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**[¶ 40,406A] HHS Papers Explaining Rejection of Oregon Medicaid Waiver.**

*HHS News Release, Secretarial Letter, and Analysis, Aug. 3, 1992.*

**Medicaid: Rejection of Oregon's Comprehensive Waiver**

**Oregon—HHS rejection of comprehensive waiver.**—Reproduced below are HHS papers explaining the federal government's rejection of Oregon's proposal to waive Medicaid requirements in order to implement its "Oregon Reform Demonstration" under § 1115 of the Social Security Act. The project would have enlarged the state's Medicaid program while excluding care to certain presently covered, disabled or chronically sick individuals under a priority scale ranking health care

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procedures. The project was rejected primarily because it would have discriminated against disabled individuals and would thus have violated the 1990 Americans with Disabilities Act.

See ¶ 14,625, 15,630.

[HHS News Release, Aug. 3, 1992]

HHS Secretary Louis W. Sullivan, M.D., today ruled that final approval for Oregon to make extensive changes in its Medicaid program cannot be granted until the state's proposal is altered to protect persons with disabilities.

"The Administration continues to encourage innovation in state health care programs, but at the same time we are determined to protect the rights of Americans with disabilities," Secretary Sullivan said. "The Americans with Disabilities Act, which was passed with the President's strong support and which went into effect last month, leaves no question that those with disabilities must enjoy the same treatment under the law as other Americans. Oregon's proposal does not meet that test, and we must return it for further work."

The proposed changes to Oregon's Medicaid program require government approval because they do not conform to current legal requirements for the federally-funded, state-administered health care program for the poor. Under its waiver request, Oregon would assign rankings to the various medical treatments and would remove Medicaid coverage for some treatments identified in the ranking as least beneficial.

However, in its reply to the state today, the Department of Health and Human Services questioned the legality of the manner in which the rankings were derived.

"The record regarding the manner in which the list . . . was compiled contains considerable evidence that it was based in substantial part on the premise that the value of the life of a person with a disability is less than the value of a life of a person without a disability. This is a premise which is inconsistent with the Americans with Disabilities Act," the reply states.

Secretary Sullivan, in a letter to Oregon Gov. Barbara Roberts, also said that "given the real possibility that Oregon's general approach will serve as a model for other states, it is critically important that it go forward only with strict adherence to the legal protections that President Bush has worked so hard to enact."

In the letter, Dr. Sullivan also said, "I urge Oregon to submit a revised application which addresses these concerns, and I look forward to approving such a demonstration."

In the reply to the state, HHS said many nonscientific information sources were used to determine ranking of treatments and conditions,

which would affect the services to be covered by the Oregon Medicaid program or removed from coverage. In particular, the reply cited a telephone survey of Oregon residents concerning quality of life issues.

"There are substantial indications . . . that the quality of life data derived from the Oregon telephone survey quantifies stereotypic assumptions about persons with disabilities," the reply states. "Scholars who have examined quality of life surveys have concluded that, as compared to persons who have the disabilities in question, persons without disabilities systematically undervalue the quality of life of those with disabilities." The reply said the Congressional Office of Technology Assessment had also found this bias against persons with disabilities in the Oregon survey results.

"A number of aspects of the ranking process reflect discrimination on the basis of disability," said HHS General Counsel Michael J. Astrue. "As a result, the government has no choice but to ask Oregon to review its waiver request and resolve these serious issues."

[Letter to Governor Roberts, Aug. 3, 1992]

Dear Governor Roberts: Thank you for submitting your application entitled "Oregon Reform Demonstration" for review by the Department of Health and Human Services under section 1115 of the Social Security Act.

The Administration is firmly committed to encouraging innovation in state health care programs, and generally favors using states as "laboratories of democracy." With this application, Oregon has attempted to fashion a wide-ranging reform of its Medicaid program, many features of which have my strong support.

I regret, however, that I am unable to give your application final approval until a number of legal issues, which relate primarily to the Americans with Disabilities Act, are resolved. Particularly given the real possibility that Oregon's general approach will serve as a model for other states, it is critically important that it go forward only with strict adherence to the legal protections that President Bush has worked so hard to enact.

We have tried to provide as much guidance as possible for the future in the enclosed analysis. I urge Oregon to submit a revised application which addresses these concerns and I look forward to approving such a demonstration.

Sincerely, Louis W. Sullivan, M.D.

### Analysis Under the Americans With Disabilities Act ("ADA") of the Oregon Reform Demonstration

The record regarding the manner in which the list of condition/treatment pairs was compiled contains considerable evidence that it was based in substantial part on the premise that the value of the life of a person with a disability is less than the value of the life of a person without a disability. This is a premise which is inconsistent with the ADA. Accordingly, the requested waiver cannot be approved until Oregon provides evidence that allows us to conclude that the program has been revised so that factors impermissible under the ADA had no effect on the list, thus bringing the program into conformity with the ADA. To assist Oregon in this undertaking, the following observations and suggestions are provided.

There are substantial indications in the material Oregon has provided that the quality of life data derived from the Oregon telephone survey quantifies stereotypic assumptions about persons with disabilities. Scholars who have examined quality of life surveys have concluded that as compared to persons who have the disabilities in question, persons without disabilities systematically undervalue the quality of life of those with disabilities.<sup>1</sup> The Congressional Office of Technology Assessment found this bias against persons with disabilities in the Oregon survey results. The Commission itself stated that "those who had experienced the problem [impaired health state] did not feel it was as severe as those who had not experienced the problem." Commission Report at C-11. The Commission acknowledged that "[t]his response has been replicated in a number of studies." *Id.*

Oregon's counsel's submissions regarding the status of the program under the ADA do not dispute that the telephone survey allowed bias against persons with disabilities to be taken into account and that the telephone survey affected the final ranking of health services. In effect, Oregon argues that the biased telephone survey's impact on the ranking of health services was real but limited. However, Oregon's own statistical analysis—which itself may incorporate distinctions based on disabilities and may thus present independent questions under the ADA—shows that the survey had an appreciable impact on the final rankings, because more than 120 services would move at least 30 places on the prioritized list and more than 50 services would move at least 50 places on the list if constant values of 0.5 were substituted for values generated by the survey. One service would move 161 places. Unless Oregon funds all of the

health services on its prioritized list every year, it is unlikely on the record Oregon submitted that the Commission could demonstrate that the telephone survey data will have no effect on which medical conditions are treated.

Accordingly, the rankings of condition/treatment pairs should be redone without using rankings derived from the telephone survey as a starting point.

Other aspects of the ranking process also reflect discrimination on the basis of disability. According to the Commission Report, the Commissioners ranked all categories and made hand adjustments to the list on the basis of certain community values, including "quality of life" and "ability to function." These two values place importance on "restored" health and functional "independence" and thus expressly value a person without a disability more highly than a person with a disability in the allocation of medical treatment. As the Commission itself notes, the adjustments also moved treatments for "severe or exacerbated conditions"—almost the very definition of a disability—to "relatively unfavorable positions." Commission Report at 28. The rankings should be redone without taking such factors into account. In addition, any methodology that would intentionally ration health care resources by associating quality of life considerations with disabilities does not comport with the mandate of the ADA.

Of course, there is a wide range of factors that Oregon may consider in allocating medical resources consistent with the ADA. These factors include, but are not limited to, the cost of medical procedures, the length of hospital stays, prevention of death, and prevention of contagious diseases. In general, Oregon may 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. See *Alexander v. Choate*, 469 U.S. 287, 302 (1985) (interpreting section 504 of the Rehabilitation Act of 1973, a model for the ADA; upholding a reduction in the number of covered hospital days from 20 to 14).

Under the priority list of condition-treatment pairs, liver transplants for alcoholic cirrhosis of the liver (line 690) and life support for extremely low birth weight babies under 23 weeks gestation (line 708) would fall below the cutoff line for covered services. The following problems with the proposal related to those items must be resolved before the demonstration program can be approved.

<sup>1</sup> See e.g., David C. Hadorn, *The Oregon Priority-Setting Exercise: Quality of Life and Public Policy*, Hastings Center Report 12 (May-June 1991) (citing other studies).

Concern about the State's treatment of liver transplants relates to the ADA. There appears to be no medical underpinning for this difference such as that a transplant is a successful treatment for one type of cirrhosis but not the other. Since liver transplants for nonalcoholic cirrhosis of the liver (line 366) would be covered, the decision on coverage or no coverage is made entirely on the basis of a disabling condition (alcoholism). A decision not to cover a treatment based entirely on the existence of a disabling condition, where similarly situated individuals without that condition would receive treatment, would violate title II of the ADA. Decisions with respect to coverage of such treatment could, however, be made based on an appropriate record. For example, the State may wish to adopt the principles followed by Medicare for the coverage of liver transplants, namely, that coverage in the case of alcoholic cirrhosis is conditioned on evidence of sufficient social support to assure assistance in alcohol rehabilitation. See 56 F.R. 15006 (April 12, 1991).

With respect to low birth weight babies, it should be noted that medical therapy is availa-

ble under the Oregon proposal for low birth weight babies that exceed 499 grams (line 22) (and, apparently, for babies that are less than 500 grams, but with gestation periods of longer than 23 weeks). This distinction drawn by the State between those low birth weight babies who will receive treatment and those who will not, raises similar concerns under the ADA.

In addition to ADA concerns with respect to low birth weight babies, Pub. L. 98-457, the Child Abuse Amendments of 1984, established standards relating to the withholding of treatment for medically fragile infants. Because those amendments provide substantial deference to the medical judgment of the treating physician and seem as well to presuppose the rendering of certain life support services (including medication, nutrition and hydration), the refusal to cover life support for such infants under the Oregon proposal would not be consistent with those provisions.