion of the program also qualify for the physician office link or the administrative component of the program. So as we entered the Boston market, we launched those two components simultaneously.

Some of the lessons we learned was the basic outreach or follow-up increased the patient percentage from four to 13 percent. It really is critical for the employers to engage their employees in this dialogue, and to educate them about the presence of the program in each market.

Public support for multiple sources, all pushing for the same thing, physicians learning what constitutes guideline care and getting by, that's been

very critical and supportive part of the program on behalf of the physicians. They were at the table from the very onset of the design of the program.

Patients need to get into the game through incentives, and that requires a lot of work on behalf of the employers and the health plans in those markets.

This will help us in future markets. Again, as I mentioned as we have in the Boston market, in terms of launching various components of the program simultaneously, and also taking a look at how we can really engage more of the small practices in each of the markets.

This will give you an idea of how we engage the consumer. We have a website where they can go and actually look up the quality of recognized physicians in their marketplace, and they can go in and see surveys filled out by other patients on quality of care, as well as the kinds of things that the doctor went through to get certified from the NCQA for the particular program. They can drill down to specific doctors in each program by community.

The other thing we engage them with is a care management website that we partner with Web MD to produce. It's almost like a frequent flyer program. Patients can go in, log in. They record all the different things they do to manage their own care, whether it's diabetic care of cardiovascular disease care.

They get points for that. Each employer kind of designs their own rewards system for those. General Electric, for example, allows the points to be turned in for diabetic supplies by the patient. So we really try to engage the patient, and it's actually a very popular -- people like the frequent flyer program kinds of things.

It's very easy, it's very simple, and it really gets the patient thinking a lot about what they do on a day to day basis, and some of the simple things like just walking for a mile every day, and the importance that that might have on care managing for themselves.

The program has really morphed and taken on a life of its own, which the employers are very

thankful for, because really it's going to be the involvement of the health plans across all of their covered lives in any particular market, that's going to get some more involvement and get more of the providers engaged.

We have some significant involvement in licensing from players such as United Health Group. They've identified four markets that they're going to work to launch the Bridges to Excellence program in.

CareFirst Blue Cross/Blue Shield of Maryland launched the program on January 18th of this year. We're currently working with CIGNA in the Arizona marketplace, along with other payors and employers down there, to launch a program which interestingly enough, will also incorporate the Leapfrog program that I'll talk about in a couple of minutes.

The National Business Coalition on Health has become a significant partner with us. They represent about 38 or 39 business coalitions on health across the country, that involve some of the smaller employers in the community. They're starting to get

their coalitions involved in coming together to try to figure out a model for themselves to use in each one of their marketplaces.

You could see that it's kind of sprung up across the country. We have interest from over 30 different markets. In addition to that, the other thing that we're excited about is the advent of CMS into the pay for quality arena.

They have reached out across the table to the private sector, to ask what kind of measures we're using in terms of quality measurement. Because clearly, as the 100 million person gorilla that they are in the marketplace, once they get in and decide on the measures they're going to use, that will really essentially drive the marketplace.

So we're really working collaboratively, which is an exciting thing. Because historically, as many of you know, sometimes we kind of work separately from each other. So we're really breaking new ground here that we're excited about.

The Human Resources Policy Association, which represents all the fairly large employers across

the country in their Human Resource departments, is involved with looking at the initiatives as well.

If you need additional information, there is some there, and we'll tell you where to go. Our website is a very good place to go, and you're welcome to contact me at any point.

With that, let me transition over to the Leapfrog portion of the program. I apologize for having this on two separate presentations, but I'm technology-challenged, and I often tell people if there's ever a phone strike and I show up at your door to fix your phone, please don't let me in. Last night, when I was trying to marry these two, it wasn't working very well and I was losing all the beautiful graphics that Leapfrog provided me with.

So here are updates from the lily pad. Again, I had nothing to do with the jargon that I'll use during this presentation. That was developed early on.

The Leapfrog Group came together in 1999, following the Institute of Medicine report on "Crossing the Quality Chasm." It actually was the one

"To Err is Human," which said probably close to maybe 98 or 100,000 lives were lost every year on an inpatient setting from preventable medical errors.

The Leapfrog Group was a group of some of the larger employers, Verizon being one of them, who actually came together just to look at health care quality and feel that we needed to get in the game. Once the IOM report came out, they really latched onto something very concrete that they could put their arms around.

There were some specific things that hospitals could be doing to prevent these errors, and thus launched the first program from Leapfrog, which is their inpatient hospital-patient safety survey and information that I'll talk about here today.

But clearly, Leapfrog is in its bigger mission, across the entire system, and not just inpatient care. But essentially why isn't the quality of care better? That's because we're really -- everybody's responsible, but nobody's accountable.

You know, we have health plans who aren't letting the providers' value show through. We have

employers who really aren't buying wisely. We used to send our premiums to the health plans on an annual basis and really not get involved with what was happening.

Consumers find it daunting to find their way into the health care system to begin with for a variety of reasons that I'm sure you all are familiar with, and providers have really been given no reason, given our current reimbursement system, to do anything different than what they're doing.

Essentially, they are in a pay for performance system now, and that is they perform a particular duty and they get paid, no matter what the outcome or quality of what they perform is. So I think everybody was doing something different, and nobody was coming together to really be accountable.

We now represent over 170 employers and purchasers around the country, covering more than 36 million Americans. Between all of us, we spend about $67 billion in health care a year.

The mission really is to trigger giant leaps forward in quality, safety and affordability, by

supporting informed health care decisions by those who use and pay for health care. So clearly, it's getting the reporting out there and having consumers use that information, and promoting the high value of health care through incentives and rewards in the system.

We feel that there are three pillars for improving quality. Standard measures and practices. While there was some resistance from the provider community at the onset, the fact that we're looking at some sort of standardization for the quality profiling of providers is exciting and more than you can believe.

We will certainly be a much better system than trying to jump through every single health plan, with a different provider profiling tool than they currently use. So they're excited to have us come along and get on the same page.

Transparency is the biggest one. You know, it's really sad at the end of the day that you and I know more about the iron that we're going to buy at our local hardware store than we do about the health care that we're going to access from our

doctors and hospitals.

Somebody said to me recently they got a picture from their daughter from Acapulco, bungee jumping over the Bay of Acapulco, and she said what scared her was that was probably safer than going down to the hospital for some kind of care that she was going to get at the end of the month. Also realigning the reimbursement through incentives and rewards in our system.

So standard measures and practices were really a cornerstone here, and it's to achieve a transparency and improved quality, you must talk the same language when asking hospitals and doctors to report. So there were some key things at the beginning.

The computer physician order entry program, which is a computerized system in the hospital setting that would prevent adverse drug events from happening in the system. Staffing the intensive care unit with doctors who are board-certified in intensive care and critical case management.

The best of the best, really looking at evidence-based hospital referrals, based on outcomes data from each of the hospitals on certain inpatient things that you can perform, operations. Then looking at the NQF for some additional quality of safe practices in the hospital setting.

Make reporting results routine and use the results to make health care purchasing decisions. It's been very difficult for us to get the hospitals to even report. We've been very lucky in the Boston market. I headed up the rollout here of Leapfrog in the Boston market, and we got nearly 90 percent of our hospitals to report.

The interesting thing is the same five that met the three leaps five years ago for the first time, are also the only, the only five that continue to meet those leaps. So there hasn't been much improvement in the system. So clearly, you know, our work is cut out for us, to continue this dialogue.

The information for consumers and purchasers. This will give you a snapshot of what it is when you go in to look for your hospital on the

Leapfrog website, and what you can find out about them. Some of the hospitals here in the Boston marketplace are listed here.

But you can go into the Leapfrog website and look up your hospital -- number one, find out if they reported and number two, if they have reported, find out how they scored on some of these measures.

The next thing is that Leapfrog is launching an incentive and rewards program, similar to the Bridges to Excellence program based on the inpatient setting. There's 90 pay for performance programs around the country that incorporate some of the Leapfrog rewards, 25 percent of them do.

So there is good news and bad news. It's good news that people are out there doing this. The bad news is, is that there is no clear signal yet for health care providers, who still have parts of our health care system, particularly health plans, who still look at this kind of program as a marketing strategy to gain market share.

One of the messages that we're trying to deliver through the employer system is that it's no

longer acceptable to use hospital and provider quality measures as a market differentiation tool. It's how you engage our own employees and make them healthier is where you differentiate yourselves as a health provider.

So the Leapfrog hospital patient safety, it's an easy way for payors to provide incentives and rewards for hospital performance. It uses some of the same measures that CMS has been using with some of its demonstration programs.

The focus is on performance improvement and both effectiveness and efficiency in five important critical areas. Hospitals can participate with minimal reporting. It builds and reinforces their participation in JCAHO and it rewards both top performers, and we also reward on improvement.

These are the five areas, clinical areas that we're looking at in this program. Pregnancy and newborns, and you can read the list there. We engage in Medstat, which is a very large health information data aggregation vendor in the marketplace, to work with us on bringing some of this data together and

measuring the quality.

This will just kind of give you a graphic representation of how hospitals are arrayed in the four groups. The upper right hand is good quality, but it's inefficient. The lower left-hand is very efficient but poor quality.

The ones that are above, you know, good quality and efficient, are in the lower right-hand corner. You'll see that there's very few are aggregated down there. So we have our work cut out for us.

The leap over the gridlock has begun. There's been rapid growth in purchasers signing on. I talked a little bit about them in the Bridges to Excellence piece. There's rapid growth in the number of hospitals and physicians disclosing their status to the community, as we achieve more consensus on how they're going to be measured.

There's become active health plan support. I think they finally got the message for many of the employers that have been out there working with them. There's massive education of consumers through

purchasers and through employers now, and there's market reinforcement beginning through different channels.

I think, if I could take a crystal ball, I honestly believe in ten years, it's going to be -- the patient and doctor and hospital relationship is going to be kind of like you and I going to sit down with maybe our financial advisor or some other person we might use to counsel us on a problem that we're having.

Our doctors and our hospitals are going to have to help us sort through a lot of this information, to make some of our best choices. So I think it's important that we really work to get these tools in the hands of that relationship of the consumer and the provider.

I'll stop there and open it up for questions.

CHAIR JOHNSON: Well, thank you Jeff, for your comments and suggestions. At the very start of your discussion, you talked about your CEO's involvement with an organization looking at interoperability. Can you explain a little bit more

how that fits into this, number one, and the focus on interoperability and the "so-what" of all of that?

MR. HANSON: Well, the Commission on Systemic Interoperability came about through the Medicare Act a year or so ago, and really, that commission has come together to set up standards on what the system would look like, so it continues to talk to each other.

It's really -- and I think it's key that our CEO is sitting on the commission. I think that they really look to the large employers as a real key in their feelings in this particular arena.

But interoperability, in and of itself, is an absolute -- it's really not up for negotiation. At the end of the day, we want our doctors and hospitals, no matter where we get sick, and ourselves, too, to be able to talk to each other.

In the past, some of our health care systems have used technology in order to create a very proprietary system of care. So that once you're in their system, you kind of get locked into their system, because that's the only place that your

records are going to talk to each other.

What we've said is that that's not going to work, as we look at infrastructure of a society such as ours, that's mobile and global, that the systems have to talk to each other, that our medical records belong to the consumer, they belong to us.

At the end of the day, if we go down the road or we get sick somewhere, the ability of those systems to be able to talk to each other and to communicate is going to be vital. Not only to the system as we see it today, but also to our public health system.

You know, I got my degree in public health, which I think has gotten me involved some in the public health system. I think this particular issue of interoperability will have a profound positive effect on beginning to really see advancement in our public health care system in this country.

CHAIR JOHNSON: Who else would be on that commission? What types of disciplines?

MR. HANSON: Well, the physician community is obviously represented. People from the technology

community even more so than Verizon. Verizon really in some indirect way might play a role in health care, via wireless communications and tele-health.

Health care systems are involved. Clearly, the people from CMS I think are involved in the Commission as well. So they've tried to bring in all the stakeholders so they at least are talking to each other.

You know, as we move from a commercial -- as I retire and get to be post-65 and my records become part of the Medicare system, I would hope that they could talk to my records that are currently with Harvard Health Care here in Boston.

CHAIR JOHNSON: Thank you. Aaron.

DR. SHIRLEY: The slide on efficient and good quality and efficient and poor quality. What are some of the variables that contribute to that dichotomy?

MR. HANSON: Well, a whole lot goes into it. It's not just doing more and doing it quicker and in a more timely fashion. It's really some of the variables that go into it that we measure is what are

the adverse outcomes that a particular doctor or hospital might have. That's part of the measure.

Safety is part of the measure. It would be what -- are they achieving the outcomes? In other words, if you're looking at a diabetic patient, for instance, is there -- are their blood sugars under control? It's not just that you did a particular test.

So we look at outcomes. We look at the timeliness of the delivery of care in a particular situation, the setting it was delivered in. So it's a variety of factors that go into the efficiency and the effectiveness of the care.

DR. SHIRLEY: What's confusing to me, the efficiency measures the same in both cohorts of the efficiency measures?

MR. HANSON: In that particular slide, they are the same. It was hospital efficiency measures, based on Leapfrog measures.

VICE CHAIR McLAUGHLIN: Are the efficiency measures just cost?

MR. HANSON: No. Again, efficiency is

really a variety of timeliness, cost, the setting, the appropriate level of service that somebody got, given their disease. So in other words --

VICE CHAIR McLAUGHLIN: So how can you have -- incorporate in efficiency appropriateness of care, and on the other axis quality measures? Appropriateness and timing is quality. How can those be plotted against each other? We're totally confused.

MR. HANSON: Want to help me, because maybe I'm not understanding your question.

MR. FRANK: Your draft had over here high efficiency, high quality, or low efficiency, high quality. Then you had high efficiency, low quality, and you --

VICE CHAIR McLAUGHLIN: And now you're saying part of efficiency is quality.

MR. FRANK: Right.

VICE CHAIR McLAUGHLIN: That makes no sense.

MR. FRANK: That's confusing.

MR. HANSON: Well, maybe a better way to

put this, efficiency -- effectiveness really is more based on the quality, what are the outcomes that you're getting ad how effective are you in delivering the care.

Efficiency is going to be cost-driven, but it's not just based on how much you pay for the care. It's the setting that it was delivered in, and some of the other components that go into that.

VICE CHAIR McLAUGHLIN: But as part of the setting, you are saying that, you know, the appropriateness and stuff which is a measure of quality. It may be that you have a very narrow -- not you personally, but in this slide a very narrow definition of quality, and that a broader definition of quality, which is I think more widely accepted in the health services community, includes a lot of the things that whoever put together these data put in efficiency?

MR. HANSON: And quite honestly, I may not be the best person you have today to answer your question, because I don't aggregate this data.

VICE CHAIR McLAUGHLIN: Right, because I

suspect Richard might have been asking the same thing. In technical terms, it's impossible to have efficient or poor quality relative to good quality but inefficient, because efficiency, as a concept, you can only compare relative efficiency, controlling for the quality of the product being produced.

So in terms of an analytic framework, this can't work, which is why I thought "Oh, they're using the word "efficient' really just to measure cost differences." But then, according to your answer, it seems like a kind of mixture. So it is a bit confusing.

MR. FRANK: Yes, I'm almost sure. If it's not 100 percent cost, it's 98 percent cost.

VICE CHAIR McLAUGHLIN: Right, and so the word "efficient" really --

MR. FRANK: Right. It means cost.

VICE CHAIR McLAUGHLIN: It should be low cost and high cost.

MR. FRANK: Right, right.

CHAIR JOHNSON: Jeff, could we ask you to research that with the people who did the data?

MR. HANSON: Absolutely. You had another question?

MR. FRANK: Yes. I want to go to your last point, which is kind of, I think, a really interesting one, which is the thing about the doctor going back, in a sense, to a role that the doctor once had, which was like the management consultant for health care, right, and I think you called it financial analyst or something, financial consultant.

And yes. I think that's -- that is good, and that's sort of the ultimate decision support tool for a patient. What I was puzzled about is at the same time you've got that trend, which seems to make sense, you've also got more joint venture and more vertical integration between hospitals and doctors going on. How is that tension going to get resolved?

MR. HANSON: Well, I think part of the resolution's going to come clearly as how, what CMS does when they get into this game. I think the tension is going to get resolved because we currently are shifting more and more cost to the consumer. The consumer is increasingly getting more skin in the

game.

I think it's going to get resolved when they start demanding something different from the system than they currently demand, and understand why.

MR. FRANK: Can I get a follow-up? I heard a rumor, and I don't know if this is true, but maybe you can determine, that at least a couple of the big high deductible health plan vendors are giving sort of the types of report cards that you showed, and they're giving, you know -- and they're giving people the names of all the doctors in the network, but they're not allowing the prices of the doctors to be published.

That seems puzzling to me. I mean, I understand why they wouldn't want it, because they're negotiating prices and they don't want everybody to know them. On the other hand, how can you say that somebody's got skin in the game when they don't know --

MR. HANSON: That's exactly what we're trying to get at.

(Simultaneous discussion.)

MR. FRANK: So are you guys going to try to force them to publish their prices?

MR. HANSON: They should have that information.

MR. FRANK: That's going to be a war. Okay.

MR. HANSON: Well, it is going to be a war.

MR. FRANK: Right. Have you heard that rumor too? Yes, okay. So it's not a rumor.

(Simultaneous discussion.)

MR. HANSON: Currently in the contracts, doctors and hospitals have with the health plans prohibits any publication of that information.

MR. FRANK: Right, right. So how you can possibly get people to shop on value?

MR. HANSON: You can't, given the current setting.

MR. FRANK: And you guys are trying to do something about that?

MR. HANSON: Exactly.

MR. FRANK: Great.

CHAIR JOHNSON: Catherine, another one?

VICE CHAIR McLAUGHLIN: I have a different question, but to follow-up on that, it's also the case that for a lot of employers, the premium that they then put forth to their workers for their choice, even when they given them either HEDIS measures of some kind of five stars, two stars, thumbs up, smiley faces, right. There are a whole bunch of them.

But the premium is usually subsidized at different rates according to how the employer wants to drive the employees. So once again as Richard's point, the employees almost never know the actual premium of the plan. They just know what the employer lets them know, in terms of the out of pocket part of that premium.

So I mean there's a group of us at Michigan who studied GTE and GM and a variety of corporate things, and they're all that way, and for good -- and for reasons, like Richard just said, that they don't want to release that information.

My question was more on the Bridges to Excellence. I'm talking about diabetes. I know that

there's quite a bit of action on self-management for diabetes, asthma, and heart disease. Those three, you know, you talk about two of those three and the results.

For obvious reasons, the Bridges of Excellence went after the easy ones. They went after the ones that there's a lot of evidence from the health behavior, health education literature that something can be done, you know. I'm sure Noreen Clark is disappointed you didn't do asthma, because at Michigan, that's her big thing, self-management for asthma.

But those are ones that, you know, it's really, really clear that something can be done. So, you know, that's a win-win. You know, it saves resources and the person's healthier, and does better.

Nonetheless, it's a small percent of the population, and it's actually a small percent of the dollars. Are you going to try -- not you again personally, but are you going to try to push into things that are much more difficult to change patient behavior, or things like dementia, where you can't

expect self-management, or other issues like that? Or do you think that this is it?

In other words, this is great. It saves some money at the margin, it makes some people's lives better, but this is sort of it. We're not going to be able to broaden the scope beyond this handful of chronic diseases, where those kinds of improvements can be made?

MR. HANSON: It's going to be a challenge, and I think you're right. We picked the easy ones primarily because there were some very agreed-upon -- there was a lot of consensus around how to measure quality in outcomes around the provider community in diabetes and in cardiovascular, controlling hypertension and stuff like that.

I'll give you an example. At Verizon, depression is our number one short-term disability cost driver. But I think what we face there is so many -- I think when you get beyond some of these initial low-hanging fruit, there is so much gray area, even in diagnosis.

It's not a black and white -- depression

isn't a black and white diagnosis, and neither is any kind of outcome measurement. So would we like to get there? Absolutely, and our goal is not to stop. We're going to look at cancer and low back pain. But again, those probably have some pretty clearly-defined kinds of outcomes right now.

We're talking about it. We're talking with some people in the mental health field about how would you even begin to measure depression, because that is, for us, a big, big issue, because it's not only a stand-alone issue; it's also one that cuts across some of these other medical diseases we have.

It's not going to be easy. I don't think we're going to stop. I mean, our goal is not to stop with just this low-hanging fruit and say that we've succeeded, by any means. I think our idea is to stay in the game until the system is transformed, until everybody in the system -- the whole system kind of looks at it this way.

But I think it's going to be terribly difficult, until there's some really good economic statistics and measures out there that say this is

what you can do. I think we have ways of getting closer. I don't know. I wish I could say yes. But we think about it.

VICE CHAIR McLAUGHLIN: We could stop our travels, but we have --

MR. HANSON: Yes. We want to probably start in somewhere else if we could have, because you're right. I mean -- but diabetes was an easy shot. But I think it was good to start there, just it was good to start there, because I think we needed to win the trust and the buy-in from the system. I think this is one good place to start. I think now, this will give us a good foundation to look at some of the things you are talking about.

CHAIR JOHNSON: Before we get to Dottie's question, Bill, just a slight amendment to Catherine's. Would you say that same thing in merely evaluating performance and outcomes of physicians, as opposed to pay for performance? Would your response be the same?

MR. HANSON: On Catherine's question?

CHAIR JOHNSON: Yes.

MR. HANSON: Yes.

CHAIR JOHNSON: Dottie.

MS. BAZOS: Just if you could expand a little, and sort of build on Catherine's question. Do patients -- do employees stay long enough with companies now for you to be interested in prevention, in you know -- would you -- long-term gains for an employer if you put money into performance measures for prevention? Is that something that you're looking at as well or not?

MR. HANSON: Well, we do look at it. You're probably asking the wrong employer, because the phone company notoriously keeps its employees forever and ever. We're Ma Bell, as you know. We have employees that are -- I think our average length of tenure right now is somewhere close to 20 years.

So there's a high degree of interest with us. But even as I get out there and talk to my colleagues, it's a high degree of interest to all of us, because even in our wireless division, where there's probably a lot more movement between companies, people recognize that they're going to come

to our company.

It's not -- what may be your cost burden today could turn out to my cost burden tomorrow. I think we all recognize that this is getting the buy-in of consumers in general, because at the end of the day, we have a vested interest in our entire population of employees being healthy and well and at work and productive. Whether they work for me today or they work for you next year, we've kind of swapped chairs.

That never used to be the case. I think you had a lot of people saying "Well, they're just going to leave me next year and I don't care."

MS. BAZOS: Right. So you're now very particularly interested, because you've chosen now diseases to focus on, or surgeries to focus on.

MR. HANSON: Right, right.

MS. BAZOS: So will your next step be to focus on pay for performance, to make certain that the people who work for you are getting the preventive measures they need, and to embrace, again, healthy lifestyles?

MR. HANSON: Right, exactly. That's where

-- the CEO of my company, at least six times a year, says "Why am I in the health benefits game?"

MS. BAZOS: Is that what you were talking about when you talked about you're seeing this as having a big impact on the health of the public? Is that where you were going?

MR. HANSON: Yes. Because I think, you know, a lot of companies would like to be out of the health benefits business. We don't do it for homeowners insurance. We don't do it for your car insurance. It was really a marketing strategy to retain employees.

But I think a lot of big companies, and GM would probably be the loudest one right now if you read about them, would like to be out of the health benefits business because of the costs.

But we don't have a marketplace to support individuals going out and buying good health care. We don't have the information for you to access good health care.

Even if we got out of the game, the CEOs of the companies recognize that we still have a vested

interest in seeing that the system delivers good quality care, preventive care to keep people from getting sick, because this is our work force out there.

Whether they're going to come to work for me tomorrow, for you tomorrow, this is our work force, and it's got to be a work force that we all are out there trying to grab. We have a vested interest in looking at it collectively.

So I think you're seeing employers have definitely changed from the high-flying 90's, where we just wrote our checks for the premiums and couldn't be bothered. We see this as a much better end game for us than just looking at benefit design, for instance, and raising co-pays. We're going to be in the health and wellness arena in a big way for the rest of the company life.

MS. BAZOS: Thanks.

VICE CHAIR McLAUGHLIN: Just, you know, that you were bringing, touching up on two things. One is the financial role of employers with being in the health benefits game. But the subject that you

brought up was the employer being in sort of the screening role in the health benefits game as well.

That those go back to the comment that caused you to laugh, because you know exactly what I'm talking about, the happy faces. The average worker cannot assimilate HEDIS measures. You can't give them raw HEDIS scores and have them understand that.

So I think that what you were alluding to is that the employer is serving a very important role in screening.

MR. HANSON: Yes.

VICE CHAIR McLAUGHLIN: Then the question is the employer paying the financial screen, versus the employer paying -- this is for someone else to say, not me -- the quality screen. GM is pushing on one of them, saying I can't do it anymore, and you're pushing on the other one, saying that we have to.

Is there -- could you envision a marketplace situation that would provide both of those screens? Does it have to be through the employer, in other words, is what I'm saying? Could there be an alternative in the marketplace, in your opinion?

MR. HANSON: Well, I think the consumer's going to make, ultimately should make that screen, and have the information to do that with. I think as an employer we'll always make some sort of screening, and it may not always be based on finances.

I think the way we envision our long-term for us working is that we would still be out there doing some quality measures of what's in the marketplace for you to buy. Maybe we'd give our employees X number of dollars a year to go out and buy their own, or at least offer them reduced rates, because we buy en masse.

But we'll tell them what it is they're buying, and we'll do quality measures because we do know all of our health plans. We do quality measures, based on HEDIS scores and we gel it down. We use stars. We don't use happy faces.

But I think ultimately there has to be a central -- is that the government? It could be the government? It could be CMS that actually goes out there, as they start representing some consensus of performance measures and measurements in general.

Whatever measurements they go out with and start publicly reporting on, you and I, whether we're Medicare or covered by one of their programs, will probably have access to that kind of screening, and will be able to make choices based on what they do.

VICE CHAIR McLAUGHLIN: What it's been earlier said not everyone works for employers that give them the stars. Not everyone works for an employer, even if they are offered insurance, that gives them any of that information. Small firms often don't screen at all. They take the only plan with a premium that they think they can possibly pass on.

So it's one thing for Verizon and GE and GM and Motorola and GTE to do this. But a substantial number of our workers aren't -- don't have that luxury. I think there is -- this is one of the things that we've been asked to look at, is this interaction between cost, quality and coverage, and sort of can the marketplace sustain it.

On all three of those elements, there are people saying that the current employer-based system is going to fail on one if not more of those elements.

You know, sort of you talked about CMS. What kind of public-private partnership maybe could take place?

MR. HANSON: I think ultimately the employer can weigh in. I personally think that the government, some entity, whether it's one that exists today, whether it's NCQA, where the consumer becomes much more aware of, as an accrediting kind of organization. But somebody out there needs to be the repository for these quality measures for all of us.

Because do we do it for our employees? Yes. Do they trust us? We don't know. I think they ultimately are going to have to have a third party out there that you're alluding to, that may or may not already exist.

Again, it could be an arm of the federal government today or an agency of the government, or even something new that's out there, as the quality place that we would even direct our own employees to go. This is where you need to go.

I think that's what Leapfrog is trying to do in its own small architecture of its inpatient patient safety survey, saying if you want to know

about safety of your hospital, you can go here. This is how it's measures and we try to gel it down. But they can't reside in ten different places, ultimately. I think we need a repository.

But I think the employers can certainly weigh in on what those measures are going to be like, because I think we're going to have a lot of information on what's affecting absenteeism. It's of great importance to look at.

CHAIR JOHNSON: Last question to Dottie.

MS. BAZOS: It's just a question. New York state for a long time has reported the CABG mortality rates for each of their hospitals, down to the provider. I think what they're finding or found, I mean, the quality has improved. Mortality rates have gone down.

But I don't think that they saw a huge shift of consumers being driven to better quality hospitals. What I think what they saw is because the data were published, the hospitals and physicians improved.

MR. HANSON: Oh yes, oh yes.

MS. BAZOS: So is there -- do you -- are you trying to serve that role as well, I guess? Is that a role that you would serve to sort of publicize data just to sort of create this ripple effect of improved quality, just because the data is there?

MR. HANSON: Yes, absolutely.

MS. BAZOS: And outside of your organization as well?

MR. HANSON: I mean, that's one of the downstream effects we're hoping will happen, and we have seen that, is that the reporting of this quality is going to -- it has -- causes improvement overall.

Ultimately, that's what we're going to need. I mean, in Boston, I don't know that I can shift a whole lot of people to some of the providers that are already accredited in this program. They may not have the capacity to take them.

So part of -- a very deliberate part of this program is to try to raise the entire quality across the system, across all providers. We found initially that just the reporting of that data out there is going to do that, because then what we hear

is some of the providers who didn't qualify the first year are coming back the second year, and have made improvement in their practices to now qualify the second time around, in terms of their obligations.

I think we're also trying to play a role, just within our own company, of trying to educate our members where to look for information that's out there today, and it is in a variety of places. I don't think that's an ideal situation to look at it.

Then we haven't yet created benefit designs that incent them to access some of that, but that's happening amongst employers. Some of the employers I've worked with already have incentives for their members who go to Leapfrog-designated hospitals, already have incentives for their members who go to particularly physicians who meet --

MS. BAZOS: But then you might end up going to one hospital for one procedure and another hospital -- I was thinking about that from a patient's perspective.

MR. HANSON: Right.

MS. BAZOS: It would be a little bumpy in

the beginning.

MR. HANSON: It will be a little bumpy in the beginning.

CHAIR JOHNSON: Well Jeff, thank you very much for your presentation and your response to our questions. We appreciate it, and we'll look forward to an e-mail from you regarding the definition of efficiency and how it's measured. I'm sure it will be helpful to all of us. Thank you very much.

I'd like to adjourn the formal part of our hearings, but just before we do, Richard again, we'd like to thank you. Our time together has been fruitful and helpful, and we've not only learned a lot but we've been in a good place to do that. So thank you very much.

Our formal meeting will be adjourned. I have a quick question. Those of you who have not made cab arrangements yet, who would like to do so and who needs a ride to the airport?

(The meeting went off the record momentarily)

CHAIR JOHNSON: Some of us have wanted to

have a discussion, a debriefing regarding our meeting last night. What went well and what are some lessons learned. To what extent would you be available for a phone call, either this Friday or next at our regular time, which would be 3:00 in the afternoon Eastern Time?

Let's -- since some of you don't have calendars, we'll send an e-mail out to you, for you to respond, regarding your availability. That's something just to keep in mind. Thank you very much.

(Whereupon, at 2:32 p.m., the meeting was adjourned.)