gives the history of the policy development to that point, as as well as an overview of the different stages and arguments involved in the policy formation.

7. T. E. Starzl, R. Shaprio, and L. Teperman, "The Point System for Organ Distribution," *Transplantation Proceedings* 21 (June 1989): 3434.
8. Daniel Wikler, "Equity, Efficacy, and the Point System for Transplant Recipient Selection," *Transplantation Proceedings* 21 (June 1989): 3437.
9. Robert M. Veatch, "Allocating Organs by Utilitarianism Is Seen as Favoring Whites over Blacks," *Kennedy Institute of Ethics Newsletter* 3 (July 1989):1 and 3.
10. Robert M. Veatch, *Death, Dying and the Biological Revolution*, rev ed. (New Haven: Yale University Press, 1989), p. 210.
11. George J. Annas, "No Cheers for Temporary Artificial Hearts," *Hastings Center Report* 15 (October 1985).
12. Task Force, *Organ Transplantation*, pp. 88-89.
13. James F. Childress, "Who Shall Live When Not All Can Live?" *Soundings* 53 (1970): 339-55.
14. See Task Force, *Organ Transplantation*, chap. 5.
15. Contrast Norman Daniels, "Comment: Ability to Pay and Access to Transplantation," *Transplantation Proceedings* 21 (June 1989): 3434. For a sharp criticism see F. M. Kamm, "The Report of the U.S. Task Force on Organ Transplantation: Criticisms and Alternatives," *Mount Sinai Journal of Medicine* 56 (May 1989): 207-20.
16. See PL 98-507.
17. H. Tristram Engelhardt, Jr., *Foundations of Bioethics* (New York: Oxford University Press, 1986), p. 369, n. 7.
18. For a sketch of a model of balancing, which is, however, not fully consistent, see "The UNOS Statement of Principles and Objectives of Equitable Organ Allocation," *UNOS Update* (August 1994), pp. 20-38. For a strong argument against balancing medical utility against justice, with justice interpreted as requiring "opportunities for equality of health," see Robert M. Veatch's response to an earlier version of this chapter.* My reasons for rejecting much of Veatch's position appear in the argument for medical utility in the previous chapter as well as in the overall argument of this chapter, even though I do not directly address his arguments.
19. Norman Daniels, *Just Health Care* (Cambridge: Cambridge University Press, 1985), which has greatly influenced these concluding remarks.
20. Guido Calabresi and Philip Bobbitt, *Tragic Choices* (New York: Norton, 1977).

*EDITORS' NOTE: See this section.

Equality, Justice, and Rightness in Allocating Health Care: A Response to James Childress

Robert M. Veatch

James Childress has given us a carefully reasoned and generally plausible account of an ethics of allocating resources and its implications for organ transplantation, one that reflects a moral theory far more subtle than a simple strategy of maximizing good consequences from the scarce health care resources we have available. He shows that the decisions made about ethical theory make a difference in how people will get treated by the health care system. Rather modest changes in the theory, however, can have important implications for decisions such as who should get scarce organs for transplantation.

I would like to suggest some places where some of these small changes in the general theory would be plausible and then comment on how that has forced me in my role as a member of the Washington Regional Transplant consortium to vote for a different kidney allocation formula.

Childress and I agree that justice or fairness is one among several right-making principles for moral action. This implies that it is theoretically possible that, depending on one's formula for resolving conflict among ethical principles, a policy that is just or fair may turn out not to be exactly the policy that is ethically right, all things considered. Before tackling the question of the correct formula for resolving

From *A Time To Be Born and A Time To Die: The Ethics of Choice*, Barry S. Kogan, editor, Aldine de Gruyter, 1991.

such conflict among principles, about which Childress and I differ on certain particulars, it is going to be necessary to clarify exactly what we mean by justice. Then I will try to reveal why this makes me opt for a somewhat different strategy for allocating kidneys than Childress appears to favor. I will close with some comments on how justice ought to relate to the other moral principles for allocating kidneys or any other scarce health resource.

THE PRINCIPLE OF JUSTICE

Deciding what is just or fair entails understanding whether there is a moral right-making characteristic of actions or polices or practices that is independent of the other usual considerations we take into account in deciding about right conduct. In particular, is the right allocation simply a matter of spreading resources around so that they produce the greatest amount of good in aggregate or so that people are free to act autonomously in using their private property; or is there some unique and independent consideration separate from these factors that pulls on us in deciding who should get a kidney or a scarce hospital bed or Medicare dollar?

Many ethical traditions have recognized that there is a moral principle independent of utility that bears on how resources should be distributed. They variously hold that there is a natural law, a law created by God, or that reason requires that one thing to consider in allocating resources is that they be distributed justly. One approach that permits some convergence of these disparate views is to ask what reasonable people would recognize as just if they had general knowledge of the facts of nature and human psychology, but no knowledge of their particular interests or needs. This approach does not necessarily require us to agree on why people under such circumstances would agree. Some might say they would agree because there is a preexisting moral law, others because reason would require it, or because it is a prudent way to protect self-interest. Regardless, there seems to be considerable convergence that, at least in certain circumstances, justice has something to do with an allocation that is not based solely on getting as much total or average utility out of the resources being allocated. Our sense of justice has something to do with recognizing the fundamental equality of persons. Although the argument cannot here be developed in detail, virtually all the ethical traditions participating in the current discussion recognize that the principle of justice creates a presumption in favor of equality. In my view, people under the circumstances I have described would agree that one right-making characteristic of an allocation practice would be that it gives people an opportunity for equality of well-being. This is what I shall refer to as the egalitarian principle of justice. Recall that whether it is right, on balance, to give people such an opportunity for equality of well-being will have to be settled later....

JUSTICE IN ALLOCATING ORGANS FOR TRANSPLANT

This brings us to the question of what would count as a just practice for allocation of kidneys or other organs for transplant. We should realize at this point that the just allocation is not necessarily the allocation that will produce the most benefit. In some cases, because of decreasing marginal utility, we find ourselves in the fortunate position that arranging resources so as to produce greater equality will also maximize the aggregate amount of good that is done. Transplantation, however, is one of many areas in health care where often a policy of giving resources to the worst-off group will be terribly inefficient in producing good because the worst off are so sick that large resource commitments do relatively little good. Thus we will have to decide not only what is just, but also whether the right course is based on producing justice, good health outcomes, or some combination thereof.

Childress is surely correct in dissociating justice from social utility. Even if considering the social usefulness of potential transplant recipients is a reasonable way of figuring out how to do the most good with organs, it is not the way to promote justice. He is also on the right track when he warns that medical criteria are not value free. Not only that, medical criteria may turn out to be surrogates for social criteria. Persons of lower social classes do more poorly medically. They lack the education, social support network, and resources to follow regimens necessary for the complex care following transplant. Physicians have correctly argued that patients were poor medical risks for transplant because of their fragile social environments.

Appeals to medical criteria may simply be social criteria in disguise.

Childress goes on, however, to a dangerously confusing claim. He says that "both patient need. . . and probability of successful transplantation reflect medical utility." It is particularly misleading, if not wrong, to say that "'medical utility' may be a criterion of fairness." I am not sure what this means, but, if I understand, I think this is simply wrong.

I take the criterion of medical utility to be that an individual has a moral claim to a transplant to the extent that it is predictable that a medical good will come from transplanting the organ to that individual. There is a great deal of room for dispute about what counts as a medical good, but that will not be critical here. We are talking about the prediction of the goods of years of life added or suffering and incapacity alleviated.

It should be conceded that allocating organs on the basis of medical utility may also happen to contribute to opportunities for equality of medical well-being, but that is surely an accident, not the result of striving for maximizing medical utility. Contrary to Childress, appeals to "medical utility" in the distribution of organs do necessarily violate the principle of equal concern and respect. The least well-off are not given equal respect; it is only luck if they happen to get the most medical utility from an organ. Often that will not be the case. Childress is correct that medical utility might be accepted in a deontological framework, but only to the extent that it incorporates some ethical principle other than justice. Some deontological frameworks do this. But it is a mistake not to recognize that, in such cases, the incorporation or medical utility takes place in spite of its prima facie violation of the justice principle. Only when we go on to examine the relation between justice and rightness will we be able to know if this is acceptable.

The UNOS point systems for allocating kidneys provide a perfect test case for practical application of one's understanding of justice in health resource allocation. As Childress describes, the original UNOS point system gave points for various factors including HLA matching, waiting time, panel reactive antibodies (PRA), logistics, and urgency. Although what follows will be somewhat of an oversimplification, it is within reason to attribute the various points in the formula to either medical utility or justice considerations. The 12-point maximum assigned to HLA were clearly points for the purpose of promoting medical utility. The degree of HLA match predicts the likelihood of a successful graft. On the other hand, the other points seem to be included as a way of giving transplant candidates a more equal chance of getting an organ even though the factors represented by the points generally have nothing to do with predicting medically good result. For example, the 10 points that could have been assigned for urgency surely have nothing to do with whether the transplant candidate would do well; to the contrary, the more urgent the transplant, the worse off the patient and the greater likelihood of a poor outcome. Likewise, points were included for PRA because persons with high PRA are more unlikely to have another chance to get an organ that is usable. Time on the waiting list is an indirect measure of how difficult it is for a person to be matched successfully. Thus persons with O blood group, high PRA, and antigens that are difficult to match are likely to be on the list a longer time and, if a suitable organ becomes available, they can be said to have greater need, not only because they have been waiting longer, but because they are less likely to get another chance.[1]

Still oversimplifying, one can say that the original Starzl formula used about one-fourth of its points (12 of 48) as a measure of medical utility and three-fourths as a measure of fairness or justice. It was thus not perfectly just, but gave justice considerable weight.

It should be pointed out how arbitrary this allocation was. Based on the original example in the Starzl proposal, if only antigen matching had been considered half as important, urgency twice as important, and waiting time scores calculated in proportion to length of wait, then the patient who scored the lowest would have moved to the top of the list. Nevertheless, the Starzl formula can be said to be approximately three-fourths committed to justice. Would that the same could be said for other governmental programs.

The real problem has arisen with the recently revised point system. Clinicians, typically being committed to medical efficiency even at the expense of justice, had protested that the Starzl formula was paying too much attention to need and not enough to medical utility. The result was a radical shift in the direction of antigen matching, the measure that is included because of the widespread belief that antigen matching increases

probability of successful grafts. Now points included for medical utility have risen to approximately two-thirds of the total. Those whose need is great and who have a substantial chance to benefit from an organ will have a much harder time getting the organ. This is thought acceptable because they have somewhat less chance of benefit than others who get a large number of points for antigen matching.

One problem with this is that, contrary to Childress's claim, likelihood of a good antigen match is far from random. Members of certain social groups are known to be statistically harder to match with an organ with a good chance of success. The losing groups strikingly are often those who are oppressed in other social allocations. Blacks and Hispanics, for example, are more likely to have antigens that are hard to match. Unidentifiable antigens are more frequent in these populations. For those for whom all six antigens cannot be identified, it is impossible to have a perfect match with a donor.[2]

Thus the point system is rigged so that blacks and Hispanics are known in advance to be at risk for not being able to get points. Likewise, women are known to have higher risk for panel-reactive antibodies. Although those with high PRA levels get points when they are matched with a suitable organ, those points can still be offset by the points assigned to others for a good tissue match, leaving the high PRA patient waiting in line even though possibly another suitable organ may never come along. Other groups known to be in need because they are difficult to match are those in the O blood group. If justice requires arranging social practices such as organ allocation systems so as to give people an equal opportunity, then the new (Terasaki) point system is far more unjust even than the original Starzl system. It is two-thirds rigged against justice, while the Starzl system is three-fourths justice-oriented.

Let me be very clear that I am not objecting in principle to the use of point systems for making allocation decisions. I agree that they provide at least some semblance of objectivity. Moreover, they give us a concrete formula for understanding how we are relating utility and justice. In the case of the new formula for kidneys, however, we are purposely demoting concerns for justice. We are making decisions that are known to work (statistically) against blacks, Hispanics, women, and others who are hard to match. Although to my knowledge the data are not available, it seems reasonable that the system will work against any who are in genetic groups distant from those that dominate the donor pool. It is likely, for example, that Jews, to the extent they reflect an atypical genetic endowment, will be hard to match. At the very least we should say of such an arrangement that we are sacrificing justice for medical utility. Whether that is ethically acceptable will have to be determined when we decide what the relation of justice to other ethical principles, such as utility or social beneficence, should be. . . .

JUSTICE AND RIGHT ALLOCATION

This leads me to the conclusion that justice requires allocating health resources so as to produce opportunity for equality of health insofar as possible. To the extent that Childress incorporates other considerations, such as medical utility, we are in disagreement. I am particularly distressed when he says, apparently conveying what is just or fair, that "macroallocation decision[s] should be subject to resolution in part through scientific and medical information about effectiveness and efficiency in reducing morbidity and premature mortality." That is a formula that invites sacrificing fairness to the altar of aggregate efficient production of utility.

Still, I have admitted, as he has, that justice or fairness is not the only ethical consideration. There are other principles that could come into play in deciding what is the right allocation of scarce health resources. Some of these considerations are based on other principles that are deontological in character, that is, they do not focus directly on the production of good consequences. For example, it is conceivable that some scarce resources have been promised to individuals who do not have claims of justice to them. I am open, as apparently Childress is, to the necessity of balancing such competing moral principles as justice or autonomy or the duty to avoid killing.

The real controversy, however, is not over these principles, but rather over the conflict between justice and utility or social beneficence.[3] Childress says that "It is not possible to indicate in advance

exactly which principle should have priority." Elsewhere, he has supported an approach that would balance competing claims. I want to go on record that I oppose this strategy as being terribly dangerous and contrary to our common moral sense.

First, note a double danger. Childress has already incorporated considerations of medical utility into his formulation of what is just or fair. He now tells us that justice or fairness will have to be further diluted by being balanced or prioritized with other principles, including utility or beneficence. If utility counts for half (or two-thirds in the new kidney formula) of what it means to be just or fair and then on top of that one must balance the fair course of action with the one that is called for by the principle of utility or beneficence, there is very little left of a commitment to equality of well-being. It is doubly diluted.

Even if Childress were to follow me in limiting justice to opportunity for equality of well-being, his approach of reconciling the claims of justice with those of utility would still be dangerous. It is a position that commits one logically to the view that in some cases if there is enough utility, the rights of individuals can always be sacrificed. In this case the right being sacrificed is an entitlement right, the right to the resources needed to have an opportunity for equality of well-being insofar as possible. In other cases the right may be a liberty right, such as the right to refuse medical treatment or refuse to be an unwilling subject of medical research. If justice and autonomy can be traded off against utility, one is logically committed to the position that, if enough good would be done, an individual can be sacrificed against his will to the aggregate good. That is a view I reject. It is a view the Judeo-Christian tradition rejects. It is a view that a liberal democratic society rejects. In particular, we are committed to the view that no amount of social good would justify coercing individuals to be subjects to Nazi-like medical experiments against their will. The only way one can remain committed in principle to that position is to acknowledge that no amount of beneficence or social utility can override the moral claims grounded in the nonconsequentialist principles such as autonomy or justice. In the example we are pursuing, no amount of medical utility should permit one to override the claim of justice that would lead to a policy of allocating scarce medical resources such as kidneys on the basis of who is worst-off.

This position is probably viewed by many, including Chidress, as extreme. It is often challenged by what I call the infinite demand (or bottomless pit) argument. It is said that as soon as we come up against someone with an incurable medical need serious enough to classify the individual as among the worst-off, that person will command in the name of justice all society's resources. That would leave others destitute, which seems absurd.

The infinite demand problem is a serious one for an egalitarian, but there is a plausible response. First, all that is called for is opportunity for equality as far as possible. The principle does not call for using resources that will do no good for the least well-off. We do not need to give a kidney to someone dying of cancer. Assuming someone in a permanent vegetative state gets no objective benefit from medical treatment, we do not need to give a PVS patient a kidney.

Second, under the principle of autonomy, persons retain the right to refuse treatment. A person with a terrible incurable illness may find it appropriate to refuse treatment to let the dying process continue. He would not find the use of resources on his behalf beneficial.

Third, if literally all the world's resources went to someone medically incurable, eventually others would be even worse-off. They would become the ones with claims of justice. Although this is a limit at the extreme, it is a limit.

Fourth, I have acknowledged that other nonconsequentialist principles legitimately conflict with justice. If resources have been promised to others, they do not necessarily go to those who have claims of justice. Likewise, persons who are legitimate owners of resources may have autonomy rights that limit the use of resources for the least well-off. Also, the autonomy of the least well-off may lead them to yielding their claims of justice either because they are altruistic or because, as in the Rawlsian maximin case, they find it is in their interests to surrender their claims to equality. Contrary to Rawls, however, I describe this as waiving justice, not allocating in the name of justice. Moreover, in my formula it is only the least well-off who have the authority to waive the claims of justice. It is not something that rationality

requires and therefore can be argued by anyone in the social system.

All of these taken together lead me to the confident conclusion that the bottomless pit problem is not an insurmountable one. If others, including Childress, do not agree, then they are forced to retreat to the dangerous territory where justice gets balanced against utility. That, however, is a terrible position to be in. I prefer to avoid it by never permitting mere utility to offset nonconsequentialist ethical considerations such as justice.

Even if such a balancing gamble is taken, however, it is still crucial to keep it separate from our conclusions about what is fair or just. If we have to incorporate points for HLA matching in our kidney allocation formula, let us at the very least state as clearly as possible that we are not doing it in the name of what is just or fair. Rather we are sacrificing justice in order to make the system more efficient or utility maximizing.

NOTES

1. It is probably fair to point out that since high PRA also contributes to length of time on the waiting list, it may be double-counted in the formula.
2. Technically, the points are assigned on the basis of mismatches. Still, if the donor organ has six identified antigens, then a recipient for whom only five antigens can be identified is said to have a mismatch for at least one of the donor's antigens. The maximum number of points is thus reduced accordingly.
3. I will use the two interchangeably. Some would attempt to distinguish between beneficence and nonmaleficence and then determine a formula for relating the two. That is an interesting issue, about which Childress and I may disagree, but it is not crucial in this context.

Last-Chance Therapies and Managed Care: Pluralism, Fair Procedures, and Legitimacy

Norman Daniels and James Sabin

I. COVERAGE FOR UNPROVEN LAST-CHANCE THERAPIES

The most difficult and explosive responsibility for any health care system is deciding whether patients with life-threatening illnesses will receive insurance coverage for unproven treatments they believe may make the difference between life and death.

Potentially life-saving treatments with proven efficacy and safety (proven net benefit) and quack treatments for which there is no scientific rationale, rarely pose major problems about insurance coverage. In a country as wealthy as the United States, effective last-chance treatments without alternatives generally are and should be covered virtually all the time. When shared resources from cooperative schemes are involved, as in public or private insurance, rather than individuals paying with their own resources, quack treatments will and should virtually never be covered, even if the patient or doctor passionately believe in the purported cure.

The difficult practical and ethical challenges come from promising but unproven last-chance treatments, for which we use high-dose chemotherapy with autologous bone marrow transplant (ABMT) for advanced breast cancer as our key example.[1] Not covering treatments that ultimately prove to be effective lets curable patients die prematurely, and even if a treatment ultimately proves to be ineffective, not covering it may create the impression that critically ill patients are being abandoned in their moment of need. Covering treatments that ultimately prove to be ineffective or harmful reduces the quantity and quality of the patient's remaining life, wastes substantial resources, and undermines clinical research. These are the moral stakes in the decision.