

Citizens' Health Care Working Group
Portland, OR
Public Listening Session
Friday, September 23, 2005

Attendees

Members

Catherine McLaughlin, Vice Chair
Frank Baumeister, MD
Dorothy Bazos
Montye Conlan
Therese Hughes
Brent James, MD
Patricia Maryland
Aaron Shirley, MD
Christine Wright

Staff

George Grob, Executive Director
Andy Rock
Caroline Taplin
Connie Smith
Jessica Federer

Catherine McLaughlin, Vice Chair, opened the public listening session at 9:00 a.m. She and Frank Baumeister provided brief comments. The indicated that the Working Group's effort would culminate in seeking to "put fire to the feet of legislators" to address needed change in the American health care system.

PRESENTATIONS

Senator Ron Wyden

Oregon led the way, engaging citizens across the state in a dialogue about what they wanted in the way of health care services. Members of the current Citizens' Health Care Working Group are not the usual set of "inside the Beltway" lobbyists, but are citizens with regular jobs who are coming together to find out what Americans want.

We don't have health care in America; we have sick care. We're paying huge checks for care. We need to do more for prevention. Should we do so even if it means taking money from immediate medical care? When the best doctors and hospitals in the country say we can't provide quality care, we need to have a debate in America over what we have and what we want.

Why should the wealthy and the poor pay the same amount for health care? What about the administrative costs? Even (former) President Clinton made a speech recently saying that 35% of the costs were for administration of health. Tax policy needs to be examined to see if we're doing what the people want.

We need this Working Group to ask the hard questions and drive the debate rather than having the debate driven by the people in Washington, DC. Usually it's the powerful lobbyists who are sitting where the citizens here are sitting; this time we've locked out the lobbyists. People have been told before that the sky is going to fall; we have forces at work today that are different. Demographics are a driving force with the imminent retirement of the baby boomers; health care technology is advancing rapidly; and we've never had a bigger gap between the amount we're spending, \$1.8 trillion a year, and what we're getting for it. Our citizens want the Working Group to wrestle with this injustice.

Today (September 23, 2005), the Working Group will hear from some Oregon pioneers about this issue. The next speaker, former Governor John Kitzhaber, MD, has said that decisions about health care in America will either be made at the front door, with the full involvement and transparency for the citizens of the country; or it will be made at the back door, by the powerful interests and lobbyists. Health care isn't just about dollars but it's about values; it's about choice.

Oregon is a state of health care firsts. Here are some firsts with this legislation (that created the Citizens' Health Care Working Group):

- It is a bottom's up effort;
- Nobody has ever been told before where the health care dollars come from and where they go; and
- After the citizens' voice is heard, Congress is required to hold hearings.

Just recently, Congress voted to spend \$60 billion to help employers keep their health insurance; but the American people weren't asked about it first.

I think the country is ready for the work of this citizens' group: if you walk people through the facts; if you ask them questions in a language that isn't "health speak." We want to liberate public opinion.

Former Governor John Kitzhaber, MD

We need change of truly revolutionary scope; we don't have time for incremental change. Zeros matter; our national debt is enormous. While Congress is preoccupied with the gap in Social Security, the real problem is in health care. Congress is focusing on the wrong problem. We need to act definitively and very boldly.

The Oregon health plan:

The story began in 1986 with my first term in the State Senate; in order to comply with the constitutional requirement that we balance the budget, we were faced with the option of

disenfranchising the poor. With the stroke of a pen we dropped 43,000 people, but balanced the budget. It was disquieting. The difference was that I was a physician; it wasn't just a sterile budget exercise. A few months later, I began to see people in the emergency room who had lost coverage. In 1987, the state stopped coverage for transplant surgery by legislative action. A few months later, a child formerly covered by this service showed up. I saw a child die before my eyes of respiratory distress syndrome because he didn't get the care he needed. A few months later Koby Briant died and the media descended on the state for these dramatic circumstances. I saw the debate as one over how we allocated limited resources. The question to me was, "If we're going to spend more on health care, where should that money go?" Where was the equity of selecting a few who needed transplant surgery while ignoring health care coverage needed by many other individuals who were equally in need but in a less obvious or dramatic manner.

It was exactly this question of trying to decide how health care should be allocated that the Oregon Health Plan has tried to address. And this group, the Citizens' Health Care Working Group, is trying to address this question on a national basis.

The major structural flaw in the health care system in America is that our system was built around categorical eligibility—built into Medicare and Medicaid—set up four decades ago rather than based on a system of universal coverage. This discontinuity is the basis of the problem today. We have avoided addressing the questions of: who has the responsibility for paying for the health care needs of people who can't pay for it themselves? The default is that we've let the market decide this and that market is based on making a profit—and the poor aren't a source of profit.

People that don't have coverage eventually get sick and go to emergency rooms where, because of national law, they must be served. These costs are then shifted to other providers who seek funding to cover this uncompensated care. It was this vicious cycle that the Oregon Health Plan was trying to address.

I think that our objective should be to seek health, not health care, per se. Not everyone has the financial assets to pay for their health care. Who should be responsible? Here in Oregon, we sought to establish the principal and practice that the state should have this responsibility. The important aspect of this decision was that it represented a rejection of the concept of categorical eligibility, replacing it with the concept that state support was in response to financial need. Of equal importance was the concept that we would establish this eligibility in statute so that there could not be manipulation of eligibility.

By making these changes, you shift the focus of the debate from WHO is covered to WHAT is covered by establishing the principal of universal coverage. It shifts the debate from 'which' individuals should receive coverage to one of 'which services' should be covered. Then we debate the funding priority for each service rather than who should be covered, and by implication, who should not be covered. Then, we would address the issue of the fact of finite budgets. States must address this issue directly because, unlike the federal government, most states have a requirement that they balance their budgets.

The implication is that people will be limited in some of the care that is made available. This is rationing, and that can be done either implicitly or explicitly. We do this implicitly now—by letting people be dropped from third level coverage. It is like high level bombing because the people making the decisions never have to see the faces of those who are being dropped (upon). This happened in Oregon when an individual wasn't eligible for anti-seizure medication.

Unless we're willing to let people die in the ambulance entrance ramp who don't have health insurance coverage—and no one has yet suggested that we should do this—we're going to pay for the care one way or the other. Our system is irrational because we are not saving any money in our current system.

The Oregon health plan was based on the premise that if health care is going to be rationed, it must be done explicitly on the basis of coverage. The Oregon Health Services Commission was created to address this. Through an open and transparent process, decisions were made regarding what the coverage would be. Physicians were used to provide the clinical advice and volunteers were used to process this information and then a public outreach process was conducted.

The first draft identified 709 types of services grouped into 17 categories. Because prevention was considered important, services such as prenatal care was rated highly. At the bottom of the list were self-limiting care categories, or conditions for which care was considered futile. The legislature was prohibited from altering the order. Provider reimbursement rates were separately set. So the only role the legislature had was to decide what level of spending it was willing to commit to, an obviously and appropriately political process.

The Health Resources Commission, under the leadership of Frank Baumeister, a member of this Working Group, was also based on the same principles, including: equity, accountability, and use of evidence.

We then had to get a waiver from the Federal Department of Health and Human Services for:

- Using a priority list of services rather than categorical eligibility and
- The right to cover all Oregonians whose incomes were below a certain level of income.

The plan ran for 10 years; recently, however, 60,000 Oregonians have lost this coverage as a result of funding decisions made by the State.

Lessons learned from the success and ultimate demise of the Oregon Health Plan include:

- It is possible to build a system based on different principles, as we did;
- It is possible to confront the reality of financial limits, address them, and get reelected; and
- Meaningful reform cannot take place unless the basic structure on the health care system is built is challenged.

This is not just a state or a Medicaid problem; it cannot be changed by a state unless the national system is also changed. We are clinging tenaciously to a 40 year old operating system. Modernizing Medicare and Medicaid is not the same thing as challenging the basic assumptions. There are millions of people entitled to this same health care. It is time to stop defending programs at the cost of not providing care to those who need it.

Discussion

Catherine McLaughlin – How do you think we should balance the tension between what the services citizens say they want and the services that experts say are most valuable at the margin?

Kitzhaber – You can't balance the tension unless you put cost into the equation and also answer the question of who has paid that cost. I don't think we're worrying about private resources; the people who can pay for health care services aren't the system problem. The allocation of public resources is what's at issue here; how do you allocate those public resources? Right now, in this country, we really believe that death is optional. We built a system of health care that maximizes health care one person at a time but then uses public resources to pay for this care; and a lot of people aren't included in this system. You have to ask whether the marginal benefit that we're receiving for one person is coming at the expense of thousands of other people who can't even get into the system. If you ask people what they want, they'll tell you pretty much everything and that doesn't get us very far in the analysis: how are we going to finance it, how assure that there is social justice, how insure equity in the way we allocate public resources? People with more money will always be able to afford more health care, more cars, more of everything. The real problem is that we're subsidizing those extra expenditures with resources paid by people who don't have access to the system.

Brent James – Sweden, Australia and Canada ration care, largely through government policy; it's done largely out of the public view. When you speak of rationing, you imply a multi-tiered or at least a two-tiered system, those who have the private funds to afford services and those who do not. In that context, the medical-industrial complex is only appropriate where people want access to public funds because it so greatly expands their market and they stand to make a lot of money from it; and they often work in conjunction with people who aren't making a lot of money but have very strong personal beliefs or a strong sense of social justice. So you have the moral push of the social justice and the money push of the medical-industrial complex.

Would you comment on the practical politics, in this complex environment, of explicitly achieving rationing of health care? Can we face that issue as a people and how would we go about doing it?

Kitzhaber – I believe you can do it; that's essentially what we did in Oregon. It was difficult; I spent a very unpleasant two years after we had acted in Oregon; I was called "Dr. Death" but I went on to be reelected.

I think people are willing to hear the truth if we tell them. People know there's a problem, but you have to create a framework in which people can make choices. When you loose your job, you don't tell your children they can't eat; you allocate resources differently. The challenge is to have a political leadership that tells us what the choices are and that creates a framework that shows people where they can engage. If you create a great framework, you get good results.

In Oregon, we had a Health Services Commission that didn't determine the benefits. They simply said, based on the framework you provided, here's what the priorities can look like. The

legislature had to make the allocation decision. It was political, it was explicit and they were ultimately accountable to the voters. And you could see exactly what was covered.

You need political leadership that is honest about what is involved. Someone once said, there's no survival value of pessimism. If we can't come to terms with that, then we're going to allow our future to be determined by chance rather than choice because the cost of this "animal" is going to overwhelm us all.

Regarding rationing, here are a couple personal stories that illustrate what needs to be addressed. My son was injured and ended up in the emergency department one of the local hospitals. I was sitting there thinking two things while I watched them with the IVs and the wonderful cardiac monitors and the things that really saved this little boy's life: to get to that hospital I drove through a section of our city that's very prosperous. I couldn't help but ask myself how they can have so much health care concentrated there and so little health care only four blocks away where women can't get prenatal care, where kids don't get immunizations, where young people get shot and where we're losing people because of the neglect and substance abuse. That's a huge contradiction that we need to think about when we talk about rationing. We need to talk about what the system is currently doing.

The second thing that occurred to me is that my mother, at 88, is very frail, had a number of medical complications including a nonspecific indication for inflammation, one of the indications of a neoplasm tumor. The clinical work up in her case would have involved an endoscope and a colonoscope and a whole lot of things that she had no desire to have done. We would have paid for all that, of course. The doctor said, "let's check her blood work in a few weeks and see how she's doing." I said, "why?" I said, "if you're going to continue to check the blood work on an 88 year old woman who has decided she doesn't want a bunch of active interventions—you know, why do it? You're going to continue to find abnormalities and you're not going to change the outcome." What my parents want is to stay in their home. It costs about \$18 an hour for in-home care to allow them to stay in their home. Medicare doesn't pay for that. But it will pay for an MRI, CT Scan, a cardiac bypass, or a transplant, and it makes no sense.

So when we talk about rationing, what we need to ask ourselves is, are we rationing in a manner that is compassionate? Is there a health benefit associated with it? And I think the answer is clearly no. I think the way you deal with it politically, is you've got to somehow tease that out. It doesn't have to be the way we did it in Oregon, but you have to tease it out so it's not just hospital services and doctor services. You have to provide treatment in cases where you can where there are none. I think there's a perfect opportunity to take the next step, which would be to take those conditions that are concrete chronic conditions and do a real evidence-based review to see if there's any evidence to support how we're managing those things and to find was to advance best practice schemes. I think there's a way to do this that will save money—there's more than enough money in the system so we don't have to deny any American the treatment and services for effective and appropriate care. I believe that further, and it's a matter of how you reallocate them. And I think the explicit nature of that will help such proposals survive the political process.

Michael Garland, MD and Ralph Crawshaw, MD

Michael Garland

Professor Emeritus, Department of Public Health and Preventive Medicine
Oregon Health and Science University
Co-founder Oregon Health Decisions
(Also See Dr. Garland's Power Point Slide Presentation)

Oregon Health Decisions was founded in 1982 to foster public participation and access to discourse around the health care system regarding what it could and should be doing. There was a sense that there were difficult decisions to be made and that the public ought to be involved in those hard decisions. We worked with then Senate President Dr. Kitzhaber—who chaired one of our project's steering committees on access issues in health care—about making sure that the public input included community meetings, not just hearings and that there would be an opportunity for discourse that was horizontal as well as vertical up and down the power lines. Since the Oregon Health Plan was formed and launched, we have sat in on follow-up public engagement programs to look at issues and fall-out from the Oregon Health Plan. That has included three random sample telephone surveys in 1996, 2000 and 2004, all of which have reasserted in particular a strong widespread and persistent commitment to Dr. Kitzhaber's theme: universal access being a fundamental fixture or value that has to be fulfilled and a notion that we should be rationing the services that are available, not the people who get access to the services. That's the core of what was done throughout Oregon in addition the importance of cost awareness and personal responsibility

There are 47 communities statewide that comprise the Oregon Health Plan. The idea was to be geographically and demographically comprehensive. Over a 1,000 people participated in the community meetings and discussions. There were 12 statewide public hearings (the traditional public hearing with people testifying) and 1,500 people participated in those. There was a telephone survey using the quality-of-well-being scale to try to get at quantitative judgments of the values that people would give to certain states of well-being; although this approach got put aside eventually. As Paul Starr, in his wonderful book on *Transformation of American Medicine* reminds us, when we start down the path of a dream of reason, we have to take power into account.

For the Oregon Health Decisions' community meetings we were always able to get people out for a couple of hours in the evening, but not for all day meetings. We would have a brief focus on the issue, beginning with a 20 minute slide show. We also had an exercise in which everybody there was divided into small groups where they made individual judgments about some scenarios in health care. Then they discussed the values that were embedded in those individual judgments. Then the values that emerged from that discussion were accumulated for the whole group to see. From all of those 47 meetings, there was further accumulation of those values into a standard list that was forwarded to the Health Services Commission. Several kinds of values were identified and I really want to stress this as you think about your community meetings.

There were some health values: prevention, quality of life, keeping people alive, making sure mental health and chemical dependency are provided for, and having the ability to function. Those were all health outcomes that were very important people. There were economic values that folks thought of when they thought of what makes health care important to them, and that was that the

treatment be effective and that it be cost effective. Another value was that if two things both work, we should get the most cost effective of them. There were also a number of social values that emerged. As soon as you talked about what's important in health care, you can see that we used the health care system to achieve some social values like equity, like the fact that it might benefit many people. Other values were for the exercise of personal responsibility for one's health. Prevention and community compassion actually provided the Health Services Commission with a couple of highs because these weren't on the list of diagnoses and procedures that they were using. People all talked about prevention being very important to them and so the Prevention Services Task Force lists were used. Community compassion focused on the fact that we can't always cure, but it's very important to stand by somebody who is suffering and dying, a lot like the experience Dr. Kitzhaber's referenced. They want to live their life comfortably—to live in their home comfortably, and not just be out chasing another health care treatment.

There are lots of methods of participation and you want to fit the methods to the goals of the outreach. Those goals are to gather information, build a political constituency, and to educate the people. All three of those goals are part of your projected activity and you want to shape the methods of those community meetings to achieve those goals and this is a real design problem. We have found in our work over 20 years that a focus on values is really important. If you think about what health care services people want, I would urge you to try to frame it so that it moves into valued outcomes rather than lists of specific services. We learned that people are much more aware of valued outcomes and able to describe and talk intelligently about those, but will be quite confused about specific services.

The data you gather is going to be both qualitative and quantitative. You want to have both and I'm delighted to hear that you're going to be using surveys as well as community meetings. That's important since surveys allow you to gauge the distribution and the intensity with which opinions are held.

There are a couple of things to be aware of on decision phases that come from a good colleague of ours, Dr. Gary Anderson who is a cognitive psychologist. At the front end of problem structuring, you want to distinguish facts and values so that it's very clear who you're going to ask for the right information and get values from the public, approach experts about facts and probabilities. And the policymakers have to weigh the alternatives. So there's work that just can't be taken from the policymakers and the public outreach can't substitute for that kind of work either; yours or later on, Congress and the President.

Just a final note about something we have learned about public participation over the years is that there are real constraints. In fact, it always has to fit some political process. And so you'll be designing this around the political process that you can hope for; timing has to be right. There's a level of concern. It's important to be able to play into that level of concern in America: the 46 million uninsured Americans who are worried about where they're going to get their next health care. Understanding the issues is important; you want to glean out a better understanding of the issues and a framework that you think will lead to intelligent discussion. Be patient and persistent with the barriers: we have a kind of a weak sense of community; our intense individualism leaves our sense of community rather weak. We have illusions about health care being a private individual

commodity rather than a mutually provided service. Alienation from politics is extreme and cynicism is rampant.

To sum up, in public participation you really want to bring together two things: messages from the public that say what's important to Americans and messages from experts saying how to get the most of what's important to Americans. Finally, the work of policy makers will be to pull together.

Ralph Crawshaw

Co-founder Oregon Health Decisions

The members of the Citizens' Health Care Working Group are in a position to uniquely see what is in America's future. You will each be a changed person from this experience. When you hear from suffering individuals, you can't say "I hear your pain;" you need to say, "I live your pain." The thing that you are not prepared to know is that you will have to use will power; you'll have to use conviction. You have to make it in words and in print, and in your behavior that you believe that you are right in speaking for all the people who spoke to you.

I'd like to close with an ancient parting from the Greeks. They had a way, when they left each other to say: "be strong, grow stronger, be ever so much stronger."

Discussion

Aaron Shirley – How did you conduct community meetings?

Garland – Most of the work involved in running community meetings goes on before the meetings: in recruiting, getting into the local networks, to partner with other groups, in setting up the meetings, in efforts to get enough demographic mix. Because health care is everybody's second or third most important issue, it is difficult to get them to come out for meetings; but those who came invariably stayed late and had to be practically shooed out at the end.

Then, with about 30 or 40 people, we'd have the room laid out so there could be small group discussions at tables with no more than ten chairs at each table.

We had materials to promote discussions among the participants. After about a half hour to 45 minutes, we'd gather material from each table focused on core values and then feed this back to the entire group, sharing this across the entire group so that each group could see what others had said. We put a trained facilitator at each table to keep the discussion going and who would make the report. We would have what we called a graffiti wall where we would put what each table was coming up with so each group could see how it compared to the others.

These materials were then processed centrally and led to the development of the 13 core values we identified—these were distilled from all the millions of comments that were received from all sources.

Pat Maryland – How were you able to take the information you gathered and work with the policy makers to develop the Oregon Health plan and how did you let people who participated in the meetings feel that they were heard.

Garland – We gave feed-back sheets to the participants. For the policy makers, you need front end conversations with the intended political recipients of the information to make sure that what you are providing will be both useful and used by them. In our experience participants came because they believed that someone with their hands on the policy levers was listening. In our case, the intended recipient was the Health Services Commission. So establishing at the front end who is going to be listening and clearly emphasizing that to participants is important in obtaining involvement and attendance.

Montye Conlan – It sounds like you were able to use both quality and quantity information.

Garland – We got qualitative information at the meetings and quantitative information from the telephone surveys. You want them to be complementary so you can say “we heard this at community meetings; I wonder how widely this is shared?” The qualitative data turned out to be very important and was used by the commissioners in their deliberations. They are both important so that you can represent that you covered the range of issues and ways of receiving information. In our federal waiver process, the qualitative data was permitted and the quantitative data was not; so the qualitative data turned out to be very important.

Crawshaw – It’s the qualitative data that starts the meeting; the quantitative may end it. Another thing that came out of Oregon Health Decisions was the formation of American Decisions, 17 states interested in seeking public input regarding the health care system.

Dotty Bazos – How, on a national scale, are we going to get in the news so people will know who we are? We want input and we want the public to know that we are serious about this. How are we going to let the public know that we are taking them seriously? How will we keep them engaged over the long term?

Garland – Invest in a communications campaign; focus on the neighborhoods that you will visit; establish communications outreach (TV, radio, newspapers, etc.); make sure that everybody that comes to those meetings and is willing to give you their name and address and email, that you stay in touch with them and give them feed back. For every meeting, we sent the participants the report that came out of their meeting and had an email follow-up. For everybody that provides a name, address, and Email, you can also send them the interim and final reports with a note that says, “Thank you; you helped create this.”

Crawshaw – Find the local political network and their star performer and get them involved. This is important in validating your role to the Congress.

Garland – Hold Senator Wyden to keeping Congress’ feet to the fire; and let people know that Let people know that this is intended to be an action item. But things are going to happen that you’ll have to compete with.

Alison Little, MD and Ellen Lowe

The Health Services Commission: Prioritizing Benefits

Alison Little

Commissioner on the Oregon Health Services Commission from 1996 to 2002

The Health Services Commission was created by legislation passed in 1989 with the following directive: it was to report a list of health services to the Governor, ranked by priority from the most important to the least important, representing the comparative status of each service to the entire population to be served. The Commission consists of five physicians, a public health nurse, a social services worker and four consumer advocates.

Prioritization was initially based on the ability of the treatment to prevent death, the cost of treatment, and the value factors derived from public meetings and public surveys across the state. These values included such things as a higher priority for maternity and preventive care and a lower priority for limited conditions and those without regular treatment. Today, the prioritized list is a ranking of 710 condition treatments.

The work of the physician commissioners comprised the Health Outcomes Subcommittee, and includes both the mundane and the controversial. Every year codes are added, deleted and modified. These changes must be reviewed and recommendations made for incorporation into the list. The subcommittee reviews action on new technology and considers changes to the list suggested by providers, enrollees and advocates who believe that a service should be prioritized differently. The Commission has responded to requests for a more evidence-based approach by conducting outreach for evaluation of new technology. Some of the changes the Commission has to consider are quite controversial. Sometimes that controversy is external and the Commission has remained remarkably united. In other cases the Commission itself was divided. Here are examples of each:

The first situation was exemplified by the need to incorporate the Oregon Death With Dignity Act which was passed into law in 1997. Although the Act was completely unrelated to the Oregon Health Plan, it still represented a health service available to the population, making it necessary for the Commission to consider it. The Commission was charged with deciding whether and where physician-assisted suicide should be placed on the prioritized list. After hearing hours of public testimony in front of an audience of over 100 people, the Commission voted ten to one to add this service to the comfort care line of the prioritized list. They were unanimous in their belief that services available to the general population of Oregon should also be available for those on the Oregon Health Plan. The lone dissenting vote was from a consumer advocate who was concerned that the law was discriminatory against someone who was so disabled they could not self-administer the medication and be unable to take advantage of it. This public debate provided reassurance that many voices were heard and helped everyone involved to understand the issues better. This service is funded strictly with state dollars and no federal monies.

An example of when the Commission experienced some discord occurred when they considered the addition of a stem cell transplant service to the breast cancer line, also in 1997. Preliminary clinical

trial results showed improved outcomes for women with advanced breast cancer, but waiting for all the randomized control trials was a slow process. Several lawsuits had been filed across the state to force private insurers to cover this treatment, and the Commission sought legal advice regarding state liability in the event of such a suit as well as the implications of covering experimental treatment which was prohibited by rule. Ultimately stem cell transplant was added to the breast cancer line, by a five-to-four vote, but with very strong dissent from the opponents.

I never once heard a physician say that they thought that the content of the prioritized list was a bad one. It is this strong support both from the public and from providers that has made the plan as successful as it is.

Ellen Lowe

Citizen Advocate on the Health Services Commission

There are people in the room today that were present 16 years ago when this system was being set up and they maintain their interest today. We knew that the existing system, including traditional Medicaid, was broken; this was an effort to come up with a better plan. Many people were concerned that the new Oregon Health Plan system would threaten the categorically eligible. They came to the listening sessions and they ended up becoming advocates for the new system.

I reached out to others; for instance, I went to local Laundromats and tried to engage young family members. It wasn't just what the benefits were, but when and where they were available. For instance, dental care was an area we heard about. When asked why dental care was not considered a medical service, I was hard pressed to answer this. Also, the public and many primary care physicians did not agree with the separation of mental health services from physical health. Anything less than full integration of mental and physical was penny wise and pound foolish. People also asked why there was funding for aggressive care but not for palliative care especially during the last years of life during a terminal illness.

Our definition of healing had to be expanded. The lack of data for some services became the impetus for further research and information collection; we didn't use the phrase "evidence-based research," it was not one that was used then, but that's what we were doing. Access has been simplified and specialists more actively involved, and connectivity with other services have been improved. We assure access to specialty care mostly through the requirement that people be involved in managed care and these services are part of the plans.

I believe that the Oregon Health Plan is truly a national resource.

Diane Lovell and Dr. McDonagh

Diane Lovell

Member of the Oregon Public Employees Benefit Board and the Oregon Health and Sciences University Employees Benefits Council

When the Health Services Commission was originally established, there was a lot of resistance from health business groups. We had a very open, transparent, public process of establishing the Commission. Subsequently there were efforts to undermine and abolish the Commission. A significant effort was made to engage consumer groups and advocacy groups, in order to hear from real people. There was a great deal of public testimony.

The Governor promoted the idea about the need for a technical group to advise the Health Services Commission to enable them to provide guidance to the development of the health plan. This effort was about compassionate science to improve the quality of life of citizens.

Because the process was so public, whenever groups, such as the pharmaceutical companies, tried to muddy the waters and confuse the issues, the technical group was able to go back to the public record and clarify what the facts were regarding what medicines were equivalent to one another.

Marian McDonagh

Assistant Professor of Medical Informatics and Clinical Epidemiology, a core investigator with the Oregon Evidence-Based Practice Center and a principal investigator of the Drug Effectiveness Review Project

We had to have a transparent, systematic and unchallengeable methodology and we made sure that the information was very readable from this body of evidence. We wanted to make sure that our researchers had the least potential for bias and had a very high bar to assure that they would not be partial in their evaluation of what constituted equivalent drugs for treatments.

There were multiple meetings with clinical experts. Each drug was looked at asking three questions: comparative effectiveness, harms and tolerability both short and long term. We looked at both these first two questions in different subpopulations (age, comorbidity, etc). We searched online data bases and contacted researchers and companies for literature on research on the drugs and searched FDA information, some of which was very useful, especially on the newer drugs. Then we applied the inclusion criteria: the population who should be included, interventions, outcome measures (health, morbidity, etc), but not intermediate outcomes; and we looked at study results for longer term population outcomes.

We would rate the drugs: good, fair, poor. There would be a report produced on each. From the studies, a cross-comparison table would be created and the development of narrative and, where possible, quantitative analysis (although this was not always possible for cross-category comparisons). A report, with a summary of key evidence, would be produced that was then subjected to peer review and posted on the web for public comment and presented at the subcommittee meetings which were open, for further public comment. Approximately 80 percent of the comments received came from the pharmaceutical industry. About 1/3 of all comments are substantive (the rest are process and other). About 1/3 of these led to changes and improved the quality of the reviews. The Health Resources and Services Administration was also sent this information for comment. Each review is updated approximately every 6 months; that is up to the subcommittee. Things change in medicine; something new may have happened since the last

review; the key questions might have been off target, new evidence comes to light, and new drugs are being added to these classes of drugs.

The key questions, draft reports, and final reports are all posted on public web site.

Catherine McLaughlin – Do you incorporate outcome evidence in your findings?

McDonagh – We present a balance of both value and harms.

Lovell – We are interested in what is effective but also in harms. With new drugs, we don't know about the potential harms, especially the long term impacts.

Christine Wright – Did new drug research get incorporated in your work?

McDonagh – We didn't review drugs until they were approved by FDA.

Lovell – We only looked at public studies.

Pat Maryland – How did you develop a formulary; how do you use that information to help reduce costs?

Lovell – The Health Services Commission advised regarding what were equivalent effective drugs/treatments; then the Oregon Health Plan determined which of equivalent drugs/treatments they would pay for.

Frank Baumeister – This meeting today is unusual because there are no drug lobbyists here. At our meetings of the Commission, the drug companies came from everywhere to assault the program. The airports were busy; we had 25 lobbyists in the state capital one day. Governor Kitzhaber drew a line in the sand creating the physician overseen drug plan in order to have an objective system. There are about 15 states now that are continuing to carry out this effort. In Oregon, the money for pharmaceuticals exceeded the costs for physician and hospital care. When the drugs were reviewed, approximately 100 of them out of about 7,000 were worth the paper they were written on, claims made about the rest were not evidence-based. It is essential to have some objectivity in this kind of effort in order to make some sense of this. The fact that there aren't lobbyists here today indicates that the Citizens' Health Care Working Group isn't being taken seriously yet.

Bruce Goldberg, MD

Lessons Learned from the Oregon Experience:

- You have to believe that you can make a difference and that your work matters.
- Leadership, political muscle, hard work, can make a difference.
- We've improved the health of citizens in the state; charity care in hospitals was reduced, low income individuals had increases in preventive care to keep them healthy.
- Explicit allocation of resources is not only necessary but we have shown that it works.

- A public process is essential for this and it has worked for Oregon; you can harness this by having a public process and then operationalize it where our line of services is now drawn; take that line and extrapolate to the entire nation and you'll save about \$5 billion a year.
- Take that money and you could add more than 2 million adults and/or 5 million children to those covered.
- Evidence is essential regardless of what we choose, we're going to have an unsustainable system unless we pay for what improves lives and reduces costs.
- Delivery systems work; communities have very different systems; communities have been most successful when all the health deliverers come together to meet their community needs.
- Cost shifting (cost sharing) to the poorest individuals reduces their health care; it undermines effective public policy; a few years ago we increased co-payments and coinsurance premiums to the Medicaid to cover more people; our experience is that these policies had a number of unintended consequences including many losing coverage and care.
- No plan is an island; the Oregon health plan is part of larger delivery system; it isn't that unique; the Oregon health plan is part of a larger system that is complex, fragmented; individuals and businesses can't afford it, the number of uninsured is increasing. Losses are because of reduced employer coverage; our system lacks incentives for efficiency and covering more people. The public and private are inextricably linked. Medicaid is neither a problem nor a solution but merely a part of the larger system.

John Santa, MD

(See written comments)

Thanks for doing this; thanks for coming to Oregon; I really love people who do this kind of work, like the people you've heard from today. You must be looking at your task of developing recommendations for improving the health care system and wondering if it's similar to the world that Woody Allen described when he said, "More than any other time in history mankind faces a crossroads. One path leads to despair and utter hopelessness, the other to total extinction. Let us pray we have the wisdom to change direction." Here in Oregon, we don't feel like that. I hope you come away feeling there's a lot of optimism that we can get this tough stuff done.

When I went to work for the state of Oregon, John Kitshaber said to me, "The goal is health, not health services; I don't care about health care. I care about health. And here are the rules: you have to improve equity, figure out value; it has to be transparent. You've got an advantage when you make it public because the other folks aren't used to that. Make what you're doing explicit; don't be afraid to tell people exactly what you're doing."

A researcher went to England and the English were at the same point we are looking at their health care system. The researcher listened in on public sessions and they talked about the same kinds of issues. She observed, "Our next great wave of empowerment is when we begin to think at the population level by asking the public for its views on the health care system: what should our country provide and how should it be paid for. These are no less life-and-death decisions than those made at the bedside....Listening to public voices could help us move our stalled efforts of health

care reform forward in a publicly sponsored and responsible way. Maybe we'll even adopt the tradition of afternoon tea. Worse things could happen."

Mark Ganz

President and CEO, the Regence Group

My company of 5,500; is the largest health insurer in the north-west; we insure over 2 million individuals.

The concept of shared community in health care has been replaced by an entitlement system in which everything happens behind the curtain. Consumers aren't at the center of this system. The focus is among the players in the system, institution to institution. Health insurers negotiate with hospitals, hospitals talk to physicians, insurers talk to physicians, and they all talk to pharmaceutical companies.

My father had a series of ailments that got treated independently of one another until, after several return visits to the doctor for these separate ailments, the doctor finally diagnosed as all relating to a single cause. The health care system is like that; it creates incentives to move people through, to necessarily to spend time with them, not creating relationships, but treating particular conditions in an episodic way and throwing technology at them.

In the hospital that my father had himself done most of his work in and in which he was well liked, when he was there, the most basic human needs were hard to come by. When he was in intensive care he got all the technology that he needed just to keep him alive. But when he was on the medical floor he was made to wait on average 45, sometimes even 60 minutes to just get help to go to the bathroom. Because we could afford it, my parents were able to get a 24 hour duty nurse privately to come and sit in the hospital room to help him with basic needs.

So from a hospital perspective, they make investments related to the many referring physicians who want a particular type of technology to be able to serve their patients. And the hospitals want to keep physicians within their hospital not going to work to somebody else's hospital. So investments are made to try to make sure that there is the right technology. But the attention is not necessarily on the patient. It's on the referring physician. When you have a system where there is not an economic relationship between the patient and their physician or the hospital, you shouldn't expect that the hospital or the physician is going to give the patient the same attention as when there is a direct economic relationship.

It's made worse by the fact that prices are hard to come by. If you want to take control of your own health care and you want to go to a hospital and you want to find out things cost, it's very difficult to be able to find out. One of the local hospitals has a beautiful maternity ward with many nice amenities. However, when I asked five different people, including the billing department, what it would cost for an uncomplicated birth, they couldn't tell me. So, how am I going to be a shopper? How am I going to know when I can't get that kind of basic information?

Although we need to address access, if all we do is change the payment relationship or come up with a novel way to address access to get more people under the tent and we don't create a better

tent, the tent will still collapse. Simply putting more people underneath it will cause it to collapse faster than it already is now. The challenge that we all have is to get at the economic rules that drive this system and change those at the same time we're trying to address access. That is where I think the long-term win is, the long-term gain is.

We have to stop the blame game; stop trying to find who is at fault since we're all at fault. Even my company has been part of the problem. We decided to shift our focus from selling insurance to businesses and brokers to selling insurance to individuals. We also refocused our efforts to measure success away our transactional capabilities and whether how fast, how many of different tasks we accomplished to a measurement system that focused on whether there was a customer satisfied at the other end. Because we had been serving businesses, we had focused on how fast and how many and how efficient we could be. You can look across hospitals, doctor's clinics, pharmaceutical companies, you name it in health care, this system is built today on an institutional wholesale proposition because that's the way the money flows. And what we're working on as a company, and what I firmly believe, is that the answer is to move back to a very clear focus on the consumer, the patient and build our processes around that.

I think it would be a terrible mistake if we embraced electronic medical record technology and use it as an institutional proposition only so that we can continue to play big brother with regard to that information as opposed to building and using the information to give consumers better tools and better information to open up what is now an opaque system to bring light there for individual consumers. One of our key initiatives for next year is to work to build out a personalized health care record, one that the patient owns, not one that is owned by the hospital or governed by a physician. But one that becomes portable and can be highly accessible so that if a patient who lives in Oregon is in Florida and is in a car accident there, they can have access, or their doctor there can have access, to the basic information that will hopefully make sure that they're only treating the conditions that were caused in the accident and not create a new problem, for instance giving a drug that they're allergic to or something else because they simply don't have access to that information. That's just a little example; but the idea is that we build it around the consumer.

Personally, I moved to a Health Savings Account product this year because I wanted to see for myself what it was like to operate without insurance, if you will. The first \$3,000 of any payment that our family needs this year is going to come out of our pocket. It has been a fascinating proposition and I've learned a lot. It has confirmed a lot of what I believe. When I have gone to the doctor I have found that it is very difficult to find out what things cost. And when a doctor wants to order a test, I've challenged them, "Well, why do I need the test? Is there anything in my history that really suggests I need this test?" In a recent encounter with the doctor, after some back and forth, he said "You know what? I don't think this is really necessary." But, had I not had the incentive to ask those questions I may have gotten that service. Also, when I asked him how much the test would cost, he didn't know. When he asked his front office person, she didn't know. So we just made an assumption of how much it would cost and then talked about whether or not there was value in having the test. And we decided that there wasn't.

I think the opportunity is to have those kinds of conversations, where the patient and the physician, the patient and the hospital, are in a direct economic relationship. And through that will come the economic discipline that you see in other areas of health care that aren't subject to a third party

payment system. For example, compare Lasik eye surgery with cataract surgery over the last ten years. Because techniques are better, they're able to do more units in the same period of time than they used to. If you look at the cost to the system of cataract eye surgery over the last ten years, you will see a marked rise that is not that dissimilar to the general inflation rate in health care, which unsustainable, we all agree. Lasik surgery, by contrast, over the past ten years: there are more people doing it, the technology has gotten better, the results and outcomes are generally better, and prices are falling pretty significantly over the last ten years. The difference? One is exposed to a market and has the economic discipline where patients are shoppers and have tools and can get information on pricing and get information on different providers, and the other is not exposed to a market and the economic discipline it encourages. That's just one example of many; if you look to alternative health care providers, you see the same thing. Prices tend to stay at reasonable levels and efficiency gets better. Customer satisfaction is very high because people—rather than operating in entitled fashion—are operating in a market fashion. And the response and the focus of the provider community, in that respect, are on the patient because that's who is paying the bill.

Our company is moving in this direction; we have said that our fundamental business proposition going forward, the value that we have, is to individuals and not to get between the individual and their provider. It's to facilitate that relationship. We are seeking to provide tools and information to help people and members of their family navigate care. We believe that over time this will yield increases in the satisfaction of individual patients by establishing a relationship and at the same time bring more fiscal and economic discipline into the individual relationship, into the point of service.

In the near term we'll probably continue to sell primarily to large employers or small employers or state entities. But our hope is that those entities will also see that the primary value proposition for the long term is focusing on the individual member and helping them become better, more disciplined shoppers of their health care. And that the overall system, as it does in any other market-based system, will respond to that and we will create a more consumer-focused system and one that better controls its costs. The alternative—merely throwing more public money at the health care system or changing who the payer is—is pandering to an entitlement mentality in which we will never have enough financial resources. And given the movement of the baby boomers into retirement years, we will be in for a perfect storm.

Catherine McLaughlin – I'd like to address this question of balance between having the health care system be patient centered (or "consumer" centered, where the consumer responds to incentives as articulated in the presentation) and, on the other end of the spectrum, a more paternalistic setup where it may be the government (or one's personal physician who used to take care of the patient and who got to know the patient and diagnosed the patient).

We have a lot of research from the RAND Health Insurance Experiment—which is the only one we really have on a large enough randomized controlled scale to really understand how people respond to financial incentives, such as mentioned in the presentation—that shows that, particularly for low income participants in that study, when they are faced with a Health Savings Account (HSA) kind of high deductible, they made choices that didn't reflect the good medical advice that they might otherwise receive. They were not able to discern between what was effective medical care and what was ineffective.

The study that is most often cited, involved parents who had children. It found that these parents were just as likely not to take an infant suffering from severe dehydration due to diarrhea to the emergency room as an infant who just had a bug bite or some sniffles. So, when you're thinking about this from your perspective, what is your recommendation of how you would adjust for that in where you're wanting to have more financial responsibility?

Ganz – We first need to determine what we want the overall health care system to be. We need to develop a common vision about where we want to go and see more clearly our individual and institutional responsibilities in the way the system operates. I trust that the average consumer can learn what they need to know to be able to operate more effectively. Under the very paternalistic system we have today, individuals are neither provided sufficient information nor are they enabled or permitted to make their own choices. The role of insurance companies would be best to operate as facilitators to help get the best information into the hands of the consumers. The Rand Study reflects more about what is wrong today rather than what is possible tomorrow. I don't believe that health care is so different that it needs an entirely separate set of rules. The real key is how to bring people that have been subject to a paternalistic entitlement system to something else.

Pat Maryland – What are your thoughts about pay for performance, relating quality to outcomes for the person?

Ganz – I believe a market works when people get rewarded for their performance. I'm somewhat suspicious about pay for performance at the institutional level when one system says they will pay for performance to their standards. It needs to be consumer focused otherwise it's just the warmed over struggles at the institutional level that we have now. It has a short-lived usefulness except as a spur to pay for performance at the consumer level.

Montye Conlan – I'm interested in what you think about people like me with expensive chronic conditions.

Ganz – The system doesn't function efficiently and it is the same system that serves everyone else. If the system doesn't function well, then those with chronic illnesses will be pushed out of the system faster because they need more care than others. It heightens my belief that we need to improve the system; that it isn't enough just to add more money to pay for chronic care.

Montye Conlan – I'm pushed to public health because private care systems don't want me. This private market your describing doesn't work for me.

Ganz – My point is that the system doesn't function as a market today because it becomes implicit rationing.

Catherine McLaughlin – Thank you for reminding us of the counterfactual and that things can keep getting worse if we don't address the systems needs.

Frank Baumeister – Employer-based health insurance is dribbling away; fewer and fewer are offering health insurance. What portion of your business is employer-based and what are you going to do about that?

Ganz – The system needs to be responsive to individuals. Businesses view it in a paternalistic fashion the want their employees to have access to health insurance to keep costs low for themselves and for their employees. There are other employers who just feel trapped because of union agreements or other reasons. That’s why we need to step back and look for a more rational system. I’d like to see employers facilitate rather than dictate health care. We should allow employees to structure their plans for their needs. Ultimately, those who we’re marketing to are individuals, not employers. Rising premiums are a reflection of the cost of the underlying care. Our earnings are a subset of what we take in minus what we pay out. The real focus needs to be on the underlying causes of health care.

Frank Baumeister – Some argue that over 30% of the health care costs are for administrative costs; do you agree?

Ganz – That could only be if you include all the administrative costs, not just insurers’ costs. Ours, as a not-for-profit company are a lot less. Everyone and no one are at fault because no one is accountable. The worst is, you have really good people who create bad outcomes. As you become an expert, don’t start acting like an expert; keep the consumer perspective on this.

Jean Thorne

Former Medicaid Administrator, currently Director
Oregon Public Employees Benefit Board
Public Sector/Private Sector Perspectives

This has been like a trip down memory lane to review all that we’ve done and accomplished here in Oregon. In 1987, the coverage for transplants was continued but the same time coverage for pregnant mothers was enacted. The publicity over the former focused on the underlying issues. In 1988 a much greater awareness came about in Oregon that we really didn’t have a health care policy. People were really astonished to realize this. In 1989 the Oregon Health Plan was passed and the state began a four-year effort to obtain Federal waivers. The state dealt a lot with the issue of rationing. A lot of advocacy groups nationally were the chief critics. The state argued that it was trying to bring rationality to the rationing that was already taking place. The Governor make it clear that he wanted to make a list that would show we gave emphasis to the types of care that would provide the most value to the most people.

In response to the criticism about, “how many people would be left to die,” we answered, “how many people are dying right now?”

Ordinary Oregonians—and Oregon as a whole—was involved in the process. The governor said that the first thing needed was a framework that would enable everyone to understand what tradeoffs had to be made. Despite the original reaction of the national press, it began to receive attention. After the initial denial of the waiver requests, there were 38 editorials from outside

Oregon and 36 of them said that the waivers should have been approved; this demonstrated that we were being effective in getting our message out.

As we implemented the Oregon Health Plan in 1994, there were three things we were doing: changing how benefits were approved, a lot of provider education; moving Medicaid eligibles into managed care plans; and raising the level of eligibility up to the federal poverty level.

We knew it would be messy; that meant constant communications with the managed care plans; we were all in this together, it was going to be difficult. We were in the national spotlight and there were those who were for and against what we were doing. We had 4,000 calls per day rather than 5,000 a month as expected. We thought that new eligibles would take 17 months and would get 70,000 but we got 85,000 in first month. People were calling in tears; people without coverage calling and in tears. We were able to put a face on those without faces. Those looking for rationing stories couldn't find them. The change in the press focus was from what are people losing to what were people gaining. The reason for the success was the success of the list. There were a lot of kinks to work through; there were a lot of advocates involved, especially when we rolled in the Supplemental Security Insurance (SSI) population; there were a variety of people worrying about the needs of people with disabilities. Everyone took great pride; people felt this was an important change that Oregon was involved in.

The list was a tool to force policy choices; it required the legislature to choose that they would provide this much but no more. It allowed policy makers to reduce covered care on a much more rational basis than other methods. What was especially disappointing was that the federal government was unwilling to allow Oregon to address budgetary shortfalls. The federal programs made it necessary for the state to go back to eliminating categories of medically needy. This undercut the viability of the plan. The physicians around the state accepted the legitimacy of the list.

As regards my current role on the Oregon Public Employees Benefit Board: we're the largest employer-based purchaser in the state.

Lessons Learned

- We are all part of the problem
- We'll all have to make some sacrifices
- Need for provider ownership to enact change (this kind of change is messy; the providers can make or break it)
- Importance of credible political leadership
- Stakeholder groups can help (advocacy groups can help make systems better and communicate broadly)
- Responsible media can be a partner (if public doesn't accept the notion that trade offs are necessary, it will not fly)
- Need to get people to focus on the greater good

Challenges

- People come in with preconceived notions (e.g., the competitive model)
- How do we float all boats

- We need all providers to concentrate on the greater good and not just on the bottom line (consumer based approaches won't solve everything; the consumer can't be expected on a large scale to effectively and efficiently manage their care; purchasers can't be expected to manage everything better)
- It is much more complex than a single solution
- Gaining public understanding is difficult; there are limited resources; how do we as a society best spread those resources
- If you don't have at the front end have provider acceptance then you can't get consumer acceptance

Aaron Shirley – What impact did the waiver have on EPSDT?

Thorne – We received one. That program requires that anything that child needed had to be provided; it was a huge issue for the feds since some of those things fell below the line on the list of essential services although we had received a waiver; it was an issue over the treatment end.

Dotty Bazos -- Can you tell me about outcome changes after your plan implementation? Why was the plan enacted now?

Thorne – Increased prenatal care, infant mortality care, on the health policy resources web site. We have no income tax.

Pat Maryland – Some States have moved toward provider taxes.

Thorne -- That's what we're moving toward.

Catherine McLaughlin adjourned the listening session at 3:30 p.m.