

## Liver Transplantation in Massachusetts: Public Policymaking as Morality Play\*

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In 1982, Jamie Fiske, the infant daughter of Mr. and Mrs. Charles Fiske of Massachusetts, was dying of congenital liver disease. Her death was imminent, except for the possibility that a liver transplant—a difficult, risky, and extremely costly surgical procedure considered by many authorities still to be experimental—could prolong her life, for months or years, under a lifetime regimen of drugs to prevent her body's natural rejection of the foreign tissue. No surgeons or hospitals in Massachusetts performed liver transplants at the time. Moreover, the Massachusetts Blue Cross and Blue Shield plans (MBCBS), the family's health insurers, advised the Fiskes that such an experimental procedure would not be covered under their policy.<sup>1</sup> Thus begins the complex morality play, "Liver Transplantation in Massachusetts."

In addition to the Fiskes, the players in this drama include: two state-appointed commissions, composed of prominent citizen-experts; the state Department of Public Health; the state Medicaid program; MBCBS and Blue Shield's president, John Larkin Thompson; and, as a kind of Greek chorus, the omnipresent media. The role of "identified life"<sup>2</sup> is

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<sup>1</sup>Because the Fiskes had initially been guaranteed coverage for the transplant by an MBCBS employee, the Blues eventually agreed to pay for Jamie's treatment even though the procedure was technically excluded from plan coverage.

<sup>2</sup>The special function of characters like Jamie—endangered individuals whose jeopardy could be relieved by heroic or extraordinary governmental action—in dramas of this kind has been observed by numerous critics. Interestingly, many if not most of these critics have been Harvard professors and citizens of Massachusetts. See, e.g., Fried, *The Value of Life*, 88 HARV. L. REV. 1415 (1969); Fuller, *The Case of the Speluncean Explorers*, 62 HARV. L. REV. 616, 623 (1949); Schelling, *The Life You Save May Be Your Own*,

played by Jamie Fiske, whose plight precipitated a dramatic medical rescue and who has so far lived as happily ever after as her circumstances permit. Absent from the play, even as off-stage voices like the unborn children in *Die Frau ohne Schatten*,<sup>3</sup> are the "statistical lives" that policymakers reputedly find easier to ignore than identified lives in allocating public resources.<sup>4</sup>

The action takes place under the full glare of publicity. The setting, the Commonwealth of Massachusetts between 1982 and 1985, features a highly regulated health care system built on assumptions that were common in the 1960's and 1970's but that are not universally embraced in the United States today. To understand the plot of this drama, it is helpful to recognize that the political ethos of Massachusetts envisions a true health care "system" governed centrally in accordance with explicit public choices. Thus, although Jamie Fiske's fate was not directly in the hands of the Commonwealth, the state government seemed to view itself as responsible for seeing that nothing so publicly heart-rending could happen again.

This review of the Massachusetts experience with liver transplantation treats it as a case study of how a centrally controlled health care system faces difficult choices concerning health care and health care technology. Despite its many special features, the problem of liver transplantation is not *sui generis*. Health care abounds with similar questions concerning marginal trade-offs between benefits and costs. Although few of them are as visible or as fraught with the characteristics of "tragic choices"<sup>5</sup> as organ transplantation, the basic dilemma of whether to spend scarce resources to achieve a particular health benefit of possibly less than commensurate value is always the same. The choice of decisionmaking mechanisms, public or private, through which to address these inescapable trade-offs has been the fundamental problem of health policy in the United States.<sup>6</sup>

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in PROBLEMS IN PUBLIC EXPENDITURE ANALYSIS 127 (S. Chase ed. 1968); Zeckhauser, *Procedures for Valuing Lives*, 23 PUB. POL'Y 419, 447, 458-59 (1975); see also Evans, *Health Care Technology and the Inevitability of Resource Allocation and Rationing Decisions*, pts. 1 & 2, 249 J. A.M.A. 2047, 2208 (1983); Friedman, *Rationing and the Identified Life*, HOSPS., May 16, 1984, at 65; *infra* text accompanying notes 37-43.

<sup>3</sup>A well-known operatic fantasy by Richard Strauss and Hugo von Hofmannsthal.

<sup>4</sup>See generally Havighurst, Blumstein, & Bovbjerg, *Strategies in Underwriting the Costs of Catastrophic Disease*, LAW & CONTEMP. PROBS., Autumn 1976, at 122, 140-45; see also *supra* references cited note 2 and *infra* text accompanying notes 37-43.

<sup>5</sup>The term is Guido Calabresi's. See generally G. CALABRESI & P. BOBBITT, TRAGIC CHOICES (1978). Tragic choices arise in situations where no decision can be satisfying because any choice necessarily sacrifices one or more irreconcilable fundamental values. Scarcity is the fundamental condition that necessitates such choices. Not all choices are tragic, of course, and markets are usually tolerated to allocate mundane goods and services. Where the opportunity cost of a particular choice includes a highly visible possibility of a lost life or other personal tragedy, however, its potentially tragic character appears.

<sup>6</sup>See generally Havighurst & Blumstein, *Coping with Quality/Cost Trade-offs in Medical Care: The Role of PSROs*, 70 Nw. U.L. REV. 6, 9-45 (1975).

American society as a whole is somewhat less committed than Massachusetts to centralized decisionmaking on questions of what health services should be provided. Indeed, although the enactment of Medicare and Medicaid in 1965 started a seemingly inexorable movement toward such centralization of authority in government hands, recent years have seen a distinct movement in the opposite direction, particularly in federal policy.<sup>7</sup> Despite the promise of this new policy and some signs that hopes for it are being rewarded, it is still not clear that private choices can effectively ration expensive, potentially lifesaving therapies or that such rationing, if effective, would be acceptable politically. Many believe that effective and acceptable rationing can be achieved only by having government assume direct or indirect control of technology and health care spending. Although the Massachusetts experience with liver transplants provides no answers to these policy questions, it yields some insights into the relative merits of both approaches.<sup>8</sup>

### I. ACT ONE

Jamie Fiske's father successfully pleaded her need for a transplantable organ (and financial assistance) before the entire country, leading to a successful transplant at the University of Minnesota in November 1982. As a direct result of Jamie's case and the publicity it attracted, several things happened back home in Massachusetts. Several hospitals in Boston, all of them nationally prominent research and tertiary care centers, began expressing an interest in undertaking liver transplants. Other candidates for transplant surgery began appearing and pressing for financial support for the expensive lifesaving therapy. Such developments immediately focused attention and pressure on state government, because Massachusetts hospitals were not free to offer the service without a "determination of need" (DON) by state health planners<sup>9</sup> and because the state Medicaid program was one of the payers being asked to cover the cost. In addition, although MBCBS were private entities, they were finding it difficult both on medical grounds and as a public relations matter to insist that liver transplantation was still "experimental" and therefore not covered by their insurance contracts. MBCBS were hopeful that the state would

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<sup>7</sup>See generally MARKET REFORMS IN HEALTH CARE (J. Meyer ed. 1983); Havighurst, *The Changing Locus of Decisionmaking in the Health Care Sector*, 11 J. HEALTH POL. POL'Y & L. 697 (1986).

<sup>8</sup>For other studies providing insight on technology assessment, rationing, and tragic choices in different health care settings, see generally H. AARON & W. SCHWARTZ, *THE PAINFUL PRESCRIPTION* (1984) (describing the rationing of health care in the United Kingdom); INSTITUTE OF MEDICINE, NATIONAL ACADEMY OF SCIENCES, *ASSESSING MEDICAL TECHNOLOGIES* (1985); MINNESOTA COALITION ON HEALTH CARE COSTS, *THE PRICE OF LIFE: ETHICS AND ECONOMICS* (Dec. 1984) [hereinafter MINNESOTA COALITION REPORT]; OFFICE OF TECHNOLOGY ASSESSMENT, *MEDICAL TECHNOLOGY UNDER PROPOSALS TO INCREASE COMPETITION IN HEALTH CARE* (1982).

<sup>9</sup>MASS. GEN. LAWS ANN. ch. 111, § 25B (West 1977).

take the heat either for denying the service or for authorizing it and the higher insurance premiums needed to pay for it. Under these circumstances, the Commonwealth government did the predictable thing—it appointed a commission.<sup>10</sup>

### A. *The Fineberg Task Force and Report*

The Liver Transplantation Task Force (LTTF), which was created in December 1982, was charged by the Commissioner of Public Health with the task of discussing several issues, including the question, "Should this type of program and procedures be encouraged or permitted?"<sup>11</sup> Notably, this charge directly raised the fundamental question of whether the state should allow livers to be transplanted at all. It envisioned a range of possible postures for the state, from prohibition to neutrality to active encouragement. Although outright suppression of either research on a new technology or use of a technology once developed would, in practice, raise serious political and legal questions, the LTTF was nevertheless asked to recommend what state policy ought to be.

The LTTF's report, known as the Fineberg Report,<sup>12</sup> was issued in May 1983. It described liver transplantation as

a technically feasible, extreme and expensive procedure, demonstrably capable of extending the lives of some patients near death, and with substantial uncertainties about optimal selection of patients, appropriate criteria for excluding other patients, optimal matching of donor organs and recipients, effectiveness under conditions of more widespread use, and the extent of benefits and costs.<sup>13</sup>

The report recommended that liver transplants in Massachusetts be limited to one adult and one pediatric program with extensive data to be gathered from these programs in order to clarify the numerous "uncertainties" it had identified.<sup>14</sup> The LTTF viewed both this data gathering and systematic evaluation of the procedure as vitally important.

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<sup>10</sup>This commission was the Liver Transplantation Task Force (LTTF), which was created in December 1982.

<sup>11</sup>Letter from Alfred L. Frechette, Commissioner of Public Health, Commonwealth of Massachusetts, to Harvey Fineberg, Harvard School of Public Health (Dec. 27, 1982) reprinted in FINAL REPORT OF THE TASK FORCE ON LIVER TRANSPLANTATION IN MASSACHUSETTS B1-B2 (May 1983).

<sup>12</sup>FINAL REPORT OF THE TASK FORCE ON LIVER TRANSPLANTATION IN MASSACHUSETTS (May 1983) [hereinafter FINEBERG REPORT] (known as the Fineberg Report after the chairman of the LTTF, Harvey Fineberg of the Harvard School of Public Health).

<sup>13</sup>*Id.* at 34.

<sup>14</sup>*Id.* at 36, 40-41. The report also recommended that liver transplantation be initiated under a special one-year DON exemption, so that the data gathered by the new programs could be evaluated before a final DON determination was made. *Id.* at 39-40. In a

In addition, the Fineberg Report provided extensive cost estimates on liver transplantation, derived largely from data supplied by MBCBS.<sup>15</sup> It identified eleven cost components, ranging from preoperative expenses, surgery, and follow-up to the costs of complications, including rehospitalization and additional transplants.<sup>16</sup> It concluded by estimating that the average cost per Massachusetts patient surviving one year after the transplant would be \$238,800.<sup>17</sup> The report candidly acknowledged that some of its assumptions may have reduced the reliability of this estimate, noting that it took hospital charges to reflect true resource costs and ignored both indirect economic effects and "potential savings attributable to averted medical expenses" incurred in caring for a dying patient.<sup>18</sup> The report's completeness and candor on these points were unprecedented; they serve to highlight the shortcomings of other prominent studies and the great need for better data gathering.<sup>19</sup>

The LTTF's average total cost figure obscures the possibility that the marginal or incremental cost of a transplant may be considerably less. Based on the observation that transplantation could be undertaken in Massachusetts hospitals without adding equipment or personnel, the LTTF concluded that hospitals undertaking transplantation should be required to do so within their respective current cost ceilings under Massachusetts' system for regulating hospital revenues.<sup>20</sup> Under this recommendation, a hospital could receive no additional funds by virtue of adding a liver transplantation program and would thus have to finance its involvement from any surpluses it might earn or by economizing on (or terminating) the provision of other services. It appears that the LTTF judged liver transplantation to have so little proven value to date that new public or private outlays for it were not warranted. A payment restriction was one of several methods by which the LTTF hoped to achieve a "controlled dissemination of liver transplantation in Massachusetts" until more data on its efficacy, cost, and desirability were collected.<sup>21</sup>

Although this decisive call for caution seemed to stem from strong reservations about the value of the new technology, the Fineberg Report stopped short of addressing the most fundamental question raised in its charge. Admitting great discomfort in addressing the question of whether liver transplantation should take place at all, the LTTF passed the buck.

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thoughtful discussion establishing the need for this data gathering, the report described liver transplantation as being somewhere "on the continuum between 'experimental' and 'established.'" *Id.* at 8.

<sup>15</sup>*Id.* at 25.

<sup>16</sup>*Id.* at 27.

<sup>17</sup>*Id.*

<sup>18</sup>*Id.* at 29.

<sup>19</sup>*Id.* at 30.

<sup>20</sup>*Id.* at 39-40.

<sup>21</sup>*Id.* at 35.

Declaring itself "not legitimately constituted to render these views on behalf of society,"<sup>22</sup> the LTTF asked the Commissioner of Public Health to "appoint a broadly representative advisory body to consider the difficult value judgments about whether society can and should support liver transplantation and to what degree."<sup>23</sup> Hidden in this response, it should be noted, is an affirmation of the assumption that a single choice for "society" as a whole is necessary and appropriate and that this choice should be made by a committee in the first instance and ultimately by political processes. By recasting the question to focus on whether society should "support" transplantation, the LTTF seemed to eliminate the possibility that transplantation would be expressly forbidden. It is also possible, however, that the LTTF simply recognized that the regulatory blanket covering Massachusetts hospitals was so stifling that a decision not to "support" transplantation was tantamount to prohibiting it.

### B. The Regulatory Setting

The specific occasion for creating the LTTF was an application by New England Deaconess Hospital to the Department of Public Health for an exemption from state DON requirements that would allow a small number of liver transplants in 1983.<sup>24</sup> On further inquiry, the Department found that the Massachusetts General Hospital, Children's Hospital, and the New England Medical Center were also prepared to perform liver transplants.<sup>25</sup> It was hardly surprising that Boston's internationally prominent research hospitals were eager to perform liver transplants after the publicity given to Jamie Fiske's ordeal.

Like those of other states, Massachusetts' certificate-of-need program (known as DON) makes capital expenditures and substantial changes of service subject to approval by state authorities.<sup>26</sup> Such regulatory programs, the adoption of which was at one time required by federal law,<sup>27</sup> were established in an effort to curb the proliferation and expansion of health care facilities so that growth would correspond to officially pro-

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<sup>22</sup>*Id.* at 31. The LTTF's reservations about its competency were based on the fact that it was composed predominantly of scientists.

<sup>23</sup>*Id.* at 42.

<sup>24</sup>See Letter, *supra* note 11. Several interviews confirmed the identity of the institution in question.

<sup>25</sup>These four hospitals supplied the LTTF with much of its information about the feasibility of liver transplantation in Massachusetts. See FINEBERG REPORT, *supra* note 12, at app. D.

<sup>26</sup>MASS. GEN. LAWS ANN. ch. 111, § 25B (West 1977).

<sup>27</sup>The Health Planning and Resources Development Act of 1974, Pub. L. No. 93-641, 93 Stat. 606 (1974) (codified in scattered sections of 42 U.S.C.), made the availability of certain federal funds conditional on the enactment of a certificate-of-need program

jected needs.<sup>28</sup> The Massachusetts DON statute and regulations give especially broad authority to the Department of Public Health to determine whether a "substantial change in services" is needed,<sup>29</sup> and it was apparently conceded that a liver transplantation program needed state approval under this provision. The immediate reason for commissioning the Fineberg Report was to assist the Department in the DON process.<sup>30</sup> Without affirmative action by the Commonwealth, Boston's research hospitals would be barred from performing liver transplantation.

For interested hospitals, getting a DON was only the first regulatory hurdle. Massachusetts places a ceiling on hospital expenditures through its "all-payer" Maximum Allowable Cost (MAC) system.<sup>31</sup> Under this system of revenue limits, each acute care hospital's annual operating budget ceiling is determined in advance by the state, and the hospital is then permitted to collect revenues necessary to cover its anticipated needs from Medicare, Blue Cross, and private insurers, roughly in proportion to the number of beneficiaries treated.<sup>32</sup> Instituted in 1982, the MAC program assures each hospital prospectively that it will receive payments reflecting its actual 1981 costs plus adjustments for inflation, exceptions, and certain other factors.<sup>33</sup> The provision for exceptions permits a hospital to seek additional revenues to cover the anticipated costs of approved new services, such as liver transplants, and capital and operating expenses associated with other DON's.<sup>34</sup>

Naturally, any hospital receiving a DON to begin performing liver transplants would also wish to receive payment for them under a MAC exception. Under the Fineberg Report's recommendation, however, the

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meeting certain standards. The federal compulsion has recently been relaxed. See *Deregulation Is Growing Trend for State CON Programs*, ALPHA CENTERPIECE, Feb. 1986, at 1. Pending legislation would make state participation voluntary. See *Health Planning Bill Passed*, 44 CONG. Q. WEEKLY REP. 268 (1986).

<sup>28</sup>On the policy underlying certificate-of-need laws, see generally C. HAVIGHURST, *DEREGULATING THE HEALTH CARE INDUSTRY: PLANNING FOR COMPETITION* 26-30, 54-63 (1982); Bovbjerg, *Problems and Prospects for Health Planning: The Importance of Incentives, Standards, and Procedures in Certificate of Need*, 1978 UTAH L. REV. 83, 84-97; Havighurst, *Regulation of Health Facilities and Services by "Certificate of Need,"* 59 VA. L. REV. 1143, 1148-69 (1973).

<sup>29</sup>MASS. GEN. LAWS ANN. ch. 111, § 25B (West 1977); MASS. REGS. CODE 105, § 100.020 (1977).

<sup>30</sup>FINEBERG REPORT, *supra* note 12, at app. B.

<sup>31</sup>The MAC system was put into place by chapter 372 of the Massachusetts Acts of 1982. See MASS. GEN. LAWS ANN. ch. 6A (West Supp. 1985). It established a prospective payment system for Medicaid and private insurers, modeling the approach after a Blue Cross hospital payment contract already in use. A federal waiver made the state's payment system binding on the Medicare program. *Id.*

<sup>32</sup>See MASS. GEN. LAWS ANN. ch. 6A, §§ 50-56 (West Supp. 1985).

<sup>33</sup>*Id.*

<sup>34</sup>*Id.*

exception would not be granted and the hospital would have to finance the service out of savings elsewhere. Under these circumstances, a transplant candidate with an insurer willing to pay for the procedure might not find a Massachusetts hospital willing to provide it, because any hospital revenue from treating that patient would have to be offset by reduced revenue from treating others.<sup>35</sup> On the other hand, a MAC exception would allow the hospital to cover the costs of transplants by cost shifting, increasing its charges to the various payers in order to pay for transplants needed by patients lacking adequate insurance.<sup>36</sup>

Under these regulatory circumstances, the willingness or unwillingness of payers to pay for, or of patients to buy coverage for, such procedures would have little or no effect on whether transplants would be undertaken. This decision was essentially the state's, and if the state decided to authorize the service, the public would pay for it one way or another. But this payment would not necessarily be through the usual method of openly levying taxes and explicitly appropriating funds for worthy public projects. The Massachusetts philosophy, with which no one seems to have quarreled throughout this episode, is apparently that the state alone, through the DON-MAC process, should finally dictate such matters. The state's potential role in frustrating transactions between a willing buyer and a willing seller was not commented upon. As will be seen, the state was comfortable with—though perhaps not entirely comfortable in—its role as giver or withholder of lifesaving medical treatment.

### C. *The Political Scene*

It is a widely noted fact of our political life that when an individual human life is placed in visible, media-covered jeopardy, a tug on the public heart strings loosens governmental purse strings, causing expenditures to save that "identified life" which far exceed what government is willing to spend to save an otherwise comparable "statistical life."<sup>37</sup> This phenomenon of our media-driven democracy can be viewed in contrasting ways. It is either, on the one hand, an inexcusable pandering to public passions by public officials freely using public funds to establish that they are compassionate and deserve re-election or, on the other

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<sup>35</sup>Freezing the resources available to an institution places responsibility for allocating those resources on the institution and its physicians. Decisions may not reflect the public's priorities because internal institutional politics allow economic interests and professional values to enter the picture. See Harris, *Regulation and Internal Controls in Hospitals*, 55 BULL. N.Y. ACAD. MED. 88 (1979).

<sup>36</sup>The MAC system effectively breaks most of the links between the private insurance coverage that individuals buy and the care they receive. Hospitals are free to provide any of the myriad of services authorized by their DON and to tax the cost proportionately to all payers, up to the MAC limit. See *supra* note 35.

<sup>37</sup>See *supra* notes 2, 4.

hand, a healthy and reassuring affirmation that the community prizes each individual and is not coldly calculating when human life is at stake. Although such seemingly inefficient expenditures may be defensible because they give the community a chance to feel good about itself, it is also possible that they cultivate false impressions and divert attention and resources away from unfulfilled obligations.

Jamie Fiske's story had poignant consequences nationwide and illustrated the dilemmas that government faces in allocating public resources to health care in a political environment that demands concern for a handful of identified lives. Following Jamie's transplant, public and private financing mechanisms across the country faced strong public pressure to cover the costs of the procedure for other individual victims, frequently children.<sup>38</sup> The pressure was particularly acute for state Medicaid programs; a number of governors and legislatures responded by issuing ad hoc directives to finance highly publicized cases with state funds. In Missouri, for example, the legislature specifically authorized an exceptional payment on behalf of a 16-year-old girl, only to reverse itself the following week when two things happened: additional candidates appeared, demonstrating that one costly symbolic act would not be enough to satisfy the media, and perhaps consequentially, such private legislation was found to violate the state constitution.<sup>39</sup>

Nowhere was the political pressure on a Medicaid program greater than in Massachusetts—the home of Jamie Fiske, as well as a major center for biomedical research and a state that had gone very far in accepting political responsibility for the operation of the health care enterprise. Massachusetts Medicaid declared liver transplants reimburseable for eligible persons in the summer of 1983. From then until January 1984, Massachusetts was in the anomalous position of guaranteeing to the very poor an extremely costly medical procedure that was not available to middle-class MBCBS subscribers. Thus, taxpayers were forced to buy for others transplants which they had not yet chosen to purchase for themselves through insurance. Although MBCBS was also under pressure, it was able as a private entity to hold out longer. This experience seems to confirm that elected officials and programs accountable to them—even more than private nonprofit organizations that strive to be perceived as benign dispensers of good things—do indeed seize opportunities to demonstrate their compassion by spending scarce public funds irrationally.<sup>40</sup>

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<sup>38</sup>See, e.g., Friedman & Richards, *Life and Death in a Policy Vacuum*, Hosps., May 16, 1984, at 79; Wessell, *Medical Quandary: Transplants Increase, and So Do Disputes Over Who Pays Bills*, Wall St. J., Apr. 12, 1984, at 1, col. 1; Rust, *Transplant Successes Stir Debate on Coverage*, Am. Med. News, Oct. 21, 1983, at 1.

<sup>39</sup>Friedman & Richards, *supra* note 38, at 80.

<sup>40</sup>One report asserts that this pattern is not universal, and suggests that public insurers are on the whole reluctant to cover expensive new technologies. Evans, *Transplant Coverage:*

Undoubtedly, Medicaid dollars allocated to transplants could have been put to better use in saving statistical lives or purchasing "quality-adjusted life years."<sup>41</sup> In California, the point was illustrated most tellingly: the legislative decision to pay for liver transplantation came at the same time that the legislature decided to terminate state support for its medically indigent population, those who cannot afford insurance for their own health care but are not deemed poor enough to warrant public assistance.<sup>42</sup> The eagerness of public officials to gain credit for their humanitarianism, especially when someone else's money was at stake, was revealed even in the White House, which made a number of dramatic appeals to state governments and private payers on behalf of particular individuals.<sup>43</sup> These scenes of elected representatives crowding onto the stage of this morality play left to the audience's imagination the effects of government policies on those who lacked the limelight.<sup>44</sup>

#### D. *The Private Sector: MBCBS*

Just as the public sector felt pressure to finance transplants for identified patients, private insurers all over the country, particularly Blue Cross plans, found themselves making difficult case-by-case decisions in full view of the media. MBCBS's particular problem in this regard was

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*A Public Policy Dilemma*, BUS. & HEALTH, Apr. 1986, at 5. As the Missouri experience (see *supra* text accompanying note 39) suggests, government's largess will stop when the costs to policymakers exceed the political benefits of being associated with a lifesaving effort.

<sup>41</sup>Expanding Medicaid eligibility and coverage of preventive services would be obvious strategies. See, e.g., PRESIDENT'S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, SECURING ACCESS TO HEALTH CARE: THE ETHICAL IMPLICATIONS OF DIFFERENCES IN THE AVAILABILITY OF HEALTH SERVICES, 19-20, 59-65, 79-90 (1983) [hereinafter PRESIDENT'S COMMISSION REPORT] (discussing what ought to be encompassed by "an adequate level of health care" available to all citizens and highlighting current problems in health services delivery). On the use of "quality-adjusted life years" as a way of assigning priorities to public investments in health and safety, see, e.g., Zeckhauser & Shepard, *Where Now for Saving Lives?*, LAW & CONTEMP. PROBS., Autumn 1976, at 5, 11-15.

<sup>42</sup>Wessell, *supra* note 38.

<sup>43</sup>*Id.*; see also Iglehart, *Transplantation: The Problem of Limited Resources*, 309 N. ENG. J. MED. 123, 126-27 (1983); Meyer, *Transplant Funding: A Controversial New Area*, Washington Post, Sept. 12, 1984, at C3, col. 1.

<sup>44</sup>In yet another demonstration of elected officials' felt need to "do something" to respond to media attention to the transplantation issue and to get media attention for themselves, the Massachusetts legislature, in late 1983, added a check-off box to the state's income tax returns so that taxpayers could direct that a portion of any tax refund go into an organ transplantation fund. In 1985, when the checkoff first appeared on tax forms, some 37,000 taxpayers contributed approximately \$187,000 to the fund, which will probably be used primarily to help pay for cyclosporin and other follow-up care for transplant recipients. Interview with Joan Gorga, Dept. of Public Health, Boston (July 1985).

not solved by the continued failure of Massachusetts regulators to authorize transplants, because insureds could still request treatment out of state. For this reason, MBCBS did not oppose the effort by local hospitals to get DON approval for transplantation. Indeed, MBCBS took the view that if they were going to have to pay for transplants eventually, it would be better to pay for in-state procedures.<sup>45</sup> They anticipated that the MAC system would control the incremental cost and that the DON system would limit the number of facilities.<sup>46</sup> Together these regulatory programs might restrict the capacity and the incentives of the system to perform more than a few procedures.

For the time being, however, MBCBS were reluctant to accept responsibility for paying for liver transplants anywhere. According to MBCBS officials, public pressure to pay for liver transplants in 1982 and 1983 was enormous. Although they did not wish to be perceived as denying potentially beneficial care, however costly, to any insured,<sup>47</sup> the plans were also hesitant to waive the contractual limitation under which they were obligated to pay only for generally accepted medical procedures. One reason for this attitude was recognition of the financial cost which transplants would impose on them immediately and which would have to be built into future premiums charged to customers already grumbling about high insurance costs.<sup>48</sup>

Another explanation, however, had to do with MBCBS's view of their precise role in the Massachusetts system. MBCBS complained that they were not getting clear signals from their usual sources. On the one hand, there were the pressures from the media and the example set by the Medicaid program. On the other hand, the health care system's central decisionmakers were not speaking with one authoritative voice.<sup>49</sup> For example, in 1982 and 1983, although liver transplants were gaining favor, MBCBS's medical advisors could not reasonably declare liver transplantation to be accepted therapy covered by their policies because any reasonable chance of a procedure's success depended upon use of a drug, cyclosporin A, which the U.S. Food and Drug Administration (FDA) considered experimental until September 1983.<sup>50</sup>

Apparently wedded to a vision of themselves as mere financing intermediaries bound to give effect to any doctor's prescription made

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<sup>45</sup>Interviews with Douglas Dickson, Ombudsman, and James Young, M.D., Medical Director, Massachusetts Blue Cross (July 15, 1985); see also Rust, *supra* note 38, at 16.

<sup>46</sup>Dickson and Young interviews, *supra* note 45.

<sup>47</sup>*Id.*

<sup>48</sup>Wessell, *supra* note 38.

<sup>49</sup>Rust, *supra* note 38. The termination of the National Center for Health Care Technology in a 1981 funding cut left MBCBS and other third-party payers without the prospect of an authoritative governmental opinion on which to base their payment decisions.

<sup>50</sup>FOOD & DRUG ADMINISTRATION, U.S. DEP'T OF HEALTH & HUMAN SERVICES, HHS NEWS, Pub. No. 83-19 (Sept. 2, 1983).

according to policies centrally determined by professional or governmental decisionmakers,<sup>51</sup> MBCBS preferred to rest coverage decisions on the actions of public regulatory agencies such as the FDA. They thus resisted any suggestion that they should embark on independent assessments of medical treatments, either paying for something officially deemed experimental or refusing on benefit/cost grounds to pay for something that enjoyed professional and governmental approval. As nonprofit corporations together constituting the dominant health insurer in Massachusetts, MBCBS were dependent on the public's perception of them as a benign source of financial assistance in meeting officially recognized medical needs. The Blues were beginning, however, to see the high cost and difficulties of marketing themselves in this way.

In mid-1983, MBCBS's arguments for not paying for liver transplants began to collapse. In May, the Fineberg Report called liver transplantation "clinically justifiable,"<sup>52</sup> and in June, a National Institutes of Health consensus conference stated that "liver transplantation offers an alternative therapeutic approach which may prolong life in some patients."<sup>53</sup> When these lukewarm semi-official endorsements of liver transplantation were combined with media attention to the plight of transplant candidates and the relative willingness of other insurers and Medicaid to pay for liver transplants, they seemed to leave MBCBS with no choice. MBCBS had to discover some way around their own guidelines or be perceived as denying treatment solely because of the procedure's high cost. The solution that MBCBS hit upon was to offer their subscribers a Transplant Insurance Program, called "TIP."<sup>54</sup> By this means, they hoped to bridge the gap until the FDA would approve cyclosporin A, which would allow MBCBS, consistent with their principles, to build transplants into their basic coverage and rates.

TIP was a separate, optional rider offered to all employment groups or "accounts" at a cost of 55 cents per individual or \$2 per family per month. TIP offered full coverage for heart, heart-lung, and liver transplants, beginning five days before the procedure and continuing for twelve months thereafter.<sup>55</sup> If an account chose to purchase TIP, it would be mandatory rather than optional for the account's insureds or "mem-

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<sup>51</sup>For complex reasons, private health insurers have long denied responsibility for influencing providers' treatment decisions, relying instead on professional or governmental decisionmakers to establish what services should be paid for. See Havighurst, *Explaining the Questionable Cost-Containment Record of Commercial Health Insurers*, in *THE POLITICAL ECONOMY OF HEALTH CARE* (H. Frech ed. to be published).

<sup>52</sup>FINEBERG REPORT, *supra* note 12, at 2.

<sup>53</sup>NATIONAL INSTITUTES OF HEALTH, CONSENSUS DEVELOPMENT CONFERENCE SUMMARY, LIVER TRANSPLANTATION (1983).

<sup>54</sup>See Rust, *supra* note 38, at 16-17.

<sup>55</sup>Blue Cross & Blue Shield of Mass., "Special Announcement: New Transplant Insurance Plan" (Sept. 1983) [hereinafter Special Announcement] (mailing to accounts).

bers." Before offering TIP, Blue Cross conducted several opinion surveys to determine whether the public pressure they were feeling would actually translate into individual choices to purchase transplant insurance. These surveys indicated considerable desire for such insurance on the part of surveyed individuals and families.<sup>56</sup> However, the response to TIP itself differed significantly from the response to the surveys.

TIP was offered to MBCBS accounts in September 1983. Although John Larkin Thompson, president of Blue Shield, called TIP "the ultimate referendum on whether or not the public wants to pay for these operations,"<sup>57</sup> TIP was not offered directly to individual members because MBCBS feared the effects of adverse selection.<sup>58</sup> It was left to employers to act for their insured employees. Conceivably, publicity given to the transplant issue placed employers in a political position vis-a-vis their workers that was not dissimilar to that of MBCBS and Medicaid vis-a-vis the larger public. Not wanting to appear to economize at the expense of employees who might need a transplant, employers may have been more willing to buy TIP than the employees themselves would have been. On the other hand, employers might be reluctant to buy transplant coverage because its cost might be perceived as difficult to pass on to employees.

Each account was sent a special announcement explaining TIP, which stated, "The public has indicated its desire to have coverage for organ transplants."<sup>59</sup> The announcement was clear and complete, but gave accounts only about a month to make a decision whether to begin TIP coverage on November 1. It left them, however, the alternative of picking it up at their regular renewal period during the next calendar year.

The TIP "referendum" was never completed because MBCBS discontinued it as of February 1, 1984. Cyclosporin A had actually received FDA approval in September 1983,<sup>60</sup> and in January 1984, MBCBS's medical advisory committee finally recommended that liver, heart, and heart-lung transplants be considered medically accepted procedures. These developments allowed transplantation coverage to be extended to all accounts, with a premium increase roughly equal to the TIP premium.

In contrast to the results from MBCBS's preliminary surveys, TIP did not prove especially popular during its brief marketing. By the time it was discontinued, only 7400 of the 24,348 accounts to which it was offered had purchased the coverage, 7100 had refused it, and the rest

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<sup>56</sup>Dickson interview, *supra* note 47.

<sup>57</sup>Rust, *supra* note 38.

<sup>58</sup>Dickson interview, *supra* note 47; Interview with Dorris C. Commander, Underwriting Manager, Blue Cross of Massachusetts (July 1985).

<sup>59</sup>Special Announcement, *supra* note 55.

<sup>60</sup>FOOD & DRUG ADMINISTRATION, U.S. DEP'T OF HEALTH & HUMAN SERVICES, HHS NEWS, Pub. No. 83-19 (Sept. 2, 1983).

—over 9800—had not responded.<sup>61</sup> Even the Massachusetts Commissioner of Insurance, who had statutory responsibility to act as the account decisionmaker for MBCBS's 120,000 nongroup subscribers (including a special group of low-income individually insured), had failed to make a decision regarding TIP before it was mooted.<sup>62</sup> There are many possible explanations for the modest response rate. Some accounts may have intended to pick up TIP when they next renewed their coverage. According to MBCBS, however, financial considerations probably loomed largest in accounts' decisionmaking. In addition, some accounts, particularly large ones based in more than one state, may have preferred to pay for transplantation in different ways so as to be able to offer uniform coverage to employees in all states. One employer, Honeywell, wanted the opportunity to approve the transplanting facility.<sup>63</sup> MBCBS were much more interested in seeing that someone other than themselves, preferably the state through DON, would be responsible for approving facilities and quality control.<sup>64</sup>

At MBCBS, there was little surprise at TIP's poor showing, and the perceived reason for it was TIP's cost. Yet no thought was ever given to making a point of the public's apparent indifference to transplant insurance once an actuarially fair price tag was attached. Perhaps MBCBS saw no difference from a public relations standpoint between denying transplants on the ground that the procedure was experimental and telling an individual that because his employer had rejected the TIP offer, he could not have a lifesaving procedure that the plan was providing for others.

In any case, MBCBS made no real effort to examine and ponder the significance of the TIP experiment. Indeed, they were quite happy to extend their regular coverage to handle transplants. TIP had been complicated and cumbersome. Because it constituted a separate insurance program with a separate pool of funds, TIP required a lot of tracking to separate costs attributable to the transplant from ordinary medical costs. This tracking difficulty led, in part, to the "five-days-before, twelve-months-after" policy under which all medical costs incurred within that period were deemed attributable to the transplant. Both this policy and, later, the demise of TIP sacrificed Blue Cross's ability to extract easily any data on transplants. All transplant data now go into the files with every other medical procedure and, as such, are entered per hospitalization rather than per individual insured; cumulative information

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<sup>61</sup>Friedman & Richards, *supra* note 38, at 79.

<sup>62</sup>Dickson interview, *supra* note 47.

<sup>63</sup>On Honeywell's transplant coverage, see MINNESOTA COALITION REPORT, *supra* note 9, at 48; Utah Health Cost Management Foundation, *Honeywell's Transplant Coverage Stresses Cost Containment*, HEALTH COST MANAGEMENT NEWS, May 1985, at 3.

<sup>64</sup>Young interview, *supra* note 47.

on rehospitalization, outpatient care costs, and related other costs are difficult to retrieve.<sup>65</sup>

Although apparently efficient, blending transplant coverage into a system geared only to paying claims and not to evaluating the costs and benefits of particular procedures may be a false economy. It is, however, a predictable feature of a health care system in which private insurers such as MBCBS perceive themselves merely as executing orders from the top. MBCBS throughout this episode seemed troubled only that they were unable to interpret the conflicting signals they received. Once transplants crossed the threshold of acceptability at the FDA, the NIH, the LTTF, and the DON agency, the Blues could go happily back to their usual business of forcing consumers to buy things that they have had no real opportunity to refuse.

#### *E. Enter the Task Force on Organ Transplantation*

The foregoing events left Massachusetts about to plunge into transplantation. Yet a number of problems still existed; these resulted primarily from the way in which the DON and MAC programs articulated. Simply granting a DON without increasing the MAC allowance, as recommended by the Fineberg Report, would give rise to the danger that hospitals, instead of cutting back on indisputable waste to finance transplants, would terminate other, more essential services, creating problems throughout the system. For example, a hospital closing a maternity service and using its MAC allowance to start transplants would leave its obstetrical patients to burden other hospitals, which could not be assured of increased MAC allowances to provide for these patients. In this way, the threat of sudden introduction of a costly new therapy revealed major flaws in the state's basic faith that hospitals' revenue needs could be predicted by a formula without creating major anomalies, windfalls, and unfairnesses.

The liver transplant challenge also revealed faults in the regulatory system. Simply granting a MAC exception on the theory that transplants had now become just another accepted therapy would mean losing the opportunity to ensure that the procedure was being used appropriately and that information on its safety, efficacy, and cost would be available for subsequent appraisal. The six-figure price tag for each procedure made it clear to everyone that letting the system treat liver transplants as it treats virtually everything else had significant fiscal implications. It of course occurred to no one to question publicly whether letting the system freely prescribe high volumes of other treatments with five-, four-, three-, and even two-figure price tags might also be socially inappropriate or wasteful. Thus, the basic belief that doctors and hospital employ

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<sup>65</sup>Commander interview, *supra* note 58.

their limited resources rationally and in accordance with public objectives, a faith on which the entire regulatory system was built, was not challenged.<sup>66</sup> Instead, it was concluded only that the transplant issue, because it had met the public eye and could not politically be ignored, had to be addressed with greater particularity. Why the system could not be trusted here, when it was trusted to make virtually all other choices, was never made clear.

The need to control transplants specially loomed so large that another commission, the Task Force on Organ Transplantation (OTTF), was appointed. This new task force had a broader scope than the earlier one. It was charged with making policy for heart and heart-lung transplants as well as livers.<sup>67</sup> It was also asked to provide a social evaluation, not just a technical report. As the next act of our morality play will show, the OTTF was equal to the challenge to pronounce on the largest questions of public policy in health care.

## II. ACT TWO

The OTTF was convened in October 1983, by the Commissioner of Public Health under the chairmanship of George Annas of the Boston University School of Public Health. It was charged "with the development of standards and processes for evaluating the use of organ transplantation."<sup>68</sup> The question expressly left unanswered by the Fineberg Report—whether transplantation should "be encouraged or [even] permitted"—was not even raised: "The work of the Task Force can be categorized in terms of the when, who, what and how of organ transplants."<sup>69</sup> Although the OTTF did hear testimony on the issue during its meetings,<sup>70</sup> the objections raised concerning whether to proceed with transplantation at all did not detain OTTF members long.<sup>71</sup> The political climate obviously precluded a firm stance against the new technology.

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<sup>66</sup>*See supra* notes 35 & 36.

<sup>67</sup>The OTTF's report was unclear why transplantation of bone marrow, kidneys, and other organs was not treated as well, but in stating that liver and heart transplants were "the [only] ones currently clamoring for wider introduction," the OTTF confirmed that its inquiry was shaped by politics, not by a desire to rationalize the provision of all expensive medical care. REPORT OF THE MASSACHUSETTS TASK FORCE ON ORGAN TRANSPLANTATION (1984) [hereinafter OTTF REPORT].

<sup>68</sup>*Id.* at 3, 119 (app. A).

<sup>69</sup>*Id.* at 119 (app. A).

<sup>70</sup>Dr. Alan Sager of the Boston University School of Public Health argued before the OTTF that "all citizens of the Commonwealth should have equal access to all effective care now routinely available before the range of therapies is expanded." Testimony of Alan Sager (Oct. 31, 1983).

<sup>71</sup>Interview with George Annas, OTTF chairman (July 1985). The recent report of the National Task Force on Organ Transplantation, created by the National Organ Transplantation Act, Pub. L. No. 98-507, 98 Stat. 2339 (Oct. 19, 1984), does not address this issue, simply assuming that transplantation of all kinds should be covered by public and private

The OTTF's report, the recommendations of which were unanimous, was released in October 1984, although preliminary recommendations were released in January.

### A. *The OTTF's Recommendations*

The OTTF's first recommendation advocates the introduction of liver and heart transplantation "in a controlled, phased manner that provides the opportunity for effective evaluation and review of its clinical, social, and economic aspects by a publicly-accountable body after an initial phase of 2-3 years of limited transplantation."<sup>72</sup> This position, which sounds and may well have been, under the circumstances, eminently reasonable, was almost certainly inevitable, given the political impossibility of saying "no" to transplants. The OTTF, like the LTTF before it,<sup>73</sup> was clearly seeking a middle ground that would accommodate the pressure to allow transplants but not open the door to unlimited spending on the new technology. The recommendation of a later evaluation was necessary to preserve the appearance that the procedure was still in an investigatory or probationary stage. As the Fineberg Report had noted, however, it is hard to stop a program once it has begun.<sup>74</sup>

The OTTF conveyed the impression that its unanimous conclusions were reached by rational planning, deep thinking by academic experts, and a collective social conscience. There is also the possibility, however, that it was simply compromising conflicting views, accommodating political pressures, and rationalizing the result. Although the charge that the OTTF's actions were in fact "political" might be taken as a criticism, many in Massachusetts would no doubt say that because the conclusions flowed from an open process and a representative body, the legitimacy and soundness of the result and of the values promoted are unchallengeable. Whether such faith in the politics of interest-group liberalism is warranted should be regarded as an open question, however,<sup>75</sup> and indeed it is one of the central questions inspiring this appraisal.

The OTTF's second recommendation elaborates on the first by emphasizing that transplantation should not be made "generally available" until after the recommended review by a "publicly-accountable body,"

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financing programs. U.S. DEP'T OF HEALTH & HUMAN SERVICES, PUBLIC HEALTH SERVICE, HEALTH RESOURCES & SERVICES ADMIN., ORGAN TRANSPLANTATION: ISSUES AND RECOMMENDATIONS (April 1986). The Minnesota Coalition Report, noting the trend to coverage, recommended that it "should remain optional for group accounts;" no opinion was expressed on public plans' policies. MINNESOTA COALITION REPORT, *supra* note 8, at 47-48.

<sup>72</sup>OTTF REPORT, *supra* note 67, at 10.

<sup>73</sup>See *supra* text accompanying notes 14 & 21.

<sup>74</sup>FINEBERG REPORT *supra* note 12, at 36.

<sup>75</sup>Cf. Havighurst, *More on Regulation: A Reply to Stephen Weiner*, 4 AM. J.L. & MED. 243, 247-49 (1980) (disputing claims by a Massachusetts advocate of regulation that politicized regulation is legitimized by the democratic process and should be immune to general criticism).

which should not be limited to assessing the technology's status as "experimental" or otherwise.<sup>76</sup> The Report also makes clear that in the task force's view, availability is synonymous with general reimburseability.<sup>77</sup> It opines, too, that general availability should not result only through the state Medicaid program's becoming "the de facto insurer for all such procedures,"<sup>78</sup> by virtue of inadequate private financing and the impoverishment of transplant candidates. To prevent this result and to "ensure fairness in the distribution of burdens regarding reimbursement," the Report suggests that coverage be prescribed by a "joint committee" of government representatives and private insurers.<sup>79</sup> Such a body might violate the federal antitrust laws, however, unless its decisions were embodied in official government action.<sup>80</sup>

Recommendations (3) and (4) by the OTTF introduce the issue of costs. During the evaluation period, authority to do transplants would be granted only to those hospitals that agree to perform them within the MAC, with an exception for each procedure that amounts to the costs of organ procurement and cyclosporin.<sup>81</sup> This attempt to force hospitals to finance a portion of the cost of transplant programs by economizing was apparently the only way, even in this heavily regulated state, in which the volume and hence the overall cost of transplants could be kept down. To protect against the concomitant risk that transplantation would displace other vital services, recommendation (3) suggests that need determinations in the DON program be made only upon a showing that the cost of adding transplantation can be borne without sacrificing more desirable services. "As a principle, the Task Force believes that if it turns out that liver and heart transplantations take resources away from higher priority health care services, and decrease their accessibility to the public, then transplantation procedures should not be performed."<sup>82</sup>

In a section antecedent to its specific recommendations, the OTTF gives its final word on how to prevent a modest amount of costly transplantation from diverting resources from essential services:

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<sup>76</sup>OTTF REPORT, *supra* note 67, at 11.

<sup>77</sup>*Id.* at 11-12.

<sup>78</sup>*Id.*

<sup>79</sup>*Id.*

<sup>80</sup>In general, the Sherman Act, 15 U.S.C. § 1 (1983), prohibits collective actions of the kind that are taken for granted in centrally governed health care systems as a useful adjunct or alternative to direct government control. Although the McCarran-Ferguson Act, 15 U.S.C. § 1001 (1983), provides a partial exemption from the Sherman Act for "the business of insurance," an agreement not to sell a certain type of coverage has been held to fall within an exception to this exemption. *St. Paul Fire & Marine Ins. Co. v. Barry*, 438 U.S. 531 (1978).

<sup>81</sup>OTTF REPORT, *supra* note 67, at 14. Such costs would amount to about \$9000 per heart transplant and \$44,000 per liver. *Id.*

<sup>82</sup>*Id.* at 13.

[T]he Task Force believes that these procedures should be performed on [all] those who are likely to benefit from them, so long as the total cost is controlled, and resources are not diverted from higher priority medical procedures to liver and heart transplantation. The question of what a "higher priority" procedure is will be based on the total number of individuals affected, and the importance to their lives of the intervention. For example, it *may* be appropriate to shut down an underutilized maternity program to do organ transplants. The burden of demonstrating that such a tradeoff is appropriate, however, should be on the hospital proposing it. Accordingly, in the [DON] process, all currently available health care services should be presumed to be higher priority than transplantation. The applicant should have the burden of demonstrating that transplantation has a higher priority than any other currently available health care service from which organ transplantation diverts funds and/or support systems.<sup>83</sup>

Such an allocation of the burden of proof would apparently require a hospital to prove its own past inefficiency and waste of public resources in order to qualify for the establishment of a transplant program; a well-run hospital doing only things highly beneficial to patients need not apply. Such paradoxes are common under regulation. Perhaps the crowning irony, which the task force itself notes in its chapter on costs,<sup>84</sup> is that transplantation can be contemplated in Massachusetts only because much of its high cost can be paid out of waste in the system—the very thing that regulation was supposed to prevent. The presumption that the OTTF created against the displacement of existing services by transplants can hardly be taken, in context, as an expression of faith that regulation has in fact achieved true efficiency.

Recommendation (5) addresses patient selection criteria and would require them to be "public, fair, and equitable" and based initially on medical suitability criteria and secondarily on the principle of first-come, first-served, in the event demand exceeds the supply of organs.<sup>85</sup> For Massachusetts residents, the ability to pay should not be a factor, nor should social class or family support.<sup>86</sup> The report suggests an "appeal mechanism" to ensure fairness, thereby conjuring up a vision of two lawyers advocating their dying clients' competing claims to a single liver before a neutral decisionmaker. This is a particularly striking example of how far the OTTF would go to ensure that the state appear legalistically fair

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<sup>83</sup>*Id.* at 9, 10.

<sup>84</sup>*Id.* at 60.

<sup>85</sup>*Id.* at 16-17.

<sup>86</sup>*Id.*

in dispensing life and death.<sup>87</sup> With almost equal plausibility, the report could have required that patient selection reflect "affirmative action" aimed at redressing past societal injustices toward certain groups.

Finally, recommendation (6) introduces the idea that heart and liver transplants in the Commonwealth should be undertaken by hospitals belonging to a consortium organized to share data, experience, and resources.<sup>88</sup> This idea apparently did not originate with the OTTF because it stated that there is no economic justification for beginning organ transplantation at more than one hospital, but that if more than one hospital is to do the procedure, there must be a truly integrated and cooperative effort—a "worthwhile consortium."<sup>89</sup> The consortium concept had appeared earlier in a staff recommendation by the Department of Public Health in connection with the pending DON application.<sup>90</sup> In addition, the consortium idea was dictated in part by the state's refusal to grant a MAC exception, thereby drastically limiting the number of procedures that any one institution could afford to perform.

Use of several institutions put the regulators on very shaky ground, however, in light of another prime goal of regulation—ensuring the quality of care. Because it is widely accepted that experience improves outcomes, the Department of Public Health could have been criticized if it authorized several hospitals each to perform less than the optimal number of procedures per year. The consortium concept, if it allows experience truly to be shared, overcomes this objection.<sup>91</sup> Its adoption in Massachusetts, however, appears to have been only a face-saving compromise, necessitated by the political unpopularity of giving all the business to one institution.<sup>92</sup>

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<sup>87</sup>For warnings of the consequences of excessive "due process" in dealing with sensitive issues of this kind, see Blumstein, *Constitutional Perspectives on Governmental Decisions Affecting Human Life and Health*, LAW & CONTEMP. PROBS., Autumn 1976, at 231; Havighurst, Blumstein & Bovbjerg, *supra* note 4, at 155-57. For scholarship approving the legalistic approach, see J. KATZ & A. CAPRON, *CATASTROPHIC DISEASES: WHO DECIDES WHAT?* 239-40, 246-48 (1975); Note, *Due Process in the Allocation of Scarce Life Saving Medical Resources*, 84 YALE L.J. 1734 (1975).

<sup>88</sup>OTTF REPORT, *supra* note 67, at 18-20.

<sup>89</sup>*Id.*

<sup>90</sup>*Id.* at app. B.

<sup>91</sup>A factitious consortium, however, could result in significantly poorer patient outcomes. This reasoning was the substance of an ultimately unsuccessful challenge mounted by the OTTF's chairman to the later-proposed Boston heart consortium. See Brief for Appellant at 10-13, *George J. Annas Ten Taxpayer Group v. Department of Public Health* (Health Facilities Appeals Board argued July 9, 1985) (Project No. 4-3306).

<sup>92</sup>George Annas has described the consortium concept as "primarily a political issue . . . grafted onto the original draft of the Report at the request of the Commissioner of Public Health." Annas, *Regulating Heart and Liver Transplants in Massachusetts: An Overview of the Report of the Task Force on Organ Transplantation*, 13 LAW, MED. & HEALTH CARE 4, 5 (1985).

The consortium approach solved problems for a number of the participants in the drama. The consortium idea was initially attractive to the Department of Public Health because it would relieve it of the politically difficult task of choosing among powerful institutions. MBCBS, which took credit for planting the seed of the consortium concept, were probably hoping to avoid having to select among or oversee competing hospitals or to adopt their own patient selection criteria.<sup>93</sup> The four hospitals seeking authority for liver transplants had figured out for themselves the advantages of a united front both in seeking a DON<sup>94</sup> and in avoiding possible future competition.

### *B. The Egalitarian Motif*

Perhaps the most notable feature of the OTTF report is its strong emphasis on equality in the distribution of transplanted organs. Perceiving this as the central question in the morality play, the task force declaimed:

On the issues of equity and fairness, we concur with the conclusions of the President's Commission for the Study of Ethical Problems in Medicine: society has an ethical obligation to ensure equitable access to health care for all; and the cost of achieving equitable access to health care ought to be shared fairly. *Transplantation of livers and hearts should therefore only be permitted if access to this technology can be made independent of the individual's ability to pay for it, and if transplantation itself does not adversely affect the provision of other higher priority health care services to the public.*<sup>95</sup>

A literal reading of the italicized lines indicates that the OTTF not only endorsed the provision of transplants to those who cannot afford them, but also took the startling position that paying patients should be denied transplants in Massachusetts until such time as every equally needful patient could get one. As noted earlier, it is easily within the power of Massachusetts regulators—without actually making the performance of this therapeutic procedure a criminal act<sup>96</sup>—to prevent a dying patient from purchasing a transplant with his own money from will-

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<sup>93</sup>Young interview, *supra* note 47.

<sup>94</sup>Some members of the OTTF viewed the consortium concept with suspicion, considering it an end run around the DON process that permits four programs rather than just one to perform transplants and makes it easier for the hospitals to demonstrate that other services are not being displaced. *Cf.* Brief for Appellant, *supra* note 91, at 9-10 (makes this argument with regard to the proposed heart transplantation consortium).

<sup>95</sup>OTTF REPORT, *supra* note 67, at 9-10 (emphasis added).

<sup>96</sup>Outright state prohibitions of therapeutic procedures can raise a constitutional issue. *E.g.*, *Roe v. Wade*, 410 U.S. 113 (1973) (abortion); *Rogers v. State Board of Medical Examiners*, 371 So. 2d 1037 (Fla. Dist. Ct. App. 1979) (chelation therapy). Regulatory programs having comparable effects are more difficult to challenge legally but should raise similar concerns.

ing providers. The OTTF apparently approved the use of the state's prohibitory powers in this way in order to coerce a public desirous of transplants for themselves into providing them for everyone. Probably, however, the task force never expected that such extortionate use of the state's regulatory power would actually be necessary to effectuate its policy objective of equity in transplantation.<sup>97</sup>

Although the OTTF may not have meant what it said about withholding transplants from paying patients as an inducement to the procedure's equitable provision, the OTTF was clearly unresponsive to the interests of those citizens who would not require the state's assistance to finance a transplant. Under the report's recommendations, transplants will occur only on the state's own terms, and only a limited number of transplants will be performed, regardless of the availability of organs. Because recipients of these few procedures must be selected, some patients who could and would pay their own way will not get treated.<sup>98</sup> Yet, if they were allowed to purchase their own treatment outside the MAC system, there would be no diversion of resources from "higher priority" health care. The OTTF appears content with a state policy that could deny a transplant to a dying person who had made explicit financial provision for it. The best explanation for this complacency in the face of a denial of lifesaving medical care may be simply that the OTTF members had lost the capacity to conceive of the purchase of health services as a private matter. If so, their attitude reveals a great deal about the political culture of Massachusetts and its approach to health care.

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<sup>97</sup>The DON for the liver transplantation consortium had already been granted in January, and a heart transplantation DON was issued in May. Letter from Department of Public Health to Dr. Richard Nesson, Brigham and Women's Hospital, May 16, 1984, reprinted in OTTF REPORT, *supra* note 67, at 129.

<sup>98</sup>The OTTF may have viewed this as only a theoretical danger. It may have expected, for example, that all medically defensible transplants would in fact be provided. Disagreement is likely, however, over whether a particular procedure is desirable or "indicated," and it is well-documented that as a technology improves, the medical indications for its use broaden. See Caplan, *Organ Transplants: The Costs of Success*, HASTINGS CENTER REP., Dec. 1983, at 23, 31. The OTTF also might have thought that anyone who could afford the procedure could also afford to travel out of state to get it. This proposition holds true, however, only if other states reject a Massachusetts-type hostility to transplantation and also permit outsiders to obtain organs and if the patient's ability to pay does not stem from the purchase of health insurance, which typically does not cover the many additional expenses associated with out-of-state treatments. Although the OTTF may have had reason to discount the risk that some self-supporting patients would be denied desired transplants, its report expressly recognizes that the number of people waiting for transplants might exceed the number of procedures that could be done. It is possible that it is simply not fashionable in Massachusetts publicly to express concern about the "right to health care" of anyone except the poor.

### C. Denouement

The OTTF Report was received by the Public Health Council of the Department of Public Health and was the subject of a public hearing on November 5, 1984. The council unanimously adopted the report's recommendations as official policy and instructed the Department to use the text of the report for guidance in DON proceedings. The current state of organ transplantation in Massachusetts appears to have followed the outlines of the OTTF's script. There are questions, however, whether the spirit of its recommendations has been observed in practice. For example, it is doubtful that hospitals seeking DONs for transplantation have given any real guarantee that "higher priority" services will not be affected. Also, it has been questioned whether the consortium is really functioning as an integrated research program dedicated to collecting useful data for later evaluation by a "publicly-accountable body."<sup>99</sup> It would appear that the drama is not yet over.<sup>100</sup>

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<sup>99</sup>See *infra* note 117. Both the OTTF and the Department of Public Health contemplated a later evaluation of the liver transplantation program to see whether higher priority services were being displaced and expected that the data collected would shed light on this issue, on which the consortium would have the burden of proof. The first annual report of the consortium, covering January 26, 1984, to January 26, 1985, was brief, even cursory, and seems not to contain the data required by the DON, let alone data that could prove anything about displacement. BOSTON CENTER FOR LIVER TRANSPLANTATION, 1984 ANNUAL REPORT (1985). Even the actual costs of transplantation per survival year are impossible to calculate from the report. Patients' rehabilitation status is only sketchily assessed, and no data are supplied as to the basis for rejection of candidates or the current health status of those rejected. *Id.* Without comparative outcomes, it is impossible to judge the procedure's value or the predictive effectiveness of the patient selection criteria used. There is also no evidence that transplants have not displaced desirable services.

Some OTTF members, including Chairman George Annas, argue that the coalition is violating at least the spirit of its DON. Annas interview, *supra* note 71. The Department of Public Health seems to feel, however, that because the data collection requirements for livers were never very well defined, the coalition's first report is satisfactory. Gorga interview, *supra* note 44. At a recent conference, panelists discussing the Massachusetts system—including Public Health Commissioner Walker, transplant surgeon Roger Jenkins, OTTF chairman Annas, and economist Marc Roberts—disagreed in almost every particular regarding whether the Department and the consortium were doing what they were expected to do. CONFERENCE ON TRANSPLANTATION AND ARTIFICIAL ORGANS: ISSUES ALONG THE EXPERIMENT-TO-THERAPY SPECTRUM (Nov. 1985). The lack of agreement on a variety of issues suggests that the apparent consensus surrounding the OTTF Report resulted from a failure to address practical issues and a papering over of potential problems. Indeed, at the conference just cited, OTTF chairman Annas labeled the OTTF "a quasi-Quixotic noble failure." *Id.*

<sup>100</sup>At present, however, the even more complicated debate over heart transplantation in Massachusetts is apparently diverting much attention from the liver issue. Gorga interview, *supra* note 44; see *supra* note 91. The parties to this debate are more experienced and sophisticated than they were at the time of the liver debate. In particular, Massachusetts expects to employ many of the recommendations developed by the Battelle Human Affairs

### III. REVIEWING THE PERFORMANCE

Viewers of the morality play "Liver Transplantation in Massachusetts" must come away unsatisfied but instructed in the difficulties of putting life-and-death choices on the political stage. Perhaps more than any other state, Massachusetts, aided and abetted by a powerful intellectual community, has assumed the role of dominant decisionmaker in health care matters. The case of liver transplantation provides a unique test of the ability of at least one model of a monolithic, highly regulated, and politicized health care system to address difficult choices involving expensive medical technology.<sup>101</sup>

In the Massachusetts system, it was necessary for the state to decide publicly whether to allow liver transplantation at all, and the action of the drama was ostensibly about the making of this choice. Politically, however, the state probably never really had the option of rejecting transplants once major research institutions resolved to perform them and the media concluded that access to them was the right of every Commonwealth citizen. As in a Greek tragedy, the outcome was fore-ordained, and the characters were never truly free to alter the inevitable result. It is in the nature of "tragic choices" that once they become political, they are driven mainly by forces beyond the power of individuals to control or escape.<sup>102</sup> To accept the decisions emerging from the black box of Massachusetts state government as appropriate societal choices is to ignore not only the previously-noted questionable features of the political process, but also the shortcomings of regulation, some troublesome ethical issues, and the possible availability of alternative decisionmaking mechanisms.

#### A. Regulatory Inadequacies

Having approved transplants in principle, the Commonwealth of Massachusetts and its respective task forces then had the problem of

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Research Center. See R. EVANS, NATIONAL HEART TRANSPLANTATION STUDY; FINAL REPORT (1984) (prepared by the Battelle Human Affairs Research Center for Health Care Financing Administration, DHHS, Washington, D.C.)

<sup>101</sup>See *supra* note 8. A particularly interesting point of comparison is provided by the Minnesota Coalition Report which, as the product of a private organization, is much less a political document than the OTTF report. MINNESOTA COALITION REPORT, *supra* note 8.

<sup>102</sup>Keeping such issues out of the political arena is itself difficult. As a societal attempt to resolve the tragic choice by finessing it, this strategy, like others, is apt to be unstable precisely because it sacrifices important values, such as openness and explicitness. Professor Calabresi predicts an inevitable and continuing oscillation among imperfect solutions as society continually reasserts those values (equity, efficiency, freedom, etc.) that are being neglected by whatever system of choosing is currently in place. See G. CALABRESI & P. BOBBITT, *supra* note 5, at 195-99. However, whether a stable system can be designed or happened upon without explicit policy choice is an empirical question. In any case, depoliticization would appear to be a vital first step toward possible stability.

rationing the costly procedure. However, the Massachusetts regulatory scheme, despite its comprehensiveness and complexity, provided no public mechanism for deciding explicitly how often and under what circumstances the procedure would be done. As one protection against high costs, the task forces recommended against a complete pass-through of expenditures for transplants, thus forcing hospitals to look elsewhere for at least some of the necessary funds. Under the state's regulatory control of hospital revenues, virtually the only way for a hospital to generate such funds would be to cut back its other activities. The OTTF's response to the danger that transplants would displace more valuable hospital services was to instruct the DON agency to withhold approval of a transplantation program that could not prove that only relatively wasteful activities would be eliminated in order to accommodate it. As a regulatory standard, this requirement was highly impractical and unrealistic,<sup>103</sup> but it protected the task force against the criticism that it had authorized a diversion of resources to lower-priority uses.

With all their regulatory paraphernalia, Massachusetts officials lack the statutory powers they need to control directly the volume and cost of transplants. As to these and all other medical procedures, the state can only identify institutional providers of needed services and control, in a rough way, the total resources at each institution's disposal. Because these powers do not add up to effective control of medical technology, the level of transplantation activity in Massachusetts remains ultimately in the hands of prestigious doctors and hospitals, subject to certain resource constraints. Although limiting the resources available to providers can control aggregate costs, the Massachusetts MAC controls relate in no recognizable or rational way to the potential benefits or costs of any particular procedure. Allocational decisions are thus left in providers' hands.<sup>104</sup> Once Massachusetts is satisfied that the resources used in organ transplantation are not obtained by eliminating "higher priority" health services currently being provided, it permits transplants to proceed without regard to the additional possibility that those resources might have still other, more valuable uses.

Thus, although Massachusetts has made it appear that it has exercised statesmanlike control in this highly publicized area, it may have done nothing more than give certain Boston hospitals the green light to rearrange institutional priorities to facilitate new adventures on the frontiers of medicine. The main constraint on these institutions is the risk

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<sup>103</sup>See *supra* note 99. Two critics of the OTTF's burden-of-proof recommendation for DON proceedings have said, "[I]t is difficult to imagine a process that is more conceptually confining, less amenable to empirical analysis, and more open to subjective interpretation." Overcast & Evans, *Technology Assessment, Public Policy and Transplantation: A Restrained Appraisal of the Massachusetts Task Force Approach*, 12 LAW, MED. & HEALTH CARE 106 (1985).

<sup>104</sup>See *supra* note 36.

that their actions will offend future state officials or the "publicly-accountable body" that the OTTF recommended to evaluate transplantation later on. The implicit threat that the state might take unspecified action in the future puts the participating institutions on notice that they had better be able to defend their use of resources or face unpleasant consequences. Such is life in a centrally managed health care system, where things fortuitously attracting public notice receive minute attention while well enough is left alone. Politicization of transplantation achieves control for its own sake but provides little assurance that resources will be put to their best use. A regulatory system that purported to make all the necessary allocational choices would be a more stifling form of regulation than even Massachusetts would be likely to tolerate.

### B. Questions of Values

Above all, Massachusetts strove for ethical high ground in establishing its position on liver and heart transplants. Yet a careful reading of state policy as reflected in the OTTF report reveals a willingness to countenance the denial of transplants to paying patients—not out of any paternalistic concern, but simply because some other person in comparable condition could not afford the same treatment. Perhaps it was the prospect of organ shortages and bidding wars that only the well-to-do could hope to win that induced the OTTF to approve the denial of transplants to paying patients. After all, the question of how to ration scarce medical resources has long inspired ethicists to philosophical debate,<sup>105</sup> and the OTTF, chaired by a leading participant in that debate,<sup>106</sup> may have assumed that it had been convened primarily for the purpose of prescribing an ethically satisfying system for rationing scarce organs.<sup>107</sup> The

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<sup>105</sup>The relevant literature is voluminous. For general sources, each of which itself draws on many others, see N. DANIELS, *JUST HEALTH CARE* (1985); *IN SEARCH OF EQUITY: HEALTH NEEDS AND THE HEALTH CARE SYSTEM* (R. Bayer, A. Caplan & N. Daniels eds. 1983); H. SMITH & L. CHURCHILL, *PROFESSIONAL ETHICS AND PRIMARY CARE MEDICINE* (1986); Childress, *Rationing of Medical Treatment*, in 4 *ENCYC. OF BIOETHICS* 1414 (W. Reich ed. 1978).

<sup>106</sup>See, e.g., Annas, *No Cheers for Temporary Artificial Hearts*, 15 *HASTINGS CENTER REP.* 27 (Oct. 1985); *The Phoenix Heart: What We Have To Lose*, 15 *HASTINGS CENTER REP.* 15 (June 1985); *Allocation of Artificial Hearts in the Year 2002: Minerva v. National Health Agency*, 3 *AM. J. LAW & MED.* 59 (1979).

<sup>107</sup>The OTTF's apparent eagerness to respond to that charge may be seen in its failure to consider seriously the possibility of encouraging the sale of organs by families of deceased potential donors to those awaiting transplants. OTTF REPORT, *supra* note 67, at 37. A market for organs would eliminate shortages and the need for rationing systems to allocate a limited supply. However, instead of seeking to break down the current cultural taboo against the buying and selling of body parts, see the National Organ Transplantation Act, *supra* note 71 (prohibiting the sale of organs in interstate commerce), the OTTF took the easier political path. Indeed, it may have welcomed organ shortages

OTTF did not, however, expressly restrict its recommendations to situations where there were not enough organs to go around. As it appears, the OTTF was entirely comfortable with a policy that would force self-supporting transplant candidates to join (and perhaps die in) the state-mandated queue even if an adequate number of organs was available.

In support of its willingness to deny transplants to paying patients, the OTTF invoked a well-known 1983 report by the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research.<sup>108</sup> Although the President's Commission did declare that society has an ethical obligation to guarantee a decent level of health care to its neediest citizens,<sup>109</sup> nowhere did it indicate that it would be ethical to hold the wealthy and well-insured sick hostage without treatment until society honored this obligation. Moreover, the President's Commission clearly stated that it was not ethically necessary for all citizens to receive the same health care.<sup>110</sup> Thus, it certainly laid no foundation for the Massachusetts policy of forcing all transplant candidates to take their chances in a state-sponsored life-and-death lottery.

The OTTF again misrepresented the President's Commission in citing its report as authority for guaranteeing procedures as costly as liver and heart transplants to persons who cannot afford the insurance necessary to purchase them.<sup>111</sup> Although recognizing a public obligation to provide a decent minimum level of health services to all, the Commission did not fully define that level or specify what services should be included in the guaranteed package. Moreover, there are numerous reasons why one might conclude that procedures as costly as liver transplants ought not to fall under society's guarantee until the nation becomes a great deal wealthier and has met a great number of other needs, including non-health needs, of its less advantaged citizens.<sup>112</sup> The OTTF seemed

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as a constraint on the number of costly procedures and as an excuse for implementing their rationing theories. See, e.g., OTTF REPORT, *supra* note 67, at 80, 83.

The shortage of organs is currently being addressed by donor education efforts, ranging from promoting the slogan "Organ Donors Recycle Themselves" to legislation requiring hospitals to request donations from families of potential donors.

<sup>108</sup>See *supra* text accompanying note 95 (citing PRESIDENT'S COMMISSION REPORT, *supra* note 41).

<sup>109</sup>The President's Commission Report states as its first premise that "society has an ethical obligation to ensure equitable access to health care for all," and continues: "Equitable access to health care requires that all citizens be able to secure an *adequate* level of care without excessive burdens." PRESIDENT'S COMMISSION REPORT, *supra* note 41, at 4 (emphasis added).

<sup>110</sup>*Id.*

<sup>111</sup>OTTF REPORT, *supra* note 67, at 74.

<sup>112</sup>As the President's Commission explains:

[T]he standard of adequacy for a condition must reflect the fact that resources used for it will not be available to respond to other conditions. Consequently, the level of care should reflect a reasoned judgment not only about the impact

to conclude that the mere fact that transplants may save lives is enough to obligate society to pay<sup>113</sup>—despite the explicit finding that at \$230,000 to \$340,000 per patient surviving one year, liver transplants were several times more costly than the most costly of other generally accepted medical treatments.<sup>114</sup> The OTTF thus backed itself into an ethically debatable position. While arbitrarily treating transplantation as being so valuable that it should be available to all, it also declared that because of the expense, only those transplants that could be financed primarily out of system waste should be provided. Thus, the OTTF's desire to demonstrate its and Massachusetts' commitment to providing lifesaving treatment for all led it to restrict transplants' availability to all patients, including those who would not require public financing. Such a policy had specifically been denounced by the President's Commission as "an unacceptable restriction on individual liberty."<sup>115</sup>

Under the circumstances, it seems probable that the OTTF and the Commonwealth were more concerned with performing a symbolic act than with giving the poor the essentials of a good life. Indeed, although the OTTF explicitly endorsed the equitable distribution of transplantation as an available means of "prevent[ing] the gulf between the haves and have nots from widening,"<sup>116</sup> the primary beneficiaries of the transplant

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of the condition on the welfare and opportunity of the individual but also about the efficacy and the cost of the care itself in relation to other conditions and the efficacy and cost of the care that is available for them.

PRESIDENT'S COMMISSION REPORT, *supra* note 41, at 36; *see supra* notes 41 & 70.

<sup>113</sup>The OTTF's conclusion that organ transplantation should be part of that adequate level of care is apparently justified by the stated public perception that transplantation is "life-saving." OTTF REPORT, *supra* note 67, at 5. The President's Commission Report, however, does not contemplate and indeed does not seem geared toward addressing the inclusion of extreme and expensive technologies in the guaranteed minimum level of care. For example, it states:

Society will reasonably devote some resources to health care but reserve most resources for other goals. This, in turn, will mean that some health services (even of a lifesaving sort) will not be developed or employed because they would produce too few benefits in relation to their costs and to the other ways the resources for them might be used.

PRESIDENT'S COMMISSION REPORT, *supra* note 41, at 19.

<sup>114</sup>On cost figures, *see* OTTF REPORT, *supra* note 67, at 43-69. These figures have been criticized as excessive. *E.g.*, Overcast & Evans, *supra* note 102, at 107. *See supra* text accompanying notes 17 & 20.

<sup>115</sup>PRESIDENT'S COMMISSION REPORT, *supra* note 41, at 20; *see also id.* at 4, 18; Pauly, *Equity and Costs*, 13 LAW, MED. & HEALTH CARE 28 (1985). A better reading of the President's Commission Report surely would conclude that the state ought to ensure equitable access to lower-cost, higher-priority services, leaving expensive technologies outside the "decent minimum" but available for purchase by those who choose to devote personal resources to that end.

<sup>116</sup>OTTF REPORT, *supra* note 67, at 75; *see* Pauly, *supra* note 115, at 29. The OTTF surely places disproportionate emphasis on catastrophic health care as a way to rectify perceived injustices in the social order. It is open to challenge not only by those who

policies adopted were not the less well-off populations, from which a few transplant candidates might come, but those who could take public credit for making the humanitarian choice. The OTTF members, the public officials involved, and the citizens of Massachusetts as a whole avoided appearing cold-hearted and uncaring in the face of imminent death by symbolically extending lifesaving assistance to a handful of afflicted patients. The troubling question remains, however, whether the Commonwealth has so far discharged its other, perhaps greater responsibilities to its disadvantaged citizens that those basking in the glow of this good work are truly entitled to feel good about themselves.

### C. *The Alternative of Off-Stage Choices*

Whenever tragic choices are made upon a public stage, it is probably inevitable that the actors will play to the audience, sacrificing some values, particularly allocative efficiency, in order to be seen as acting vigorously in the defense of human life. Before one can criticize the performance in Massachusetts, therefore, it is necessary to ask whether there is any way in which these difficult issues could have been resolved without public posturing and with a greater expectation that resources would not be used in pursuit of health benefits too modest to justify the outlays. Can the role of politics in these difficult matters be limited? One discussion of this question frames the challenge as follows:

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would be prevented from purchasing transplants but also by the have-nots in question, who might reasonably choose to have the resources applied where they have greater need and can expect greater benefit. It appears, however, that the OTTF had a larger political agenda. Chairman Annas has acknowledged as much in responding to criticisms such as those suggested here:

The Task Force . . . saw its charge as an opportunity to express our views on how the system *ought* to work. The Task Force believed that fairness and equity are critical values that are more important than perpetuating a system where only the rich and those with the right insurance or publicity acumen can obtain transplants. The fact that we have not tried for equity and fairness elsewhere in the system does not make it somehow wrong to take the opportunity we have in heart and liver transplantation to try to introduce equity and fairness in the real world. We must begin somewhere. Anywhere will entail some arbitrariness. But the symbolic nature of transplantation, and its ability to capture the public's attention and support, commend it as a reasonable place to begin. Far from presuming "the validity of the status quo," the Task Force believed that transplantation provides a unique opportunity to modify some of the the health care system's fundamental operating assumptions.

Annas, *The Dog and His Shadow: A Reply to Overcast and Evans*, 13 LAW, MED. & HEALTH CARE 112, 113 (1985). Annas's visionary goal is, however, as remote as ever. The OTTF Report's passionate concern for equity ironically succeeds only in raising to the level of principle the political preference for identified over statistical lives, while doing little to clarify the debate over the extent to which government should guarantee the provision of health care services.

[A]lthough there are good reasons for our society to seek to spare its individual members catastrophic health care costs, in doing so it will almost inevitably commit more resources than it really wants to commit, or should commit, to such a purpose. This result is probable because government will find it difficult to impose, or even tolerate, needed limits on very expensive medical efforts to save lives and preserve health without seeming to deny the sanctity of human life. The challenge is thus to design social institutions which neither unduly sacrifice society's humanitarian ideals nor overspend on medical services not warranted by the benefits they yield. . . . [G]overnment cannot safely assume too central a role in decisionmaking on life-and-death and similar issues and . . . society will be better off if institutional arrangements are such that death and suffering from catastrophic disease continue to be perceived as "more an act of God than of the legislature." Careful attention to program details and to the allocation of decisionmaking responsibility is necessary if society is to succeed, in the context of expanded protection against catastrophic medical expenses, in preserving both humanitarian values and democratic government's benign—if not its beneficent—image.<sup>117</sup>

The quoted study "identifies a critical need to keep government's profile low in order to facilitate saying 'no' when it is appropriate to do so" and "seeks to help government limit its moral as well as its financial exposure while honoring a substantial commitment to assist victims of catastrophic disease."<sup>118</sup>

The Massachusetts performance reviewed here casts only a little light on the possibility that government can be removed from center stage in these dramas and that there can be introduced instead the *deus ex machina* of an unregulated, demand-driven market for health services. The foundation of the Massachusetts system is, after all, the assumption that regulation is essential to prevent inefficient growth and wasteful spending on health services of all kinds. Although there was a time when this assumption seemed unchallengeable, actual reforms in some health care financing mechanisms have recently begun to reveal the potential of private purchasing decisions in a competitive marketplace to curb the excessive flow of resources into the health care sector and to confine spending to activities that are relatively cost-effective.<sup>119</sup>

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<sup>117</sup>Havighurst, Blumstein & Bovbjerg, *supra* note 4, at 123-24 (quoting ARTIFICIAL HEART ASSESSMENT PANEL, NAT'L HEART & LUNG INST., THE TOTALLY IMPLANTABLE ARTIFICIAL HEART 247 (1973) (separate views of C. Havighurst)).

<sup>118</sup>*Id.* at 124.

<sup>119</sup>See, e.g., Arnett, *Health Spending Trends in the 1980's: Adjusting to Financial Incentives*, HEALTH CARE FIN. REV., Spring 1985, at 1; Davis, *Is Cost Containment Working?*, HEALTH AFF., Fall 1985, at 81.

Certainly what is known about the efficacy and costs of liver transplantation does not suggest that only irrational or impoverished persons would ever choose to forgo this treatment even in the face of certain death.<sup>120</sup> It thus may be socially desirable and practically feasible to leave decisions about whether or to what extent to cover liver transplantation to private choices of employers, health insurers, and organized health plans, all of which are accountable to consumers in a competitive market.<sup>121</sup> Even where public financing is necessary, government may recede from its current role as dominant decisionmaker by cashing out current in-kind benefits and letting beneficiaries shop for private coverage with financial help in the form of a government-supplied voucher.<sup>122</sup> In this fashion, government can fulfill its responsibility for providing a decent minimum level of health services without having to rule definitively on what services beneficiaries must select.

Whether the performance of a competitive, demand-sensitive market for health care will satisfy the full range of public expectations is still an open question, but there is at least some evidence that health care consumers and providers are now economizing in ways previously resisted. Thus, it may be possible

to eschew trying to solve the [catastrophic disease] problem in any definitive fashion and instead to take steps to enhance each

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<sup>120</sup>Available data suggest not only that liver transplantation is uniquely expensive but that it can plausibly be viewed as of questionable benefit. Although the OTTF Report's survey of liver transplantation morbidity and mortality is brief, OTTF REPORT, *supra* note 67, at 29-32, other sources raise some important questions concerning the toxicity of cyclosporin, the effect of long-term administration of immunosuppressive drugs on the growth and development of children, and the near-total lack of measures of the quality of survivors' lives. See NAT'L CENTER FOR HEALTH SERVICES RESEARCH, DHHS, LIVER TRANSPLANTATION (1983); STARZL, 1 TRANSPLANTATION PROCEEDINGS (1985). The OTTF addressed these major concerns only in connection with the prospect that too many transplant seekers might die in the state-mandated queue; if this happens, the OTTF Report advocates that individuals meeting the medical criteria for inclusion "be persuaded not to attempt to join the queue" by telling them the truth about transplantation. OTTF REPORT, *supra* note 67, at 83. The implication is that if people understood all of the risks, consequences, and side effects of transplantation and their implications for the duration and quality of life of survivors, a significant number of candidates would voluntarily forgo the procedure. One would suppose that potential candidates deserve the opportunity to achieve that full understanding regardless of the size of the organ supply. The OTTF was even farther, of course, from seeing any connection between doubts about the value of the procedure and the procedure's extraordinary costs; it was also opposed to letting individuals compare likely benefits and costs before deciding whether to invest in the necessary insurance. *Id.* The Minnesota Coalition Report specifically contemplates such choices. MINNESOTA COALITION REPORT, *supra* note 8, at 47-48.

<sup>121</sup>Allowing individual consumers to exercise free choice creates problems of adverse selection and may be questionable policy for other reasons. See *infra* note 124.

<sup>122</sup>See MINNESOTA COALITION REPORT, *supra* note 8, at 38-41. This report discusses two alternative strategies for "implementing the 'basic level of health care' principle." *Id.* One of these is a voucher-type strategy that would leave the private sector substantial decisionmaking freedom.

individual's ability to solve his own personal problem by choosing among a variety of available options, with public financial assistance where necessary. Such a strategy lacks the tidiness and specificity which policymakers often desire and would doubtless leave many residual problems. . . . But the fundamental values of pluralism and freedom . . . suggest an obligation not only to tolerate but also to foster diversity on matters as intensely personal and private as the means of coping with life-threatening disease and the attendant tragic choices.<sup>123</sup>

Such an approach provides a major challenge to society's ability to educate consumers and foster rational decisionmaking about low-probability events.<sup>124</sup>

The Massachusetts experience with liver transplantation yielded one interesting datum helpful in appraising the market alternative when MBCBS offered TIP at an actuarially fair price to their group accounts and fewer than one third of them accepted the offer. Unanswered, of course, are many questions, including the ultimate one—whether a situation in which some citizens are protected against a highly visible health care need and others are not is a stable and tenable one or one that would disintegrate upon the appearance of a transplant candidate who

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<sup>123</sup>See Havighurst, Blumstein, & Bovbjerg, *supra* note 5, at 189.

<sup>124</sup>The simple view is that "organ transplantation is the epitome of an insurable event; transplants are random, rare, their risk probabilities are measurable, and transplants are prohibitively expensive for most individuals." MINNESOTA COALITION REPORT, *supra* note 8, at vi. But letting *individuals* choose is not necessarily the optimal policy. For example, Calabresi observes:

I'd like to know, for instance, if any individual does value his own life in a way that can meaningfully be used in choosing between life and death risks. If each of us were paid to take a one in a million chance to lose our life, realistically, how much would we ask? How much more would we ask if the chance of death were one in one thousand? Or one in two? I would suggest that the value that most of us would give to our lives would not be the same value in the three cases, after discounting by mathematical risk. In other words, the value we as individuals put on our life is not independent of the gamble we are taking. This fact makes it very, very difficult as a practical matter to define any value as the appropriate one in creating incentives for safety.

Calabresi, *Commentary*, in *ETHICS IN HEALTH CARE* 48, 52 (1974). For findings from psychological research suggesting inconsistencies and incoherence in consumer decisions that require the weighing of risks and valuation of alternative outcomes, see Kahneman & Tversky, *The Psychology of Preferences*, 246 *SCI. AM.* 12 (1982); Tversky & Kahneman, *The Framing of Decisions and the Psychology of Choice*, 211 *SCI.* 453 (1981). Although these difficulties suggest the shortcomings of individual choice, most market choices of insurance coverage are not made by uninstructed consumers. Instead, they are most likely to emerge from collective processes in employment groups and to reflect the sophistication of employers, insurers, and medical care providers. Such collective choices are likely alone to reflect both shared values and the existence of alternative uses of the resources at stake.

turned down the available protection. This empirical question deserves more thoughtful attention than it has yet received. For example, it would not be conclusive evidence against relying upon market choices to ration transplantation if an occasional patient should receive, at an employer's or insurer's expense, a treatment that was not included in purchased coverage. Informal provision of such charity for occasional exceptionally appealing cases is not an unthinkable alternative to the Massachusetts rationing system. Indeed, it could supply just the buffer against highly publicized denials of care that is needed to maintain an effective barrier to spending vast resources on marginally beneficial treatments.

Attention must also be given to the design of coverage that can survive the inevitable questioning and legal challenges. One can imagine, for example, insurance policies that provide liver transplants for the most appealing patients, such as children, but deny them to victims of less attractive diseases, such as alcoholism. Other mechanisms for controlling costs and ensuring quality include limiting coverage to transplants obtained in centers that have been identified by the insurer as efficient and low-cost. Although much remains to be learned about whether and how to purchase this costly and still questionable service, privatization of catastrophic insurance, perhaps with tax and other incentives to encourage coverage broad enough to minimize the demoralizing effects of tragic choices, would seem to make possible sensible rationing techniques that the public sector could not itself sustain.<sup>125</sup>

Perhaps the best way to conclude this reflection on how society handles these difficult matters is to ask how these problems will be addressed a hundred years from now. Is there any doubt that society will somehow reassess its commitment to saving lives without regard to cost and will come to accept as a matter of course some deaths that could be prevented by the application of high technology? There are many different ways in which patients can be selected for treatment, not all of which require reliance on government to act directly or indirectly as the giver or denier of life itself. Without question, our attitudes toward such matters are changing. Ultimately we must give up some cherished but so far unexamined collective beliefs. The frightening but certain truth is that we are acting out our own morality play—one in which some simplistic values, of the kind that flourish most in a political environment, must eventually give way to some hard realities of the human condition. As in any great drama, the central question is whether other, more vital values will be preserved.

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<sup>125</sup>Current proposals to provide catastrophic health insurance protection, *see, e.g., Perspectives, Catastrophic Insurance*, Washington Rep. on Med. & Health, Apr. 21, 1986, would benefit from being examined in light of the concerns expressed herein about placing government in a central decisionmaking role.

