

First, let me say what an honor it is to have been asked to contribute to your work here today. My thanks to Senator Wyden, to Dr. Baumeister and to all of you for your commitment of time and energy to this great cause.

Let me also offer my personal thanks to Commissioner Sam Adams and his staff who worked diligently to help arrange the meeting rooms and other logistics essential to the success of this work today.

Before I begin, let me add to what Senator Wyden said about the urgency of this issue. I do not believe that incremental reform will get us where we need to be in time to avert the catastrophe which is bearing down on us. We need change of revolutionary proportion. To impress upon you the urgency of your task, let me quote Denis Hayes, the Executive Director to the Bullitt Foundation in Seattle who puts it this way.

“Zeroes are important. A *million* seconds ago was last week. A *billion* seconds ago, Richard Nixon resigned the presidency. A *trillion* seconds ago was 30,000 BC, and early humans were using stone tools. America's national debt is now \$7.5 trillion, and it's skyrocketing, even as America's population ages.

While Congress is preoccupied with the solvency of the Social Security system, the real challenge is Medicare. The Social Security gap is around \$5 trillion – which is huge – but it is a long term problem and very manageable if we act now. By comparison, with the aging of the baby boomers, Medicare represents well over \$60 trillion in unfunded entitlements.

We cannot afford to wait if we hope to avert what is an enormous social and fiscal crisis confronting our country.

I was asked to give you an overview of the “Oregon Story” – one state’s effort to create a more rational and accountable framework for the allocation of resources for health care. To do that I would like to offer a personal perspective on how the Oregon Health Plan came about, some thoughts about the larger context in which it was developed and the lessons that can be learned from both its successes and its failure which might be relevant to the work of your group.

For me the story began in the spring of 1986 when I was serving my first term as senate president. In the interim – after the full legislature had adjourned – a budget deficit developed, over half of which was due to unanticipated increases in caseload and utilization rates in Medicaid program. In order to comply with the constitutional requirement for a balanced budget the Emergency Board, at its May meeting, rebalanced the budget by, among other things, changing income eligibility criteria for the state's Medically Needy program -- affecting 4,300 poor Oregonians.

I remember being astonished at how easy it was. We sat in a room, looked at some numbers on a piece of paper, took some votes and produced a balanced budget. At the same time, however, with the stroke of a pen, we excluded 4,300 people from the health care system. At the time, of course, none of us considered the fact that we were rationing people. It was simply a sterile budgetary exercise -- but for me it was disquieting. Unlike the other members of the emergency board, I was also a physician.

Five months later, when I was back practicing in my Emergency Room, I saw and treated several people who had lost coverage as a result of the Emergency Board's action in May. In each case, they had delayed seeking treatment for minor problems because of their concern over how to pay for the care. In each case the minor problems had evolved into much more serious ones. I clearly remember a middle aged man with a history of hypertension who presented to the E.R. with a massive stroke after going without his medication for several months.

This experience had a profound effect on me. It substantiated the disquiet I had felt when the Emergency Board had disenfranchised 4,300 nameless, faceless people. Now I realized that they did have both names and faces. They were not just statistics but real people. I began to realize that the fiscal decisions we had made to balance the budget had the effect of limiting access to the health care system for large numbers of our fellow citizens. The seemingly sterile budgetary exercise had very real human consequences -- we simply didn't have to confront them or be accountable for them.

The next year, in 1987, the Oregon legislature voted to discontinue Medicaid funding for major organ transplants – at the time, an optional service. Although this was clearly an explicit social rationing decision, it was uncontroversial and largely unreported in the press -- undoubtedly because

at the time there was no highly visible individual in need of a transplant, something that was soon to change.

The legislature adjourned in June of 1987 but in November Coby Howard, a seven-year-old boy who had acute lymphoblastic leukemia, requested a bone marrow transplant. Although the child was covered by Medicaid, he was not eligible for the transplant under the new state policy. The family turned to private fundraising.

Throughout November, the drama unfolded in the media, which fanned public emotions to a fever pitch, while completely ignoring the larger policy issues involved.

I remembered watching a very premature infant die quietly of respiratory distress syndrome in a neonatal intensive care unit during my internship. The cause of his death -- inadequate prenatal care -- was not as dramatic or as “newsworthy” as the failure to obtain an organ transplant. Yet I knew from firsthand experience that the death of a neonate from respiratory distress syndrome is no less tragic because it is not reported.

Then on Wednesday, December 2, Coby Howard died at Emanuel Hospital in Portland. This was indeed a human tragedy, but it was also a sensational human interest story, and both local and national media seized upon it -- although they had virtually ignored the original decision made by the legislature.

In the wake of this publicity, there was an effort to partially refund the transplant program for eight individuals in immediate need – an effort which, as Senate President, I opposed.

The media saw this as a debate about transplants, but I saw it as a debate over allocation of health care resources. To me, the question was not whether transplants have merit -- clearly they often do. The question was not whether the legislature had sufficient resources to make the appropriation. It did. The question was simply this: If the state was going to invest more money in its health care budget, where should the next dollar go?

What was the policy that would lead us to fund transplants as opposed to further expanding the availability of prenatal care? Is one more important

than the other? What was the policy that would lead us to offer transplants to eight individuals as opposed to nine, or to nineteen? Where was the equity in taking one group of poor Oregonians who were covered under Medicaid and giving them additional services on top of that, before we offered the basic Medicaid services to other equally needy Oregonians who currently were receiving nothing?

It became readily apparent that there was no policy. And while we could easily have funded another eight transplants, we had no way of knowing -- or being accountable for -- the consequences of not using that money to expand access to other individuals who were excluded from the system altogether. And it is precisely this lack of accountability in the way in which we allocate public resources for health care which the Oregon Health Plan was designed to address.

To understand the nature of the OHP and the rationale behind it, it is first necessary to review the underlying structure of the U.S. health care system in which all state reform efforts must necessarily take place.

Perhaps the major structural flaw in the current U.S. health care system is that it was built around the concept of categorical eligibility rather than around a commitment to universal coverage. In other words to be eligible for publicly subsidized health care you must fit into a category -- and those categories were established by Congress with the enactment of Medicare and Medicaid back in the mid-1960's.

The enactment of these two programs left the U.S. with a public private financing system comprised of two major third party payers: the government, through Medicare and Medicaid, and the business community, through employment-based insurance coverage.

However, because our system was built around categorical eligibility rather than universal coverage a huge and growing gap developed between its public and private arms. Into this coverage gap fall those Americans who do not fit into a category: citizens under the age of 65, who do not yet qualify for Medicare; who do not meet the categorical or income eligibility standards for Medicaid; and who are unable to obtain coverage through their place of employment. Today, over 45 million Americans -- including over 600,000 Oregonians -- find themselves in this coverage gap.

The gap exists because we have organized our system around categorical eligibility rather than around universal coverage and thus avoided explicitly answering the most fundamental of questions: who has the responsibility to pay for the health care needs of those who cannot afford to pay for it themselves? Instead we have, by default, left the economic market to answer the question for us.

But markets are designed to turn a profit, not to foster social responsibility so it should come as no surprise that no one competes for people who cannot pay. In fact, in today's market-oriented terminology, people with a payment source are referred to as "market share" and we compete for them. Those who cannot pay are referred to as "liabilities" and, as you know, we seek to avoid them through adverse selection and cost shifting.

The ability to cost shift serves as a kind of pressure valve in the system which reduces accountability – and, thus, the political pressure needed for meaningful reform. And here is how it works. When those without coverage get sick enough, they go to the emergency room where federal laws like EMTALA require that they be seen and treated. But the resulting uncompensated cost is simply shifted to both public and private third party payers through incremental increases in their premiums or their bills.

The third party payers, in turn, shift this cost back onto individuals. States manipulate income eligibility to reduce the number of people covered by Medicaid; while employers drop people from coverage altogether or increase co-payments and deductibles which shifts more out of pocket expenses to employees.

And as more and more people cannot get timely access to primary care in the community they are forced back to the Emergency Room and the uncompensated costs are then shifted back onto the third party payers repeating the cycle. And it was this cycle – and the implicit rationing that goes along with it – that we were trying to address with the creation of the Oregon Health Plan.

As I mentioned earlier, during the two day debate over the Oregon transplant program, I kept asking myself: "If the state is going to invest more money in its health care budget, where should the next dollar go?" The answer, of course, depends on what we were trying to accomplish with that investment which raises a very fundamental question.

Is the objective our health care system to ensure that our citizens have access to health care, or is it to ensure that we can keep our citizens healthy? It is clear to me that our policy objective is – or certainly should be – health not just the financing and delivery of health care. Health care, after all, is a means to an end, not an end in itself. It has no intrinsic value outside its relationship to health, except as an economic commodity – which, unfortunately, is pretty much how our current system views it – and that, of course, is a big part of the problem.

Clearly, access to some level of health care is needed for individuals to remain healthy – yet the fact remains that not everyone has the financial means to pay for their own health care needs which gets us back to the question of who has the responsibility to do so?

We attempted to explicitly answer this question in the Oregon Health Plan by establishing that the state would assume responsibility for financing the health care needs of those with an income at or below the federal poverty level. In retrospect, particularly given the cost of health care today, one can certainly argue that we should have set income eligibility at a higher level – perhaps at 150 percent of the poverty level, or even at 200 percent.

The important aspect of this decision, however, was that it represented a clear and conscious rejection of the principle of categorical eligibility. We believed that the sole criteria for determining eligibility for a public subsidy – at least in the Medicaid program -- should be financial need, not a set of categories created decades earlier. Of equal importance was the fact that we proposed to establish this eligibility criteria in statute thus making it difficult for it to be arbitrarily manipulated -- thus depriving the legislature of one of its primary tools of implicit rationing.

By clearly defining the public sector responsibility in terms of eligibility we were able to significantly shift the focus of the debate from who is covered to what is covered – from eligibility to benefit. Thus, instead of debating which individuals should receive funding for a given service – and, by implication, which individuals should be denied -- we would instead ensure that everyone had access to health care and then debate the funding priority assigned to each specific service available.

Establishing priorities through an open, explicit and accountable process was the centerpiece of the Oregon Health Plan and it was based on a clear-eyed recognition that we were dealing with public resources and that public resources are ultimately finite. States, unlike the federal government cannot simply push their difficult fiscal choices into a budget deficit for our children to deal with. Most states must operate within a balanced budget which means that the resources that can be committed to health care – as opposed to education, public safety and other priorities – are limited.

What does that mean? It means that health care rationing in some form is inevitable. If public budgets are constrained by fiscal limits – and we are thus unable to purchase everything that might possibly benefit each individual -- then it follows that people who depend solely on public resources to finance their health care will necessarily have limits imposed on how much health care will be paid for.

There are two basic ways in which health care can be rationed: implicitly and explicitly. Today, with no explicit policy of universal coverage, most health care rationing is done implicitly by dropping people from third party insurance coverage. This is the most insidious and impersonal kind of rationing which is based on no policy and is utterly void of accountability. It is like high level bombing where those making the decisions never see the faces of those who suffer because of them.

Let me give you a tragic case in point. In February of 2003, in order to save money, the Oregon legislature discontinued prescription drug coverage for the Medically Needy Program – an implicit rationing decision very similar to the one I had participated in back in 1986. And the result was every bit as tragic. As a consequence of this decision, Douglas Schmidt, a man in his mid-30's suffering from a seizure disorder was no longer able to afford to purchase the medication, which controlled his seizures. He was still eligible for Medicaid, but the program no longer covered the cost of prescription drugs. He subsequently went into a sustained grand mal seizure and ended up with severe brain damage and on a ventilator in a Portland hospital. He remained in the hospital for several months and was then transferred to a long-term care facility where he finally died in November 2003 when life support was withdrawn.

Now, the cost of his anti-seizure medication was \$14 a day. The cost of his care in the intensive care unit was over \$7,500 a day – a total bill of \$1.1

million – all of which was billed back to the state Medicaid program. So the legislature did not save any money by its decision on the contrary, it increased its fiscal liability and, in order to absorb it was forced to drop more people from coverage – perpetuating this kind of human tragedy and fiscal disaster.

My point is simply this: we are going to pay these costs one way or another – either implicitly or explicitly. And by failing to do so explicitly the cost will ultimately be much higher in both economic and human terms.

Think about it. Douglas Schmidt died because of political and budgetary expediency based on a policy which says, in effect, that we will not pay pennies for medication to manage a seizure disorder in the community, but will pay hundreds of thousands of dollars to keep an individual on life support after his uncontrolled seizures caused severe brain damage.

It is a policy that says we will not pay to manage hypertension in the community, but we will pay to care for the victim of a massive stroke in the hospital; that we will not pay to provide all pregnant women with good prenatal care, but we will pay to resuscitate their 500 gram infants in a neonatal intensive care unit. And this should not be acceptable to any of us.

The Oregon Health Plan was based on the premise that if publicly financed health care must be rationed, it must be done explicitly and accountably and it must focus not on people but on benefit levels based on their relative value and effectiveness in producing health. This, in turn, required that we be able to establish priorities through the creation of a framework for evaluating the effectiveness and appropriateness of the health services being purchased.

To carry out this responsibility the Oregon Health Services Commission was created consisting of five primary care physicians, a public health nurse, a social worker, and four consumers. Through an open and transparent process specific services and treatments were prioritized according to their clinical effectiveness and on the basis of their social value. Physicians provided the necessary clinical information and judgment, volunteering thousands of hours of their time to do so, while social values were determined through an extensive series of town hall meetings conducted across the state. You will be hearing more detail from subsequent speakers about the work of the commission as well as the community outreach process.

The first priority list, completed in February 1991, consisted of 709 condition/treatment pairs (appendectomy for acute appendicitis, bone marrow transplant for leukemia, antibiotics for bacterial pneumonia, etc.) which were grouped into 17 categories. The categories were prioritized on the basis of the social values gleaned from the public outreach process while within each category, the individual condition/treatment pairs were prioritized on the basis of their clinical effectiveness.

Services in the highest category were those for acute fatal conditions where treatment prevents death and returns the individual to their previous health state (such as an appendectomy for appendicitis). Because of the high value placed on prevention by those participating in the community outreach process, the category of maternity care (including prenatal, natal, and postpartum care) and that of preventive care for children ranked very high. Also ranked high, because of the social value placed on compassion, was hospice care.

At the bottom of the list were categories of services for self-limiting conditions, futile care, and services that had little or no effect on health status.

The final priority list was given to an independent actuarial firm which determined the cost of delivering each element on the list through capitated managed care. The list and its accompanying actuarial data were given to the legislature.

Since the legislature is statutorily prohibited from altering the order of the priorities as established by the Health Services Commission, it was required to start at the top of the list and determine how much could be funded from available revenues and what additional revenues would be needed to fund an acceptable "basic" package. In this way, the question "what is covered?" was directly linked to the reality of fiscal limits.

Before I comment briefly on the fate of the Oregon Health Plan and the lessons it has to teach us I want to say that the same principles around which we built the health plan are also reflected in the Health Resources Commission and its work which you will be hearing about later this morning. Equity, transparency, explicit decision making, accountability, value and the use of evidence continue to serve as the guiding principles for

the Health Resources Commission and for the Center for Evidence Based Policy at OHSU which has continued the systematic evidence review of major class of prescription drugs first started by the Health Resources Commission

Now, let me conclude my comments on the Oregon Health Plan. To implement our program we required waivers from the federal government because the plan violated Medicaid policy on a number of levels. First, we would be establishing a covered benefit through the use of a priority list rather than by simply relying on the services mandated by the program. Second, we would be covering poor Oregonians who – although their income was below the federal poverty level – did not fit into a federal category. We wanted federal matching dollars for these “new eligibles” who did not fit into an existing Medicaid category.

After first being denied in August of 1992 by the Bush Administration, the waivers were finally granted by President Clinton in March of 1993 and the Oregon Health Plan was implemented on February 1, 1994.

After a ten year run – during which time over a million Oregonians benefited from the program – the Oregon Health Plan was largely dismantled in 2004 when the legislature in effect eliminated coverage for the new eligibles who came into the program under the waiver I mentioned earlier. Since then over 60,000 people have lost coverage and sadly enough Oregon is moving back toward the old system of categorical eligibility, implicit rationing and huge cost shifting which were the very problems the plan was designed to address in the first place.

While you will be hearing more from other speakers about the history of the Oregon Health Plan over the last decade, I want to take a moment to touch on the lessons it has provided – both from its halcyon years and from its ultimate demise.

First it has taught us that it is, in fact, possible to develop a clinically and politically defensible priority list and to use that list to establish a covered benefit.

Second, it has taught us that it is possible to confront the reality of fiscal limits and to assume accountability for the difficult choices which those limits make inevitable.

Perhaps the most important lesson, however, is that meaningful reform cannot take place unless the basic structure of the U.S. health care system is dramatically revised – unless we are willing to openly challenge the underlying premises and assumptions on which it has been built.

The demise of the Oregon Health Plan was not simply due to the depression, the budget deficit and the lack of funding. It was also due to the larger system in which it existed – by the fact that we were trying to bring about meaningful reform within the constraints and contradictions of a fatally flawed federal structure. This is not a state problem; it is not a Medicaid problem – it is a national problem, a system problem -- and it cannot be resolved at the state level without fundamental changes in the structure of the federal system in which states efforts must take place.

How long would Microsoft last if Bill Gates held onto a ten year old operating system; or a five year old system; or even a two year old operating system? We are clinging to a forty year old operating system and wondering why we cannot meet the health care challenges of the 21st century.

What we are doing is nibbling around the edges. “Modernizing” Medicare and Medicaid is not the same as challenging the underlying assumptions of these programs themselves. Certainly there are many poor elderly citizens who need and deserve publicly financed health care --but there are also many poor children and poor working adults who deserve the same yet who are entitled to nothing.

It is my hope that this Working Group will provide the leadership necessary for the Congress to realize that it is time to stop defending programs at the expense of solving problems and that we cannot successfully meet the challenge which this crisis poses continuing to allow our thinking and our reform efforts to be constrained by a 40 year old eligibility and financing structure which reflects the realities of the mid-20th century.