Oregon Puts Bold Health Plan on Ice

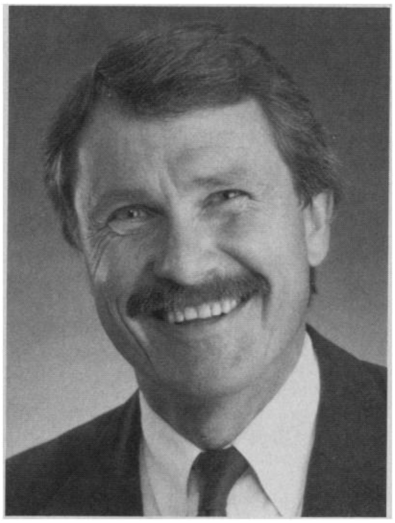
Widely touted, though controversial, the state's revolutionary effort to contain health care costs by prioritizing procedures is back on the drawing board

"I LOOKED AT THE FIRST TWO PAGES of that list and threw it in the trash can," says Harvey Klevit, a Portland, Oregon, pediatrician and member of the Oregon Health Services Commission. "That list" should have been a proud achievement in Oregon. After all, it was a first—and very bold—step toward rationing Medicaid dollars in an era when one patient with little hope of survival can soak up millions simply because no mechanism exists for making hard choices in allocating funds. Indeed, the problem of providing the greatest benefit without increasing taxes is now plaguing every government agency, national or local, that funds health care.

Oregon's commission thought it had the solution. And so did all the newspapers, magazines, and television stations that covered the commission's announcement last May. A means had been found, the stories went, to assign a cost-benefit rating to nearly 2000 medical procedures. The basis of the list was a mathematical formula. All that had to be done was to feed piles of data into a computer, and the machine would respond with a list of procedures, carefully ordered according to their cost-benefit ratios.

Sounds great. But the list the computer actually spit out last May left the 11 commissioners reeling. Take thumb-sucking and acute headaches. Treatments for these problems ranked higher than those for cystic fibrosis and AIDS. Immunizations for childhood diseases did not appear. Deeply embarrassed, the commissioners hastily withdrew the list, and 3 months later Oregon appears to be no closer to a second version. The current prognosis: a revised list is not expected until some time in the fall.

While commission members dismiss the first draft's failure as unimportant ("Anything you do the first time isn't perfect," says Klevit, "it's like Edison's light bulb."), it does indicate the complexity of the problem they face. Few people disagree with the idea of providing some form of basic health care to all. But in an era of shrinking financial resources and soaring medical costs, the question becomes just how basic is "basic"? And who decides? The traumatic Oregon experience might serve as an object lesson for the entire nation in the complexities of trying to simultaneously achieve equity and contain health care costs.



Plan's champion. *State senator (and emergency room physician) John Kitzhaber of Oregon.*

Today, Americans spend nearly $540 billion a year, or 11.1% of the gross national product, on medical treatments. As the price tag climbs, programs like Medicaid suffer. Its costs have risen 10% annually over the last 10 years. Last year alone, $61.3 billion went to Medicaid, $34.6 billion in federal funds, $26.7 billion in state monies. Not surprisingly, many states are seeking ways to cut those expenditures. But Oregon is the first to actually suggest a concrete reform plan, and from California to Washington, D.C., health care professionals—and politicians—are keeping a close watch to see how the Oregon experiment turns out (see story on facing page).

Oregon's search for a better way to deliver health care began in 1987 after its cash-strapped legislature halted Medicaid funding for most organ transplants, arguing that they were a high-cost procedure that benefited only a very few. The money was funneled instead into prenatal care, a move that two other states, Virginia and Arizona, have also taken. Initially, the legislature's decision received little attention. But its first victim was a 7-year-old named Coby Howard. Ineligible for state funds for a bone marrow transplant, he died while his parents were pleading for contributions to finance the operation.

At least four other children and one adult who might have been saved by organ transplants have died since the legislature's decision. As a result, the Oregon legislators have been faced with angry advocates for the poor, lobbyists for transplant patients, and citizen groups favoring socialized medicine—all demanding a new way of distributing the Medicaid dollars. In the president of the Oregon Senate, John Kitzhaber—himself an emergency room physician—they found a sympathetic ear.

Arguing that "there must be universal access for the state's citizens to a basic level of health care," Kitzhaber drafted three bills, which the legislature passed last June. One bill addressed the health care of Oregon's poorest citizens; the second made the private sector responsible for the health care of people whose income was higher than the federal poverty level; and the third established an insurance pool to provide coverage for people unable to qualify for private insurance. Together, the three bills were designed to weave a health-care safety net assuring every Oregonian of basic medical care. At the same time, physicians and hospitals were promised full reimbursement for the services they render—putting an end to a practice which often sees providers receiving 70% or less of their fees.

But the quid pro quo here was that the state would no longer finance all medical procedures—only the ones that had the highest ratio of costs to benefits. Which is where the first version of the famous list came in. "It's a step from an inequitable position to one that is more equitable," says Kitzhaber. "What we're doing now, nationally, is rationing poor people, so that some have access to health care and others do not. But then you have situations where 35 people die from measles. To me, that is outrageous." Instead of limiting the number of people who are eligible for Medicaid, Kitzhaber would reduce the services that each recipient gets. "We need to change the debate from who is covered to what is covered."

Congress created Medicaid in 1965 to provide health care to the poor; the federal and state governments would share its cost and operation. But millions of poor Americans do not qualify because each state sets its own eligibility standards, adjusting them annually to match their budgets. Alabama currently has the most stringent standards: a family of two qualifies only if it earns less than $88 a month, or 13% of the federal poverty level of $700 a month for one parent and one child. In Oregon, a family is eligible if it earns less than 58% of the federal poverty level, or approximately $400 a month. Because eligibility requirements can be raised, a family can be supported by Medicaid one year and dropped the next—subjecting citizens to a devastating medical roller coaster.

Under the new system, this practice of "forcing more and more people under the table," as Kitzhaber calls it, would come to an end. Instead, Oregon would enroll everyone eligible for Medicaid but restrict access to treatments at the bottom of the list: those that are, according to some measure, most expensive and least effective. State officials estimate that this will add 77,000 people to the current 130,000 now receiving Medicaid benefits. Another 300,000 people would be covered by the private sector. The Health Services Commission list—in its final form—will serve as the guideline for deciding which treatments are funded and which are not, for both Medicaid and private insurance recipients.

Oregon's Plan Comes to the Capital

In Washington, just mentioning the idea of rationing health care charges the political atmosphere. Oregon's proposal to ration its Medicaid services—by means of a list of medical procedures ranked according to the "net benefit" they provide—is no exception. From the time that Oregon issued its preliminary list in May, there has been a sharply partisan, political reaction in Washington.

With the exception of Oregon's bipartisan congressional delegation, members of Congress have reacted to the rationing plan along party lines. Democrats worry that the plan unfairly targets the state's most politically vulnerable citizens—children and poor women. Republicans, on the other hand, like it for its innovative qualities and presumed fiscal austerity.

But why should anyone care what Washington officials think? The answer is that Medicaid is a federal program with strict eligibility and care requirements. Oregon needs waivers of some of those rules to put its plan into effect—and other states that are thinking of following suit may be influenced by whether Oregon is successful in obtaining waivers.

Under Medicaid law states are barred from refusing medical services to eligible individuals, but, through the use of a ranking system, Oregon proposes to restrict the treatments it will cover. And by expanding coverage for poor families while restricting their benefits, Oregon would violate a requirement that families receiving federal aid through the Aid to Families with Dependent Children program automatically receive full Medicaid coverage as well. Altogether, the state is seeking waivers of nine separate Medicaid regulations, which can be granted either administratively through the federal agency that manages Medicaid or legislatively through Congress. The state is pursuing both avenues, although the legislative route is running into political trouble. Last year, for instance, Senator Bob Packwood (R–OR) attempted to attach a waiver provision to the legislation reconciling the entire federal budget. A Packwood aide calls that move "entirely non-controversial."

But the waiver was dropped in a House-Senate conference when congressional leaders agreed to strike non-germane provisions from the bill. And Packwood's maneuver still rankles among the plan's opponents. "This was not appropriate in a procedural sense," says an aide to Representative Henry Waxman (D–CA). "You don't make a major change like this without hearings and investigation, and there just wasn't time for any of that."

But far more than procedural issues are at stake. "If you're going to ration health care, you do it across the population, not just for poor women and children," says Waxman. "The state says it's making the tough choices, but politically it's not making a tough choice at all." At the heart of Waxman's argument is the fact that poor women and children—the only ones whose treatments would be restricted under the plan—make up 70% of Oregon's Medicaid population but receive only 30% of the state's Medicaid budget. The rest of the Medicaid population is composed of the blind, elderly, and disabled. Those groups are a much tougher target because they have potent political lobbies, according to Children's Defense Fund analyst Sara Rosenbaum.

But the plan's congressional supporters aren't discouraged. Oregon's reform "might provide a lifeline to those who now fall between the cracks in our health care system," Packwood and Representative Ron Wyden (D–OR) wrote in the *Washington Post*.

For now, both the legislative and administrative waivers are stalled until Oregon revises its priority list. And, says an aide to the Senate Finance Committee, Congress is in a wait-and-see mode: "Most members are keeping their mouths shut until they see what the final list looks like. Then they'll say whether they're opposed or not."

■ **DAVID P. HAMILTON**

But as the commission, along with Kitzhaber and his allies, discovered, deciding how to rank health care treatments is no simple task. The procedure Oregon hit on combined community values—as described by Oregonians themselves—with a mathematical technique for estimating costs and benefits (see box, page 470). "We attempted to assess what value a community places on health, what types of care it deems important," said Michael Garland, a bioethicist at the Oregon Health Sciences University and president of Oregon Health Decisions. OHD held 47 public meetings throughout the state, and conducted a telephone survey, asking participants to rank a variety of health situations in terms of "quality of well-being."

These findings—which indicated that Oregonians generally favor preventive health care—were then mathematically correlated with cost-benefit data for various medical procedures to produce the controversial list. The ranking method clearly needs revision. How much revision is needed is a matter of debate, however. Some commissioners favor keeping the mathematical formula, while others believe the list needs a human touch and should be done by hand. Nevertheless, says Harvey Klevit, "We can make it work. It's just going to require some more time."

Yet complex as they are, the problems with the list are only part of the political, ethical, and financial quagmire in which the state of Oregon now finds itself. None of Oregon's Medicaid reforms can be implemented until the state receives a federal government waiver that would allow the state to cut some types of care for the "categorically needy" in order to add more people to the program. The state has sought the approval of the U.S. Department of Health and Human Services and Congress.

In so doing, it has run headlong into Washington's lobbying process and found itself outflanked and outgunned. Several groups, notably the Children's Defense Fund, the American Academy of Pediatrics, and the National Association of Community

Health Centers, have spoken strongly against granting the waivers. The state does not have funds for a full-time lobbyist, and Kitzhaber's own trip to Congress was, he says, "one of the most depressing experiences" of his life. His opponents, he says, were "more interested in berating Oregon for not raising taxes" than they were in discussing the problems besetting Medicaid.

Ironically, the plan's critics argue that the scheme will work against exactly those whom it is intended to help, the poorest and most defenseless part of society—in particular, poor women and children. "Whether or not it's Oregon's intention, the only people who will have prioritized, rationed health care are the women and children who are currently covered by Medicaid," claims Molly McNulty, a health specialist at Children's Defense Fund. According to CDF and other critics, this is because one of the federal waivers would allow Oregon to redirect its Medicaid monies, except for those funds spent on the elderly, handicapped, and blind. The services these people now receive would remain the same. But 70% of the state's Medicaid dollars go to those three groups. The remaining 30% go mostly to women and children. Rationing the Medicaid dollars of women and children to expand

Listing to Starboard: The Oregon Formula

Under the proposed Oregon health care plan, Medicaid's services (as well as the health insurance provided by small businesses) will be ranked according to their net benefits—a method that theoretically should offer the greatest benefit to the greatest number of people. But trying to determine the net benefit of 2000 medical procedures has proved to be more daunting than the Oregon Health Services Commission initially envisioned.

At the heart of the commission's reform package lies a highly regarded mathematical ratio. Called the "net benefit value ratio," the formula weighs the benefits of a medical treatment against its financial costs—a balancing act that seems ethically tricky at first glance. Who, after all, are better judges of the benefits than the physician and patient?

Yet it is possible "to define some common unit of what constitutes a benefit," says Robert Kaplan, a professor in the Division of Health Care Sciences at the University of California, San Diego, who, together with his colleagues John Anderson and J. W. Bush, designed this ratio 18 years ago. Their formula reduces the benefits of a medical treatment—its probable result, its duration, and its value on a "quality of well-being scale"—to one figure. This figure is weighed against the cost of the treatment, producing the net benefit.

In Oregon, data for the formula were gathered by the commission from physicians and the general public. Physicians were given a list of various medical conditions and asked to do three things: prescribe a treatment for each, predict the treatment's effectiveness, and estimate its cost. For the "quality of well-being" values, the commissioners turned to the overall Oregon community. At 47 public meetings, they discussed the idea of health care, seeking a state-wide consensus.

"A number of themes emerged at these meetings, with prevention of disease ranking as number one and quality of life number two," said Michael Garland, a bioethicist at the Oregon Health Sciences University and president of Oregon Health Decisions, which helped collect the data. The commission also conducted a random telephone survey of 1000 Oregonians, asking them to rate such health situations as "You can go anywhere and have no limitations on physical or other activity, but have a bad burn over large areas of your body," on a scale of 0 to 100, with zero being death and 100 good health.

It all sounded great, but in several instances, the project went off the rails. Ironically, perhaps, the input of the average citizen—the QWB values—seems the most solid to the commissioners. The medical costs cited by the physicians are largely incorrect because they do not reflect the number of office visits a particular treatment requires. As a result, certain "self-limited diseases," such as acute headaches and thumb-sucking, ranked higher on Oregon's initial priority list than AIDS treatments, for example. Why? Because they can be treated relatively easily at a low cost and the benefits last a long time. "The duration of the treatment had the greatest impact on a disease's rank," said Paige Snipes-Metzler, the executive director of the commission. "It's not what we wanted and we're reviewing that data as well as the costs."

Formula's father. *Robert Kaplan came up with the math underlying Oregon's list.*

The technique's godfather, UCSD's Kaplan, claims he isn't surprised there were hitches in this first, large-scale effort to apply his formula. The formula, he points out, has been used primarily on a theoretical basis and in smaller clinical trials (for example, the QWB scale has been used to measure the health of burn patients at the UCSD Medical Center), but never on such a large scale.

"Oregon is taking a very bold step," says Kaplan. "The idea has been in the literature for some time, but they [the Oregon officials] are taking it far more seriously than I thought they would"—a decision that both pleases and worries him. "I think the formula provides a good way to think about health care priorities—that is what it is designed for—but there are difficulties with the way Oregon is doing it."

Kaplan actually went up to Oregon and had a talk with the folks who are putting together Oregon's famous list. He discussed the problems with people at Oregon Health Decisions—in particular the fact that the state's method of determining the outcome of each specific medical treatment is vulnerable. "In the best of all possible worlds, you would have clinical trials [instead of clinical judgments] to determine the efficacy of each treatment," he says. "But that would take you 30 years to do, by which time the treatments would be obsolete."

Still, Kaplan argues, what the state is attempting to do will result in "a net benefit of health for all," and disagrees with those critics who charge that the plan will harm rather than benefit children. "If our model works correctly, children should do very well because the emphasis is on prevention, and the benefits from whatever treatments they receive will last many years." But right now, that remains a big if. ■ V.M.

the program to include another 77,000 people is, say the critics, grossly unfair.

The critics think that along with the rationing program a tax increase of some sort is necessary—an idea that raises difficulties in a state where there is tremendous resistance to new taxation. "The Oregon politicians want you to believe that they can give health care to all the poor, pay the providers for the cost of doing this, and not raise taxes. But in reality, you can't do all these things, and it's disingenuous to say so," says Maxwell J. Mehlman, director of the Law Medicine Center at Case Western Reserve University, where a special conference was held in June to discuss the Oregon proposals.

In Mehlman's eyes, the Oregon plan will simply take services from the poorest people, "people at the bottom of the barrel," in order to give to people who are only slightly better off. "It's a zero-sum game," he claims. Kitzhaber disagrees, arguing that to him "the most vulnerable people in our society are the uninsured." and those are the folks that the plan would cover. Unlike the critics, he expects women and children to benefit most because of the emphasis on preventive care. Nor does he worry about finding additional funds. He believes that once all Oregonians are involved in health care policy—through voting and participation in formulating the list—they will be more willing to increase funding if necessary.

"Health care will no longer be just a line item in the budget, where you can throw people out of the system to balance the bottom line, and then hold no one responsible for what happens to them." Under his plan, Kitzhaber sees citizen advocacy groups pressuring the legislature to increase funds for health care if the budget provides only skimpy coverage. He is also optimistic enough to think that wasteful spending in medical services will be identified by the Oregan rationing plan and eliminated.

Yet until the commission produces the final version of its much criticized list and the waivers from Washington come through, much of this debate will remain academic. Without the list, no one can predict just how Oregon's plan will affect the health, or pocketbooks, of its citizens. Nor are there any promises that situations like Coby Howard's won't occur again. Overall, Oregon's exercise in rationing may be seen as either a grand experiment or a crazy aberration. But if nothing else, it has stirred the pot in a national debate that won't go away: health care reform.

■ **Virginia Morell**

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NIH Sued Over Misconduct Case

Investigations conducted by the National Institutes of Health into alleged scientific misconduct have long made a convenient punching bag. For years, a small band of critics has charged that investigative panels move too slowly, ignore important evidence, and shut whistleblowers out of the process. These days, it's more common to hear complaints from lawyers and the targets of investigation themselves, who complain that NIH's Office of Scientific Integrity (OSI), which conducts the investigations, confuses investigation with adjudication and provides its subjects with little or no due process (*Science*, 20 July, p. 240). Who's right? It may soon be up to the courts to decide. NIH's investigative procedures are about to face an acid test—a legal battle over whether NIH affords the subjects of such inquiries their constitutionally guaranteed rights.

Claiming that a protracted OSI investigation of fraud allegations threatens his reputation, neurologist James H. Abbs of the University of Wisconsin filed suit against the OSI and a handful of officials in the Public Health Service on 12 July. Abbs claims the investigation violates his right to due process because OSI can recommend any sanction short of the most severe punishment possible—debarment from receiving NIH funds—without allowing Abbs a hearing or affording him any opportunity to confront his accusers. According to court papers filed in the case, Abbs is seeking a preliminary injunction and a judgment dismissing the entire investigation as "constitutionally deficient."

At the center of the controversy are three graphs in a 1987 paper Abbs published in the journal *Neurology*. These graphs compared the lip, jaw, and tongue tremors in healthy patients with those in patients suffering from Parkinson's disease. Shortly after publication, a former graduate student in Abbs' laboratory named Steven Barlow noticed that these graphs bore a striking resemblance to smoothed versions of three graphs he and Abbs had published in an earlier paper in the *Journal of Speech and Hearing Research*. Barlow then widely distributed a letter to *Neurology* accusing Abbs of illicitly copying the graphs.

Like many such misconduct investigations, the resulting NIH inquiry into Abbs' work is replete with stumbles, missed cues, fits and starts of enthusiasm, and retraced footsteps. In 1987, NIH formally accepted the report of a University of Wisconsin investigation that found Barlow's allegations "unsubstantiated." Then, in April 1988, Charles McCutchen, an NIH scientist with a personal interest in scientific fraud, presented the NIH office responsible for the investigation with a statistical analysis in which he claimed the odds of a chance correspondence between the graphs were one in a billion. Within 2 weeks NIH was reviewing McCutchen's analysis for "soundness," and several months later the agency decided to convene a panel of external statistical experts to examine the graphs themselves. This panel apparently disagreed with the earlier dismissal of Barlow's charges, and by last February OSI deputy director Suzanne Hadley informed Abbs that OSI was pursuing a formal investigation.

Abbs has long maintained that the graphs contain data taken from separate patients. Unfortunately for his defense, Abbs no longer has the original data. He says he produced the graphs by hand, tracing oscillograph signals and then cutting up and photocopying his traces, a process in which he often discarded the original data. Abbs does argue that the apparent similarity of the graphs can be explained by the fact that parkinsonian patients exhibit a "characteristic instability" or by artifacts introduced by the measurement apparatus. Furthermore, Abbs says that another set of data taken from one of the original patients closely resembles the published data, providing "strong counterfactual evidence" that supports his case.

The Abbs case is unusual in at least one respect—it has been fought out in public, in a sharp exchange of letters between Abbs and his critics published in *Neurology* in March 1989 and January 1990.

Some NIH critics believe that a suit like Abbs' was bound to occur sooner or later. "It was a foregone conclusion that someone would challenge the rules, or rather, lack of rules at NIH," says Robert Charrow, a former Department of Health and Human Services attorney. OSI officials, on the other hand, express confidence in their investigative procedures. "We have substantial due process rights," argues OSI director Jules Hallum. "The burden of proof is always on the scientist whose data is challenged." But even Hallum doesn't believe that existing procedures are fixed in stone. "We're evolving—we've only been in existence for 15 months. There may be changes in the procedures as we go along."

A hearing is scheduled in U.S. District Court on 2 August.

■ **David P. Hamilton**