Inequalities in access to health care and in health insurance, combined with dramatic increases in the costs of health care, have fueled debates about what social justice requires in many other countries. But is inequality in access to health care a serious problem of justice? Should all age groups, for example, have equal access to health care resources? In attempting to answer such questions, we encounter uncertainty over how to reconcile goals such as equal access to health care, the freedom to choose a health plan, health promotion, a free-market economy, social efficiency, and the beneficent state.

In a short story titled, "The Lottery in Babylon," Jorge Luis Borges depicts a society that distributes all social benefits and burdens solely on the basis of a periodic lottery. Each person is assigned a social role, such as a slave, a factory owner, a priest, or an executioner, purely by the lottery. This random selection system disregards achievement, training, merit, experience, contribution, need, and effort. The ethical and political oddity of the system described in Borges's story is jolting because assigning positions in this way fails so noticeably to cohere with conventional standards. Borges's system appears capricious and unfair, because we expect valid principles of justice to determine how social burdens, benefits, and positions ought to be allocated.

However, if we attempt to expound principles of justice, they seem as elusive as the lottery method seems capricious. The construction of a comprehensive and
unified theory of justice that captures our diverse conceptions is even more elusive. Moreover, many principles of justice that have been proposed in biomedical ethics are not distinct from and independent of other principles, such as nonmaleficence and beneficence.\(^2\) We begin to explore these problems in this chapter by analyzing the terms *justice* and *distributive justice*. Later, we will examine substantive principles of justice as well as several problems of social justice that concern how to allocate resources for and within the health care system.

**The Concept of Justice**

The terms *fairness*, *desert* (what is deserved), and *entitlement* have been used by various philosophers in attempts to explicate *justice*.\(^3\) These accounts interpret justice as fair, equitable, and appropriate treatment in light of what is due or owed to persons. Standards of justice are needed whenever persons are due benefits or burdens because of their particular properties or circumstances, such as being productive or having been harmed by another person’s acts. A holder of a valid claim based in justice has a right, and therefore is due something. An injustice thus involves a wrongful act or omission that denies people benefits to which they have a right or distributes burdens unfairly.

The term *distributive justice* refers to fair, equitable, and appropriate distribution determined by justified norms that structure the terms of social cooperation. Its scope includes policies that allot diverse benefits and burdens, such as property, resources, taxation, privileges, and opportunities. *Distributive justice* refers broadly to the distribution of all rights and responsibilities in society, including, for example, civil and political rights. It is to be distinguished from other types of justice, including *criminal* justice, which refers to the just infliction of punishment, and *rectificatory* justice, which refers to just compensation for transactional problems such as breaches of contracts and malpractice.

Problems of distributive justice arise under conditions of scarcity and competition to obtain goods or to avoid burdens. If ample fresh water existed for industrial disposal of waste materials, and no subsequent harm to human beings or other forms of life occurred from this disposal, it would not be necessary to restrict use. Many contemporary discussions of just benefits in prepaid health maintenance programs, just programs of care for the mentally retarded, and appropriate sources of funds for national health insurance similarly involve such trade-offs that have been fashioned under these conditions of society and competition.

A compelling example of distributive justice appears in the recent history of research involving human subjects. Until the 1990s, the paradigm for ethical analysis focused on the *risks and burdens* of research, especially nontherapeutic research, and on the need to protect potential and actual research subjects from harm, abuse, and exploitation. This history in the United States, as Carol Levine notes, “was born in scandal and reared in protectionism.”\(^4\)
search sought to protect vulnerable persons from exploitation in scientific efforts to benefit others. The dominant model in protectionist policies is *nontherapeutic* research, i.e., research that offers no prospect of direct therapeutic benefit to the subject. The concern is about an unfair distribution of *burdens*. However, a paradigm shift recently occurred, in part because of the interest of patients with AIDS in gaining access to new, experimental drugs within as well as outside of clinical trials. The focus shifted to *therapeutic* research and to the possible *benefits* of clinical trials (deemphasizing their risks). As a result, justice as *fair access to research* (both participation in research and access to the results of research) became as important as protection from exploitation. Similar observations apply to the participation of women in research.

Issues concerning the fairness of a distribution generate questions about *principles* of justice. No single principle can address all problems of justice. Somewhat like our division of principles under the heading of beneficence, several principles of justice appear in the common morality and merit acceptance. One principle of justice is *formal*, the others *material*. We indicate in this chapter how to specify and balance these principles in particular contexts. Specifying and balancing promote the coherence that we seek in principles of justice. Sometimes, however, conditions of scarcity force a society to make "tragic choices." In these situations, principles of justice may end up being infringed, compromised, or sacrificed.

*The Formal Principle of Justice*

Common to all theories of justice is a minimal formal requirement traditionally attributed to Aristotle: Equals must be treated equally, and unequals must be treated unequally. This principle of formal justice (sometimes called the *principle of formal equality*) is "formal" because it identifies no particular respects in which equals ought to be treated equally and provides no criteria for determining whether two or more individuals are in fact equals. It merely asserts that *whatever* respects are relevant, persons equal in those respects should be treated equally.

An obvious problem with this formal principle is its lack of substance. That equals ought to be treated equally does not provoke debate. But how shall we define *equality*, and which differences are relevant in comparing individuals or groups? Presumably all citizens should have equal political rights, equal access to public services, and equal treatment under the law. But how far should equality extend? A typical problem is the following: Virtually all accounts of justice in health care hold that delivery programs and services designed to assist persons of a certain class, such as the poor or the elderly, should be made available to all members of *that class*. To deny benefits to some when others in the same class receive benefits is unjust. But is it also unjust to deny access to equally needy persons outside of the delineated class (e.g., workers with no health insurance)?
Material Principles of Justice

Principles that specify the relevant characteristics for equal treatment are called material because they identify the substantive properties for distribution. One such principle is the principle of need, which declares that distribution of social resources based on need is just. To say that a person needs something is to say that, without it, the person will be harmed or at least detrimentally affected. However, we are not required to distribute all goods and services to satisfy all needs, such as needs for bedboards, athletic equipment, and antilock brakes. Presumably our obligations are limited to fundamental needs. To say that someone has a fundamental need is to say that the person will be harmed or detrimentally affected in a fundamental way if that need is not fulfilled. For example, the person might be harmed through malnutrition, bodily injury, or nondisclosure of critical information.

If we were to analyze in great detail the notions of fundamental needs, we could progressively specify and shape the material principle of need into a public policy for purposes of distribution. For the moment, however, we are emphasizing only the significance of the step of accepting the principle of need as a valid material principle of justice. This principle is only one material principle of justice. If, by contrast, one were to accept only a principle of free-market distribution, then one would oppose a principle of need as a basis for public policy. All public and institutional policies based on distributive justice ultimately derive from the acceptance (or rejection) of some material principles and some procedures for specifying, refining, or balancing them, and many disputes over the right policy or distribution spring from rival, or at least alternative, starting points with different material principles.

Philosophers and others have proposed each of the following principles as a valid material principle of distributive justice (as well as other principles):

1. To each person an equal share
2. To each person according to need
3. To each person according to effort
4. To each person according to contribution
5. To each person according to merit
6. To each person according to free-market exchanges

No obvious barrier prevents acceptance of more than one of these principles, and some theories of justice accept all six as valid. A plausible moral thesis is that each of these material principles identifies a prima facie obligation whose weight cannot be assessed independently of particular contexts or spheres in which they are applicable.

Most societies invoke several of these material principles in framing public policies, appealing to different principles in different spheres and contexts. For example, unemployment subsidies, welfare payments, and many health care pro-
grams are distributed on the basis of need (and to some extent on criteria such as previous length of employment); jobs and promotions in many sectors are awarded on the basis of demonstrated achievement and merit; the higher incomes of some persons are allowed and often encouraged on grounds of free-market wage scales, superior effort, merit, or potential social contribution; and, at least theoretically, the opportunity for a basic education is distributed to all citizens.

Conflicts among the above principles create a serious priority problem as well as a challenge to a moral system that aims for a coherent framework of principles. These conflicts indicate the vital need for both specification and balancing of these principles, as is illustrated by the case of Mark Dalton, a histology technician employed by a large chemical company.\textsuperscript{8} Dalton was an excellent worker, but, after a week of sick leave, a company nurse discovered that he had a chronic renal disease. The company determined that the permissible levels of chemical vapor exposure in Dalton's job might exacerbate his renal condition. Management found him another job, with the same salary, but two other employees eligible for promotion were also interested in the job. Both employees had more seniority and better training than Dalton, and one was a woman. In this situation, each of the three employees could legitimately appeal to a different material principle of justice to support his or her claim to the available position. Dalton could cite the material principle of need, arguing that his medical condition required that he either be offered the new position or be dismissed from the company with compensation. With their superior experience and training, the other two employees could invoke material principles of merit, societal contribution, and perhaps individual effort in support of their claims. Considerations of equal opportunity and the past record of promotions in the company also gave the woman valid grounds for claiming that justice entitled her to the position. Without further specification and balancing, such conflicts among general material principles are not resolvable.

\textit{Relevant Properties}

Material principles identify relevant properties that persons must possess to qualify for a particular distribution, but theoretical and practical difficulties plague the justification of alleged relevant properties. Tradition, convention, moral and legal principles, and public policy can and do function to establish relevant properties. For example, a tennis tournament awards trophies on the basis of achievement (as determined by the tradition-bound rules of tournament tennis) and individuals receive prison terms only if they are found guilty of crimes (as determined by legal and moral norms). However, in many contexts, it is appropriate either to institute a policy establishing relevant properties where none previously existed or to develop a new policy that revises established criteria. For example, it has repeatedly been asked how we should address the question
whether nonresident aliens should be allowed on waiting lists for cadaveric organ transplantation in the United States.

Courts often mandate policies that revise entrenched notions about relevant properties. For example, the United States Supreme Court decided, in the case of *Auto Workers v. Johnson Controls, Inc.* that employers cannot legally adopt "fetal protection policies" that specifically exclude women of childbearing age from a hazardous workplace, because these policies discriminate illegally based on sex. Under the challenged policies, only fertile men could choose whether they wished to assume reproductive risks. The majority of justices held that this gender-based policy used the irrelevant property of being a woman, despite the fact that mutagenic substances affect sperm as well as eggs.

Such problems show us again that abstract principles provide only rough guidelines for forming specific policies or taking concrete actions. We need further moral argument that specifies and balances principles and assesses competing claims in order to determine which concrete aspects of a situation are morally relevant and decisive in forming a reasoned judgment. Agreement will often be difficult to achieve, and, for this reason, some philosophers have concluded that abstract material principles of justice can offer little help until they have been integrated into a systematic framework or theory. But how much help will a general framework or theory of justice provide, and which one(s), if any, should we accept?

**Theories of Justice**

Theories of distributive justice attempt to connect properties of persons with morally justifiable distributions of benefits and burdens. Philosophers have proposed several theories to determine how to distribute, or, in some cases, redistribute, social burdens and goods and services, including health care. These theories differ with respect to the specific material criteria they emphasize, how they interpret and weight those criteria, the areas or spheres to which they apply them, and the forms of justification they employ.

The following are influential types of theory: *Utilitarian* theories emphasize a mixture of criteria for the purpose of maximizing public utility; *libertarian* theories emphasize rights to social and economic liberty (invoking fair procedures rather than substantive outcomes); *communitarian* theories stress the principles and practices of justice that evolve through traditions and practices in a community; and *egalitarian* theories emphasize equal access to the goods in life that every rational person values (often invoking material criteria of need and equality).

We can expect these theories to succeed only partially in bringing coherence and comprehensiveness to our fragmented visions of social justice. Policies for health care access and distribution, in many countries, provide an example of the problems that confront these theories. People in many countries seek to provide the best possible health care for all citizens, while promoting the public interest through cost-containment programs. They promote the ideal of equal access to health care...
for everyone, including care for indigents, while maintaining aspects of a free-market competitive environment. These laudable goals of superior care, equality of access, freedom of choice, and social efficiency are extremely difficult to render coherent in a social system. Different conceptions of the just society underlie them, and pursuing one goal is likely to undercut another. Nonetheless, several theories of justice try either to achieve a balance between such competing social goals or to eliminate some health objectives while retaining others.

**Utilitarian Theories**

Utilitarian theories, which will be treated in more detail in Chapter 8, regard distributive justice as one among several problems of maximizing value. Utilitarians argue that the standard of justice depends on the principle of utility (which demands that we seek to maximize overall good). *Justice* is merely the name for the paramount and most stringent forms of obligation created by the principle of utility. Typically, utilitarian obligations of justice establish correlative rights for individuals that in this theory should be enforced by law, if necessary. These rights are strictly contingent upon social arrangements that maximize net social utility. Rights have no other basis, and disputes even erupt among utilitarians as to whether rights have a meaningful place in moral theory. However, if a system of rights is justified entirely on the grounds that its existence will maximize utility, utilitarians cannot seriously object to rights. The only question is whether any particular system of rights does, in fact, work to maximize social utility.

Many utilitarians favor social programs that protect public health and distribute basic health care to all citizens. However, various questions emerge about rights if utilitarian principles of justice are accepted as solely sufficient. Individual rights, such as the right to health care, have a tenuous foundation when they rest on overall utility maximization, because social utility could change at any time. Furthermore, utilitarian approaches neglect considerations of justice that focus on how benefits and burdens are distributed independently of aggregate welfare. For example, it seems unjust for a society to maximize utility by denying access to health care for some of its sickest and most vulnerable populations.

Principles of utilitarian justice thus present serious problems, but we will see that, when carefully restricted in scope, they do have a legitimate role in forming health policies.

**Libertarian Theories**

The United States has traditionally, though not exclusively, accepted the free-market ideal that distributions of health care are best left to the marketplace, which operates on the material principle of ability to pay, either directly or indirectly through insurance. In general, under this conception, a just society protects rights of property and liberty, allowing persons to improve their circumstances and protect their health on their own initiative. Health care is not a right
under this conception, and the ideal health care system is privatized. A libertarian interpretation of justice focuses not on increasing public utility or meeting the health needs of citizens, but on the unfettered operation of fair procedures.

A major contemporary libertarian theory appears in an influential book by Robert Nozick, who argues for an “entitlement theory” of justice in which government action is justified if and only if it protects citizens’ rights. He argues that a theory of justice should affirm individual rights rather than create patterns of economic distribution in which governments redistribute the wealth acquired by persons under the free market. Governments act coercively and unjustly when they tax the wealthy at a progressively higher rate than those who are less wealthy, and then use the proceeds to underwrite state support of the indigent through welfare payments and unemployment compensation.

Nozick accepts a form of procedural justice with three and only three principles: justice in acquisition, justice in transfer, and justice in rectification. More specifically, no pattern of just distribution exists independent of free-market procedures of acquiring property, legitimately transferring that property, and providing rectification for those whose property was illegitimately taken or who otherwise were illegitimately obstructed in the free market. Accordingly, justice consists in the operation of just procedures (such as fair play), not in the production of just outcomes (such as an equal distribution of resources). There are no welfare rights and, therefore, no rights or claims to health care can be based on justice.

Libertarians do not oppose utilitarian or egalitarian patterns of distribution if they are freely chosen by participants. Any distribution of goods, including that for health care, is just and justified if (and only if) individuals in the relevant group freely choose it. As a result, libertarians generally support a health care system in which health care insurance is privately and voluntarily purchased. In this system, the state does not coercively take any one’s personal property to benefit another. Investors in health care and insured persons have property rights, physicians have liberty rights, and society is not morally obligated to provide health care. Indeed, society is morally obligated to refrain from providing funds by coercive taxation or assigning physicians conscription.

Competing theories of justice reject this uncompromising commitment to liberty and pure procedural justice. In recent years, communitarian and egalitarian theories have offered influential challenges.

Communitarian Theories

Communitarians react negatively to models of society (such as those developed by Mill, Rawls, and Nozick) that base human relationships on rights and contracts and that attempt to construct a single theory of justice by which to judge every society. Communitarians regard principles of justice as pluralistic, deriving from as many different conceptions of the good as there are diverse moral communities. What is due individuals and groups depends on these community-derived standards.
Communitarians emphasize either the responsibility of the community to the individual or, increasingly in contemporary policy, the responsibility of the individual to the community. Some communitarians eschew the language of justice and adopt the language of solidarity, which is both a personal virtue of commitment and a principle of social morality based on the shared values of a group. For example, in the Netherlands, solidarity is sometimes viewed as a collective obligation to take care of citizens. The 1991 report of a Committee for Choices in Health Care, assembled under the Dutch Secretary for Public Health, argued that certain services or procedures are vital to ensure the “adequate functioning of society as a whole,” and that their provision should be “consonant with the basic values of Dutch society.” The report assigned an “absolute priority . . . to care for the elderly, the handicapped, and psychiatric patients.” 12

Some moderate communitarian writers in biomedical ethics attempt to incorporate aspects of liberal theories into their accounts. For example, Ezekiel J. Emanuel envisions small deliberative democratic communities that develop shared conceptions of the good life and justice. 13 He proposes thousands of community health programs (CHPs), each involving citizen-members who join in a federation. Each family would receive a voucher for participation in their community’s CHP, and the CHP would determine democratically which benefits to provide, which care is most important, and whether expensive services, such as heart transplants, will be included or excluded. Justice is located in the guarantee that services will be provided to fulfill a particular community-endorsed conception of social goals.

Michael Walzer’s communitarianism, by contrast, focuses on past and present socio-moral practices. According to Walzer, no single principle of distributive justice governs all social goods and their distribution. Rather, several principles constructed by human societies constitute distinct “spheres of justice.” Notions of justice do not derive from some rational or natural foundation external to the society, but from standards developed internally, as a political community evolves. Walzer holds that community traditions and practices often include developed commitments of equal access to health care. While conceding that a two-tiered health care system—a decent minimum for all and then liberty of contract for the advantaged—is not unjust in principle, Walzer contends that this system would be unjust in a country such as the United States, where traditions of justice and the “common appreciation of the importance of medical care” have already committed the American people to more in the way of distributive justice than a two-tier system acknowledges. 14

Egalitarian Theories

Egalitarian theories of justice hold that persons should receive an equal distribution of certain goods, such as health care, but no prominent egalitarian theory requires equal sharing of all possible social benefits. Qualified egalitarianism re-
quires only some basic equalities among individuals, and permits inequalities that redound to the benefit of the least advantaged.

As the major contemporary example of qualified egalitarianism, John Rawls’s theory of justice challenges libertarian, utilitarian, and communitarian theories. Rawls argues that “what justifies a conception of justice is not its being true to an order antecedent and given to us, but its congruence with our deeper understanding of ourselves and our aspirations, and our realization that, given our history and the traditions embedded in our public life, it is the most reasonable doctrine for us.”15 A theory of justice therefore matches our commonly accepted judgments of fairness with our general principles.

Although Rawls has not pursued the implications of his theory for health policy, others have. In an influential interpretation and extension, Norman Daniels argues for a just health care system based mainly on a Rawlsian principle of “fair equality of opportunity.” Although Daniels offers no explicit defense of this principle, he relies implicitly on the importance of health care needs and on a considered judgment that fair opportunity is central to any acceptable theory of justice. Daniels’s thesis is that social institutions affecting health care distribution should be arranged, as far as possible, to allow each person to achieve a fair share of the normal range of opportunities present in that society. The normal range of opportunity reflects the range of life plans that a person could reasonably hope to pursue, given his or her talents and skills. This theory, like Rawls’s, recognizes a positive societal obligation to eliminate or reduce barriers that prevent fair equality of opportunity, an obligation that extends to programs to correct or compensate for various disadvantages. It views disease and disability as undeserved restrictions on persons’ opportunities to realize basic goals. Health care, then, is needed to achieve, maintain, or restore adequate or “speciesotypical” levels of functioning (or the equivalents of these levels), so that basic goals can be achieved. A health care system designed to meet these needs should attempt to prevent disease, illness, or injury from reducing the range of opportunity open to the individual. The allocation of health care resources, then, should ensure justice through fair equality of opportunity. Forms of health care that have a significant effect on preventing, limiting, or compensating for reductions in normal species functioning should receive priority in designing health care institutions and allocating health care.16

This Rawls-inspired theory has far-reaching egalitarian implications for national health policy. On this account, each member of society, irrespective of wealth or position, would have equal access to an adequate, although not maximal, level of health care—the exact level of access being contingent on available social resources and public processes of decision-making. Better services (e.g., luxury hospital rooms and optional, cosmetic dental work) would be available for purchase at personal expense, including through private insurance.

Daniels and others have used a Rawlsian theory of justice to move beyond ac-
cess to health care to the social determinants of health outcomes. In doing so, they concentrate on the distribution of welfare, as measured by health indices such as life expectancy, rather than on the distribution of resources.¹⁷ Studies have long indicated that increasing access to health care does not correspondingly reduce inequalities in health among all socioeconomic classes, but Daniels and colleagues contend, in addition, that social justice itself, apart from specific health care services, is “good for our health.”¹⁸ They hold that empirical literature on the social determinants of health suggests that societal failures to meet Rawlsian or similar criteria for a just society—protection of equal liberties, provision of equal opportunity in a robust sense, fair distribution of resources, and support for our basic self-respect—contribute to health inequalities. The thesis is that social justice would improve a society’s overall health and, at the same time, reduce health inequalities in that society.¹⁹ Policies that stand to improve health by reducing socioeconomic disparities include early childhood intervention and investment, providing basic nutrition, raising the minimum wage, and improving the work environment.²⁰

The power of Rawls’s theory of justice, together with the political significance of the decent-minimum proposal, have engendered wide support for egalitarianism. As one of their achievements, Rawlsian theories have encouraged discussion of the role of the rule of fair opportunity in a theory of social justice, a topic that merits further discussion.

**Fair Opportunity**

Daniels’s appeal to fair opportunity is only one use of the fair-opportunity rule. To explore this rule further, we need first to consider certain properties that have served as bases of distribution, although, as a matter of justice, they should not be considered relevant properties. These properties include gender, race, IQ, linguistic accent, national origin, and social status. In anomalous contexts, these properties may be relevant. For example, if a script calls for an actor in a male role, then females may be properly excluded (although this example is sometimes contested in contemporary film and theater). But general rules such as “To each according to gender” and “To each according to IQ” are unacceptable material principles. These properties are both irrelevant and discriminatory because they permit differential treatment of persons, sometimes with devastating effects, based on differences for which the affected individual is not responsible and which he or she does not deserve.

**The Fair-Opportunity Rule**

The fair-opportunity rule says that no persons should receive social benefits on the basis of undeserved advantageous properties (because no persons are responsible for having these properties) and that no persons should be denied social benefits on the basis of undeserved disadvantageous properties (because they
also are not responsible for these properties). Properties distributed by the lotteries of social and biological life do not provide grounds for morally acceptable discrimination between persons in social allocations if they are not properties that people have a fair chance to acquire or overcome.

The attempt to supply all citizens with a basic education raises thorny moral problems analogous to those found in health care. Imagine a community that offers a high-quality education to all students with basic abilities, regardless of gender or race, but does not offer a comparable educational opportunity to students with reading difficulties or mental deficiencies. This system seems unjust. The students with disabilities lack basic skills and need special training to overcome their problems; they should receive an education suitable to their needs and opportunities, even if it costs more. The fair-opportunity rule requires that they receive the benefits needed to ameliorate the unfortunate effects of life’s lottery.

By analogy, persons with functional disabilities lack capacity and need health care to reach a higher level of function and have a fair chance in life. If they are responsible for their disabilities, they might not be entitled to health care services. But if they are not responsible, the fair-opportunity rule demands that they receive that which will help them ameliorate the unfortunate effects of life’s lottery of health.

Mitigating the Negative Effects of Life’s Lotteries

Numerous properties might be disadvantaging and undeserved—for example, a squeaky voice, an ugly face, poor command of a language, or an inadequate early education. But which undeserved properties create a right in justice to some form of assistance?

One hypothesis is that virtually all abilities and disabilities are functions of what Rawls calls the natural lottery and the social lottery. “The natural lottery” refers to the distribution of advantageous and disadvantageous genetic properties. “Social lottery” refers to the distribution of social assets or deficits through family property, school systems, and the like. It is possible that all talents and disabilities result from heredity, natural environment, family upbringing, education, and inheritance. From this perspective, even the ability to work long hours and the ability to compete are biologically, environmentally, and socially produced. If so, talents, abilities, and successes are not to our credit, just as genetic disease is acquired through no fault of the afflicted person.

Rawls uses fair opportunity as a rule of redress. In order to overcome disadvantaging conditions (whether from biology or society) that are not deserved, the rule demands compensation for those with the disadvantages. The full implications of this approach are uncertain, but the conclusions Rawls reaches are challenging:

[A free-market arrangement] permits the distribution of wealth and income to be determined by the natural distribution of abilities and talents. Within the limits allowed by the background arrangements, distributive shares are decided by the outcome of the natural lottery; and this
outcome is arbitrary from a moral perspective. There is no more reason to permit the distribution of income and wealth to be settled by the distribution of natural assets than by historical and social fortune. Furthermore, the principle of fair opportunity can be only imperfectly carried out, at least as long as the institution of the family exists. The extent to which natural capacities develop and reach fruition is affected by all kinds of social conditions and class attitudes. Even the willingness to make an effort, to try, and so to be deserving in the ordinary sense is itself dependent upon happy family and social circumstances.21

At a minimum, our social system of distributing benefits and burdens would undergo massive revision if we were to accept this approach. Rather than allowing broad inequalities in social distribution based on effort, contribution, and merit, as some Western nations do, we would achieve justice only if we reduced radical inequalities. Any remaining inequalities would be permissible only if “disadvantaged” persons benefited more from them than from an equal distribution of benefits.

At some point, the process of reducing inequalities introduced by life’s lotteries must stop, and occasionally persons who are disadvantaged may not be protected by the fair-opportunity rule.22 Libertarians rightly stress that the fair-opportunity rule must be constrained by limited resources. However, their principled rationale for this conclusion is questionable. Some disadvantages are merely unfortunate, they argue, whereas others are unfair (and therefore obligatory in justice to correct). Tristram Engelhardt has argued that society should call a halt to claims of fairness or justice precisely at the point of this distinction between the unfair and the unfortunate: “Where one draws the line between what is unfair and unfortunate will, as a result, have great consequences as to what allocations of health care resources are just or unfair as opposed to desirable or undesirable. If the natural lottery is neutral, in the sense of not creating an obligation to blunt its effects, one does not have [even] prima facie grounds for arguing for a right to health care on the basis of claims of fairness or justice.”23

We are inclined to think that the problems of rationing addressed later in this chapter create a need for criteria other than the distinction between the unfortunate and the unfair, a criterion that may only beg the central questions of justice. Either way, the implications of the Rawlsian approach and the demands of the fair-opportunity rule remain very uncertain in biomedical ethics and health policy. No bright lines distinguish the unfair and the unfortunate or fair and unfair rationing schemes. It would be inappropriate to explore these theoretical problems further here. The point of exploring them as far as we have is to show that if one accepts the fair-opportunity rule, as we do, it will potentially affect many areas of moral reflection and social policy.

Unfair Distributions of Health Care Based on Gender and Race

We can now sketch some implications of the fair-opportunity rule for health care distribution, with particular attention to unfair distributions based on racial and gender properties.
Compelling evidence exists that health care has often been covertly distributed on the basis of these properties, resulting in a differential impact on women and minorities. Several recent studies indicate that African Americans and women have poorer access to various forms of health care by comparison to white males. For example, gender and racial inequities in employment have an impact on job-based health insurance; and the race and gender of physicians often play a role in the quality of patient–physician interaction.24 An example of the problem of health care distribution appears in at least some parts of the United States in a large difference in the rates of coronary artery bypass grafting (CABG) between white and African-American Medicare patients, as well as between male and female Medicare patients. Differences have been evident since the mid-1980s in many parts of the United States, although differences have been more pronounced in the southeast’s rural areas.25 Differences in need cannot entirely account for the variance, and it remains unclear how far the rates can be explained by physician supply, poverty, awareness of health care opportunities, less willingness among African Americans and women to undergo surgery, and racial prejudice. A recent study found that, after controlling for age, payer, and appropriateness and necessity for CABG, African-American patients in New York State had significant access problems unrelated to patient refusals.26 Another study found that African-American patients, once their lung cancer had been diagnosed and staged, were 12.7 percent less likely than white patients to have surgical resection.27

Evidence suggests that discrimination against African Americans, other minorities, and women occurs at the point of referral to transplantation centers and admission to waiting lists, whose criteria vary greatly. For instance, African Americans are much less likely than whites to be referred for evaluation at transplant centers (a difference of about 23 percentage points) and to be placed on a waiting list or receive a transplant within 18 months of starting dialysis (a difference of about 28 percentage points). These differences cannot be accounted for by patient preferences.28

In addition, questions arise about the use of human lymphocyte antigen (HLA) matching for the distribution of kidneys for transplantation. The degree of HLA match between a donor and a recipient influences the long-term survival of the transplanted graft. As a result, the United Network for Organ Sharing (UNOS) revised its criteria for the allocation of donated kidneys to give greater weight to the HLA match, thereby reducing the importance of time on the waiting list, logistics, and urgency of need.29 However, assigning priority to tissue matching could produce further discriminatory effects for minorities. Most organ donors are white, and certain HLA phenotypes are different in white, African-American, and Hispanic populations. The identification of HLA phenotypes is less complete for African Americans and Hispanics, and yet they have a higher rate of end-stage renal disease. Nonwhite populations are also disproportionately represented on dialysis rolls. African Americans typically wait months longer than whites,
almost twice as long, according to some studies, to receive a first kidney transplant.\textsuperscript{30} It also appears to be the case that if organs are allocated on the basis of tissue match, whites gain an advantage.\textsuperscript{31}

Justice minimally requires careful monitoring of point systems to determine whether discriminatory effects occur. In the case of transplantation, it may be justified to sacrifice some probability of success in order to take action, based on the fair-opportunity rule, to protect minorities. Defenders of the primacy of tissue matching argue that allocation rules can be constructed to reflect the natural lottery (which determines the spread of HLA types in the population), but the social context may still cause problems of injustice. For example, there are legitimate worries about the exploitation of minorities as sources of organs for others. Social factors also play a role in the higher rate among African Americans of medical conditions, such as hypertension, that contribute to end-stage kidney failure and the need for both dialysis and transplantation.\textsuperscript{32}

Problems plaguing minority patients are parallel to those facing women patients. The Council on Ethical and Judicial Affairs of the American Medical Association has examined data that raise concerns about whether women are disadvantaged because of inadequate attention to research, diagnosis, and treatment of their health problems.\textsuperscript{33} Some studies indicate that women have more physician visits per year than men and receive more services per visit, yet gender disparities still appear in three critical areas: (1) diagnosis of lung cancer, (2) diagnosis and treatment of cardiac disease, and (3) access to kidney transplantation. Biological differences alone do not account for these disparities. The Council notes that gender bias need not be manifest in an overt manner. Social attitudes involving stereotypes, prejudices, and gender-role attributions may be present, including the attribution of women's health complaints to emotional rather than physical causes.

In the use of diagnostic and therapeutic procedures for patients with coronary heart disease, for example, evidence exists that men and women are treated differently for reasons that appear unrelated to their medical conditions. One study found that women reported more cardiac disability than men before myocardial infarction, but that they were less likely than men to have procedures recommended that were known to reduce symptoms and improve cardiac function.\textsuperscript{34} There is ongoing debate about whether these procedures are overused in men, underused in women, or both. However, at least for heart disease and perhaps for lung disease as well, many health care professionals and public officials still appear to have a biased view of these diseases as male diseases.\textsuperscript{35}

The Right to a Decent Minimum of Health Care

We have seen that questions about whom shall receive what share of society's scarce resources generate controversies about a national health policy, unequal