

READINGS

Is There a Right to Health Care and, if So, What Does It Encompass?

NORMAN DANIELS

Daniels argues for a strong right to health care, deriving it from John Rawls' justice principle of "fair equality of opportunity." He reasons that disease and disability diminish people's "normal species functioning" and thus restrict the range of opportunities open to them. 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.

Is There a Right to Health Care?

Legal Versus Moral Rights to Health Care

One way to answer this question is to adopt the stance of legal positivists, who claim that there are no rights except those that are embodied in actual institutions through law. We would then be able to reply that in nearly every advanced industrial democracy in the world, there is a right to health care, since institutions exist in them that assure everyone access to needed services regardless of ability to pay. The notable exception is the United States, where many poor and near poor people have no insurance coverage for, and thus no assured access to, medically necessary services, although by law they cannot be denied emergency services.

The legal right to health care is embodied in a wide variety of types of health-care systems. These range from national health services, where the government is the provider of services, as in Great Britain, to public insurance schemes, where the government finances services, as in Canada, to mixed public and private insurance schemes, as in Germany and the Netherlands. Despite these differences in the design of systems, there is a broad overlap in the scope or content of the legal right to health care in these countries. Most cover "medically necessary" services, including a broad range of preventive, curative, rehabilitative and long-term care for physical

and mental diseases, disorders and disabilities. Most exclude uses of medical technologies that enhance otherwise normal functioning or appearance, such as purely cosmetic surgery. The legal rights vary in significant ways, however, for example, in the degree to which they cover new reproductive technologies, or in the types of mental health and long-term care services that are offered.

In the context of rising costs and the rapid dissemination of new technologies there is growing debate in many countries about how to set limits on the scope of a right to health care. This debate about the scope of rights to health care pushes moral deliberation about such a right into the forefront, even where a legal right is recognized. Legal entitlements, most people believe, should reflect what society is morally obliged to provide by way of medical services. What, then, is the basis and scope of a moral right to health care?

Positive Versus Negative Rights

A right to health care is a positive as opposed to a negative right. Put quite simply, a positive right requires others to do something beneficial or enabling for right-bearers, whereas a negative right requires others to refrain from doing something, usually harmful or restrictive, to right-bearers. To say that others are required to do something or to refrain from doing something is to say they must so act or refrain even if they could produce more good or improve the world by not doing so (Thomson, 1990). For example, a negative right to free expression requires others to refrain

From *A Companion to Bioethics* edited by Helga Kuhse and Peter Singer, pp. 316–25. Copyright © 1998, 2001 by Blackwell Publishing Ltd. Reprinted with permission.

from censuring the expression of the right-bearer even if censuring this speech would make a better world. Some public-health measures that protect people against interference with their health, such as environmental protections that protect people against polluters of air, water and food sources, might be construed as requirements of a negative right. More generally, however, a right to health care imposes an obligation on others to assist the right-bearers in obtaining needed and appropriate services. Specifically, claiming a right to health care includes these other claims; society has the duty to its members to allocate an adequate share of its total resources to health-related needs; society has the duty to provide a just allocation of different types of health care services, taking into account the competing claims of different types of health-care needs; each person is entitled to a fair share of such services, where a "fair share" includes an answer to the question, who should pay for the services? (Daniels, 1985). Health-care rights thus form a part of a broader family of positive "welfare" rights that includes rights to education and to income support. Because positive rights require other people to contribute their resources or skills to benefit right-bearers, rather than merely refraining from interfering with them, they have often been thought more difficult to justify than negative rights, and their scope and limits have been harder to characterize.

Theories of Justice and Rights to Health Care

If we are to think of a right to health care as a requirement of justice, then we should look to more general theories of justice as a way to specify the scope and limits of that right. On some theories of justice, however, there is little basis for requiring people to assist others by meeting their health care or other needs. Libertarians, for example, believe that fundamental rights to property, including rights to personal assets, such as talents and skills, are violated if society coerces individuals into providing "needed" resources or skills (Nozick, 1974). Libertarians generally recognize an "imperfect" duty to act beneficently or charitably, but this duty involves discretion. It can be discharged in different ways that are matters of choice. People denied charity have no right to it and have no complaint against people who act charitably in other ways. Though some have argued that the difficulty of coordinating the delivery of charitable assistance might justify coercive measures

(Buchanan, 1984), and others have tried to show that even libertarians must recognize some forms of welfare rights (Sterba, 1985), most libertarians resist any weakening of the property rights at the core of their view (Brennan and Friedman, 1981).

A spectre sometimes raised by libertarians against the idea of a right to health care is that such a right is a "bottomless pit." Since new technologies continuously expand the scope of "medical needs," a right to health care would give rise to unlimited claims on the resources of others (Fried, 1969; Engelhardt, 1986). Protecting such an expansive right to health care would thus not be compatible with the function of a libertarian "minimal state" to assure the non-violation of rights to liberty and property.

Though there remains controversy about whether utilitarians can provide a basis for recognizing true moral rights, there are strong utilitarian arguments in favour of governments assuring access to at least some broad range of effective medical services. Preventing or curing disease or disability reduces suffering and enables people to function in ways that contribute to aggregate welfare. In addition, knowing that health-care services are available increases personal security and strengthens the ties of community. Utilitarians can also justify redistributing the burden of delivering these benefits to society as a whole, citing the decreasing marginal utility of money to support progressive financing of health-care services (Brandt, 1979).

Beneath these quite general arguments, however, there lies a more specific controversy about the scope of utilitarian entitlements to health care. There seems to be little utilitarian justification for investing resources in health care if those resources would produce more net welfare when invested in other things, yet many people believe they have moral obligations to assist others with their health-care needs even at a net cost in utility. For example, some highly expensive and effective medical treatments that most people believe should be offered to people might not be "cost beneficial" and thus not defensible on utilitarian grounds. Similarly, many forms of long-term care, especially for those who cannot be restored to productive social activity, are also difficult to defend on utilitarian grounds, yet we insist our health-care systems are obliged to provide such services.

Lack of moral acceptance of the distributive implications of utilitarianism makes many uncomfortable

with the use of methods, such as cost-effectiveness analysis, that are intended to guide decisions about resource allocation in health care. For example, an assumption of cost-effectiveness analysis is that a unit of health benefit, such as a quality-adjusted life year (QALY), is of equal value or importance regardless of where it is distributed. But this assumption does not capture the concerns many people have about how much priority to give to the sickest patients, or when aggregating modest benefits to large numbers of people it outweighs the moral importance of delivering more significant benefits to fewer people (Nord, 1993; Daniels, 1993).

Two points about a utilitarian framework for a right to health care are worth noting. Recognizing a right to health care is compatible with recognizing limits on entitlements that result from resource scarcity and the fact that there are competing uses of those resources. Consequently, recognizing a right to health care need not open a bottomless pit. Second, just what entitlements to services follow from a right to health care cannot be specified outside the context of a system properly designed to deliver health care in a way that promotes aggregate utility. For the utilitarian, entitlements are *system-relative*. The same two points apply to other accounts of the foundations and limits of a right to health care.

Because many people reject the utilitarian rationales for health care (and other welfare) rights, theorists have explored other ways to ground such rights. Some claim that these rights are presupposed as enabling conditions for the exercise of other rights or liberties, or as practical presuppositions of all views of justice (Braybrooke, 1987) or as a way of avoiding vulnerability and exploitation (Goodin, 1988). One approach that has been developed in some detail views a right to health care as a special case of a right to equality of opportunity (Daniels, 1985). This approach shows how the most important contractarian theory of justice, Rawls' (1971) account of justice as fairness, can be extended to the problem of health care, since that theory gives prominence to a principle protecting equality of opportunity (Rawls, 1993). Without endorsing that account here, we shall use it to illustrate further the complexity surrounding the concept of a right to health care.

Equal Opportunity and a Right to Health Care

The central observation underlying this account of a right to health care is that disease and disability restrict the range of opportunities that would otherwise be open to individuals. This is true whether they shorten our lives or impair our ability to function, including through pain and suffering. 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. Since we are complex social creatures, our normal functional capabilities include our capabilities for emotional and cognitive functioning and not just physical capabilities. Health care thus preserves for us the range of opportunities we would have, were we not ill or disabled, given our talents and skills.

The significant contribution health care makes to protecting the range of opportunities open to individuals is nevertheless *limited* in two important ways. It is limited because other things, such as the distribution of wealth and income and education, also profoundly affect equality of opportunity. It is also limited because health care, by restricting its aim to protecting normal functioning, leaves the normal distribution of talents and skills unmodified. It aims to help us function as "normal" competitors, not strictly equal ones.

Some argue that an equal opportunity account of health care should abandon the limit set by a focus on normal functioning (see Arneson, 1988; G. A. Cohen, 1989; Sen, 1992). They claim our concerns about equality, including equality of opportunity, require us to use health-care technologies whenever doing so would equalize opportunity for welfare or equalizes capabilities. For example, if through medical intervention we can "enhance" the otherwise normal capabilities of those who are at a competitive disadvantage, then our commitment to equality of opportunity requires us to do so. Obviously, this version of an equal opportunity account would vastly expand the moral requirements on medicine, yielding a right to health care much more expansive than any now embodied in actual systems and, arguably, one that would make administration of a health-care system unwieldy (Sabin and Daniels, 1994).

This expansive version of the appeal to equal opportunity ignores an important fact about justice: our

concern for equality must be reconciled with considerations of liberty and efficiency in arriving at the overall requirements of justice (see Sen, 1992; Cohen, 1995; Daniels, 1996). Such a reconciliation seems to underlie the limits we commonly accept when we appeal to equality of opportunity. We generally believe that rights to equal opportunity are violated only if unfair social practices or preventable or curable diseases or disabilities interfere with the pursuit of reasonable plans of life within our society by making us lose competitive advantage. We accept, however, the fact that the natural distribution of talents and skills, working in an efficient market for them, will both enhance the social product and lead to inequalities in social outcomes. A just society will try to mitigate the effects of these inequalities in competitive advantage in other ways than by eliminating all eliminable differences in capabilities. For example, on Rawls' account, transfers that make the worst off as well off as they can be mitigate the effects on equality of allowing the natural distribution of talents and skills to enhance productivity. In what follows, the account of a right to health care rests on a more limited appeal to equal opportunity, one that takes the maintenance of normal functioning as a reasonable limit.

What Does a Right to Health Care Include? System-Relative Entitlements

By making the right to health care a special case of rights to equality of opportunity, we arrive at a reasonable, albeit incomplete and imperfect, way of restricting its scope while still recognizing its importance. The account does not give individuals a basic right to have all of their health-care needs met. At the same time, there are social obligations to design a health-care system that protects opportunity through an appropriate set of health-care services. If social obligations to provide appropriate health care are not met, then individuals are definitely wronged. For example, if people are denied access—because of discrimination or inability to pay—to a basic tier of services adequate to protect normal functioning, injustice is done to them. If the basic tier available to people omits important categories of services without consideration of their effects on normal functioning, for example, whole categories of mental health or long-term care or preventive services, their rights are violated.

Still, not every medical need gives rise to an entitlement to services. The scope and limits of rights to health care, that is, the entitlements they actually carry with them, will be relative to certain facts about a given system. For example, a health-care system can protect opportunity only within the limits imposed by resource scarcity and technological development within a society. We cannot make a direct inference from the fact that an individual has a right to health care to the conclusion that this person is entitled to some specific health-care service, even if the service would meet a health-care need. Rather the individual is entitled to a specific service only if, in the light of facts about a society's technological capabilities and resource limitations, it should be a part of a system that appropriately protects fair equality of opportunity. The equal opportunity account of a right to health care, like the utilitarian account, makes entitlements to health care system-relative.

Effective Treatment of Disease and Disability

The health care we have strongest claim to is care that effectively promotes normal functioning by reducing the impact of disease and disability, thus protecting the range of opportunities that would otherwise be open to us. Just what counts as "effective," however? And what should we do about hard cases on the boundary between treatment of disease or disability and enhancement of capabilities?

It is a common feature of public and private insurance systems to limit care to treatments that are not "experimental" and have some "proven effectiveness." Unfortunately, many services that count as standard treatment have little direct evidence about outcomes to support their use (Hadorn, 1992). They are often just customary treatment. Furthermore, it is often controversial just when new treatments or technologies should count as "safe and efficacious." What counts as "reasonably effective" is then a matter of judgement and depends on the kind of condition and the consequences of not correcting it. We might, for example, want to lower our standards for effectiveness when we face a treatment of last resort, or raise them if resource scarcity is very great. On the other hand, we do not owe people a chance to obtain miracles through whatever unproven procedures they prefer to try.

By focusing a right to health care on the maintenance of normal functioning, a line is drawn between uses of medical technologies that count as legitimate "treatments" and those that we may want but which do not meet our "health-care needs." Although we may want medical services that can enhance our appearance, like cosmetic (as opposed to reconstructive) plastic surgery, or that can optimize our otherwise normal functioning, like some forms of counselling or some uses of Prozac, we do not truly need these services to maintain normal functioning. We are obliged to help others achieve normal functioning, but we do not "owe" each other whatever it takes to make us more beautiful or strong or completely happy (Daniels, 1985).

Though this line is widely used in both public and private insurance practices, it leaves us with hard cases. Some of the hardest issues involve reproductive technologies. Abortion, where there is no preventive or therapeutic need, does not count as "treatment" because an unwanted pregnancy is not a disease or disability. Some nevertheless insist that requirements of justice, including a right to control one's body, means that non-therapeutic abortion should be included as an entitlement in a health-care system. Some national health-insurance schemes do not cover infertility services. Yet infertility is a departure from normal functioning, even if some people never want to bear children. Controversy may remain about how much social obligation we have to correct this form of impaired opportunity, especially where the costs of some interventions, such as in vitro fertilization, are high and their effectiveness is modest. Different societies will judge this question differently, in part because they may place different values on the rearing of biologically related children or on the experience of child-bearing.

Hard cases involve non-reproductive technologies as well. In the United States, for example, many insurers will cover growth hormone treatment only for children deficient in growth hormone, not for those who are equally short but without any pathology. Yet the children denied therapy will suffer just as much as those who are eligible. Similar difficulties are involved in drawing a line between covered and non-covered uses of mental health services (Sabin and Daniels, 1994). As in the cases of reproductive technologies, there is room for different societies to "construct" the concept of mental disorder some-

what differently, with resulting variation in decisions about insurance coverage.

Rights and Limits on Effective Treatments

Even when some health-care service is reasonably effective at meeting a medical need, not all such needs are equally important. When a disease or disability has little impact on the range of opportunities open to someone, it is not as morally important to treat as other conditions that more seriously impair opportunity. The effect on opportunity thus gives us some guidance in thinking about resource allocation priorities.

Unfortunately, the impact on our range of opportunities gives only a crude and incomplete measure of the importance or priority we should give to a need or service. In making decisions about priorities for purposes of resource allocation in health care, we face difficult questions about distributive fairness that are not answered by this measure of importance. For example, we must sometimes make a choice between investing in a technology that delivers a significant benefit to few people or one that delivers a more modest benefit to a larger number of people. Sometimes we must make a choice between investing in a service that helps the sickest, most impaired patients or one that helps those whose functioning is less impaired. Sometimes we must decide between the fairness of giving a scarce resource to those who derive the largest benefit or giving a broader range of people some chance at getting a benefit. In all of these cases, we lack clear principles for deciding how to make our choices, and the account of a right to health care we are discussing does not provide those principles either (Daniels, 1993). Some methodologies, like cost-effectiveness analysis, are intended to help us make appropriate resource allocation decisions in these kinds of cases. But these methodologies may themselves embody controversial moral assumptions about distributive fairness. This means they cannot serve as decision procedures for making these choices and can at best serve as aids to decision-makers who must be explicit about the moral reasoning that determines the distributive choices they make (Gold et al., 1996).

In any health-care system, then, some choices will have to be made by a fair, publicly accountable, decision-making process. Just what constitutes a fair decision-making procedure for resolving moral

disputes about health care entitlements is itself a matter of controversy. It is a problem that has been addressed little in the literature. Our rights are not violated, however, if the choices that are made through fair decision-making procedures turn out to be ones that do not happen to meet our personal needs, but instead meet needs of others that are judged more important (Daniels and Sabin, 1997).

How Equal Must Our Rights to Health Care Be?

How equal must our rights to health care be? Specifically, must everyone receive exactly the same kinds of health-care services and coverage, or is fairness in health care compatible with a "tiered" system? Around the world, even countries that offer universal health insurance differ in their answers to this question. In Canada and Norway, for example, no supplementary insurance is permitted. Everyone is served solely by the national health-insurance schemes, though people who seek additional services or more rapid service may go elsewhere, as some Canadians do by crossing the border. In Britain, supplementary private insurance allows about 10 per cent of the population to gain quicker access to services for which there is extensive queuing in the public system. Basing a right to health care on an obligation to protect equality of opportunity is compatible with the sort of tiering the British have, but it does not require it, and it imposes some constraints on the kind of tiering allowed.

The primary social obligation is to assure everyone access to a tier of services that effectively promotes normal functioning and thus protects equality of opportunity. Since health care is not the only important good, resources to be invested in the basic tier are appropriately and reasonably limited, for example, by democratic decisions about how much to invest in education or job training as opposed to health care. Because of their very high "opportunity costs," there will be some beneficial medical services that it will be reasonable not to provide in the basic tier, or to provide only on a limited basis, for example, with queuing. To say that these services have "high opportunity costs" means that providing them consumes resources that would produce greater health benefits and protect opportunity more if used in other ways.

In a society that permits significant income and wealth inequalities, some people will want to buy

coverage for these additional services. Why not let them? After all, we allow people to use their after-tax income and wealth as they see fit to pursue the "quality of life" and opportunities they prefer. The rich can buy special security systems for their homes. They can buy safer cars. They can buy private schooling for their children. Why not allow them to buy supplementary health care for their families?

One objection to allowing a supplementary tier is that its existence might undermine the basic tier either economically or politically. It might attract better-quality providers away from the basic tier, or raise costs in the basic tier, reducing the ability of society to meet its social obligations. The supplementary tier might undermine political support for the basic tier, for example, by undercutting the social solidarity needed if people are to remain committed to protecting opportunity for all. These objections are serious, and where a supplementary tier undermines the basic tier in either way, economically or politically, priority must be given to protecting the basic tier. In principle, however, it seems possible to design a system in which the supplementary tier does not undermine the basic one. If that can be done, then a system that permits tiering avoids restricting liberty in ways that some find seriously objectionable.

A second objection is not to tiering itself but to the structure of inequality that results. Compare two scenarios. In one, most people are adequately served by the basic tier and only the best-off groups in society have the means and see the need to purchase supplementary insurance. That is the case in Great Britain. In the other, the basic tier serves only the poorest groups in society and most other people buy supplementary insurance. The Oregon plan to expand Medicaid eligibility partly through rationing the services it covers has aspects of this structure of inequality, since most people are covered by plans that avoid these restrictions (Daniels, 1991). The first scenario seems preferable to the second on grounds of fairness. In the second, the poorest groups can complain that they are left behind by others in society even in the protection of their health. In the first, the majority has less grounds for reasonable resentment or regret.

If the basic tier is not undermined by higher tiers, and if the structure of the inequality that results is not objectionable, then it is difficult to see why some tiering should not be allowed. There is a basic conflict here

between concerns about equality and concerns about liberty, between wanting to make sure everyone is treated properly with regard to health care and wanting to give people the liberty to use their resources (after tax) to improve their lives as they see fit. In practice, the crucial constraint on the liberty we allow people seems to depend on the magnitude of the benefit available in the supplementary tier and unavailable in the basic tier. Highly visible forms of saving lives and improving function would be difficult to exclude from the basic tier while we make them available in a supplementary tier. In principle, however, some forms of tiering will not be unfair even when they involve medical benefits not available to everyone.

REFERENCES

- Arneson, Richard (1988). Equality and equal opportunity for welfare. *Philosophical Studies*, 54, 79–95.
- Brandt, Richard (1979). *A Theory of the Good and the Right*. Oxford: Oxford University Press.
- Braybrooke, David (1987). *Meeting Needs*. Princeton, NJ: Princeton University Press.
- Brennan, Geoffrey and Friedman, David (1981). A libertarian perspective on welfare. In Peter G. Brown, Conrad Johnson and Paul Vernier (eds), *Income Support: Conceptual and policy issues*. Totowa, NJ: Rowman and Littlefield.
- Buchanan, Allen (1984). The right to a decent minimum of health care. *Philosophy and Public Affairs*, 13, 55–78.
- Cohen, G. A. (1989). On the currency of egalitarian justice. *Ethics*, 99, 906–44.
- Cohen, Joshua (1995). Amartya Sen: *Inequality Reexamined*. *Journal of Philosophy*, 92/5, 275–88.
- Daniel, N. (1985). *Just Health Care*. Cambridge: Cambridge University Press.
- (1991). Is the Oregon rationing plan fair? *Journal of the American Medical Association*, 265, 2232–5.
- (1993). Rationing fairly: programmatic considerations. *Bioethics*, 7, 224–33.
- (1996). *Justice and Justification: reflective equilibrium in theory and practice*. Cambridge: Cambridge University Press.
- Daniels, N. and Sabin, J. (1997). Limits to health care: fair procedures, democratic deliberation, and the legitimacy problem for insurers. *Philosophy and Public Affairs*, 26/4, 303–50.
- Engelhardt, H. Tristram (1986). *The Foundations of Bioethics*. Oxford: Oxford University Press.
- Fried, Charles (1969). *An Anatomy of Value*. Cambridge, MA: Harvard University Press.
- Gold, Marthe, Siegel, Joanna, Russell, Louise and Weinstein, Milton (eds) (1996). *Cost-Effectiveness in Health and Medicine: recommendations of the Panel on Cost-Effectiveness in Health and Medicine*. New York: Oxford University Press.
- Goodin, Robert (1988). *Reasons for Welfare*. Princeton, NJ: Princeton University Press.
- Hadorn, David (ed.) (1992). *Basic Benefits and Clinical Guidelines*. Boulder, CO: Westview Press.
- Nord, Eric (1993). The relevance of health state after treatment in prioritizing between different patients. *Journal of Medical Ethics*, 19, 37–42.
- Nozick, R. (1974). *Anarchy, State, and Utopia*. New York: Basic Books.
- Rawls, J. (1971). *A Theory of Justice*. Cambridge, MA: Harvard University Press.
- (1993). *Political Liberalism*. New York: Columbia University Press.
- Sabin, James and Daniels, Norman (1994). Determining “medical necessity” in mental health practice. *Hastings Center Report*, 24/6, 5–13.
- Sen, Amartya (1992). *Inequality Reexamined*. Cambridge, MA: Harvard University Press.
- Sterba, James (1985). From liberty to welfare. *Social Theory and Practice*, 11, 285–305.
- Thomson, Judith (1990). *The Realm of Rights*. Cambridge, MA: Harvard University Press.