Dividing Up Health Care Resources

In this land of plenty, many are rich; many are poor. Many are healthy; many are not. Many who are afflicted by disease, disability, or injury can get the health care they need; many cannot and they suffer and die for its lack. For any sensitive observer (and any decent society), these cold inequalities are surely cause for concern, dismay, even alarm. They also raise ethical questions of the most basic kind. To what are the less fortunate entitled, and what is society obligated to give? Are the needy due only the health care they can afford to buy for themselves, even if they can afford nothing? Or is society obligated to provide more? Is society obliged to provide everyone with access to health care regardless of ability to pay? Or is the claim on society's resources even stronger: Do people have a *right* to health care? If so, to what exactly are they entitled? To a guarantee of a state of well-being equal to that of everyone else? To an equal share of health care resources? To the best health care available? Or to something more modest—a decent minimum amount of health care? And what, exactly, is a decent minimum?

These are moral concerns on a larger scale than most of those we have grappled with in previous chapters. Here we ask not what is right or good in the person-to-person dramas of moral conflict; rather, we ask what is good or right in the policies and actions of society or government. The central issue is: Who should get health care, who should provide it, and who should pay for it? In other words, what is just? In the painful, complicated task of dividing up society's health care resources (including medical treatment, disease prevention, emergency care, and public health measures), what does justice demand?

Whatever answer is devised, it must take into account some hard realities. No system can provide maximum health care for everyone; there are limits—sometimes severe—to what any system can provide. Costs restrict how much health care can be delivered and how much can be obtained, and they can rise rapidly enough to destroy the best laid plans for fair access. Moreover, a society's finite resources must be allocated to satisfy many needs besides health care-education, defense, transportation, law enforcement, and others. Some kinds of health care can increase the well-being of more people to a greater degree than others, so considerations of efficiency will have to shape the allocation of resources. And somehow these quantitative factors must be reconciled with freedom of choice. In a free society, this value is paramount and cannot be entirely discarded for the sake of a more rational distribution of health care.

Most careful thinkers on the subject believe that a just apportioning of health care is possible. But how?

HEALTH CARE IN TROUBLE

Regardless of their political views, most tend to think that in this free and prosperous nation, all citizens should somehow have access to health care. But many people go without. Health care is so expensive that many can't afford it unless they have some type of health insurance, which is itself expensive—so expensive in fact that the high cost is the main reason for lack of coverage. In 2010, almost 49 million people under the age of 65 were uninsured, and almost 8 million of those were children. Nearly

a third of the under-65 population—almost 90 million people—had no health insurance for at least part of 2006 or 2007.1 In 2013, just before the Affordable Care Act (ACA, or "Obamacare") began to take effect, more than 44 million people under age 65 were without coverage. But by 2014, the ACA had expanded government health insurance (Medicaid), and many people were able to get tax credits to buy coverage from an ACA health insurance marketplace. Millions of people took advantage of these programs, but millions more were still left without coverage. By 2016, there were still 26.7 million people under 65 who had no health insurance coverage.2 In 2019, the number climbed to 28.9 million. The reasons for lack of coverage were the same then as they are today: high cost of insurance, the absence of coverage acquired through employment, and ineligibility for public coverage.

The consequences of going without health coverage are just what you might expect. The uninsured are less likely than the insured to get needed medical treatment, prescription drugs, preventive tests (pap smears and prostate exams, for example), and follow-up care when they do manage to see a doctor. Not surprisingly, researchers have estimated that the risk of death is 25 percent higher for the uninsured than the insured, resulting in about 18,000 more deaths in 2000 among those aged 25 to 64.³

Of course, being without health insurance is a major financial burden as well as a health risk. A nonpartisan research organization explains the problem like this:

For many uninsured people, the costs of health insurance and medical care are weighed against equally essential needs, like housing, food, and transportation to work, and many uninsured adults report being very or moderately worried about paying basic monthly expenses such as rent or other housing costs and normal monthly bills. When uninsured people use health care, they may be charged for the full cost of that care (versus insurers, who negotiate discounts) and

often face difficulty paying medical bills and potential medical debt. Providers absorb some of the cost of care for the uninsured, and while uncompensated care funds cover some of those costs, these funds do not fully offset the cost of care for the uninsured.⁴

Traditionally most people under age 65 got health coverage as a benefit of employment, but a smaller percentage of them are now obtaining insurance this way—69 percent in 2000 down to 57 percent in 2013, and 50 percent in 2019. Fewer employers are offering this benefit, and even when they do, many employees are either not eligible for it or cannot afford to pay their portion of the insurance premium. Over 75 percent of the uninsured are members of families with full-time workers.⁵

People who are age 65 and older and some adults under 65 with permanent disabilities are covered by the public health insurance program known as Medicare. It collects payroll taxes from workers during their employment years and provides coverage when they turn 65, paying many health care expenses, including physician and hospital services and prescription drugs. Medicaid, another publicly supported program, covers some under-65 low-income people, including children and the disabled. But coverage varies from state to state and, because of eligibility rules, does not extend to millions of people below the federal poverty level.

Critics of the U.S. health care system point to discrepancies between the huge expenditures for health care and surprisingly low grades on standard measures of national health. According to 2019 data, the country's per capita spending on health care was more than \$10,000—far more than the amount spent by the richest nations in the world. (The list of the richest comprises 30 democracies in the Organization for Economic Cooperation and Development [OECD], including France, Germany, Switzerland, Denmark, Canada, the United Kingdom, Norway, and Japan.) The countries coming

closest to that level of spending were Switzerland at \$7,317 and Norway at \$6,187. The United Kingdom, Japan, Australia, Canada, Iceland, and France all spent about half of what the United States did.

Yet in the United States, life expectancy at birth (81.1 years) was lower than that of most of the other economically advanced OECD countries, including Canada (83.9), France (85.5), Japan (87.1), the United Kingdom (83), Switzerland (85.6), Iceland (84.1), Australia (84.6), and Spain (86.3). The infant mortality rate in the United States was also higher than the OECD average—5.9 deaths per 1,000 live births compared to an average of 3.9. In fact, it was higher than the rate of any other developed country except Mexico.6

Though the United States spends more on health care than any other country, the quality of the care is not obviously better overall than that of other countries. The U.S. system outshines them in some ways, but lags behind in others. For example, it excels in the development and use of medical technologies and in some important measures of health care quality:

- 30-day mortality for heart attacks and ischemic stroke is lower in the United States than in comparable countries.
- Obstetric trauma during vaginal delivery is less common in the United States than in some comparable countries.
- Five-year survival rates for certain cancers (colorectal, breast, and cervical, ages 15 and over) are higher in the United States than in comparable countries.
- Mortality rates for breast and colorectal cancer in the United States are lower than in comparable countries.

But on other measures the quality of U.S. health care falls short:

• The United States has the highest rate of deaths amenable to health care among comparable countries.

- Disease burden (disability) is higher in the United States than in comparable countries.
- Hospital admissions for preventable diseases are more frequent in the United States than in comparable countries.
- The United States has higher rates of medical, medication, and lab errors than comparable countries.
- The mortality rate for respiratory diseases is higher in the United States than in comparably wealthy countries.
- Adults in most comparable countries have quicker access to a doctor or nurse when they need care.
- Use of the emergency department in place of regular doctor visits is more common in the United States than in most comparable countries.7

In the United States most health care is allocated through managed care, a system for providing care to a particular group of patients (members of the system) using regulatory restraints to control costs and increase efficiency. People who enroll in a managed care plansuch as a health maintenance organization (HMO) or a preferred provider organization (PPO)—get health care at discounted prices from the plan's network of providers (physicians, hospitals, etc.). Managed care plans try to control costs by influencing the kind and amount of care that providers offer and by restricting the choices that members have. Though cost control and efficiency are laudable goals, many critics worry that they are at odds with patient welfare. The concern is that for the sake of economical medicine, providers may cut corners, decide not to order necessary tests, pay less attention to patients' needs, or refuse to treat certain serious health problems. Some charge that managed care as it is currently practiced forces physicians to try to serve the patient and provide organizational efficiency, an impossible task that weakens the patient's trust in the physician.

In 2010 this troubling picture of American health care began to change when President Barack Obama signed into law the Patient Protection and Affordable Care Act (ACA). It was an attempt to provide health coverage to many more Americans and to contain the insidious rise of health care costs. Getting the law through Congress was a wrenching ordeal of high-stakes partisan brawling that seemed to arise largely from diverging answers to fundamental philosophical questions: What duties does the state have toward its citizens? How much should the state do to ensure the well-being of its people? What benefits do citizens have a right to expect from a government that is supposed to "promote the general welfare"?

Here's a rundown of the legislation's major provisions summarized by a nonpartisan foundation:

- Most individuals will be required to have health insurance beginning in 2014.
- Individuals who do not have access to affordable employer coverage will be able to purchase coverage through a health insurance exchange with premium and cost-sharing credits available to some people to make coverage more affordable. Small businesses will be able to purchase coverage through a separate exchange.
- Employers will be required to pay penalties for employees who receive tax credits for health insurance through the exchange, with exceptions for small employers.
- New regulations will be imposed on all health plans that will prevent health insurers from denying coverage to people

Fact File U.S. Health Care

- In 2019, 28.9 million Americans under age 65 had no health insurance.
- In 2019, 74 percent of uninsured adults said the main reason they were uninsured was because the cost was too high.
- Enrollment in ACA coverage corresponds with large declines in the uninsured rate. Between 2013 and 2014, the uninsured rate dropped significantly, from 16.2 percent in the last quarter of 2013 to 12.1 percent in the last quarter of 2014. The uninsured rate in 2019 was 10.9 percent.

Hispanic people and Native Hawaiians and Other Pacific Islander people experienced the largest increases in the uninsured in 2019.

- Many people do not have access to coverage through a job, and some people, particularly poor adults in states that did not expand Medicaid under ACA, remain ineligible for public coverage.
- In 2019, over 73 percent of uninsured people were in a family with a full-time worker.
- The United States has earned surprisingly low grades on several standard measures of the quality of health care.

From Kaiser Family Foundation, "Key Facts about the Uninsured Population," November 6, 2020, https://www.kff.org/uninsured/issue-brief/key-facts-about-the-uninsured-population/; Peterson-Kaiser, Health System Tracker, "How Does the Quality of the U.S. Healthcare System Compare to Other Countries?," September 30, 2021, https://www.healthsystemtracker.org/chart-collection/quality-u-s-healthcare-system-compare-countries/; the Kaiser Commission on Medicaid and the Uninsured, "The Uninsured: A Primer," Kaiser Family Foundation, October 2010, http://www.kff.org/uninsured/7451.cfm.

- for any reason, including health status, and from charging higher premiums based on health status and gender.
- Medicaid will be expanded to 133 percent of the federal poverty level (\$14,404 for an individual and \$29,327 for a family of four in 2009) for all individuals under age 65.

The provisions of the law were implemented over the next few years. In the meantime it has been repeatedly challenged in the federal courts, and the partisan divide over it remains as wide as ever.

In 2012, in the case of National Federation of Independent Business v. Sebelius, the Supreme Court held that the ACA was constitutional but that states could opt out of the law's requirement to expand Medicaid. In 2014, the Court ruled that under the law, employers with religious objections are not required to cover contraceptives. In 2015, the Court upheld the legality of the ACA's mandate to provide health insurance subsidies to all qualifying Americans. But in 2017, Congress got rid of the mandate. Yet despite repeated attempts by Republicans in Congress to kill the ACA, it is still substantially intact.

THEORIES OF JUSTICE

All these difficulties bring us around again to the question of what is just. Justice in the most general sense refers to people getting what is fair or what is their due (see Chapter 1). At the heart of every plausible notion of justice is the principle that equals should be treated equally—that people should be treated the same unless there is a morally relevant reason for treating them differently. When we ask what justice demands in society's allocation of health care, we are dealing with matters of distributive justice—justice regarding the fair distribution of society's advantages and disadvantages, or benefits and burdens, including income, property, employment, rights, taxes, and public service.

Debates about ethical allocations of health care resources rely heavily on general theories of justice. To justify a particular scheme of allocation, philosophers, politicians, and others may appeal to a theory of justice, and those who criticize the scheme may do so by arguing against that underlying theory of justice or by offering an alternative theory they believe to be superior. Three types of theories have had and continue to have—an enormous impact on the discussions: libertarian, utilitarian, and egalitarian.

According to libertarian theories of justice, the benefits and burdens of society should be distributed through the fair workings of a free market and the exercise of liberty rights of noninterference. The role of government is to protect the rights of individuals to freely pursue their own interests in the economic marketplace without violations of their liberty through coercion, manipulation, or fraud. Government may use coercion, but only to preserve liberty. Beyond these protections, the government has no obligation to adjust the distribution of benefits and burdens among people; the distribution is the responsibility of free and autonomous individuals. People may have equal rights or equal worth, but that does not entitle them to an equal distribution of society's benefits. The government acts unjustly if it coercively redistributes those benefits.

On this view, no one has a right to health care, and a government program using tax dollars to provide universal health care or even health care only for low-income families would be unjust. Such a program would be a coercive violation of people's right to use their resources as they see fit. The libertarian would accept a system of health care only if it is freely endorsed and financed by those who participate in it. So health insurance acquired through free choice by a group of private citizens to meet their own health care needs is acceptable. State-supported health insurance financed by taxes is not. But none of this would rule out voluntary charity by well-off citizens to provide health care for the poor.

IN DEPTH

COMPARING HEALTH CARE SYSTEMS: UNITED STATES, CANADA, AND GERMANY

UNITED STATES

The U.S. health system is a mix of public and private, for-profit and nonprofit insurers and health care providers. The federal government provides funding for the national Medicare program for adults age 65 and older and some people with disabilities as well as for various programs for veterans and lowincome people, including Medicaid and the Children's Health Insurance Program [CHIP]. States manage and pay for aspects of local coverage and the safety net. Private insurance, the dominant form of coverage, is provided primarily by employers. . . .

The United States does not have universal health insurance coverage. . . .

The federal government has only a negligible role in directly owning and supplying providers, except for the Veterans Health Administration and Indian Health Service. The ACA established "shared responsibility" among government, employers, and individuals for ensuring that all Americans have access to affordable and good-quality health insurance. The U.S. Department of Health and Human Services is the federal government's principal agency involved with health care services.

The states cofund and administer their CHIP and Medicaid programs according to federal regulations. States set eligibility thresholds, patient cost-sharing requirements, and much of the benefit package. They also help finance health insurance for state employees, regulate private insurance, and license health professionals. Some states also manage health insurance for low-income residents, in addition to Medicaid.

CANADA

Canada has a decentralized, universal, publicly funded health system called Canadian Medicare. Health care is funded and administered primarily by the country's 13 provinces and territories. Each has its own insurance plan, and each receives cash assistance from the federal government on a percapita basis. Benefits and delivery approaches vary. All citizens and permanent residents, however, receive medically necessary hospital and physician services free at the point of use. To pay for excluded services, including outpatient prescription drugs and dental care, provinces and territories provide some coverage for targeted groups. In addition, about two-thirds of Canadians have private insurance.

Canadian Medicare—Canada's universal, publicly funded health care system—was established through federal legislation originally passed in 1957 and in 1966. The Canada Health Act of 1984 replaces and consolidates the two previous acts and sets national standards for medically necessary hospital, diagnostic, and physician services. To be eligible to receive full federal cash contributions for health care, each provincial and territorial (P/T) health insurance plan needs to comply with the five pillars of the Canada Health Act. . . .

Canadian P/T governments have primary responsibility for financing, organizing, and delivering health services and supervising providers. The jurisdictions directly fund physicians and drug programs, and contract with delegated health authorities (either a single provincial authority or multiple subprovincial, regional authorities) to deliver hospital, community, and long-term care, as well as mental and public health services.

The federal government cofinances P/T universal health insurance programs and administers a range of services for certain populations, including eligible First Nations and Inuit peoples, members of the Canadian Armed Forces, veterans, resettled refugees and some refugee claimants, and inmates in federal penitentiaries. It also regulates the safety and efficacy of medical devices, pharmaceuticals, and natural health products, funds health research and some information technology systems, and administers several public health functions on a national scale.

(continued)

GERMANY

Health insurance is mandatory in Germany. Approximately 86 percent of the population is enrolled in statutory health insurance, which provides inpatient, outpatient, mental health, and prescription drug coverage. Administration is handled by nongovernmental insurers known as sickness funds. Government has virtually no role in the direct delivery of health care. Sickness funds are financed through general wage contributions (14.6 percent) and a dedicated, supplementary contribution (I percent of wages, on average), both shared by employers and workers. Copayments apply to inpatient services and drugs, and sickness funds offer a range of deductibles. Germans earning more than \$68,000 can opt out of SHI and choose private health insurance instead. There are no government subsidies for private insurance.

Chancellor Otto von Bismarck's Health Insurance Act of 1883 established the first social health insurance system in the world. At the beginning, health insurance coverage was restricted to blue-collar workers. In 1885, 10 percent of the population was insured and entitled to cash benefits in case of illness (50 percent of wages for a maximum of 13 weeks), death, or childbirth. While initially limited, coverage gradually expanded. The final step toward universal health coverage occurred in 2007, when health insurance, either statutory or private, was mandated for all citizens and permanent residents. Today's system provides coverage for the entire population, along with a generous benefit package.

From The Commonwealth Fund, "International Health Care Systems Profiles," June 5, 2020, https://www. commonwealthfund.org/international-health-policy-center/ countries/united-states.

In utilitarian theories of justice, a just distribution of benefits and burdens is one that maximizes the net good (utility) for society. Some allocations (or principles of allocation) of society's resources are more beneficial overall than others, and these are what utilitarian justice demands. A utilitarian may grant some principles of allocation the status of rights-rules that can be enforced by society and that can override considerations of utility in specific situations. But the ultimate justification of the rules is utilitarian (actually, rule-utilitarian): consistently following the rules may maximize utility generally, although rule adherence in some instances may not produce a net good.

On a utilitarian view, a just allocation of health care can take several forms depending on the facts about society's resources and needs and the likely effects of various allocation policies and programs. Thus, depending on calculations of net benefits, a utilitarian might endorse a system of universal health care insurance, or a qualified right to health care, or a two-tiered plan (like the U.S. arrangement) in which

government-supported health insurance is combined with the option of privately purchased health coverage for those who can afford it.

Egalitarian theories of justice affirm that important benefits and burdens of society should be distributed equally. To achieve greater equality, the egalitarian (unlike the libertarian) would not be averse to mandating changes to the distribution of society's goods or to interfering in the workings of a free market. And the egalitarian (unlike the utilitarian) would not allow utility to be the ultimate overriding consideration in a system of distribution. From egalitarian premises, theorists have derived several schemes for allocating health care, including systems that give equal access to all legitimate forms of health care, that offer a guaranteed minimal level of health care for everyone, or that provide care only to those most in need.

Besides these familiar theories of justice, there is another entirely different perspective on justice and health care: the human rights approach. The idea is that we can best achieve just distributions of health and health care by ensuring that human rights in general are respected. Respecting human rights (which encompass fair treatment, freedom from coercion, nondiscrimination, protection from abuse, equality, and other entitlements) contributes to well-being and health (including access to health care), and these positive contributions to health depend on respect for human rights. According to proponents of this view,

Health and human rights are not distinct but intertwined. Viewed as a universal aspiration, the notion of health as the attainment of physical, mental, and social well-being implies its dependency on and contribution to the realization of human rights. From the same perspective, the enjoyment by everyone of the highest attainable standard of physical and mental health is in itself a recognized human right. From a global normative perspective, health and human rights are closely intertwined in many international treaties and declarations supported by mechanisms of monitoring and accountability (even as their effectiveness can be questioned) that draw from both fields.⁹

A RIGHT TO HEALTH CARE

No matter what theory of justice people accept, they are likely to agree that it would be good for everyone to have adequate health care, or that beneficence may justify society's providing health care to the neediest, or that making particular kinds of health care available to certain groups may produce a net benefit for society. But some assert a much stronger claim: People have a moral right to health care. A right is an entitlement, a bona fide claim, to something. A person's rights impose duties on others—either (1) duties not to interfere with that person's obtaining something or (2) duties to help that person in her efforts to get something. Rights entailing the former obligations are called *negative rights*; those entailing the latter are called positive rights. Those who insist that an individual has a

right to health care are referring to a positive right and are claiming that society has an obligation to provide that benefit in some way.

Libertarians are likely to deny that there is a right to health care, for generally they accept negative rights and disallow positive rights. Utilitarians can admit a right to health care, though it would be what some have called a derivative right, a rule ultimately justified by assessments of utility. Others, including egalitarians, can accommodate a right to health care and interpret it in the strong sense of being an entitlement that ultimately outweighs calculations of maximized utility.

But what reasons are there for believing that there is such a strong right to health care? Norman Daniels believes that such a right can be derived from one of the principles of justice articulated by John Rawls, specifically the right to "fair equality of opportunity." Rawls maintains that everyone is entitled to an equal chance to obtain the basic goods of society, though there is no guarantee of an equal share of them (see the discussion of Rawls's theory in Chapter 2). A just society would ensure equal opportunities to its citizens. Daniels argues that disease and disability diminish people's "normal species functioning" and thus restrict the range of opportunities open to them. But "health care in all its forms, whether public health or medical, preventive or acute or chronic, aims to keep people functioning as close to normally as possible. . . . Health care thus preserves for us the range of opportunities we would have, were we not ill or disabled, given our talents and skills."11 Since people are entitled to fair equality of opportunity, and adequate health care can protect or restore their normal range of opportunities, they have a positive right to adequate health care.

A pivotal question that confronts every serious advocate of a moral right to health care is what health care resources it includes. Some have thought the right encompasses universal equal access to all available health care resources. But this arrangement is not technically or economically feasible; a right to health care, it seems, must

have limits. Recognizing this, many have argued for a weaker right to a "decent minimum" level of health care. On this view, everyone would have access to a minimal, basic array of health care resources. This tier of care would be universally available, publicly supported, and guaranteed for all in need. A second tier of additional health care services (elective or nonessential therapies, for example) would be available in the free marketplace for those who can afford them.

Allen Buchanan rejects the idea of a right to a decent minimum of care, but he understands its attractions:

IN DEPTH **PUBLIC HEALTH AND BIOETHICS**

Public health is bioethics on a large scale. Most of the time bioethics concerns ethics as it applies to individuals and personal morality, but it also encompasses morality as it pertains to the health of whole populations. This is public health. It focuses on communities, from neighborhoods to countries to the world, working to prevent disease and disabilities, promoting health and well-being, tracking the incidence of illness, and intervening when the health of a community is imperiled.

Public health involves agencies of the government but also many professionals and nonprofessionals in the community. It can function locally, nationally, or globally. Public health programs provide vaccinations, promote healthful habits such as handwashing and not smoking, guide the treatment of wastewater, distribute condoms to prevent the spread of sexually transmitted diseases, help insure the safety of food and water, investigate pandemics and other disease outbreaks, provide early warning of emerging public health hazards, prevent epidemics after natural disasters, and much more.

First, the notion that people have a right to a decent minimum or adequate level, rather than to all health care that produces any net benefit, clearly acknowledges that, because not all health care is of equal importance, allocational priorities must be set within health care and that resources must also be allocated to goods other than health care. Second, this [decent minimum] position is also consonant with the intuitively plausible conviction that our obligations to the less fortunate, although fundamental enough to be expressed in the language of rights, are nonetheless not unlimited. Third, the decent minimum is a floor beneath

Public health ethics, like any other area of applied ethics, deals with the application and reconciliation of moral norms. The same moral principles and concepts that inform the whole field of bioethics also do work in the subfield of public health. In public health, we still must strive to respect autonomy, avoid harming others, act with beneficence, maximize utility, behave justly, protect privacy and confidentiality, deal honestly with others, and keep promises. The proper balancing of these demands a job that falls to both professionals and ordinary citizens—is often difficult and controversial. Implementing these ideas is a separate job that is frequently even more challenging.

Moral norms can conflict in public health ethics just as they do in personal ethics. Suppose public health officials quarantine or treat a man against his will because he has contracted a deadly communicable disease. Here respect for the man's autonomy clashes with the need to protect the public from harm. In other cases the need to protect the public might conflict with people's right to privacy or with fairness or with confidentiality. Suppose the state mandates that all adults must be vaccinated against a lethal, spreading infection. A key issue is whether the government is wrongfully infringing on the population's personal liberty. Disputes like these can (and do) happen in nearly every public health endeavor, and disagreement is frequently widespread.

which no one should be allowed to fall, not a ceiling above which the better-off are prohibited from purchasing services if they wish.¹²

But the implications of the decent-minimum standard have been extremely difficult to specify in a plausible way. What is, after all, a *decent minimum* of health care? We may assume it includes such things as immunizations, annual physical exams, and "routine" medical care. Should it also include heart transplants, treatments for rare or orphan diseases, cosmetic surgery, expensive but marginally effective care for very elderly or dying patients, and costly lifelong therapies for mentally impaired persons who will never reach "normal" functioning?

Buchanan believes that although there is no right to a decent minimum of health care, there are good reasons for supposing that society should nevertheless provide the kind and amount of health care that a decent-minimum right would demand. That is, there is no individual right, but there may be a societal duty. Among these reasons are arguments that people have special rights (as opposed to universal rights) to health care—rights of restitution to certain groups for past wrongs, rights of compensation for "those who have suffered unjust harm or who have been unjustly exposed to health risks by the assignable actions of private individuals or corporations," and rights to health care for honorable service to society (for wounded soldiers, for instance). There are also prudential arguments, Buchanan says, such as that "the availability of certain basic forms of health care make for a more productive labor force or improve the fitness of the citizenry for national defense." Arguments for what he calls "enforced beneficence" can also be made out. To maximize the practical effect of our moral obligations of charity or beneficence regarding health care for those in need, "an enforced decent minimum principle is needed to achieve coordinated joint effort."13 Thus, for example, the government could levy taxes to provide health care to the poor—not in the name of egalitarian justice, but for the sake of beneficence.

THE ETHICS OF RATIONING

Rationing has been a dirty word in debates about health care, laden as it is with images of extreme measures of last resort for managing a dearth of resources. But in health care, rationing-in the broad sense of parceling out important limited goods—has always been with us and probably always will be. People's health care needs are virtually boundless, yet the supply of health care resources is ever limited. So we ration: Medicare and Medicaid allot health care to the elderly and the poor; HMOs limit medical procedures, tests, and access to doctors to control costs; hospitals restrict the use of intensive care units (ICUs), cardiac surgical teams, emergency departments, hospital beds, and expensive drugs; organ transplants are doled out to the few because of shortages of usable organs; and the health care system as a whole rations a great deal of care by people's ability to pay for it. (See Chapter 12 on rationing health care resources during a pandemic.)

Thus, the tough choices of rationing fall hard upon us, and we are forced to ask: Who should get what share of limited health care goods and services? In countless troubling instances, the question reduces to this: Who should live and who must die? In nearly the same breath we have to ask: On what ethical grounds do we make these choices? The fundamental issue of the proper allocation of insufficient resources troubles on several levels at once. It arises both on the scale of the total health care system (concerning what portion of society's resources should go to health care and how this allotment should be used—so-called macroallocation) and on the scale of individual patients and providers (regarding who should receive specific resources—known as microallocation).

Let's consider just a few of the smaller scale (microallocation) questions raised by one of our scarcest life-saving resources—organ transplants. Transplant operations are incredibly expensive, organs are in very short supply, and transplants are desperately needed by far more

people than can be accommodated. The waiting list for transplants is long, and thousands die every year for their lack. Screening committees at transplant centers decide whether someone should be placed on the waiting list and what ranking they should receive. They use various criteria to make these decisions, some explicit, some informal or unspoken, some plausible (such as the patient's need and likelihood of benefit), and some controversial (such as ability to pay, social worthiness, and health habits).

But what criteria should be used? What rationing policy for transplants is morally justified? Many proposed criteria are utilitarian, concerned with maximizing benefits to the patient and society. Many are egalitarian, focusing on justice and the moral equality of persons. Some philosophers propose rationing policies that emphasize one or the other, while some try systematically to accommodate both.¹³ No policy is completely satisfactory, but some seem to capture our moral intuitions better than others.

One utilitarian approach to rationing care to patients is to measure objectively the benefits that a treatment is likely to give each patient and then selectively treat particular patients or conditions to maximize total benefits. The objective measure of benefits that has often been used in such calculations is known as a QALY, or quality-adjusted life year. One QALY is equivalent to one year of life in good health, and a year of life in poor health is equal to less than 1 QALY. The lower the quality of life for a person in poor health, the lower the QALY value. A transplant operation that allows a patient to live seven years without disability or suffering is worth 7 QALYs; if it results in the patient's living seven years burdened by severe pain, it is worth less than 7 QALYs. Thus, QALYs gauge a treatment's impact by, plausibly, trying to take into account both the length of life and its quality. Intuitively this seems right because both quality of life and length of life matter to people. Most would probably rather enjoy a few years of good health than suffer through many years of terrible illness or disability. Suppose, then, that three people are awaiting heart transplants, without which they

will die within six months, and only two transplants are possible. Two of the potential recipients are young, so a transplant for either one of them would yield 10 QALYs. The third person is much older; a transplant for her would yield only 5 QALYs. So a transplant selection committee using the QALY standard alone would likely allocate the available transplants to the two younger patients, maximizing total benefits.

The utilitarian purpose behind using QALYs is to do the most good with the resources available. But critics have charged that relying on QALYs to allocate or ration health care can lead to morally unacceptable decisions. John Harris argues, for example, that QALYs discriminate against older people:

Maximizing QALYs involves an implicit and comprehensive ageist bias. For saving the lives of younger people is, other things being equal, always likely to be productive of more QALYs than saving older people. Thus on the QALY arithmetic we always have a reason to prefer, for example, neonatal or paediatric care to all "later" branches of medicine. This is because any calculation of the life-years generated for a particular patient by a particular therapy, must be based on the life expectancy of that patient. The older a patient is when treated, the fewer the life-years that can be achieved by the therapy.14

QALYs, he says, are also unfair to the disabled:

Suppose for example that if an accident victim were treated, he would survive, but with paraplegia. This might always cash out at fewer QALYs than a condition which with treatment would give a patient perfect remission for about five years after which the patient would die. Suppose that both candidates wanted to go on living as long as they could and so both wanted, equally fervently, to be given the treatment that would save their lives. Is it clear that the candidate with most QALYs on offer should always and inevitably be the one to have priority? To judge so would be to count the paraplegic's desire to live the life that was available to him as of less value than his rival's.15

CLASSIC CASE FILE

Christine deMeurers

The era of managed care has changed health care in the United States radically—for the worse, many say. Whatever the case, it has surely set off a host of conflicts that were previously unimagined: clashes between patients and their insurance companies, between physicians and their cost-conscious managed care employers, and between the physicians' duty to put the patient's welfare first and the economic incentives to put it last. Out of this maelstrom many unsettling stories have come, including this one.

In 1992, Christine deMeurers—a 32-year-old wife, mother of two, and schoolteacher—found out that she had breast cancer. She fought back promptly and aggressively, enduring a radical mastectomy, radiation therapy, and chemotherapy. But in May 1993, a bone scan revealed that the cancer had spread and now rated the ominous label of Stage IV metastatic breast cancer. Every standard therapy available had been used against her disease with no apparent effect. She was running out of time.

Christine and her husband, Alan, were subscribers in an HMO, Health Net of Woodland Hills, California. They got the insurance through their employer (they both were teachers at the same school) and had opted for the least expensive coverage.

After the standard treatments failed, the deMeurerses thought they had no options left, but Christine's oncologist, Dr. Mahesh Gupta, was hopeful. He held out the possibility that she could benefit from a promising new treatment, a bone marrow transplant. Its effectiveness against Christine's type of cancer was unproven, but it had been used successfully on other kinds of malignancies. In violation of Health Net rules on referrals, Dr. Gupta referred Christine directly to an expert he knew, an oncologist at the Scripps Clinic in La Jolla.

According to the deMeurerses, the Scripps doctor was reluctant to help them or even to provide them with information about the bone marrow transplant. So they flew to Denver, where Christine was examined by Dr. Roy B. Jones at the University of

Harris and others contend that a crucial failing of QALYs is that these objective measurements cannot accommodate the subjective nature of people's assessments of the value of their own lives. A paraplegic may value his life and think its quality extremely high despite his disability. A perfectly healthy person may think her life miserable despite a lack of physical ailments. The subjective valuation seems to be the important one; the objective measurement seems to be beside the point.

Policies for rationing transplants to a particular group of patients generally try to take into account the probability of transplant success or the urgency of the patients' needs. Both factors can be morally relevant. Regarding the former, because transplants are a scarce resource, fairness seems to demand that they be given to those who are likely to benefit from themotherwise the resource will be wasted, and people will be deprived of a treatment that could have saved them. Regarding the latter, giving transplants to those who cannot survive for much longer without them fulfills a duty to preserve lives.

Nevertheless, some maintain that allocating resources in light of one of these considerations while disregarding the other is a mistake:

For example, although heart-transplant surgeons sometimes list their patients as urgent priority candidates for an available heart because the patients will soon die if they do not receive a transplant, some of these patients are virtually certain

Colorado. He told them that the bone marrow procedure might be beneficial to Christine. But about the time that the deMeurerses consulted with Dr. Jones, Health Net resolved that the company would not pay for the transplant because it was disallowed under the investigational clause in Christine's contract.

Increasingly desperate, the deMeurerses started trying to raise the thousands of dollars needed to pay for the procedure, and they hired a lawyer to appeal Health Net's ruling. They also got permission to see another oncologist. He, too, encouraged Christine to consider the bone marrow transplant and referred her to the UCLA Medical Center. where Dr. John Glaspy presented the operation as an option and agreed to perform it.

This encounter between the deMeurerses and Dr. Glaspy was strained by mutual ignorance of some significant facts. Wary of possible interference from Health Net, they did not tell Dr. Glaspy that they were Health Net subscribers and told him instead that they would pay for the transplant out of pocket. At the same time the deMeurerses did not know that Dr. Glaspy was on the Health Net committee that

had voted recently not to cover bone marrow transplants for Stage IV breast cancer patients.

Later, news came that Health Net had rejected the appeal filed by the deMeurerses' lawyer.

Dr. Glaspy found himself caught between conflicting loyalties. As the deMeurerses' physician, he felt a responsibility to help Christine get the transplant. But as a Health Net physician, he was required to uphold the regulations of the HMO, some of which he had helped make. Discussions ensued between Health Net administrators and UCLA physicians and officials. Finally, a way out of the conflict appeared when UCLA agreed that it would pay for Christine's operation.

Christine began the treatment on September 22, 1993, at UCLA Medical Center. She died on March 10, 1995. Health Net officials expressed doubt that the treatment helped much. Alan deMeurers said that it gave Christine four disease-free months.

Eventually an arbitration panel ruled that Health Net should have paid for Christine's transplant and that the company had improperly interfered in the doctor-patient relationship.

to die even if they do receive the heart. High quality candidates are passed over in the process. A classification and queuing system that permits urgent need to determine priority exclusively is as unjust as it is inefficient.16

Neither probability of success nor urgent need seems to be as controversial as another kind of criterion: the social value of people's lives. Here the question is which potential recipients-if given the chance to live-are expected to contribute most to the good of society. To state the issue concretely: All things being equal, should the medical student get the transplant instead of the poet or prostitute? Nicholas Rescher thinks this question of social utility important and morally relevant:

In "choosing to save" one life rather than another, "the society," through the mediation of the particular medical institution in question which should certainly look upon itself as a trustee for the social interest—is clearly warranted in considering the likely pattern of future services to be rendered by the patient (adequate recovery assumed), considering his age, talent, training, and past record of performance. In its allocations of [exotic life-saving therapy], society "invests" a scarce resource in one person as against another and is thus entitled to look to the probable prospective "return" on its investment.17

Others reject this line altogether, arguing from an egalitarian or Kantian perspective that all persons have equal worth. Morally, the medical student is not worth more than the poet or prostitute, and vice versa. Education, achievement, occupation, and the like are not morally relevant.

Nevertheless, while generally taking this view, some philosophers maintain that in very rare cases, social worth can outweigh egalitarian concerns. It seems reasonable that in a natural disaster involving mass casualties, injured physicians or nurses should be treated first if they can aid the other survivors. We can imagine analogous situations involving organ transplants, says Walter Glannon:

Suppose that Nelson Mandela needed a liver transplant in 1992. This was the time when he was leading the transition from apartheid to democracy in South Africa. The transition turned out to be peaceful; but the political situation was potentially volatile. Mandela was essential to maintaining social stability. Suppose further that a younger individual also needed a liver and would have at least as good an outcome with a transplant. In the light of the political and social circumstances, Mandela should have been given priority over the younger patient in receiving a liver. His survival would have ensured the social stability of the country. It would have ensured that many people would not suffer a loss of welfare or life from the social instability that might have resulted otherwise. Mandela's social worth was a function of the dependence of many people's welfare and lives on his survival. That worth would have been a decisive factor in giving the organ to him rather than to another person with the same need.18

KEY TERMS

distributive justice egalitarian theories of justice libertarian theories of justice managed care utilitarian theories of justice

SUMMARY

The U.S. system of health care has been ailing—or failing, as some would say—for years. Its most obvious symptoms are 47 million uninsured

people under age 65, soaring costs, and low grades on some measures of national health, such as infant mortality rates.

Debates about ethical allocations of health care resources often reduce to clashes between theories of distributive justice—that is, theories regarding the fair distribution of society's benefits and burdens. Libertarian theories of justice say that the benefits and burdens of society should be distributed through the fair workings of a free market and the exercise of liberty rights of noninterference. The role of government is to protect the rights of individuals to freely pursue their own interests in the economic marketplace without violations of their liberty through coercion, manipulation, or fraud. On this view, no one has a right to health care. In utilitarian theories of justice, a just distribution of benefits and burdens is one that maximizes the net utility for society. Depending on calculations of net benefits, a utilitarian might endorse a system of universal health care insurance, or a qualified right to health care, or a two-tiered plan. Egalitarian theories of justice say that important benefits and burdens of society should be distributed equally. To achieve greater equality, the egalitarian would not be averse to mandating changes to the distribution of society's goods or to interfering in the workings of a free market. Egalitarian theorists could consistently endorse several schemes for allocating health care, including systems that give equal access to all legitimate forms of health care, that offer a guaranteed minimal level of health care for everyone, or that provide care only to those most in need.

Some theorists assert the strong claim that people have a positive moral right to health care. Libertarians would reject this view, utilitarians could endorse a derivative right to health care, and egalitarians could favor a bona fide entitlement to a share of society's health care resources. Some of the latter argue for a right to a decent minimum of health care.

Because people's health care needs are virtually limitless and the supply of resources is always bounded, rationing of health care in