

most serious and pervasive disabilities, the government must significantly increase its investments in welfare, employer subsidies, and job training. But such measures are matters of distributive justice, and the fact that they are not among the remedies mandated by the ADA suggests the limitations of the anti-discrimination model upon which the current law rests.

Nevertheless, the specific provisions of the ADA on employment, transit, and public accommodation reflect, in Chief Justice Earl Warren's famous phrase, "the evolving standards of decency that mark the progress of a maturing society." To say that the question of fair treatment for people with disabilities does not have an obvious or final answer is not to say that we cannot reach a consensus on what fairness requires at our level of affluence and technological development. The ADA represents a major step towards achieving such a consensus.

— David Wasserman

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Defining Basic Benefits: Oregon and the Challenge of Health Care Reform

On March 19, the Clinton administration approved Oregon's proposal to extend Medicaid benefits to thousands of poor people who are currently ineligible for the program while limiting Medicaid coverage of health services to include only those that are judged to be most effective. The Medicaid reform is part of a larger plan designed to assure access to health care for all of the state's residents. The Bush administration had rejected an earlier version of the Oregon proposal, ruling that it violated provisions of the Americans With Disabilities Act (ADA). But Bill Clinton endorsed the proposal

during the presidential campaign, and in February he promised the nation's governors that he would be open to innovations in the Medicaid system, which operates with state and federal funds.

The decision to allow implementation of the Oregon proposal comes at a time when a White House task force is developing a national health care reform plan. The two goals of this task force are the same ones that Oregon officials have been pursuing since their own reform process began in 1989: to secure health care for all citizens and to gain control of rising health care costs.

The Health Care Crisis

As Mr. Clinton has repeatedly observed, the current problems in the American health care system affect not only the poor and disenfranchised, but also many people who once took affordable health care for granted. According to the Kaiser Commission on Medicaid, about 36 million Americans have no health insurance. Working people are continually joining the ranks of the uninsured — as their employers drop health plans, as they lose their jobs, or as those with preexisting conditions are turned away by insurance companies. Workers who are insured, and their employers, are feeling the pain of rising health care costs, as more and more of the burden of paying for health care shifts to private payers.

The President has framed the health care issue in human terms, speaking with empathy of people he has met who are without insurance or fearful of losing it. He has also emphasized the impact of the health care crisis on long-term economic strength. Rising health costs make it more difficult for American businesses to compete globally and are driving much of the expected growth in the budget deficit. Federal spending for Medicare and Medicaid was \$200 million in 1992, and is expected to double by 1998; the two programs account for 46 percent of the projected increase in federal spending from 1992 to 1998.

Hidden Costs and Necessary Choices

At first glance, the two goals of national health reform — universal coverage and cost containment — might appear to be at odds. It would seem that covering more people will cost a great deal more money than we spend now. But under the current system, people with health insurance are already paying for the care provided to those who don't have insurance; the costs of that care are being passed on, routinely and invisibly, in the form of higher insurance rates and higher fees for medical services. Such cost-shifting also occurs whenever the government cuts Medicare or Medicaid reimbursements, which is why such cuts offer only an illusion of savings. Universal access would allow us to control costs we can't control now because the system is so fragmented. It would also allow more people to receive preventive and primary care before their health conditions became serious and costly to treat.

As one way of containing costs, most reform plans that provide for universal coverage, including the Oregon plan and the "managed competition" model that Mr. Clinton is likely to propose, require the formulation of a basic benefits package. What we call "basic benefits" are those that we think any decent society would offer to all its citizens. Because the

idea of excluding some health services from coverage is a political land mine, the talk surrounding basic benefits has often been less than precise: even as politicians endorse the idea of a basic or core benefits package, they tend to indicate that nothing will be left out of it. In his campaign manifesto, *Putting People First*, Mr. Clinton promised that "every American will be guaranteed a basic health benefits package that includes ambulatory physician care, inpatient hospital care, prescription drugs, basic mental health... [and] expanded preventive treatments. We'll provide more services to the elderly

Because the idea of excluding some health services from coverage is a political land mine, the talk surrounding basic benefits has often been less than precise.

and disabled by expanding Medicare to include more long-term care."

In true campaign style, this statement seems to have something for everyone. More recently, in a televised town meeting on February 10, Mr. Clinton suggested that there is enough administrative waste in the current system to fund all care, including a government long-term care program. His use of the phrase "basic benefits" seemed to imply, in the end, *all* benefits.

And yet, inherent in the word "basic" is the notion that not all medical services would be universally available under the plan. This, after all, is what makes a basic benefits package a cost-containment measure: it embodies a recognition that perhaps we cannot afford to provide all possible care to all people. And as soon as we ask what services *won't* be provided, we find ourselves confronting a complex ethical problem.

Oregon faced this problem head-on when it decided to amend its Medicaid program; and as a result of its efforts to develop a reform plan, it now has the most comprehensive experience of any state in constructing a basic benefits package based on clearly articulated principles. This experience holds important lessons for health care reform on the national level, since the question of how a basic benefits package should be constructed is likely to be a subject of continuing debate, even after the White House task force makes its recommendations.

The Oregon Approach

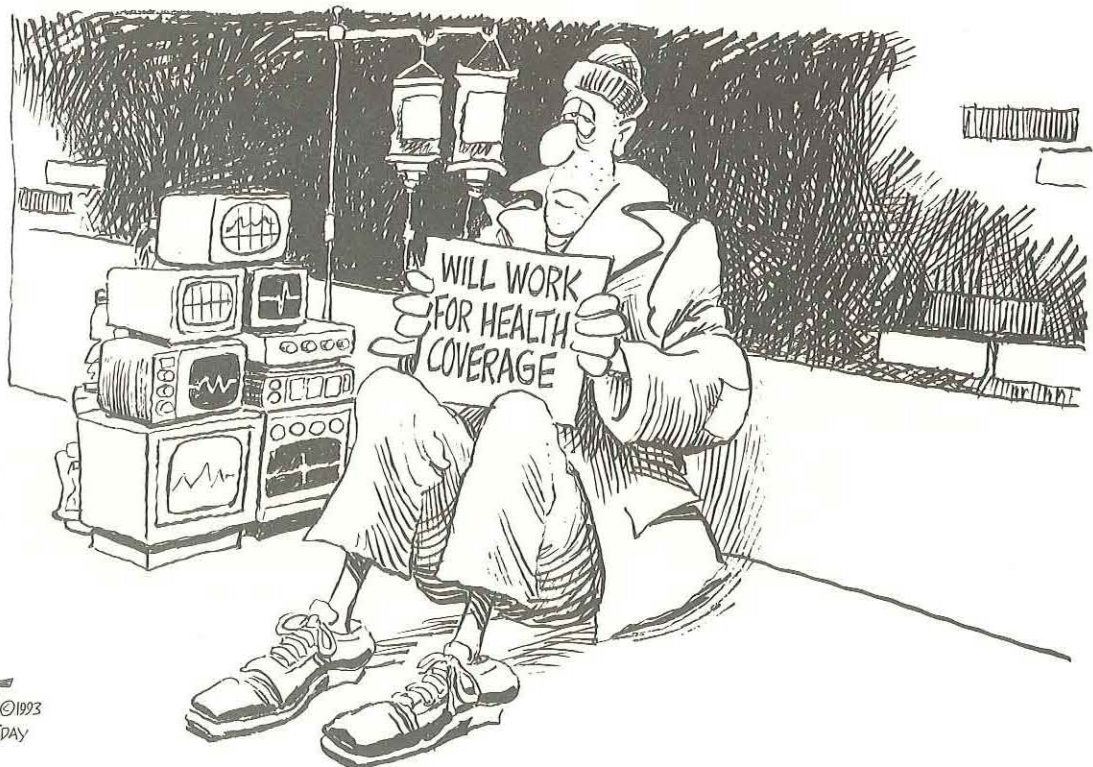
From the beginning of its reform process, Oregon's view was that the current system rations health care according to ability to pay. Such rationing is not explicit, but instead is the result of decisions about things other than health care benefits, such as the distribution of insurance coverage and provider reimbursement. The baffling categories of Medicaid eligibility are also a form of rationing, allowing some citizens to qualify for care but not others.

The Oregon plan will reform this system by bringing all citizens with incomes below the poverty line into the Medicaid program, increasing the number of eligible residents from 240,000 to 360,000. (At present, fewer than half of the poor people in the state qualify for Medicaid benefits.) However, in order to help finance this extension of coverage to more people, the state will restrict its Medicaid funding of health services to those that are most effective. It will not cover some services that are of limited benefit, and it will add others (hospice care, for example) that Medicaid does not cover now.

As Oregon set out to formulate its basic benefits package, it asked citizens to articulate community values that would guide the process, and gathered health experts' assessments of the effectiveness of

particular services. After a series of revisions in methodology, a state commission prepared a prioritized list of these services, and the state legislature agreed to fund 568 of the 688 items on that list. Oregon will require private employers to offer this same basic benefits package to an additional 330,000 workers and immediate family members who currently have no insurance, and it will create an insurance risk pool for otherwise uninsurable Oregonians.

In future years, if the state faces budgetary pressures, the legislature can vote to fund a smaller portion of services. This feature of the proposal came under sharp criticism last year from Sara Rosenbaum of the Children's Defense Fund, who argued that there was no assurance that the legislature would continue to finance an adequate level of health care for the state's most vulnerable citizens. Oregon responded by noting that under its proposal, the legislature could not save money by cutting *people* from Medicaid, as many states currently do. More recently, Gov. Barbara Roberts has promised that for the first two years of the program, the funding cutoff will not be lowered below #568, and the Clinton administration has said that any future cutbacks in service coverage must be approved by the Department of Health and Human Services.



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Doug Marlette, New York Newsday

Ranking Health Care Services

In its first attempt to develop a prioritized list of health care services, the Oregon commission looked at three categories of data and combined them into a formula for ranking medical treatments for specified conditions: 1) expected clinical outcomes of condition/treatment pairs; 2) net cost of these treatments; and 3) public values concerning various health states. The data on expected clinical outcomes were gathered from expert practitioners and researchers across the country. Public values were gleaned from a telephone survey in which respondents gave relative rankings to various health states.

In May 1990, the commission ran these three sets of data on a computer and came up with a ranking of

The pursuit of equity and efficiency in allocating health care resources inevitably collides with other competing values.

services based on measurements of how cost-effective they were. But this approach often led to non-sensical results. For example, almost everyone would say that an appendectomy is more important than tooth capping: though the latter procedure may relieve suffering for a great many people, appendectomies save lives. But since an appendectomy costs about 150 times as much as tooth capping, it ranked below tooth capping on Oregon's first list.

As David Hadorn, one critic of this approach, observed, the pursuit of equity and efficiency — the most health for the greatest number of people at the lowest cost — inevitably collides with other competing values. These values include what ethicists call the Rule of Rescue: our perceived duty to act when an identified person's life is threatened and it is possible to save it. Although some analysts proposed alternative methodologies that would still have kept cost as a factor in determining what health services to cover, Hadorn concluded that the commission should consider *only* the net benefit of services, without regard to cost.

The Oregon commissioners largely agreed with Hadorn's view, and in revising the first list they all but removed cost as a factor, relying instead on net benefit as the primary basis on which to evaluate health services. The commission also developed a set of categories that describe types or degrees of health benefit. The highest-ranking category was

"Treatment of acute, life-threatening conditions, where treatment prevents imminent death with a full recovery and return to previous health state." The lowest-ranking category was "Treatment of fatal or nonfatal conditions with minimal or no improvement in quality of well-being or life span." The commissioners assigned each of the condition/treatment pairs to one of the categories, and ranked them within categories according to their degree of net benefit. In this ranking scheme, where cost was no longer a significant factor, expensive but effective lifesaving treatments that may have been at the bottom of the first list moved up higher on the second. Those treatments that provide little benefit, or whose effectiveness is uncertain, were at the bottom of the list.

Finally, after this second list was generated, the commissioners made adjustments in the rankings in response to the views expressed at citizens' meetings concerning health care priorities. They gave added priority to preventive measures, moved maternity care services higher on the list, funded some services for reasons of compassion, and denied funding for conditions that get better on their own or for which a home remedy is sufficient. At this stage in the process, the commission allowed cost to be a minor consideration in some cases.

In response to citizens' views, the commissioners gave added priority to preventive measures, moved maternity care services higher on the list, and funded some services for reasons of compassion.

Characterizing Treatments and Outcomes

Oregon's revised list, which was completed in August 1992, met some of the objections that had been brought against the earlier scheme, but it also continued to meet with criticism. In his evaluation, David Hadorn argued that the condition/treatment pairs were not defined in sufficient detail to take different types of patients into account. For example, in determining whether breast cancer is "treatable," the commission did not distinguish among different cell types and stages of breast cancer, or among all the different treatments for the disease (chemotherapy, surgery, radiation).

Hadorn believed that it was possible to fine-tune the scheme so as to remedy this flaw. But other critics weren't so sure. They wondered whether the subtleties of case-by-case medicine can be reflected in official definitions of conditions and treatments. Won't there be patients who would receive a signifi-

cant net benefit from treatment, but whose claim to services will go unrecognized because their specific condition hasn't been adequately differentiated on the list? If so, then does the cost of overlooking such cases outweigh the gains in equity and efficiency produced by use of the definitions?

As the federal government's recent creation of the Agency for Health Care Policy Research suggests,

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increasing attention is being focused on the development of clinical outcomes data that would be nuanced and reliable enough to assuage such concerns. Many policymakers, including Mr. Clinton, have called for a larger investment in outcomes research. But experts agree that most of the data now in hand are not yet adequate to distinguish appropriate from inappropriate care, and it is unclear when and if they will be adequate to provide a basis for making coverage decisions. On the other hand, some supporters of Oregon's approach have pointed out that case-by-case medicine yields a significant amount of inappropriate and harmful care, and so should hardly be held up as an ideal standard against which clinical guidelines based on outcomes data are to be judged. They argue that it would be folly to wait for "perfect" guidelines before implementing reforms that would improve the current system.

Evaluating Different Health States

In creating its prioritized list of services, the Oregon commission acted on the view that some health services are more effective than others, and that effectiveness is measured by the benefit a service produces in terms of improved functioning and/or life span. In order to measure this improvement, Oregon placed a value on different health states. It did so by conducting a telephone survey in which Oregonians were asked to rank such states, including various physical and mental impairments, on a scale ranging from perfect health to death. These ratings were then used, along with the clinical outcomes data, to calculate the net benefit resulting from treatment (as opposed to non-treatment) of each condition on the commission's list.

It was Oregon's use of the telephone survey data that provided the grounds for the initial rejection of its Medicaid proposal. The Bush administration argued that the quality of life experienced by persons with disabilities is systematically undervalued by others who do not share their condition. As a result of this bias, treatments of particular importance to persons with disabilities were said to have received unfairly low rankings on the prioritized list. The Bush administration therefore found that the Oregon proposal violated the ADA, which says that "No qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity."

This aspect of the first Oregon proposal raises both legal and ethical questions. The ethical question is: does the assignment of differential values to particular health states treat persons with disabilities unfairly? The legal question is: does the ADA trump any attempt at reform that includes judgments about outcomes of medical procedures?

It is certainly true that the values placed on different health states affect the probability that persons with disabilities will receive treatment. The philosopher Paul Menzel describes a trade-off that persons with disabilities face in these circumstances. The

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lower their initial health state is rated in the survey, the less likely persons with disabilities are to receive *lifesaving* treatment, but the more likely they are to receive treatment that would *improve their condition*. On the other hand, if the functional state of persons with disabilities is rated almost as high as that of the non-disabled, that will improve their position in competition for lifesaving treatment, but treatment that would improve their functioning will no longer be as high on the list.

In his analysis of the first Oregon proposal, Menzel argued that persons with disabilities were underrepresented in the statewide survey, and that therefore

the reform plan was discriminatory. It is persons with disabilities, Menzel wrote, who should decide whether they want to make the trade-off between lifesaving and condition-improving treatment. Furthermore, he argued that it is dangerous if ratings of functional states "represent some people rating other people's lives — especially lives of which they know little and whose conditions they never anticipate sharing."

David Hadorn disagreed with Menzel's criticism. He wrote that "Oregon was correct in surveying generally healthy citizens... because the inevitable biases

Some scholars maintain that it is impossible to average the perceptions of persons with and without disabilities in order to produce a valid valuation of outcomes.

of [acutely ill patients] would hopelessly confound the rating process." But it seems unreasonable to describe the views of people with disabilities as inevitably biased and therefore unworthy of consideration. If we are to construct a basic benefits package that rests on clinical outcomes and that values those outcomes differentially, it is not only more valid, but ethically imperative, to include the perceptions of persons with disabilities about their own conditions.

Some scholars, however, maintain that it is impossible to average the perceptions of persons with and without disabilities to produce a valid valuation of outcomes, and that a social policy based on such an average would be unethical even if the views of people with disabilities were fairly represented. Although Oregon officials continue to believe that an average of citizens' perceptions provides legitimate grounds for making coverage decisions, their revised proposal no longer proceeds on that basis.

Lawful Reasons for Excluding Services: Oregon and the ADA

A passage from the Bush administration's analysis of the Oregon proposal goes to the question of whether the ADA makes it *illegal* to consider clinical outcomes data in allocating coverage for health services. In formulating its list of services, Oregon was free, the analysis said, to "consider, consistent with the ADA, any content-neutral factor that does not take disability into account or that does not have a particular exclusionary effect on persons with disabilities." However, "a decision not to cover a treatment based *entirely* on the existence of a disabling condi-

tion... would violate Title II of the ADA" [emphasis added].

In support of this distinction, the Bush administration cited the 1985 Supreme Court case *Alexander v. Choate*, in which the Court ruled that Tennessee Medicaid could shorten the length of hospital stay that it would pay for, even though that action might have a disparate impact on persons with disabilities. In that opinion, the Court found that there is a difference between a factor that has a disadvantageous effect on some persons with disabilities, and one that contains a bias against persons with disabilities as a class.

One aspect of the Oregon proposal that received extended discussion in the Bush administration analysis will further illustrate this point. Oregon initially ranked liver transplants for patients who are alcoholics at #690, below the funding cut-off, while it ranked transplants for non-alcoholics at #367, well above the cut-off. The Bush administration claimed that this difference in ranking seemed to rest "entirely on the basis of a disabling condition (alcoholism)," and therefore violated the ADA.

But Oregon officials say that the presence of a disabling condition alone was not the deciding factor in their original ranking. The state commission, they

There is a difference between a factor that has a disadvantageous effect on some persons with disabilities and one that contains a bias against persons with disabilities as a class.

say, acted on the basis of data indicating that patients with alcoholic cirrhosis of the liver have poorer outcomes from transplants than patients with other kinds of cirrhosis. Subsequently, the commission learned that it had been misinformed: the outcome of liver transplants is not actually related to the underlying cause of the cirrhosis. But it is true that an alcoholic patient who continues drinking after a transplant is more susceptible to recurrence of the disease than a non-alcoholic or a rehabilitated alcoholic. That is why, for example, the Medicare program makes coverage of liver transplants for alcoholic patients contingent upon "evidence of sufficient social support to assure assistance in alcoholic rehabilitation." Such a policy does not deny transplants to alcoholic patients because they are alcoholics, but rather because their disability diminishes the ultimate likelihood of success for that particular treat-

ment. If Oregon were to adopt the same policy, it would not be violating the ADA. In fact, though, its new list includes coverage of liver transplants for all patients with cirrhosis of the liver.

In response to the Bush administration's concerns about quality-of-life judgments, Oregon has removed assumptions about the value of different health states from its methodology. It did so by discarding the results of its telephone survey and by dismantling the list of categories assigning values to various degrees of health benefit. In the latest ranking scheme, condition/treatment pairs are initially ranked based on the probability of preventing death. If two items tie, they are then ranked based on the probability that the patient will return to an asymptomatic state. If there is still a tie between two items, the one that costs less receives the higher ranking.

Finally, Oregon's revised proposal offers coverage for a number of treatments – intensive care for extremely low-birthweight babies, for example – that were not covered on the initial list. Though some groups representing persons with disabilities were satisfied with these changes, more than 70 advocacy organizations joined on March 18 in submitting an appeal to Mr. Clinton, urging him to reject the Oregon proposal. Clearly, the danger of discrimination in a program designed to allocate coverage for health services is one of the lessons that Oregon's experience, and the reaction to it, has made explicit.

The Prospects for National Reform

As Oregon's long struggle to win approval of its reform plan suggests, there are ethical and technical problems, as well as political ones, with explicit refusal to fund even minimally effective treatments as a means of controlling costs. Even the Oregon plan, as approved, funds almost all effective services. The state expects to save only about 3 percent of its Medicaid costs over time. However, it will realize additional savings through the introduction of managed care and the new mandates requiring employers to provide health coverage to their workers. As a result, although the Medicaid program will now increase the number of people it covers by 50 percent, the reform plan as a whole is budget-neutral.

If there is to be any limitation at the national level on the use of health services, it will probably be accomplished at first through methods less direct than denying coverage for particular services. One such method, common in other countries, is global budgeting – a form of "supply-side" rationing which would limit the availability of health care resources, including expensive technologies. For example, doctors and hospitals with fixed budgets could no longer

buy as much state-of-the-art diagnostic equipment (such as MRI machines) as they do now. A smaller supply, in turn, would limit utilization of such costly services. Another method is to rely on managed care to reduce the provision of inappropriate and harmful treatment, which by some estimates accounts for one-quarter to one-third of all care. Outcomes data and resulting clinical guidelines are likely to be used in this way before they are used to make coverage decisions on a national basis.

Since Oregon submitted its original proposal in 1989, this country has come a long way towards recognizing the inequities in the health care system and the need to limit health care spending. Whatever its shortcomings, the Oregon plan is the first to go beyond rhetoric to define a basic benefits package. Although a national health care reform plan enacted in the next year or two is unlikely to imitate Oregon's approach, denial of coverage for some beneficial services is inevitable in the long run. New technology and an aging population ensure that less controversial cost-containment measures will only temporarily slow the rise in health care spending. Sooner or later, Americans will have to decide just what they view as basic health care.

— Jane Forman

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