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CHILD HEALTH AND THEORIES OF RIGHT ALLOCATION

Robert M. Veatch†

IT IS BECOMING INCREASINGLY APPARENT that some children are not getting what could be called their fair share of health care.¹ However, before we can render such judgments, we have to have some idea of what a fair share might be. We shall see that the answer may not be obvious and that different ethical theories can have very different notions of what constitutes a just or right allocation of health care.

The very terminology can cause trouble. As Aristotle wrote, the word "justice" can have two different meanings.² In what he called the "broad" sense of the term, Aristotle claimed that justice can be a synonym for rightness.³ When Amos pleads, "Let justice roll down like waters and righteousness like an everflowing stream,"⁴ he meant, as Hebrew writers often mean, to treat the two as synonyms. Justice in this sense is not a term referring to a particular theory of distribution; it is merely another word for rightness. However, Aristotle goes further to point out that justice can also be used in a narrower sense to mean "fairness in distribution."⁵ We often, but not always, have this narrower meaning in mind when we call an arrangement just.

This ambiguity begs for confusion when we talk about justice in health care for children. It could turn out, for instance,

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1. See Robert F. St. Peter et al., *Access To Care For Poor Children: Separate and Unequal?*, 267 JAMA 2760, 2761-63 (1992) (demonstrating that children living in poverty are less likely to receive usual sources of medical care, relieved somewhat by Medicaid).

2. ARISTOTLE, *NICOMEACHEAN ETHICS* 112-17 (Martin Ostwald trans., Bobbs-Merrill Co. 1983) (drawing distinctions between notions of "unjust" and "unfair" and "lawful" and "fair").

3. *Id.*

4. *Amos* 5:24.

5. *Id.* at 118 (stating equality in distribution can be placed on a median and tracked for justness).

that the just distribution (in the sense of morally right distribution) is the one that is not the most just (in the sense of being the fairest arrangement). In fact, if there are other moral principles than justice, according to some theories the result may often be that the right distribution, considering all the morally relevant dimensions, is not the one that is the fairest distribution. To avoid this confusion, I shall use the word "justice" only in the narrower sense as meaning the fairest distribution, even if it turns out that the distribution is not morally the most moral arrangement when taking into account other principles of ethics such as autonomy and beneficence.

To oversimplify, there are three major theories of what is the most moral or most right allocation of resources. One, generally called the libertarian view, emphasizes the principle of autonomy.⁶ The second, which is often called the utilitarian view,⁷ emphasizes the principle of beneficence. The third, called the egalitarian view, emphasizes the principle of justice in the narrowest sense of the term.⁸ Virtually any theory of a morally right distribution can be seen as an example of one or some combination of these three approaches. Thus, to understand what a morally right distribution of health care for children would be, we need to first determine which of these theories or combinations thereof is the right one.

6. TOM L. BEAUCHAMP & JAMES F. CHILDRESS, *PRINCIPLES OF BIOMEDICAL ETHICS*, 265, 266-68 (3d ed. 1989) (stating that the theory focuses on fairness in the process versus fairness in the outcome).

7. *Id.* at 265-66 (dictating that under this principle "justice is the . . . most paramount and stringent forms of obligation created by the principle of utility").

8. ROBERT M. VEATCH, *A THEORY OF MEDICAL ETHICS* 264-69, 275, 300-01 (1981) (stating that those who ascribe to the egalitarian view believe that justice dictated that resources should be allocated so that individuals have equal access to them). For other applications of the three major alternative theories, see also BEAUCHAMP & CHILDRESS, *supra* note 6, at 265-70 (as applied to health care goods and services); NAT'L COMM'N FOR THE PROTECTION OF HUMAN SUBJECTS OF BIOMEDICAL AND BEHAV. RES. U.S. DEP'T OF HEALTH, EDUC. & WELFARE, *THE BELMONT REPORT. ETHICAL PRINCIPLES AND GUIDELINES FOR THE PROTECTION OF HUMAN SUBJECTS OF RESEARCH* 4 (1973) (as applied to biomedical and behavioral research); Allen Buchanan, *Justice: A Philosophical Review*, in *JUSTICE AND HEALTH CARE* 3 (Earl E. Shelp ed., 1981) (as applied to bioethics).

THREE THEORIES OF MORALLY RIGHT DISTRIBUTION

These three theories — the libertarian, utilitarian and egalitarian — are central to the debate over allocating health resources.

Libertarian Allocations

The libertarian theory gives priority to the liberty or autonomy of the individual. It begins with the premise that within certain constraints (not addressed here), individuals have a right to that which they appropriated from unowned resources or from which they acquired by gift or exchange.⁹ It may be unfortunate that some have more than others, but it is not unfair.¹⁰

In terms of health, some may be fortunate to have been born with good genes, born to wealthy and devoted parents or born into a society where access to health care is plentiful. Others, however, may have been less fortunate in the natural lottery. For the libertarian entitlement theorist, this is simply the way life is; it is not unfair. There is no moral imperative to rearrange the distribution since the underlying moral principle that governs allocation of health resources is the principle of autonomy or liberty.

Medical commentators have with more and less sophistication applied this theory to health care.¹¹ Those who are generous claim that, out of charity, society might provide health care to the needy who are in poor health and have no resources, even though there is no moral imperative to do so.

This libertarian entitlement theory faces some severe problems. For one, it incorporates a peculiar theory of private property in which resources, including knowledge, skills and material assets, are acquired and "owned" by individuals.

9. ROBERT NOZICK, *ANARCHY, STATE, AND UTOPIA* 150-53 (1974) (explaining the concept and elements of the entitlement theory).

10. H. TRISTRAM ENGELHARDT, JR., *THE FOUNDATIONS OF BIOETHICS* 342-43 (1986) (discussing how the lines should be drawn between the unfair and the unfortunate).

11. *Id.* at 343 (providing health care as a right conflicts with the autonomy of the health care provider to choose how he wishes to dispense with his services); Robert M. Sade, *Medical Care As A Right: A Refutation*, 285 *NEW ENG. J. MED.* 1288, 1288-92 (1971) (arguing that medical care is not a right and that the government should avoid placing legislative restraint on medicine).

Many would challenge that assumption. They would question, for instance, that a physician should be thought of as "owning" his knowledge and skills. Even if a physician paid for his medical school tuition from his private funds, much of medical education, including private schools, is funded with public funds and subsidized resources. The knowledge transmitted is often produced through government-funded projects and in a real sense, much of this could be considered "public assets." However, the idea of personal private ownership of knowledge, skills and resources is a gross over-simplification.

More importantly, the libertarian theory of distribution, at least in its crude form, is simply not plausible. The U.S. surely has one of the most private, autonomy-based health care systems in the world, yet, no matter how inadequate, it hardly treats children as if they were literally on their own, left to fend for themselves or rely on charity. After all, there is Medicaid¹² and Hill-Burton hospitals have at least some obligations.¹³ Thus, no one believes that allocations of health care are truly a matter left to private, autonomous individuals whose health care is dependent on the deals they are able to make.

Utilitarian Allocations

The second major theory of allocation is far more plausible. The utilitarian theory holds that the arrangement of resources is most right when the aggregate net benefit of the arrangement is the best possible.¹⁴ Any rearrangement would hurt the one from whom a good was removed more than it would help the one receiving it.

The ethical principle given priority in utilitarian allocations is the principle of utility. It holds that the arrangement of resources that produces the greatest possible overall net good is morally the best. Sometimes philosophers refer to the principles of beneficence and nonmaleficence, or to doing good and avoiding harm. Utility is simply the integration of these two. The integration takes place in complicated and controversial ways.

12. 42 U.S.C. § 602 et seq. (West 1994).

13. See Hospital Survey and Construction Act, ch. 958, 60 Stat. 1040, 1041, 1043-44 (1946).

14. BEAUCHAMP & CHILDRESS, *supra* note 6, at 266 (stating that the theory balances "public and private benefit, predicted cost savings, the probability of failure, [and] the magnitude of risks").

Jeremy Bentham combined them numerically, subtracting the amount of harm from the amount of good.¹⁵ Most modern cost-benefit analyses, which are essentially driven by the principle of utility, look at the ratio of benefits to harms rather than the arithmetic sum.¹⁶ The two approaches often produce very different conclusions. Maximizing the difference between expected benefits and expected harms can lead to an aggressive, interventionistic policy. The net difference in a high-risk, high-gain policy is likely to be larger than the net difference where the benefits and harms are both very small. Calculating benefit/cost ratios, on the other hand, can have conservative implications. Thus, assuming a decreasing marginal utility, an interventionist high-risk, high-gain policy will have a lower benefit/harm ratio than a more conservative minimalist approach.

It is important to note that certain professional groups, such as economists and health policy analysts, lean toward utilitarian assumptions when making choices between alternative policies or practices. Often they feel it is so obvious that the right course is the one that maximizes the net benefit that they cannot even comprehend that any alternative is worth considering.

There are also some severe problems with utilitarian theories of distribution. Some critics charge that determining which policy or practice produces the maximum net good requires virtually impossible quantifications due to the comparison of incomparables.¹⁷ For example, a child's happiness must be compared with the value of preserving a suffering child's life; pain must somehow be put on a linear scale and compared with

15. John Stuart Mill, *Utilitarianism* (1863), in *ETHICAL THEORIES: A BOOK OF READINGS* 365, 367 (A.I. Melden ed., 2d ed. 1955) (addressing Jeremy Bentham's greatest happiness principle).

16. See Hastings Center Institute of Society, Ethics and Life Sciences, *Values, Ethics, and CBA in Health Care*, reprinted in OFFICE OF TECHNOLOGY ASSESSMENT, U.S. CONGRESS, *THE IMPLICATIONS OF COST-EFFECTIVENESS ANALYSIS OF MEDICAL TECHNOLOGY* 170 app. D (1980) (arguing that cost-benefit analysis like utilitarianism focuses on maximizing the welfare of a defined society); Tom L. Beauchamp, *Utilitarianism and Cost/Benefit Analysis: A Reply to MacIntyre* (1978), in *ETHICAL THEORY AND BUSINESS* 278-80 (Tom L. Beauchamp & Norman E. Bowie eds., 1979) (stating that the currently accepted interpretation of "cost/benefit analysis" encompasses the use of nonquantitative data).

17. See Beauchamp, *supra* note 16, at 276-82 (responding to the criticisms of Alasdair MacIntyre, whose objections to the cost/benefit analysis is based generally on the lack of specificity in the process).

other, qualitatively different harms. While the quantification tasks may be extremely difficult, this may not be the most serious flaw in utilitarian thinking. After all, clinicians, parents and patients must routinely make comparisons of incomparables. Somehow we make our approximations and get on with the task.

There are other complications for utilitarians to face. One is whether identifiable lives count the same in a utilitarian calculation as unidentifiable ones. Another is whether the benefit of preventing a harm counts less than rescuing someone from a harm. If statistical lives count equally, and preventing a harm counts as much as a rescue, then since there are an infinite number of future statistical lives that could benefit from research on prevention, those research investments would seemingly always produce more good than any efforts at rescue, where the amount of benefit would be finite and limited.

Consider, for example, a choice between immunizing ten thousand children to save one life and spending the same resources on one liver transplant which in turn will also save one youngster's life. While utilitarian reasoning generally favors something called basic medical care¹⁸ in the form of preventive interventions, such as immunizations, the utilitarian should have no preference if the benefit of the liver transplant in aggregate is actually one life saved just like the ten thousand immunizations. In fact, if identifiable lives have moral priority over statistical ones, then the child needing the liver transplant would actually receive priority.

While these are notable problems in utilitarian theories of allocation, the real problem is why one should consider an arrangement "good" or "right" or "ethical" just because it produces the maximum aggregate net benefit. The libertarian theory, at least, had an empirically plausible psychological premise going for it. We can understand a psyche that strives to maximize its own welfare through autonomous choices, but it is difficult to understand why one would feel compelled psychologically to maximize the aggregate net good or why, if feasible, it would be a morally right arrangement.

18. See Robert M. Veatch, *Should Basic Care Get Priority? Doubts About Rationing The Oregon Way*, 3 KENNEDY INST. ETHICS J 1287, 187-206 (1991) (analyzing Oregon's medical care system which construes "basic" in terms of cost-effectiveness versus ethical considerations).

Utilitarians sometimes make the strange move of challenging certain traditional moral rules, such as the rule requiring truth-telling,¹⁹ on the grounds that there is no rational reason to hold to such a rule. At the same time, utilitarians assuming — without being able to give any reason why — hold that the utility maximizing arrangement is morally the best.

Physicians also traditionally tend to think in a utilitarian way. Since the day of the Hippocratic Oath,²⁰ physicians have been taught the ethic of maximizing net good consequences. They are partial to the ethical principles of beneficence and nonmaleficence. The Oath states that the physician should always strive to benefit the patient and protect him from harm.²¹ Assuming that it is an imperative to maximize the net of benefit minus harm to the patient or to maximize the ratio of benefits to harms for the patient, the reasoning is similar to that of the utilitarian. The one major difference is that the Hippocratic physician imposes an arbitrary limit so that the only benefits and harms that count are those to the patient; all others are morally off the table.

From the point of view of a strict utilitarian, this is hard to justify. It must be that physicians have let at least one nonconsequentialist consideration slip in—the rule that the only consequences that count are those affecting the patient. But once the pattern of the distribution of the consequences is fair game, then surely other considerations relating to the pattern of distribution of the benefits and harms must count as well. This introduces the notion of whether certain patterns of distribution are morally preferable to others, or whether all that matters, as the utilitarian would have us believe, is the aggregate amount of the consequences.

19. See Sade, *supra* note 11, at 1288. Specifically, utilitarians believe that each individual must choose the values which he/she deems essential to upholding one's own life, including the flexibility to decide the best methods to fulfill those values or to change the selected values in the future. *Id.*

20. See Ludwig Edelstein, *The Hippocratic Oath: Text, Translation And Interpretation*, in *ANCIENT MEDICINE: SELECTED PAPERS OF LUDWIG EDELSTEIN* 3, 3-64 (Ousei Temkin & C. Lillian Temkin eds., 1967) (describing ethical duties of physicians and their historical origins).

21. The Oath reads: "I will apply dietetic measures for the benefit of the sick according to my ability and judgment; I will keep them from harm and injustice." *Id.* at 6. This has been interpreted as the ethical code of the Oath. *Id.* at 20-39.

Justice or Fairness in Distribution

The third major theory of allocation of resources focuses on the pattern of the distribution of the benefits and harms rather than the aggregate net amount. Exactly what the correct pattern is can be disputed, but one dominant group emphasizes something related to equality. Hence, these theories are called egalitarian.

The arrangement of resources is considered morally right when it patterns the benefits and harms so they are distributed as equally as possible. Equality of net benefit is considered a morally right arrangement independent of the aggregate amount of good.

Consider two real examples involving children. In the first, a public health officer wanted to screen school girls for asymptomatic bacteriuria.²² Since there were not enough funds to screen everyone, he conducted a study to see which of two methods would find cases most effectively.²³

The utilitarian cost-benefit assumption would be that the method that caught the most cases per unit of investment would be morally preferable. After identifying the method that found the cases per unit of investment, the officer discovered that while the method was more efficient it tended to find middle-class cases at the expense of lower-class ones.²⁴ The problem then became whether he wanted to find as many cases (that is, do as much good as possible) regardless of the pattern of distribution, or whether he purposely ought to choose the method that was less efficient, but found cases more equitably among all social classes. The principle of justice favored the less efficient, more equitable method.

In the second example, the National Institute of Health ("NIH") Consensus Conference on Dental Sealants²⁵ debated what to recommend for a community policy on the use of seal-

22. See Gordon Rich et al., *Cost-Effectiveness of Two Methods of Screening For Asymptomatic Bacteriuria*, 30 BRIT. J. OF PREVENTIVE & SOC MED 54, 54-59 (reviewing a study which compares the cost-effectiveness of screening mechanisms of children of different social classes and which favors a high output result).

23. *Id.* at 55-59 (noting that the two methods used were a home method and a supervised method, with the supervised costing (in money) around 40% more than the home method).

24. *Id.*

25. In 1983, a panel of 11 dental professionals, sponsored by the NIH, recommended that all children, beginning at the age of two, should get their teeth sealed in order to

ants on children's teeth.²⁶ The panel easily agreed the sealants were beneficial, but disagreed on how the community should distribute the sealants if there were not enough funds to seal all the children's teeth.²⁷

It turns out that for technical reasons it is more efficient to seal the teeth of children living in communities that have community fluoridated water.²⁸ The NIH panel was divided between utilitarians who favored the most efficient use of the sealants, regardless of the pattern of distribution, and egalitarians who held that justice required giving all children an equal chance to get their teeth sealed.²⁹ The latter maintained their position because it was not the fault of the children who did not get fluoride that their teeth were somewhat less efficient to seal. The utilitarians chose the most efficient plan knowing that the distribution of the benefits would be inequitable. The egalitarians chose an equitable distribution of the benefits, despite knowing that their choice was less efficient.

Egalitarians hold to a principle of justice in the narrow sense. They believe that the pattern counts; that all children have an equal claim to benefits regardless of the fact that the aggregate benefit will be less. Even among those who hold to the egalitarian principle of justice, there are additional matters to be resolved. For example, it may not be clear exactly how we determine who is worse off and, therefore, has a claim of egalitarian justice.

Consider the following dilemma. Suppose you were a health officer having to choose between two groups of patients.

combat tooth decay. See Victor Cohn, *NIH Panel Urges Teeth Be Coated To Fight Decay*, WASH. POST, Dec. 8, 1983, at A01.

26. Sealants, developed in the 1960's and 1970's, are placed on the surface of teeth forming a thin, clear plastic layer which helps guard against decay. See Jeffrey P. Cohn, *Shrink Wrap For Molars: Plastic Coating Seals Teeth So Bacteria Can't Cause Cavities*, WASH. POST, Jul. 17, 1990, at Z16. Sealants are most effective when applied to children when their permanent molars begin to come in. *Id.*

27. In 1990, the estimated cost of sealing one child's tooth ranged between seven and \$25. *Id.* Actually, the NIH panel recommended that the sealants be used with fluoridated water. Cohn, *supra* note 25. The panel further advocated that public (i.e. Medicaid) and private insurance companies cover this process. *Id.*

28. The fluoride prevents cavities on the surface between teeth while the sealant protects the occlusal [biting] surfaces. Those children without fluoridation would have to have their sealant destroyed to fill the larger number of cavities between the teeth, making the sealant more efficient on the children getting the fluoride. *Id.*

29. *Id.* (urging that sealants be given to those children who were poor and either obtained deficient dental care or suffered from extreme decay).

One group had experienced miserable lives, but lately they were doing somewhat better and only had moderate medical needs. The other group had lived long, healthy lives but had recently contracted a serious illness that would take considerable effort to treat. If you were an egalitarian and decided to treat the worst off group, which group would get priority? The first group had lives that were, on the whole, much worse than the second, but they were arguably better off at the moment.

These groups represent two ways in which we can measure who is worse off.³⁰ One approach — I call it the moment-of-time approach; it asks who is worse off at the moment? The other which I call the over-a-lifetime approach, looks at the cumulative well-being over one's entire life. Each could make a case that his or her group was worse off.

Even among egalitarians there is a split between the moment-in-time egalitarians and the over-a-lifetime egalitarians. In fact, some health care resources should be allocated according to one formulation; some according to the other. For example, I believe that food, pain medication and safe, simple, sure cures of acute illness probably should be allocated on the basis of who is worse off at the moment regardless of one's past history. On the other hand, an egalitarian would probably allocate expensive treatment for chronic disease, use of experimental treatments and heroic, high-tech life-saving equipment/procedures on the basis of who had had less opportunity for well-being over a lifetime.

There are, of course, other problems with the egalitarian approach beyond the determination of the method for deciding who is worse off. One of the main problems is what is sometimes called the "bottomless pit" or the "infinite demand."³¹ If the goal of an ethical allocation of resources is to produce

30. See Robert M. Veatch, *Distributive Justice And The Allocation of Technological Resources To The Elderly*, in 3 LIFE-SUSTAINING TECHNOLOGIES AND THE ELDERLY. WORKING PAPERS: LEGAL AND ETHICAL ISSUES, MANPOWER AND TRAINING, AND CLASSIFICATION SYSTEMS FOR DECISIONMAKING 0, 17-37 (U.S. CONGRESS. OFFICE OF TECH ASSESSMENT 1987) (surveying theories of justice in the allocation of medical resources to the elderly, focusing on life-sustaining technology); Robert M. Veatch, *An Egalitarian Argument For Rationing*, AGING TODAY, Dec. 1990/Jan. 1991, at 9-11 (stating that age should be used as criterion in the distribution of health care, especially when it comes to expensive treatments).

31. Robert M. Veatch, THE FOUNDATIONS OF JUSTICE: WHY THE RETARDED AND THE REST OF US HAVE CLAIMS TO EQUALITY 159-64 (1986) (discussing types of limitation which can be placed on medical compensation to avoid an infinite demand sensation).

equality of outcome, meaning the distribution of health care according to need, then a terribly sick and incurable patient would continue to command all of our health care resources as long as the investment provided him even a minimal amount of good. He is, therefore, a bottomless pit.

There are ways for the egalitarian to climb out of this pit. In comparing alternative uses of health resources, we have to conduct the mental exercise of imagining how all parties would be affected with each alternative. While it might appear that the chronically ill youngster experiencing kidney failure is worse off than someone who does not get a polio immunization, we must imagine that if we spend all our resources on kidney transplants and none on polio immunizations, some child will eventually get polio. Thus, this child will get polio because we have invested in kidney transplants. However, if it turns out that having polio is worse than being in kidney failure, then the egalitarian principle of justice itself would actually require using the limited resources to help the worse off patient—the child who would contract polio if the immunizations were not funded.

While this maneuver may avoid some of the bottomless pit cases, it will not avoid all of them. Some people at this point would insist that we must return to the other principles, especially the principle of utility. We must somehow trade the principle of justice off against the principle of utility so that neither efficiency nor equity are entirely lost.

TRADING OFF PRINCIPLES

If there are at least three major theories of allocating scarce medical resources it is because there are three alternative views about what ethical principle should dominate. Among autonomy, utility and justice, different priorities will lead us to different theories of distribution. Only by developing a meta-theory for ordering these principles will we finally know which theory is the correct one. For example, libertarians and utilitarians each hold that only one principle counts in morality: autonomy and utility, respectively. A more sophisticated theory will accommodate a more subtle combination of the principles.

One major approach is to affirm all the principles and insist that either they be balanced so that none gets priority,³² or that they be intuitively combined using one's "judgment."³³ While this approach is currently an attractive option, it poses some serious difficulties. For example, once utility is permitted in the mix, the rights of individuals can, in theory, be swamped by enough social good. Since there are potentially infinite numbers in future generations, good for future citizens could always overpower the claims of those presently alive. If utility can overcome autonomy, then compulsory participation in health care, even dangerous experimental health care would, in principle, be justified if only enough good were envisioned.

The only way around these serious problems is to affirm that utility is a moral consideration that is always subordinate to other non-consequence-maximizing principles such as autonomy and justice. That permits an easy account of why it is never acceptable to force medical treatment on someone without consent, no matter how much good is envisioned. It leaves us with a bottomless-pit problem that cannot be overcome by appealing to the principle of the greater good.

The bottomless-pit problem is amenable to other solutions. For example, as long as autonomy, promise-keeping and other non-consequence maximizing principles are allowed to offset justice, justice will be held in check. If promises have been made to others, these might justify failing to give infinite resources to the sickest or the incurable patient. The principle of autonomy will also come into play. Some who are worse off with incurable illnesses will exercise their autonomy to decline the care to which they are entitled in the name of justice. They might do this either out of altruism or out of a sense that the marginal benefits from the extensive medical intervention simply are not worth it.

On the other hand, the relationship between autonomy and justice is more subtle. We have already seen that autonomy might lead a patient who has a claim of justice to decline the

32. See BEAUCHAMP & CHILDRESS, *supra* note 6, at 265-301 (emphasizing the need to provide the most comprehensive health care by balancing cost and demand in light of the various theories of justice).

33. See BARUCH A. BRODY, LIFE AND DEATH DECISION MAKING 6-11 (1988) (suggesting that there is not one adequate moral theory of decision-making, therefore requiring an overhaul and pasting of the several existing theories).

benefit. However, that does not mean that autonomy always has a claim against justice. The wealthy and talented may not morally withhold their care from the worse off, even if they have the right to do so. At least for the basic minimum of health care, justice takes priority over autonomy. Once we get above the basic floor of services signified by the notion of a decent minimum, it may well be that autonomous choice has a more legitimate place. If people are allowed to have discretionary funds at all and are allowed to spend those funds on trivialities, it seems that trivial health care services might be among the things they could buy, if in doing so, they do not compete for inherently scarce resources like transplantable organs or talented health professionals.

CHILDREN AND THE KIDNEY FORMULA: A FINAL CASE

This final example will test the implications of health care for children under these three major approaches to allocation. In allocating kidneys for transplant, a mathematical formula is used. The formula takes into account histo-compatibility, the length of time spent on the waiting list and the level of the antibodies that predict the risk of rejection.³⁴ The issue has arisen whether children should have a special claim on available organs and, if so, why?

The implications of the three theories of resource allocation seem clear. The libertarian would give kidneys to those who could prevail on the individuals who control the distribution of the kidneys, thereby, obtaining access. They might use money or some other inducement to obtain access. It is not clear how children would make out in this situation. If they had to obtain the organs by buying them with their own funds, they would probably fail. If they could rely on parents or adults in whom they could generate sympathy, some of them might fare better. This is especially true for the children of the

34. Robert M. Veatch, *Equality, Justice & Rightness in Allocating Health Care: A Response to James Childress*, in *A TIME TO BE BORN AND A TIME TO DIE* 210-13 (Barry S. Kogan ed., 1991) (noting that while these are basic elements of the formula, various weights have been assigned to the elements, resulting in divergent allocations in the organ transplant arena).

wealthy and those fortunate to be cute enough to generate sympathy.

The utilitarian theory has quite different implications. Under this theory, the total net good for all in society is taken as the goal. Therefore, the kidneys should go to the potential recipients who would contribute the most to society; those who society views as the most valuable. Hence, talented young adults might do well because their talents, arguably, would contribute to society for a long time. It is unlikely that children would score very high simply because it would be hard to predict which children were really going to be sufficiently useful; we would have to wait a number of years before determining if our investment would produce a return.

The idea of allocating organs to the most socially valuable is repulsive and our society has generally rejected this concept. In fact, the very process of trying to identify the most useful members of society is viewed as so threatening and counter-productive that it may not even be defensible on utilitarian grounds.

Most who think in a utilitarian framework have replaced social utility with what is called medical utility.³⁵ Organs could be allocated to those who would receive the greatest medical benefit; measured in the number of years a life would be prolonged or through the reduction of morbidity. Sophisticated utilitarian analysis uses units that attempt to combine mortality and morbidity measures by utilizing "quality-adjusted life years" or "well-being index scales."³⁶ The ones who would predictably get the most benefit would get the organ regardless of the individuals' social value. It is important to note that there is no valid theoretical reason why a true utilitarian would limit the relevant good to medical benefit. Only if the disutility of attempting to measure social utility were greater than the ex-

35. See *id.* at 209 (noting that medical criteria are not exempt from value and "may turn out to be surrogates for social criteria").

36. Richard Zeckhauser & Donald Shepard, *Where Now For Saving Lives?* LAW & CONTEMP. PROBS, Autumn 1976, at 5, 11-15 (employing "quality-adjusted life" as an example of utility function which could be used to ultimately anticipate what treatment an informed patient would select for himself); Abraham Mehrez & Amiram Gafni, *Quality-adjusted Life Years, Utility Theory, and Health-years Equivalents*, 9 MED DECISION-MAKING 142 (1989) (negating theory that "quality-adjusted life years" is an accurate predictor of an individual's preference).

pected benefits would a true utilitarian consider only medical benefits.

There are two reasons why, when focusing on medical utility, a child might be given priority in the allocation of a kidney that, due to its size, is equally well-suited for a small adolescent or an adult. First, since the length of time in which the benefit accrues is relevant for a medical utilitarian, children would have a special claim because they would get the benefit from the kidney for a longer time, as arguably would be true for any curative medical treatment. Second, kidney failure in small children is particularly harmful because it can impact on neurological development.

In fact, the United Network for Organ Sharing ("UNOS")³⁷ has recently amended its allocation formula to give two bonus points for a child on the kidney waiting list who is under six years of age and one point for children under age eleven.³⁸ Many people assume that these are defensible medical utilitarian arguments. However, if the priority for children is defended on grounds of medical utility, there would be radical implications on health resource allocation. First, some children have serious medical conditions that are hard to treat. They would not prevail in a competition for resources based on maximization of medical benefit. Second, we have seen that lower-class patients are generally less efficient to treat. They too would get lower priority if allocations were based on strict medical utility. Third, if medical benefit were measured by multiplying the amount of benefit by the expected length of benefit, children would get priority even if a special neurological benefit was not present. In general, if medical utility is the basis for allocating health resources, the younger patient will always have a stronger claim, and the elderly patient would, in

37. UNOS, a computerized national registry, was created in 1987 in order to coordinate organ donors and transplant recipients. See Robert Steyer, *Network Coordinates Organ Donation in U.S.*, ST. LOUIS POST DISPATCH, Apr. 1, 1990, at 3E. Its goal is to ensure that the neediest patient gets the next procurable organ and accomplishes this through strict guidelines. *Id.* UNOS matches donors and recipients based on "blood type, body size, geographic proximity, length of time on the waiting list and medical urgency." Don Colburn, *The Dilemma of Repeat Transplants If A Donated Heart or Liver Fails Should There Be a Second Try?*, WASH. POST, Nov. 30, 1993, at Z07.

38. Steyer, *supra* note 37 (noting that points are assigned based on medical criteria, with generally little distinction in the matching process between pediatric and adult transplants).

general, be excluded from health care on the grounds that he/she is inefficient to treat.

Allocation based solely on medical utility raises severe doubts concerning ethical acceptability. In general, utilitarian allocations can be criticized as being unfair. They do not take into account the moral principle of justice. A more sophisticated case can be made for the system of bonus points for children; this case is based not on medical utility, but actually on justice. If such a case succeeds, then in certain instances children might have a priority based on justice rather than on utility. If utility-based arguments have unacceptable moral implications, then basing the allocation on justice may be more acceptable.

A priority based on justice begins with the principle that practices such as kidney allocation are fair to the extent that they give priority to the least well off. In the case of end-stage renal failure, for example, there are two ways that the children might be considered the least well off. First, if they are at risk for neurological damage while older patients are not, surely they would get priority even if the benefit to them were actually not as great as giving the organ to an older person. It is possible, in fact quite common, in medicine that giving resources to the worse off patients would do less good than giving them to better-off patients. In such cases an allocation based on medical utility would purposely give the priority to the healthier patient,³⁹ while one based on justice would give the priority to the sicker individual, knowing that such an allocation was less efficient.

Second, it has been suggested that egalitarians calculate who is worse off in two ways — the “moment-in-time approach” and the “over-a-lifetime approach.” The former, noted earlier, seems better for certain allocations such as food, pain medication and safe, simple, sure treatments of acute disease, while the latter seems more appropriate for other allocations including high-tech treatments and chronic disease. A case can be made that if one is concerned about the principle of justice

39. This is the outcome in the commonly held theories of triage, in which better-off patients get priority if they will receive more benefit (or in the case of battlefield triage, if the military cause will reap more benefit). See Robert Baker & Martin Strosberg, *Triage*, 2 KENNEDY INST. ETHICS J 103 (1992) (refuting the utilitarian theory in favor of priority for the sickest).

as applied to organ transplants, the "over-a-lifetime" determination of well-being should prevail. The claim is that an "over-a-lifetime" older person needing a kidney transplant is better off, and therefore less deserving, because he or she has had more years with good kidney function than an infant who is suffering from kidney failure.

This would provide a basis for giving priority to children who need kidneys without relying on medical or social utility. The formula, giving two extra points during the first five years of life and one extra point during the second five years is a crude approximation of such a priority. It is defensible on this basis, as well as on the grounds of medical utility. Because the two principles have such radically different implications for other health care allocations, it is important to understand on which basis the points are being awarded.

While these bonus points are just an approximation for determining how to distribute medical treatment, they are only rough measures of either medical utility or "over-a-lifetime" justice. In an earlier article, I suggested a different formula, which is more precise and avoids the crude transitions at ages five and ten.⁴⁰ This formula awarded bonus points for any allocation based on over-a-lifetime justice calculated: a constant divided by the patient's age. If the constant were ten, which seems fairly accurate for the kidney formula, a one-year-old would get ten extra points, a five-year-old two and a ten-year-old one point. The transitions, however, would be gradual from one year to the next. Above age ten, the bonus would be vanishingly small, but would function as a tie-breaker when histocompatibility, length of time on the waiting list and antibody counts were equal for two or more candidates. This would have the advantage of avoiding any sharp age cut-off, which is implied in Daniel Callahan's suggestion for a cut-off age for certain kinds of health care for people in their seventies, eighties and beyond.⁴¹ Rather than a sharp cut-off at a specific age, my

40. See Veatch, *supra* note 34, at 205-16 (criticizing Childress' theory of medical utility in the venue of organ transplants).

41. See Daniel Callahan, *Natural Death and Public Policy*, in *LIFE SPAN: VALUES AND LIFE-EXTENDING TECHNOLOGIES* 162, 173-74 (Robert M. Veatch ed., 1974) (proposing that natural death as a consideration in health care allocation for the elderly does not preclude the elderly from receiving health care); DANIEL CALLAHAN, *SETTING LIMITS: MEDICAL GOALS IN AN AGING SOCIETY* 173-74 (1987) (stating that the mere existence of life-sustaining technology is not sufficient reason to use such technology).

formula would recognize that for treatments justly allocated on an over-a-lifetime well-being basis, those who have lived longer would have slightly less of a claim to treatment. Children would, therefore, have a claim not only of medical utility, but also of justice due to priority. This would be the case at least for those services such as high-tech, experimental treatments and interventions that attempt to cure chronic illnesses which are believed to be justly allocated on an over-a-lifetime basis.

The moral claims of children to health resources would be allocated on the basis of some combination of the libertarian, utilitarian and egalitarian theories. Even if we could figure out what a just allocation would be, that would not necessarily inform us of what the morally right allocation should be. It would depend on how justice would be combined with other principles such as liberty and utility. Yet, it seems hard to deny that justice is at least a morally relevant consideration, if not the dominant one. Since the just allocation for children may not be the utility-maximizing one, we will need to be much more precise in deciding what the relationship should be among these theories.