
Who shall live? Who shall die?

— Oregon's health
financing proposals

Frank Honigsbaum

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Who shall live? Who shall die?

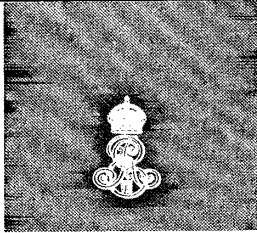
— Oregon's health
financing proposals

by Frank Honigsbaum
Author of "The Division in British Medicine",
and "Health, Happiness and Security,
the Creation of the
National Health Service"

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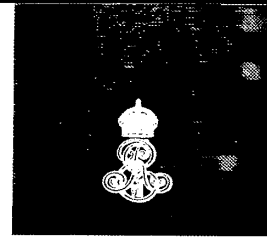
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Contents

	Page
Acknowledgements	3
Introduction	6
1. How the Oregon plan evolved	8
2. How the priority list was prepared	16
3. Assessment	42
4. Implications for Britain	53
References	56

Acknowledgements

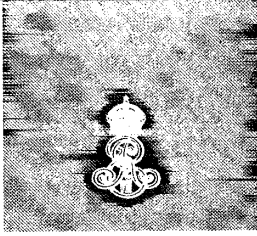


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I wish to thank Dr Robert Kaplan for supplying articles explaining how his quality of well being scale is devised. I am also indebted to the staff of the Oregon Health Services Commission: the Executive Director, Paige R Sipes-Meltzer, answered several queries and her assistant, Sandra Galati, supplied basic material. Not only the reports but all the minutes of Commission meetings have been made available, thereby enabling me to keep abreast of the plan as it developed.

Essential background information was obtained from articles that appeared in *The Oregonian*, a newspaper published in Portland, Oregon, and I am indebted to its Librarian, Sandra L Macomber, for making these available. Without her aid, a paper of this nature would not have been possible and I cannot thank her enough for the generous way in which she responded to my repeated requests.

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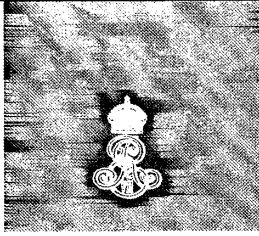


'Everybody dies: we cannot keep people alive forever. That is a part of life. What we can do with our limited money is try to reduce the number of deaths . . . to save as many people as we can save.'

— a defence of care restrictions for the poor in Oregon by its leading proponent, Dr. John Kitzhaver, President of of the Oregon Senate, in *The Oregonian*, 31 January 1988

'Life is valuable. Science has given us the technology to save lives. Not to use it is immoral.'

— an attack on care restrictions for the poor in Oregon by a leading opponent, Susan McGee of the Oregon Transplant Project, in *The Oregonian*, 7 April 1988



Introduction

After 18 months of preparation, Oregon's controversial health rationing plan for the poor under America's Medicaid system is complete. Over 700 services have been ranked in priority order and the state Legislature has said that it can cover 587 with the funds at its disposal.¹ Since over half the money required comes from Washington, federal approval will be needed; but if that is granted and other states follow Oregon's lead, the plan could set a pattern for the nation, affecting not only the poor but those covered by private insurance.

Medicaid has suffered the same fate in Oregon as in many other states with funding problems limiting income coverage to 58% of the federal poverty level.² Those entitled to benefit have received a wide range of care but Oregon sees its mission as extending a narrower pattern of service to a wider segment of the population. Instead of restricting people, it wants to restrict treatment, with costly and less effective services being the first to go.

This plan has aroused interest in Britain as well as America. Though the National Health Service, unlike Medicaid, covers everyone, treatment is not always available. Hospital waiting lists exist everywhere and some patients, because of age or other reasons, may be denied the right to care. Restrictions on renal dialysis are perhaps the most notable example.

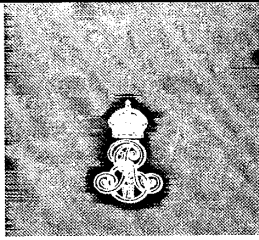
Since April, 1991, the Service has been in the throes of a reform which may extend restrictions across a broad front. With the creation of an internal market introducing a division between purchasers and providers, those on both sides of the contracting process are looking more critically at care, with competition forcing providers to cut costs and accelerate access. In an attempt to reduce hospital waiting lists, the North East Thames Regional Health Authority has suggested that patients needing five minor



procedures be removed unless there were some overriding clinical reasons to retain them. These procedures are varicose vein repair, removal of tattoos, excision of lumps and bumps, extraction of wisdom teeth and 'in vitro' fertilisation.³ Only those with lumps and bumps may be referred back to their general practitioner for treatment; the rest will have to pay privately or do without. One district health authority in the region, Mid-Essex, has already acted, removing from its waiting list more than 500 persons seeking varicose vein repair and extraction of wisdom teeth — with the Oregon example being cited as the inspiration for its decision.⁴

Unlike America which spends more on health care than any nation in the world, Britain spends the least among developed countries. Many believe the Health Service to be seriously underfunded. While America devotes nearly 12% of its gross national product to health care and most countries in Europe spend around 8%, Britain lags behind with under 6%. If only two percentage points were added to Britain's expenditure, that would put £10 billion more on the £32 billion now available and enable waiting lists, along with equipment shortages, to be cut dramatically. Rationing and resource allocation may not be seen to be fair until Britain spends more — but that will not remove the challenge Oregon has posed. Costly medical technology is proceeding at such a pace that hard judgements about its use cannot long be deferred. Instead of leaving decisions to doctors and managers in private, Oregon has brought the subject into public view and sought to introduce a more rational process.

This paper will trace the origins of the Oregon plan, explain how it works and pass judgements on its worth. Will the Oregon way help to resolve the difficult decisions that have to be made in Britain about rationing and resource allocation? That is the question this paper seeks to answer.



I. How the Oregon plan evolved

Oregon came to this plan as the result of difficulties in funding its Medicaid programme, a state-run system that covers not only the poor but low income elderly people, blind and disabled people and children in foster care. With Federal support ranging from 50% to 83% varying inversely with per capita income, each state decides how much it wants to offer above the mandated services required by the federal government. Arizona did not have a Medicaid programme until 1982 because it was not willing to shoulder the substantial costs involved in caring for its large, impoverished Indian population.⁵

Oregon offered a wide range of care under Medicaid with the federal government paying 63% of costs⁶ — but like many states, it could not afford to cover all below the federal poverty level. It had to reduce its proportion to 58% of the federal figure, which in 1989 amounted to \$10,000 for a family of three, thereby setting its Medicaid level at \$5,800, or about £3,400 at current exchange rates.⁷ Assets are now considered in establishing eligibility but under the proposed plan, income alone would be assessed with a review every six months.⁸

Oregon first tried to cope with its funding problem in 1987 as the result of concern with the state's high infant mortality rate. To foster pre-natal care and extend coverage to 1,500 women and children, it cut off all transplants (heart, liver, pancreas, bone marrow) under Medicaid except for cornea and kidney, the latter being financed almost entirely by the federally-run Medicare programme designed mainly for the elderly.⁹ This led to the death of a seven-year-old boy, Coby Howard, who needed a bone marrow transplant for leukaemia.¹⁰ A strong reaction followed, which eventually forced the federal government to order, as of 1 April 1990, the restoration of transplants for poor children under the age of 21 across the nation as a whole.¹¹

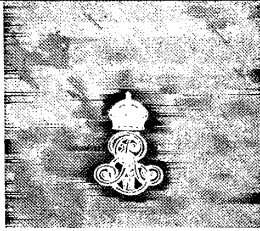


Costs kept rising and in 1989 Oregon tried a different approach. In an attempt to extend Medicaid coverage to all below the federal poverty level, it decided to prepare a prioritised list of treatment that would be on offer to the extent that state and federal funds would allow. This was contained in Senate Bill SB 27, passed in June 1989 as the Oregon Basic Health Services Act. Once the list was prepared, the Legislature would decide how far down the state could go.

Alaska is the only state which has tried to rank services before, though it did so merely by providing for the elimination of whole categories of treatment and without taking effectiveness or public values directly into account.¹² Colorado came closer to anticipating the Oregon plan but that effort failed because the state wanted to include the low income elderly, blind and disabled¹³, all concerns of powerful interest groups. To forestall opposition from that source, Oregon excluded those persons, along with children in foster care, but only from the demonstration project. If the plan proves successful, these groups may be added later.¹⁴ Meanwhile, Oregon planners could take comfort from the thought that most health costs for the elderly are financed by Medicare with only long-term care and social support being the main concern of Medicaid.¹⁵

Oregon wants its plan to set a pattern not only for the poor but for the population in general. The Legislature thus passed two companion measures which are designed to extend coverage, giving employed persons and others a stake, thus making provision under Medicaid as wide as possible:

- SB 935 encourages small businesses to offer health insurance to employees and dependants, providing services similar to those in SB 27 at affordable rates. It also offers a tax credit of \$25 per month for each person covered with the credit ending on 30 December



1993. This is intended to stimulate immediate participation but if 150,000 people are not added by October 1991, then insurance will become compulsory;

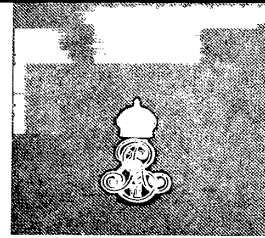
- SB 534 provides health insurance to high risk individuals at 150% of the average annual premium. A state subsidy will be given to enable insurers to provide coverage to those with a pre-existing medical condition.

There are 400,000 uninsured people in Oregon out of a population of 2.7 million, about 15% or roughly the same proportion as in the nation as a whole.¹⁶ These three measures are expected to add coverage for a number ranging from 250,000 to the full 400,000. Of this number, 118,000 will eventually be added to the 130,000 already covered by Medicaid.¹⁷

Concerned mainly with rationing, the Oregon plan pays little attention to the efficiency with which care is delivered. All it proposes is to promote the spread of prepaid managed care contracts using agencies like health maintenance organisations, and that effort will be offset by the need to raise Medicaid reimbursement fees to encourage greater medical participation. At the moment Oregon has one of the lowest physician reimbursement rates in the nation and spends less on Medicaid (as a proportion of total state spending) than all but five of the 50 states in the Union.¹⁸

Alternative to national health insurance

The Oregon plan is a bold experiment that will require federal approval as a demonstration project before it can go into effect. Hitherto, rationing in America has taken the form more of restricting the number of people eligible for care than of restricting care itself. Once given access through public or private means, America has been generous in what it offered. Restrictions on some



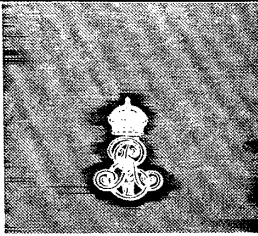
services, along with deductibles and co-insurance charges, still apply, but the rate of surgical operations and other forms of expensive treatment exceeds anything known in Britain.

This has led many policy makers in America to fear the advent of national health insurance even if, unlike the European variety, it merely takes the form of requiring employers to provide insurance or pay a tax. They do not feel the nation can afford to give everyone the wide range of care to which insured Americans have become accustomed. All that is feasible, they feel, is an acceptable minimum offering a basic package of treatment. As long ago as 1978, a prominent English economist and adviser to Labour governments, Professor Brian Abel-Smith, endorsed this approach at a round-table conference in America:

'... it has become increasingly appreciated that even in a very affluent country it is not practicable for everyone to have all that can be provided. The key to providing greater equity may be to find a way of defining the minimum that all should have.'¹⁹

The President of the Oregon Senate subscribes strongly to this view. He is Dr John Kitzhaber, a physician in accident and emergency care who is a leading figure in the state's Democratic party. When his Democratic colleague, Michael Dukakis, made universal health insurance a major plank in his abortive 1988 presidential campaign, Kitzhaber dissented: 'I think that system is unsustainable economically; society cannot afford universal access to everything (in the way of medical services) to everybody.'²⁰

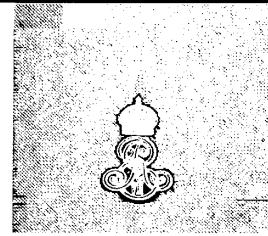
Nor did he dissent from the state's decision in 1987 to end many organ transplants under Medicaid; on the contrary, he strongly supported it, thereby drawing the painful appellation, 'Dr Death'.²¹ When the federal government ordered the restoration of trans-



plants for poor children in 1990, Kitzhaber complained that this was 'diametrically opposed to the approach that we're trying to put together'.²² He preferred to see the money devoted to prenatal care with the aim of reducing the state's high infant mortality rate. And by confining care to sustainable proportions, more people would be covered by Medicaid, thereby reversing what he saw as the injustice of the present system. The nation, he argued, 'rations people while maintaining an increasingly rich benefit package for the shrinking number of people who are entitled. And this constitutes rationing of the very worst kind — rationing that reflects no social policy, which has no ethical or clinical basis, which is being done silently, implicitly and by default.'²³

Support and opposition

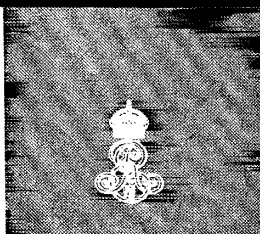
Within Oregon, Kitzhaber was backed by a group which had prepared the way for legislation. This was Oregon Health Decisions, formed in 1984 by health activists who had been concerned by the failure of health planning organisations created under the National Health Planning and Resources Development Act of 1974. These bodies were intended to curb excessive spending on hospitals and medical technology but they did not achieve their aims and died a quiet death in the 1980s. Those who formed Oregon Health Decisions blamed the demise on the absence of community forums. Somehow, they felt, the public had to be given the chance to express its health values and they proceeded to organise 19 meetings across the state. With Kitzhaber chairing the steering committee, a lobbying effort was mounted which paved the way for the 1989 Acts. So successful was this movement that it inspired action in other states, resulting in the formation of American Health Decisions in October 1989, with the aim of duplicating the Oregon way.²⁴



Support for this effort came from groups aggrieved at the way Medicaid worked. They were concerned with the plight of single parent families, pregnant women and others who were denied Medicaid rights despite having incomes below the federal poverty level. Though they would have welcomed a national health insurance plan free from the stigma of Medicaid, they saw little hope of creating it. Rather than have Medicaid injustices continue day by day, they were ready to accept whatever the state had to offer. And by having a priority list prepared, they believed most of the services their followers needed would be funded.

These feelings were not shared by others. The firmest opposition came from those concerned with the provision of transplants. Though poor children were now protected by federal legislation, they feared adults would be denied access through the priority plan.²⁵ Milder resistance came from the Oregon Health Action Campaign, a coalition embracing a wide range of groups, including labour unions, consumer organisations, senior citizens and the churches. It did not oppose the plan as such but refused support unless the benefits were adequate.²⁶ It wanted to see how far down the list the state Legislature would go. Employers were divided, the larger ones for it, the smaller ones against. Since the major firms already provided health insurance, they hoped the plan would reduce their health bill, while the smaller ones, free of such costs, did not want to assume the added burden.²⁷

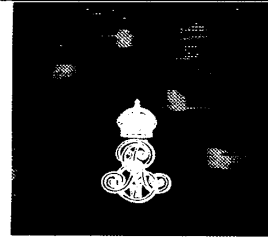
Much stronger opposition emerged outside the state. Seven national health care organisations did not think it fair to single out the poor for a special kind of rationing and a dangerous one at that; they were the Catholic Health Association, the Children's Defense Fund, Citizen Action, the Epilepsy Foundation of America, Families USA, the Gray Panthers and the National Council of Senior Citizens.²⁸ It was hoped that the exclusion of the low-income



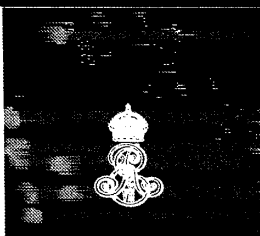
elderly would weaken opposition but that only served to inflame others who feared the cutbacks would fall on pregnant women and children.²⁹ That threat alarmed some doctors as well for though the American Medical Association gave its cautious support,³⁰ the American Academy of Pediatrics ruled otherwise: like the Children's Defense Fund and other consumer health organisations, it opposed the plan.³¹ Even *Business Week* — the voice of the corporate community — registered its objection, feeling it more important to 'Cut health costs, not health care'.³²

However, Kitzhaber was not without prestigious support in medical circles. It came from Dr Samuel Thier, president of the Institute of Medicine. He told the City Club of Portland that he preferred a two-tiered system to a three-tiered one in which those at the bottom received no care at all. Somehow, he suggested, a method had to be devised to measure the quality and effectiveness of treatment, giving priority to those services on top. Such a system, he felt, should be structured around prevention, immunisation and nutrition, with less emphasis on high technology. Only where organ transplants were concerned did he dissent from Kitzhaber; they, he argued, should not be an issue because, if successful, they extended life. Far more dispensable were expensive treatments for seriously ill patients with little chance of recovery: 'Don't not pay for something that is effective because it is expensive until you've routed out all that doesn't work that is being paid for unnecessarily.'³³

There was little dissent in the Oregon Legislature when the time came in June, 1989, to vote on the bills setting forth the structure of the plan. It was approved by the vote of 58-2 in the House, and 19-3 in the Senate.³⁴ Even its most fervid opponent, Representative Tom Mason, a professor at Portland State University, made clear his intention to have the list drawn as accurately and fairly as possible.³⁵



Since the plan was designed mainly for the poor, there was little pressure coming from Oregon's predominant white, middle class population, the state being described once as 'one big suburb'.³⁶ As long as the priority list did not affect them, house-owners had taxes to save from a system that promised to relieve the pressure on Medicaid spending. The way was clear for the state to develop its plan.



2. How the priority list was prepared

To prepare the list, the Legislature created an eleven-member Health Services Commission (HSC) which worked initially through three sub-committees: Social Values, Health Outcomes, and Mental Health Care and Chemical Dependency (MHCD). Two more were added as the methodology developed: Alternative Methodology and Ancillary Services.

The Commission, as required by statute, is composed of five physicians, a public health nurse, a social services worker and four consumers of health care. The five doctors, also as required, come from the specialties of obstetrics, perinatal, paediatrics, adult medicine, geriatrics or public health. No surgeons were appointed. The chairman is a businessman, Bill Gregory, owner of a forest products firm. Members serve four year terms.

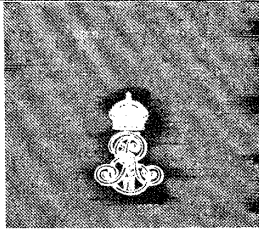
Commission members chair the sub-committees but the statute only required the creation of the MHCD Subcommittee. Ten members were appointed to that body with only the chair, Donalda Dodson, a nurse with the Marion County Health Department, being a member of the Commission itself. The other subcommittees were apparently run as open affairs; anyone interested could attend and it drew participation from a wide variety of people concerned with health care. However, final preparation of the list rested solely with the eleven HSC members and they were assisted by six staff. All but the staff served without pay and they were aided by hundreds of volunteers who contributed thousands of hours to the preparation of the list. The total cost came to \$565,356 or nearly £329,000 at an exchange rate of \$1.72 to the pound.³⁷ The Commission is required to prepare a list once every two years with costs supplied by an independent actuary, Coopers & Lybrand receiving the initial appointment.



Since no comparable list had been prepared before, the Commission had little to guide them. A trial run was made early in 1989 under the direction of John Golenski, a Jesuit priest and a founder of the Bioethics Consulting Group of Berkeley, California. Ratings were carried out by a panel of health care professionals and community volunteers using consensus methodology.³⁸ Some forty categories of care were listed with the highest rating going to prenatal care, immunisations and nutritional supplements, while the lowest went to organ transplants and infertility services.³⁹ However, accurate cost figures were hard to obtain⁴⁰ and the study was not done in sufficient detail to permit the prioritisation of distinct services.⁴¹

After a review of several methods, the Commission decided to use the quality of well being (QWB) scale developed by Dr Robert Kaplan of the Department of Community and Family Medicine at the University of California in San Diego.⁴² This scale, combined with the cost of treatment and duration of benefit, provided a single number to determine the worth of a procedure, showing the amount of money needed to produce a quality adjusted life year (QALY). Thus, a procedure which costs \$10,000 and produces 10 well years would have the number 100 assigned to it since that is the amount required to purchase each QALY.

Costs were based on average charges in Oregon and included diagnosis, hospitalisation, professional services, prescribed drugs and other ancillary services. Cost data was gathered first from Medicaid records and this was supplemented with information from providers. Outcome data was collected first from a literature search and this was supplemented with information obtained from 29 specialty panels, each composed of doctors practising in that specialty.⁴³



To calculate the QWB scale, the patient was first placed in one of 23 categories describing his major symptom, such as loss of consciousness, burn over large areas of the body, coughing or shortness of breath, headache or dizziness. Since it was felt that the Kaplan list did not adequately address MHCD problems, four symptoms were added with Kaplan's permission: trouble falling asleep or staying asleep, trouble with sexual interest or performance, is often worried, trouble with the use of drugs or alcohol.⁴⁴

Next, assessment was made of three aspects of daily functioning, dealing with questions like these:

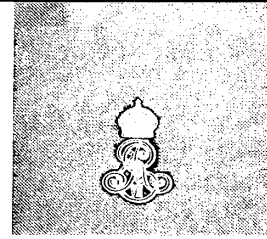
mobility: can the patient use public transport or drive a car? is he confined to hospital?

physical
activity: can the patient walk on his own or does he need a cane, crutches or wheelchair? can he climb stairs?

social
activity: can the patient work at his usual job or care for himself at home? can he perform his normal domestic duties or does he need help?

Each of these attributes was classified according to a numerical procedure which assigned 0 to death and 1 to optimum health. Some conditions may leave the patient comatose or in some other undesirable state. This was considered worse than death and a minus figure was assigned. So that the attributes could be combined into one figure, weights were given which reflected how closely the patient approached 1 for optimum health. These weights were then subtracted from 1 to show the state of well being.

Thus, a patient who had difficulty walking would have a weight of



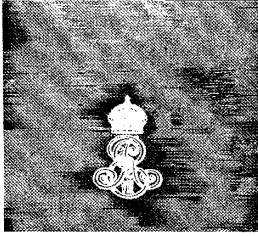
-.253; if he were not able to drive or use transport, he would have a weight of -.046; if he could use a wheelchair under his own control, he would have a weight of -.373; if he needed help eating or going to the bathroom, he would have a weight of -.106. Taking these four weights together produces a total of -.778; that subtracted from 1.000 for optimum health leaves .222. Thus a treatment which added 10 years of life to a patient with this condition would yield only 2.22 well years. The weights used here were developed from a survey carried out in Oregon and differ from those prepared by Kaplan.⁴⁵

Consultation with public

The different weights used in Oregon were developed from a phone survey of 1,001 respondents from around the state. Scores ranging from 0 for death to 100 for good health were obtained for 30 conditions of health and activity based on Kaplan's QWB scale. The survey also sought data on the extent to which the 30 conditions had been experienced in Oregon.⁴⁶

In several respects, the weights differed significantly with Oregonians attaching greater importance to impairment of physical activity than to mobility or social activity. They also saw alcohol and drug problems, followed by the ability to learn and to think, as the conditions most severely affecting the quality of life.⁴⁷

Twelve public hearings were also held in seven localities to elicit testimony from advocates of those likely to use Medicaid as well as those involved in the provision of services. The number testifying ranged from 13 in Coos Bay to 62 in Portland with a total of over 1,500 people attending. However, only 280 testimonies were recorded with the greatest stress being put on the desirability of preventive care and MHCD services. Nothing useful emerged to indicate which services were most effective.⁴⁸



Community meetings, organised by Oregon Health Decisions, were also held in an attempt to determine the extent to which the public put values on certain conditions. In all 47 meetings were held with a total of 1,048 attending, the average thus being 22.⁴⁹ Here is an example of the conditions for which a value was sought:

- after three heart attacks a patient is getting worse despite taking several medications daily; an operation to insert a pacemaker would probably help the heart's rhythm but not the general condition of the heart; the day-to-day activities of the patient would improve.

At the meetings the public was also asked to rate various forms of treatment with expected outcomes, using the classifications of essential, very important or important. There were nine categories and the public was asked to place three categories in each classification. Here is an example of a condition that would probably be classified as 'essential':

- treatment of sudden or ongoing condition were the person is likely to get well. If the person does not receive care, the length of quality of life will be reduced.⁵⁰

No attempt was made to rate specific conditions because it was felt that the public lacked the competence needed to make judgements. An attempt was made to build a consensus of values and determine preferences but this was abandoned for the same reason.⁵¹ However, 13 public values did emerge and these were listed according to the frequency with which they were expressed (see Table 1).



Table I

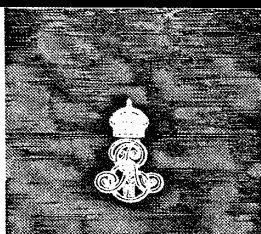
Public Values in Oregon listed according to the frequency expressed at community meetings

- 1) Prevention — very high, all meetings.
- 2) Quality of life — very high, all meetings
- 3) Cost effectiveness — high, more than $\frac{3}{4}$ of meetings
- 4) Ability to function — moderately high, $\frac{3}{4}$ of meetings
- 5) Equity — moderately high, $\frac{3}{4}$ of meetings
- 6) Effectiveness of treatment — medium high, over $\frac{1}{2}$ meetings
- 7) Benefits many — medium, $\frac{1}{2}$ of meetings
- 8) Mental health and chemical dependency — medium, $\frac{1}{2}$ meetings
- 9) Personal choice — medium, $\frac{1}{2}$ of meetings
- 10) Community compassion — medium low, less than $\frac{1}{2}$ of meetings
- 11) Impact on society — medium low, less than $\frac{1}{2}$ of meetings
- 12) Length of life — medium low, less than $\frac{1}{2}$ of meetings
- 13) Personal responsibility — medium low, less than $\frac{1}{2}$ of meetings

Source: Oregon Health Services Commission, *Prioritization of Health Services*, A Report to the Governor and Legislature, 1991, Appendix F, Report of Community Meetings, April, 1990, pp 5-6

Preliminary list

Initially, the Commission was expected to complete its report in six months, by 1 March 1990, but by then it had not devised a method for incorporating the public values listed in Table I. The Commissioners were also expected to exercise their expert judgements and no method had been worked out to combine their individual



assessments. All that could be done quickly was to issue a preliminary list ranked according to the QALY figures produced by the modified Kaplan scale. This was done on 2 May 1990, and it produced so many anomalies that the Commission considered withholding it.⁵²

Procedures were ranked in the form of condition-treatment pairs such as 'uterine cancer-hysterectomy'. Though some duplicates appeared, there were 1,680 on the list, with the least costly at the top and the most at the bottom. Numbers had to be inserted to locate a condition's place on the list but they showed reconstructed breast surgery at 1,181 holding a higher place than an open fracture of the thigh at 1,284, while the repair of crooked teeth at 19 fell between two conditions that referred to Hodgkin's disease, a disorder that can prove fatal if left untreated. Procedures that were expected to rank high appeared much lower (such as obstetrical care of pregnancy at 1,028) and the opposite applied for procedures expected to rank low (such as infertility treatment at 73). Dr Harvey Klevit, the paediatrician on the Commission, was shocked by the misplacements,⁵³ and Dr Alan Bates, the HSC's family physician and osteopath, later described the list as a 'strange hodge-podge'.⁵⁴

A few weeks later the Commission tried a shortened version of the list as a test but half the items contained flaws. This led another family physician on the HSC, Dr Rick Wopat, to call the data 'useless': 'If we want to use the formula system, we have to start collecting data all over again.'⁵⁵

The most serious defects lay in the data dealing with costs and effectiveness of treatment. Outcome figures were based mainly on a review of medical literature but the shelf-life of some projects was short and others used questionable methods.⁵⁶ Only a few conclu-



sive studies were found, such as those dealing with transplantation and cardiac surgery.⁵⁷ Even then, hard data applied only to mortality rates, not quality of life, and little was available on the course of outcomes if no treatment were given. Indeed, so difficult was it to calculate the cost of outcomes without treatment that it was dropped from the cost benefit formula used to evaluate effectiveness.⁵⁸

At this point, June, 1990, the Commission was near despair and even its most committed member, Dr Tina Castanares, a distinguished public health officer deeply concerned with the care of the poor, had doubts about the ability to construct a viable list.⁵⁹ But with the prospect of more time being allowed, the Commission plodded on, creating a new sub-committee to consider alternative methods, while the one concerned with health outcomes continued with its effort to make the formula approach work, making an exhaustive review of line items.

Category method adopted

The alternative method adopted was a classification based on categories similar in concept to the one devised by Dr David Hadorn of the University of Colorado and used by Alaska as well as Golenski in his trial run. Though this had initially been rejected, it was now seen as a sensible way to start the process, particularly since it would enable a higher ranking to be given to controversial life-saving treatments like transplants.

The Commission started with 26 categories but removed or merged nine to reduce the total to 17. Ranking was determined by the Commission alone but it made use of the 13 values supplied by community meetings, grouping them into three attributes (see Table 2).

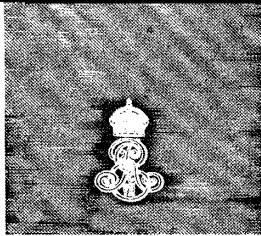


Table 2
Grouping of Community Values

Value to society

prevention	cost effectiveness
benefits many	community compassion
impact on society	mental health and
quality of life	chemical dependency
personal responsibility	

Value to an individual needing the service

prevention	equity
quality of life	effectiveness of treatment
ability to function	personal choice
length of life	community compassion
mental health and	
chemical dependency	

Essential to basic health care

prevention	cost effectiveness
benefits many	impact on society
quality of life	

Source: Oregon Health Services Commission, *Prioritization of Health Services*, 1991, pp 21-22

As can be seen, only two of the 13 values were included in all three attributes — 'prevention' and 'quality of life'. Only three others were included in the most important attribute, 'Essential to basic health care' — or the level below which no person should fall. These were 'benefits many' (a treatment which many people will need), 'impact on society' (those problems like infectious diseases which would endanger others if left untreated) and 'cost effectiveness'. Neither 'benefits many' nor 'impact on society' held a high place in the order of frequency in which values were expressed at community meetings (see Table 1), but the Commission felt them too essential to ignore.



The Commission then had the task of applying these attributes to the ranking process and a consensus was secured by a procedure which allowed scope for individual judgement and discussion. However, the costs of treatment were not considered in this discussion⁶⁰ and no allowance was made for personal responsibility, or the extent to which lifestyle was the cause of illness.⁶¹

Seventeen categories now existed in rank order with life-saving treatments at the top, followed by maternity care and preventive services for children. At the bottom came a category containing treatments which would have little or no effect on the quality of life (see Table 3). No ranking had to be given to the diagnosis of the presenting problem since that would be available to everyone and head the list.

Table 3

Categories of Care

<i>Rank</i>	<i>Condition and effects of treatment</i>	<i>Examples</i>
1	Acute fatal, prevents death, full recovery	appendectomy, medical therapy for myocarditis
2	Maternity care, including disorders of the newborn	obstetric care of pregnancy; medical therapy for low birthweight babies
3	Acute fatal, prevents death, without full recovery	medical therapy for bacterial meningitis; reduction of open fracture of joint
4	Preventive care for children	immunisations; screening for vision or hearing problems
5	Chronic fatal, improves life span and patient's well being	medical therapy for diabetes mellitus and asthma; all transplants
6	Reproductive services	contraceptive management, vasectomy



Rank	Condition and effects of treatment	Examples
7	Comfort care	palliative therapy for conditions in which death is imminent
8	Preventive dental care	cleaning and fluoride
9	Proven effective preventive care for adults	mammograms; blood pressure screening
10	Acute nonfatal, treatment causes return to previous health state	Medical therapy for vaginitis; restorative dental service for dental caries
11	Chronic nonfatal, one-time treatment improves quality of life	hip replacement; medical therapy for rheumatic fever
12	Acute nonfatal, treatment without return to previous health state	relocation of dislocated elbow; repair of corneal laceration
13	Chronic nonfatal, repetitive treatment improves quality of life	medical therapy for migraine and asthma
14	Acute nonfatal, treatment expedites recovery of self-limiting conditions	Medical therapy for diaper rash and acute conjunctivitis
15	Infertility services	in-vitro fertilisation, micro-surgery for tubular disease
16	Less effective preventive care for adults	dipstick urinalysis for haematuria in adults under age 60; sigmoidoscopy for persons under age 40
17	Fatal or nonfatal, treatment causes minimal or no improvement in quality of life	medical therapy for end stage HIV disease; life support for extremely low birthweight babies (under 500gm)

Source: Oregon Health Services Commission, *Prioritization of Health Services*, 1991, Appendix G, pp G-11 and G-12

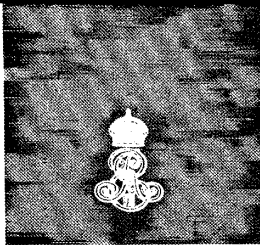


Ranking within categories

The next step was to group condition-treatment pairs within categories. On the preliminary list, 1,680 items were ranked but this did not include preventive services since they were not susceptible to QALY analysis. Through a process of consolidation, the Commission managed to reduce the total to 709, though a long definition of preventive services had to be added at the end of the list.⁶² Some saving was due to the omission of MHCD items (with the exception of screening services) since they were not due to start until 1993, and a separate integrated list had to be prepared for them.⁶³

Since preventive and other services could not be subjected to cost-benefit analysis, the classification process was confined to the 10 categories which did contain conditions that could be so examined. As can be followed on Table 3, these were 1, 3, 5, 10, 11, 12, 13, 14, 17 (fatal and nonfatal counting as two). Conditions were first divided into those which could be cured and those which could not, followed by a further division into acute or chronic. To facilitate this process, the Commission's staff developed an algorithm based mainly on varying rates of mortality and quality of well being. For example, within the first category came fatal acute conditions with treatment resulting in at least a 25% reduction in mortality during the five years following treatment and with at least 90% of patients returning to a very high quality of life, .9 QWB on a scale which had 0 for death and 1 for optimum health.⁶⁴

Ranking was then carried out by a mathematical procedure similar to the one used for the preliminary list but with less weight attached to cost and more to duration of benefit and quality of well being. However, limits for some conditions were now put on duration of benefit instead of lasting throughout a patient's life as had been assumed before. Thus, only 10 years was now allowed for



a hip replacement since that, on average, was how long the benefit was expected to last before another were needed.⁶⁶

All of this work was reviewed by the 29 panels of doctors and other providers who had earlier contributed information on treatment effectiveness. An immense amount of time was devoted to this process, each panel spending an average of 100 hours.⁶⁷ As a result, 116 changes were made in the rankings and six were deleted.⁶⁸

This still left some services in awkward positions and the Commissioners used a 'reasonableness' test to adjust the rankings. That applied particularly to preventable or readily treatable conditions; they were put above severe or exacerbated conditions wherever it seemed justifiable.⁶⁹

The extent to which these adjustments were made can be seen on Table 4.



Table 4

Outlier Dispersion

— extent to which line items digress from category rankings

Category	number of line items at estimated cost points												
rank	200	255	310	365	420	475	530	585	640	695	709	Total	
1	58		3			1	1					63	
2	34	2	5	6		1				1		49	
3	51	1	2	1	3		2		1			61	
4	3	1										4	
5	42	49	43	14	7	2	19		4	2		182	
6	3			1								4	
7	1											1	
8	1											1	
9	1											1	
10	5	2		8	11	14	6	10	3	1		60	
11			1	13	14	31	23		11	3	1	97	
12	1			6	6		1	18				32	
13			1	4	13	3	3	27	26	8		85	
14				2	1	2			5	22		32	
15									3		1	4	
16										1		1	
17									2	17	12	32	
Total	200	55	55	55	55	55	55	55	55	55	14	709	

As Table 4 indicates, some startling adjustments were made. Though category five had the largest number of items with 182, 134 or 74% were included in the first 310, ahead of 17 in the first three categories. Similarly, though half the items in category 12 came near the bottom of the list, one item was moved to the top, among the first 200. On the other hand, eight items in the first five categories may not be offered under Medicaid since they came below the 587 rank to which state funds are available.

The process was completed with the Commission's unanimous approval and a new list (still subject to a few changes) issued on 20



February 1991, 18 months after work began. A separate draft integrated list, this time including MHCD conditions, was issued on 27 March 1991 and included in the report sent to the Governor and Legislature in May.⁷⁰

Completed list

The Oregon Legislature has indicated that it cannot afford to fund line items below 587, so Table 5 indicates how this will affect selected condition-treatment pairs.

Table 5

Ranking of Selected Condition-Treatment Pairs

<i>Condition</i>	<i>Treatment</i>	<i>Category</i>	<i>Rank</i>
pneumonia	medical	1	1
appendicitis	appendectomy	1	5
ischaemic heart disease	cardiac by-pass op	3	149
HIV disease	medical	5	158
imminent death	comfort care	7	164
cancer of uterus	medical and surgical	5	186
end stage renal disease	medical including dialysis	5	319
cataract	extraction	11	337
osteoarthritis	hip replacement	11	399
wisdom teeth*	surgery	11	480
tonsils and adenoid disease	tonsillectomy and adenoidectomy	11	494
hernia without obstruction	repair	11	504
back pain (spondylosis)	medical and surgical	13	586
<i>all below 587 may not be funded</i>			
varicose veins*	stripping/ sclerotherapy	11	616
bronchitis	medical	13	643

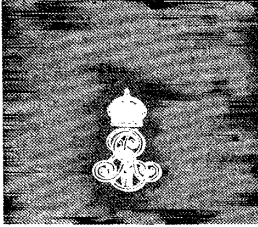


▶ cancer where treatment will not result in 10% of patients surviving 5 years	medical and surgical	17	688
tubal disfunction*	in-vitro fertilisation, GIFT	15	696
haemorrhoids, uncomplicated	haemorrhoidectomy	17	698
AIDS, end stage HIV disease	medical	17	702
extremely low birth-weight (under 500gm)	life support	17	708

* Services which may no longer be offered under the National Health Service in districts covered by the North East Thames Regional Health Authority

Source: Oregon Health Services Commission, *Prioritization of Health Services*, 1991, Appendix J

As Table 5 indicates, common procedures like appendectomies, hip replacements and hernia repairs will be covered, as will the more expensive cardiac by-pass operations and renal dialyses. But other common procedures will not, like medical therapy for bronchitis or haemorrhoidectomies. Similarly, expensive life support for extremely low birthweight babies will no longer be available and the same applies to medical and surgical services for cancer patients with limited life expectancy, or medical therapy for those with AIDS. However, largely due to public demand, comfort care to relieve pain will be available to all who are terminally ill no matter what the cause. Of the services currently under the threat of rationing in Britain, only the removal of wisdom teeth may be provided in Oregon.



Care was taken to correct the misplacements that had caused such controversy when the preliminary list was published. Thus, treatment for crooked teeth at 548 now ranked well below that for Hodgkin's disease at 189. Similarly, reconstructed breast surgery at 600 fell far below treatment for open fracture of the thigh at 116. The incongruous placement of two items on the preliminary list was now reversed: obstetrical care of pregnancy at 21 now ranked far above infertility treatment at 602.

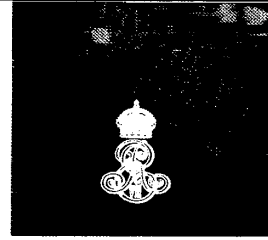
New rankings for HIV and AIDS

The completed list made a significant change in the ranking of treatments for HIV and AIDS, conditions which are the concern of powerful pressure groups. On the preliminary list, about one-third of the services associated with these conditions came at the very bottom of the list because they had a QWB score of .000. No condition for HIV ranked higher than 677 (on a list with 1,680 items) and it had a QWB score of .462. No other QWB score for HIV exceeded .269.

On the completed list, only four items were cited for HIV compared with over 150 on the preliminary list, and three received high rankings: medical therapy for HIV at 158, comfort care for the terminally ill at 164, and treatment for opportunistic infections at 255. Only medical therapy for the end stages of HIV disease came low at 702, and may not be available.

New rankings for transplants

Even more significant was the change in the rankings for transplants. On the preliminary list, they came near the bottom because of the substantial costs and low QWB scores associated with such operations. Though this was in keeping with cost-benefit analysis, it was certain to arouse strong opposition as these were the treatments which had started the controversy. Thier had dissented



from Kitzhaber (among others) on this point and the Commission saw the wisdom of his argument. Of the 19 transplants on the completed list, 12 came near the top half, and seven of these dealt with the controversial bone marrow transplants. Though all were placed in category five, that did not prevent four from being put near the bottom the list, below the 587 level at which funding is available. Rankings for all transplant operations are shown on Table 6.



Table 6

Ranking of Transplants (all in category 5)

<i>Condition</i>	<i>Transplant</i>	<i>Rank</i>
Hodgkin's disease	bone marrow	209
other specified aplastic anaemias	bone marrow	214
myeloid, monocytic, acute lymphocytic anaemias	bone marrow	244
agranulocytosis	bone marrow	249
lymphoid leukaemia	bone marrow	294
constitutional aplastic anaemias	bone marrow	307
acute non-lymphocytic leukaemias	bone marrow	311
end stage renal disease	renal	312
biliary atresia	liver	365
cirrhosis of liver without mention of alcohol	liver	366
heart disease	cardiac	367
necrosis of liver	liver	368
diabetes mellitus with end stage renal disease	pancreas/kidney	512
multiple myeloma leukaemias	bone marrow	523
malignant neoplasm of endocrine glands	bone marrow	524
<i>all below 587 may not be funded</i>		
other deficiencies of circulating enzymes	lung	607
cancer of liver	liver	610
alcoholic cirrhosis of liver	liver	690
non-Hodgkin's lymphomas	bone marrow	691

Source: Oregon Health Services Commission, Prioritization of Health Services, 1991, Appendix J



New rankings for dental and mental health services

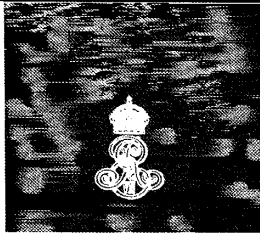
The Oregon plan covers dental and mental health services, only mental handicap conditions being excluded. Both dental and mental health services were included in the preliminary list but only dental in the completed list as the plan does not propose to cover mental health services until 1993. Screening services for mental health found their way into the May, 1991 list as they were covered by the expanded definition of preventive care. The MHCD Subcommittee had the option of having an entirely separate list prepared but chose an integrated one, no doubt in the hope that this would produce higher rankings and more secure funding. Such a list in draft form and without cost estimates was appended to the official report issued in May, 1991.⁷¹ If approved, this list would go into effect in July, 1993 and replace the list due to start a year earlier.

Dental services did well on the preliminary list despite low QWB scores. Of the 47 conditions listed, 34 ranked below 600 and 40 below 1,000 out of a total of 1,680 — yet the highest QWB score was .278. For the most part, low QWB scores were offset by low costs and long durations of benefit, thereby producing fairly low costs per QALY.

On the completed list, dental services did not fare so well. The number of conditions was reduced to eight, with only three in or near the top half of the list: infections (165), prevention (166) and caries (398). With the remaining five at ranks 548, 549, 550, 676 and 697, it is doubtful if they will be funded once mental health services are included in an integrated list.

High rankings for mental health services

By contrast, mental health services came out better on the draft integrated list issued in March, 1991 than on the preliminary list. For example, while schizophrenia services received low rankings on



the preliminary list (1,352, 1,387, 1,464), on the March, 1991 list they were placed as high as 187, ahead of all but six of the 47 cancer services. Out of a total of 65 MHCD services, 25 were included in the first 200 and 50 in the first 500.

The MHCD Subcommittee called for funding through line 480 so as to cover the 49 MHCD conditions it considers necessary for basic care. These figures do not include the screening services which are due to start a year earlier, but they also received a high ranking, being cited in the expanded definition of preventive services holding rankings for children at 143 and for adults at 166.

Most MHCD services were put in categories 1, 3 and 5 as follows:

- category 1: major depression, single episode; acute post-traumatic stress disorder and drug-induced deliriums
- category 3: alcohol and drug abuse diagnoses
- category 5: dysthymia, chronic post-traumatic stress disorder, alcohol and drug dependence, eating disorders, bipolar disorder, recurrent major depression, schizophrenia, conduct and personality disorders.⁷²

The risk of suicide was cited as the main reason for the high ranking assigned to mental health conditions, while chemical dependency conditions were put near the top because of their 'epidemic proportion, death due to suicide and accidents, and cost to society'.⁷³ However, the state of Alaska, ranking by category alone, did not treat MHCD services nearly so well. They were put in categories 13 through 16 out of the 22 under its system which excludes entire categories from funding.⁷⁴



MHCD services were aided greatly by the decision to consider them as a continuum of care rather than as isolated episodes of treatment, each forming a separate condition-treatment pair. As the MHCD Subcommittee made clear in its report, 'A continuum of care includes locus of care (outpatient, day or residential facility, or inpatient hospital), and all necessary modalities and services (individual, family or group therapy; vocational training and occupational therapy; case management; medication and medication management).'⁷⁵ What this presumably means is that once a patient is diagnosed as schizophrenic, he will be entitled to a lifetime of care, not just to the occasional out-patient visit.

High ranking for preventive care

When the preliminary list was published in May, 1990, advocates for children were the most adamant opponents of the Oregon plan.⁷⁶ This seemed strange since the original impetus behind the plan came from those, like Kitzhaber, who wanted to reduce the state's high infant mortality rate. But the exemption allowed for the elderly, blind and disabled made it appear to many, including paediatricians, that the burden would fall on pregnant women and children. In developing the plan, it therefore became necessary to do all that was possible to protect these groups from cuts in funding. The way was led by Castanares, herself active in the treatment of poor women and children.⁷⁷

The issue came forcefully before the Commission on 2 February 1991. Then, with the ranking of categories nearly complete, one member (Professor Paul Kirk, a prominent obstetrician who was educated in Britain and spent 14 years working in the National Health Service) wanted to divide preventive care for children, which had been listed in one category, into two — one for highly successful interventions like immunisations, and others not proven. This had been done with preventive services for adults, separating

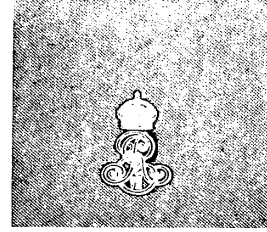


them into categories 9 and 16 (see Table 3), but not for children out of fear that it would arouse opposition in Washington. If a waiver were to be secured, it was argued, one category was needed to cover all preventive care services for children.⁷⁸

Nor was that the only means devised to give preference to children. The single preventive care category assigned to them was initially given a ranking of 5, well above the rankings of 9 and 16 assigned to preventive care for adults. But even that was not high enough for one member (Ellen Lowe, a consumer representative) who wanted it raised to number 3. This drew a protest from Dr Harvey Klevit, a paediatrician, who 'posed the concept that prevention of death with a small amount of disability in a high proportion of cases might conceivably be more important than preventive care for children where one is preventing diseases that are fatal but in a very small part of the population'.⁷⁹

In the end, the category was raised to number 4 after Castanares warned that everything above 5 could be viewed as a basic health package. With the Commission split on ranking, she feared funding problems if children's preventive care were divided, and that would create political difficulties for the Oregon Legislature. At that time it was thought cost estimates might be made by category and the Commission was not willing to run the risk of having the benefit line drawn above that category.⁸⁰

The MHCD Subcommittee showed similar concern for children. It made sure, with the exception of a few diagnoses, that children's conditions were highly placed on the integrated list. Similarly, it saw to it that a 'pretty high' ranking was given to those conditions which interfered with a parent's ability to function.⁸¹

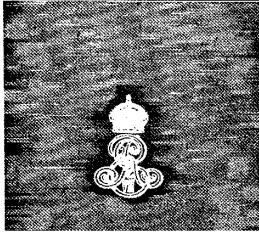


Basic health care package

The Commission was required by statute only to create a priority list, leaving the Legislature to decide how far down funding should go. But in its report it went further and recommended a basic health care package as 'a floor beneath which no person should fall'. This, it stressed, must include all services in categories considered 'essential' and most of those considered 'very important'.⁸² Categories 1 to 9 (on Table 3) were designated 'essential', and categories 10 to 13 'very important'.⁸³

However, the Commission made one qualification in a footnote at the beginning of the report⁸⁴ and not repeated thereafter. This indicated that some services in the 'essential' category had been moved to 'outlier' (or lower) positions than their category ranking would suggest. What it failed to point out was that this applied even more to services in the 'very important' category.

The effect can be seen by making the basic care package cut at the line suggested by the MHCD Subcommittee. The Commission itself was reluctant to offer such advice, confining its recommendation to categories, but the MHCD Subcommittee had no inhibitions. Out of the total of 65 MHCD diagnoses, it wanted the first 49 to be considered as a minimum and that requires funding through line 480 on the integrated list, or line 439 on the list without MHCD services which is scheduled to start in July, 1992.⁸⁵ Indeed, the cut could even fall below 439 as MHCD services are costly and the actuaries have not yet estimated them. But even if the cut were made at line 475 (the nearest point to 480 estimated by the actuaries), it can be shown that a large number of services in the 'essential' and 'very important' categories would not be on offer:



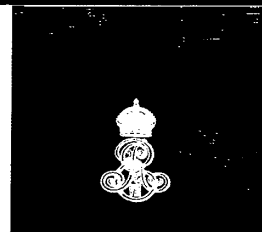
	Total services	Outliers below 475	% of total
Essential categories (1 to 9)	366	30	8.25%
Very important categories (10 to 13)	<u>275</u>	<u>141</u>	51.0%
	641	171	26.7%

Taking the two classifications together, over a quarter of the services would be excluded from funding and this applies to over half the services in the categories considered 'very important'. With the funding level set by the Legislature at 587, the effect is less, but that would still leave unavailable nearly one-fifth of the services in the 'very important' category.

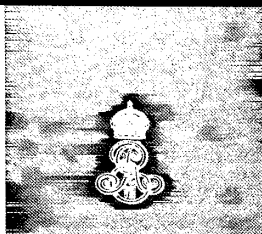
Aims largely achieved

Nevertheless, in compiling the list, the Commission has produced a significant shift in priority from curative to preventive care and from high technology services to those concerned with maternity, child care and MHCD conditions.⁸⁶ This was the aim of the plan's prime movers and the result largely conforms with their wishes. They also have succeeded in silencing opposition from advocates of transplant operations by assigning safe ratings for most of those services.⁸⁷ The leader of the Oregon Health Action Campaign appears to be pacified as well. Though she would have preferred a cut at line 640,⁸⁸ the line was probably drawn close enough to win her support, thereby enabling lobbyists to go to Washington with wide backing from the state.

It remains to be seen whether a waiver will be granted. A decision is expected in January, 1992.⁸⁹ Approval will also be needed for the



payroll tax credit in SB 935, designed to encourage small business provision of health insurance. If that is not approved, then the hard-won support of trade unions and low income groups may be lost.⁹⁰



3. Assessment

Though the Oregon plan will have dire implications for some Medicaid patients, it was inspired by decent motives and good intentions. Those who provide care for the poor were tired of waiting for wider reform and wanted the funds at their disposal to be used in a more equitable manner. Castanares put it well when she said:

'... I've been asked by reporters how I would feel if I had to tell a patient that a treatment which might benefit her won't be paid for because it falls low on the list. I reply that I already have to do something very similar almost every day in my practice... only it's the *patient* who is low on somebody's list of priorities for receiving help and the services she can't afford are *basic*: routine lab tests to find out what's wrong; echocardiograms for her child with heart murmur; antibiotics for abdominal infections; care for her abscessed teeth; insulin and syringes for her diabetes.'⁹¹

Various forms of rationing might have been devised but Oregon chose the laborious task of preparing an extended list of services, in ranked order, that covers the whole spectrum of medical, dental and mental health care. Though rooted in American conditions, the Oregon plan presents a challenge to health planners throughout the world: is this the way to deal with the difficult decisions that have to be made in face of the relentless rise in health spending?

In Britain as well as America, many will find the Oregon plan unfair because it singles out the poor. Even those who fathered the plan like the leaders of Oregon Health Decisions seem to accept the justice of this criticism: 'Morally and politically, a democracy cannot long tolerate legislation that explicitly permits the rich to live at the expense of the poor.'⁹² They hope the Medicaid plan will mark the start of a movement that will spread throughout the population generally, but the attempt to extend its affects only to high risk



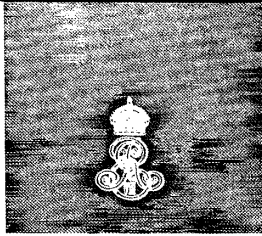
individuals and those covered by small employer plans does not go far enough. Though the people of Oregon were said to accept this discrimination, it is noteworthy that a large number refused to participate in the phone survey of health values; indeed, the refusal rate was as high as the completion rate.⁹²

If the Oregon plan were tried in Britain, this criticism would have less force. Since everyone is covered by the National Health Service, no group would be singled out for what is widely regarded as a dangerous experiment. Only those with private means would be able to avoid its effects, thereby stirring interest from proponents of private insurance and possibly making them anxious to see the Oregon experiment duplicated in Britain.

Is this a sensible way to ration health care?

But many in Britain as well as America will wonder whether this is a sensible way to ration health care. The QALY technique may be useful for appraising discrete treatments like cardiac by-pass operations, but as the Commission learned to its embarrassment, it cannot be applied across the whole spectrum of health care. The data does not exist, nor is it ever likely to be available. Mortality rates are now the only sure guide, not morbidity, and little information exists on quality of life or outcomes if no treatment is given.

The method by which the QWB scale is estimated does not take account of the age of the patient, the degree of family or home support, his contribution to society or his ability to cope with adverse circumstances. Nor, not even with the four additions made in Oregon, does it really measure mental health conditions, suggesting 'only the broadest measure of impairment'.⁹⁴ Rather, it reflects mainly the degree of physical flexibility and this discriminates against those with disabilities like Christy Brown, the cerebral



palsy sufferer depicted in the film, 'My Left Foot', who managed to live a creative life despite his appalling handicap.

The cost benefit formula used was of a bewildering complexity, one that must have frightened even those members of the Commission who lacked numerate skills. Here is what it looks like:

$$B_n = \frac{c}{Y * \left[\sum_{i=1}^5 (P_{i1} * QWB_{i1}) - \sum_{i=1}^5 (P_{i2} * QWB_{i2}) \right]}$$

[With Treatment] [Without Treatment]

with $QWB_{ik} = 1 + \sum_{i=1}^5 d_{ijk} w_j$

where

B_n = the net benefit value ratio for the n^{th} condition/treatment pair to be ranked. This value will be used in determining the actual rankings of health services from highest (0) to lowest ($-\infty$).

c = cost *with* treatment, including all medications and ancillary services as well as the cost of the primary procedure.

Y = the years for which the treatment can be expected to benefit the patient with this condition. This may be the remainder of the patient's lifetime or some shorter amount of time.

P_{i1} = the probability that the i^{th} outcome will occur five years hence *with* treatment.



d_{ij1} = an indicator variable denoting the presence (=1) or absence (=0) of the j^{th} health limitation (MOB, PAC or SAC) or chief complaint for the i^{th} outcome *with* treatment.

w_j = the weight given by Oregonians to the j^{th} health limitation or chief complaint ranging from 0 = no significant effect to -1 = death.

P_{i2} = the probability that the i^{th} outcome will occur five years hence *without* treatment.

d_{ij2} = an indicator variable denoting the presence or absence of the j^{th} health limitation or chief complaint for the i^{th} outcome *without* treatment.

Source: Oregon Health Services Commission, *Prioritization of Health Services*, 1991, Appendix D, p D-2

Even this impressive array of mathematical symbols could not stand up to data deficiencies. Without treatment costs had to be eliminated from the formula because they were not available and this, the Commission acknowledged, 'could have resulted in a different rank order of the list of health services'.⁹⁵

There was thus no quick mathematical fix to the ranking process; common sense and a concern for political realities had to be applied before a completed list could be prepared. 'Intuition', admitted Castanares, was 'as important as mathematical formulas'.⁹⁶ In Britain, one of the leading proponents of the QALY technique, Professor Alan Maynard of the University of York, described the ranking process used in Oregon as nothing more than a 'crude guessestimate'.⁹⁷



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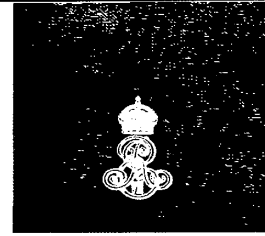
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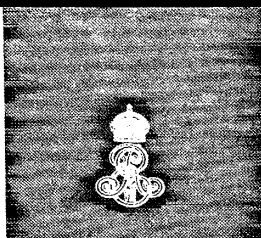
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Will the rankings be accepted?

Some rankings may prove controversial if the demonstration project goes ahead. Preventive services for children were given the high ranking of 143, yet they include many of no proven effectiveness. The Commission itself acknowledged the need for further study.⁹⁸ Similarly, obstetrical care of pregnancy received a high ranking of 21, but may include a number of prenatal visits of little value. Such was the finding of a panel experts convened by the National Institutes of Health.⁹⁹

The ranking process, subjective as it was, still took no account of the degree to which a person is responsible for his own illness, yet this will have to be considered if a patient's behaviour may cancel out the benefit of treatment. In a private communication, the Commission's Executive Director indicated that the Oregon plan may give discretion to doctors to deny liver transplants to alcoholics who refuse to give up drink.¹⁰⁰ However, no special consideration is being shown for haemophiliacs who contract the HIV virus from blood transfusions. Treatment for this condition is listed without regard to probable cause and the ranking for the end stage has been ranked so low (702) that it may not be funded. This may prove acceptable in America but probably not in Britain where haemophiliacs have even been awarded special monetary compensation.

Of the 13 public values expressed in Oregon, personal responsibility was the only one not used, yet it is closely associated with two others which were stressed — prevention and cost effectiveness. The Commission called for further study of the subject.¹⁰¹

Likely opposition to MHCD rankings

The high rankings for MHCD conditions may also prove controver-



sial. The MHCD Subcommittee said it used the same method to assess rankings as the Commission itself,¹⁰² but it had even less data to work with. Services required for MHCD conditions are notoriously difficult to anticipate and the Subcommittee acknowledged that it found 'research weaknesses'. All it could say with certainty was that care is effective, people recover, and that treatment reduces costs, crime, injuries and death.¹⁰³

For chronic conditions like schizophrenia, data was particularly deficient. The Subcommittee stressed the need for longitudinal studies, but despite this it assigned a ranking of 187 to the disorder. If the integrated list goes into effect in 1993, those afflicted with schizophrenia will be entitled to a lifetime of care before a whole host of cancer sufferers are eligible for any form of treatment. In Britain, an outcry arose in one district when the health authority committed itself to the payment of £93,000 for the treatment of one mentally ill patient for one year, while more than 100 people had to wait over two years for surgery.¹⁰⁴ The long-standing neglect of the mentally ill certainly needs repair but the Oregon method may not be the way to do it.

Difficulties for doctors

Doctors are likely to find the priority list difficult to apply. They have become accustomed to working with the diagnostic related groups (DRGs) used under the Medicare programme for the elderly, but that classification was ruled out because DRGs are too broadly defined, do not cover out-patient therapies and may include co-morbidities.¹⁰⁵ Instead, the Commission based its system on the standard code of diseases which contains more than 10,000 diagnoses. In an attempt to reduce this to manageable size, they combined conditions to cut the number to 709, but that total is still unwieldy and makes some conditions hard to locate.



Earlier, when the preliminary list contained 1,680 conditions, two experts writing in the New York Times made the same point, noting that 'a wide range of diseases of different character and severity often appear under a single heading'.¹⁰⁶ This applies not only to conditions like 'infectious skin disease' (ranked at 277) but to a whole host of preventive services for adults, classified only as 'of proven effectiveness' (217) or 'of questionable or no proven effectiveness' (671). Only those in the effective rank are defined and some only in a general sense.¹⁰⁷ How, aside from the three examples given in the Report on page 19, are doctors to be sure of those considered ineffective?

Even if conditions can be found, doctors may wonder whether the treatment needed will be available. Expensive AZT drugs may prolong the lives of patients with HIV disease but are they included in the medical therapy offered with both the higher rankings assigned to this condition — 158 and 255 (for opportunistic infections)? If so, they will no doubt be cut off when a patient reaches the end stage of the disease since that holds the low ranking of 702. But then doctors will have the task of deciding when that time has come.

Other conditions may result in a curious pattern of treatment with funding supplied at one stage but not at another.¹⁰⁸ Thus, while medical therapy for epilepsy may be available at rank 159, surgical treatment, with a rank of 615, most likely will not. Even more curious is the array of rankings assigned to conditions affecting the esophagus. If the funding line were not drawn at 587 but just above it, then medical therapy for esophagitis, which is the item ranked at 587, would not be available. But if the esophagus ruptured, then surgery, with a ranking of 96, would be covered. But if cancer develops in the esophagus and the funding line were drawn below 500, treatment for that would again be excluded since it holds the



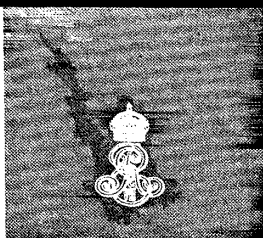
500 rank. The problems caused by conditions at this site were highlighted by two experts in the *New York Times* who found the Oregon plan fundamentally flawed.¹⁰⁹ This may explain why the state Legislature drew the line at 587 instead of at the nearest cost point estimated two ranks above.

Depressing effect of averages

One of the most serious defects of the plan arises from the wide variation in costs and outcomes that apply. Among other factors, a patient's general health can greatly alter the effectiveness of treatment, but to make the list manageable, average age, QWB scores, duration of benefit and cost figures have been used to calculate cost benefit. Patients with conditions that might deserve a higher ranking may find themselves deprived of treatment because of the depressing effect of averages.¹¹⁰

Nor should it be forgotten that medicine is not an exact science. If priority is based on diagnosis, many mistakes may be made. No one is more aware of this than those involved in the treatment of mental illness and here is the warning issued by the MHCD Subcommittee in its report:

'A human being is an organism of complex interactions. No emotional or somatic problem is a simple one-way street of linear cause and effect. It is a two-way street with many intersections. A condition may begin as a somatic problem but result in mental illness or chemical dependency; a MHCD condition may mask itself somatically. Recovery from an illness is affected by the patient's state of mind. Compliance with the regimens of medication, exercise and other lifestyle change is dependant on an individual's attitude and the social support system.'¹¹¹



Problems caused by co-morbidities

Perhaps most perplexing of all may be the problems caused by multiple disabilities or diseases: in what category should they be placed and what rank should they hold? A patient with both heart disease and diabetes will be most difficult to treat since the presence of diabetes can complicate heart care. The Commission acknowledged the need for further study of co-morbidity since it had been ignored in its work.¹¹²

But the Commission does not seem to be aware of the potential problems that can be caused by co-morbidity. Illness often comes in a mixture of forms and the progress of conditions like cancer can be difficult to predict. Patients are likely to appear with one condition that is funded while the other is not: is the patient to be treated for the first, only to die from the second? The ranking of cancer at various sites of the body ranges from a high of 172 (breast) to a low of 526 (pancreas). Conversely, those afflicted with bronchitis may not be treated since that condition holds the rank of 643, but if they suffer an attack of influenza or pneumonia which proves fatal, they will be entitled to treatment before they die since those conditions come at the very top of the list.

The Commission does not seem to be aware of the legal difficulties this can cause. The Oregon plan offers doctors and other providers immunity from court action if they fail to provide treatment for conditions which are not funded, but this is not likely to hold if another funded condition is present. Malpractice claims filed by zealous lawyers are bound to concentrate on the illness that was treated.

Efficiency of care largely ignored

The Oregon plan deals mainly with equity and says little about the efficiency with which care is delivered, aiming only to encourage

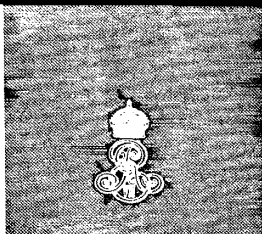


the use of managed care agencies providing treatment on an all-in capitation basis rather than the traditional fee-for-service form. In 1991, Kitzhaber and the new Governor, Barbara Roberts who is also a Democrat, tried to do more by creating a single state purchasing authority to compete with private insurers and, by restricting the number of providers, curb the duplication of expensive medical technology. This proposal was inspired by a bill, sponsored by the Oregon Health Action Campaign, which calls for the creation of a state health insurance system on the Canadian model, a measure which the Governor's own husband, state Senator Frank Roberts, supports.¹¹³ But neither proposal progressed very far after arousing strong opposition from insurance and business interests.¹¹⁴ The Oregon plan thus remains exposed to the criticism of those, like one medical Rhodes scholar from Oregon, who feel it should do more to cut costs.¹¹⁵

Doubts about public support

The Commission attached great importance to consultation with the public, needing its support to silence critics of a priority list and to put pressure on the state Legislature to be as generous as possible.¹¹⁶ Values expressed by the public were used both to prepare the list and expand the basic care package the Commission wanted the Legislature to fund. However, there is reason to doubt whether the public supports the concept as much as the Commission contends. Not only was there a high refusal rate to the phone survey but neither the community meetings nor the public hearings attracted the numbers one would expect.

The phone survey was the most important technique employed but it dealt only with generalised health values, not specific conditions,¹¹⁷ and failed to ask respondents how they would react if they themselves, or their loved ones, were the patients involved. Jean Thorne, manager of health services for the state's Medicaid



agency, made no attempt to hide her feelings. In 1988, when the withholding of transplants resulted in the death of a seven-year old boy, she had this to say: "It's been an interesting experience for me because I've got a little boy and you hear the pleas of the people . . . and you think, 'My God, that could be me'."¹¹⁸

Most surprising of all is the way the Commission seems to have ignored findings of the phone survey which helped to establish weights for QWB scores. Respondents considered some MHCD conditions — problems with drugs and alcohol, trouble learning and thinking, depression — among the worst that patients can endure,¹¹⁹ thereby calling for low QWB scores. But this did not prevent such conditions from being placed among the top 200 on the priority list.

Perhaps it was the stress placed on MHCD conditions at community meetings that supplied the rationale needed to justify this decision. So highly were MHCD conditions regarded that they were considered a public value in themselves. But the meetings were so poorly attended and so overloaded with health workers (more than two-thirds of the total and no doubt including many employed in MHCD services) that one wonders whether any weight should be attached to them.¹²⁰

Even more disturbing was the failure to elicit views from many Medicaid recipients. Fewer than 50 attended the community meetings, and although others had the chance to express views at public hearings, the testimony was of a rambling nature, useful only 'for understanding the general tone of public needs and concerns.'¹²¹

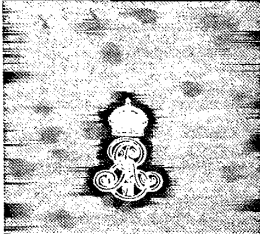


4. Implications for Britain

What effect will the Oregon plan have in Britain? Much interest has been generated and there is no doubt but that it will accelerate the pace towards rationing. The recent reform of Health Service operation, creating as it does a split between purchasers and providers, provides fertile soil for Oregon ideas to grow. A movement towards explicit rationing has already begun, producing one of the unexpected effects of Health Service reorganisation. The Department of Health is promoting the use of QALYs and as part of their new purchasing role, district health authorities are searching for ways to make more rational choices in the provision of services.

Whether this will proceed as far as duplication of the Oregon plan is unlikely. No doubt some public health directors would like to make the effort and they may find support among proponents of preventive and priority services who are tired of seeing so many funds being absorbed by high technology treatment in the acute sector. (In Oregon, it may be relevant to note, one of the founders of Oregon Health Decisions and a leading supporter of the priority list is a psychiatrist, Dr Ralph Crawshaw.) But the general tide of administrative opinion is likely to be against them. The Oregon plan demonstrates as nothing else can how difficult it is to construct a priority list across the whole spectrum of medicine.

To many in Britain, it will make more sense to pursue a cautious approach to rationing, concentrating first on services which are costly and less effective, such as those which make use of expensive technology in intensive care units to extend for a few days the hopeless lives of the terminally ill. From there, the process may proceed to cover more services and here the QALY technique can serve as a guide, but as the Oregon experience demonstrates, it offers no quick mathematical fix to the rationing process. Judgement, intuition, compassion and a concern for political realities all have to be employed in the making of decisions.



Movement toward public consultation

One part of the Oregon plan has already taken root and is likely to grow. That is the process by which the public was consulted, a procedure that has stirred interest among DHAs anxious to secure public support for the hard choices that have to be made. Mid-Essex DHA is leading the way, consulting not only the general public but voluntary organisations, the community health council and GPs on the assessment of priorities.¹²² Parkside DHA has started a similar process,¹²³ and no doubt others will follow.

Whether this exercise will prove any more fruitful than the one conducted in Oregon is doubtful. As the Oregon experience shows, the public lacks the competence to assess specific conditions or even to fix preferences on health values. Only generalised expressions of interest may be expected and they could be influenced by the way questions are framed. Mid-Essex DHA did not wait for public approval before it removed certain patients from its waiting list, but it no doubt hopes the values or feelings expressed in the consultation process will justify the decision. It will be interesting to see whether any attempt will be made to find out how individuals would respond if asked to indicate how they would feel if their own health were at stake.

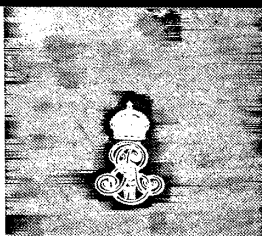
Public aid could prove useful in making general resource allocations, particularly in producing more funds for priority services than has been forthcoming in the past. But harsh as this may appear, it is doubtful whether the general public feels more compassion for groups like the mentally ill than it does for those needing high technology care in the acute sector. Only purposeful planning and ring-fenced financing, it seems, can alter the balance.



Need for an expert body

The rationing of specific services presents an even thornier problem. Protection is certainly needed against medical bias and misjudgement, but the Oregon experience suggests that considerable discretion must be left with doctors. Even the leaders of Oregon Health Decisions recognise the need for 'actual life-and-death choices' to be made 'as close to the bedside' as possible.¹²⁴ And John Kilner, the author of a profound work on the ethical dilemmas involved in patient selection, has shown how difficult it is to resolve conflicting policies.¹²⁵

The most the public can expect is to have an expert body lay down guidelines and offer an appeal procedure against medical decisions. Here, the Nuffield Foundation has pointed the way forward: the Council on Bioethics it has formed to deal with the moral issues from genetic engineering provides a model for health planners to follow.¹²⁶ What is needed in the Health Service is a similar body with consumer as well as medical and management representation to start the process of rationing specific services. That, in place of an unwieldy list of 709 items, is what a study of the Oregon experience suggests.



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Material for this study came mainly from two sources: the Oregon Health Services Commission and *The Oregonian*, a newspaper published in Portland, Oregon. Frequent references are made to the official report issued by the Commission in May, 1991, under the title, *Prioritization of Health Services, A Report to the Governor and Legislature*. This will be cited in the references below as HSC Report, 1991.

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- 4 *Daily Mirror*, 8 August 1991
- 5 Brown, E Richard, 'Medicare and Medicaid: Band-aids for the old and poor', in Sidel, Victor W and Ruth (editors), *Reforming Medicine*, New York, Pantheon, 1984, p 61
- 6 *Oregonian*, 10 August 1991, p D1
- 7 *Oregonian*, 26 April 1989, p D9, and 5 November 1989, p B2
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- 9 *Oregonian*, 3 August 1988, p B1
- 10 *Oregonian*, 2 January 1988, p E11
- 11 *Oregonian*, 28 January 1990, p C1
- 12 HSC Report, 1991, p 5
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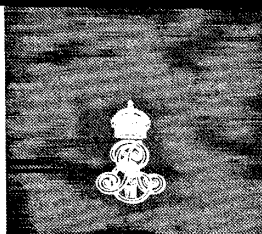
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- 26 Oregonian, 18 October 1989, p B6 with correction on 19 October 1989
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- 29 Oregonian, 4 February 1990, p C7 and 20 August 1990, p B5
- 30 Oregonian, 24 July 1989, 20 August 1990, and 24 April 1991, all on p B5
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- 32 *Business Week*, 21 May 1990, p 98
- 33 Oregonian, 19 September 1988, p D17
- 34 Oregonian, 24 July 1989, p B5
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- 42 HSC Report, 1991, pp 6-7
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- 48 HSC Report, 1991, Appendix E
- 49 HSC Report, 1991, Appendix F, 'Health Care in Common', report of Oregon Health Decisions, April, 1990, p 28
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- 64 HSC Report, 1991, Appendix G, p G-3
- 65 HSC Report, 1991, p 28 and Appendix D, p D-13
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King's Fund



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Health Service Purchasing at the King's Fund College

The successful implementation of the NHS reforms hinges on the development of effective purchasing of health care. District Health Authorities and Family Health service Authorities often in partnership with local authorities are now actively considering how to tackle health needs assessment including the involvement of and consultation with the local community, the establishment of priorities for commissioning, the use of purchasing power to lever service improvements, systems of care for patients and the development of effective contractual mechanisms.

The College has developed a range of programmes to assist non-executive and executive members and other staff of DHAs, FHSAs and social services leaders in local authorities to tackle their purchasing role effectively. A range of options are offered. These include short organisational development programmes such as the "Purchasing Dilemmas" programme (which will enable health authority teams to consider needs assessment and priority setting mechanisms) and extended classroom/learning set programmes for Directors of Public Health.

In addition the College offers an important new opportunity through the establishment of learning sets for fundholding GPs. The "community focus" of DHAs (in association with FHSAs and Social Service departments) is dealt with in a special programme entitled "Health Authorities: Peoples Champions", whilst a further programme has been developed on organisational development for leading edge purchasers.

This range of activity complements the provider focused programmes. "Managing through Contracts" considers the interface between purchasers and providers. Further programmes are being developed to enable purchasers and providers to work together on utilisation review and contract management.

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