

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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Monday, April 11, 2005

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Agency for Healthcare Research and Quality
540 Gaither Road
Rockville, Maryland

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8:30 a.m. - 5:00 p.m.

MEMBERS PRESENT:

- RANDALL L. JOHNSON, Chair
- CATHERINE G. McLAUGHLIN, Vice Chair
- FRANK J. BAUMEISTER, JR., Member
- DOROTHY A. BAZOS, Member
- MONTYE S. CONLAN, Member
- RICHARD G. FRANK, Member
- THERESE A. HUGHES, Member
- PATRICIA A. MARYLAND, Member
- ROSARIO PEREZ, Member
- AARON SHIRLEY, Member
- DEBORAH R. STEHR, Member
- CHRISTINE L. WRIGHT, Member
- MICHAEL O'GRADY, Assistant Secretary for Planning and Evaluation, Department of Health and Human Services

STAFF PRESENT:

LARRY PATTON, Senior Adviser to the Administrator,
Agency for Healthcare Research and Quality
Ken Cohen, Department of Health and Human Services
ANDY ROCK, Department of Health and Human Services
CAROLINE TAPLIN, Department of Health and Human
Services

SPECIAL PRESENTERS:

SENATOR ORRIN HATCH
SENATOR RON WYDEN
CAROLYN CLANCY, Director, Agency for Healthcare
Research and Quality

CITIZENS' HEALTHCARE WORKING GROUP
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1 just a second, and then we're going to hear from
2 Senator Orrin Hatch and Senator Ron Wyden regarding
3 their perspective on the Working Group as well.

4 But before we proceed further, let me just
5 ask each of you to introduce yourself, those of you
6 who are Working Group members, and where you come from
7 -- no more than 10 seconds each and we'll give you
8 more time later -- and then we'll ask Cassandra
9 Browner to introduce the oath of office to us. So,
10 Christine?

11 MS. WRIGHT: Chris Wright, Sioux Falls,
12 South Dakota.

13 DR. SHIRLEY: Aaron Shirley, Jackson,
14 Mississippi.

15 MS. STEHR: Deb Stehr, Lake View, Iowa.

16 MS. PEREZ: Rosie Perez, Houston, Texas.

17 MS. MARYLAND: Patricia Maryland,
18 Indianapolis, Indiana.

19 MS. CONLAN: Montye Conlan, Ormond Beach,
20 Florida.

21 MS. HUGHES: Therese Hughes, Family
22 Clinic, Los Angeles, California.

23 MR. FRANK: Richard Frank, Boston,

1 Massachusetts.

2 MS. BAZOS: Dorothy Bazos, Concord, New
3 Hampshire.

4 DR. BAUMEISTER: Frank Baumeister,
5 Portland, Oregon.

6 MR. HANSEN: Joe Hansen, Rockville,
7 Maryland.

8 MS. CLANCY: I'm Carolyn Clancy, the
9 Director of the Agency, and you'll be hearing from me
10 a little bit more formally later today.

11 VICE CHAIR McLAUGHLIN: Catherine
12 McLaughlin, Ann Arbor, Michigan.

13 CHAIRPERSON JOHNSON: Well, thank you very
14 much. Cassandra, we will turn the next part of our
15 meeting over to you.

16 MS. BROWNER: First off, thank you all so
17 much for having me out this morning to do this. After
18 37 years of doing this, I still get excited. Thank
19 you all so much on behalf of Stephen Perry, our
20 Administrator. We certainly do appreciate you all
21 letting GSA take part in providing this administrative
22 support to the Working Group. That being said, would
23 you all please stand, those to be sworn, please raise

1 your right hand. After "I", please all repeat your
2 names and the oath after me.

3 (Whereupon, the members of the Working
4 Group was sworn in en masse.)

5 MS. BROWNER: Thank you all so much.
6 Would you please sign now your "Oath of Office". And
7 again, on behalf of our Administrator, we thank the
8 Working Group, and if you need anything from us in the
9 administrative area, please, we are just a phone call
10 away. Thank you.

11 CHAIRPERSON JOHNSON: Thank you very much.
12 Well, thank you each again for joining us. We have
13 had a number from Health and Human Services who have
14 been working with us and helping us get started, and
15 we also want to thank David Walker and Marjorie Kanof
16 from the Government Accountability Office for their
17 role in getting this project moving forward as well.
18 But there were two people who worked to develop the
19 concept of the Citizens' Healthcare Working Group
20 earlier than any of us, and that is Senator Ron Wyden
21 and Senator Orrin Hatch.

22 And just briefly, I'd like to introduce
23 you to them, and then we'll turn our meeting over to

1 them to share their perspective on this Working Group.

2 Senator Hatch has been a member of the
3 Senate since 1976. Now, when I think of that, that's
4 almost 30 years. And I can remember, Senator Hatch,
5 when you were dealing with health care in the '80s,
6 and Senator Hatch has been a significant contributor
7 on health care initiatives over his years in the
8 Senate. A graduate of Brigham Young and the
9 University of Pittsburgh, on a variety of committees
10 that deal with health care -- the Senate Finance
11 Committee, the Senate Health Committee, the Judiciary
12 Committee, as well as on the Joint Committee on
13 Taxation. So, we are just delighted that you are here
14 today to share your perspective, and we honor you for
15 your role in serving U.S. citizens in terms of health
16 care and other issues nationwide.

17 Senator Ron Wyden came to the United
18 States Senate in 1996 after serving 15 years in the
19 House of Representatives. Graduate of Stanford, with
20 a law degree from University of Oregon. Anybody who
21 knows Senator Wyden understands his sense of passion
22 on the health care initiatives, and we are the
23 beneficiaries of that this morning. So, we thank you,

1 Senator Wyden. Serves also on the Senate Finance
2 Committee, Select Committee on Intelligence, the
3 Budget Committee, the Special Committee on Aging, and
4 there's another feature that I found interesting in
5 looking at his background, it's more important to me
6 as I go year by year, and he's been a professor in the
7 subject of gerontology over the years. So, we're glad
8 you're here. And, Senator Hatch, since you have the
9 seniority on Senator Wyden, we'll ask you to go first
10 if you would, and we're just glad you're here, and
11 we'll take whatever time you'd like to share your
12 perspective.

13 SENATOR HATCH: Thank you, I'm delighted
14 to be with you. I'm very respectful and appreciative
15 of your willingness to serve on this committee. And of
16 course, I want to particularly welcome Randy Johnson,
17 the Chairman of the Citizens' Working Group, and
18 Catherine McLaughlin, two excellent people who I think
19 will do an excellent job helping us all to understand
20 health care better.

21 I want to compliment Senator Wyden. He
22 came to me a long time ago and said, "I have a really
23 wonderful idea". And the more I looked at it, the more

1 I thought about it, I thought, well, you know, it's
2 not a bad idea. Let's get a citizens' group that can
3 work outside the congressional box because, as you can
4 see, we've messed up a lot of health care in this
5 country. We'll work outside that box, be independent,
6 and really look at the real problems of health care in
7 our society, and not be subject to parochial interest,
8 and try to come up with a way or set of suggestions,
9 or legislation, if you will, that will help us to save
10 our health care programs in America. It's no secret
11 that we're going downhill rather rapidly.

12 The President has mentioned that Social
13 Security is a very, very serious problem as it is.
14 There's no question we need to resolve some of the
15 problems and conflicts of Social Security. But
16 compared to Medicaid and Medicare, it's a zero
17 problem. I shouldn't say zero, but it's a 1 on a
18 scale with 100 being the most important. The fact of
19 the matter is that we could find ourselves over the
20 next number of years actually not being able to give
21 the health care that we give today, let alone giving
22 better quality health care for people down the line.

23 So, the assignment you have is a very,

1 very important assignment. The first thing you should
2 do is ignore Senator Wyden and me. We should not be
3 giving you our ideas, although we'll give you plenty
4 of them this morning probably. You should ignore
5 anybody and just look -- ignore anybody and pay
6 attention to everybody. In other words, many of you
7 have had distinct experience with some of the federal
8 health care problems, but it isn't just the federal
9 government, it's the State and local governments as
10 well. It isn't just the large pharmaceutical
11 companies, it's the generic pharmaceutical companies
12 as well.

13 Long ago, we worked hard to pass in 1984
14 the Hatch-Waxman Act which created the modern generic
15 drug companies and industry. At that time, generic
16 drugs were like 16 percent of the total output of
17 prescription drugs. Today it is over 50 percent. And
18 we have saved consumers \$10 million a year every year
19 since 1984, and probably more than that today because
20 of thinking outside the box and getting one of the
21 leading liberals in the House, Henry Waxman, and one
22 of the conservatives in the Senate, Orrin Hatch, to
23 get together, bridge the faults and the problems and

1 the irritations and the complexities and the partisan
2 politics, and do something that really does work.

3 Now, some people think we should adopt
4 what I would call socialized medicine--that means
5 everybody would get the same care-- but I think you
6 ought to look at that very carefully. Others think we
7 ought to adopt a total private system.

8 Doctors complain that they don't want to
9 make Medicaid patients anymore just because of the
10 paperwork. That's a big problem. If there's a way
11 that we could somehow alleviate a great deal of the
12 paperwork, we'd save a ton of money in the health care
13 industry.

14 I might add that one of the biggest
15 problems is something I had expressed when I was a
16 younger practicing lawyer -- I defended doctors,
17 hospitals, nurses, health care providers, et cetera,
18 in medical liability cases. We would tell doctors
19 when we lectured to them, "You should make sure you
20 have everything in your history that could possibly go
21 wrong, that you've examined that, so that your history
22 shows you did not only the standard of care in the
23 community which back in those days was the legal

1 liability, but that you went way beyond the standard
2 of care.

3 Consequently, we all like defensive
4 medicine, we all want defensive medicine. We want
5 doctors to do their best to help us to rule out any
6 and all possible problems -- but because of that, I
7 estimated 25 years ago that there was \$300 billion
8 spent on unnecessary defensive medicine. We all want
9 defensive medicine, but there's a difference between
10 necessary defensive medicine and unnecessary medicine,
11 and drawing the line is a very, very difficult thing
12 to do. And I can't blame any doctor for wanting to go
13 the full length of medical services to make sure to
14 rule out any possible problem that might exist.

15 In the old days, if you came in with a
16 common cold like I have -- they'd say take two aspirin
17 every six hours, drink all the liquids you can, and in
18 seven days you're going to feel better, or if you
19 don't do anything, in seven days you'll feel better.

20 Today, if you go in with what you think is
21 a common cold, they may have a whole battery of tests
22 that they're going to do that run costs up
23 tremendously because they can't afford to take the

1 chance that this might be the one in a million case
2 where they miss some dread disease or some dread
3 allergy or some dread problem that can lead to a
4 lawsuit.

5 Now, if the American Medical Association
6 estimates that there's about \$67 billion in
7 unnecessary defense medicine, can you imagine what it
8 must really be, because they are never going to admit
9 how much it really is. On the other hand, there are
10 cases that really deserve huge settlements. I
11 personally have seen -- these are top doctors, by the
12 way--the wrong eye taken out, the wrong leg taken off,
13 the wrong kidney taken out.

14 Now, I think we'd all agree that you can't
15 have a \$250,000 or \$500,000 or \$750,000 lid on
16 damages, on noneconomic damages, if you have that kind
17 of a problem. I had one of the top medical liability
18 lawyers come to me recently and he said, "Senator, the
19 only way to solve this problem is to have
20 specialization" -- in other words, one must qualify to
21 bring about a medical liability case -- because that
22 gets rid of all the attorneys who are advertising for
23 these cases, who really aren't good trial lawyers for

1 the most part. I would never go to an attorney that
2 advertises, because if they have to advertise, they're
3 not very good, to be honest with you. Now, there may
4 be some good ones, but I haven't seen any.

5 The fact of the matter is that if you
6 specialize, according to this top lawyer, you get rid
7 of about 90 percent of the cases that are basically
8 frivolous. Why are they brought? Because it costs
9 between \$50- and \$100,000 to defend a medical
10 liability case. Now, what does that mean? That means
11 that if you have 10 or 20 of those a year as a
12 practicing attorney, you don't have to be very good
13 because the insurance company is going to want to
14 settle for \$50- to \$100,000 rather than go to a trial
15 and get a runaway jury that might hit them for
16 hundreds of thousands, if not millions, of dollars.

17 Now, this is a problem that we have to
18 resolve somehow in a fair decent way. It's one that
19 you're going to find continually crops up as you go
20 through the reviews throughout the country. You're
21 going to listen to everyday people who are going to
22 say that their biggest concern is health care. They
23 don't know what to do. Some of them can't afford

1 insurance. Then you have our young people who think
2 that they're going to be able to go on forever without
3 any problems, so they don't buy insurance. Then again
4 insurance is now costing an arm and a leg.

5 I remember about seven years ago, the head
6 of IBM -- I was sitting at a dinner with him -- and he
7 said to me, "Senator, we're paying \$7,000 a year per
8 employee for health care. If it goes any higher,
9 we're just going to give them the \$7,000 and say 'go
10 find your own'". Now, they haven't done that, to my
11 knowledge, but that's how serious it was then. Can
12 you imagine what is it now where health care is
13 approaching \$12-1300 a month?

14 Now, I don't know of a group in my time in
15 the United States Senate or in my work as an attorney
16 that has a greater potential, or a greater obligation,
17 or a greater hope than this group right here. You
18 really are important. This isn't just another run-
19 through. There are a lot of commissions that are
20 ignored in the breach. You cannot be ignored if you
21 really do this job well. And it can't be a liberal
22 approach, can't be a conservative approach, it's got
23 to be a right approach.

1 There are so many aspects of health care
2 that we could discuss, and I've taken enough time. I
3 just wanted to get out here, pay my respects to all of
4 you for your willingness to serve, to our two co-
5 chairmen for their willingness to serve and to hold
6 these hearings all over America, to their company and
7 university for being willing to let them do this, and
8 for all of you because you are all busy people, that's
9 why you're picked. Do you realize that of 500
10 applicants, you are the 14 who were picked--and you
11 were picked because we think that you can do the job.

12 We think that when you get through, you come up with
13 a bunch of suggestions, Senator Wyden and I are
14 willing to carry the ball and see what we can do to
15 get those through.

16 Now, I haven't even touched on mental
17 health. We're living in a day and age where we have a
18 lot of mental health problems. I haven't touched on a
19 lot of health problems, but mental health is one that
20 could eat us alive if we don't learn how to handle it
21 well. Even the medical school approaches are serious
22 approaches. When I went to the University of
23 Pittsburgh, it was one of the top medical schools in

1 the country - it still is -- where they were finding
2 all kinds of breakthroughs. The University of Utah is
3 also one of the tops in the country. One of the
4 interesting things about the Huntsman Cancer Institute
5 in Salt Lake City is that because of the LDS Church,
6 the Mormon Church -- called the Church of Jesus Christ
7 of Latter Day Saints -- which church has the best
8 genealogical system in the world. They can go back
9 generations in order to trace their illnesses. And so
10 the geneticists are attracted to the University of
11 Utah and Huntsman Cancer Institute because they can
12 trace these injuries and these genetic markers all the
13 way back. We need more of that kind of research. And
14 as you know, there are some very, very important
15 aspects of medical care that I'm not even touching on.

16 You really have an opportunity here, and
17 both Senator Wyden and I are very serious about
18 leaving you alone. We don't want the Congress of the
19 United States to start dictating to you what you
20 should look at or what you shouldn't look at. And
21 we're happy to answer questions. We're happy to give
22 you support, but really the best thing you can do is
23 ignore us and every other member of Congress. That

1 doesn't mean you shouldn't read our articles or you
2 shouldn't read what we have to say, but you should
3 ignore us personally because you're more important
4 than we are.

5 We haven't been able to solve these
6 problems. Now, we've done a lot of good things. I
7 can name a lot of health care bills that I've passed
8 through the years, and a lot that Senator Wyden has
9 passed. And in every case, we think they're pretty
10 good bills. But it's clear that we haven't solved the
11 problems. It's also clear that we're not in a
12 position to solve those problems without help, but we
13 are in a position to solve those problems if the ideas
14 that you come up with are really great ideas, and
15 they've got to make the practice of medicine, the
16 practice of science, very attractive in the end.

17 As you know, our young people aren't going
18 into science, engineering and science programs today,
19 and engineering is a very important part of medicine,
20 as you know. They're not going into it today. It's
21 too easy to become lawyers. Some think it's much more
22 lucrative to become lawyers. We've got to find some
23 way in our educational processes to get young people

1 into the field of medicine, into the field of science,
2 into the field of chemistry, genetics, and you name
3 it. Maybe you can come up with these answers, and I
4 think you can. And I want to compliment Senator Wyden
5 for his dedication to this group. He really feels very
6 deeply about it, as do I. He's an excellent Senator,
7 and we're both going to be there as kind of adjuncts
8 to make sure that we can break through some of the
9 problems that might exist. If you have problems, all
10 you have to do is get with us and we'll see what we
11 can do to break through.

12 Now, last but not least -- there are a lot
13 of other things I'd like to say, but I've taken enough
14 time and we might want to have some questions. Last
15 but not least, it is important that we analyze all of
16 our current health care approaches not only from a
17 Federal Government standpoint, but from a State and
18 local standpoint as well. It is important that we
19 find some way of encouraging the best of the best and
20 the brightest of the brightest to go into these fields
21 of science and medicine.

22 It is important that we think outside the
23 box; and that even though an idea might sound screwy

1 at the time, it might turn out to be the burgeoning
2 genesis of something that might answer a lot of
3 problems. We hope that you'll send us things from
4 time to time to keep us up to speed on what you're
5 doing because we're the two who believe more in you
6 than anybody else in Congress, and we're going to try
7 and help you in every way we can.

8 Again, I just want to thank you for being
9 willing to serve, for the expertise that you've
10 acquired over the years, for the faithfulness to our
11 country and to the people in this country who need
12 help, and I just want you to know that we're very
13 grateful to you. So, with that, I'll end and let my
14 colleague Senator Wyden take over.

15 SENATOR WYDEN: Well, Senator Hatch has
16 said it very well, and probably the only thing I
17 differ with him a little bit on is: feel free to
18 ignore me, but pay a lot of attention to what Orrin
19 Hatch says.

20 SENATOR HATCH: Well, I can agree with
21 that.

22 (Laughter.)

23 No, ignore me, too.

1 SENATOR WYDEN: If you look at the last 20
2 years in terms of health legislation, what's passed
3 has been important, nearly always has Orrin Hatch's
4 name on it including the Children's Health Initiative
5 and generic drug legislation. He's played down his
6 role in community health centers, which I think all of
7 us would agree has been an extraordinarily important
8 part of the health care safety net. So, you can live
9 without my various and sundry proclamations, but you
10 ought to pay a lot of attention to Senator Hatch as we
11 go through it.

12 Let me pick up on what Senator Hatch has
13 said and tell you that to some extent I see this
14 effort as the equivalent of hiking in the health care
15 Himalayas. You are out there trying to find a path
16 through frozen debates that we have been having for
17 decades. The way we got into this -- and Frank
18 Baumeister, my old friend from Portland, knows about
19 this because in Oregon we've had some experience
20 trying to walk through choices in health care and I've
21 spent about two years after the debacle of '93 and
22 '94, the Clinton Plan, just kind of gnashing my teeth,
23 I was so frustrated, as Senator Hatch was. Senator

1 Hatch and I wanted to get something done. We were so
2 frustrated because we really felt there was a time
3 when we could have done it. And I spent essentially
4 two years going back and reading everything I could to
5 try to figure out what went wrong. And I came to the
6 conclusion that we basically tried the same thing for
7 60 years, six decades, and that's what we hope all of
8 you will change.

9 If you look at the last six decades, and
10 you can literally go to Harry Truman in 1945, and the
11 81st Congress, and compare it to Bill Clinton in '93
12 and '94, and literally for six decades the same thing
13 was tried, and I would describe it as somebody
14 important -- a president, or a chairman of a committee
15 -- writes a bill in Washington, D.C. to provide health
16 care to everybody. Tremendous fanfare.

17 The American people look at this
18 legislation, kind of scratch their heads and go, "Boy,
19 this is complicated, I can't figure this stuff out".
20 Then the special interest groups attack the bill and
21 each other, and it all dies. And it is just
22 remarkable how for 60 years you're getting exactly the
23 same thing, literally six decades worth, from Truman

1 to Clinton.

2 So, trying to build on some of what I'd
3 seen in Oregon in terms of -- Frank, I think, will be
4 invaluable to you in giving you some of that history -
5 - Orrin Hatch and I started talking about something
6 very different. It starts with something that nobody
7 has ever done, which is to actually tell the American
8 people where the health care dollar goes now. Nobody
9 has ever done that, ever, ever, ever. It's astounding.

10 Never been done.

11 So, because of the tenacity of Randy and
12 Catherine along about the late fall -- I think Randy
13 and Catherine are talking about October or something
14 like that -- the American people will for the first
15 time get this breakout where the health care dollar
16 goes. They are going to be able to get it online.
17 Nobody has ever done that. I think that's going to be
18 attractive. But for the many people who are in senior
19 centers and grange halls and the like who might not
20 get it online, they are going to get it the old way,
21 hard copies. So, that first step, which I suspect is
22 going to be when people really see how incredible your
23 work is, is going to be a very important kind of

1 process.

2 Then of course that triggers all of the
3 steps in the statute. In fact, there's even a
4 beginning step before the report, which is you have
5 some hearings to educate yourselves and to gather
6 information for the report so that the country knows a
7 bit what you're up to as well. Do that first, then
8 the report, then the public participation process.
9 Two parts to the public participation -- one, the
10 initial part after you come up with some preliminary
11 findings, then you go back to them when you're
12 essentially ready to report to Congress. Then you get
13 to the last part which I think hasn't gotten much
14 attention, but the statute says the committees of
15 jurisdiction have got to hold hearings within 60 days
16 after you're done. So, that means that if you follow
17 the steps, we have an exercise, as Senator Hatch has
18 said, that is not some setting up a commission on
19 acoustics and ventilation or something -- you know,
20 another federal commission -- but you have had public
21 involvement and political accountability. Those are
22 the four words that I try to use to describe the
23 statute -- public involvement, political

1 accountability.

2 Now, nobody can force Congress to do
3 anything, but what we hope is that we will have a
4 citizens' roadmap at the end of this. We will have so
5 much involvement from people in every part of the
6 country that Congress will get this citizens' roadmap
7 from all of you, and Congress will say, "Hmm, here's
8 something now that we could really write a law that
9 would provide health care for all Americans and the
10 President of the United States would sign". So that's
11 a very important point that Senator Hatch touched on.

12 The idea is not to please Senator Hatch and Senator
13 Wyden, the idea is to come up with a proposal that's
14 going to provide health care for all Americans that
15 Congress will pass and that the President will sign
16 into law, and Congress will say out of all of this
17 public involvement and the fact that people have been
18 told how health care dollars are being spent--
19 reforming the health care system without the
20 information is like getting dressed in the morning in
21 the dark. How do you do it? Well, that's what you
22 have a chance to give folks the opportunity to do.

23 Now, I want to just give you a few of my

1 thoughts, just as Senator Hatch did, that come with
2 the right to exercise your constitutional right to
3 ignore.

4 The first is I come to this with a sense
5 that we're spending enough money today to provide
6 health care that works for all Americans. Last year
7 we spent \$1.8 trillion on medical care. You divide
8 \$1.8 trillion by 290 million Americans, and you could
9 send every family of four a check for \$24,000 and say,
10 "Here, buy your medical care". What that means is
11 that we could go out and hire an internist for every
12 four families in the United States for the amount of
13 money we're spending. That's an astounding thing. Go
14 out and hire an internist for every four families in
15 the United States and say, "Here, here is your
16 personal internist. He or she does nothing except work
17 for your four families". That's how much money we're
18 spending on health care.

19 So, I come to this -- again, your right to
20 ignore it -- with the sense that the biggest issue in
21 health care is not should we spend more, but can we
22 spend the dollars that are out there in the system
23 sloshing around in a more cost-effective kind of way?

1 Can we get more for that \$1.8 trillion than we're
2 doing today?

3 A second part of this picks up on
4 something Senator Hatch said as well, and that is that
5 I think that one of the factors that has derailed
6 health care reform in the past is what I call the
7 "blame game". If you go to a meeting about health
8 reform and legislators show up, they'll say, "Glad
9 you're doing it". And if they are Republicans, they
10 will say, "Ron, go to it, you're a good guy,
11 independent, go to it, we can reform this health care
12 system, just nail the trial lawyers. If you get the
13 trial lawyers", the Republicans say, "that will work
14 great". Then you go to a Democratic meeting to talk
15 about health care reform. They say, "Oh, you're a
16 good guy, got a lot of energy, we can get this done.
17 Nail the insurance companies. If you get the
18 insurance companies, that will do it". So, the
19 Republicans say it's the trial lawyers' fault, the
20 Democrats say it's the insurance companies' fault.
21 Right away, the first thing that goes on is the blame
22 game.

23 My sense is that part of what we need to

1 do to get health care that works for all Americans is
2 try to persuade all of these powerful interest groups
3 they are going to have to accept some measure of
4 reform, but we're not going to tell one of them they
5 are at fault. We're not going to get up one day and
6 say it's the drug companies' fault, it's the insurance
7 companies' fault, it's the trial lawyers' fault, it's
8 the providers' fault.

9 If you want to play the blame game,
10 there's enough to go around. I think that if you want
11 to go that route, you can do it. My sense is that any
12 successful effort will get beyond that kind of
13 consideration.

14 The personal responsibility aspect of
15 health care strikes me as very important. I think
16 that's what the debate about health savings accounts
17 has been all about, and flexible plans and the like.
18 I'm sure each one of you has your own ideas about
19 personal responsibility. One I'm attracted to is if
20 you want to make it simple, have somebody pay on the
21 spot every time they use a medical service in the
22 United States, unless they are destitute. If they are
23 destitute, you don't take any money from them, but if

1 they're not, somebody pays something when they walk
2 into a doctor's office, a hospital, a clinic,
3 something like that. You all have your own ideas
4 about personal responsibility.

5 Something I feel very strongly about is
6 cutting the administrative costs of health care. The
7 literature says that people who are conservative think
8 that administrative costs are maybe 6-8 percent.
9 People who are liberal, who are for single-payer
10 systems, say it might be 50 percent. Well, maybe it's
11 a third. You all will make your own judgment about
12 that. But if we're spending a third of the health
13 care dollar on administration and it's \$1.8 trillion
14 we paid out last year, that's \$600 billion on forms
15 and paper and bureaucracy and red tape. I bet you all
16 can tell us a lot more horrifying stories than we
17 know.

18 I think that part of this has got to focus
19 on what works in health care. I hope that you can be a
20 force post-Terri Schiavo in helping to bring the
21 country together because I think we understand that
22 the country is polarized. Much of the health care
23 dollar gets spent in the last few months of somebody's

1 life. The best doctors and the best hospitals tell us
2 that in many of those instances they can't be
3 medically effective and they can't do anything to make
4 the quality of the person's life better. So, what you
5 all recommend to us in terms of spending on what's
6 medically effectively, what produces better quality of
7 life for our citizens, I think would be very
8 important.

9 It was difficult three months ago, I think
10 it is even more difficult now, given the divisions in
11 our country with respect to this tragic case involving
12 Terri Schiavo, but I think this is an area where you
13 could make a big contribution.

14 Finally, I think there's a great
15 opportunity just in terms of getting understandable
16 information out to citizens about health care as part
17 of a reform effort. I mean, health care doesn't even
18 resemble English, when you look at it. When you look
19 at the verbiage and the words in the contracts and the
20 like, and you'll have your first crack at doing that
21 in terms of the health care report, but again you'll
22 have much better ideas than I can convey in a few
23 minutes here, but making this understandable to people

1 is obviously a big part of this.

2 Randy and Catherine, of course, your point
3 people, are going to have their hands full, and we're
4 grateful that they've been willing to do it. I met
5 with Secretary Leavitt, who is of course a close
6 personal friend of Senator Hatch. I think we're very
7 fortunate to have the Secretary's support.

8 Where is Larry Patton? Larry has just
9 been fantastic. Pattie DeLoatche and Stephanie
10 Kennan, from Senator Hatch's office and my office, are
11 available to you as well. Both of them have good
12 radar in terms of what somebody in Congress might
13 think about something, so if you're ever interested in
14 that, if you pick up a particular idea or not, I'd
15 urge you to call Pattie and Stephanie and take their
16 temperature on something.

17 Carolyn Clancy, many thanks to you for
18 being so helpful, between you all and Larry, the
19 detailees, are being brave and jumping in where nobody
20 has gone. I will tell you I personally think we've
21 got an opportunity that you don't get and isn't going
22 to come around again anytime soon.

23 When I was director of the Gray Panthers

1 for seven years before I got elected to Congress, I
2 sort of dreamed that I could be part of this. And
3 after six decades, folks, of trying the same thing --
4 I'm going to close with this -- what we want to do now
5 is to figure out a way to build the public in and to
6 make it so attractive that after that citizen
7 involvement aspect, you then have the kind of
8 political accountability where great coalition-
9 builders like Senator Hatch -- I mean, what will
10 really be the litmus test to this is if the kind of
11 product that comes from the citizens has the most
12 influential people in the Congress, people like
13 Senator Hatch and Senator Kennedy, say, "We can work
14 with this. We can really make something out of this".

15 Nobody builds a coalition in the United
16 States Senate better than Senator Hatch. Senator
17 Hatch and Senator Kennedy have done it time after
18 time. There are some young Turks like me that can be
19 of help to them, but that's what I hope we will do, is
20 to get a kind of citizens' roadmap so that Senator
21 Hatch and Senator Kennedy and people in the Congress
22 with gavels in their hands are going to say, "This is
23 really something we can build on". I personally think

1 we could have done this in '93. In fact, you'll
2 probably see -- Catherine has seen it -- floating
3 around in the files, a letter from Bob Dole and Bill
4 Bradley who were then on the Senate Finance Committee,
5 and Bob Dole said, "If we had done this in 1993 and
6 1994, we'd have gotten a bill. We'd have made it
7 happen". That's what people who were there then have
8 said.

9 So, end of my speechifying, and many
10 thanks to all of you. Buckle your seatbelts, folks,
11 this is going to be a different sort of ride, but one
12 where I think there's a chance to produce something
13 very exciting, and thrilled all of you are going to do
14 it.

15 SENATOR HATCH: We'd be happy to take any
16 questions that they might have.

17 CHAIRPERSON JOHNSON: Just before you do,
18 let me reintroduce Pattie DeLoatche, who is kind of
19 walking across the back of the room, who is a very
20 capable individual working with Senator Hatch, and
21 Stephanie Kennan over here, who is similarly capable
22 of working with Senator Wyden. Both of you have been
23 very helpful, and we appreciate your contributions to

1 our group already, and I just want to make sure the
2 Working Group connects the name with the face before
3 you leave.

4 Questions for Senator Hatch or Senator
5 Wyden?

6 (No response.)

7 I'll get the ball going a little bit,
8 Senator Wyden, with you. I've heard you say on a
9 couple of occasions "tell us where the dollar is going
10 for medical care". I'm assuming that you mean it's
11 going this amount to trial lawyers, and this amount to
12 -- more than this amount to trial lawyers and this
13 amount to insurance companies. Can you build on those
14 comments a little bit, please?

15 SENATOR WYDEN: Randy, you know, my sense
16 is you'll start with sort of the big areas --
17 Medicare, children, private insurance, various
18 government programs -- and then I hope as you all go
19 forward you can get it down to areas where there's
20 overlap and duplication and places where people might
21 say when they see it online, "Holy Toledo, we've got
22 to change this". I mean, people like Frank Baumeister
23 and physicians -- my sense is if you have a clinic

1 with five docs in it in Iowa or Oregon or somewhere,
2 you might have two people who do nothing except sit on
3 the phone trying to pry information out of insurance
4 companies about their matrix to figure out what
5 they're going to cover.

6 So, I think, Randy -- and I want to hear
7 what Senator Hatch thinks on this -- the idea of
8 starting with the big areas, the big ones up on the
9 canvas -- what employers are paying, and what's paid
10 for Medicare and VA and Medicaid -- and then to sort
11 of break it down from inside with a particular eye on
12 areas where you think there are inefficiencies and
13 duplications, and the opportunity to produce savings.

14 My guess is that particularly in administrative
15 areas, -- I mean, people tell me now that as we go to
16 electronic medical records, for example, just the fact
17 that we have had such a crazy quilt of rules and
18 programs, that we've got a lot of systems that aren't
19 interoperable and we're wasting money just there. But
20 start, in my view -- and I want to let Senator Hatch
21 speak on that -- with big items and then sort of break
22 them down. Orrin, do you want to add to that?

23 SENATOR HATCH: Well, one of my very close

1 friends was building the first fully digital
2 integrated hospital for Health South, when Health
3 South went south there for a while. I was really
4 interested in that because I wanted to see if they
5 could actually put it together so that they could save
6 an awful lot and be much more accurate in
7 prescriptions and other health care approaches.

8 There's no question we're going to have to go
9 to a system that really works. And I don't disagree
10 with Senator Wyden that you start with the big
11 programs-- I mean, let's face it, Medicaid and
12 Medicare are in trouble. They are very, very
13 important programs for our society. But I was shocked
14 -- my wife recently had a knee replacement, and I was
15 absolutely shocked at how much that cost. I hadn't
16 heard of many people having knee replacements until
17 she had hers, then almost everybody I knew had a knee
18 replacement, and those costs were multiplied
19 extraordinarily. It's going to be very, very difficult
20 to come up with an overall approach that basically
21 saves money, makes the system very efficient, and
22 gives incentives to people to be part of a system, and
23 that's going to be a very tough job for you, but it's

1 one I think you can handle.

2 Some people think, well, just have
3 universal health care. Everybody does the same thing,
4 we all get the same health care. Then there's a
5 tremendous argument against that on the other side.
6 We found many times in Congress bridging the gap
7 between the private sector and the public sector is
8 very important.

9 I'll give you another illustration. I was
10 at dinner not too long ago with a bunch of hospital
11 leaders in this country. One was from HCA, the
12 largest hospital chain in the country. And I asked
13 him, "How much uncompensated care do you give a year?"
14 And he said, "\$800 million a year", that they have to
15 absorb in their system. You wonder why you're paying
16 four bucks an aspirin? Well, there's your answer. I
17 probably shouldn't have chosen that illustration, but
18 literally these hospitals are giving a whopping amount
19 of uncompensated care because people don't have
20 insurance. On the other hand, some of the people who
21 don't have insurance could afford to have it.

22 One reason that I and Senator Kennedy came
23 up with the CHIP bill, the Child Health Insurance

1 Program, was because these were the only kids left out
2 of the system, they were the children of the working
3 poor. Everybody else -- the poor were taken care of
4 by Medicaid -- but everybody else was taken care of.
5 That system has worked very, very well, but I can
6 remember the tough time we had to bring that through.

7 The new litigation -- just so you know
8 this -- the new litigation that's going to cause
9 health care plenty of ulcers is the fact that a lot of
10 nonprofit hospitals have been paying huge salaries and
11 putting monies offshore in the Cayman Islands and
12 elsewhere, while at the same time giving uncompensated
13 care but then dunning the poor to death trying to make
14 sure they never come back. In other words, they scare
15 them to death so they don't come back. Now, that's
16 the new tobacco lawsuit.

17 Now, I don't mean to bring things down to
18 such a base level as that, but that's something we're
19 going to have to face -- how do we solve this problem
20 of uncompensated care and be fair to those who provide
21 it, without having government put more and more
22 regulations on everybody so that it costs an arm and a
23 leg? These are tough problems. And I have to say

1 I've spent 28 years -- I'm now in my 29th year in the
2 Congress -- working on health care problems, and I
3 haven't been able to solve them all, and neither have
4 those who have worked with me and with whom I've
5 worked, neither has anybody else in Congress.

6 So, we're giving you an overwhelming
7 responsibility that I really believe practical,
8 decent, down-home citizens could help with. Fifteen
9 years ago I passed a bill called The FDA
10 Revitalization Act. The FDA is in better than 30
11 different locations over the Greater Washington Area.

12 Some of them in converted chicken coops. You wonder
13 why they haven't hired a top researcher in the last 40
14 years? That's the reason. They want to go to NIH,
15 they'll even go for less money than they can make in
16 the private sector because of the prestige of working
17 for NIH, but they don't want to come to the FDA. So,
18 the FDA now takes up to 15 years of patent life and a
19 billion dollars for a prescription drug to come
20 through the process.

21 So, what I did is, I said, "We need to
22 revitalize FDA and create a central campus with state-
23 of-the-art equipment, digital equipment if you will,

1 among others, that will entice the best of the best to
2 come work for FDA. FDA handles up to 25 percent of
3 all of our consumer products in America. We treat it
4 like an illegitimate step-sister. Well, it just
5 started. We dedicated the first building in December
6 of 2003. But it's going to take ten years and probably
7 \$3 billion to get it done. It would have taken ten
8 years and \$1 billion if they had moved right in after
9 Congress, once we passed the FDA Revitalization Act.

10 Can you imagine what that would do to
11 maybe bring drug costs down if we had more efficiency
12 in the system and we could bring that loss-of-patent
13 law? You wonder why drugs cost so much? Basically,
14 drug companies have five years to get their research
15 and development costs back for those billion dollars
16 that they spent over 15 years, with 6,000 missed and
17 failed experiments to get to the 1 success. Now,
18 these are the kind of practical things that you're
19 going to have to get into. Plus, the new world of
20 science and medicine that is way beyond what anybody
21 in this room thinks today. You're going to find that
22 is going to crop up, too, as you meet with the top
23 health care providers.

1 You have some terrific support with your
2 staff and others on this Working Group. I am very
3 excited about what you're going to do. I really
4 believe that you, with your practical wisdom,
5 knowledge, and expertise, will be able to make some
6 very profound suggestions, maybe even create an actual
7 set of bills or bill that we might be able to carry,
8 Senator Wyden and I, and really put the pressure on
9 the whole Congress.

10 It's amazing to me how many people decried
11 this Working Group at first, but how many of them are
12 now looking, sitting back and saying, "Gee, I hope it
13 words", because if it works, you will have saved
14 America, at least in health care, but I think in much
15 more than health care. Ron was right in how much the
16 total costs of health care really are in our society
17 today. It's unbelievable how high it is. And like
18 you say, the answer is not to give everybody \$24,000
19 and say "get your own health care", the answer is for
20 us to find a system that's efficient, scientifically
21 sound, workable, with a minimum of bureaucracy and
22 paperwork, that encourages people to get into the
23 field and where we have a system that might help solve

1 this medical liability problem that is a much bigger
2 problem than most of my colleagues really understand
3 or think.

4 And it isn't just as simple as trial
5 lawyers and insurance companies; Ron knows that as
6 well, we both know that. It's a very, very serious
7 problem. If you can solve that problem, you may be
8 well on your way to solving many, many other problems
9 in health care that drive across beyond across beyond
10 where they should be driven.

11 We are both going to take a great deal of
12 interest in what you do. I hope that you'll keep us
13 informed through Stephanie and Pattie. They are two
14 of the best health care people on Capitol Hill. They
15 both work their guts out. These are not 40-hour-a-
16 week jobs, these are like 100-hour-a-week jobs, and
17 these two are so dedicated that we want them to listen
18 to you, not tell you what to do. And I don't want to
19 tell you what to do, and neither does Ron. But this is
20 really important. This is the first time we've tried
21 this. And if you hold these hearings all over America
22 and you hold them with everyday people, but also the
23 top scientists and the top medical researchers, the

1 top computer specialists -- I can see one on the
2 Redmond Campus with Microsoft -- I can see you going
3 to IBM to find out what they've got on their minds. I
4 think you're going to be so fascinated with this, that
5 some of you may get lost in it; it will be so
6 interesting to you. But the key is to come down with
7 practical solutions in the end that will help us to
8 maybe carry the ball and, if in the end you get
9 something done here that we can carry the ball on and
10 get enacted, you're going to go through the rest of
11 your life saying "I did it, we did it, and we've
12 helped save our country."

13 So, this is important, and I just
14 appreciate all of you. We're taking too much time to
15 answer these questions.

16 CHAIRPERSON JOHNSON: Well, are there
17 other questions? If you have a couple more minutes,
18 few more minutes, other questions from our group.

19 VICE CHAIR McLAUGHLIN: I actually have a
20 question that follows from what you were saying. The
21 reality is we have two years to do a lot, and some of
22 the examples the two of you have given are at a very
23 global level, and some are, as you just said, at a

1 very specific level.

2 Is the expectation that we come up with
3 recommendations as specific as some of the examples
4 that you have just given, or -- do you understand --
5 or a more global set? I worry that if we get too
6 detailed, that not only will we have the problem that
7 Senator Wyden mentioned of the public saying "what is
8 all this", but if it's not detailed enough, it's too
9 easy for it not to go anywhere?

10 SENATOR HATCH: Well, you have to do both.
11 There's no question you have to look at it globally,
12 but you also have to look at practical solutions. If
13 we don't have any practical solutions come out of
14 this, then your work will be wasted. If all we have
15 is esoteric concepts, our difficulties in getting a
16 health care bill through will be magnified beyond
17 belief. Then we've got to do all that work. Now, I'm
18 not against doing all that work if you can tell us
19 which way to go and so forth because we do it all the
20 time, but I'd sure like to have the best suggestions
21 you can possibly give us, and I think you've got to do
22 both. You can't ignore the global, but you can't
23 ignore the finite either. Then again, we can't expect

1 you to be saviors from on high to solve every problem
2 in health care in just two years.

3 VICE CHAIR McLAUGHLIN: But we're hiking
4 through the Himalayas.

5 SENATOR HATCH: That's what Senator Wyden
6 says and, if he says it, it must be so.

7 (Laughter.)

8 SENATOR WYDEN: I want to make the trek
9 with all of you and Senator Hatch. Here's how I've
10 come to feel about that, Catherine, and it is
11 something I've given a lot of thought to, as has
12 Senator Hatch. You're trying to strike a balance
13 between asking people in Des Moines and Tallahassee do
14 they want to pay 6.2 percent FICA or do they want to
15 pay 5.8 percent FICA, which obviously nobody can sit
16 out there and ask themselves this kind of thing, and
17 going the other way, do you want quality health care
18 for all Americans -- those are the two extremes, micro
19 detail and essentially platitudes.

20 What I hope you'll do -- and we can give
21 you some of this in terms of what we saw in Oregon
22 which was a different setting -- is to try to give
23 people enough information so that they can understand

1 the choices and the tradeoffs. I mean, a big part of
2 this, folks, is walking people through the choices and
3 the tradeoffs in a big picture sort of way. For
4 example, if you want this particular service and you
5 want to stay within the confines of the amount that's
6 being spent, are you willing to give up something
7 else. And I think if you do it that way, you can get
8 in the ballpark of what Senator Hatch is talking
9 about.

10 It's enough that it's really helpful for
11 the Congress without bogging people down in things
12 that are just incomprehensible. That's why areas like
13 administration and shared sacrifice and the like -- I
14 think we ought to learn something. I think that after
15 the Terri Schiavo case we'll see that more people want
16 to spend more on hospice and programs that unite
17 people rather than the divisive ones. I think this is,
18 in my view, about giving people enough information so
19 that they can really make choices and tradeoffs. I
20 mean, would they be willing to pay more out-of-pocket,
21 for example, in order to get a richer benefit for
22 people? There's a perfect example of a kind of
23 tradeoff that you would have to make. We all know

1 that we want Cadillac health care for Studebaker
2 prices, I mean, that's kind of how we got into this,
3 but I think --

4 SENATOR HATCH: Studebakers are pretty
5 expensive today.

6 (Laughter.)

7 SENATOR WYDEN: Now you can't get anything
8 in health care or anywhere else for those kinds of
9 prices. I think there's a reason for the title in this
10 bill called "Healthcare That Works For All Americans".

11 It took Senator Hatch and I three months just to get
12 the title of the bill, if you can believe it. Some
13 people said it should be "Access", some people say,
14 "Oh, some kind of National Healthcare", well,
15 "Healthcare That Works For All Americans" was
16 agreeable to all concerned.

17 This is not, as Senator Hatch has said,
18 just about the uninsured or about technology, all of
19 those are parts of it. This is about healthcare as an
20 ecosystem. What you do over here affects what you do
21 over there -- I think, Catherine, to the extent that
22 you can walk people through the choices and make sure
23 that they come to these hearings and say -- this is

1 one of the things that I woke up a few times as we did
2 it, at night saying, "My God, are people going to come
3 to these hearings and say, 'I really like Senator
4 Hatch, I really like Senator Wyden, and I want a lot
5 of chiropractic', and then people in the audience who
6 like chiropractic clap and everybody goes home?"
7 That's not what the community meetings are about.

8 The meetings are about trying to get
9 people to swallow hard and say, "I'm trying to think
10 about what it's going to take to create healthcare
11 that works for all Americans, and I showed up in this
12 drafty hall in Minneapolis or spent 45 minutes online,
13 with the idea being I think I've got to say we're
14 going to give this up in order to get that", and
15 that's right, to me, at the heart of this exercise, is
16 it's kind of forcing all of us to do what we've never
17 really wanted to do in health, where we just say we
18 want it good for our families and our loved ones, we
19 want them to have good care, and we want to have a lot
20 of it, and now we're trying to tell them it can't
21 really be that way if you want healthcare that works
22 for all Americans at their choices.

23 MR. O'GRADY: Back to Senator Hatch's

1 point for a second about this idea being both general
2 and specific in terms of just trying to think of what
3 that might look like at the end of a couple of years.

4 If there was something like nine principles, things
5 that focused on major things like making folks more
6 prudent consumers of their own healthcare, health IT,
7 some of those sorts of things, and then underneath
8 sort of those more global principles there were four
9 or five very specific steps that could be taken. Is
10 that the sort of product at the end of this process
11 that would meet their needs?

12 SENATOR HATCH: Go ahead.

13 SENATOR WYDEN: I just don't want to
14 filibuster. I don't think that maximizes --

15 SENATOR HATCH: I don't know why he
16 doesn't want to filibuster --

17 (Laughter.)

18 SENATOR WYDEN: I don't think that
19 maximizes your potential. I sort of started and
20 walked backwards. Here's where the \$1.8 trillion
21 goes, and then just make a list almost at the
22 beginning of all the areas where you might spend it
23 more efficiently. In other words, if you did nothing

1 else, you said here's where the \$1.8 trillion is
2 today. You tell everybody here are some opportunities
3 for changes and the like, and then you start with a
4 list of things where you might end up spending \$1.8
5 trillion. If you start with something like that
6 rather than with the principles, that would be my
7 sense in terms of trying to strike a balance. But you
8 all are going to find your own way on this. It is,
9 kidding aside, in the Himalayas, and nobody has found
10 the right path, but you know some things, for example,
11 about why people are falling off mountains in the
12 past, and some precautions to take and that kind of
13 thing, and that I think would be my seat-of-the-pants,
14 and maybe Senator Hatch has a different thought.

15 SENATOR HATCH: I appreciate all that
16 Senator Wyden has said, he's an excellent leader in
17 healthcare. I don't think there's any one way you can
18 do this, and you're going to have to come up with a
19 way of doing it, and you have to make those decisions.

20 But I remember -- just one illustration. I remember
21 in India people would line up for their prescription
22 drugs 500 at a time every morning until they charged a
23 quarter. The next day there were only five. You

1 don't even have to get into mundane things like should
2 there be a co-pay to make the system fair, so people
3 don't over-utilize the system.

4 That's a very modest thought, but it's a
5 very important one -- should we have a co-pay? Should
6 this \$800 million in uncompensated care that HCA goes
7 through every year, shouldn't those folks have to pay
8 something as they go to those emergency rooms? Should
9 they have to at least sacrifice something? To me, and
10 to those who think like I do, it doesn't have to be
11 very much, but it has to be something that says to
12 them "this is costly".

13 Now, that's a whole discussion that you
14 might want to go through, do we have co-pays and, if
15 we do, how do you make them fair and how do you do it?

16 You'd be shocked how many people go to multiple
17 doctors for pharmaceuticals that may be playing
18 against each other. You know that, Doctor, but it's
19 shocking. What do they say, 45 percent of America is
20 on prescription drugs? That's shocking when you stop
21 and think about it, yet you reach my age and you're
22 bound to have to take some prescription drugs, there's
23 just no question about it. But all of this, of course,

1 causes the cost to rise.

2 Now, I think you've got to look at it
3 globally, I think you've got to look at it narrowly, I
4 think you've got to look at it pre-enterprise, I think
5 you've got to look at government's role, and hopefully
6 you can balance all those interests and come up with a
7 way of making a system that will not be overutilized
8 by people but will take care of those who truly need
9 care.

10 Again, I cite to you the overwhelming
11 problem of mental health in our society today. We
12 haven't been able, as members of Congress, to come up
13 with answers there because the costs are always so
14 expensive. Senator Domenici, who is an advocate - as
15 am I -- gets depressed every year -- to use a mental
16 health term -- because he can't get his legislation
17 through because the costs are so overwhelming in this
18 day and age, and yet we're finding we have the
19 greatest pharmaceutical help for mental help that
20 we've ever had in the history of the world.

21 So, how do we afford those? How do we get
22 the cost of drugs down? How do we get the cost of
23 healthcare down? How do we get the paperwork down?

1 How do we get the Congress to be more responsible?
2 How do we get the medical liability problem solved so
3 that it's not eating the system alive? This is
4 exactly what's happening today, in my opinion, and it
5 may be partly the insurance companies' fault. There's
6 no question in my mind, as a trial lawyer, that it's
7 definitely partly the trial lawyers' fault. I think a
8 lot of that started when trial lawyers were able to
9 advertise, when the Supreme Court said they could
10 advertise rather than practice the profession without
11 advertising.

12 So, you may come up with a suggestion that
13 lawyers should not be able to advertise. Now, the
14 Supreme Court says they can, so you'd have to come up
15 with a very, very unique suggestion to get around that
16 problem, but I'm just throwing out a bunch of ideas
17 that are on the surface just to kind of get you
18 thinking how important your job really is.

19 Now, what I don't want to have happen is
20 that you get discouraged because of all the crap we're
21 throwing at you because we're throwing a lot of stuff
22 at you, and you think, "Holy cow, they can't do it and
23 there's 535 of them and there's only 14 of us." Well,

1 I'll guarantee you, the people generally can do things
2 better than Congress as a whole, I'll put it that way,
3 but Congress can do some wonderful things if they are
4 given the right ideas. So, you're our key to the
5 right ideas. And I for one am so grateful to all of
6 you for being willing to serve, and I hope you'll make
7 every meeting. If you can't, we understand, but I
8 hope you make every meeting. I hope you'll
9 participate.

10 I hope that you'll take it upon yourself
11 to realize -- sometimes you don't want to speak up
12 because you might think they think your comments are
13 not important. Don't ever think that, all comments
14 are important. And you'd be surprised, if this is
15 going to work, it's going to be because people are
16 concerned about the average American, not the average
17 Senator or Congressperson. I just want to thank you
18 for your service.

19 I certainly want to thank Senator Wyden,
20 who I happen to love and care for very much, for his
21 zeal with regard to this Working Group, and I think
22 you'll find that I'm just as zealous as he is because
23 when I get the bit in my teeth, there's nothing going

1 to stop me from getting it done. And I'm hoping that
2 you'll put the bit in our teeth and help us to get
3 this done in the interest of our country. It's the
4 difference between saving our country or having us go
5 the way of all flesh, like some great countries have
6 gone in the past. We've got to solve this problem,
7 it's absolutely monumental.

8 MS. MARYLAND: You mentioned I am actually
9 sitting here a little overwhelmed with the task that
10 we have before us, and I am a little concerned then
11 over the two-year period of time that we're to put
12 together a report, I hope there is an opportunity as
13 we start to present or start to formalize some of the
14 recommendations, that we have an opportunity to bring
15 those forward to your group, and maybe even to see if
16 there is some support perhaps in Congress to start to
17 have these ideas presented to them --

18 SENATOR HATCH: That's a good point.

19 MS. MARYLAND: -- because what I would
20 hate to see happen is after a two-year period we've
21 done all this work and it's like in '93, it would be a
22 failure. That would be very disconcerting to me.

23 SENATOR HATCH: Well, that's something you

1 should always keep in mind because '93 was an
2 overreach in the eyes of most people, I think
3 including Ron and myself, and it was a move towards
4 what the Republicans thought was socialized medicine.
5 But there were many good ideas that came out of that,
6 some of which are law today. There were a lot of
7 lousy ideas, too, in my humble opinion. But I think
8 it might be good every once in a while -- I don't want
9 us to interfere with your work at all -- but if you
10 felt like you wanted to come down to Capitol Hill or
11 here and just pick our brains, we'd be happy to do
12 that. But I'm going to try to not tell you what to
13 do. I mean, I've given you a lot of suggestions on
14 what you might consider doing, but I'm not going to
15 tell you what to do unless you ask me. Now, if you
16 ask me, I'm going to tell you what to do because I
17 know how to do it all, to be honest with you.

18 (Laughter.)

19 I'm just kidding. Nobody knows how to do
20 it all, that's why you're here. And, frankly, each
21 one of you brings to this table and to this Working
22 Group a whole set of life experiences that could
23 benefit the whole country, if you can all work

1 together. If I hear of any fistfights -- even that's
2 good sometimes, but not very often -- but I just think
3 that nobody should be afraid to speak his or her
4 ideas. Sometimes the greatest ideas come from the
5 most simple practical suggestion, and I can give you a
6 lot of bills that are law today that came from simple
7 practical suggestions from experts like you.

8 So, you know, we sometimes get lost in the
9 thickets in the Congress because of all the conflicts
10 and problems that we have. But you'd be shocked, if
11 you come up with a really workable approach that
12 America can accept, the whole Congress is going to be
13 afraid to ignore what you come up with. And Ron and I
14 will make sure that they are afraid, we'll see to it
15 for you. And I think the key is to be open, to be
16 open to all ideas, and to not think anybody's idea is
17 stupid, and of course to have regular working meetings
18 where you're just sitting down and brainstorming
19 together as well. That's up to your two co-chair
20 people, but I think you can do a lot in those type of
21 meetings as well, after you've had a lot of hearings
22 and so forth.

23 But I just want to again thank Senator

1 Wyden for allowing me to work with him on this and for
2 the hard work he does in Congress, especially in
3 healthcare, and I want to thank each of you again for
4 your willingness to serve. This is a terrific thing,
5 I'm really caught up in it myself.

6 SENATOR WYDEN: Randy, can I pick up on
7 this just for a second because I think Senator Hatch
8 really was instrumental as we wrote this bill in
9 making sure that you went in with a clean slate. For
10 example, along the way I would have one idea or
11 another, Senator Hatch would sort of take me aside and
12 say, "Ron, that's a good idea, but you can't start
13 skewing the kind of process, this is supposed to be a
14 clean slate for the citizens". So, this is not
15 something like in '93 and '94, Bill Clinton produced
16 1,290 pages that was so dense it was sort of
17 incomprehensible, and that was a big factor in it not
18 going forward.

19 You can bounce ideas at any step along the
20 way off us, and Pattie and Stephanie are available to
21 do it. Randy and Catherine, as we talked, we found
22 that Senator Dole and Senator Kerrey, Bob Kerrey, are
23 available to have you bounce ideas off them, and both

1 of them have been involved in talking with Senator
2 Hatch and I about it, and you can just call them up
3 and say "what do you think" about this or that.

4 SENATOR HATCH: Both of them are very
5 innovative as well.

6 SENATOR WYDEN: They are both innovative,
7 they both have indicated that you can just pick up the
8 phone and they'll be happy to take your ideas.

9 And I guess the last point that I want to
10 mention goes back to your point about sort of how do
11 you deal with principles and the like. If you almost
12 draw a sheet of paper right down the center, and you
13 say here is what we want people to have and here is
14 what chunk of the \$1.8 trillion we are willing to
15 devote to that, I think that might be a way to get
16 into this that helps to simplify it. And the two of us
17 are available particularly on this point because how
18 you go to people and talk about it in something
19 resembling English that they can participate in is
20 key. As I've been listening this morning and thinking
21 about your question, this is what the Working Group
22 says you want citizens to have in this country for
23 healthcare that works for everybody, and this is what

1 portion of the \$1.8 trillion you are willing to devote
2 to it. Those kinds of things might be a way for you
3 to take this extraordinarily complicated exercise and
4 put it into a manageable package.

5 SENATOR HATCH: We've taken too much of
6 your time. You were supposed to have a few minutes to
7 relax before -- and after listening to us, I'm sure
8 you need a few minutes to relax --

9 CHAIRPERSON JOHNSON: Well, we want to
10 express appreciation to both of you for joining us and
11 for initiating the legislation and for your foresight
12 in inviting participation from American people as
13 well, and we'll do our best to represent the intent of
14 the legislation and come back to not only you, but
15 others on Capitol Hill and with the Administration,
16 with a product that will represent the American people
17 as well. So, thank you very much.

18 SENATOR HATCH: Thank you.

19 SENATOR WYDEN: Thank you.

20 (Applause.)

21 MS. CLANCY: Before you two leave, I've
22 been asked to ask you if you would please stand with
23 the group for a photo.

1 SENATOR HATCH: Sure.

2 (Whereupon, a short recess was taken.)

3 CHAIRPERSON JOHNSON: Okay. While we are
4 reconvening, let me introduce to you the staff who
5 have been working with us and will be working with us,
6 in addition to those we've mentioned already. The
7 first some of you have talked with already and met --
8 Larry Patton, who has been assigned to work with us on
9 a variety of issues, and we've gained a whole lot of
10 input and excellent consultation working with Larry
11 already.

12 Ken Cohen, who is sitting in the back row
13 over here -- that's the "sinner's row" in many
14 churches -- Ken's a good guy even though he's sitting
15 in the sinner's row -- and he's going to be working
16 with us in a variety of ways; Andy Rock and Caroline
17 Taplin, over here as well, working with us from the
18 staff. In addition to that, Mike O'Grady, who is from
19 Health and Human Services, is going to be representing
20 Secretary Mike Leavitt on our Working Group, and we're
21 pleased already just on the conversation that we've
22 had, Mike, that you are with us.

23 Larry, just to make sure that we're all in

1 sync and we're doing what we're supposed to do on
2 these forms, do you have any further instruction or
3 are there any questions regarding these forms that
4 we're in the process of completing?

5 MR. PATTON: I am just going through the
6 forms, just double-checking to make sure everything is
7 done, and what I'm giving you one by one now are just
8 your W-2 withholding forms for the pay that you'll
9 receive from here, if you want to fill it out. If we
10 have a State form for you to reflect the State
11 withholding also, and hopefully we've done that right
12 and matched up the States. But that's the only other
13 thing that we'll want -- and if anyone did not have a
14 chance to do direct deposit and wants to send it to us
15 later, that's fine, too.

16 MS. HUGHES: I don't have the W-2 form.

17 MR. PATTON: I'm giving those out now one
18 by one. I'm just going through the folders and
19 pulling them out because we didn't have -- the one
20 thing that I wanted to stress is that the race form
21 and the disability form, it's only until they put it
22 into the system to try to assess ongoingly the fact
23 that commissions are appropriately representative.

1 The information about you is destroyed as soon as it's
2 put in. It goes in anonymously. They are just
3 verifying that we've collected it from the people who
4 are here. Other than that, it gets destroyed.

5 CHAIRPERSON JOHNSON: And later tomorrow,
6 Larry will be updating us on even more information
7 regarding how we'll coordinate with some of the
8 government in terms of travel expenses, ethics, and so
9 forth. In fact, that gives us a good opportunity
10 right now.

11 Why don't we look at the agenda together
12 and we can talk about how we're going to proceed, and
13 I'll do this initial discussion, and then Catherine
14 McLaughlin, who has been working carefully and closely
15 and collaboratively with us, will also share some of
16 her thoughts and welcome as we get started. But we'll
17 do that, and then what we're going to do is we're just
18 going to walk through the legislation requirements.
19 Some of you have seen it, some of you have looked at
20 it in layperson's language, but we'll walk through the
21 agenda of some of the legislative requirements.

22 Following that, what we're going to ask
23 you to do -- and you can begin to think of it -- is

1 ask you two questions: What made you decide to apply
2 to be part of the Working Group? And then, what are
3 the issues that you see in healthcare today? What are
4 the healthcare issues that are faced by American
5 citizens? And Senator Hatch and Senator Wyden have
6 already shared some of their perspectives, but we're
7 going to ask you for yours as well. And we'll
8 actually collect your ideas, your input regarding
9 that, and that will then serve as a foundation for
10 some discussions later on today in which we talk about
11 what are some of the initiatives that are out there
12 already that we see addressing some of the issues?

13 Toward the end of the day, we have asked
14 Carolyn Clancy to join us, and she'll be sharing some
15 of her perspectives from the Agency of Health,
16 Research, and Quality, and if you haven't already
17 learned, you'll find that Carolyn really is expert on
18 this whole subject of healthcare quality and research.

19 So, we're looking forward to that.

20 Tomorrow we will reconvene and we'll spend
21 most of the day talking about what's our approach to
22 this task. And Catherine and I will be just taking us
23 through some dialogue with you regarding how do we

1 approach the task that's in front of us, and we'll
2 focus principally tomorrow on the hearings and the
3 potential initial paper.

4 Now, there are other discussions that
5 we'll have with respect to community outreach, town
6 hall meetings later on, so forth, but tomorrow our
7 focus is this initial series of hearings and the
8 initial report that we develop, and some of the
9 logistics that will be surrounding that.

10 Toward the end of the day tomorrow, Larry
11 Patton and others will brief us on things like
12 something called FACA. If you don't know what FACA
13 is, we're going to learn more than probably we want to
14 know, but it's important to know it, because we're
15 going to have to comply with it. We're going to ask
16 that you participate carefully on that. What are
17 documentation requirements, some of the ethics rules
18 that we'll need to be considering and following as
19 we're participating in the Working Group, and then
20 travel arrangements and so forth.

21 So, that's our agenda. We'll deal with
22 other organizational matters tomorrow afternoon before
23 we adjourn at 3:00 o'clock. Any questions regarding

1 the agenda at this time?

2 (No response.)

3 You want to add words of whatever?

4 VICE CHAIR McLAUGHLIN: Of welcome?

5 CHAIRPERSON JOHNSON: Yes.

6 VICE CHAIR McLAUGHLIN: I guess as some of
7 you have already heard that after hearing this
8 morning, I'm not sure whether all of us should flee
9 for the door with our hiking boots on, for the
10 Himalayas.

11 But when I first read this public law, I
12 must admit I was overwhelmed by the list of things
13 that we were to look at, and it never occurred to me
14 that I would end up being on the group that actually
15 has to do all this. I suspect all of us are facing
16 this with that same ambivalence. We're really excited
17 and flattered and thrilled that we were called to this
18 task, but also somewhat concerned about our ability to
19 do this. And I guess in the last couple of weeks that
20 Randy and I have been talking and meeting and meeting
21 with the staff, I've become more and more convinced
22 that we can do this, and I'm not sure what the "this"
23 is yet, but that's part of why we're here, and I am

1 excited to get going. As some of you have met me
2 know, I'm one of these people that puts on running
3 shoes and just gets running. And so I am really
4 looking forward to this and have been -- all of us I
5 think have been excited about meeting here today and
6 starting to get some ideas going.

7 I am going to be looking at a lot of the
8 stuff to go into the report, and I just want to make
9 it clear, echoing what Senators Hatch and Wyden said,
10 the staff really need input from all of us. I think
11 the only group that's not represented around this
12 table are the young people. Senator Hatch was talking
13 about the young people who think "why do I need
14 insurance", and I guess they just decided not to have
15 a 25-year-old on the Working Group, but we really need
16 to all give our input to Ken and Andy and Caroline and
17 other staff as they come onboard, to make this really
18 work. So, I hope that all of you are going to be
19 active and not just come to the meetings, but send e-
20 mails and telephone calls and contribute.

21 CHAIRPERSON JOHNSON: Okay. Thank you
22 very much. Why don't we just go through the
23 legislation, make sure that we all understand it, and

1 if you have questions, please raise them, and if
2 Catherine or I are not able to respond to them, we'll
3 ask Larry or Ken or even Senator Wyden, who remains
4 with us at least right now, to share thoughts and so
5 forth.

6 So, first, the legislation that we have in
7 front of us has come out of the Medicare Modernization
8 Act, and it calls for a nationwide public debate about
9 improving the healthcare system to provide every
10 American with the ability to obtain quality affordable
11 healthcare coverage and, at the end, to provide a vote
12 by Congress on the recommendations that will result
13 from the debate.

14 As a result of that, we are asked to hold
15 hearings to examine a list of subjects, and we are
16 going to show you the list of subjects on which we'll
17 hold hearings in the legislation. The subjects are
18 listed in the legislation. However, we can add
19 additional subjects to that, and we'll be talking
20 about that as we move forward.

21 And then we are asked to prepare and make
22 available to the American public The Health Report to
23 the American People, and as we've already heard, it's

1 our intent to communicate that using a Web site and
2 other methodologies, and we'll talk more about how
3 that might happen as we move into our meetings.

4 Another phase is to hold healthcare
5 community meetings throughout the United States, and
6 those meetings will be what I would call Phase 3 of
7 our initiative, and again we'll talk more about those
8 as we get into our discussions and, ultimately, to
9 submit recommendations to Congress and the President
10 for their review of our findings.

11 Some of the subjects to be considered in
12 the hearings as directed by the statute are: First,
13 the capacity of the public and private healthcare
14 systems to expand coverage options, what kind of
15 capacity is there to expand coverage options; to learn
16 about local community solutions to accessing
17 healthcare coverage; third, efforts to enroll
18 individuals currently eligible for public and private
19 healthcare coverage; fourth, to look at innovative
20 State strategies to expand healthcare coverage and
21 lower healthcare costs; further, to look at innovative
22 State strategies to expand coverage; cost of
23 healthcare and effectiveness of care provided at all

1 stages of diseases; strategies to assist purchasers of
2 healthcare, including consumers, to be more aware of
3 the impact of costs and to lower the cost of
4 healthcare; and the role of evidence-based medical
5 practices that can be documented as restoring,
6 maintaining, or improving a patient's health, and the
7 use of technology and supporting providers in
8 improving quality of care and lowering costs.

9 So, those are some of the subjects that
10 are required by the statute. In addition, the statute
11 says we may hold additional hearings on subjects other
12 than those included in the statute, so long as we
13 determine that they are necessary in meeting our
14 charge and, secondly, they don't delay the other
15 activities of the Working Group.

16 So, as we proceed later this morning and
17 this afternoon and tomorrow, we'll be kind of
18 beginning to think of what other subjects we might
19 want to hold hearings on. Yes, Aaron?

20 DR. SHIRLEY: Quick question. For the
21 purpose of the statute, define "coverage".

22 CHAIRPERSON JOHNSON: For the purposes of
23 the statute, define "coverage". How do I respond to

1 that? Let me see if I can start and see if we're
2 going to answer your question. There's a difference
3 between care and coverage. Coverage, as I understand
4 it, typically means those who have some other
5 organization bearing the risk. Care means providing
6 the actual healthcare, the delivery of the medical
7 treatment or prescriptions or preventive care itself.

8 Have I responded to your question?

9 DR. SHIRLEY: Yes.

10 MR. O'GRADY: Can I just -- I think it's
11 still an open -- I mean, it's an evolving definition,
12 I think. When we do our large national surveys of who
13 has coverage and who doesn't, what's the number of the
14 uninsured and who isn't, what becomes quite clear is
15 that there is this middle ground that is sort of -- I
16 mean, using a community health center, is that
17 coverage or not? Most of us would say not real
18 insurance coverage, but it's certainly some access to
19 care. The Indian Health Service, VA, are we counting
20 that as coverage or not? How do we think about those
21 things? And what is becoming clear is there are these
22 other mechanisms that people use to get access to
23 care. And of course access to care is the real policy

1 goal, coverage is just the way most Americans get
2 access to care.

3 So, I think I wouldn't limit the group in
4 terms of the way you think about these sort of things
5 and the traditional ways of thinking about things like
6 coverage as just a BlueCross/BlueShield card, is that
7 what we mean by coverage. I think there's a lot of
8 other ramifications to it.

9 CHAIRPERSON JOHNSON: Not differing with
10 Mike, but we do want to look at providing coverage in
11 addition to just the care. When I'm thinking of
12 access, I'm thinking of how do we provide coverage as
13 well as care. Now, we'll talk more about that,
14 already we're getting into some dialogue, and that's
15 good, but we'll continue to address that. Thank you
16 for raising the question.

17 By the way, we do have folks who are, No.
18 1, recording our discussions, not necessarily for CBS
19 News or anything like that, but they are being
20 recorded, and notes are being taken of the meeting as
21 well. It's part of the overall legal requirements for
22 our meetings, so feel free to understand that there
23 will be good records of our discussion which we might

1 have to come back to, and want to come back to in the
2 future, but also speak using the microphones, if you
3 would.

4 Phase 2, a list of summaries that are to be
5 included in the report. First, healthcare and related
6 services that may be used by individuals throughout
7 their life span. And some of the data show that we
8 use an awful lot of the dollars during our lifetime in
9 the latter stages of our career. Those of you who are
10 working in the medical profession especially know
11 that, even more than some of the rest of us. That's a
12 very significant item, and that's one of the cost
13 items, I believe, that Senator Wyden will be - and
14 others - will be looking to hear about.

15 Cost of healthcare services and medical
16 effectiveness in providing better quality of care for
17 different age groups. Healthcare costs containment
18 strategies. Information on healthcare needs that need
19 to be addressed. Further, summary of sources of
20 coverage and payment including reimbursement for
21 healthcare services. Reasons for which people are
22 uninsured or underinsured and the cost to taxpayers.
23 Purchases of healthcare services in communities where

1 Americans are uninsured or underinsured. Further, the
2 effectiveness of healthcare of and cost when
3 individuals are treated in all stages of the disease.

4 Also some items to be included in the report.
5 Examples of community strategies to provide healthcare
6 coverage or access. Information on geographic-
7 specific issues related to healthcare. And
8 information concerning the cost of care in different
9 settings, including institutionally-based care and
10 home- and community-based care. Some other items:
11 Summary of ways to finance healthcare coverage, as
12 well as the role of technology in providing future
13 healthcare, including ways to support the information
14 needs of patients and providers.

15 So all of these are the items to be included in
16 the report, and let me stop and see if you have
17 questions or observations regarding this Phase 2.
18 Other than the point that Catherine made, it's an
19 overwhelming kind of, and that's why we have staff
20 people like Ken and Andy, Caroline and Andy to help us
21 in our initiative here.

22 Phase 3 would begin next year, as required by
23 law, but we may want to start earlier than that. Yes?

1 MR. FRANK: Can I ask a question about
2 Phase 2?

3 CHAIRPERSON JOHNSON: Sure.

4 MR. FRANK: That set of issues is very, as
5 you say, daunting, but we're not the only ones who
6 have ever written about this. So, I was just
7 wondering, for example, the IOM just came out with a
8 series of reports on the uninsured and the health --
9 to what extent are we dovetailing with that and sort
10 of using that information to help us do our work?

11 VICE CHAIR McLAUGHLIN: As the person who
12 has been doing the most thinking to date about the
13 report, let me respond, Richard. Tomorrow we are
14 going to spend quite a bit of time talking about the
15 hearings and the report as we've been conceiving it.
16 Right now, just setting out, all right, this is what
17 our charge is, this is what we were told to do. Then
18 we can say, all right, what do we as a group -- how do
19 we think we should implement it?

20 The report that we'll talk about tomorrow,
21 you'll see that we have on there absolutely have staff
22 do a critical synthesis of the literature that's
23 already out there, the evidence, et cetera. So, no,

1 we definitely are not going to reinvent the wheel.

2 CHAIRPERSON JOHNSON: Let me just build on
3 that. Already, we have made two reports available to
4 you. If you haven't picked yours up yet, they are on
5 the back table. Excellent reports put out by the
6 Agency of Healthcare Research and Quality. We've also
7 sent you another report of a forum that was conducted
8 last year by the Government Accountability Office.
9 It's not our intent to duplicate those reports. We
10 may take data from those reports and condense it and
11 use it here, but we don't want to duplicate the
12 efforts of others, but we want to provide, as
13 Catherine suggested, consolidation of some other
14 information plus the hearing information. And one of
15 the differences that we'll talk about later, in the
16 hearings that we'll conduct is that we expect not only
17 to do hearings in Washington where we'll have some of
18 those who have provided information in the past, but
19 also look at the possibility of doing hearings outside
20 the Beltway with practitioners in different areas of
21 the country, provide information based on their
22 findings and their experience. So, thank you for
23 your question, Richard. Other questions on the

1 hearings?

2 MS. PEREZ: How would you determine where
3 the locations are?

4 CHAIRPERSON JOHNSON: We'll talk about
5 that tomorrow, if that's okay. We'll share some
6 information with you and gain your feedback as well,
7 but that's still to be discussed. So, no decisions
8 for sure have been made on that, just some ideas
9 generated and so forth.

10 Okay. The community meetings -- and we're
11 continuing just to share with you ideas that are in
12 the statute, comments that are in the statute. We will
13 potentially build on some of these, but the required
14 topics are: what healthcare benefits and services
15 should be provided; how does the American public want
16 healthcare delivered; how should healthcare coverage
17 be financed -- now that's a subject of a report that
18 could be thousands of pages in itself, right -- how
19 should healthcare coverage be financed. And then
20 Senator Wyden made this fourth bullet a point of his
21 conversation earlier with us, very important point --
22 what tradeoffs are the American public willing to make
23 in either benefits or financing to ensure access to

1 affordable high-quality healthcare coverage and
2 services -- what are the tradeoffs, what are the tough
3 decisions that we'll make, and we're going to not make
4 those decisions ourselves only, we'll get some input
5 from the American people, but what are the tradeoffs
6 that the public are willing to accept in terms of
7 benefits, financing, and so forth. And again we might
8 include other topics other than these that are the
9 required topics for community meetings.

10 Questions or comments on that?

11 (No response.)

12 Okay. The community meetings must be
13 initiated by next year, but hopefully we might be able
14 to get moving with some of them before that time since
15 this is going to be such a significant endeavor that
16 we're going to have to go through. They must be
17 sufficient in number to represent diverse populations,
18 represent and reflect geographical differences
19 throughout the United States, and reflect a balance
20 between rural and urban differences. So, already when
21 we're thinking of our responsibilities next year,
22 we're contemplating how do we make sure that the
23 meetings that we hold are going to be sufficient to

1 represent all of those differences.

2 In terms of our participation in the
3 meetings, the regulations or the law says that we'll
4 have at least one Working Group member attending each
5 community meeting. So, I don't know if we're going to
6 do a meeting in Montana, or California, Wisconsin, New
7 York, wherever those meetings are, we would have one
8 person attending that meeting, and the Working Group
9 member would chair each meeting, although the statute
10 does indicate that a State Health Officer may be asked
11 to facilitate some of the meetings.

12 Also, that the Working Group encourage
13 public participation through information technology
14 and other means. And earlier today again, Senator
15 Wyden talked about using technology and many of us are
16 doing that in our own work world and public life, and
17 there are some ideas that we'll be contemplating,
18 sharing, discussing, regarding how do we use
19 information technology in getting some of our messages
20 across, and hearing from people as well. So, those
21 are some of the things that we're looking at doing.

22 What we are going to do is prepare and
23 make available to the public an interim set of

1 recommendations not later than 180 days after the
2 completion of community meetings, allow for a 90-day
3 comment period, and then put together a series of
4 recommendations to the Congress and the President.
5 The President will have 45 days, according to the
6 statute, to look at our report and then submit a
7 report to Congress within 45 days that will include
8 his own views and comments and recommendations for
9 legislation and administrative action that he believes
10 is important.

11 And, finally, to hold hearings, and at
12 least one hearing on the President's report and our
13 Working Group recommendations would be conducted by
14 the Senate committees that deal with healthcare, as
15 well as the House of Representatives committees that
16 deal with healthcare, and those would be expected to
17 be held within 45 days after receiving the President's
18 report.

19 So, that's a summary of the plan. The
20 timetables kind of look like this, the one-sheeter
21 that indicates all of these steps that we've been
22 discussing, and our agenda for today is primarily to
23 develop this preliminary list of major issues that

1 we're facing as a healthcare system in the United
2 States, from your perspectives. And once we've done
3 that, to identify some initiatives designed to deal
4 with major issues. Questions or comments?

5 (No response.)

6 Well, if there are none, we will just
7 proceed, and I'm sure that we will have questions and
8 comments as we go along.

9 SENATOR WYDEN: Randy, can I just make a
10 very quick comment and response to Dr. Shirley's point
11 about coverage just because it's fresh in everybody's
12 mind and I mentioned it to Mike.

13 When I met with Secretary Leavitt, we
14 talked about that. And at one point the Secretary and
15 I said, you know, if we were to do nothing else in the
16 United States -- nothing else -- other than make it
17 possible for people to have a card so they could go
18 see a community health center, and to have a
19 catastrophic healthcare benefit, those two steps alone
20 would be a huge and monumental step forward in terms
21 of coverage. And the irony, of course, is that both
22 of them are really cost-effective and would provide a
23 significant level of protection to everybody, and you

1 have the Secretary of Health and Human Services and a
2 Democratic United States Senator saying, wow, there's
3 real potential there. And so I think those are the
4 kinds of things that you all -- and that may not be
5 where you want to end up. I'll tell you, I thought
6 Mike Leavitt made a lot of sense when he talked to me
7 about it, and he seemed to think I was talking about
8 something that was plausible to him, too. I'd just
9 bring that up, and this is really going to be the last
10 you're going to hear from me this morning.

11 (Laughter.)

12 Thank you, Randy.

13 CHAIRPERSON JOHNSON: Okay. Why don't we
14 then go into introducing ourselves, and then talking
15 about what some of the issues are that we face, and
16 we're going to ask that you limit your time to ten
17 minutes, and some of us could talk for probably some
18 hours on some of our thoughts on the initiatives and
19 so forth, but if you would be kind to kind of monitor
20 your time and limit your comments to ten minutes.

21 I think to kind of get us thinking, I'll
22 start, and then maybe we can just go around the table
23 this way, if that would be okay, and everybody share

1 their thoughts.

2 Well, my own personal background is that I
3 have been involved with employee benefits for more
4 than 30 years, from a company perspective. I got into
5 employee benefits through the bank in Detroit before I
6 knew what benefits were all about, and initially I was
7 asked to review claims that employees would submit to
8 the healthcare company. Well, today, I'm not sure how
9 that would be perceived, but that's what was done a
10 number of years ago. And more recently I've been
11 working with Motorola, for the last actually 22 years,
12 and every year I've been involved with the benefits
13 function there, although my current role is to be
14 involved with more than just employee benefits, but
15 for my first 18 years I led the benefit strategy
16 development at the bank, or at Motorola.

17 Part of my involvement has also been to
18 work with other organizations to think about
19 healthcare policy, and my current role is to serve as
20 a spokesperson on human resources issues on behalf of
21 Motorola. And I used to think, well, would I want that
22 job? No. I like what I'm doing better. But then
23 when I got to thinking about it, I thought to myself,

1 Social Security needs to be fixed, and Medicare needs
2 to be fixed, and retirement plans need to be fixed,
3 and healthcare really needs to be fixed, and maybe I
4 can take some of my own experience and share some of
5 that. So, that's how I got involved with my current
6 role, and basically it's that background that has
7 caused me to apply to be part of this Working Group as
8 well.

9 Initially, when I saw the notice of the
10 Working Group being formed, I said, no, I'm not going
11 to apply for anything. They know where I'm at if
12 they'd like to talk with me, and of course I figured
13 no one would ever want to come and talk to me, so I
14 decided I wouldn't do that.

15 But a few people, like probably some of
16 you, asked me to apply to be part of the Working
17 Group, and so I did. And the reason is, I really
18 think we are in a very, very serious situation in our
19 healthcare needs today. I wrote down some numbers,
20 and I'm not asking anybody else to do the same thing,
21 but I wrote down some numbers, and maybe you can read
22 them in the back -- can you see them okay? 10-15
23 percent, 25 percent -- what do you think that is?

1 MS. MARYLAND: Percent of GDP spent on
2 healthcare.

3 CHAIRPERSON JOHNSON: Pardon me?

4 MS. MARYLAND: Percent of GDP spent on
5 healthcare.

6 CHAIRPERSON JOHNSON: This is really,
7 typically in the last several years, the rate of
8 healthcare increases -- the rate of healthcare
9 increases absorbed by the first numbers are large
10 companies, and the last number is some of the smaller
11 companies -- \$6400, anybody know what that number is?

12 (No response.)

13 That's the average cost per person in the
14 United States today -- \$6400. Senator Wyden made the
15 reference to that earlier when he talked about \$24,000
16 for a family of four, well, that's the cost, the
17 average cost. And for a person who is my age -- that
18 is, between 55 and 65 -- the average cost today is
19 double. So, if I were to buy healthcare on the open
20 market, the cost is \$15-18,000 a year for costs that
21 many of us now enjoy -- not everybody enjoys, but many
22 of us.

23 Now, when you think that the average

1 401(k) balance today for people 55 and 65 years old is
2 \$50,000, that means they have three years of their
3 life savings to spend for healthcare if they are going
4 to retire before 65, and then they're going to live on
5 Medicare and Social Security for the rest of their
6 life. And of course today we're living in the 80s,
7 and sometimes many of us beyond that. So, huge
8 issues.

9 \$11,045, that's the number that the
10 average cost is projected to be by 2014. Well, imagine
11 that. If you're a family of four, \$44,000 per year
12 for healthcare costs. In my estimation, we can't
13 continue to absorb these kinds of costs, and so we
14 need to find some solutions.

15 98,000 and \$29 billion -- 98,000 is the
16 number of lives lost each year in hospitals due to
17 medical errors. So we're not only talking about a
18 cost issue, we're talking about a quality issue.

19 The 50 percent is the percentage of us, who get
20 the right care at the right time at the right place
21 when we seek medical coverage every year -- 50 percent
22 of us. So, if Catherine and I are both going to go to
23 the doctor, the data says one of the of two of us are

1 going to get the right care at the right time at the
2 right place, and I hope it's me, but that's not good
3 quality.

4 VICE CHAIR McLAUGHLIN: Remember we were
5 supposed to talk about shared sacrifice, Randy.

6 CHAIRPERSON JOHNSON: Yes. 90 million,
7 that's the number that the U.S. Surgeon General -- 90
8 million people his report said in the United States
9 are healthcare illiterate, and \$58 billion is lost
10 each year because of that illiteracy. So, those are
11 some of the issues that we're facing, and I personally
12 believe that we have a real challenge to overcome some
13 of those. Now, I didn't put the 44 million people who
14 are not covered today. That's another statistic that
15 just rings out at all of us whenever we're reading
16 this.

17 So, we have some real issues. We'll talk
18 about some initiatives that are used to address those
19 issues, but that's a little bit about myself and why I
20 asked to be involved. Joe, how about you? Can we
21 move to you next?

22 MR. HANSEN: Thank you, Randy. I don't
23 think I'll take ten minutes. I'll introduce myself

1 first. My name is Joe Hansen, and I am President of
2 the United Food Commercial Workers International
3 Union. It's a union of almost 1.4 million members in
4 the United States and Canada, and we represent people
5 in the retail food stores, in meatpacking, poultry and
6 food processing. We also have a sizable number of
7 members who are providers in the healthcare industry
8 in hospitals and nursing homes, and some other
9 facilities. So, I get a perspective on healthcare
10 because part of the union's job, when somebody asks
11 what a union does, they say, well, you deal with
12 wages, hours and working conditions, and we bargain
13 over that, and we represent people over that. But in
14 recent years, our bargaining has really come down to
15 the crisis in healthcare, and that's basically what
16 we're bargaining over as far as monetary, shifting
17 costs, and the benefits.

18 I additionally serve on the Executive
19 Council of the AFL-CIO, and I get a perspective of not
20 only the industries that I represent, but other
21 industries and similar problems in different
22 industries, so I get some viewpoints from there.

23 An odd thing that I do -- it's kind of

1 odd, but it gives me a little bit of a background
2 coming into this type of meeting -- I serve as a
3 pension trustee on the Wyeth Pension Fund, and I've
4 done that for a number of years, for ten years, so I
5 get some perspective from the drug companies and, of
6 course, they get very involved when there's
7 initiatives about cost of prescription drugs and they
8 have their viewpoints about research and stuff like
9 that, and some intelligent people that I've been
10 exposed to.

11 So, I have kind of a broad background as I
12 come into this. I asked to be on this committee for
13 two reasons, really -- it applies to the work that I
14 do and the responsibility I have to the members that I
15 represent, and how do we keep providing coverage and
16 the issues that come up at the bargaining table, and
17 also I have a personal reason. I have four kids and
18 five grandkids. And what was normal for me when I
19 entered the workforce in the '60s was, you took
20 healthcare for granted and you expected decent care.
21 The same expectation is not there for them as we go
22 into the future.

23 Some personal experiences I have -- and I

1 was reading through some of the backgrounds -- and the
2 concerns I have about healthcare and how it changed,
3 and what we used to take for granted. We represent
4 people in the grocery industry, but we also represent
5 people in the meatpacking industry, and in Sioux
6 Falls, South Dakota a number of years ago, one of the
7 biggest employers there was Morrell Packing, and they
8 were one of the first companies that jettisoned
9 retiree healthcare, which now has become more and more
10 the practice as the expenses go up, and I think that
11 is part of the problem of what we do with our elderly
12 and how we cover them and keep putting all the costs
13 onto Medicare and Medicaid and that type of situation.

14 Basically, I think that, first of all, I'm
15 very pleased to be on this committee. I think the
16 challenges are daunting, but I don't think we have any
17 choice. I think that we have to find out a way to fix
18 it or, as Senator Wyden and Senator Hatch said, the
19 economy and the life style and the greatness of our
20 country is going to be in real jeopardy. I'm not
21 trying to be dramatic, but I see it as that big a
22 problem.

23 I am daunted. I tried to break down as I

1 was listening to both the Senators, how you address
2 this, all the different categories, the cost category
3 and the problems, and you've got insurance and you've
4 got the prescription people and you've got the lawyers
5 and you've got the providers and the educators and the
6 research people and the government, and the Chair and
7 the Vice-Chair have got a difficult job of leading us
8 through there, but I think it can be done. So, I'm
9 pleased to be here, Randy, and look forward to
10 participating.

11 CHAIRPERSON JOHNSON: Have we captured
12 your primary issues, would you say?

13 MR. HANSEN: That's it.

14 CHAIRPERSON JOHNSON: Okay, thank you.
15 Well, glad you're here, Joe.

16 MR. HANSEN: Thank you.

17 DR. BAUMEISTER: I guess I'm glad to be
18 here. And I say that honestly. I'm a physician. I'm
19 a gastroenterologist. I've been in practice now in
20 Oregon since 1970. I go way back. I graduated from
21 medical school in 1961. I was at Jackson Memorial
22 Hospital when they integrated the hospital. I served
23 in the military. I was a lieutenant colonel in the

1 Army for four years. I actually served as a
2 gastroenterology consultant for Europe in a time when
3 all the Regular Army people were serving in Vietnam.
4 And I have practiced and been a leader in the medical
5 community where I practice. I've been president of
6 the hospital staff, president of the Oregon Medical
7 Association, I've been a delegate to the AMA. I'm a
8 liberal Democrat, my mother was a precinct worker for
9 Claude Pepper, who was a proponent for socialized
10 medicine back in the '40s, and I still share those
11 beliefs.

12 I was active in the formation of the
13 Oregon Health Plan and saw it essentially die, and I
14 still think it was a wonderful plan. I think it could
15 be applied on a national level. What we are hearing
16 and talking about this morning is much of the
17 principles of the Oregon Health Plan that grew out of
18 the Oregon Health Services Commission that came up
19 with the benefit package and sort of the cooperation
20 between the business community and the public
21 financing the healthcare.

22 As a physician and as a representative
23 physician, which I've been, I hear things like \$98,000

1 deaths due to errors. I'm not really sure that's
2 accurate. I read the Institute of Medicine's report.

3 I don't know what the answers to any of this are.
4 I've worked in a Veteran's Hospital. I've worked in a
5 military hospital. I've worked in a county hospital
6 where it was all charity work. I've been a very
7 successful practitioner of gastroenterology. I see
8 next door they are advocating colon cancer screening
9 for every citizen, so my financial security is set.

10 (Laughter.)

11 But I think when we get into these
12 discussions, I think of a couple of things. I think
13 of Oscar Wilde's definition of a cynic was somebody
14 who knew the price of everything today and nothing.
15 And I think of Joni Mitchell's song, "Don't you know
16 it seems to go" -- what is it -- "you don't know what
17 you've got 'til it's gone: they paved paradise and put
18 up a parking lot" -- and I think we've got to watch
19 out that we don't throw out the baby with the
20 bathwater here in dealing with American medicine, but
21 I still think it's the best in the world. There is
22 some uneven distribution, but there is incredible
23 uneven distribution of every facet of American life.

1 The haves are getting to have more, and the have-nots
2 are sinking deeper into the abyss, and healthcare is
3 one of those issues, and we're here to address that,
4 and I'm going to do what I can to help it, but we're
5 dealing with a society that's in chaos, not just
6 healthcare, and I'm here to contribute what I can.

7 CHAIRPERSON JOHNSON: Frank, thank you for
8 your comments. What I'm hearing you say is that this
9 is a huge complex issue, and there's a distribution
10 issue on healthcare that's reflective of society in
11 general. That's what I was about to put down here
12 based on your comments.

13 DR. BAUMEISTER: Absolutely.

14 CHAIRPERSON JOHNSON: Would there be other
15 issues that you would like us to include? Well,
16 first, is that correct?

17 DR. BAUMEISTER: That's correct. I agree
18 emphatically with Senator Wyden who said this morning
19 that we are spending enough on healthcare. The \$24,000
20 apiece seems to be sufficient. But we've got to
21 figure a better way to -- I think it was Coleridge
22 that said that prose was words in their best order,
23 poetry was the best words in the best order, and we're

1 looking at just poetry here.

2 CHAIRPERSON JOHNSON: Thank you. Dotty?

3 MS. BAZOS: I hate to follow Frank; I
4 won't be quite as eloquent. When I initially was
5 asked to apply to this committee, I was actually going
6 to say no. I just have been -- I'm a nurse, I started
7 my career as a nurse, and then finished my degree and
8 taught. As soon as I was married, when I was young, I
9 went overseas, and I lived and worked overseas for a
10 period of 15 years, sometimes in European countries,
11 often in third-world countries. And when you stay out
12 of the United States for a long period of time, you
13 get a very warped view of what the U.S. should be. And
14 when I came back, I just believed that we were the
15 best country, the best nation in the world, and I was
16 shocked. I actually was just shocked.

17 You go through a tremendous period of
18 culture shock when you come back here because you do
19 believe that everything is perfect. And I went back
20 to work in our healthcare system, looking for a place
21 where I wanted to work. And I couldn't believe that
22 we had not solved the issues that I saw when I was a
23 young nurse, the issues of educating consumers, the

1 issues of poverty, the issues of access, that we were
2 still debating the same old things.

3 So, I believe that more education would
4 help me begin to help this country to develop a better
5 system, so I got my Masters and did my graduate work
6 at Dartmouth, and looked at the research and was again
7 shocked that we've been having the same debates for a
8 long, long time, but we're not coming up to any
9 solutions.

10 So, I weighed that when I was asked to
11 join this committee, thinking that what I really
12 wanted to do was to work with populations that had
13 nothing, but then decided that if there is a chance in
14 the United States to help citizens of the United
15 States develop some political will about moving
16 forward to make certain that everyone in America has
17 the right to basic healthcare, that I wanted to be a
18 part of that. Although, after listening to the
19 Senators today, now I want to go home.

20 (Laughter.)

21 So, I'm hoping that I can offer a little
22 bit to the discussion that we have. Some of the
23 issues that I think we have are, first, that we don't

1 really have a healthcare system. If you ask policy
2 students to describe the system, they give you all
3 these answers, but everyone usually agrees that there
4 is no system, and I think that's part of the
5 complication of actually fixing what we call a broken
6 system because we don't actually have a system.

7 I asked the question to the United States,
8 who is actually responsible for the health of the
9 population of American citizens. Sometimes it is
10 government, sometimes it's State, sometimes we have
11 the expectation that as individuals -- where I work in
12 communities, communities want to be responsible or
13 think they should have some responsibility, but no one
14 really can answer the question. And since no one can
15 say who is responsible, it's often very difficult to
16 know where to point the change. And in my own
17 research, I've worked with communities thinking that
18 that might be the place where the rubber could hit the
19 road, but what we found is there's no data for
20 communities to really look at as far as the capacity
21 utilization and outcome of their healthcare systems
22 locally. We don't have good data. So, it becomes
23 very difficult to change a system from a local level,

1 although people who I work with at a local level think
2 they want to be part of the change. They are very
3 interested in it. They feel that top-down approaches
4 don't work, haven't worked for them, that local
5 solutions may work, but they are grappling with not
6 wanting to have change for change sake, so they need
7 data to do that.

8 Another question that I think about a lot
9 is, what does it take really to produce health? I
10 mean, I think that's what we want when we talk about
11 what does it cost, do people have access, the outcome
12 we're looking for is health, and what does it take to
13 produce that, and I think for different populations it
14 takes different things, and I don't think the
15 healthcare system itself should be the center of the
16 issue. We know from research that there's multiple
17 determinants of health, and we know that for some
18 vulnerable populations, they really need us to
19 consider funding some kind of resources around the
20 social determinants, around their education, those
21 types of issues. So, I hope we don't lose track of
22 that as we narrowly focus on these costs of our system
23 per se, because I don't think we're going to get the

1 outcomes that we want. So, I'd just like to keep
2 thinking a little bit broadly.

3 And then in my graduate work, I also have
4 grappled with the big issue in the United States of
5 whether the American public really believes -- and I
6 think that sometimes they do -- that more is always
7 better. More healthcare is just always better. Some
8 of the preliminary data is showing us that, in some
9 cases it's not, and I think that we really need to
10 look at that, but also to very methodically and
11 carefully help to educate the public about what it is
12 that will really help them when they are sick, and
13 what do we know that will really help them when they
14 are sick.

15 So, I'm happy to be here, and I hope that
16 I can contribute something.

17 CHAIRPERSON JOHNSON: May I ask a couple
18 questions to clarify?

19 MS. BAZOS: Sure.

20 CHAIRPERSON JOHNSON: Can you talk about
21 what I put down here as the big issue, health itself.

22 Can you build on that a little bit, your comments
23 just before you got into more is better?

1 MS. BAZOS: The big issue is health,
2 defining health, or how we want to produce health?
3 Well, I think people have grappled with the definition
4 of what is health. For everyone it is different. The
5 IOM has a definition that actually is very, very
6 broad, and if you use a very broad definition of
7 health -- that is, that people will be able to
8 function as best as possible in their own communities
9 so that they are productive, productive human beings
10 living with the best quality of life that they can
11 have.

12 Then you really need to think about, how
13 are you going to get people there. And it isn't
14 always that for some people you're going to just put
15 all of your focus on funding a healthcare system. When
16 we talk about tradeoffs, we have to think about what
17 tradeoffs we're going to make. The tradeoff you might
18 make for somebody is that you need to focus upstream.

19 You need to really focus in the education system.
20 You need to focus in the job market. You need to
21 focus on getting that single mom a babysitter so she
22 can actually go to work. And all of these things
23 actually will eventually -- you know, they sort of

1 have an impact on a person's health. I'll just give a
2 quick example. In the '70s we told everybody to
3 exercise, and we began to make the American public
4 believe that it was an individual responsibility to
5 exercise and lose weight.

6 Well, if you think about some of our
7 elders who can't walk outside, they might live in
8 neighborhoods that are violent, they might not have
9 transportation to get to a place. We need to think
10 about all of these things when we think about
11 producing health. All of the answers for producing
12 health aren't in the healthcare system. That's what I
13 meant.

14 CHAIRPERSON JOHNSON: Okay. Thank you.
15 Richard?

16 MR. FRANK: I'm an economist by trade.
17 I'm a professor of health economics at Harvard. Most
18 of the time, I'm a pretty nerdy guy, meaning I do
19 research, I teach, and I co-edit one of the journals
20 in the field. My research areas are mental health and
21 substance abuse, the economics of the pharmaceutical
22 industry, and sort of how you pay providers for
23 performance are the three areas I work on most.

1 Over the years, I've done a few policy
2 things. I was a regulator in the State of Maryland.
3 I served on a regulatory commission there that
4 regulates hospitals -- I guess it still regulates
5 hospitals there. And I --

6 MR. O'GRADY: Here.

7 MR. FRANK: Yes.

8 VICE CHAIR McLAUGHLIN: We're in Maryland.

9 (Laughter.)

10 MR. FRANK: I learned a lesson in policy
11 failure by serving on the Clinton Healthcare Task
12 Force, and I've spent a number of years working on
13 various Institute of Medicine type committees over the
14 last seven or eight years. Perhaps my most formative
15 experience related to this committee happened about a
16 little over a year ago when my wife was diagnosed with
17 breast cancer, and through serving the role of the
18 informal case manager, I got to see all the
19 pathologies, and also all the greatness of the
20 healthcare system sort of right next to one another.
21 At the end of the day, she got terrific care, but the
22 amount of chips I had to call in, and battles I had to
23 fight, and tantrums I had to throw in order to make

1 sure that happened was just stunning to me. And it
2 was stunning just because the results were so good and
3 the process was so difficult. And so I got to see the
4 impact of incentives information and kind of human
5 fallibility all sort of come together in a very sort
6 of unique way. So, it actually gave sort of a new
7 perspective to what I'd been studying for a long time.

8 And when somebody suggested to me that I think about
9 applying for this commission, I hadn't even heard of
10 it. I will admit to having cheated and only read the
11 summaries of the MMA and not every single page -- the
12 Kaiser Family Foundation highlighted things in the
13 summary, so I wasn't really aware of it. But then I
14 went and looked at the legislation and I said, this is
15 a very new way, and it seemed that my own experience
16 is so salient about understanding some of the
17 pathologies of the system, that if people got out
18 there and understood that in a more personal way, you
19 might get more attraction.

20 So, going to your main question, Randy,
21 what is sort of the big issue for me, the puzzle that
22 I've been sort of, both on the research front and the
23 policy front, been thinking about for a while is, why

1 is it that after a doctor and a patient get together
2 and they go their separate ways, too frequently the
3 patient didn't get good advice from the doctor in
4 terms of what the best thing to do was, and when they
5 did, too frequently the patient doesn't follow it.
6 But at least it's extraordinarily expensive to do all
7 that, and there's just a whole bunch of incentive,
8 organizational, informational, and psychological
9 things at play here, that I think are what make this
10 problem difficult, but I think the heart of it is, a
11 lot of this is about how doctors and patients interact
12 and the sort of environment that governs that
13 interaction.

14 CHAIRPERSON JOHNSON: Richard, I've put
15 down several things, although even though you said
16 this was your principal issue, what I thought I heard
17 you say -- and maybe I didn't, that's why I'm asking -
18 - earlier in your discussion I thought I heard you say
19 some inappropriate incentives, I thought I heard you
20 say lack of information available, I thought I heard
21 you say -- you didn't use these words, but the
22 bureaucracy of trying to move through the healthcare
23 system as you experienced yourself, and then toward

1 the end, in the patient/doctor relationship,
2 oftentimes poor advice is given. But in addition to
3 that, when people get advice, patients get advice,
4 they often don't follow that. Have I captured your
5 thoughts here?

6 MR. FRANK: Yes, although on the second
7 one, I wouldn't say that, it's not so much -- I
8 wouldn't be blaming the patient that one way or
9 another they wound up not following it, not
10 necessarily only because of an act of volition on
11 their part, but for a variety of other reasons.

12 CHAIRPERSON JOHNSON: Can you build on
13 that?

14 MR. FRANK: Well, the most obvious thing
15 is, they haven't got the money to pay for some things.

16 MS. PEREZ: Prescriptions.

17 MR. FRANK: Yes, that would be at one
18 extreme. On the other extreme, the doctor didn't ask
19 him a question, and so when they tried to pursue a
20 treatment, it really wasn't practical for them for a
21 variety of reasons. And then there was just the "I'm
22 scared, I'm nervous, I don't want bad news, I'm not
23 going to follow up on this." So, there's all of those

1 things, some of which are things that the patient
2 owns, but many of which are not.

3 CHAIRPERSON JOHNSON: Thank you. Okay.
4 Therese.

5 MS. HUGHES: I'm sort of at a loss of what
6 to say, and this may be the only time you'll find out
7 that I am at a loss.

8 (Laughter.)

9 So, first of all, I'm from California.
10 And I wrote down seven lines, just with very few words
11 on it, when I was coming across country, to say who I
12 was or who I am, and so this is what I wrote. I work
13 for the Venice Family Clinic. We're the largest free
14 clinic in the nation. I'm responsible for advocacy,
15 government relations, and legislative analysis on all
16 matters affecting our clinic, and in healthcare
17 policy, as well. I have a Master's in environmental
18 analysis and protection in social policy from UCLA.
19 I'm involved in healthcare because the issues are part
20 of my passion, which is where institutions fit in the
21 built environment, and do we pay attention to where
22 those institutions occur, or are they just randomly
23 placed throughout the built environment.

1 After hearing these people before me
2 speak, I want to say that I'm here because this is one
3 of my life goals, and it's going to sound kind of
4 hokey, but when I was 14 I saw the Table of Life in
5 Life Magazine, but my husband says it's the Table of
6 Seven. It was six men and one woman who were -- they
7 showed the tabletop and their legs only -- who were
8 the individuals who decided who got dialysis across
9 the United States. And I took that picture to my mom
10 and I said, "When I grow up, I'm going to work to make
11 this different." At the time, I don't know if I was
12 looking at having more women at the table, if I was
13 looking at having people of color at the table, or if
14 it was directed towards healthcare, I really can't say
15 that, but I knew that I wanted to work, and I do
16 believe that it was healthcare, and the reason I say
17 that is my father sold life insurance for New York
18 Life, health and disability, and I did the same when I
19 first graduated from college.

20 But more recently, the reason I decided to
21 do this, apply for this committee, is because I'm one
22 of the people that had a very difficult time in the
23 system. I was diagnosed at a very young age with

1 kidney disease. I was given six months until I had to
2 go on haemo-dialysis. I understand a lot of how the
3 healthcare system works for someone who has health
4 insurance and who meets terrific barriers in trying to
5 access care for the product which is going to be very
6 costly for that company, but which is going to "save
7 my life," and that is dialysis. The barriers were
8 very tremendous, and perhaps that's what, you know, in
9 the "Great Plan" in the universe, directed me towards
10 looking at health policy when I was in graduate
11 school.

12 I had the incredible opportunity of
13 serving as a summer Fellow for Senator Ted Kennedy and
14 worked on transplantation issues. I am now
15 transplanted seven and a half years. I ended up
16 getting a living related kidney, which is the best of
17 all opportunities. But there are still, of course,
18 all these remaining issues.

19 I am absolutely thrilled and excited to
20 participate here because it is a life goal, because
21 this is part of who I am, having been in the system.
22 I work now for Venice because they offered me a job.
23 Actually, Venice and the Westside Family Health

1 Center, community clinic and a free clinic, wanted
2 some advocacy done, and I didn't know how to create an
3 advocacy department for them because my position had
4 been a position of a patient, of a mom that stayed at
5 home that did representatives and advocate between
6 government and business and people, citizen, and back
7 and forth in those different categories over 20 years,
8 and what I found out was what they wanted was oxygen
9 in my blood, and which of course, like this committee
10 -- this is why I'm thrilled about this -- this is
11 oxygen in my blood. I don't pretend to have the
12 answers, but this I understand, and I understand it in
13 ways that I don't know how to articulate.

14 So, I think that -- I'm just really
15 thrilled about being here. I have two children who
16 grew up with me being ill, so I bring another
17 perspective of a parent that raised children with an
18 illness, and they were young, very young, who are now
19 doing extremely well. And I have a husband who is
20 just like, incredible. So, I also had the privilege
21 when I was at UCLA to have Frank Correll, from the
22 Robert Wood Johnson Foundation, as my mentor, and who
23 helped move me into this arena of healthcare, but

1 perhaps the most was my physician, Dr. Rodriguez, who
2 said, "Therese, you have a voice, and you must speak
3 for those without a voice." And at the time, I kept
4 pushing him off because I was on the edge and I didn't
5 want to think about people not having a voice, which
6 meant they had no insurance, which meant they had no
7 access, which meant there were barriers, when I was
8 having such a difficult time myself.

9 I now, at the Venice Family Clinic, have
10 been able to help work on a bipartisan level at the
11 State and at the Federal level with different
12 legislators, although not with Senator Wyden here, but
13 have been able to effectively create networks to look
14 at the issues of providers of the uninsured as well as
15 the issues of need regarding access and barriers for
16 uninsured patients themselves, which brings me to your
17 question about issues.

18 I think that from where I am the first
19 issue that comes to mind is the issue of patient
20 compliance, which is a part of the system that is
21 talked about but which equals to me patient education.

22 I was on peritoneal dialysis, which at the time meant
23 I dialyzed every four hours around the clock, and the

1 idea was for me not to have an infection over the
2 years that I was on dialysis. That's patient
3 compliance, because I understood what an infection
4 could do. I was educated by this physician to say,
5 "If you think you are harmed now, you need to know
6 that by not being compliant you will really harm
7 yourself." So, for me, the first issue that we look
8 at, or I hope we will consider, or somewhere on the
9 agenda is patient compliance as equaling patient
10 education.

11 The second is the underinsured, and I put
12 this in this category because patient compliance and
13 education go across the board, but if you have
14 insurance and you don't know that you need to take
15 care of your high blood pressure or else you'll end up
16 on dialysis like I did and that that bites, you don't
17 know to do that, you are underinsured and you have
18 under-access. So, I think that those two really go
19 hand-in-hand.

20 Chronic illness is a result of being
21 uninsured, being underinsured, as well as -- for me,
22 it just was something that happened, but now it ends
23 up that I've been a chronically ill patient for quite

1 a few years.

2 And then the third issue is one that the
3 clients that I represent have, and that is that at our
4 clinic there are over 20,000 patients that live at
5 100-percent Federal poverty level, and they are
6 working poor. They have two, three jobs that they
7 hold, and yet none of their positions offer them the
8 ability to get access to healthcare, so they show up
9 at our clinic. And they come back because we provide a
10 continuum of care in a clinic setting that is primary
11 care, that is mental health care, that looks at issues
12 of a whole system, and so the clinic system that is in
13 our nation today is a system that provides whole-
14 healthcare in many areas, and I would like to suggest
15 that that is something that we need to look at as
16 well.

17 But then from the employer side and the
18 economic side of my job, uncompensated care,
19 uncompensated adult care -- and by adult care, that's
20 anyone from 19 to 64 years of age -- is the largest
21 cost factor in our clinic, and the reason is because
22 we have to raise money to provide the services for
23 these individuals, and that's over and above accessing

1 our homeless healthcare grants, that's over and above
2 accessing other foundations for programs that we can
3 set up for three or five years to start a program
4 because we then have to carry it on, which means that
5 we have to look at a provision of economic value as
6 well for that. So, I think that those are perhaps my
7 issues that I bring.

8 CHAIRPERSON JOHNSON: Let me see if I've
9 captured your comments. What I heard you say right at
10 the start was there are terrific barriers to accessing
11 care. Cost is a major one of them, but I wasn't clear
12 -- it didn't seem to me like that's the only one, and
13 I'll ask you to comment on that in just a second.

14 You said there's a combination of patient
15 compliance that's an issue because oftentimes of
16 patient education -- and those two go pretty closely
17 together -- patients complying with medical care
18 prescribed. Many times that doesn't happen, I
19 understood, because they are not educated as they
20 should be regarding the impact.

21 The underinsured, people must know what is
22 available to them and how to go about getting the kind
23 of care that they really need to have. Coverage for

1 the working poor is an issue. Need for whole-
2 healthcare, we haven't focused as much on that as much
3 as we focus -- and I'm putting some words in your
4 mouth to see if I'm understanding -- haven't focused
5 on whole-healthcare as much as we have focused on
6 treating illnesses.

7 And, finally, what I thought I heard you
8 say was another issue is uncompensated care, and what
9 I thought you were implying was resulting in cost-
10 shifting to some others. Have I heard you correctly?

11 MS. HUGHES: Absolutely. Absolutely.

12 CHAIRPERSON JOHNSON: So, is there
13 anything I haven't captured that you'd like us to make
14 sure we've heard you on?

15 MS. HUGHES: I think that the clinic
16 system in our nation needs to be looked -- no, you've
17 captured it. That's fine.

18 CHAIRPERSON JOHNSON: This kind of
19 represents it?

20 MS. HUGHES: Yes.

21 CHAIRPERSON JOHNSON: Thank you very much.
22 Okay, Montye, you're next.

23 MS. CONLAN: Well, I guess I have a very

1 personal story. I'll touch on some of the things that
2 some of the rest of you have mentioned as I go along
3 because it has triggered things in my mind.

4 I think for many years I saw myself -- and
5 maybe I represent those young people -- as a
6 completely healthy person. Sometimes I had healthcare
7 coverage and sometimes I didn't. It seemed irrelevant
8 because I could probably count on one hand the number
9 of times I had to go to the doctor, and that's even
10 including having a baby. I used a midwife and had my
11 child at home. Of course, I took her for care at an
12 early age, but my family really had minimal use of the
13 healthcare system, and that seemed to work real well.

14 I thought I had it figured out -- lots of exercise,
15 good diet, sometimes -- I lived out west and did a lot
16 of hiking, so all the experience with that -- and I
17 think I represent the innocence of many Americans and
18 certainly many young people.

19 That worked well until about the age of
20 45, and then something was different. And I continued
21 on my same course of, well, more exercise and better
22 diet, and all of that. But the thing that was
23 different is I started going to doctors, many doctors,

1 and I was misdiagnosed. There were many tests, many
2 misdiagnoses. Eventually, I became very sick. I was
3 partially paralyzed on one side, lost some of my
4 hearing, a lot of my vision, and could only work part-
5 time, but I still got up every day and went to work
6 even though I had to live with my parents. They
7 provided all of my care so that I could go to the job
8 and work part-time.

9 I ended up hospitalized for quite a long
10 period of time, with many tests. I was diagnosed with
11 MS. I was very sick, and asked my employer for a
12 reasonable accommodation to come back to work, was
13 denied that, and then promptly fired, and I was
14 plunged into this world that I really had not
15 experience with, and it was very rough going for quite
16 a while. I like the way Senator Hatch acknowledged
17 the need for mental healthcare because I certainly
18 needed a whole lot of it at that time. I became very
19 angry and very isolated in trying to access the
20 system. I also didn't work for a year and had no
21 income, and in that way depleted all my personal
22 savings.

23 At that time, I became eligible for public

1 healthcare, Medicaid first, and that is administered
2 through our Department of Children and Families, a
3 bunch of very jaded, cynical people who were very
4 suspicious of me. They were sure that this was all a
5 ploy to scam the State of Florida.

6 So, anyway, I became a beneficiary of
7 Medicaid. So then I applied for disability and went
8 through that horrible maze and gauntlet, and after a
9 year I received disability. I had to go through many
10 hearings, fight every step of the way. You see, I
11 didn't have a significant other, I had to do all the
12 fighting myself when I was at my sickest in my life.
13 So, that made me very angry and very needy for mental
14 healthcare, and I acted out a lot. But eventually
15 things got better. I was on disability, and then
16 after two years I was eligible for Medicare. So, at
17 this point I'm a dual-beneficiary. I do have
18 Medicare, but I am so affluent now, I don't qualify
19 for regular Medicaid, I qualify for what is known as
20 the "Medically Needy", or "Share of Cost", and that is
21 a wonderful program, and that provides coverage for
22 catastrophic care. I do have my prescription drug
23 costs covered. I am dependent on expensive, self-

1 injectable drug, \$1300 a month, and the Medically
2 Needy Program does provide that to me.

3 So, becoming a Medicaid beneficiary, I --
4 again was very angry -- until I met up with Florida
5 Legal Services. They are a wonderful advocacy group
6 for people like myself in the State of Florida. And
7 they really taught me how to advocate for myself. Not
8 only that, they started asking me to come to
9 Tallahassee to advocate for others because each year
10 we have a ritual in Florida when the State Legislature
11 comes into session for 60 days and is looking at
12 balancing the budget. They always pick on the
13 Medically Needy Program because it's a very expensive
14 program, and that triggers all of us -- organ
15 transplant survivors and people with MS and others --
16 to go and carry on and act out, and then ultimately we
17 usually get our coverage, although it is whittled
18 away. Each year, we lose a little ground, but we seem
19 to retain the most important features.

20 So, that has been my life for quite a
21 while, and it's been a healing process. Normally,
22 when someone is diagnosed with a chronic disease, I
23 understand it's about one to two years until they come

1 to accept it. Well, it's probably been -- I'm a slow
2 learner and, you know, that youthful attitude -- it's
3 taken me about five or six years, so I'm at the six-
4 year mark now, and I've just started to regain that
5 desire to be actively engaged in life again. And when
6 the notice came across the Internet from Florida Legal
7 Services that this group was forming and soliciting
8 applications, they sent it to every Medicaid patient
9 that was in our chat group, and I don't know how many
10 applied, but I certainly did. And I didn't think I
11 ever had any chance of being called or interviewed or
12 anything. I was going to check at the end of the
13 month when it was designated that word would come out,
14 but I had no idea I would receive a call. But I am
15 very pleased, and I want to bring the voice of the
16 dual-beneficiary.

17 I also now, since I am disabled, spend a
18 lot of time around senior citizens because we are in
19 the same little niche. We're out during the daytime
20 and we're involved -- I'm very involved in exercise
21 programs at the YMCA, as are many of them, so I'd like
22 to bring their voice and bring the voice of the dual-
23 beneficiary. This is part of the healing process for

1 me, and I'm proud of myself that I applied, and I'm
2 even more proud that I've been accepted, and I guess
3 life goes on.

4 CHAIRPERSON JOHNSON: Before that, you
5 were a highly qualified math and science teacher.

6 MS. CONLAN: Yes. You know, I was
7 thinking about that earlier. I had no great desire,
8 as a child, to be a science teacher. I started
9 working -- we lived in Montana for many years. Came
10 back to Washington. And there was a sign at the
11 National Zoo one day, "Come work at the Zoo", and kind
12 of on a lark, I said, I'd like to do that. And then I
13 started getting more and more involved in the work
14 there, and I was open to the possibility when they
15 approached me about teaching classes for children. I
16 really had had no other experience in the teaching
17 area. And one thing led to another, and I ended up a
18 science teacher. But I think the message there and
19 what I was thinking of earlier is that I was open to
20 the possibility. I feel the same way here. I'm open
21 to the possibility of this process, and I have a lot
22 of faith that good things will come of it because
23 that's been my personal experience in the past. If

1 you are open to the possibility and you're sincere in
2 it and you work hard, and with the wonderful seed
3 that's been planted, if we nurture that, I think good
4 things will come.

5 CHAIRPERSON JOHNSON: Montye, I've
6 captured a few of your thoughts, but would you like to
7 be more specific than I have been in articulating what
8 you perceive to be the principal issues that we're
9 facing? Maybe I just haven't -- I don't want to
10 surmise based on your comments.

11 MS. CONLAN: Well, I do think that I said
12 that I was in charge of my health, and also I think
13 that I continue to be a completely healthy person.
14 I'm a very healthy person. I have this little
15 electrical problem that -- on the nerves running from
16 my brain to my legs in particular but I'm really
17 interested in this wellness approach because I think
18 it has carried me throughout my life. I'm in charge
19 of my health. I'm interested in wellness. I am a
20 healthy person. And at this point, I still continue
21 to be in charge, but the game has changed a little bit
22 in that I have to use my ability to scope out and
23 access the best healthcare coverage that I can. I

1 currently go to the Mayo Clinic in Jacksonville, and
2 they accept dual-beneficiaries such as myself.

3 In Florida, the legislators have a
4 different saying, why provide Cadillac coverage to
5 people like me when a Chevy will do -- not Studebaker
6 -- but I happen to think I'm going to seek out places
7 like the Mayo Clinic, and there are other places that
8 I have gotten healthcare recommendations to develop a
9 management plan. I've gone to the Heuga Center in
10 Colorado. It's kind of like MS boot camp. And there
11 were 45 practitioners there. They assessed me from
12 top to bottom, and I left there with a management
13 plan, and now I'm invested in that management plan
14 because I understand it. They educated me. They gave
15 me personal counseling so that I understand why I need
16 to manage my MS. Things like infections are very
17 critical to me, too, and why I need to now follow up
18 on all those infections. Dental care is really
19 important. So, I understand in terms of my chronic
20 disease how to better management and why it's a
21 lifetime pursuit. So, I think those things are
22 important, too.

23 CHAIRPERSON JOHNSON: I've added these two

1 things that capture some of your thoughts. Okay.

2 Thank you. Glad you're here.

3 MS. CONLAN: Thank you.

4 CHAIRPERSON JOHNSON: Pat?

5 MS. MARYLAND: I'm Pat Maryland. I've
6 been in healthcare for about 26 years. Just to share
7 a little bit about my background, my father was in the
8 military, in the Air Force for about 31 years, and we
9 lived in probably four different countries, and
10 probably in total count about 12 different places by
11 the time I was 18 years of age. Born in England, went
12 to high school in West Berlin, Germany, lived in
13 places like Cheyenne, Wyoming, California, so I've
14 been all over. And I share that to show a little bit
15 of my experience and how that weighs into the type
16 person I've become today.

17 I have a Doctorate Degree in public health
18 from the University of Pittsburgh, started my career
19 really off in the math area, Bachelor's Degree from
20 Alabama, Montgomery, Alabama at the university in
21 applied mathematics, and went on to get a Master's
22 Degree because I'm real interested in wanting to
23 somehow bridge the -- take the quantitative experience

1 and knowledge and apply that to the field of medicine
2 in biostatistics. I have a Master's Degree in
3 biostatistics from the University of California at
4 Berkeley. And I knew that I wanted to do something in
5 terms of management, really getting more involved in
6 how do you take these disparate areas and pull them
7 together in a way that's coordinated and provide more
8 comprehensive care to patients. And so I thought I'd
9 like to make that next move to healthcare management,
10 and moved to the University of Pittsburgh and took the
11 advanced degree in actually health services
12 administration.

13 I've worked in places, with very well-
14 rounded experience, starting off at the Cleveland
15 Clinic Foundation, worked there for about 15 years in
16 planning hospital operations and then in corporate
17 development, and then moved from there to Detroit and
18 worked as president at a hospital within the Detroit
19 Medical Center, and really became exposed to the
20 opposite end of the spectrum from the Cleveland Clinic
21 Foundation. It was great in terms of grounding,
22 taking me back to my roots, if you will, in terms of
23 understanding the needs of a number of citizens who

1 were either underinsured or uninsured. And then most
2 recently, I moved about a year and a half ago to St.
3 Vincent's Hospital in Indianapolis, Indiana.

4 What's interesting, while I was at the
5 Detroit Medical Center, I became very frustrated that
6 we were dealing with a significant number of issues in
7 terms of the uninsured, but really didn't have a plan
8 in terms of how to manage those patients. We sucked
9 it up. We tried to take as much as we could. We went
10 out, holding our hands out to State and others to try
11 to give us more money to pay for this uncompensated
12 care, but really did not have a proactive plan in
13 place to really address the needs.

14 What intrigued me about the move to St.
15 Vincent -- St. Vincent's Hospital in Indianapolis is
16 part of a larger system called Ascension Health. It's
17 the largest Catholic health ministry in the country.
18 And what impressed me with the Ascension Health system
19 was that it truly had a mandate to look at three key
20 areas. One is, create a system across the country
21 that provides healthcare that works, that's efficient;
22 healthcare that's safe -- looking at the medical
23 errors and really create through IT, information

1 technology, ways to be able to address those needs --
2 and then most importantly to me, healthcare that
3 leaves no one behind. The whole issue of the uninsured
4 is a major issue.

5 I was reading -- and I wanted to share a
6 couple of things that I found very interesting. I was
7 reading a study that was published in Health Affairs
8 last week that projects by the year 2013 that more
9 than 28 percent of our population will be uninsured --
10 11 million more people by the year 2013 will be
11 uninsured, a third of our population uninsured. At
12 this rate -- as you said, Social Security is important
13 -- but this is even more far-reaching than that. It's
14 just hard to fathom the statistics.

15 I am hopeful, after hearing some of the
16 stories and hearing a lot about the background of our
17 members of the committee, that we can put faces to
18 these numbers, if you will, and it's important for us
19 to come up with some practical rational
20 recommendations that hopefully can be implemented and
21 accepted by all groups that will be nonpartisan
22 recommendations that we can move forward on because it
23 is very personal.

1 And my personal story as to why I'm
2 interested in healthcare and why I wanted to bridge
3 that gap between the quantitative to the medicine area
4 was because my mother, as with most African Americans,
5 was obese, had nutritional problems. Her obesity led
6 to Type 2 diabetes, that then led to congestive heart
7 failure, and then to renal failure, and then to
8 subsequent death. Very typical in African Americans.
9 And I really believe that if there had been earlier
10 intervention and better education and more
11 understanding from the family's perspective, educating
12 the family about the need, that my mother should have
13 been more concerned about compliance to medication
14 protocols, that she would be alive today. And I think
15 that lack of coordination between the caregivers and
16 the lack of comprehensiveness of the care that she
17 received is part of the explanation. Yes, there
18 should have been some personal responsibility, but I
19 think it starts with the educational piece.

20 So, I'm hoping that with the process in
21 the committee, we'll use within our own areas concrete
22 examples of programs that seem to be working, that
23 maybe we can take and develop and really replicate at

1 a much larger level.

2 I'm thinking about one program in central
3 Indiana now, it's called the Central Indiana Help
4 Underserved Access to Health Program that's a part of
5 our St. Vincent Health System. This is a program
6 that's truly in partnership with the Federal
7 Government, it's a program that is funded by Ascension
8 Health, but also funded by the Federal Government.
9 So, it's a private and public partnership, if you
10 will. It has moved primary care services from the
11 emergency rooms to the clinics, to a primary care
12 setting. We are taking care of a large number of
13 Hispanic patients, so we've provided translation
14 services to address the whole issue of patient
15 education. And we've also provided support for the
16 prescription drugs.

17 What's important about this program is
18 several things. One is that there is personal
19 responsibility because there is a sliding fee scale
20 where if you can pay based on income, we expect some
21 payment be provided for the services rendered. And I
22 think that personal responsibility translates into
23 compliance, quite frankly. But at the same time,

1 we're providing services that are truly needed, and
2 we're removing the patients to a setting that is less
3 costly. So we believe that it's going to have an
4 impact, and we've seen some initial results -- and I'd
5 like to share those maybe at a future meeting --
6 specifics in terms of the results where we've actually
7 seen improved outcomes. And I believe it's through
8 those partnerships that it can make a difference in
9 terms the type of programs or recommendations that we
10 might be able to come up with that could be replicated
11 at a more national level.

12 So, I'm excited about being a part of this
13 process. I believe that one of the things I want to
14 make sure we capture is that whole issue of
15 information technology. Our industry is so far behind
16 other industries in terms of making use of technology
17 to coordinate the care better, share and move
18 information along so that we're more efficient is an
19 area of great frustration. I've made this statement
20 before, when you go to the airline industry and you
21 look at what they're doing with technology -- you come
22 in and you can use your debit card just to get your
23 electronic ticket -- why can't we have a card

1 available where you have all the information, all the
2 past medical history about that patient and just
3 update it, and that it continues with that person. If
4 other industries can be more sophisticated, I don't
5 understand why we can't catch up. It's just a big
6 frustration. So we really need to look at how do we
7 capitalize on the technology that exists to make
8 ourselves more efficient and reduce costs overall.

9 And the final statement I want to make is
10 that we are spending a lot of money for healthcare,
11 and it has truly not translated into the type of
12 outcomes when you look at other countries. We can do
13 better, and we can take those same dollars and be much
14 more efficient in terms of the management of those
15 dollars.

16 CHAIRPERSON JOHNSON: Okay. We'd like to
17 come back later to hear more about some of the
18 solutions you've just touched on, but let me see if
19 we've captured your issues. Starting at the bottom,
20 what I heard you say is at the end we need better
21 quality outcomes. We're behind in the area of IT, why
22 can't we bring the medical system up to speed in the
23 use of information technology, probably including the

1 electronic health record, but we need to be much more
2 efficient in that area.

3 We have, I think I heard you say, not only
4 a lack of coordination, but a lack of comprehension.
5 What I thought you intended by that is an
6 understanding between the caregivers of what one is
7 doing and the other is doing, and maybe that gets down
8 to this is a potential solution for that.

9 And I put down transfer of numbers to be
10 personal, and what I thought I heard you say is we've
11 talked about these big numbers -- and I used a bunch
12 to start with -- but oftentimes those are distant to
13 us. They don't always apply personally. You've
14 shared a little bit about your experience with your
15 mom and how this has become personal to you. And I
16 think all of us would share certain examples. Senator
17 Hatch talked about some of his colleagues who have had
18 medical errors in which they have been involved. But
19 you're not only reflecting on that, you're saying
20 let's take some of these -- what I'd like to do is
21 make sure that we're making some of the numbers that
22 we're talking about felt personal to us as we're going
23 through this process.

1 MS. MARYLAND: The other comment I made
2 was that it was personal responsibility, too. That
3 was another piece that you might include in there. If
4 you're personally on the hook for paying some portion,
5 given what you can afford based on your income, that
6 translates I think into personal compliance.

7 CHAIRPERSON JOHNSON: Another thing I
8 thought I heard you say at the start was we did have -
9 - where I was before, we did have a plan to cover the
10 uncompensated care. We weren't doing that in a
11 financial and viable method.

12 MS. MARYLAND: That was my frustration
13 with the Detroit Medical Center, and they're an
14 important system to Detroit, but there was a lack of
15 pro-activeness, I think, in that system, other than
16 asking the State for more money for Medicaid funding
17 and increasing that pool. To me, that's not
18 proactive. What I've been impressed about when I made
19 the move to St. Vincent is that the system that we
20 belong to, Ascension Health, has been very proactive,
21 that we are responsible for making sure that
22 healthcare is provided and it leaves no one behind,
23 but let's be more proactive about it. Let's have a

1 shared type of way of being able to address the needs
2 of the uninsured.

3 CHAIRPERSON JOHNSON: Thank you. Rosie.

4 MS. PEREZ: I'm Rosie Perez, and so far
5 everyone has said a little of something I wanted to
6 say, so that's cut down my list a little bit, so I
7 thank you for that.

8 CHAIRPERSON JOHNSON: Well, don't hesitate
9 to repeat the issues that you're facing so we really
10 capture them.

11 MS. PEREZ: I've been a nurse for 19
12 years. I was counting up, and actually a few minutes
13 ago, it kind of took me by surprise that I've been a
14 nurse for 19 years. It kind of freaked me out that
15 I'd been doing this for that long, but started out
16 very young. Started out in a suburban hospital,
17 worked trauma, ER and, as Dorothy had mentioned, I
18 thought, well, all these people coming in accidents,
19 if they would just wear their helmets and put their
20 seatbelts on, we wouldn't have these issues.

21 So, then I made the transition to try to
22 do more public health, community health, believing if
23 people just had the information we'd be better off,

1 but that hasn't worked either because then you get
2 into other issues of they can't read English, or they
3 don't have access to care, or they can't afford to pay
4 for care, or a doctor gives them a prescription for a
5 pill to take three times a day with meals and maybe
6 they're lucky if they get one meal a day, and so now
7 that person is, like, "They said three times a day
8 with meals, so now what am I supposed to do?" so
9 that's been kind of my work for the past 11 years as
10 Director of Community Outreach at Christa St. Joseph
11 Hospital. We're the seventh largest Catholic
12 healthcare facility, with Ascension being the first.

13 But that has brought a different
14 perspective as well because our mission to extend the
15 healing ministry of Jesus Christ makes it very broad
16 as to what we do, and the expectations of a faith-
17 based healthcare facility, people come in and you're
18 the Sisters of Charity, or you're Christas, or you're
19 faith-based, you're supposed to give the care for
20 free. Well, our Sisters fortunately have stayed in
21 business for over 150 years and they didn't do that by
22 just giving away free healthcare. So, how do we kind
23 of balance some of those issues.

1 My family has been in Texas forever. We
2 have a saying that the border crossed us, we didn't
3 cross the border. So that's another piece. We talked
4 about the uninsured, but I'm going to put it out
5 there. One of my major issues and concerns is how do
6 we pay for healthcare for undocumented people? That's
7 a reality. That's something that we're coming to
8 terms with. I know in Houston that's a backlash. If
9 we didn't have so many illegals -- I don't care for
10 that term, I'll use undocumented -- if we didn't have
11 so many undocumented people here, we'd have healthcare
12 for everyone. But the reality is that we've created a
13 culture that brings them in, we use them for our
14 workforce, we need them for our workforce, but then we
15 don't want to offer them the services that are due
16 everyone else. So, that's something that we have to
17 come to terms with.

18 They can't apply for prescription programs
19 because they don't have a Social Security Number.
20 Well, we want them to pay taxes, but then we don't
21 have a system set up for them to do that. So, I think
22 it's all kind of interrelated and we need to know how
23 we're going to come to terms in dealing with these

1 populations, and then there's others. There's other
2 immigrants who have come here to the country and their
3 coverage is spotty. Some people will qualify for
4 Medicaid by virtue of their visa status, or they won't
5 access certain benefits that are due them because they
6 are afraid that's going to affect their citizenship
7 applications. And so we kind of have just made it
8 very difficult for a lot of people to access services.

9 In Houston, believe it or not, we just
10 found out what federally qualified health centers are,
11 and we've just gotten our second one. So, yeah,
12 everyone else in the nation has got 15 of them, and
13 we've just now got our second one, and we have several
14 communities that are working on FQHC status if not
15 look-alike status. Why is that? Well, we have the
16 Texas Medical Center, so I think there was a
17 perception that we had this world-famous medical
18 center and people were accessing healthcare and the
19 latest technology and access to the latest research
20 when that is not the reality. We have the worst
21 health outcomes in Texas and Houston for immunizations
22 down to cancer. Fortunately, we have M.D. Anderson
23 and Dr. Lovell Jones, who sit on the ICC Council

1 examining the unequal burden of cancer, a minority
2 group making a lot of changes, but the reality is that
3 still we have large groups of communities and people
4 that do not access that care in the medical center.
5 So, they're excited about FQHCs.

6 Another issue and concern is we have a lot
7 of those communities, where the initiatives for
8 applying for those statuses comes out of, again, a
9 faith-based coalition. So, a lot of them have issues
10 with the government and the requirements to apply for
11 federal funding, which would be the family planning
12 issues, so have to struggle with whether they're going
13 to make the decision about going after federal funds
14 being that there are certain requirements built in
15 that it's all or nothing. So people are trying to
16 work around some of those issues and trying to provide
17 access points in communities to reach people.

18 I think another issue that I find of great
19 interest is the nonprofit status for hospitals. In
20 Texas, if you want to be a nonprofit, 5 percent
21 charity care is the requirement. Some hospitals would
22 choose to do that right off what comes in through the
23 emergency room. Other people will say, "Oh, it's

1 health fairs out in the community." So, there are
2 thiese differing criteria as to what charity care is
3 or what needs to be given. And of course there are
4 also disparities in that a lot of hospitals will
5 pretty much stick to 5 percent, and then there are
6 healthcare facilities such as mine and others that
7 will give upwards of 13 percent.

8 So, again, there's no one saying, "Hey,
9 you're doing more than your share, it's time for other
10 people to come up." We've started this, we're in
11 this, we're committed to this, so now we can't cut
12 back and say, "Well, everyone else is only giving 5
13 percent, so now we need to cut back and make a little
14 money ourselves."

15 So, I have an interest in how these
16 systems are created and how they come to be, and if
17 there's anything we can do to change that.

18 I think everyone has talked about personal
19 responsibility, and I think that's very big. And I
20 think something that maybe I haven't heard yet because
21 it's all come up in forms of payment, monetary
22 payment, but I run a free clinic in a community out of
23 a church, and we have plenty of people that come up

1 and say, "I really can't afford to pay anything."
2 And I visit these people in their homes as I'm
3 delivering their free medications, and they are living
4 in Third World conditions. They have no running
5 water, they have no electricity, they have no food.
6 The food that they get -- talk about nutrition
7 education -- they're going to pantries. They don't
8 have choices about what they're going to get. But
9 they come back to the clinic very willingly and say,
10 "I don't have any money to offer." Some statements
11 are, "I don't know anything, I'm stupid, I'm
12 illiterate, but I'm here to help, whatever I can do --
13 if it's to take out the trash, or if it's to sign in
14 people, or if it's to file -- I want to give back."
15 So, I think we also need to look other ways of having
16 people pay back into the system other than monetary.

17 And they're very concerned about Medicaid.

18 On the plane over here, there was a report released
19 in Texas, and the number of providers that are
20 accepting new Medicaid patients is dwindling.
21 Fortunately, in Houston, we're still like 36 percent
22 of the providers will accept a new Medicaid, but we
23 have other large cities in Texas, like Austin and

1 Dallas, where 76 percent of providers are not
2 accepting new Medicaid or, if they do, it's because of
3 a sibling or it's very limited services that they are
4 providing. So, I think that that's some issues that
5 we'll start to deal with as well.

6 CHAIRPERSON JOHNSON: Is that both
7 Medicaid and Medicare?

8 MS. PEREZ: Medicaid only.

9 MS. BAZOS: Would you talk a little bit
10 about the reimbursement in your region to put up on
11 the board for Medicaid?

12 MS. PEREZ: Well, it's not enough. And
13 that maybe extends to CHIP. We had our major Texas
14 Children's Hospital who aggressively went into
15 communities of color and underserved communities to
16 sign up children for CHIP, and we assisted in doing
17 that. And then a year after that, they're kind of
18 like, well, the \$18 reimbursement per child isn't
19 enough, and of course you have people like me saying,
20 well, before you were getting zero, so this is
21 something better than nothing, but they don't see it
22 that way.

23 So, obviously the amount, and then the

1 paperwork. We have providers that won't even apply
2 for the Vaccine For Children Program which gives free
3 immunization because of the paperwork. They say
4 they'd have to hire another staff just to keep up with
5 the paperwork and the inventory and the reports, and
6 it's the same for Medicaid. So, big issues.

7 CHAIRPERSON JOHNSON: Here's what I heard.

8 Let me test. Patients can't read English, so how can
9 they follow the instructions that they're given?
10 Poverty makes it difficult to comply with
11 prescriptions, and would it be not only prescriptions
12 of medication, but maybe other types of prescriptions
13 of care, but what you pointed out as an example was
14 "I'm supposed to take my medication with food three
15 times daily, and I only have one or two meals a day".

16 Just plain uninsured, that's an issue.
17 Payment of care for undocumented folks. They can't
18 apply for assistance, or they won't apply for
19 assistance. They may not be aware -- we, or others,
20 or some of us may not be aware of assistance programs
21 already in place. There are programs that might be out
22 there and funded, but either we as individuals or
23 maybe even certain groups aren't aware of programs

1 already in place available to help people, which
2 implies maybe marketing of those programs might be
3 helpful, I suppose.

4 Availability of federal funds for faith-
5 based programs. What I thought I heard you say is
6 that there still are some issues having federal money
7 available to faith-based programs because they happen
8 to be affiliated with a church or synagogue. And,
9 finally, what I heard you say is there a reduced
10 number of doctors accepting Medicaid patients, and I
11 suspect we will find the same issue relating to
12 accepting Medicare patients, although we haven't
13 addressed that so far. But the number you talked
14 about was 76 percent are not accepting in your area.

15 MS. PEREZ: Right. And that was kind of
16 an important thing because I think up on one of the
17 slides it talked about educating and enrolling people
18 about existing programs. Well, that's great, and if
19 you put all that resource and money to doing that but
20 then they don't have a provider to go to.

21 CHAIRPERSON JOHNSON: Okay.

22 MR. HANSEN: If I could just add something
23 that goes along the lines about the comment of society

1 that Frank made, but directly to Rosie's point about
2 the undocumented. And we deal with tens of thousands
3 of those in the poultry and the packing industries,
4 and there are literally millions in the United States.

5 But a lot of the companies -- and they're here -- I
6 don't like the word "illegally" here, but they're here
7 without papers, and you have to sign up for the
8 insurance. And sometimes, and more often than not,
9 they are told to sign this, it goes in the record and
10 all that stuff, so they don't, and that adds to the
11 uncompensated costs. And where a lot of these plants
12 are, they are in small towns in rural America, and it
13 really drives up some tremendous costs and I think
14 leads to a lessening of quality care, from our
15 experience anyway.

16 CHAIRPERSON JOHNSON: Thank you. We're at
17 12:15, but I'm just pointing that out to you not to
18 push you along because if we don't get through each of
19 you before lunch, we'll take some time after lunch, so
20 we want to hear from each of you.

21 Deb, why don't we continue with you and
22 Aaron, Chris, and Mike, and Catherine as well.

23 MS. STEHR: I'm Deb Stehr. I'm from Lake

1 View, Iowa, which is a very rural community in
2 northwest Iowa, population of about approximately 1200
3 people, and like no jobs. The jobs that are there
4 don't have health insurance. I'm married to my
5 husband now for almost 27 years. We have two
6 children. Mike is 25, and he is one of those young
7 adults who doesn't have health insurance. And our
8 youngest son, Jonathan, is 22. He was born
9 prematurely, in December of 1982. We didn't have
10 health insurance. He was born en route to the
11 hospital in a car, in intensive care for six weeks in
12 Children's Hospital in Des Moines. We didn't have
13 health insurance, so not only were we very worried
14 about this sick baby, we were worried how we were
15 going to pay for this because I can remember the bill
16 was like far more than what we would make even in a
17 year.

18 My husband is self-employed, he has an
19 auto body repair shop, so he pays for the business,
20 all the overhead for the business. So, when John was
21 growing up, it took basically two of us to take care
22 of him. Even today he pretty well needs 24-hour
23 care. So, I waited tables at night, and my husband

1 worked the business during the day, and we shared the
2 role of childcare. It didn't make sense for me to
3 work during the day because you never knew when he was
4 going to be sick. He was sick a lot, and in and out
5 of the hospital for surgeries.

6 He's doing quite well today. He's a
7 Medicaid recipient. He's an adult. He's actually his
8 own guardian, which is kind of cool, except we,
9 through the whole Terri Schiavo thing, realized we do
10 need to make sure we have some authority over his
11 medical care because there are decisions he's going to
12 make that may not be the best. I'll admit he's a
13 little hypochondriac. He watches too many of those
14 drug advertisements on TV every day, and he's
15 convinced he's got acid reflux disease, now he's got
16 kidney problems. I mean, he sees the stuff on TV, he
17 will actually go to the doctor and say "I want this
18 drug", and I'm going to the doctor "No, no, no, he
19 doesn't need it".

20 CHAIRPERSON JOHNSON: He's just like the
21 rest of us.

22 (Laughter.)

23 MS. STEHR: Yeah. And I think it just

1 goes to show a good point about the whole advertising
2 thing. And I guess Jonathan has really changed my
3 life a lot, like not having the health insurance.
4 Because of him and seeing what we went through with
5 him and him on Medicaid, it makes me far more
6 interested in what's going on with the healthcare
7 system.

8 I got very involved in a Citizens' Action
9 Organization ten years ago during the first major
10 attack on Medicaid in 1995, had spoken out -- actually
11 have my ten-year anniversary coming up of public
12 speaking when I spoke out at a press conference in May
13 of '95 and shared my personal story, and I've
14 literally been at it ever since.

15 I'm concerned about the healthcare system.

16 I literally applied for this Working Group more or
17 less out of like sheer frustration. I applied on a
18 whim out of sheer frustration thinking, I'm not going
19 to get it anyway, and applied. And after going back
20 and reading more on it and talking to people, I
21 thought, wow, this is such a wonderful opportunity.
22 So, I bring to the table what it's like to not have
23 health insurance, and to live in rural Iowa where

1 there's not a lot of doctors.

2 And I can also look back 20-25 years ago,
3 we were lucky enough to have those good hometown
4 family doctors. They would see you, and if you didn't
5 have money, you still paid for it, but you paid a
6 little bit. You paid it when you could afford it.
7 They were really open about giving you drug samples.
8 A couple of us would go in together and they might
9 charge for one office call. Or even if there was an
10 emergency -- my 25-year-old had attention deficit
11 disorder and he was a hyperactive and really risk-
12 taking kid, so we spent a lot of time in what might
13 have been emergency rooms, but because we had this
14 great family doc and his office was two blocks away,
15 we could get in on a Sunday, or at night. He'd make a
16 point of coming and providing healthcare, and that
17 doesn't happen, I don't think, anymore.

18 I don't know, it's just like I said,
19 worried about Medicaid, worried about cuts. I know
20 Medicaid doesn't just pay for the healthcare, it's all
21 those additional services that come with it. For
22 someone that has severe disabilities and needs the
23 extra care -- he uses a lot of home computing based

1 services, he's on the Medicaid MR waiver, so through
2 the years he's had supportive community living, we've
3 accessed respite services, and he currently uses CDAC,
4 which is Consumer Directed Attendant Care, and we went
5 to that system because he was using nursing after a
6 major, major surgery when he was laid up for six
7 months after he'd had his spine straightened for
8 scoliosis, but we got to the point where a healthcare
9 agency wouldn't take us, the home healthcare agency
10 wouldn't take us because he had grown and was a high
11 care level, so we went to CDAC.

12 We lost our provider shortly after he
13 graduated from high school, and I ended up becoming a
14 Medicaid provider, and I am now his CDAC for life. I
15 get paid for five hours a day, I'm with him 24 hours.

16 And it seems to be working. Most of the time it
17 works. He can get pretty stubborn at times. He's
18 threatening to fire me if I'm going to be gone too
19 much. It's like, "Okay, Mom, you've got this job.
20 I'm going to fire you". I'm like, "Jon, I'm not going
21 to be gone that long, don't worry about it". It just
22 makes me more aware how important Medicaid is, and I
23 don't think it's taken into consideration the

1 different needs and how they impact the different
2 families. And also with his disability, it would be
3 hard to get him health insurance. And like I said, my
4 family being uninsured, as I've gotten older it really
5 scares the hell out of me I don't have health
6 insurance. I can't think of anything else to add, so
7 I hope that we can accomplish something really good
8 and get something done.

9 CHAIRPERSON JOHNSON: Let me see if I've
10 captured some of your thoughts. The challenges of
11 actually being uninsured go beyond just being
12 uninsured.

13 MS. STEHR: Yes. Well, you can access
14 care, you just can't pay for it.

15 CHAIRPERSON JOHNSON: Secondly, you talked
16 about the drug advertising, and I don't know if that
17 was just kind of a throwaway comment or --

18 MS. STEHR: I think it's a problem.

19 CHAIRPERSON JOHNSON: You think it's an
20 issue.

21 MS. STEHR: I think it's a problem. And
22 now they are even advertising artificial joints, knee
23 replacements. They advertise knee replacements on TV.

1 It's insane. Some of the stuff just doesn't need to
2 be advertised, the advice needs to come from the
3 doctor, not off the television.

4 CHAIRPERSON JOHNSON: Well, even Jane
5 Fonda this last week has kind of promoted that
6 business, I think. Availability of Medicaid docs,
7 someone mentioned that earlier, but --

8 MS. STEHR: Well, not just the Medicaid,
9 the doctors in general, particularly in your rural
10 areas, it's hard to recruit them. We had a wonderful
11 doctor that came into our rural clinic, and he was
12 there two to three years -- he just went to Florida --
13 so we're back to we don't have a doctor again. You
14 know, they come to rural areas, they work -- they're
15 required -- I suppose there's some minimum requirement
16 they need to work, and then they leave. So, that's a
17 problem.

18 CHAIRPERSON JOHNSON: And then what I
19 heard you say is there's a difficulty in obtaining
20 healthcare coverage not because of the cost only, but
21 the availability if you've had a history of health
22 challenges can be a problem -- the ability to get the
23 coverage even if you could afford to buy it.

1 MS. STEHR: Yes, the pre-existing
2 conditions.

3 CHAIRPERSON JOHNSON: Have I captured your
4 issues, or are there others that I missed?

5 MS. STEHR: That's pretty well it, it adds
6 to what's already up there, and I'm sure other people
7 are going to throw more.

8 CHAIRPERSON JOHNSON: Thanks, Deb. Aaron?

9 DR. SHIRLEY: I'm Aaron Shirley. I'm a
10 pediatrician by training. Prior to becoming a
11 pediatrician, I was one of those frontier doctors who
12 made house calls, delivered babies, did a little of
13 everything.

14 What got me there, I went to school on a
15 State scholarship that required me to spend a minimum
16 of five years in a rural area in Mississippi. I ended
17 up in Warren County, Mississippi, which is part of the
18 Mississippi Delta, and that's where I practiced for
19 five years.

20 I always wanted to be a pediatrician. Oh,
21 by the way, I accepted cash, live chickens, as payment
22 for services, and I did get a lot of that. My kids
23 were used to me bringing home live animals from the

1 office, and they liked that a lot.

2 I always wanted to be a pediatrician, so
3 when I completed the five-year obligation, I applied
4 for a pediatric residency at the University of
5 Mississippi Medical Center. To my surprise, (as my
6 surprise with being named to this group) I was
7 accepted as a resident, and I was the first black
8 resident in any discipline that they'd ever had, and
9 that was 40 years ago. And for ten years, I was the
10 only black pediatrician in the State. And what that
11 meant was the University, being a teaching hospital,
12 received patients from all over the State. We have 82
13 counties.

14 So, people from every county knew me if
15 they had had a child hospitalized at the University,
16 by virtue of the fact that I was black and I stood
17 out, and they knew me. And what that did was, when I
18 was chief resident, one night I lost 11 babies, and I
19 lost them to conditions that could have been
20 prevented. In those days, infectious diseases -- we
21 lost babies from infectious diseases, severe
22 dehydration, two of the major reasons we lost them.

23 We had antibiotics back then and we knew

1 how to treat those conditions, but in many of the
2 communities where those babies were coming from --
3 they saw the University as a place for sick kids -- so
4 they didn't apply -- because the individuals were
5 poor, they didn't apply the knowledge and the
6 technology that they had, they just shipped them to
7 the University. And that had a lot to do with
8 formulating what I would do once I completed the
9 residency.

10 I had planned to do the residency, enter
11 private practice, and be a comfortable practicing
12 pediatrician. But having been exposed to those
13 conditions that I saw as a resident, I decided that
14 there had to be a better way.

15 So, I completed the residency, opened up a
16 private office, but at the same time started pursuing
17 alternatives, and this is when I learned about the
18 community health centers. So I set out to develop
19 that concept in Mississippi for the first time, and to
20 my surprise it was a concept at that time that was
21 opposed by the local and State health officers, the
22 governor and key policymakers because the community
23 health center concept was a little foreign from the

1 typical AMA type provider, it was viewed more as
2 somewhat of a type of socialized medicine, and that it
3 was the government interfering.

4 The governor at the time had veto
5 authority over those community health center grants,
6 and the governor would summarily veto the grants that
7 had been approved. We had then what was called the
8 Office of Economic Opportunity, and the Office of
9 Economic Opportunity had the authority to override the
10 governor's veto. And each year -- the funding was on
11 an annual cycle. Each year, as long as the authority
12 for community health centers was within the Office of
13 Economic Opportunity, the governor would summarily
14 veto the grant, and we'd have to go through a process
15 of justifying and refuting what the governor and the
16 medical society used as justification for vetoing the
17 grant.

18 All that did was to kind of make us more
19 determined. So, instead of ending up with one
20 community health center, I got involved in developing
21 four or five other community health centers in other
22 parts of the State.

23 One interesting thing about that in

1 today's world, the person who had the authority to
2 override the governor's veto at that time in 1970 was
3 one Donald Rumsfeld. And I got to know him at that
4 time because we would have to write him to justify his
5 overriding the governor's veto, and on one occasion he
6 did make a visit to Mississippi and visited with us
7 and looked at the health center and decided that we
8 were doing what we were supposed to do, doing it
9 right, and he overrode the veto. So, every time I see
10 him at the Department of Defense, I think, wow, he's
11 come a long way.

12 I applied to become a part of this group
13 because I wanted a second chance. I did spend time
14 with the Clinton Administration efforts to implement a
15 program. I co-chaired the Subcommittee on Vulnerable
16 Population, and that is my concern as we move forward,
17 the population that's vulnerable. And you say, "Who
18 are they, what makes them vulnerable?" Well, things
19 that make them vulnerable are race, poverty,
20 geography, and I think the most dangerous, troubling
21 feature that makes them vulnerable is -- and it has to
22 do with what I think contributes to some of the
23 disparities that we see, and I'll use a personal

1 experience to explain that.

2 Several years ago I got careless cleaning
3 fish and I cut my hand in the middle of the night, and
4 I went to the emergency room and they sewed it up, did
5 what an emergency room is supposed to do. About three
6 or four months after the wound healed, I lost some
7 flexion in this thumb. So, I pursued a solution to
8 it, and it was determined that a tendon had been
9 severed and it wasn't sewn back.

10 Now, where my office is located is in a
11 medical facility, and just around the corner from my
12 office is a hand clinic, it's a group of doctors who
13 specialize in treatment of the hand. So, I go around
14 to the hand clinic -- it's part of the University's
15 teaching component -- and I go around to the hand
16 clinic to request an appointment. And the question
17 was, okay, what's the problem? I told them I couldn't
18 bend my thumb, and they said, okay. Well, we can get
19 you an appointment next week. What's your method of
20 payment? I pulled out my BlueCross/BlueShield card
21 and said "here it is". They said, "Oh, we can't see
22 you here, you have to go to Providian". I didn't
23 realize this. I worked for the University, I knew

1 there was a Providian, but I also knew that there was
2 a clinic right next to me. And they said, "You have
3 to go to Pavilion because we don't accept private
4 insurance here".

5 CHAIRPERSON JOHNSON: That was another
6 clinic of some sort?

7 DR. SHIRLEY: No. "You'll have to go to
8 Providian." I said, "Well, who do you accept?" They
9 said, "We accept only Medicaid and uninsured". So I
10 put on my arrogant hat, and I said, "No, you're going
11 to see me here".

12 The point I'm making is we have a dual
13 system, and I wonder if dual systems inevitably
14 contribute to some of the disparities -- racial
15 disparity, economic disparity -- because if a
16 physician is trained in an environment that segregates
17 on the basis of pay status, whether that doesn't carry
18 over in some respect as to how that patient is viewed,
19 and whether that physician once he completes his
20 training, a Medicaid client walks in, having been
21 exposed to a system that systematically segregates
22 people based on that, whether there are some
23 subconscious desires -- maybe not desires -- some

1 subconscious element that determines how that patient
2 is treated. And I find it difficult to separate out
3 how a person can say if you are Medicaid you are
4 treated over here, does that make you less worthy than
5 if you have BlueCross/BlueShield. What is the reason
6 for restricting -- I'm talking about access -- I was
7 restricted access because I had good insurance.
8 That's one.

9 And the other has to do with so much that
10 others have mentioned, the Medicaid -- the other
11 Medicaid situation where fewer physicians accept
12 Medicaid. Here we have physicians who accept them,
13 but in different parts of the healthcare system.

14 You mentioned Medicare. In Mississippi,
15 there's a growing number of physicians who are
16 limiting their Medicare practices now. And most of
17 that is driven by paper regulations and the level of
18 payment. In rural Mississippi, there are fewer and
19 fewer physicians to speak of, and there are fewer and
20 fewer physicians who routinely accept Medicaid, and
21 that's been mentioned before.

22 The next concern I have is we, as other
23 States, have a major crisis in Medicaid funding, and

1 there are some deliberate barriers being implemented
2 to reduce the number of individuals, first of all, who
3 will apply, to modify the eligibility criteria, and as
4 far as the Child Health Insurance Program, the CHIP
5 program, all outreach efforts have been curtailed
6 because it was too successful. There were more kids
7 enrolled than had been anticipated, so it is viewed as
8 contributing to the financial crisis of the program.

9 CHAIRPERSON JOHNSON: Have I captured your
10 comments?

11 DR. SHIRLEY: That's basically it. Most
12 of whatever else I had has been covered already.

13 CHAIRPERSON JOHNSON: Okay. You'll have
14 another chance, I suspect, along with the rest of us.
15 Pat?

16 MS. MARYLAND: I'll talk to all the
17 doctors now, MDs in the room, no one has mentioned
18 medical malpractice and the escalating cost of that.
19 I'm just throwing that out as just a comment.

20 CHAIRPERSON JOHNSON: I was thinking about
21 the same thing, and I wondered, well, should we
22 address that, ask the question now. So, maybe we'll
23 take lunch, and we'll come back and ask, especially

1 those of you who are physicians, if you have any
2 comments on that as we get started this afternoon.

3 It's about 20 to now, 20 to 1:00, and I'm
4 wondering if this would be a good place to take a
5 break, and then Chris will come back and ask you to
6 start, so maybe when we reconvene at ten after 2:00,
7 if that's okay -- ten after 1:00, I beg your pardon.

8 (Whereupon, at 12:41 p.m., the luncheon
9 recess was taken.)

10

11

12

1 A-F-T-E-R-N-O-O-N S-E-S-S-I-O-N

2 (1:20 p.m.)

3 CHAIRPERSON JOHNSON: You'll notice that
4 what we're doing is we're putting the issues up on the
5 wall over here. And when we're through going through
6 each of us raising our issues, we're going to actually
7 go outside and talk about them.

8 (Laughter.)

9 No. I'm looking at another group that's
10 sitting out here, and I'm thinking to myself, why
11 don't we do that? We'll be thinking through some of
12 these as we're going through the next session of what
13 are some of the initiatives already in place or we
14 think would potentially help us here. But we'll
15 proceed, and I think, Chris, you're up next.

16 MS. WRIGHT: I'm up next, to start us off
17 after lunch.

18 I'm Chris Wright, a registered nurse from
19 Sioux Falls, South Dakota. I have a few years lead on
20 you, Rosie, in that I've been doing nursing for 28
21 years. You will notice a little bit of a varied
22 accent when I talk. I can say "dawg" because I'm
23 really from New Jersey, but I lived 27 years in

1 Florida, so I also say "y'all". I moved out of
2 central Florida, Orlando area, in 1996, to Sioux
3 Falls, South Dakota, and what a difference in
4 healthcare. We went from HMOs to PPOs to very little
5 penetration in the South Dakota area, to actually
6 going back to your internal med/family practice docs.

7 They do, even in Sioux Falls, still make home visits.

8 Some of our oncologists have to make home visits. We
9 also have physicians that do outreach into a lot of
10 the rural areas in our tri-state area.

11 Sioux Falls is in the southeast corner of
12 South Dakota. The other side of the state is Mount
13 Rushmore, so we also include parts of Iowa and
14 Minnesota. There's a large ruralness. We are the
15 largest -- I work for Sioux Valley Hospital and Health
16 System, the largest healthcare provider in the state.

17 The state population is 750,000, with the town
18 population of 135,000. There are only three major
19 healthcare systems in the state, and we are one of the
20 three. In the whole State of South Dakota, Sioux
21 Valley is the second-largest employer, with the state
22 being the largest employer. John Morell's is in town,
23 so we do work with them and have those issues.

1 I have a varied background in nursing but
2 I currently am Director of Oncology Services and
3 Radiation Therapy at Sioux Valley Hospital. We've
4 built that center from the ground up. I have past
5 experience as an emergency room nurse, trauma nurse,
6 and EMT. Therese, I did 12 years on dialysis. I've
7 worked with end-stage renal disease and know that part
8 it inside and out also. In fact, we're applying to do
9 renal transplants at our hospital, so I'm lending my
10 expertise, or at least some knowledge, I should say,
11 to that area.

12 The way I got involved with this group is
13 I actually got an e-mail -- I'm the Healthcare Policy
14 Liaison through the Oncology Nursing Society for our
15 State of South Dakota, and we get on conference calls
16 at least quarterly, and also get e-mails from them,
17 and the local Washington representative did go ahead
18 and e-mail to all the state health representatives
19 that application. And I sort of took a look at it and
20 said, I can do this, for numerous reasons. I first
21 and foremost thought about my clinical side and my
22 expert side, but also thought about personal
23 experiences that I can bring to this, and what I've

1 seen even recently with family issues.

2 I think some of the healthcare issues
3 concerning America today are, No. 1, we take a look at
4 our eldercare and numerous issues that the elderly
5 have. I have an 85-year-old mother who is healthy
6 except for blood pressure medicine, who does live with
7 me and has lived with me since 1989. It has been my
8 philosophy, though, that she will continue to live
9 with me, and that we need to take care of our senior
10 citizens and not -- I hate to say -- dispose of them
11 in nursing homes, but we too much turn to nursing
12 homes. Certainly it is not an obligation of the
13 children or a family then to go ahead and take care of
14 their parents, but in some way we need to get back to
15 the basics there.

16 I have seen her issues, too, with even the
17 elderly on their own with medication, and she just
18 takes hypertension medicine, but the cost of the
19 medications today for the senior citizens where it
20 really hit me that it does have to come down to a
21 choice of do they buy their medications or do they buy
22 food for the table and get something decent to eat.
23 So that is a tough choice.

1 There is VA care. Certainly in the State
2 of South Dakota there is the Indian Health Service
3 which serves a large Native American population, and
4 they are an interesting, diverse culture to work with
5 and with their beliefs. It's interesting because their
6 service is provided by the government, but the funding
7 comes in in one lump sum in the beginning of the year,
8 so that towards the end of their fiscal year when they
9 run out of money, we are having problems getting those
10 people to our tertiary hospitals for care, such as
11 renal dialysis. Who provides that transportation? So
12 the funding is not there.

13 The affordability I said of prescriptions,
14 the affordability of hospital bills and costs. I have
15 personal experience in navigating through that system.

16 I had personal experience with my husband in two
17 ways, in that he had some major surgery, but also then
18 my in-law who had cancer, also in another State, but
19 to get them through the system by saying home health
20 is available, palliative care is available, hospice is
21 available, they can bring in this for you, they can
22 bring in that for you, you can get so much per day, or
23 whatever.

1 Since that time, I guess, word has sort of
2 gotten out on a personal level, and I have numerous
3 people, my associates in the hospital, that call me
4 for their relatives that are out of state saying, "My
5 father-in-law is dying of cancer, what can we do", and
6 that type of stuff. So helping someone actually
7 navigate that tremendous web of our healthcare system,
8 and understanding the bills and understanding what the
9 payment is.

10 The uninsured. Taking a look at not only
11 the diverse groups we have, but our state is largely
12 rural, in that they are mostly farmers and ranchers,
13 so they are a single independent business that have no
14 insurance whatsoever, and one hospitalization, the old
15 saying is, can literally cost them their farm.

16 Also seeing no standardization of payment
17 with insurance companies beyond the opposite end now,
18 with your major payers and your intermediaries, where
19 one may cover a chemotherapeutic drug and another
20 large company will not pay either as much or disallows
21 it altogether, so there is no standardization of
22 payments received and what is allowable.

23 I have recently, in the past four years,

1 gotten involved with palliative care and built a
2 palliative care team in our hospital, which I could
3 talk about forever. But, again, that is sort of the
4 way I see it going where you actually take that person
5 -- I've heard a lot of it here today -- where you take
6 that person in the beginning of their chronic illness.

7 We don't wait for the last six months to try to get
8 them into hospice and get the care, but actually at
9 the beginning of that chronic illness, throughout the
10 trajectory of the disease, walk with them hand-in-hand
11 to provide that support and medical need and education
12 and guidance of nutrition and therapy and that sort of
13 thing.

14 The other part, on a personal note, that
15 is really scaring me these days so much is that I'm on
16 listserves where I get news about different hospitals
17 and different happenings going on throughout the
18 United States and the number of mental health
19 hospitals that are closing down, and the access to
20 there.

21 My husband was diagnosed in 1999 with
22 bipolar disease, and it has been, to say the least,
23 quite an interesting and challenging battle to get

1 help and services and medication, and get Social
2 Security income for him -- you're talking about a man
3 who has a Bachelor's Degree, who worked in law
4 enforcement for 30 years -- and to see a change in
5 that. So you wonder, because I am an ordinary
6 citizen, how other ordinary citizens are coping and
7 managing and doing that. Again, thanks to the job that
8 I have and the salary that I make, I was able to
9 support us. It took us three years to get his Social
10 Security income accepted and now through the state,
11 but I'm able to support him. But my fear was what
12 would happen to me -- because I am the caregiver for
13 him and for my mother, what would happen to them, what
14 would happen to our house, those payments, if I became
15 majorly ill and that type of stuff.

16 The VA system. We have a large VA
17 Hospital also in South Dakota, right in Sioux Falls,
18 and don't have access problems like I know of and have
19 heard of in other states. Again, coming from Florida,
20 you call the VA, and you used to have to wait several
21 weeks, if not months, to get into that system to take
22 care of those servicemen and women that have paid
23 their dues for our country and joined the military

1 services and protected and defended our rights. I
2 think there is an amount that goes back to them that
3 is needed for access to care.

4 Costs. Again, back to costs and the cost
5 of pharmaceuticals. Being in oncology, we certainly
6 encourage research and new programs, new drugs, and
7 obviously that research is how we get to our new
8 standards of care for today, through that research,
9 but the amount of money and time that goes into
10 research and development and then finally coming out
11 with that high cost of the drugs makes it impossible
12 for some of the people, even insurance companies, to
13 go ahead and pay.

14 When we talk about one chemotherapeutic
15 drug costing about \$60,000 a month for treatment, it's
16 beyond reasoning. Again, going back to my husband's
17 personal experience with some back surgery, even
18 though I had insurance, he had insurance at the time,
19 the hospital stay didn't go as well as we planned. We
20 expected him to be in and out in two days. He wound
21 up on a respirator in the intensive care unit for five
22 days, in a neuro-acute unit for four more days. The
23 20 percent of my bill that I would have had to have

1 paid was \$80,000. And I sit back and think, it is
2 just phenomenal how even at \$80,000 and the salary
3 that I make per year, how other people can afford that
4 and afford to pay that. So it is time to go ahead and
5 take a look at this -- obviously, way beyond time --
6 and I am excited to go ahead and do that.

7 I was quite surprised I was chosen. I
8 hope it was, again, the geography, the ruralness of
9 the state, the diversity in the state with Native
10 Americans, plus also then the urban background that I
11 bring in, along with my nursing career.

12 About ten years ago, I decided I couldn't
13 see myself at the age of 60-something pushing a
14 medication cart down the hallway. I didn't think
15 physically I'd be able to do it, so I did make myself
16 go back to college, and was thankful that I did. And
17 actually this is quite useful because my undergraduate
18 degree and then my graduate degree turned out to be in
19 public administration, so it does go quite hand-in-
20 hand.

21 CHAIRPERSON JOHNSON: Okay. Chris, we
22 heard you talk about just briefly at the start some
23 issues for Native Americans. Can you just share a few

1 more thoughts on what you are perceiving the needs for
2 those citizens to be?

3 MS. WRIGHT: If you take a look at the
4 reservations in South Dakota, they are in the rural
5 part of our State. You can say, okay, whole state is
6 rural, Chris, but truly the western part of the state.

7 The reservations are out there by themselves. There
8 is no business. They have no economy. So you go to
9 the Indian Health Services, and you see in their
10 hospitals and clinics where they want to eradicate
11 alcoholism. Our fetal alcohol syndrome baby rate is
12 horrendous, the teenage pregnancy rate, the drug and
13 alcohol abuse, but there is no industry on the
14 reservation.

15 A lot of them think, and still think, and
16 thought maybe, that the cure-all and end-all was to
17 get casinos on the reservations. Well, it's nice you
18 have these casinos on the reservations, but they are
19 literally in the middle of nowhere with nothing else
20 around it. So people come and spend the day, but then
21 leave because there is nothing around it. So the
22 housing conditions.

23 Some of the hospitals they have are

1 absolutely gorgeous and they are trying to bring the
2 best services and equipment there to them. But,
3 again, they are a secondary hospital; they are not a
4 tertiary hospital.

5 Their dietary habits. We do have a high
6 rate of diabetes. We have a high rate of end-stage
7 renal disease that goes along with that.

8 CHAIRPERSON JOHNSON: Thank you. And then
9 what we heard is that you believe that we have an
10 issue with eldercare, and my sense was you weren't
11 talking about elder healthcare. You're thinking about
12 care for the elderly, like long-term care and so
13 forth, and healthcare for the elderly as well. And
14 then what I thought I heard you say was for some of us
15 who have out-of-state parents, there can be issues as
16 to how we coordinate for them hospice care or
17 appropriate nursing care, nutrition, therapy, and so
18 forth. Did I hear correctly there?

19 MS. WRIGHT: Truly, the way I defined that
20 is navigating. How do we navigate the system?

21 CHAIRPERSON JOHNSON: Okay. Thank you.
22 And then we talked a little bit about critical care in
23 the rural areas, and that applies to both Native

1 Americans and others in places like South Dakota,
2 Iowa, other areas. I'm sure Mississippi. The lack
3 of payment standardization. You're not sure, if a
4 doctor treats someone, whether or not it is covered by
5 the health plan.

6 MS. WRIGHT: That we can very easily check
7 on. It is different health plans, your major health
8 intermediaries are covering different things,
9 especially taking a look at some of your new
10 treatments that are coming out where BlueCross and
11 BlueShield may very easily accept payment, but even
12 BlueCross of Minnesota is not paying the same or would
13 recognize --

14 CHAIRPERSON JOHNSON: Different
15 exclusions. Closing of mental health care facilities,
16 and the cost of pharmaceuticals. Then you talked
17 about some potential issues in the VA system, and you
18 said yours is working pretty well, I think, but are
19 there others --

20 MS. WRIGHT: I do see other large ones
21 throughout the United States where there's a long
22 wait, and it's a tiered system so that, again, it is
23 by percentage of disability or based on a percentage

1 of the years they served or whatever. So if you're at
2 80 percent, you can come in; if it's 20 percent, don't
3 even bother coming in.

4 CHAIRPERSON JOHNSON: Okay. Thank you.

5 MS. BAZOS: Could you just add an
6 interface with the VA system? Would you add Medicaid
7 and Medicare to that, the Medicare-VA interface, just
8 so we don't forget to talk about that later, because
9 that's important.

10 CHAIRPERSON JOHNSON: Thank you.

11 MS. HUGHES: Excuse me, Randy. Would you
12 also, with the Native Americans, put down mental
13 health because I know in California we're working with
14 mental health issues that are specific to Native
15 Americans, not to leave anybody out, in terms of
16 mental health needs.

17 CHAIRPERSON JOHNSON: Thank you.

18 DR. BAUMEISTER: The insurance variability
19 is a huge issue for practicing doctors. I have to be
20 very careful with Senator Wyden sitting back there
21 thinking I'm going to get into the blame game here.
22 But if you have 15 or 20 different insurance companies
23 reimbursing you for your fees, every one of them is

1 different.

2 MR. O'GRADY: At the same time, when she
3 was talking, I was thinking we could be very uniform
4 and just say, no, it's not covered. I mean, you want
5 to be careful how you -- I mean, to a certain degree,
6 the situation of which BlueCross you're dealing with
7 at least allows some window of opportunity to try new
8 things and do different things. I mean, it cuts both
9 ways was all I was thinking while she was talking.

10 DR. BAUMEISTER: You're right, but it's
11 very interesting.

12 CHAIRPERSON JOHNSON: Maybe we'll move to
13 health information technology that will help us with
14 that, but before we get there -- Frank, I don't want
15 to minimize your comment.

16 DR. BAUMEISTER: Oh, sure. I understand.

17 CHAIRPERSON JOHNSON: Mike O'Grady is from
18 HHS and has been designated by Secretary Leavitt, Mike
19 Leavitt, to be working with us and share his
20 expertise. And having been in just a few meetings
21 with Mike prior to today, I have an increased
22 appreciation for the expertise he brings. So, Mike,
23 we're glad you're here, look forward to your counsel

1 as well as your participation with us, and please do
2 what we've been doing.

3 MR. O'GRADY: Thank you. I'm Mike
4 O'Grady. I'm the Assistant Secretary for Planning and
5 Evaluation at HHS, and as you saw in the enabling
6 legislation, there are the various members and then
7 the Secretary of HHS. And hopefully we'll get Mike
8 Leavitt out for some of these, but in the meantime I'm
9 sitting in that chair. And there's a number of
10 different things that I'd like to bring up in terms of
11 listening to everybody talk and thinking about how to
12 do this.

13 One of the reasons that Mike Leavitt asked
14 me to do this other than one of the other assistant
15 secretaries is that I've had a fair amount of
16 experience with commissions and these sorts of groups
17 over the years. I was on the staff of what's called
18 the Medicare Payment Advisory Commission -- I was a
19 senior health economist there -- and I was also a
20 senior health analyst on what was called the
21 Bipartisan Commission for the Future of Medicare, a
22 somewhat contentious commission that many people
23 thought was not particularly bipartisan. So there're

1 a few lessons to be learned in terms of commissions,
2 and there're certain "rules of the road", or let's
3 just say best practices, things that worked and things
4 that I've seen that haven't worked, so I'd like to
5 share some of those with you.

6 At the same time -- everybody has sort of
7 run through their bios a little bit to give us a feel
8 from where they come from -- I have a Ph.D. in
9 political science from the University of Rochester,
10 and I've been with the feds for about 25 years, mostly
11 as a civil servant but in the last five or ten as a
12 political appointee. And I come out of a research
13 background. I spent a number of years at the
14 Congressional Research Service, then over at the
15 Medicare Payment Advisory Commission, the Bipartisan
16 Commission, and then to the staff of the Senate
17 Finance Committee. I worked for Chairman Roth. You
18 all remember his IRA. He's no longer in the Senate,
19 but he's in the dictionary, which he took great pride
20 in, that he is in there as the Roth IRA.

21 So there's a number of things that I've
22 seen evolve in health care over the years, and
23 certainly you can hear the tone, and what are the

1 themes as they've sort of evolved as different people
2 talk, and there's always this balance that goes on.
3 And I think that if I had to predict the kind of
4 things we'll confront over the next couple of years,
5 balance and sort of finding that right balance between
6 these sort of competing factors will become very
7 important, very key to what we do. There certainly is
8 this notion of helping those that need help the most,
9 and how do you perceive that, how do you think about
10 that, and how to go forward, and that's clearly always
11 balanced by who pays for it, how much is affordable,
12 how you can do that, and what compromise you reach
13 between those.

14 We certainly have heard the idea of how
15 you protect people, but then we've also heard the
16 themes about people being sensitive to the cost of
17 things and what they really cost, and certainly you
18 can see that in benefit design -- deductibles, co-pay.

19 There's this sort of notion. which we've heard a
20 number of times, about people should have to pay at
21 least a little something to know that this is an
22 expensive procedure or whatever, expensive service, at
23 the same time not wanting to ding those who really are

1 not in a position to be able to pay very much.

2 We've also heard the theme, which I would
3 agree with, of personal responsibility. That takes
4 many different forms in my experience. It takes a
5 form in terms of people thinking about themselves as
6 consumers of their own healthcare. One of the things
7 in the work I've done and the research I've done over
8 the years has focused on the notion of the approaching
9 demographic of the retiring of the "Baby Boom", and
10 there's a number of aspects of that that will have
11 fairly serious triggering events that will go on.
12 Clearly, this idea of what you can provide and who
13 will finance it is going to only accelerate in terms
14 of the hard choices and the various conflicts that
15 will come up.

16 The patient-doctor relationship. As, in
17 effect, money gets tighter and tighter, we're used to
18 a situation where the patient and doctor -- their
19 interests are aligned very closely in terms of health
20 care. We've heard from a number of people that that
21 relationship isn't always as smooth as we would like,
22 but the idea of when you think about, as financing
23 becomes tighter, the relationship between -- I

1 wouldn't say physicians -- I would say providers in
2 general and their patients, economically they're going
3 to be more and more -- there will be pressure that
4 they be on opposite sides of the table. You can see
5 this now in terms of the announcement of increased
6 beneficiary premiums for the Medicare program. What
7 caused that? Increased payments to physicians. The
8 beneficiaries pay 25 percent of the cost of any
9 increase, and they said, "Whoa, why did this go up 12-
10 15 percent last year?" The answer from the AARP or
11 anyone else, or the Congressional Budget Office, is,
12 if you're going to pay physicians more -- because
13 there was a question about whether the payments were
14 too low and therefore not adequate and people were
15 starting to be concerned that there would not be
16 access -- somebody has to pay for that, and that comes
17 out of -- in Medicare anyway, a quarter comes out of
18 the beneficiary's pocket, the other 75 percent comes
19 out of the taxpayers. So, again, these balances are
20 going to become more and more -- not only are they
21 always underlying, but they will become more
22 heightened, I think, as the Baby Boom continues to
23 retire.

1 Some of the very good things that we've
2 seen, that you've heard from a number of different
3 people here, is the notion of pushing health care out
4 of a clinical setting. Don't wait until they get to
5 the emergency room, think about prevention, think
6 about different things like that, and that's part of
7 personal responsibility, I think, too, as you've heard
8 other people talk.

9 Now, I've been a Type 1 diabetic since I
10 was a teenager, and there certainly are a number of
11 things that I have found kind of pertain to this sort
12 of where we're going. One is personal responsibility,
13 and you very quickly learn with something like that
14 that this lovely endocrinologist is not going to lose
15 his eyesight or lose his kidneys or lose his toes,
16 it's going to be you. So whatever advice you get from
17 your physician, we know who the final person who pays
18 the price is going to be. And, therefore, if you don't
19 like your physician, you better find yourself another
20 one fast. And so if you ever talk to Type 1
21 diabetics, you'll find that they tend to be very
22 prudent consumers in terms of that sort of stuff. And
23 there's a very important area especially living with a

1 chronic illness of not ending up in a position where
2 you find yourself perceiving yourself as a victim. So
3 there's some of that sort of ramifications of personal
4 responsibility.

5 There's a number of things that I think
6 are real opportunities for this commission to sort of
7 delve into areas that are not -- to look at them in
8 nontraditional ways. You've heard a number of things
9 here from other people about uncompensated care, often
10 in a hospital setting or a clinic setting. There was
11 a policy decision made in this country 20-30 years
12 about the way that we would deal with uncompensated
13 care was to make payments to hospitals,
14 disproportionate share payments, those sorts of
15 things. That's the way we tried it, and it's worked
16 to a certain degree.

17 There are other people now that are
18 talking about do you want to not reprogram that money
19 and give actually the uninsured health insurance with
20 that same money. It's fungible. Now, that, I think,
21 is sort of worth thinking about. At the same time, I
22 think it is an example of the sort of stuff this group
23 will hit. If you're talking about a change where

1 you're actually talking the kind of stuff that Senator
2 Wyden was talking about of actually moving money
3 around on the board here a little bit, you have to
4 know you're coming up against some very strong vested
5 interests in terms of how that money is currently --
6 and people have gotten used to that money and
7 dependent on that money. And these are not mean
8 people; these are good people trying to do the right
9 thing. And, therefore, change is difficult.

10 There's also questions that came up about
11 access and whatnot. We have a certain policy in this
12 country having to do with the supply of providers, how
13 many new doctors come out every year. That's not set
14 in stone. Those are open questions that go on. How
15 we finance graduate medical education. It's done a
16 certain way. Is that the most cost-effective way?

17 Senator Moynihan used to argue very
18 strongly that it was a public good, like a lighthouse,
19 to have the public finance the education of doctors.
20 Other people have argued that there is clearly a very
21 large private market that would loan medical students
22 a fair amount of money to pay for their medical
23 training and that there would be a pretty good

1 likelihood of paying back those loans later on.

2 So there's a number of these issues that
3 are conventional wisdom of how we do things in this
4 country, and part of what I've heard today is that
5 part of this group's charge is to think about, well,
6 is that the way we want to continue to do them, or are
7 there other things that we want to think about how to
8 do that sort of stuff.

9 Another one is Senator Wyden brought up
10 Senator Bob Kerrey, who was on the Bipartisan
11 Commission and just a really good innovative thinker.
12 And he must have made the point any number of times
13 about how you think about categorical eligibility for
14 things. We talked about S-CHIP, we've talked about
15 Medicaid, we've talked about Medicare. We have a
16 system in this country that basically looks at certain
17 criteria -- your income level, whether you've fought
18 in a war, what you did -- and then it determines
19 whether you have health care or not.

20 A big forgotten population, I think, are
21 the people we normally think of as the homeless. If
22 you are an unmarried man or woman or a childless
23 couple in this country, you can be at 2 percent of the

1 poverty line, and unless you have a particular
2 disability or some other triggering event, you're not
3 going to get Medicaid, you're not going to get these
4 other things. We have a notion of categories of
5 people that we tend to go on, and those are -- I mean,
6 they're perfectly good policy reasons why we set up
7 programs for the disabled, programs for veterans, but
8 it has ramifications when you think about who slips
9 through.

10 I wanted to talk to you a little bit about
11 the idea of, like I said, what I think of as
12 commission lore and lessons that I've seen from
13 watching them on, as I say, two or three of them over
14 the years.

15 Each of you has, in effect, two roles.
16 You have a representative role in terms of being
17 picked because you had various experiences, or are
18 from a union, or you're a doc, or you're from a
19 hospital, or however you think about that stuff.
20 That's an expertise you bring to the table that is an
21 attempt to make this a representative body.

22 At the same time, you have a role as a
23 trustee. And the ones that I've seen that have been

1 effective commissions and work groups are the ones
2 where the members can step beyond their constituency,
3 step out of not just being the hospital guy, or the
4 doc guy, or the HMO guy, or whatever, can look at the
5 situation overall, and that's what I call a trustee,
6 be a trustee of the overall -- whatever the question
7 that's being answered.

8 Now, you're certainly expected to be able
9 to bring to the table your expertise in terms of your
10 particular area and speak to those, but it's a very
11 delicate balance. I've seen too many that have gone
12 south very quickly because the nurse stands up and
13 says how great nurses are, and the chiropractor stands
14 up and says -- okay. We can all do ten minutes of how
15 great whatever our particular point of view is, you
16 know, but that's not going to move the ball forward in
17 reality.

18 There's also a notion of consensus and
19 diversity, and I think that one of the things I
20 noticed certainly in my time working on the Hill was
21 that the United States is an extremely diverse
22 country. And I don't mean necessarily racially or
23 ethnically, but even just the way you think of things.

1 And the media I think does a real disservice by
2 implying that this is sort of bickering. But if you
3 go and talk to a group of people and you ask them a
4 question about, like, the uninsured, and you ask a
5 group of a dozen people in Massachusetts what they
6 think and what is the right solution, and they'll come
7 up with a solution, and it will be pretty obvious and
8 slam-dunk. And you go to Texas and you ask another
9 dozen people and they'll pretty quickly, after a day
10 or so, come to a conclusion. They could be a 180-
11 degrees apart in terms of what that is.

12 And I'll take a little chance here with
13 Senator Wyden, but if you look at what the Congress
14 does, what they really have to do is to find that
15 middle ground across those very, very diverse ways
16 that Americans look at things like their health care,
17 what they think their relationship should be with the
18 government. And I can assure you the dozen folks in
19 Massachusetts are going to have a very different
20 notion of the government role than the dozen folks in
21 Texas are going to have, much less the dozen folks in
22 Alaska, or the dozen folks in Florida, or however you
23 think about that.

1 So there's a wide diversity out there, and
2 the ability of a group like this to be able to step
3 out of their own shoes for a little bit, have a little
4 different perspective, at least will help to be able
5 to bring to bear and come to a point where you can at
6 least understand where the other person is coming from
7 and why some things seem such a slam-dunk when you
8 talk to people who tend to agree with you -- you know,
9 and why can't we just do blah. You see lots of ideas
10 like that never really take hold -- don't really get
11 the momentum that they need. And if this group is
12 going to be successful at pulling together things that
13 then the Senators can run with and do something with -
14 - you know, the charge is to be innovative and to come
15 up with new things, at the same time they have to be,
16 I think, practical enough that they have something to
17 work with when we're done with it.

18 I say there's also this notion of what I
19 tend to think of as left brain/right brain kind of
20 stuff. A number of people have talked about putting a
21 human face on things, or a personal -- that's
22 absolutely true. And if you ever look at a
23 congressional hearing, there's always a panel of

1 people who actually have whatever or have experienced
2 whatever. And when I used to do hearings, I would
3 have to set up what I would call a "wonk" panel. You
4 know, it was the next group of people that were sort
5 of, okay, now technically how do we do this? How do
6 we change payment policy or coverage policy, or how do
7 we do this? And I think a group like this has an
8 opportunity, has a potential to be able to do both,
9 and I don't know how, if you can't do both, if you
10 can't put a human face on it, but also be practical
11 enough to say, okay, who's eligible, who's going to
12 pay for it, how is it going to work, is this
13 sustainable. I don't think any of us wants to be
14 known as the "great founders" or the "great thoughts"
15 behind a program that is constantly bankrupt. You
16 want to think about how you do these things in a way
17 that really works. And if you look across different
18 government programs, you'll see some that are well-
19 designed and whatnot -- Social Security is catching
20 fire to a certain degree right now. At the same time,
21 if you look at it from -- and I'll put words in
22 Randy's mouth. If you look at it from sort of the way
23 it benefits people -- you know, the notion you have a

1 government program and then you have private programs
2 through pensions, and if those two programs line up
3 nicely and one adds to the other in terms of just
4 providing a higher income level for the retirees,
5 there's other programs that we have -- we've talked
6 about Medicare and Medicaid and private health
7 insurance -- you can see those three, two government,
8 one private, they tend to bump into each other and not
9 integrate in as smooth a way as we would like. So
10 design is important, I would say, in this sort of
11 stuff. And I guess that's it. I'm sorry I didn't have
12 a good wrap-up there at the end.

13 CHAIRPERSON JOHNSON: Thanks, Mike. I
14 appreciate it. I've captured some of your ideas here.

15 I think, at least, you talked about the parent-doctor
16 relationships, how Baby Boomers entering retirement
17 ages are going to be increasing costs because we cost
18 more as we get older.

19 MR. O'GRADY: Yes. And it's also -- I
20 mean, I think what is sometimes missed in the debate
21 is that Boomers are right now at their peak earning
22 years. So some of the money coming in, you know --
23 you've caught them at the crest of their wave. So the

1 idea of -- the point I was trying to make, this point
2 about kind of triggering events -- if they are now
3 paying their highest taxes and the highest amount that
4 they are able to put away, they are doing that now.
5 But once they hit that 65 and they start to retire in
6 big numbers, that's when you'll see the sort of stuff
7 that the President is putting out -- you know, we used
8 to have 16 workers for one retiree, now we have two
9 workers -- how that whittles down pretty quickly.

10 CHAIRPERSON JOHNSON: And then increasing
11 costs in terms of premiums. Premiums are going to
12 continue to go up, co-payments and co-insurance are a
13 problem because they are increasing, but they are also
14 having us focus on the cost as individuals, overall.
15 We have a need for a personal responsibility, I think
16 I heard you say that. Payment for uncompensated care,
17 something we've talked about earlier and we need to
18 focus on. Supply of new providers. Specifically, I
19 think you mentioned doctors, but those of you who are
20 nurses probably would suggest that nurses fall in the
21 same category, a shortage there. And then how do we
22 care for the homeless. Those are some of the issues
23 at least that --

1 MR. O'GRADY: I would change that to
2 "categorical eligibility" for the homeless one. It's
3 more the notion that many homeless fall between the
4 cracks, and that we provide entitlement in this
5 country based on category, not always need.

6 CHAIRPERSON JOHNSON: Thank you. Okay.
7 Last, but certainly not least, is my esteemed
8 colleague.

9 VICE CHAIR McLAUGHLIN: I feel like I'm
10 sort of a clean-up person here.

11 CHAIRPERSON JOHNSON: And that's a good
12 sign when you're clean-up. But two other things I'd
13 like to just kind of get on our agenda when Catherine
14 is done. No. 1, Senator Wyden, you've sat here
15 listening. If you would like to bring up any other
16 comments or issues that you're hearing among your
17 constituencies we haven't identified, appreciate that.
18 And then at least a couple of you -- Richard Frank and
19 Aaron Shirley -- were on another commission, and if
20 you would come back to us and share what are the
21 lessons learned from that. You said you wanted a
22 second chance. Well, how is a second chance going to
23 be different than the first one? And, Richard, if you

1 will share some of your thoughts, how could we be
2 successful if, in fact, they weren't as successful as
3 we might have wanted them to be. If you'll give some
4 thought to that, we'll come back to you in just a
5 little bit.

6 VICE CHAIR McLAUGHLIN: I was thinking
7 about -- you said everybody here is representative of
8 something. I'm not sure what I'm a representative of.

9 I've been listening to all these stories going around
10 the table, and they're really wonderful and
11 fascinating.

12 I'm an economist, like Richard, and so my
13 professional life is as a researcher and as a teacher.

14 I'm on the faculty at the University of Michigan
15 School of Public Health, and I teach in the Department
16 of Health Management Policy, which is the oldest and
17 largest program in teaching health management/health
18 policy in the country, and for decades has been ranked
19 No. 1. I had to throw that in, Richard, I'm very
20 sorry.

21 So we come from this premier program,
22 sometimes called "The Michigan Mafia" because we have
23 trained so many -- see, Pat knows about this -- we

1 have trained so many hospital administrators and
2 managers and HMO managers who do this that we've
3 really influenced how this is done. So it is with
4 some chagrin that we hear the health system is broken
5 and everything is terrible because we feel as if our
6 alum have failed us, which means that we have failed.

7 We're in the business of curing ignorance,
8 so I guess we didn't cure as much ignorance as we
9 tried to. But one of the reasons that I bring up the
10 fact that we're in the School of Public Health is
11 because even though we teach management -- and as an
12 economist, I'm part of the group that teaches
13 economics -- we have more required courses in
14 economics and strategic planning and operations
15 research and finance and statistics than any other
16 program in the country. It has a very strong analytic
17 bent. But we're not in the Business School; we're in
18 the School of Public Health. And even though the
19 Business School at Michigan just got a \$100 million
20 gift and we get \$100,000 gifts and get excited, we
21 stick in the School of Public Health. And that's
22 because, as we tell all of our Masters students who
23 come, we're not only trying to teach you how to do

1 well, we're trying to remind you that you're in the
2 business of doing something good.

3 And I think that is one of the drivers for
4 this committee as well. We can't ignore the fact that
5 we have to look at efficiency issues and survival
6 issues. And you talked about your hospital, that if
7 you didn't charge for things, you couldn't survive.
8 You're supposed to be a faith-based initiative, but if
9 you didn't charge, the Sisters wouldn't be able to do
10 good anymore. And so I do think we have to keep this
11 in mind, this symbiotic relationship between doing
12 good and doing well, that you can't help anybody
13 unless you also are doing well. And so I think that
14 maybe as an economist, and Richard also, that's part
15 of what we bring to this committee, is just the
16 economist's vision of efficiency and production, but
17 the reminder from the rest of you as well as our own
18 personal experiences, that we're not producing shoes,
19 we're producing something that's terribly important to
20 individuals.

21 Maybe another thing that I'm a
22 representative of and didn't realize until I listened
23 to all of you is that I'm married to an immigrant.

1 He's documented. And in fact he was sworn in as a
2 U.S. citizen on July 4th, 1976, so he's even what's
3 known as a "bicentennial citizen". But I think
4 because of him, I also have a full understanding of
5 what's good in our health care system. And I keep
6 hearing us list all those things that are bad, but I
7 guess I'm one of these people that sees the glass
8 half-full rather than half-empty, but I do think we
9 need to build on what's good in the system, and I
10 think that's partly what Frank was saying earlier,
11 that we can't forget that there's a lot of things that
12 this country's health care system does very, very
13 well, and we don't want, as he said, to throw the baby
14 out with the bath water, which is one of my husband's
15 favorite phrases as well. We want to make sure that
16 we understand whatever recommendations we make are
17 going to have what economists sometimes call
18 "unintended consequences", that we have to think
19 through the sequelae of how are people going to change
20 to these new incentives, how are people going to
21 change to these new regulations, and are we sure that
22 what we are recommending isn't going to make things
23 worse off than they were to begin with because we

1 neglected to do that, we neglected to see that. So I
2 think we have to remember that.

3 As an example, too, we brought my in-laws
4 to this country about eight years ago, as senior
5 citizens, but they are not eligible for Medicare.
6 They are not eligible for Social Security. And when
7 you have 84- and 89-year-old in-laws, you really have
8 a full appreciation of how wonderful Medicare and
9 Social Security are relative to what could exist.
10 They were in a country with neither, and they also
11 were in a country with really horrid medical care.
12 Some of the things that they were recommending for my
13 in-laws, my husband would be flying down there saying,
14 "No, you cannot do this, it is really quite
15 appalling". And his aunt -- and this is strictly
16 relevant today -- his aunt recently died of
17 Parkinson's in Warsaw, Poland, and I'll tell you one
18 thing, the Pope had a lot better care than his aunt
19 did in Warsaw. Earlier when she needed a heart valve,
20 they only had three sizes of valves in Warsaw. And if
21 the hole in your heart just doesn't quite fit, they
22 make it fit.

23 We ended up flying her to this country, to

1 New York, where because of my husband's cousin -- he's
2 the Chief of Thoracic Surgery at Mt. Sinai Hospital --
3 we were able to get free care for her. She's a Yad
4 Vashem Award recipient, so at Mt. Sinai, they provided
5 her free care as a payback for what she did. It's sort
6 of "you saved our people, now we're going to save
7 you". But she was stuck in Warsaw with Parkinson's,
8 and her daughter had to bring sheets. The hospital
9 doesn't supply clean sheets. You just lie on a
10 mattress.

11 So let's not forget some of the wonderful
12 things we do do here, I guess is what I'm saying, but
13 at the same time I agree with what was said earlier,
14 we can do better. And the fact of the matter is that
15 there are people in this country who are experiencing
16 care like my husband's aunt did in Warsaw. They are
17 getting truly horrible care. And something that
18 Senator Wyden and several people referred to is the
19 fact -- he said we're spending enough, and that may be
20 true, but we certainly need to redistribute it. And
21 that's when the political headaches begin, which is
22 what Mike referred to, because you are talking about
23 shared sacrifice and having to couple that with shared

1 gains. So we have to make clear to people that we are
2 recognizing shared gains as well as shared sacrifices.

3 One of the things that I do think we need
4 to look is the tie of coverage to unemployment, and
5 this may be because for the past three years I've been
6 the Director of Economic Research Initiative on the
7 Uninsured, and so I've been doing a lot of studying
8 about the uninsured. And economists generally talk
9 about the fact that having such a strong employment-
10 based system -- we're talking about Medicare and
11 Medicaid -- but having such a strong employment-based
12 system leads to distortions in the labor market.
13 Okay, fine. But it goes much beyond that. It means
14 that our insurance system is tightly aligned with the
15 economy.

16 Michigan just last week came out as No. 1
17 -- we're No. 1. Unfortunately, what we're No. 1 in is
18 the unemployment rate. And so at a time in which state
19 budgets are being squeezed for Medicaid coverage, our
20 state is having the highest unemployment rate, and
21 therefore people have lost their coverage, and they've
22 lost their coverage at a time when the government
23 can't step in and help them.

1 In addition to that -- as Richard knows
2 well from his research and this was alluded to by
3 Montye -- often when you do lose your job and are
4 unemployed, you have mental health problems. And so
5 it's this double-whammy that they can't get back on
6 their feet. And so I think it's not that we have to
7 turn the system upside down, but we have to build on
8 what works. But understand that as long as we link
9 health insurance to employment, we have to have some
10 kind of system for those gaps, some kind of system to
11 complement the swings of the economy. And whenever you
12 have that, you're going to have these problems of just
13 when the pressure point is the greatest on the public
14 purse, is when the public purse is the smallest. So
15 we have to just recognize that and talk about some
16 kind of system that can even out those flows over
17 time, instead of this roller coaster that we tend to
18 be on.

19 I think I would like to see us redefine
20 the services covered. Several people have mentioned
21 mental health, and I think we need to stop thinking
22 about physical health versus mental health and start
23 realigning services according to chronic and acute,

1 according to medically effective versus questionable,
2 children versus adults, I don't care, but the physical
3 versus mental health division I think artificially
4 separates that, and I think that's what gets us into
5 the trouble that we're in now of the mental health
6 coverage not being there as several people have
7 mentioned, and so we need to think about how we
8 specify the services that are covered, along what
9 lines. Do we make this what I think of as an
10 artificial separation between mental health and
11 physical health.

12 And then the final thing is that the
13 uncompensated care problem that several people
14 mentioned is not uniformly distributed, and there are
15 certainly some providers who are really hit hard by
16 uncompensated care. But some research indicates that
17 90 percent of the providers have a very small, very
18 manageable burden of uncompensated care. And so,
19 again, it's the shared sacrifice/shared gains, that
20 there are some physicians who are really doing as much
21 as they possibly can, and some hospitals that are
22 doing as much as they possibly can, but we haven't
23 asked for others to step up to the plate. And I think

1 some of this is fear, quite frankly, fear that once
2 they open the door, they're going to be drowned. And I
3 was thinking about this a little bit yesterday morning
4 when I went into a Starbucks at home to get something
5 to help me get to the office at 7:30 on a Sunday
6 morning and get work done so I could come here today,
7 and I walked in the door, and because it's one of the
8 few places open at 7:00 on a Sunday morning, it's
9 often a place where homeless people come to sit in
10 comfortable chairs, listen to nice music, often there
11 are papers lying around. And I walked in and there was
12 a fairly disheveled looking older man sitting in a
13 chair facing the door, and as I came in he looked up
14 at me with very bloodshot eyes and missing teeth --
15 and so I don't want to assume he was homeless, but I'm
16 pretty sure he was. And he said, "Do you have some
17 spare change". And I think most of us tend to say no ,
18 and I thought, well, we're told not to do that, Ann
19 Arbor being the kind of town that says "Please don't
20 give money to the homeless because we're afraid
21 they're going to use it for drugs or alcohol or
22 whatever", and instead we have a food gatherers
23 program, and we have shelters, and we have free

1 clinics, so refer them to the clinic". I guess each
2 consumer is supposed to walk around with a little
3 piece of paper and say, "No, but here you can go for
4 food".

5 But I walked over and I got my tea, and I
6 also bought a cup of coffee. And I walked over and I
7 said, "Here's a cup of coffee, and there's a lot of
8 milk over there, and sugar, so I got you an empty cup.

9 And what you need to do is stretch this cup of coffee
10 for quite a while". "Oh, thank you, thank you, thank
11 you. Oh, God bless you, have a wonderful day". And
12 then as I was walking out, he said, "Oh, miss", and I
13 turned around and he said, "Could you buy me lunch?"

14 (Laughter.)

15 And I'm not making this story up, this is
16 for real. And I think this is what a lot of providers
17 are worried about, you know, if I take this, then it's
18 going to be that and that. And if I help you with
19 your hand, then when you come in with a leg, it's the
20 leg. And then it's -- you know -- and then you're
21 going to tell your neighbors, and they're going to
22 tell -- so I think we really need a way to think about
23 distributing the sacrifice more equitably in order to

1 relieve the burden on those safety net providers that
2 really are being pushed beyond where they can be
3 pushed, and try to get everybody to share the blame --
4 excuse me. See, this is the blame game -- share the
5 sacrifice, but also impress upon them that this is
6 really seeing the glass half-full, that there are
7 gains that we can all share from, too.

8 So I just close with: Ron, we share this
9 interest in history, only I beat you. You went back
10 to the Truman era in preparation for this, and partly
11 it's because of the tie to Michigan, the Michigan
12 program was started seven years ago by Nathan Sinai,
13 who was a primary contributor to the Committee on the
14 Cost of Medical Care, and we actually have his notes
15 and records in the library at Michigan, and they came
16 out after five years of study and investigation, with
17 the Medical Care for the American People final report,
18 in which they start off talking -- they start off
19 saying "Today, there is a vast amount of unnecessary
20 sickness and many thousands of unnecessary deaths" --
21 this is 1932. "We know how to do many things which we
22 fail to do or do in an incomplete and often most
23 unsatisfactory manner. As a result of our failure to

1 utilize fully the results of scientific research, the
2 people are not getting the service which they need,
3 first, because in many cases its cost is beyond their
4 reach and, second, because in many parts of the
5 country it is not available. The cost of medical care
6 has been the subject of much complaint. Furthermore,
7 the various practitioners in medicine are being placed
8 in an increasingly difficult position in respect to
9 income and facilities with which to work. The report
10 which follows presents many phases of these various
11 problems." This is 1932.

12 So here we are, 70 years later, and we can
13 do better. And so I'm thinking a lot of these
14 problems are still there, but I'm really hoping that
15 we can do better.

16 CHAIRPERSON JOHNSON: Well, Catherine,
17 this is what we put down based on your comments. Let
18 me see if we've heard you correctly. Need to balance
19 doing good and doing well. Cost for care for senior
20 citizens who do not have Medicare. You shared a
21 personal experience with that, but there are others.
22 We're spending enough, we need to redistribute some of
23 the spending, or maybe find -- you didn't say this --

1 but maybe find ways of more efficiently spending some
2 of the monies we're spending. Healthcare spending
3 coverage tight, the economic cycle. And what I heard
4 you say is that we're having some layoffs in Michigan.
5 Car companies are big in southeast Michigan
6 especially. They have wonderful healthcare coverage,
7 but when they have layoffs there are some potential
8 issues that have rippling effects. Artificial
9 separation between mental health and med/surgical
10 care.

11 VICE CHAIR McLAUGHLIN: Well, physical,
12 but -- that's different.

13 CHAIRPERSON JOHNSON: And uncompensated
14 care --

15 VICE CHAIR McLAUGHLIN: Unequal burden.

16 CHAIRPERSON JOHNSON: -- unequal burden.
17 Okay. Well, thank you very much.

18 Well, Senator Wyden, you've been sitting
19 patiently for a high energy person. It's a challenge,
20 I think, for many of us to sit and listen, but each of
21 you have been, and you have been included in this.
22 Are there issues that you're hearing about that we
23 haven't addressed so far?

1 SENATOR WYDEN: I'll tell you, I've been
2 excited over the last three and a half years about the
3 possibilities of what could be done here, but
4 figuratively you could be pulling me off the ceiling
5 right now because I am just really awed by the kind of
6 talent and energy that is around this room. I thought
7 we were going to get good people, and this has so far
8 exceeded my expectation. For example, in the last --
9 I guess it's now been three and a half hours -- nobody
10 has once committed "healthspeak". I mean, there has
11 not been any example of arcane health babble that
12 nobody could understand. That alone makes you unique
13 in terms of people who are involved in healthcare.

14 I was sure that Catherine was going to
15 bring up this question of the history in the 1930s.
16 Catherine, we've really been going back to Otto von
17 Bismarck to talk about this.

18 (Laughter.)

19 I've got only just a couple of --

20 VICE CHAIR McLAUGHLIN: Yes, but can you
21 quote some of that?

22 SENATOR WYDEN: Yes. First, I think Mike
23 made a really important point about trying to find

1 consequence in this really diverse country. This is
2 such a gargantuan education task. I don't know how
3 many of you saw it, but Health Affairs did an article
4 not long ago that said that most Americans believe
5 that we're spending more money on children than we're
6 spending on the elderly today. Now, that's where
7 we're starting as we go out on the education process.

8 And of course kids don't have "Kiddiecare". Seniors
9 have Medicare and kids don't have it, so we're
10 spending vastly more, of course, on seniors than we're
11 spending on children, but that's where you're starting
12 in terms of this education kind of task.

13 And one of the things I'm really hopeful
14 is that we can get this report, which will probably be
15 the first thing that people see in a sort of broad-
16 sweeping way out as wide as possible -- Catherine
17 mentioned Starbuck's, Howard Schulz and Starbuck's
18 wants to get this in Starbuck's, for example. I think
19 the Internet will be a huge opportunity for all of us.

20 I mean, I can see small business people, members of
21 the NFIB, National Federation of Independent
22 Businesses, that wouldn't go to a drafty hall, asking
23 their members to sit there at the laptop and sort of

1 walk through some of the choices, which nobody has
2 ever done before. So, I think the first point is the
3 education task is enormous. It's going to be the first
4 thing that people are going to see, and your ideas and
5 suggestions to -- Randy and Catherine -- I think will
6 be extraordinarily important there.

7 Second is, I think there's a chance to
8 sort of grow coalitions and sort of grow ideas that
9 seem to have common ground. We go back to Mike's
10 point about how the Congress is going to look at it.
11 I told you about the conversation I had with Mike
12 Leavitt, where the two of us were excited about the
13 idea of sort of starting with community health centers
14 and a catastrophic benefit.

15 Well, just visiting with Dr. Shirley for a
16 minute, he just said how could faith-based programs
17 that don't necessarily fit into the community health
18 center definition, could they sort of be deemed to be
19 part of that network? Well, I can't speak for 535
20 members of Congress, but I've got to think that's an
21 idea with some legs. I mean, that's something where
22 people could say, we've got these faith-based
23 programs, certainly some like them more than others.

1 We've got community health centers. Couldn't we carve
2 out an opportunity to sort of grow that kind of
3 concept, and I think it goes to Mike's point about
4 what might actually be movable in Congress.

5 I mentioned to Joe during the break that I
6 think we're at a tipping point with employers and
7 labor in terms of what's going on in the private
8 sector. If Joe and Randy say, "Let's see what our
9 people think in terms of the labor business piece, in
10 terms of some kind of common ground, and cost
11 containment and the like", Joe and Randy kind of start
12 a little coalition there, and something that you can
13 fold into what you're doing.

14 Only other two points are, first, keep in
15 mind the timetable. We've basically got two years in
16 terms of what Congress thinks it's appropriating money
17 for. Actually, you can probably take a little bit
18 more time if you think about it in terms of the
19 statute, but the Congress thinks it's going to be
20 asked to put out money twice, and we ought to kind of
21 keep that in mind as well.

22 And the last point is, I wouldn't be
23 reluctant to take on some of these sort of big seat

1 powerful interests as long as you can find something
2 that really allows us to say at the end of the day,
3 "Look, we didn't just spend our time scapegoating one
4 side", and that's why I said there's enough blame to
5 go around here, folks. If you want to like just say
6 it's the trial lawyers' fault, the insurance
7 companies' fault, the docs' fault, the consumers'
8 fault, we can do that all day, there is enough blame
9 to go around here. And I think a lot of this,
10 particularly in terms of public health policy, just
11 sort of came up because nobody really kind of thought
12 it through.

13 Stephanie found the other day, as we were
14 getting ready for a speech to talk about the post-
15 Terri Schiavo kind of politics, that the hospice
16 benefit is set up to tell people they've got to give
17 up the prospect of a cure in order to get the benefit.

18 Now, I've got to tell you, I don't think anybody got
19 up in the morning and said "I want to be rotten to
20 suffering people, and tell them to give up hope in
21 order to get the benefit", but nobody really thought
22 it through in terms of how the American people, as
23 we've now seen after the Terri Schiavo case, they want

1 both. People want to have the chance to dream about a
2 cure, they want to have a chance to get the benefit.
3 Easier said than done, no question about it, but it's
4 the kind of thing that can be part of your effort to
5 look at end-of-life issues, and I wouldn't be
6 reluctant to take on big interests and concepts that
7 probably came into law because nobody had thought of
8 them. And you've got to be bold in order for the
9 Congress to be bold.

10 And I will tell you that there are only
11 two ways that we'll get healthcare that works for all
12 Americans. Maybe some knight on a shining horse will
13 go down to 1600 Pennsylvania Avenue and say, "Here's
14 my plan", and they will ride that horse all the way
15 through the countryside, and they will go to every
16 corner Mike is talking about -- Texas and
17 Massachusetts and the like -- we can wait for that.

18 Personally, I think that this working
19 group's process is just as likely to do it, where we
20 walk people through the issues and then we go get many
21 knights on shining horses to follow up in the
22 Executive Branch and in the Congress. And I think by
23 your doing all this heavy lifting -- in a lot of ways

1 we've got an opportunity here. I mean, we can have a
2 conversation. You do not have 12 television cameras
3 thrown in your face when you turn around. This may be
4 the exact kind of environment needed in order to be
5 able to do what everybody thinks is impossible.

6 So, I'm available to you all 24/7. I
7 consider this the most important thing I have been
8 part of in public life, I'm telling you that. This is
9 what I want to do more than anything else, and people
10 can get me through my office, half of you have my e-
11 mail and cell phone, and I am available to you. And
12 Senator Hatch and Pattie DeLoatche I think will be
13 extraordinarily responsive to you, and since we have
14 folks here from HHS, I couldn't be more appreciative
15 of Mike Leavitt. He talked at his first hearing about
16 -- I think his words were a "transformative dialogue"
17 in terms of health, and by God, that's what you're
18 doing, and thanks for being part of it. So, you'll
19 see me often, and this is going to be a good ride.
20 Thanks.

21 CHAIRPERSON JOHNSON: Thank you. Aaron
22 and Richard, you participated in at least one other
23 commission -- and, no, we're not called a commission,

1 but we have similar objectives -- talk about what you
2 thought were the challenges and issues that might have
3 resulted in not moving forward as might have been
4 hoped, and what you think we might do differently.
5 You want to go first, Aaron?

6 DR. SHIRLEY: The thing that stands out
7 the most for me right now is we then, in '93 and '94,
8 placed so much dependency on experts. We commissioned
9 papers by experts. We had experts come in and talk to
10 us. We would work from 8:00 in the morning until
11 11:00 at night digesting all kinds of information that
12 was being produced by others and given to us. And then
13 our responsibility was to react and to tweak it into
14 some kind of legitimate language. And it wasn't until
15 maybe three months of this type of dialogue that we'd
16 go out and talk to the people. So we were top down.
17 And when we got out to the people, the special
18 interests that had different views had prepared for
19 that, and I know I traveled all over the country
20 attempting to promote the thing, but I would run into
21 groups and opposition types that I'd never heard of
22 whereas I believe if we had come more in the direction
23 that we are doing now in which people will be talking

1 to us hopefully more than the experts, then we'll come
2 up with some potential solutions that the people have
3 bought into. They then will deal with the special
4 interests or help deal with the special interests for
5 us.

6 CHAIRPERSON JOHNSON: Let me see if I've
7 heard you correctly. What I've heard you say is there
8 were people who are known experts, who came and
9 testified before the commission, and that testimony
10 was heard not only by the commission, but by others as
11 well. And that testimony also was then used to mount
12 opposition to some of the things that you as a
13 commission thought might be necessary or helpful.

14 DR. SHIRLEY: That was part of it, yes.

15 CHAIRPERSON JOHNSON: And so what the
16 implication of that is what we can do differently is
17 not only hear that testimony -- now, I'm going to try
18 to put some words in your mouth and see if you agree -
19 - go ahead.

20 DR. SHIRLEY: Not so much from the
21 experts, but we were relying too much on the people
22 who already knew what we needed and how to do it. And
23 we were trying to respond to the need of the uninsured

1 across the country. We heard very little from them
2 before the fact. We told them -- ended up telling
3 them what they needed and what they should have,
4 rather than their telling us what they needed and how
5 best to provide it.

6 VICE CHAIR McLAUGHLIN: Did you have
7 hearings at all? You talked about papers, you
8 commissioned papers. Did you have hearings early in
9 the process or -- you were saying that the commission
10 had a lot of papers written and that you would be
11 there from early in the morning until late at night
12 reading the papers. Did you -- I mean, I know there's
13 been a lot of criticism that it was behind closed
14 doors, et cetera, et cetera. Was most of it internal
15 paper-reading and -- or did you actually have hearings
16 at the beginning of the process?

17 DR. SHIRLEY: There were about 400 of us,
18 and we had several different components, and we would
19 have some insurance, some purchasers, then others
20 would come in. We would commission somebody to go and
21 do some research on this particular topic, bring back
22 the latest information. And we as a group would
23 listen, and they would help us to interpret the data

1 and information, and we crafted our recommendation
2 around that information. And then it was our task to
3 go out and sell it after the fact whereas the way we
4 are going here, we're more inclined to listen to not
5 just the experts prior to developing any paper.

6 CHAIRPERSON JOHNSON: One of the things
7 that Catherine and I have talked about, along with
8 some of our friends from HHS such as Larry and Ken and
9 Caroline and Andy, has been the possibility of doing
10 hearings outside of Washington so we hear from
11 practitioners such as yourself, as well as more what
12 I'll call theoretical or research folks in Washington,
13 or who come to Washington often.

14 Richard?

15 MR. FRANK: I met Mike O'Grady for the
16 first time during Health Reform. He was the CRS
17 analyst who is doing several parts of the cost
18 including the mental health piece which I worked on,
19 so I've known Mike a long time since then. There he
20 is.

21 Mike, I was just saying that I met you
22 during Health Reform.

23 MR. O'GRADY: Yes, you did.

1 (Laughter.)

2 Still bear the scars.

3 MR. FRANK: We both do. I guess one thing
4 actually, from what Mike started off with, which had
5 to do with kind of facing up to certain realities and
6 certain facts I think was a problem. I think a lot of
7 the jumping off point for Health Reform was something
8 of a delusion, which was that managed care was going
9 to save enough money so that you could finance the
10 whole thing at zero cost. And when you're working on
11 that presumption, it so distorts everything that you
12 have to do that that it starts to create all sorts of
13 design challenges and things like that.

14 So, I think there was a jumping off point
15 that was not sort of grounded in reality and the data,
16 that I think was a real problem from the get-go.

17 There have been books written on this, I'm
18 not going to sort of go through it all. I'll just say
19 I think the issue of essentially sunshine instead of
20 respect for the diversity of opinion is sort of an
21 important piece. I think that, you know, everyone is
22 sort of paranoid anyway, and I think that absence of
23 sunshine makes it worse, and so just kind of being

1 open, having things on the table, I don't think it
2 hurts you very much to do that. It hurts you a lot,
3 in retrospect, not to do that. So, I guess that's a
4 second lesson that I walked away with.

5 Third is making sure of your facts. I
6 think it's easy to organize opposition, it's easy to
7 be critical when the facts are either murky or not
8 well documented or organized, and I think kind of
9 being meticulous, but the positions that you're taking
10 and having a very solid grounding in fact really helps
11 as a jumping off point. And also I think it forces
12 you to be very respectful of the other opinions. You
13 take them seriously and you say, okay, we investigated
14 that, here's the way it shakes out, and you may not
15 like it, but at least we've done due diligence. And I
16 think people sort of at least somewhat respect each
17 other in the morning when that happens.

18 There are lots of other things. Something
19 that we don't have to worry about is kind of managing
20 Congress. I mean, if you can imagine this -- and Mike
21 I'm sure remembers it -- they didn't know what
22 committee to put the bill through, and so they put it
23 through, what, three?

1 MR. O'GRADY: Yes.

2 MR. FRANK: And they didn't know which way
3 -- they had no management plan for --

4 MR. O'GRADY: They walked away. Just
5 dropped it and left.

6 MR. FRANK: Right. They had no management
7 plan for the committee. Obviously, that's not the
8 same point here, but it's sort of a shocking piece of
9 history when you think about that in retrospect. I
10 guess that's it.

11 Actually, going to Aaron's sort of
12 observation, I think that taking people's ability to -
13 - on one hand, you have people easily getting wrong
14 impressions about how things work and the facts and
15 stuff. It doesn't mean that when given the
16 opportunity to think hard, they won't come up with
17 sensible things. And I think perhaps what I hear is
18 helping us engage in a process that will make regular
19 people think hard about these issues and not say,
20 okay, well, they can't think hard, let's just give
21 them the right slogans and things like that. I still
22 have my "healthcare that's always there" card, but --

23 CHAIRPERSON JOHNSON: Do you still have

1 yours?

2 MR. O'GRADY: That and my Mickey Mantle
3 baseball card. With inflation now --

4 CHAIRPERSON JOHNSON: Well, thank you both
5 for your input. One of the things that I'm sitting
6 here asking myself -- and we'll take a break in just a
7 second -- I'm sitting here asking myself, we've got
8 all these issues that we've talked about, which
9 implies that we need more of this, this, this, this,
10 this, and this, but the cost today per person is
11 \$6,000-plus per person. And if we continue under the
12 same trends, it's \$11,000 by 2014.

13 Some of Joe's colleagues in the union
14 world are negotiating with Big 3 automakers, and we've
15 seen the signs of the Big 3 in the paper because they
16 spend more than \$1,000 of every car that we buy for
17 healthcare. And those that are spending that kind of
18 money are losing market share to those who have lesser
19 healthcare programs and who are not providing retiree
20 medical coverage to the same degree. And we see
21 companies who are moving some of their businesses
22 offshore, some of their employees offshore, because
23 the cost of labor -- one of the reasons, not the only

1 reason -- because of the cost of labor is less
2 expensive offshore.

3 Senator Wyden suggested and the
4 legislation talks about, well, what are the tradeoffs
5 that we are willing to come up with? And that's going
6 to be a subject I suspect that we're going to have to
7 spend quite a bit of time on.

8 And the other subject that we haven't
9 talked about but we're going to have to have in the
10 back of our minds, I think, is what kind of
11 initiatives that we would potentially, with citizens
12 around the United States input -- what kinds of
13 initiatives would make it through Congress, and would
14 make it through the White House, whoever is in the
15 White House. So, these questions, I think, are some
16 of the questions that we're going to have to give some
17 thought to.

18 Someone earlier talked about
19 administrative cost. In my health plan, 8 percent or
20 so of the total cost is spent on administration. The
21 rest is on medical claims. And that 8 percent goes
22 toward network management and medical management,
23 disease management strategies, processing the claims,

1 answering all the questions. It's 8 percent. Now,
2 that's not -- there are other insurance companies who
3 will spend more, maybe because they've not been as
4 efficient, and that will be up close to 20 percent in
5 some cases, but typically between 8 and 22 percent for
6 administration, based on my own experience.

7 There's got to be more that we address
8 than administrative costs. And yet we've talked about
9 giving healthcare -- we haven't spent as much time
10 today talking about wellness initiatives and healthy
11 people as I thought we might have, but that might be
12 something that we're going to have to address as well,
13 as we're moving through some of our dilemmas and
14 criteria for improving the system.

15 But I think we've spent all day so far
16 talking about the issues. Before we close off this
17 part of our discussion, are there any other comments
18 that any of you would like to make?

19 MS. MARYLAND: Not being able to put aside
20 my administrative hat for now, I just want to add to
21 the table specialty hospitals and the impact on
22 potentially the shifting, if you will, of patients is
23 a major issue that's out there that's sort of starting

1 to surface.

2 CHAIRPERSON JOHNSON: Shifting of
3 patients?

4 MS. MARYLAND: There's a school of
5 thought, and it hasn't truly been validated, that with
6 the advent of specialty hospitals -- and I'd like our
7 physicians maybe to weigh in on this issue --
8 orthopedic specialty hospitals, cardiovascular
9 specialty hospitals, that what tends to happen is
10 those are hospitals that are physician-owned. The
11 potential exists that there could be some skimming off
12 the cream, if you will, and shifting to the acute care
13 hospitals the burden, especially with the noninsured
14 uncompensated patients.

15 I know that a number of studies have been
16 conducted, but I don't know if it's been truly
17 validated one way or the other, but I want to put that
18 on as just an issue because it certainly could affect
19 what happens going forward, to acute care hospitals.

20 And then the other issue is the issue of
21 increasing cost of medical technology. Senator Orrin
22 Hatch talked about his wife and her knee replacement,
23 titanium versus ceramic implant, and with younger

1 patients actually there's been a real push to go with
2 the more expensive ceramic implant. I mean, that's
3 really increasing the cost, if you will, of those
4 cases, and a lot of it is not always reimbursed, and
5 how do you control that? So, it's just a general
6 statement about the increasing cost of technology and
7 its impact on the overall cost of healthcare. It's
8 something that we haven't talked about really, and I
9 just wanted to make sure it was at least thought
10 about.

11 DR. BAUMEISTER: Well, it's already
12 happened with endoscopy centers and surgery centers
13 where they skim off the payers and send the welfare
14 patients to the hospital.

15 MS. MARYLAND: I just think it's something
16 we need to look at in more detail.

17 MR. HANSEN: Well, isn't there -- a
18 personal example. My wife has got leiomyosarcoma
19 cancer, and she takes advantage of all the new
20 technology, and newer technology comes out all the
21 time, much more expensive. So, it is a choice, it's a
22 choice between life and death.

23 MR. O'GRADY: But we have seen changes. I

1 mean, when you look at the new Medicare bill, you'll
2 see that no matter how much they've spent, there's
3 always a 5 percent paid by the Medicare beneficiary,
4 and that came right out of CBO, and it had to do not
5 so much in terms of the beneficiary's behavior as it
6 had to -- if you're a drug company and you're about to
7 introduce a new drug on the market, and you have a
8 choice between introducing it at \$10,000, \$15-, or
9 \$20-. If some third-party payer, government or
10 otherwise, is picking up 100 percent of the cost, you
11 would be irresponsible to your stockholders not to put
12 it at the very highest price. So, the idea there being
13 that you didn't want to ding people too badly, but you
14 wanted at least something there all the time to make
15 them somewhat price-sensitive. Now, is that free? By
16 no means. You're going to have some people who are
17 just going to be hit with 5 percent of a very, very
18 large bill, and the only solace they can take is that
19 the taxpayers picked up another 95 percent, and that's
20 certainly better to only pay 5 than 100.

21 I'm trying to look at this 10, 20 years
22 out. Boomers retire, all these pressures hit. The
23 notion of technology and what we do with technology --

1 now, we've grabbed on to information technology
2 because that's the first bit of technology we've seen
3 in a while that might actually save a little money as
4 well as improve care. The other definitely improves
5 care, but it costs us an arm and a leg. So, we're
6 kind of hoping that that one will really -- but the
7 other kind of two types of technology, the one that is
8 breakthrough but really expensive -- but people get up
9 out of their wheelchairs and walk now -- and the other
10 one which is sort of what I think of when you're using
11 the knee example.

12 It's the sort of stuff we had before, but
13 only a small percentage of people -- it may even drop
14 the unit cost of it and that means everybody gets
15 arthroscopic now, and so all of a sudden we're
16 generating a lot more money even though we took
17 arthroscopic from \$10,000 down to \$5,000, we've
18 proliferated it now in such a way that again it's a
19 technological improvement that drives additional
20 spending.

21 But we're trying to think about where the
22 whole system is going, we don't want to be locked into
23 today, and technology and how you deal with that, it's

1 going to be key, there's no doubt about that.

2 MS. MARYLAND: And I just wanted -- not
3 with any personal opinion -- to put these additional
4 issues on the table for us to consider because I think
5 they are just in the forefront of what we know are
6 challenges facing us now.

7 CHAIRPERSON JOHNSON: Thank you. Therese,
8 you had a comment?

9 MS. HUGHES: Well, actually it had three
10 parts to it. The first was I just wanted to say that
11 there's an awareness. In California before the
12 Legislature there's a bill that because of the
13 problems that we had with our emergency rooms and the
14 number of hospitals that are closing their emergency
15 rooms because of the cost of uncompensated care, is
16 that they are trying to create a system where you get
17 seen in triage, and then you get shifted around
18 through -- well, let's look at L.A. County -- gets
19 shifted around through L.A. County based on how -- for
20 lack of a better word, how important it is that you
21 get immediate care right now, which I think is part of
22 this problem because, to me, I see the shifting of the
23 costs going to those with money, those with insurance,

1 and then those that could need this care immediately
2 but may not present, or they may present but enough
3 attention isn't given because they are uninsured or
4 they are underinsured, that they end up being out here
5 in the tailspin where they don't have the access to
6 care. So, I'm just giving that as something in
7 response to what you said because I certainly think
8 that -- when I spoke to the author of the bill and his
9 staff, he said, "Oh, but, Therese, that's not our
10 intention". And I said, "But I think that it is
11 possibly an unintended consequence based on the
12 reality of finances and economics of healthcare
13 today".

14 So, just having said that, the next thing
15 I wanted to just say is that technology -- the one
16 technology -- I think there may be technology out
17 there today, medical technology as well as IT
18 technology, that is working but is not either known or
19 is not allowed for some reason to be put into the
20 universe of care-- and by that I mean for years
21 everybody thought the best way to have dialysis was
22 haemo, and peritoneal dialysis was used in hospitals
23 for emergency situations. Well, peritoneal dialysis

1 is a better way of providing dialysis because it's
2 continuous and because patient have responsibility for
3 themselves and can take care of themselves. So, what
4 took it so long to get out to where now --
5 nephrologists have to bring up the issue of peritoneal
6 dialysis to their patients instead of automatically
7 putting them on haemo-dialysis. And I think that the
8 cost up front is more maybe, but I think extended over
9 the period of utilization for the patient it is less
10 -- well, this is just my experience. So, I do think
11 that there's technology that's being utilized in
12 certain areas like that.

13 CHAIRPERSON JOHNSON: That can bring
14 greater efficiency even though there's an up front
15 cost.

16 MS. HUGHES: Exactly. And I don't know --
17 I can't pretend to know what they are, but I do know
18 that that CAPD, continued ambulatory peritoneal
19 dialysis, is one that sat a long time in a hospital,
20 were in the hospitals or in that setting, that once it
21 came out to the public was --

22 MR. O'GRADY: That's the essential dynamic
23 of what Randy was talking about before, prevention.

1 If you're going to get your folks in, you're going to
2 get them screened, you're going to get your
3 chronically ill guys to get the kind of testing they
4 really need so they don't end up showing up in the
5 emergency room -- it's not a free lunch. It's going
6 to cost you up front. If you can avoid one
7 hospitalization, you've probably covered the whole
8 thing, but I get a little nervous when I see -- I
9 mean, we're having a big push on prevention, and we
10 think it's the right thing, but there's an up front
11 cost, there's no doubt about it.

12 MS. HUGHES: Absolutely, and that's what
13 I'm saying. I mean, I think that there's this
14 technology there, but I also am aware that there's
15 that up front cost that we'll have to count on.

16 And then the other thing is - and this is
17 all that's being said, we're talking about rationing
18 healthcare in a different way than the way it's
19 rationed today. Transplantation is the perfect issue
20 of rationing healthcare that is top up front rationing
21 in terms of our healthcare system, and it's a
22 difficult subject for me to talk about, but there are
23 some benefits to some of it, and I recognize that

1 there's something close to rationing.

2 CHAIRPERSON JOHNSON: Thank you, Therese.

3 DR. BAUMEISTER: I have to put in a plug
4 for Oregon here again. I can't help where I come
5 from. But ambulatory peritoneal dialysis has been
6 used in Oregon widespread for a long time because
7 Drake, a friend of mine, along with an engineer in his
8 garage, developed the first dialysis machine,
9 (inaudible) machine, and it's very popular in Oregon.

10 CHAIRPERSON JOHNSON: Well, thank you very
11 much for your input. One last comment before we
12 break.

13 MS. CONLAN: Oh, well, I have two. When I
14 was listening today, I just wanted to offer some
15 comments about Medicaid. In my county, once I got
16 Medicaid, there were no neurologists that were
17 accepting Medicaid, and at an uninsured rally and
18 press conference, a doctor told me that it wasn't
19 about pay, it was about having to sign a form assuming
20 all liability, and doctors were reluctant to do that.
21 So, I think it's not just a matter of payment, it's
22 that additional liability.

23 And in Medicare, there was something I

1 wanted to offer. Mayo Clinic, the doctors voted and
2 they do not accept Medicare assignment anymore. So
3 they are forcing patients to pay up front the Medicare
4 assignment plus an additional cost, which Medicare
5 still controls, and then the patient has to do a lot
6 of the administrative work of sending bills to
7 Medicare and doing what doctors have had to do in the
8 past. Patients seem to be balking at that, they don't
9 like that. Imagine that. Doctors didn't like it, and
10 patients don't either. But I think it's having an
11 effect on them as far as their business.

12 CHAIRPERSON JOHNSON: Okay. Thank you.
13 Well, we're going to take a break right now instead of
14 waiting, and we'll take a 15-minute break, if that's
15 okay, and then when we return, we're going to start to
16 try to get on the solution side of some of these
17 issues. By the way, I don't think anybody expects that
18 we'll have all of the answers, but we can begin to
19 think about them.

20 (Whereupon, a short recess was taken.)

21 CHAIRPERSON JOHNSON: If you'll have a
22 seat, we'll reconvene and get going. We have a few
23 people who aren't here, but they can join us in just a

1 minute or so.

2 First, I'd just like to thank you for your
3 dialogue and your sharing and your willingness to
4 participate in not only this meeting but this
5 initiative. And I think already we've got good input
6 and helpful ideas as we're beginning to move forward.

7 What we thought we would do between now
8 and when Carolyn Clancy comes at 4:30 is just begin to
9 share some of the ideas that you have, your
10 observations on initiatives that have worked. Already
11 we've heard Frank inching in some of his ideas from
12 Oregon, and we're looking to hear about those. And
13 some of you have some community initiatives that have
14 worked. Aaron, I was in a meeting last week where I
15 heard a person by the name of Janice Bacon, who was on
16 a panel. The room was probably 500 people, and she
17 had more questions asked of her regarding her
18 initiatives than any of the other speakers. And so we
19 know there are initiatives that are already beginning
20 that direct attention to some of the issues that we're
21 facing, and we're not going to cover all of these
22 issues today, but at least we'll get a start maybe in

1 addressing some of those.

2 Really, we don't have a mandated
3 organization by which we sort through these issues.
4 Over here, we talked about some numbers. And we have
5 some issues that are duplicated, but maybe we can just
6 take a look at these, if you would, and you start
7 where you think we should be starting, some
8 initiatives that you've seen that really have been
9 working or have great potential to help attack some of
10 the issues we've addressed today. And I'm not going to
11 take notes up here, that will slow us down too much, I
12 think, but we'll have notes taken and we'll share
13 those with you. Who would like to start and share
14 some ideas regarding some of the initiatives that
15 we've talked about? And those of you who are on this
16 side of the table, we apologize because they're here
17 on the wall at your backs, but when you start
18 speaking, if you will speak into the microphone, that
19 will be helpful.

20 MS. PEREZ: I think maybe just one of the
21 most simple things when I think of educating the
22 consumer, patients can't read, and learning how to

1 communicate with a medical provider -- I think in our
2 area, the use of a health promoter, or what we call in
3 Spanish a promotora de salud. It's a peer person from
4 the community that is used by community clinics or
5 different kind of healthcare programs. Hospitals are
6 now beginning to use them. Just to be able to have
7 that peer relationship to get that patient to
8 understand how to navigate the system -- the term
9 Patient Navigator is used as well -- but how to access
10 healthcare systems, help them access healthcare
11 systems, sit down and say "This is what diabetes is",
12 "This is a nutrition plan", "This is what you're going
13 to have to be doing for the next several weeks", you
14 know, pamphlets, brochures, how to fill out
15 information for everything from CHIP to everything
16 else, it's always lots of papers that need to be
17 filled out. So those kind of programs.

18 It's one thing for me as a nurse to hold a
19 little session and say, "Okay, this is what we're
20 going to do today", but then to turn it over to
21 someone that comes out of their same community and
22 then really say, "Rosie said this", or "the doctor

1 said this", so let's just have a little bit more
2 discussion about it, and what are we going to do to
3 address an issue. So, a health promoter program,
4 promotora de salud, community health workers - people
5 use different terms -- is great to get some basic
6 education.

7 In the State of Texas, we do have a
8 certification program for them. Other States, other
9 communities don't. And then we adapt them into our
10 system to say this is what they need to know, just
11 something that's very basic and very simple and just
12 something to kick us off in this discussion.

13 MS. HUGHES: Who pays for that?

14 MS. PEREZ: A lot of times they are
15 volunteers, so they will come in -- like, at my free
16 clinic, they started off as patients in an effort to
17 give back, so they will not accept any funding. Some
18 programs will write into grant requests and they'll be
19 funded by foundations. And then there are some -- we
20 have healthcare systems down in south Texas that
21 actually pay the salary, and that's along the lines of
22 a minimum wage, benefits and health insurance

1 included, but for the most part it's a volunteer. A
2 lot of them are volunteers.

3 DR. SHIRLEY: There's some effort by the
4 Center for Sustainable Health Outcomes, that's an
5 agency that's promoting that concept, and they have
6 been pursuing the possibility of some third-party
7 reimbursement for that type service. Many of the
8 facilities would like to implement, but where they
9 don't have a grant they aren't able to do it, so they
10 are pursuing some type of reimbursement for that --
11 the Center for Sustainable Health Outcomes.

12 MS. PEREZ: Then you get a little pushback
13 because then the nurses and the doctors are saying "I
14 don't get reimbursed for that", but then you're going
15 to reimburse maybe someone that doesn't even have a
16 high school education or formal training. I know in
17 Texas we had some of that type of discussion, but I
18 think we need to discuss it.

19 MS. BAZOS: In New Hampshire, we've been
20 very successful using the Medicaid program actually to
21 do something similar, but New Hampshire by the charge
22 for developing the family support system that started

1 in the '80s, providing support for families who had
2 someone with a developmental disability. I worked in
3 the '90s to use that as a model to develop a system of
4 support for families who had children with chronic
5 health conditions. And the notion was that many of
6 these families, because of their need to be home and
7 provide care, become very isolated. Mothers were
8 often depressed, not integrated well with their
9 community or their community support and did not know
10 about supports that were available to them. Actually,
11 the program that I worked with was funded through a
12 Medicaid administrative contract. Medicaid can be
13 very flexible at times. We're worried now, of course.
14 But through that contract we really did outreach to
15 families, first to make sure that children were
16 getting the medical services they wanted, but then to
17 support the family in areas to help them get jobs if
18 they needed to support their family, to provide
19 respite care for the family, and those types of
20 things. New Hampshire now is looking at that as a
21 model for elders, to help elders stay at home, be
22 supported, get the right medical care, that type of

1 thing. But that's all under Medicaid.

2 CHAIRPERSON JOHNSON: Same subject

3 MS. HUGHES: Yes.

4 CHAIRPERSON JOHNSON: Okay. Thank you.

5 MS. HUGHES: At Venice, one of the things
6 that we're doing -- well, we have promotoras that are
7 patients. We have promotoras that we pay to go out
8 into the community to do health education outreach,
9 and they go to the job centers and different parts of
10 the community that are known to have people that do
11 not have normal access to healthcare. But we have a
12 new program now where we're using the promotora. The
13 promotoras that go out to the community, we pay them a
14 salary.

15 We have a new program that we're just
16 initiating now, and this where we have a doctor who
17 goes with one promotora every week, and we have a
18 selection of asthma patients who have had high
19 incidences of repeat need of immediate medical care,
20 which indicates that they are falling off their
21 regime, and so the promotoras and the doctor are going
22 through a group of I believe it is 50 of our patients,

1 to the families, to the homes, and they make home
2 visits once a week to the different patients, in the
3 hope of showing how they can keep their care better
4 inside their own home environment. And this has been
5 -- it was initiated six months ago, and we are just
6 starting to get results in where there's reduction of
7 emergency room visits by many of our parents who have
8 children with asthma, which is critical in our area --
9 well, it's actually critical everywhere. So, that's
10 an initiative that we're looking at that. I know that
11 our asthma one is I believe the first one that's being
12 tried, but using the promotoras model as well the
13 physician going out to the homes to help the patients.

14 MS. CONLAN: I just wanted -- this is a
15 little different, but you mentioned about thinking out
16 of the box -- talk about the Heuga Center again
17 because it's an experience that I had. It was a full
18 week and it was very intensive. But I think there's a
19 really long life -- you know, it has a long half-life,
20 this program. Twenty-five people came for a full
21 week, with our significant others -- could be a family
22 member, spouse, child -- and we had educational

1 programs. We had evaluations and testing in terms of
2 our disease. Sometimes they broke the significant
3 others off into another group and they had their own
4 counseling sessions and we had our own counseling
5 sessions. I had one person who was -- I call her my
6 mentor -- and over the course of the week -- she's a
7 physical therapist and she guided me through that
8 week-long process, making sure that I learned what I
9 wanted, met with the people -- we had the
10 practitioners that did classes, but then they were
11 available to meet with us individually -- day-long
12 programs for a whole week. And then, like I said, at
13 the end they had our lab results, they had our test
14 results, and they developed a management plan.

15 The only thing on my management plan I've
16 never been able to accomplish was the one they made as
17 a recommendation for mental healthcare. But then the
18 patient has a battle plan. That management plan is
19 sent back to a primary doctor or a neurologist with
20 recommendations for referrals in the local community.

21 And there were many things that my doctor said, "Oh,
22 I didn't know you thought you needed that", or "I can

1 do that for you". And so that furthered the process
2 of management of my disease.

3 Then they have a booster shot that they do
4 a few years later when you can come back. The first
5 program is called the Can Do Program, second program
6 is called Can Do Too, so that if you forget or you get
7 slack or whatever, or you need to ask more questions,
8 you can come back. So, it's an intensive program.
9 It's more costly than what you're talking about, but I
10 think it's very longlasting because I thoroughly
11 understand what I need to understand, and then I'm
12 empowered to go about getting the things that I've
13 learned about and know that I need.

14 CHAIRPERSON JOHNSON: Good. Mike, you had
15 a comment?

16 MR. O'GRADY: Yes. It was just that
17 Dorothy had brought up before about Medicaid and
18 flexibility, and that brings up a couple of things
19 that we've started to see because we've tried to do
20 different things as waivers and allowing same amount
21 of money and see what you can do with it. And one of
22 the problems that at least Medicaid waivers have

1 started to crack a little bit is the idea where we
2 have these different eligibilities for different
3 programs.

4 So, you'll see a family where, two parents,
5 two children, and especially if immigration is part of
6 the calculation, you could have a situation where dad
7 has employment-based, and one kid is S-CHIP, one kid
8 is Medicaid, and mom is uninsured, and that's
9 certainly not great public policy or great healthcare.

10
11 And so through some of the waivers -- I
12 think they are called HIFA, and don't ask me what HIFA
13 stands for -- but that idea of can you in effect take
14 that pot of money and figure out a way to either buy
15 everybody into SCHIP, or buy -- use the SCHIP and
16 Medicaid money to buy them into family coverage
17 through the employer.

18 And right now some of that stuff is
19 limited somewhat because it has to budget-neutral --
20 and not so much in terms of just the per capita
21 spending, but we're trying to push a little bit to
22 say, you know, if mom and dad wanted to put in the

1 difference, or the employer is willing to do it -- and
2 part of what is being negotiated between the Feds and
3 the governors right now is how much do you do on that
4 sort of stuff. But it is an attempt to say, can you
5 open this up a little bit in terms of just not be so
6 inflexible, and allow different States to do it the
7 way they think they want to do it.

8 MS. BAZOS: Well, the other thing is
9 Medicaid is the way you do get into the system, and
10 then -- you know, some people, through poverty -- so
11 then they are in, and then they get a job and get
12 bumped up a little, then they're off, then they're in,
13 then they're off -- so some way to bridge that gap
14 through the system actually would be another thing
15 that --

16 MR. O'GRADY: Right. Now, there is some
17 of that -- and I wouldn't say that there are not bumps
18 in the road, but part of Welfare Reform '96, almost
19 ten years ago, was that idea -- it used to be that
20 Medicaid was really only if you had the old AFDC, so
21 if you were on welfare, you got Medicaid. That was
22 being linked with the notion of you didn't want losing

1 Medicaid to be a disincentive to finding work.

2 Now, in different places it takes -- like
3 I say, I wouldn't imply that it's seamless, but there
4 is some improvement. I guess one of the conflicts
5 that we have in this country is do we like the idea of
6 innovation that would allow New Hampshire to handle
7 it, what works well for New Hampshire? At the same
8 time, we also have these concerns about equity in
9 terms of if you were eligible for something in New
10 Hampshire but you might not be in New York, how
11 comfortable are we with that.

12 At the same time, you know, most
13 healthcare tends to be local, and many questions
14 related to the uninsured and these sorts of dynamics
15 are very local, and therefore there is this balance.
16 You'd like a State and the governor to be able to do
17 what fits for their circumstance. But at the same
18 time it does end up with the cost issues that they are
19 working on right now. And part of that tradeoff is
20 more flexibility -- but you also have to agree to hit
21 certain savings targets, so every negotiation has its
22 two sides.

1 But I was just trying to point out, in
2 this HIFA waiver discussion, the States who tried it--
3 -- and it was a little different in every State, but
4 they had a lot of ability to be a little more
5 rational, let's either get them all employment-based
6 insurance or let's get them all State-based, but
7 whatever it is, let's not have four different members
8 of the family with four different coverage.

9 CHAIRPERSON JOHNSON: Rosie, what I heard
10 you starting off with is talking about a program that
11 involved either volunteers or paid people to kind of
12 act as a Big Brother/Big Sister appear to others, and
13 I was wondering, as you were discussing that and as we
14 were having some follow-up discussions, if there's a
15 potential of that's a foundational idea for some
16 things we could do in the future because as some of us
17 are entering retirement ages, we're going to have many
18 people who will be looking for things to do to find
19 fulfillment. I'm wondering if that's a resource of
20 people on a volunteer basis, if not on a paid basis,
21 that could help do something like that.

22 MS. PEREZ: Absolutely. And in Harris

1 County, as a result of -- we had the big tropical
2 storm Allison -- and I think it made a Movie of the
3 Week just recently -- but our medical center -- and
4 downtown was flooded out. I mean, talk about crisis
5 in healthcare -- because of the flood -- we were shut
6 down, medically we were shut down. Ambulances couldn't
7 get in. Power was out. You know, stories of people
8 trying to carry patients from the sixth floor down to
9 the second and were using stairs -- I mean, it was
10 just a really horrendous situation. And to know that
11 it was shut down -- then we found out we couldn't
12 communicate with each other. We have 23 mobile
13 clinics that could have been dispatched out to the
14 areas that were suffering in the community, and we
15 didn't have that technology, the capacity to be able
16 to do that.

17 So, out of all of that we started to work
18 on some of those issues that came out, but one of them
19 was a volunteer health corps where it was made up of
20 doctors and nurses and plain regular people that would
21 sign up, and it was volunteering time. So, we waived
22 things like medical privileges at hospitals because if

1 my doctor could not get downtown and he was available
2 for service, then let him go into the hospital that
3 was nearest him to be able to provide services. So,
4 we kind of allowed a little flexibility for those
5 kinds of things.

6 And then the executives -- they were like
7 "I'm flooded out of my building at" -- you know, Enron
8 or wherever - "but I can type, I can answer the phone,
9 I can do whatever -- I can direct people places." And
10 so we came up with this volunteer corps within Harris
11 County to be able to fill in the gaps for crisis
12 situations or just in general, and we've been looking
13 at it at the local level for just the simple "One Stop
14 Shop" -- you know, they come in for a Diabetic Day
15 clinic, the nurse and the doctor are tied up with the
16 lab work or whatever, we don't have a salary because
17 we are free or nonprofit or whatever -- so let's put
18 them in a room and let's discuss all the other aspects
19 of it. So they are going to leave with the
20 information that they need because we don't know when
21 we're going to see them again.

22 CHAIRPERSON JOHNSON: Also, one of the

1 things I've heard in our discussion so far is that we
2 have complexity in our delivery systems and, Mike,
3 your comment regarding -- I think it was you --
4 multiple people in the family having different options
5 for coverage or care or whatever.

6 Would something that we might want to
7 address be how do we deal with those complexities?
8 Are there some potential solutions to take away from
9 some of the bureaucracy that providers and hospitals
10 face, to see if we could combine some of those or
11 simplify some of those as opposed to
12 compartmentalizing all of these kinds of programs.

13 Similarly, there are some who have felt
14 that in the insurance world one of the issues on
15 coverage -- we haven't talked about this yet -- one of
16 the issues on coverage is there are so many different
17 State regulations and so forth. What is the
18 possibility of having a uniform set of rules so that
19 if, let's say, Pat is working in Indianapolis and has
20 some relatives in Detroit maybe, they would be under
21 the same set of rules as in each State. That gets at
22 the idea of simplicity, but it gets at also then what

1 is the State authority, and how do we develop
2 regulations and so forth?

3 MR. O'GRADY: To a certain degree we're
4 talking about a State flexibility to do what fits in
5 in a particular State, and at the same time can we
6 have a uniform national standard for certain things.

7 MS. PEREZ: Some States do that in regards
8 to like nursing licensure and -- like I've got a
9 partnership in Louisiana and some other States, so if
10 I wanted to get a nursing job, I don't have to take
11 their State exam. I mean, there's some leeway on some
12 things between certain States -- not all across the
13 nation, but some States kind of buddy-up to make
14 things a little bit easier.

15 CHAIRPERSON JOHNSON: Well, Mike is right.
16 I've just talked about different kinds of approaches,
17 and I'm just not identifying solutions, just asking
18 some questions.

19 MR. O'GRADY: Can I refine that a little
20 bit? I mean, there are some things we've seen in
21 terms of -- when you think about national standards
22 versus otherwise -- that there comes a question of who

1 is setting them. Now, there's an awful lot of stuff
2 that we do through Medicare, but I'm not sure why we
3 do it through Medicare. Why is Medicare the guy who
4 decides about -- you know, restraints in nursing
5 homes.

6 Now, we are a payer. I know that much has
7 evolved from logical policy analysis, and maybe horror
8 stories of restraints in nursing homes-- but there are
9 times when you're thinking about what the different
10 actors in a system like this do and do well, and I'm
11 not sure -- I mean, what do you want the government to
12 be? Do you want the government to be a large
13 insurance company? Do you want the government to be a
14 regulator? And so it ends up with these
15 contradictions. I mean, right now the government is a
16 major purchaser of healthcare and at the same time
17 it's a major regulator of healthcare. I don't know if
18 we were starting with a blank sheet of paper that that
19 would be our ideal design to go from.

20 So, it's just sort of how you think about
21 these different things. Do you want a uniform
22 national standard, or do you want to allow this

1 geographic variability either by State or county or
2 however you want to think about it? It may depend on
3 the particular policy issue you're going after,
4 whether you really -- I mean, I think we want things
5 like eligibility for Medicare to be nationwide. Other
6 things like flexibility -- we talked about New
7 Hampshire's ability to go off and use their Medicaid
8 dollars, as long as it stays within some general
9 federal guidelines that the Feds are comfortable that
10 their share is being spent right. Why would you stop
11 New Hampshire from doing it?

12 CHAIRPERSON JOHNSON: I think Joe has a
13 comment, then Richard. By the way, if you have a
14 comment and you want to talk, I'm not seeing you want
15 to talk, you want to stick that up, that would be
16 fine, we don't need to be formal about that, but if
17 I'm missing you, feel free.

18 MR. HANSEN: Mine was more of a question,
19 and I think it goes to what Michael was saying. As I
20 understand Medicaid and the State's argument,
21 different programs in different States, but I thought
22 what you were getting at when you talked about

1 standards for insurance that cross State lines is
2 private insurance, but we are not

3 CHAIRPERSON JOHNSON: Well, my comments
4 were intended to be more open than that, but that's
5 one area where potentially there could be some
6 simplicity of the total system that would allow
7 increased access. And we could talk more about that
8 at a different time. Richard?

9 MR. FRANK: I just had an observation
10 which leads me, I think, in a direction that's not
11 very specific, which is if you look at the last 30
12 years -- well, certainly 20 years or 25 years -- the
13 only time that I can remember us making progress on
14 coverage and reducing the uninsured was during the
15 sort of middle part of the '90s. There was just a
16 jolt in the way we dealt with healthcare at that
17 point. And that coincided with managed care. On one
18 hand, we didn't like it, but on the other hand it did
19 contain costs for a while, which then allowed more
20 people to buy into insurance, but it also gave people
21 optimism and so led to the passage of CHIP -- you
22 know, the economic boom and all that stuff -- and it

1 was an historic departure from all the cost trends,
2 from the uninsured trends, all of those things changed
3 dramatically. And it, at least to me, suggests that
4 you've got to think about, at the very least on the
5 Medicare side and on the Medicaid side, but probably
6 more broadly thinking about something on a cost-
7 containment front so that you have something to (a) to
8 prevent the uninsured problem from getting worse,
9 going to 28 percent, and then possibly give people
10 enough optimism that they can handle this thing so
11 that they are willing to do something else because
12 right now everybody is just battening down the
13 hatches. Just that historical observation -- it's
14 striking.

15 MR. O'GRADY: I'd say, just to support
16 that a little bit and to tie in the article that she's
17 talking about-- his previous piece on this was looking
18 at those folks right on the cusp, sort of employers
19 who were offering but -- you know, if things got any
20 worse, they were going to have to drop, or employers
21 who were doing pretty well and were about up to a
22 point and they were growing their business, that they

1 were ready to start thinking about offering coverage.

2 And not to pick on him because he described it as
3 sort of insight into the obvious, but he tried to put
4 some numbers on this idea that, yeah, in 12-15 percent
5 premium growth years, those two subpopulations of
6 employers are going to be more likely to drop or less
7 likely to start offering, but in a 3 percent year
8 that's a whole different calculation.

9 MR. FRANK: Yeah, but the big fact that
10 sort of goes along with that is that in recent years
11 it's the take-up rates that have been going down,
12 which has been a big -- I think it's what, like two-
13 thirds or something like that, of the growth in the
14 uninsured or something -- I mean, you know these
15 numbers, right, isn't it something like that?

16 VICE CHAIR McLAUGHLIN: Particularly among
17 low-income people, the take-up rates have really been
18 dropping. So, more than employers stopping --
19 offering health insurance, it's been passing on higher
20 percentages of premiums, and then a reduction of pick-
21 up rates.

22 MR. FRANK: Right.

1 VICE CHAIR McLAUGHLIN: But I think,
2 Richard, part of your point, too, fits into the
3 comment I was making earlier about the relationship
4 between the economy, labor markets, unemployment, lack
5 of coverage, Medicaid -- I mean, all of those things -
6 - and this is what both Senators were saying this
7 morning -- I mean, it's like a plumbing system -- I
8 mean, the water is just flowing in and out of these
9 pipes, but it's the same amount of water, it's just
10 going up and down. And so there has to be some way --
11 I think what you were suggesting -- to smooth it out.

12 MR. FRANK: Right. I thought you were
13 actually -- I'll come back and put what I thought you
14 were getting at before back on the table, which was
15 isn't it odd that the sort of safety net which is
16 Medicaid suddenly has become pro-cyclical rather than
17 counter-cyclical.

18 VICE CHAIR McLAUGHLIN: Right, that is
19 what I'm saying, but what you brought up is part of
20 that same --

21 MR. FRANK: Right, everything is pro-
22 cyclical, which is bad. You want negative correlation

1 --

2 MR. O'GRADY: Well, it's certainly good
3 that the entire safety -- you know, from the work I do
4 on welfare and -- you know, I mean, it's the same sort
5 of thing. States -- you know, when they are in the
6 worst spot is when they are -- you know, they got the
7 lead money, that's when they're going to spend more.

8 VICE CHAIR McLAUGHLIN: Right. This is
9 what FDR's policies were all about, right, is to make
10 the government counter-cyclical, right, which is --

11 MR. FRANK: Earlier on, Medicaid was
12 counter-cyclical, it's only recently that it's --

13 MR. O'GRADY: Well, it is, but that's
14 States deciding that they wanted balanced budget
15 amendments in their States, and so the Feds are the --

16 VICE CHAIR McLAUGHLIN: We're not doing
17 the blame game, we're just --

18 MR. O'GRADY: No, no, no, but it is that
19 idea. But Richard's point about how you -- and it gets
20 back to the earlier point about the Sisters of
21 Charity, that idea if you can do this efficiently, if
22 you can be as cost-efficient as possible, that frees

1 up resources to be able to do more good. I think
2 that's absolutely right. And if you look at this
3 long-term -- you know, part of the stuff I have to
4 work on is the Medicare Trustees Report -- boy, when
5 you look at the 75-year estimate, boy, it just makes
6 your eyes roll in the back of your head -- 85 percent
7 of the economy will be healthcare? You couldn't sit
8 in the doctor's office that many hours of a day.

9 (Laughter and simultaneous discussion.)

10 MR. FRANK: Medicare starts to bite in
11 2007. I mean, that's scary -- the big jump in
12 percentage of the budget going to Medicare starts in
13 2007, right?

14 (Simultaneous discussion.)

15 CHAIRPERSON JOHNSON: Okay. What I'd like
16 to do here is kind of move us towards some potential
17 solutions, or initiatives -- that's a word I'd prefer
18 to use. What are some of the initiatives that you have
19 observed that deal with some of these issues that
20 we've talked about? And by the way, I'm not
21 belittling any of the comments that we have on our
22 current situation. We do have some real issues, and

1 Medicare is one of those. But what are some of the
2 current initiatives that you see working in your
3 environment, that have begun to attack some of these
4 issues?

5 MS. BAZOS: I'm just going to mention Bob
6 Masters' work that he did -- and maybe we should write
7 down two people because -- I mean, I haven't been
8 involved in his work other than -- he did a lot of
9 work, again, using Medicaid as a way to help patients
10 with end-stage renal disease and HIV/AIDS stay out of
11 the hospital, to decrease their hospitalization.

12 CHAIRPERSON JOHNSON: Who was this?

13 MS. BAZOS: Bob Masters. He sort of built
14 this program using practitioners -- it's a carve-out
15 program with Medicaid, and same thing using Medicaid
16 in a very flexible way to pay various practitioners to
17 make home visits, to actually again provide those
18 support ancillary pieces of care that people need to
19 actually allow them to stay home and out of the
20 hospital. And he did find cost-savings,
21 unfortunately, in negotiated contracts he never got,
22 and so those dollars went back into his program. And

1 they said, "Oh, you found cost-savings, well, you're
2 only going to get this much next year then". So, he's
3 written about this.

4 MR. O'GRADY: Along those lines also is a
5 cash counseling program -- have you ever seen that one
6 -- it has to do with, again, disabilities and the
7 ability to in some way -- it's particularly successful
8 in rural areas where you are, in effect, kind of
9 cashing out. You have a counselor that works with the
10 person in terms of their Medicaid money, but it is the
11 idea that if you need a care provider who is not from
12 a traditional sort of home health agency or whatnot,
13 you have the flexibility to go out into the community
14 you live in and find someone to come into the home or
15 whatnot. And we got write-ups on that, too. That's
16 four States, I think, five maybe.

17 CHAIRPERSON JOHNSON: Aaron.

18 DR. SHIRLEY: My State Medicaid program
19 implemented a disease management product two years ago
20 that's budget-neutral to Medicaid, and it's built
21 around a nurse call center and community nurses being
22 available to Medicaid beneficiaries with the diagnosis

1 of diabetes, hypertension and asthma. And the first
2 analysis of cost-savings to Medicaid is showing
3 something like for asthma and hypertension a 2-to-1
4 cost benefit.

5 And the education component that we talked
6 about, the nurses are available to eligible Medicaid
7 clients 24/7, and when the individual has difficulty
8 understanding the instruction, the advice that the
9 physician or provider gives, that individual can call
10 a nurse. When the physician has a noncompliant
11 patient, the physician can call the nurseline, and the
12 nurseline in turn contacts the patient to see if the
13 patient understood the instructions, and if the
14 patient needs help the community-based nurse can make
15 a home visit. And it's beginning to show some promise
16 both in terms of better control of the diabetes, fewer
17 ER visits for asthma, those kind of things.

18 CHAIRPERSON JOHNSON: So, diabetes, asthma
19 and --

20 DR. SHIRLEY: And hypertension. They are
21 about to implement a similar program in Texas.

22 CHAIRPERSON JOHNSON: May I follow up a

1 question with you, Aaron? How do doctors -- and,
2 Frank, you as well -- how do doctors feel about
3 disease management strategies provided by health
4 insurance companies or others such as you've just
5 identified? Are they supportive? Do they like them?
6 Do they dislike them?

7 DR. SHIRLEY: Once they got beyond the
8 notion that the disease management company was
9 interfering with their relationship with their
10 patients and the patients became more compliant, that
11 they could recognize and they accepted pretty well.
12 The main concern now is that whereas paper already was
13 a burden, this program has added additional paper.

14 CHAIRPERSON JOHNSON: Thank you.

15 DR. BAUMEISTER: I haven't had that much
16 experience with it, but what I anticipate is another
17 industry developing, that is a disease management
18 industry that will contract to provide the services,
19 and if you could work it out somehow within the
20 medical community, I think it would be a better
21 program.

22 DR. SHIRLEY: I should have mentioned that

1 this is a contractual arrangement-- the State Medicaid
2 has contracted with a company to do the disease
3 management.

4 CHAIRPERSON JOHNSON: Thank you. By the
5 way, employers have put in place disease management
6 strategies. We've had them in place since 1997, and
7 we've had very good response to them. We've done it
8 earliest with pregnant women, to avoid premature
9 births, low-birth weight babies, really significant.
10 It's a win-win there. But in other areas as well.
11 Montye?

12 MS. CONLAN: One of the things I
13 participate in on a regular basis is teleconferences.
14 Often they are sponsored by the drug companies, but
15 sometimes they are sponsored by other groups. And they
16 will typically have a doctor, often a nurse-
17 practitioner, that will speak on a particular topic of
18 interest to all of us, and then afterwards take
19 questions from the people that are listening. They
20 open up the lines and they will take questions. And
21 sometimes they get more or less personal, but
22 generally the patients feel that the questions are as

1 informative as what the doctors are presenting because
2 it shows that there's some common ground there, and
3 things that are "my concerns are not just my problems
4 but are common", and so some good is done there. But
5 that's another forum besides having volunteers come
6 out to the home or whatever, is these teleconferences.

7 CHAIRPERSON JOHNSON: Thank you.

8 MS. HUGHES: In the 1995 L.A. waiver, one
9 of the things that was required of the county was that
10 they form a public/private partnership with the safety
11 net providers of the uninsured. And I think of all
12 the things that I'm familiar with with that waiver and
13 the subsequent 2000 waiver, the single most successful
14 item in the waiver is the public/private partnership.
15 And just to give you an example, in '95 they started
16 out with they gave a dollar amount per patient per
17 number of visits per year, and that has been what has
18 happened actually up until right now, which is being
19 renegotiated -- not the waiver, but with the county,
20 the public/private partnership. And now the
21 public/private partnership is looking at the clinics,
22 and the clinics are looking at kind of a block grant

1 idea, and then the money -- for instance, there's a
2 group that's asking if they can use the money for
3 diabetes care, for disease management in diabetes and
4 asthma, and so those are two areas that some of the
5 clinics are looking at to see if they can negotiate
6 the money and so that we have a better -- we have more
7 control over what the dollars are that are coming into
8 the provision of care.

9 There are several layers to the program.
10 There are strategic partners, and the strategic
11 partners meet the highest quality and the highest
12 county requirements, and probably federal
13 requirements, for what the clinics are, what they
14 provide, if they have a doctor in place. Some of our
15 clinics have a doctor onsite two days a week, so they
16 are clearly not strategic partners, but they would
17 move down the line. And then the percentage of money
18 that is allocated to the different levels of
19 partnership also depends on the amount of -- if
20 there's improvement in care. And that is something
21 that I think has been very successful and it's done at
22 the clinic level.

1 We've been trying to work with the current
2 administration in California to look at that on a
3 Statewide level because it's something that works. I
4 mean, it's worked from '95 on, and actually in L.A.
5 County the clinics have honed what are good practices
6 in cooperation or hand-in-hand with the county, and I
7 think it's an effort -- and by public it means there's
8 public monies coming down to private organizations
9 where we provide the care, it's not public dollar and
10 private dollar, it's specifically meaning foundation
11 dollar. Does that make sense?

12 MS. MARYLAND: Let's talk a little bit
13 about -- and actually picking up from your point,
14 Therese -- Ascension Health, as I indicated earlier,
15 currently funds a number of demonstration practices
16 across the country -- actually, seven different States
17 at this point in time -- called HCAP, Healthy
18 Community Access Programs -- and I want to talk
19 specifically about what's going on in Indianapolis.

20 We have a number of rural counties in
21 Indiana. And if you know anything about Indiana,
22 everything -- the epicenter is in Indianapolis and

1 everything else is rural essentially. And the health
2 system consists of 16 hospitals that represent most of
3 central Indiana.

4 A number of our hospitals are critical
5 access hospitals, and within those communities there
6 are variable populations, particularly Hispanic
7 patients, that have significant needs similar to what
8 you talked about in terms of Texas. And what this
9 program essentially provides is that there's a
10 partnership including the Butler School of Pharmacy
11 where they send pharmacists out to rural communities
12 to work with these clinics, along with the
13 administrative plan that's called Advantage -- they
14 handle the managed care aspects of this -- along with
15 funding that's provided by Ascension Health, and also
16 federal dollars that are matched. So, this is sort of
17 a private and public, but joint, investment of dollars
18 coming together to provide support. And some of the
19 resources that these dollars pay for would be outreach
20 workers, as we talked about before, that are
21 bilingual, and they go out -- and they are like system
22 navigators. They go out and identify families who

1 have no primary care. And the goal is to try to get
2 them connected to some type of primary care clinic,
3 physician, specialist, and will oversee that they are
4 going -- that that family unit is going in for care.

5 And also working on development of the disease
6 management programs. The one that they've been very
7 successful is the cardiovascular disease management
8 program. And really with this population because of
9 the high risk in terms of hypertension, cholesterol
10 problems, obesity, felt this was a key area that
11 needed to be focused on.

12 And then to link that with Butler School
13 of Pharmacy means that there is a pharmacist out there
14 making sure that they understand how to use their
15 medications and that there's follow-up, that they are
16 complying with taking their medication on time. We've
17 seen some great results in terms of how often they use
18 the emergency department. We have actually a database
19 set up for each of the family units, tracking the use
20 of how often do they go to their primary care
21 physicians for follow-up visits, are they complying
22 when they are called in for their follow-up visits,

1 and how often are they now going to the emergency
2 department in lieu of going to that primary care
3 physician or clinic. And we've seen some great results
4 -- and I don't want to go through the detail at this
5 point, but we can certainly share those results --
6 that are showing that this investment is paying off
7 and that we're seeing certainly a huge reduction in
8 emergency room visits, a reduction in preventable
9 hospitalizations also, and there's some basic counts
10 of how many people have been served, the community
11 that is at-risk, what percentage of that population
12 are we actually reaching.

13 I think this program, which is one of the
14 seven States where Ascension Health made this
15 financial investment along with the federal dollars
16 that we've received, to really make this -- and then
17 dollars are coming from the Health Resource and
18 Service Administration of Department of Health and
19 Human Services. This HCAP program is, I think, very
20 effective, and I would like to have you consider it as
21 a potential model. It could be expanded further and
22 replicated in other areas.

1 CHAIRPERSON JOHNSON: Do you have an
2 explanation you can share with all of this? Do you
3 have a written explanation of --

4 MS. MARYLAND: Yes, I have the data.

5 CHAIRPERSON JOHNSON: Can you get that to
6 maybe Ken, and can you make sure that Pat has your e-
7 mail address and then get it out to all of them?

8 MS. MARYLAND: I can do that.

9 CHAIRPERSON JOHNSON: Thank you.

10 MS. PEREZ: As Pat was talking, I was
11 thinking of the reverse, too, to use that similar
12 program to identify those patients that -- I hate the
13 term "frequent flyers" -- but they are frequent
14 visitors to the emergency room. They are using that as
15 their primary care because they may not know about
16 resources in the community -- so to use it on the flip
17 side and identify those patients that come in through
18 the emergency room, and partner with a knock on their
19 door and say "are you aware of all these other
20 resources and enrollment and programs", and try to
21 figure out why it is that they are showing up in the
22 emergency room. So, it could go the other way as

1 well.

2 MS. MARYLAND: And those system navigators
3 or outreach workers really have been very effective in
4 identifying those family units, and with that those
5 "frequent flyers", and really working with them to get
6 them into a primary care setting so that they go on a
7 routine basis. And the responsibility from the
8 physician's perspective, primary care physician, is
9 that you go out and you are connecting with that
10 family on a routine basis and say "did you bring the
11 children in for their immunization, did you follow up
12 in terms of this", and then the pharmacists are back
13 with them in terms of -- you know, "the cardiovascular
14 disease management protocol says the following, are
15 you following these prescribed requirements?",
16 particularly in terms of drug compliance, medication
17 compliance.

18 CHAIRPERSON JOHNSON: Okay. Thank you.
19 So far, I think we've spent more of our time talking
20 about access issues. In our earlier discussions,
21 Catherine has been talking to me and others about
22 looking at not only access, but quality and cost

1 issues. And maybe we can focus on those as well.

2 What kinds of initiatives have you seen,
3 or worked with, or heard about, that get at the
4 quality issues that we've talked about or the cost
5 issues that we've talked about here?

6 VICE CHAIR McLAUGHLIN: Actually, I wanted
7 to add one -- I think several of these examples that
8 were given of initiatives are wonderfully illustrative
9 of how those three things go together -- access, cost
10 and quality. A lot of these initiatives were proposed
11 to improve access for people of different cultures or
12 languages, or people who are disenfranchised. But in
13 so doing, you are improving the quality of the care
14 that they are getting, and the coordination, the
15 continuity, hopefully the health status all together,
16 which in turn in the long-run will save costs. So,
17 actually saw those as examples of how all three of
18 these things are knitted together.

19 MR. FRANK: There are a number of pay-for-
20 performance schemes underway. They're sort of the
21 solution du jour for that quality problem. I think
22 the idea is promising. I think the evidence is it's

1 less so at this point. I think that the sense to
2 almost all of us suggesting that you pay for quality
3 makes good sense, and that you pay for performance.
4 However, I've been involved in the evaluation of a
5 couple of them, and I think it's very hard to do in
6 our type of health system, and I think it's also
7 complicated and we just haven't gone very far down the
8 learning curve.

9 The CMS program that just got underway for
10 hospitals will be pretty instructive, I think, but CMS
11 is in a unique position compared to like --

12 MR. O'GRADY: Good or bad.

13 (Laughter.)

14 MR. FRANK: It has a lot more clout.
15 Nobody is going to ignore CMS, no hospital is going to
16 ignore Medicare whereas it's pretty easy to ignore
17 PacificCare even if you're in California because they
18 are only 15 percent of your action. And so I think
19 there are some issues there, and I think people are
20 learning a lot, but I think so far the evidence has
21 got to be -- (a) it's not all that cheap -- you can't
22 do it on the cheap easily, and you can't do it small

1 scale are at least the two lessons I've taken away
2 from the things that I've looked at. And also there's
3 this big philosophical issue which is do you pay for
4 performance or do you pay for improvement? If you pay
5 for performance, then you give all the money to the
6 guys who have been good forever, and so you're just
7 making the rich richer. And if you pay for
8 improvement, then you're sort of ignoring people who
9 have done good deeds. So, it's figuring out what that
10 balance is. I think that's what I know about today.
11 But the folks out in California -- I think it's under
12 the Pacific Business Group on Health -- have started a
13 pretty large-scale pay-for-performance for doctors,
14 and PacificCare started one a year earlier. And we're
15 just finishing up the evaluation of PacificCare one,
16 but the really big thing is probably another year or
17 two away.

18 CHAIRPERSON JOHNSON: Does anybody want to
19 talk on those?

20 MR. O'GRADY: Yes, I just want to follow
21 up. To a certain degree, Richard has hit on a couple
22 of the big points: he laid out there the idea that we

1 saw a good four or five years where managed care
2 really did flatten this growth rate for us in a way we
3 really hadn't seen for a very long time, and then
4 there was a managed care backlash that we see in
5 employees and other subscribers who were just not
6 interested in that kind of level of gatekeeping and
7 whatnot.

8 And so there's two things that, as far as
9 I can see, have grown out of that, and they make sense
10 if you think of healthcare spending, anyway, as this
11 expense curve where you know that you have an awful
12 lot of people that are down on an end -but they are
13 not your big high-cost cases, and then you've got 10
14 percent of your people who may be 40 percent of your
15 total spending.

16 And so you see two movements coming out of
17 that. If you're not going to use a gatekeeper, well,
18 then you start moving -- especially if you're a small
19 business -- you start moving towards high deductibles
20 because you know that a lot of people spend an awful
21 lot -- you know, still a lot of your money goes to
22 routine care. And you say, well, this is insurance

1 against really bad things happening to you. If you
2 have just a doctor visit or two a year, you pay for
3 it. It will make you more cost-sensitive to what a
4 doctor visit really costs, and we're not that worried
5 about the bad end, it's when you get into really
6 serious trouble that we're going to provide the
7 insulation. And the other side is just what we're
8 talking about here in terms of focusing on how do you
9 drill down on the 10 percent that is 40 percent of
10 your spending. You do it through disease management
11 and you do it through pay-for-performance.

12 And it brings up some of the other stuff
13 we talked about here like the program that Richard was
14 talking about, where the physician practices in
15 California have started to have some pretty nice
16 results. One of the real tools they used there was
17 health IT. And so you say, well, -- how do you get
18 to pay-for-performance?

19 Well, the first thing is -- especially
20 when you start identifying three or four major groups
21 -- diabetics, congestive heart failure folks, and your
22 -- you know, different key subpopulations of who, if

1 you get a better handle on it, you can both deliver
2 higher quality healthcare and save some money. So,
3 it's sort of your key target subpopulations. And
4 part of what they do is they first set up a registry
5 so -- I mean, it may sound a little simplistic -- so
6 they at least first know who their diabetics are in
7 the practice, and then are they getting their
8 recommended tests, and then the final stage is do you
9 have enough of the health IT to be able to know --
10 it's not enough that your diabetics are getting their
11 hemoglobin A-1cs two or three times a year, but how
12 are they doing on those? And so it does get to that
13 sort of thing.

14 Now, there have been some questions, early
15 results look good, but we're talking about California
16 where 200 guys in Bakersfield where they all work out
17 of the same company-- that's a little different than
18 if you're the two-man operation in the Outer Banks of
19 North Carolina someplace, and how much these models
20 convey -- and that gets back to -- but that's one of
21 the uses I've seen that health IT has really shown at
22 least some early promising results, although I don't

1 know how to project it to -- I mean, when you think
2 about what you want: Is the outcome there? What is the
3 policy goal? It's the higher quality care and a
4 little smarter about how you've spent your money.

5 If the guys in the Outer Banks can do it,
6 sending Mildred to the back room to go through the
7 files and she figures out their diabetics and sees
8 what -- you know, how am I invested in health IT? I
9 mean, you want to get to the point of the higher
10 quality healthcare and spend your money in a smarter
11 way. If health IT is the tool to get you there, great.

12 If it doesn't, it's a tool. And that's another
13 question-- are things like health IT an end in
14 themselves, or are the simply tools to get you to a
15 greater goal? But it is part of this whole notion of
16 if you're not going to do managed care anymore, at
17 least hire a gatekeeper, what are you going to do?
18 So, it seems to me there's this two-pronged approach,
19 one end of the distribution and the other.

20 CHAIRPERSON JOHNSON: Maybe I can share --
21 I'd like to step out of my facilitator role here for
22 just a second and share what larger employers are

1 doing because it gets to this subject that Mike has
2 talked about. And there is a perception based on the
3 studies that have been done and provided by and for
4 employers that mentioned earlier, 50 percent of the
5 care is not delivered -- and that's a report by the
6 IOM, that's not employers saying that -- but if you
7 and I go to the doctor, we really don't know who are
8 the good doctors and who aren't. And Medicare and
9 Motorola, University of Michigan, pays the same for
10 every doctor whether or not they are providing
11 outstanding care or they are not.

12 And so what's happening in the employer
13 community is the larger employers are kind of leading
14 this, but others are beginning to think about it, and
15 that is what we are going to do is, No. 1, we're going
16 to push for the measurement transparency and
17 disclosure of healthcare outcomes, and we're going to
18 use nationally accepted standards to do this -- risk-
19 adjusted data, sex-adjusted, age-adjusted, risk-
20 adjusted as well. So that's the first part.

21 The second is moving more and more towards
22 consumers. And what employers have done up until now

1 -- I call it the Studebaker, to use a widened
2 reference -- the Studebaker method of healthcare cost
3 management is just to share higher cost with the
4 patients or with the employees, but that doesn't help
5 control the cost. I just charge more to Mike's kind
6 of premium every month, that doesn't help control the
7 cost. They don't have any visibility for that.

8 So, what we're moving now more toward is
9 consumerism, and what we mean by that is giving
10 strategic decisions with tools employees or patients,
11 so that they can make better decisions when they buy
12 healthcare.

13 Now, will that help out the emergency
14 case? No, not so much, but it will help on preventive
15 care and it will help get the chronic care that Mike
16 O'Grady has been talking about, and especially there.

17 We think that as we -- and we've seen other companies
18 move in this direction -- as we identify better
19 providers and as we identify disease management
20 strategies that work in collaboration with the doctors
21 -- not excluding the doctors, but in collaboration
22 with the doctors -- and then in addition to that, if

1 we pay the doctors based on their performance. So, now
2 we have the reports, we have the consumerism, we have
3 the patients going to who are the quality doctors,
4 efficient doctors -- by the way, hospitals and
5 treatment plans as well -- patient satisfaction, and
6 equity -- that means treating people along racial
7 lines and ethnic lines and socioeconomic lines -- and
8 all of those performance ratings would be available.

9 Now we'll have physicians who have not
10 known in the past how they've been performing, they'll
11 be able to see their ratings. And we'll see hospitals
12 who haven't known in the past how they've been
13 performing -- am I better than St. Vincent's or not as
14 good, and how do I compare. And then what we'll see --

15 VOICE: It's in the newspaper.

16 CHAIRPERSON JOHNSON: That's right, it
17 will be public, and we'll provide information to the
18 doctors as well to the hospitals, as well as to the
19 patients. And we think that that will help us re-
20 engineer the system, and the data seems to say about
21 30 percent of wasted medical dollars could be
22 recovered.

1 Now, that's a direction that employers are
2 moving. And we see a little bit of that with CMS and
3 programs that Mark McClellan and Leslie Norwalk have
4 implemented as demonstration projects. So these are
5 not pie-in-the-sky, they are initiatives that have
6 already been established.

7 Aaron, and then down here.

8 DR. SHIRLEY: I didn't quite get clear,
9 who is going to define the standards by which the
10 quality --

11 CHAIRPERSON JOHNSON: If you didn't hear
12 Aaron back there, the question is who is to define the
13 standards? And there's an organization -- by the way,
14 I'm going to back up and say two things first. I
15 think there are some things that have come out of
16 prior commissions, and one of those that came out of
17 the Quality Commission during the Clinton
18 administration, I believe, was the formation of the
19 National Quality Forum, and we can come back and talk
20 about that. But there's another new thing that I
21 believe has come out of the recent MedPAC Commission,
22 and that's a recommendation that Medicare doctors be

1 paid based on their performance and improve the SGR,
2 the Stabilization Growth Rate, so that we have a new
3 methodology of paying doctors. I think those are
4 significant contributions by other commissions, and
5 the reason I mention that is I'm hoping that we'll
6 come out with at least those kind of good quality
7 ideas.

8 But to answer your question directly,
9 Aaron, the National Quality Forum is the organization
10 that these employers are pushing to be the evaluator
11 of the measurements. And just for others who may not
12 be as aware as Aaron probably is, the board or
13 stakeholders on that, primary stakeholders are
14 providers, researchers, patients or consumers, and
15 employers or purchasers. So, it's broad stakeholders,
16 and that's why we think if those measurements are
17 used, that would be moving in the right direction.
18 Now, it's not -- when I'm saying "I", I'm saying as
19 one of many large employers.

20 MS. MARYLAND: I wanted to just add
21 something for clarification in your comment. When you
22 said that employers were looking to -- I believe I

1 heard you say that employers were looking at providing
2 information to the consumers on the cost of what their
3 healthcare plan may be.

4 What size employer are you looking at as
5 providing this sort of benefit to consumers?

6 CHAIRPERSON JOHNSON: Well, right now I'll
7 respond -- I'm happy to respond on all of this, but I
8 don't want to personally dominate the conversation.
9 Just briefly, there's an organization called Bridges
10 to Excellence and another that's called Leapfrog.
11 Leapfrog is dealing with hospitals, Bridges to
12 Excellence is dealing with doctors, and the Bridges to
13 Excellence has primarily been working with large
14 employers, but it has now been licensed by United
15 Healthcare which I think has something like 50 million
16 members, and CIGNA, which is another large nationwide
17 carrier. And they will begin to move forward with
18 those kinds of initiatives. Of course, those
19 organizations are dealing with small as well as large
20 employers.

21 MS. MARYLAND: Two additional thoughts.
22 One that not only are employers looking at

1 performance, if you will, but so are the major
2 carriers. For example, Wellpoint in Indiana
3 reimburses its carrier rate level given the outcome,
4 so they do look at risk-adjusted clinical outcomes to
5 evaluate what level are they going to reimburse you
6 for services rendered.

7 The only other point I'd like to make is
8 the concern that I brought up about specialty
9 hospitals earlier knowing as you start to look at the
10 report card for acute care hospitals, where there are
11 specialty hospitals within the region because what
12 tends to also happen is there is a transferring or
13 shifting of those patients when they have morbidities
14 and complications, to those general acute care
15 hospitals. And when you put together that final
16 report card, mortality and those complications may not
17 be on the books of some of those specialty hospitals.
18 So, that's a major area of concern as we look at
19 markets where there are other specialty hospitals in a
20 region.

21 CHAIRPERSON JOHNSON: That's why the
22 validity of the data, and the reliability, is going to

1 be so important, to make sure it is adjusted for risk
2 and so forth.

3 MR. O'GRADY: One of the things I think
4 that Aaron said -- when you asked who is going to set
5 it, that sort of sent shivers down my back. I think
6 we've seen different things. We can point out the
7 things that you certainly have to be very careful and
8 you have to be very rigorous on those. I think that
9 the Centers of Excellence Program that was attempted
10 by HCFA in the old days, and of course if you have
11 five hospitals in a city and one gets called a Center
12 of Excellence and the other four go, "What the hell
13 are we, Centers of Mediocrity" -- you know, it's sort
14 of the notion of a panel in Baltimore -- the
15 government deciding -- that rubbed people the wrong
16 way, so certainly it has to be done very carefully.

17 I wanted to point out another program that
18 I saw -- and I'm blank on which of the Wall Street
19 firms did it, but it was one of these where they
20 basically had these big traders that were dropping
21 like flies, basically heart attacks -- and I forget
22 who it was, but it cost the company like a million

1 dollars every time one of these guys was out for eight
2 or nine months. So, they basically bought their own
3 cardiologist, put him on staff, and what he did is --
4 they'd see the claims coming in, so they'd see the
5 different people -- who was going in, who was getting
6 their checkups and whatnot. Now, it was the same
7 notion of pay-for-performance, but what that meant was
8 the cardiologist just called over to the person's
9 internist and said, "This guy could really use a
10 stress test", or whatnot. Now, in effect, that
11 started out a little bumpy, but it worked out not
12 badly -- and took it the next step -- beyond a report
13 care in terms of you have an internist there who is
14 not a cardiologist. And so, in effect, you're giving
15 kind of a free consultation there -- you know,
16 bringing in the specialist to sort of say "Are you
17 aware that" -- for this guy, maybe a -- you know,
18 whatever it happens to be, and especially as these
19 guys who live fairly far out of whatever the large
20 metropolitan area -- it was Merrill Lynch who did
21 this, that's who it was.

1 So, what this sort of feedback move is doing for you
2 is, in effect, giving practitioners access to more
3 resources than they would have had otherwise. They
4 had a pretty good track record. That was not
5 necessarily telling them what we do, it was telling
6 them what the latest thinking was, what cardiologists
7 were doing for this guy or that kind of a case. And
8 they were pretty happy in terms that they kept the
9 relationship with the primary physician on more
10 cooperative grounds.

11 CHAIRPERSON JOHNSON: First, Dotty, and
12 then, Frank, you've been kind of quiet, but I know
13 that you've got some thoughts regarding what's been
14 done in Oregon. Would you be willing to share some of
15 those when Dotty is done?

16 MS. BAZOS: I'll just be real quick. You
17 might want to look at as a model the report card from
18 New York State. They've been providing State level
19 data on their outcomes for CPR surgery since I think
20 early 1990s. And they publish a report every year.
21 Everyone is compared to a State standard. So, you
22 might want to look at that. And it's hospital data,

1 also physician level data also.

2 MR. FRANK: Thank you. I don't want to
3 put you on the spot, Frank, but you kind of alluded to
4 some of your initiatives earlier, and didn't want to
5 miss those.

6 DR. BAUMEISTER: Well, a lot of what we're
7 talking about was what Oregon tried to do. I don't
8 know how many of you are familiar with what went on
9 out there, but years ago, once upon a time, there was
10 a kid named Coby Howard who had acute leukemia. And
11 at that time the Medicaid payments came to the State
12 as sort of a block grant type pot of money. And the
13 Medicaid population would use the money up and then
14 the Medicaid population was left hanging. And they
15 either got care from kind-hearted docs and emergency
16 rooms, or they didn't get any care at all.

17 And the situation came up with Coby Howard
18 where they wanted to do a bone marrow transplant only
19 there wasn't any money. And he had been seen by a
20 number of physicians who had concluded that a bone
21 marrow transplant would not be valuable, but the media
22 got on it and there were some advocates for a hopeless

1 situation, and he didn't get it. And it brought a lot
2 of bad publicity down on the State and particularly
3 Dr. Kitzhaber, who was a former emergency room
4 physician and at that time was -- I can't remember
5 whether he was governor or president of the senate at
6 that time -- but he was referred to as Dr. Death in
7 the New York Times, and all sorts of bad publicity.

8 Well, anyway, they decided -- one night,
9 he and Barney Spate, who was a health policy person in
10 Oregon of some renown -- I think they were sitting in
11 a bar in Salem, Oregon, and they came up with the idea
12 for the Oregon Health Plan, which basically was --
13 I'll use the analogy or metaphor, or whatever you want
14 to say, of dinner party where you had so many guests
15 and you had so much money to spend and you had to
16 decide on your menu, and that's what they came up with
17 was that's the way healthcare needs to be delivered.
18 You need to figure out how much money you've got to
19 spend and then how you're going to divide it and what
20 are you going to serve your guests.

21 And so the concept of a basic benefit
22 package circulated around. They said how are we going

1 to decide what a basic benefit package is? And so
2 this group called Oregon Health Decisions, which was -
3 - there were several ethicists from Oregon Health
4 Sciences University, several people from the clergy,
5 some elderly retired physicians among whom was a
6 psychiatrist who had an interest in public policy, and
7 formed Oregon Health Decisions, and started a group of
8 town meetings around the State. And it went on
9 interminably, taking testimony from all walks of life
10 -- farmers, stock brokers, nurse-practitioners,
11 chiropractors, specialists, urban, rural, university,
12 you name it. And they came up with the Health Services
13 Commission, the Oregon Health Services Commission,
14 which came up with a prioritized list of diagnosis and
15 treatment payers. And I think there were 800
16 diagnostic treatment payers that would comprise the
17 list, and if the State were to be flush with money,
18 they would cover all 800 as the Legislature had to
19 make the decision out in the open, had to be
20 transparent. We've only got so much money to spend,
21 so we'll only cover 700 or 600 or 500 or whatever. It
22 would be out in the open. So, that was part of the

1 Oregon Health Plan, was that the Health Services
2 Commission would come up with a list and that would be
3 what would be a basic benefit package, but let's offer
4 it to all Oregonians.

5 And the way they did that was they passed
6 a series of Senate bills, and Senate Bill 27 covered
7 the Medicaid population. Senate Bill 935 was an
8 employer mandate. And small employers, as you said,
9 were going to see their bills increase 25 percent over
10 the next few years, and large employers up 10 percent,
11 or whatever. The ones who would be hit the hardest
12 would get tax rebates. So, it would be a
13 public/private enterprise. And that was Senate Bill
14 935.

15 Senate Bill 541 was to cover all the
16 uninsurables, and that was to be by contribution from
17 the insurance companies that would take care of those
18 people who absolutely could not get insurance under
19 any circumstances. And that was the Oregon Health
20 Plan.

21 CHAIRPERSON JOHNSON: Did the insurance
22 companies provide the coverage?

1 DR. BAUMEISTER: They would have, yes.
2 Well, the first thing to die was the employer mandate.
3 Mandate is a dirty word in Oregon, as it is
4 elsewhere. So, essentially, the Oregon Health Plan
5 fizzled and became a Medicaid program that was
6 embraced by the community, by the medical profession,
7 by the hospital association, and for a while there it
8 essentially did away with uncompensated care.

9 And over a period of several years, the
10 doctors' income from those patients went up like 1 or
11 2 percent. The hospitals made more money out of it,
12 and so that set up a big battle between the hospitals
13 and the doctors.

14 And of course Medicaid is basically a
15 State program where the State comes up with money,
16 they put in a dollar and the Feds put in two dollars,
17 and dollars got short in Oregon. And so now they've
18 changed eligibility criteria and it's really
19 struggling. But that was the history of the Oregon
20 Health Plan over about an eight or nine-year period.
21 A sad demise.

22 CHAIRPERSON JOHNSON: Advantages and

1 disadvantages, lessons learned for us.

2 DR. BAUMEISTER: I guess the lessons
3 learned -- one lesson, you can't mandate anything.
4 You can't -- people just don't want to pay for things.

5 I mean, that's the bottom line. It never got a
6 chance, I don't think, from the business standpoint.
7 You've got a welfare program over here, and you've got
8 a self-sufficient program over here, and it's hard to
9 make self-sufficient program over here -- it's like
10 the guy at Starbuck's who "would you buy me lunch" --
11 it's a real problem.

12 We have a mess in Oregon right now. Mental
13 health out there is a travesty, it's a disaster.
14 Mental health in Oregon has been turned over to
15 Corrections. And you read about it once in a while
16 when a policeman guns down a psychotic, and we've had
17 three or four of those in the last few years.

18 The biggest mental hospital in Oregon is
19 the Inverness County Jail. I've toured the jail. It
20 has 78 beds, I think. I was on a mental health task
21 force in Oregon, in Multnomah County which is
22 Portland, and all the mental health cases from the

1 State migrate to Portland. You can't be homeless and
2 sleep on the street in a small town where there are no
3 streets. And it's a difficult situation.

4 But the Oregon Health Plan was a generous
5 plan that would balance things across a wide
6 population, which is basically what insurance is
7 supposed to do, and it took care of the most needy of
8 our people -- you know, the haves helped the have-
9 nots. And it was a sad day for all of us.

10 CHAIRPERSON JOHNSON: Thank you for
11 sharing your perspectives and your experience.

12 MS. MARYLAND: Tell me how we're going to
13 be inspired by those --

14 (Laughter.)

15 MR. O'GRADY: I got the no-mandates
16 message real clear.

17 (Laughter.)

18 CHAIRPERSON JOHNSON: I think actually --

19 DR. BAUMEISTER: We had a hard time
20 getting a waiver, if you recall, because it was
21 rationing.

22 MR. O'GRADY: It sounds now almost like

1 you're saying it didn't ration enough to be
2 financially viable with the people who would have to
3 pay for it at least within the State.

4 DR. BAUMEISTER: Maybe not.

5 CHAIRPERSON JOHNSON: Dotty has a comment.

6 MS. BAZOS: I just do. I did work with
7 Eliot Fisher and Jack Wennberg, and I've worked for
8 them for years, so I just have to bring up this
9 question about rationing. I mean, I think when we
10 started this discussion we started making some
11 assumptions that there's enough money in the system to
12 support really good quality healthcare for everyone.
13 And before we leap to rationing, we're thinking about
14 rationing, I just wanted to have a conversation about
15 what we're overusing in the healthcare system. Let's
16 not forget we talked a lot already about the variation
17 in distribution of providers and capacity across the
18 system. And I just don't want to lose that. I know
19 that all the work that's been done -- they've been
20 sort of singing the same song and saying the same
21 things for years, and research is getting really good,
22 but they don't have solutions yet. I would just like

1 to keep that on the table so we don't leap to quickly.

2 I do think the term "rationing" in the
3 United States would really be a death sentence for all
4 of us, and what you see in other countries where they
5 do ration care -- I mean, in Third World countries --
6 and when I was in Pakistan with one hospital where you
7 could get any treatment for cancer, if you couldn't
8 pay for it yourself there was nothing. So, the people
9 who had money went there, or they flew to the United
10 States where we have higher technology, better care,
11 and the poor people got nothing. So, I think we don't
12 want to set up that kind of scenario either.

13 CHAIRPERSON JOHNSON: Let me respond and
14 then we'll switch to our next agenda item. Two
15 things: First, part of what we should be about is
16 learning from the experiences of others. So, Frank,
17 there might be some things we can learn that we
18 shouldn't do, and some things that we can learn that
19 we should do.

20 DR. BAUMEISTER: I think it's important to
21 know that the plan failed when we had gatekeepers,
22 when Oregon had the highest managed care penetration

1 of anywhere in the country, that Oregon's expenditures
2 annually for a Medicare recipient is about one-third
3 of what it is I think in Florida, New York -- I mean,
4 we are tight-fisted out there, and part of it has to
5 do with that tradition of our managed care -- Kaiser
6 came to Oregon in 1945, and they played the tune and
7 everybody else danced to it until now all the private
8 plans have out-Kaisered Kaiser. So we have a long
9 tradition of that, and the Oregon Plan still failed.

10 CHAIRPERSON JOHNSON: The other thing I'd
11 like to end on a positive note in this session, and
12 we're going to have to come back and talk about
13 initiatives, was just the one you've mentioned. There
14 are smart people -- we've talked about some of the
15 challenges of health here, but there are smart people
16 within the United States who have done some great
17 studies, some great research, and the two you've
18 mentioned are just two of those. And we're going to
19 have an opportunity to draw on their expertise, I
20 think, to see if we can build some of their research
21 and some of their concepts into what we end up with
22 recommending, or at least share with the public some

1 of their findings. So, I appreciate that.

2 And speaking of bright people, we're
3 privileged this afternoon to have Carolyn Clancy. You
4 know, I've heard a lot about Carolyn Clancy over the
5 years because I've been in this Healthcare Benefit
6 Strategy group for a number of years, but I didn't
7 have an opportunity to meet her until within the last
8 year. And Carolyn is a doctor. She is a director of
9 AHRQ, was the interim director for a while, and before
10 that director of Centers for Outcomes and
11 Effectiveness Research, and the director for the
12 Center for Primary Care Research, so she's got
13 practical experience and the research experience as
14 well. She has done a superb job, is counted on -- and
15 typically we sometimes use the word "expert" kind of
16 with a negative tone to it. We don't have that tone
17 when we're introducing Carolyn to us this afternoon.
18 So, welcome, glad you're here, and we look forward to
19 your comments.

20 DR. CLANCY: Thanks very much, Randy, and
21 it's very nice segue at this point in time. I've been
22 looking at all of you and trying to figure out where

1 you are on the exhilaration-exhaustion continuum, but
2 then I look at the list on the wall, and you have
3 certainly identified a lot of very, very important
4 issues.

5 It's an interesting segue right at this
6 moment to have been talking about this because in many
7 ways the agency is here because of Jack Wennberg's
8 work. Long before you could click on the Internet and
9 get the pretty maps from the Dartmouth Atlas, he made
10 it very, very clear to policymakers what were the
11 implications of variations of practice, and what is
12 meant that we are spending much more for Medicare
13 beneficiaries in some areas than others, and you don't
14 have to be a rocket scientist and you don't even need
15 the pretty colored maps, although they help, to begin
16 to ask questions: wait a minute, how come we're
17 spending much more over here than over here, and what
18 are the implications? So, in many ways, that set the
19 stage for the agency coming into being 15 years ago.

20 So, I just wanted to share with you a few
21 high points of where we are now. The mission of AHRQ,
22 as we say it, is to improve the quality, safety,

1 efficiency and effectiveness of healthcare for all
2 Americans. Depending on the day, I either think of
3 this as ambitious or psychotic, and many days I think
4 it's right at that line. Our overall budget for this
5 fiscal year is \$319 million, which is a high-water
6 mark for us and we're very proud of that, but if you
7 think what we're spending -- and, boy, you're going to
8 hear a whole lot more about what we're spending in
9 really granular detail -- that's a pretty tall order.

10 And the only way we believe we can do that is through
11 partnerships with those stakeholders that actually do
12 directly provide or regulate or purchase healthcare.

13 In terms of where our research fits into
14 what goes on at HHS and what's supported, where NIH
15 supports basic biomedical science and focuses on what
16 can work to cure or prevent disease, and the CDC
17 focuses on the public health system and community-
18 based interventions. We're really focused on the
19 effectiveness of what works in healthcare and for
20 whom, and we're hoping to focus that work on those
21 potential solutions and the evidence that will help
22 people develop solutions in what we call the real

1 world. Now, we're not entirely confident where the
2 real world is, it's probably not within the Beltway.
3 So we like to say that our research is really patient-
4 centered rather than disease-specific.

5 So, where NIH might focus very
6 specifically on a particular condition like diabetes,
7 we're focused on the people with diabetes, and that
8 matters because a little over 80 percent of adults
9 with diabetes have at least one other condition, so
10 you're starting to look at co-morbidities and those
11 kinds of intersections.

12 And in addition to focusing on the
13 clinical contents, we're also focused on the
14 environment in which those services are provided
15 because all of us know all too clearly that how
16 healthcare is organized and financed has a big impact
17 on what kind of care people get. And very, very
18 importantly -- and I'll probably reinforce a couple
19 more times, so I'll apologize in advance -- our
20 mission really includes both the production and the
21 use of evidence-based information.

22 I see along all of your flip-charts the

1 theme of information in many different ways, whether
2 it's consumers or whether it's policymakers having
3 information and so forth. And I think in policy
4 dialogues, we treat this as a production problem.
5 And I would assert that it is at least as much a
6 dissemination or communication problem as well, so I
7 hope that you might want to consider that.

8 You all got copies of our annual reports
9 on the Quality of Healthcare and Disparities in
10 Healthcare. These were mandated by the Congress when
11 the agency was reauthorized in late 1999, and came
12 from very different parts of the Congress. The
13 Quality report really came because, if you recall,
14 this was sort of the tailend of the so-called Managed
15 Care Backlash, so members of Congress and their staffs
16 were besieged by constituents saying "quality of care
17 is going to hell in a handbasket, the green-eyeshade
18 guys have gone too far, you need to do something", and
19 they had no framework to even think about this. I
20 mean, all the stories sounded terrible and, indeed,
21 were terrible tragedies for individuals, but they
22 didn't know how to interpret it, so that's why they

1 really wanted a Quality Report. They were fairly
2 confident they didn't know enough to regulate or make
3 laws about this, but they wanted to have an annual
4 report sort of along the lines of leading economic
5 indicators.

6 That same year was a year that there was a
7 very high profile publication in the New England
8 Journal of Medicine. This was the study where
9 physicians attending professional meetings actually
10 looked at videos of actors portraying patients. Now,
11 the genius of this study -- and there's been a lot of
12 debate about the statistics that were used in terms of
13 portraying the results -- but the genius of the study
14 design itself was that every doctor saw a patient who
15 was either 55 or 70, black or white, male or female,
16 but they used the exact same words to describe their
17 symptoms. It was very, very well done.

18 Watching these computer videos, I felt
19 like I was in the clinic -- you know, patients had the
20 examining gowns on and so forth -- and they could also
21 control for socioeconomic factors and so forth. And
22 the bottom line of the study was that the physicians

1 were significantly less likely to recommend evidence-
2 based diagnostic treatments for patients who had a
3 very, very good story for having serious cardiac
4 disease -- much, much less likely to recommend those
5 for older African American women. And for whatever
6 reasons of timing with the media, a window of
7 opportunity and so forth, this really cut the public
8 right away -- in fact, was a cartoon within hours of
9 publication in the New England Journal, which to me
10 seemed like a new measure of research impact. Ted
11 Koppel was weighing in within a couple of days, and so
12 forth. And so that was how we got a mandate for a
13 disparities report.

14 We've linked the two together very closely
15 for one reason. Every study of quality where there's
16 information on patient race, ethnicity, income and
17 education has two take-home messages: One is that
18 there's a big gap between best possible care and
19 actual care at a population level, and the second is
20 that, in general, that gap is larger still for people
21 who are members of racial or ethnic minorities, low
22 income, low education.

1 Now, the size of that gap tends to vary a
2 lot by clinical condition and as -- blocking on the
3 name -- Jim Weinstein's study looking at knee surgery
4 in the Medicare population showed it varies a lot by
5 community as well. So, for example, in the Bronx
6 there are no disparities in knee surgery for Medicare
7 beneficiaries, so that's good news associated with
8 race and ethnicity. The only problem is the overall
9 rates are so low that either everyone had knee surgery
10 before they got into Medicare, or there's other
11 factors going on there. So, you can't get away from
12 the variations challenge. So, I was pleased to hear
13 you say that you'll be coming back to that.

14 Just to highlight one or two findings from
15 the reports, one of my personal favorites is the
16 percentage of people who are admitted to the hospital
17 with a heart attack, who are advised to quit smoking
18 before they go home. It's just under 50 percent.
19 Now, this is what you would call a "teachable" moment
20 because -- and I'm not being sarcastic--people who are
21 advised to quit then have a one-year quit rate of 50
22 percent. If you do everything right in primary care -

1 - and I myself have never had the opportunity of
2 providing care in a practice that had the right
3 infrastructure to do this, this is when you make
4 contracts with patients and call them up to remind
5 them, and do all the things that we know can be
6 effective. The quit rate at one year is 8 percent.
7 So, missing this opportunity is missing a big one.

8 And I know what's going on here. Every
9 health professional thinks that somebody else is
10 taking care of it. I think the other thing that's
11 going on is there's not a system in place -- and it's
12 almost an embarrassing conversation to have, right --
13 I mean, we've done such a good job on one level
14 getting the message out that there's a connection
15 between smoking and heart disease, that it's almost a
16 little embarrassing one-on-one to say, "By the way,
17 you know the cigarettes in your pocket you came in
18 with" -- I mean, that's like a hard conversation to
19 have, so we drop the ball.

20 In your handouts I've listed how we
21 portray our portfolios of work rather than talking
22 about specific research programs or specific projects,

1 although at a moment's notice, at the drop of a hat, I
2 would be happy to entertain you for hours, or put you
3 to sleep, whichever, in telling you in very fine
4 detail about some of the work we're supporting.

5 But the big priorities for us right now
6 would be improving patient safety and quality -- and
7 Larry mentioned that earlier that the issue of safety
8 came up -- and just to get back to the question of
9 variations for a moment, lots of people frame quality
10 problems as overuse, underuse, misuse of services.

11 Underuse of effective treatments, no
12 problem getting a lot of convergence on that topic,
13 lots and lots of stakeholders I think want to work
14 together on that. And I think safety issues capture
15 the public's imagination in a way that's very, very
16 tangible, as in "this could be me", "this could be a
17 member of my family". Not only does 30 to 40 percent
18 of the public say that they or a family member have
19 been the victim of a medical error, but about a third
20 of doctors say the same thing. So, this is very, very
21 real. Makes quality really kind of important for
22 folks.

1 Overuse of services, I think, is very
2 delicate. I've never been in a medical or policy
3 setting where people don't agree that overuse is a
4 problem, and that would be your overuse. So, I just
5 say that in cautionary terms. On the other hand, I
6 think no one believes that we should be paying for
7 care that ultimately leads to harm. So, I think that
8 in a way may create an avenue to discuss some of these
9 issues, and I think learning from other industries in
10 healthcare -- one message that's beginning to take
11 hold is the idea that rework costs a lot. So, if we
12 don't do the right thing the first time and we then
13 have to go back and fix that problem, that costs a lot
14 of money as well as leads to avoidable pain and
15 suffering and so forth.

16 Identifying what's avoidable is not quite
17 so easy, that is actually probably the weak link in a
18 lot of the patient safety issues, but that's a big
19 issue.

20 Another big focus area for us beginning
21 last year, or beginning last year in a big focused
22 way, has been evaluating the impact of selected

1 applications of health information technology,
2 including some strategies that are emerging for
3 sharing healthcare information across settings. Most
4 information in healthcare is enterprise-specific. It
5 stays with the hospital, it stays with the outpatient
6 setting, the nursing home, and so forth. So, our
7 researchers over the years, including those at
8 Dartmouth, have gotten amazingly clever about linking
9 datasets and so forth to essentially follow a patient.

10 One of the big areas focused in the
11 Department's strategic framework is trying to figure
12 out how healthcare information can actually follow the
13 patient as they move from one setting to another, and
14 for Medicare, this becomes incredibly important
15 because there are Medicare beneficiaries routinely
16 seeing seven or eight doctors, who don't necessarily
17 either have a strategy or any easy way to share
18 information, so to say that coordination gets to be a
19 little tricky is a problem.

20 Now, at a policy level, of course, people
21 are talking about IT is transforming healthcare, and
22 that's incredibly exciting to talk about. And

1 Secretary Leavitt will be, I think, at the head of
2 that parade. He's very excited and knows these issues
3 well, so that's really exciting for us.

4 At the ground level, I think what's going
5 on particularly in small practices is we're dying
6 here. We don't know what we're doing. We've tried
7 every trick we know to make practice work, let's call
8 the computer guys. So, our role is somewhere between
9 those poles, trying to figure out which applications
10 are most likely to be successful, and not only how do
11 I make my practice work, but how do we make sure that
12 that leads to improvements in quality and safety. And
13 what I've found fairly stunning recently is hearing
14 from lots of docs who have adopted this and it's
15 great, they love it -- quality. So, we're having a
16 lot of fun.

17 And then the third big area is the
18 evaluating what works and for whom proposition. Some
19 of the specific mechanisms I wanted to make you aware
20 of because we can be available to you for technical
21 support as specific issues come up.

22 First, we have a long history and are

1 very, very proud of our work in data development and
2 analysis. Two big data sources that we have, one is
3 the Medical Expenditure Panel Survey. As you get more
4 and more into the issues of the multiple payers and
5 multiple ways that we deliver healthcare, what has
6 always been stunning to me is that there's really one
7 source of information that can give you national level
8 estimates of all the healthcare that people get. If I
9 go to BlueCross and say "what are you spending" -- I
10 mean, in theory, they can tell me, whether they would
11 or not is another question. Randy knows what Motorola
12 is paying, or other purchasers know what they are
13 paying. This is the only source that actually brings
14 together what employers are paying, what insurers pay,
15 what people pay out-of-pocket, and all the healthcare
16 that they get. So, it's about 15-16,000 households
17 that are followed continuously. If you should be
18 lucky enough to be one of the households in this
19 survey, you are followed for two and a half years,
20 after which, I think you will never be part of another
21 survey. Catherine is laughing because she has some
22 idea of the depth in which these people are

1 interviewed. There's actually one household respondent
2 for the household. For selected areas, we actually go
3 out with supplemental surveys to get information from
4 individuals as well. Very, very rich data source.
5 And to keep economists happy, a lot of this
6 information is verified because, after all, what do
7 people know about what they are paying for healthcare?

8 They might forget, they might get expenses confused
9 across different years and so forth. This is all
10 verified, so very, very rich data source, and we've
11 got a really fabulous team of folks working here. So,
12 that's available for additional analyses, as needed.

13 In addition to that, we have a partnership
14 with 36 States where we work with them and collect
15 their hospital discharge data and make it available in
16 a uniform format. So you get into the intersections of
17 federal and State jurisdiction and healthcare, it's
18 endlessly fascinating, sometimes Byzantine, but even
19 across States, different entity in different States
20 that actually does this, but most States do have
21 hospital discharge data. So, with that much data,
22 there's almost no condition that's too rare. It's also

1 been a platform for us to develop some indicators for
2 improving quality and safety and so forth. And those
3 two data sources among many, many others are the
4 foundation of the report. And I do need to say that
5 we wouldn't have been able to publish either report or
6 produce either report without help from our colleagues
7 and the Assistant Secretary for Planning and
8 Evaluation and across the Department.

9 The second area that is sort of a unique
10 focus for us is what we call "evidence reports". When
11 the agency was first created, there was this tension
12 between learning more about what's going on in
13 healthcare and where we could make a difference, and
14 doing something right now. And that tension persists
15 to this day.

16 When the agency was first created, we were
17 in the business of supporting the development of
18 clinical practice guidelines. Now, this was great
19 stuff, right, it's on page 1 every time a guideline
20 was released, and the first Administrator was quite
21 strategic in his choice of the releases. So the first
22 one I believe was on post-operative pain management.

1 Well, everyone was incredibly excited. Who was for
2 post-operative pain? Absolutely no one. And we have
3 some indication that this actually had an impact on
4 hospitals purchasing and implementing patient-
5 controlled analgesia, which if you've ever had the
6 opportunity to have surgery, just let me tell you,
7 having had one with and one without, huge, huge impact
8 on post-operative pain management.

9 Eventually, we got to slightly more
10 sensitive topics, and I'll just make the story short
11 by saying we got out of the guideline business. But
12 the core systematic review of existing evidence is
13 something that we were consistently told was highly
14 valued by employers, by those providing care, health
15 professional organizations, and so forth, because they
16 didn't have the resources to do this on their own.

17 Ironically, it's become almost a revenue
18 generator for us. I mean, we spend about \$3 million as
19 part of our core budget on these evidence reports,
20 driven by expressed needs of stakeholders in
21 healthcare, but many parts of the Federal Government
22 actually give us money to do them as well. So, when

1 NIH does a consensus conference, that's actually
2 preceded by the development of an evidence report. In
3 fact, the whole structure of the conference is pretty
4 much driven by how the report is framed.

5 This is a systematic review that actually
6 draws as many studies, published and published
7 together, as possible, and evaluates the quality of
8 that work, and then puts out reports. So, recently,
9 for example, there was a report on obesity which found
10 that for people with a body mass index of 40 or
11 greater, surgery is really the only effective option,
12 and then walked people through where we had good
13 information and, frankly, where we needed better
14 information for people in different categories of
15 overweight and obesity.

16 So, essentially, then, what we are doing
17 is trying to identify what are the needs of people
18 providing healthcare, people receiving healthcare,
19 using that to drive the development of evidence and so
20 forth, and that really cuts across almost all of our
21 research programs.

22 I've included some other specific

1 findings, one that I found particularly interesting,
2 was published last fall, looking at the effect of co-
3 payments on underuse of medications for treating
4 chronic illness, finding that many individuals don't
5 want to tell their doctors that "I'm not taking my
6 medication for blood pressure", or whatever the
7 problem may be, "because I can't afford it", so a
8 topic that's of growing concern to lots of folks.

9 In the Medicare Bill that was passed at
10 the end of 2003, we're given a new opportunity to look
11 at the "what works" section, so Section 1013, for
12 those of you who haven't memorized the bill, actually
13 directs the agency to focus research and synthesis on
14 issues affecting the quality, effectiveness and
15 efficiency of healthcare delivered through the
16 Medicare, Medicaid, and SCHIP programs.

17 Now, even at a very high level, you might
18 ask the questions, well, haven't you been doing that
19 anyway, and on some level we have. What's new about
20 this section is that it actually articulates a very
21 clear priority-setting process and directs us to
22 address both are we doing what we know works question

1 as well as where there's two of more interventions,
2 how can you produce information so that people can
3 make informed decisions. So, this is both about
4 developing synthesis and more evidence, but also about
5 communicating that information effectively so that
6 people can make decisions. I told you that I was
7 going to come back to that theme of communication and
8 dissemination.

9 I've included the priority list in your
10 handout. You might look at this list and say, wait a
11 minute, where's HIV, or where's infant mortality. The
12 Department, senior level group in the Department which
13 was the priority-setting community, informed by a very
14 broad call for input across the healthcare system --
15 and, frankly, I was quite gratified by the input that
16 we got, very, very thoughtful detailed input -- the
17 priority-setting group in the department thought that
18 because the Medicare drug benefit was coming online in
19 early 2006, that the initial priority list should be
20 driven by the needs of the Medicare program, so HIV is
21 not on that list, but this list will be updated. It's
22 going to be an iterative process over time.

1 And then at the end of the handout, I
2 closed with a little cartoon about us all being in
3 this together. So, I don't know if I've helped the
4 exhilaration/exhaustion index or continuum here, but I
5 wanted to just give you at least a brief overview of
6 what the agency is up to, how we might be able to help
7 with your work as you go forward over the next couple
8 of years, and would be happy to answer any questions.

9 CHAIRPERSON JOHNSON: I'll start with a
10 question, Carolyn -- actually two -- one is
11 elementary, I think, for some of us, but maybe not for
12 all of us, and that is, would you distinguish between
13 AHRQ, IOM, and the NIH? What's the difference in roles
14 between those organizations? How do you fit in with
15 the other two?

16 DR. CLANCY: Really, really good question.
17 We work very closely with the Institute of Medicine
18 and with NIH, depending on the particular topic and so
19 forth.

20 NIH obviously funds some very, very basic
21 stuff like proteomic and nanotechnology -- notice how
22 that rolled right off my tongue, I'm not sure I could

1 tell you much more about it than that -- but they are
2 clearly focused on discovery of new interventions.
3 Now, at the very applied end of what NIH is doing,
4 they also have reason to worry and, in case they
5 don't, people usually remind them -- Congress in
6 particular -- that they need to be concerned it's not
7 enough to know what works for hypertension, it is
8 indeed we're seeing mortality or morbidity from heart
9 disease and stroke increase and so forth, so the
10 Hypertension Detection and Followup Committee is about
11 30 years old, a very, very concerted outreach project
12 that's led by the NIH, that continues to this day.
13 There's a somewhat younger version that focuses on
14 appropriate treatment of cholesterol and so forth. But
15 because of the way NIH is created, there are 27
16 institutes, centers, offices, divisions. They tend to
17 focus on their specific area, which is fine except
18 that of course -- I guess like disease management
19 programs, many people have more than one of these. So,
20 we're focusing more at the intersections. There's also
21 something of several orders of magnitude of budgetary
22 with them, their budget being in the \$30 billion range

1 and ours -- so we look for leverage opportunities
2 anytime we can.

3 But in the what-works question and how do
4 we get this information out, we found lots and lots of
5 ways to partner very effectively. So, for example,
6 we've created some research networks -- primary care
7 clinicians in practice, and also some networks with
8 integrated delivery systems that are of great interest
9 to the NIH. And next door, we're actually sponsoring a
10 meeting with the Cancer Institute today, focusing on
11 improving the rates of colorectal cancer screening,
12 and one of your colleagues is there. So, sort of a
13 small world. I told them that you were here, and so
14 forth. So, that's where we might intersect with NIH.

15 The Institute of Medicine being part of
16 the National Academy of Sciences, I think has some
17 very unique opportunities in bringing people to
18 consensus and making declarations that are informed to
19 the greatest extent possible by empirical evidence,
20 but there are situations where we simply need an
21 expert group to come together and say "these are the
22 priorities and this is what's important". So, I think

1 that's where the department frequently turns to the
2 Institute of Medicine. So, their reports on patient
3 safety and quality have been enormously helpful to us.

4 They were very helpful to us in giving us advice
5 about how to frame both reports on quality and
6 disparities and so forth. Does that help?

7 MR. O'GRADY: But they're not the
8 government.

9 DR. CLANCY: Yes.

10 MR. O'GRADY: And also there are different
11 times when certainly we find that if you're going into
12 a brand new area and you just need the research done,
13 IOM can't help. I mean, you need pick-and-shovel kind
14 of work done, not a group of 12 experts to come and
15 give you a consensus from the experts, you need base
16 research, going out there and surveying and doing the
17 different stuff. So, it's which tool you bring to
18 bear.

19 CHAIRPERSON JOHNSON: Other questions,
20 comments?

21 (No response.)

22 I have one more. Top of page 8, Working

1 Definitions, the difference between effectiveness and
2 comparative effectiveness. It would seem to me that
3 as we proceed, this could be a real challenging area
4 of discussion to become involved with. Can you share
5 a little bit more of how you're working in this, and
6 any comments that you have for us?

7 DR. CLANCY: Sure. Our budget
8 appropriation to begin this work, and our new
9 authority under Medicare is \$15 million, now those of
10 you who followed the Congress over any period of time
11 will know that the difference between zero and any
12 budgetary amount is huge. Having said that, \$15
13 million is a really small downpayment, given that in
14 part because of advances in public biomedical science
15 as well as what's going on in the private sector,
16 there are more and more innovations coming online all
17 the time, and that's great news for all of us.

18 The problem is, of course, regardless of
19 whether you're talking about consumer-directed
20 healthcare or just any one of us making decisions on
21 behalf of ourselves or our family members, trying to
22 sort through that information is really, really

1 challenging, to put it mildly, because no place really
2 organizes it very well for you. So, it would be nice
3 to think, okay, great, my doctor or other clinician
4 will guide me through this, but oftentimes they are
5 just as clueless. So, any of you who have ever
6 searched for information about health or healthcare
7 know there are two possibilities and everything in
8 between are possible. One is that you get your answer
9 almost right away. You go right on Google, you type
10 in an issue and, zingo, there it is, you're done.

11 Other times you get a little piece of the
12 problem and you keep going to more and more sites, and
13 at the end of an hour you look up and it's like, oh,
14 boy, I've learned a lot of stuff, and I've learned
15 about stuff that people are doing that, oh, my God, I
16 had no idea, but you're not any closer to answering
17 your question than you were when you started.

18 So, I think a big part of our focus in
19 this new authority is going to be how do you organize
20 that information in a way that brings it to bear on
21 people's decisions.

22 Some of that information exists, it just

1 hasn't been organized, in part because the academic
2 structure tends to reward what John Eisenberg used to
3 refer to as "salami science", you know, the narrower
4 the slice, the more publications you can get, and that
5 tends to lead to promotion and tenure. And there's
6 nothing wrong with that inherently, it's just that I
7 would have to say that synthesis and the kind of
8 evaluation that brings it all together isn't as
9 inherently valued.

10 So, through our evidence-based practice
11 program and other strategies, we're trying to do that.

12 Having said that, there's clearly a huge need and
13 growing recognition among healthcare providers and
14 payers that they need this information as well. So,
15 there's been some discussions with the Institute of
16 Medicine and with some folks from NIH and with folks
17 in the private sector about how might we work
18 together, and that's kind of an ongoing conversation,
19 but one that we could certainly keep this group in
20 touch with as we move forward.

21 MR. O'GRADY: Can I give a real quick --
22 just on the nuts and bolts that highlighted this for

1 me as I was sitting in a meeting with an FDA guy and a
2 CMS guy. So we're talking about, you know, is the new
3 drug or the new tech or bio going to come through and
4 whatnot. And the FDA guy goes, "You know, safe and
5 effective, that's the motto of FDA -- safe and
6 effective". And the CMS guy goes, "Well, is it more
7 effective than we currently have, though? Is it more
8 expensive? Is it as effective, but what is its cost?"
9 -- I mean, there's this whole notion -- safe and
10 effective is a great mantra to have if you're the FDA,
11 but once you move to being a payer, whether it's an
12 individual payer or an organized payer, there are
13 these other questions that come up. And certainly as
14 we see this rapid advance of technology, these
15 questions will just come up as rapidly.

16 DR. CLANCY: And I guess the other point
17 I'd make is the area that in this country has been
18 known as technology assessment, and it's defined and
19 operationalized a bit differently in Europe, it's a
20 much broader category of issues in Europe, which might
21 be called clinical evaluation sciences, as they do at
22 Dartmouth, but it includes a much broader range. But

1 in this country, technology assessment, I think, has
2 always been viewed as kind of a gatekeeper function.
3 No innovations will be paid for until people weigh in
4 and look at it, and who wants to be kept away from
5 promising technologies, especially if you're near
6 death and have a very serious illness.

7 So, in essence, we're trying to reframe
8 this effectiveness question as how do you make sure
9 that people likely to benefit get that information and
10 that treatment as rapidly as possible whereas people
11 who are likely to be harmed do not. And I guess
12 Exhibit A here would be bone marrow transplant for
13 people with breast cancer. I mean, this was a fine
14 idea, plausible hypothesis, heavily marketed to
15 patients, many of whom had no other options left, but
16 at the end of the day it go so much hype that it
17 became almost impossible to do any kind of trial. And
18 a couple of payers tried to fund one, but by then
19 people felt like this was an excuse to deny them
20 treatment. By the time the trials were done, it became
21 really, really clear that it wasn't an added benefit
22 and, in fact, we probably managed to hasten death for

1 many women and to help them spend a whole lot more
2 time away from home and family because they were in
3 isolation after the treatment and so forth.

4 So, innovation is wonderful, unless it's
5 harmful. So trying to figure out how we can make that
6 information available for folks, I think, is one holy
7 grail of this whole big, big challenge that you're
8 taking on.

9 CHAIRPERSON JOHNSON: Carolyn, thank you
10 very much.

11 DR. CLANCY: My pleasure.

12 CHAIRPERSON JOHNSON: We will take your
13 invitation to call on you. I'm not sure when, but we
14 will, and we'll look forward to your input.

15 DR. CLANCY: And, really, best of luck to
16 you.

17 (Applause.)

18 CHAIRPERSON JOHNSON: Okay. We've reached
19 the end of our agenda that's formal, but what we'd
20 like to do now is take a minute or two to have Ken and
21 Larry update us on logistics instructions that we may
22 need to hear before we leave and in anticipation of

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tomorrow.

(Whereupon, at 5:06 p.m., the proceedings were adjourned, to reconvene Tuesday, April 12, 2005.)