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## CHAPTER 2

# Moral Considerations: Bases and Limits for Public Health Interventions

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### LEARNING OBJECTIVES

By the end of this chapter, the reader will be able to

- Understand how general moral considerations function in deliberation about and justification of ends and means in public health
- Understand the principle of utility and its applications in public health, including the distinction between social utility and medical or health utility
- Explain the formal and material criteria of justice and how different theories of justice present different material criteria
- Understand how utility and egalitarian justice sometimes conflict in triage in public health crises and possible ways to resolve these conflicts
- Describe and use the Intervention Ladder
- Understand the place and function of respect for autonomous choices and liberties in assessing interventions in public health
- Distinguish and assess strong paternalism and weak paternalism
- Distinguish and relate privacy and confidentiality

### INTRODUCTION

Public health ethics rests upon a set of general moral considerations (GMCs) that have been widely discussed in the literature. These general considerations include the following:

Our task in this chapter is to further develop these GMCs in several clusters. First, we will consider (#1) producing benefits in conjunction with other connected moral considerations: (#2) avoiding, preventing, and removing

**TABLE 2.1** Moral Considerations in Public Health

1. Producing benefits
2. Avoiding, preventing, and removing harms
3. Producing the maximal balance of benefits over harms and other costs (often called utility)
4. Distributing benefits and burdens fairly (distributive justice) and ensuring public participation, including the participation of affected parties (procedural justice)
5. Respecting autonomous choices and actions, including liberty of action
6. Protecting privacy and confidentiality
7. Keeping promises and commitments
8. Disclosing information as well as speaking honestly and truthfully (often grouped under transparency)
9. Building and maintaining trust

Data from Childress JF, Faden RR, Gaare RD, et al., et al. Public Health Ethics: Mapping the Terrain. *Journal of Law, Medicine, & Ethics* 2002;30(2):169–177.

harms, and (#3) producing the maximal balance of benefits over harms and other costs. We will examine all of these under the heading of utility, with particular attention to applying the principle of utility in public health through cost-effectiveness analysis, cost-benefit analysis, and risk-benefit analysis. We conclude that these formal, analytic techniques are useful with qualifications and within limits, including limits set by principles of justice.

The next section investigates (#4) distributing benefits and burdens fairly (*distributive justice*) and ensuring public participation, including the participation of affected parties (*procedural justice*). It outlines competing criteria of justice for determining what is due to individuals and groups. It further considers how to allocate resources in a public health crisis, such as a bioterrorist attack or pandemic influenza, as well as how to incorporate both utility and egalitarian justice in substantive criteria, public participation, and procedural fairness in determining ethically justifiable triage in such contexts.

We then turn to (#5) respecting autonomous choices and actions, including liberty of action. The chapter to this point will have considered how in public health to formulate goals and benefits, balanced against costs and harms, and how to distribute benefits and burdens fairly. In this section, it turns to potentially limiting moral considerations that may put some presumptive—i.e., nonabsolute—obstacles in the way of producing maximum benefit. Which means may public health officials ethically use in getting individuals to act in ways that will prevent personal and societal ill health or promote good health? Here we will start from and modify the Intervention Ladder proposed by the Nuffield Council on Bioethics to explore different interventions and the circumstances under which they can be ethically justified. We will also consider the conditions under which specifically paternalistic interventions, i.e., interventions aimed at the welfare of the individual himself or herself, can be ethically justified.

Privacy and confidentiality (#6) are two moral considerations that may create important but nonabsolute obstacles to the pursuit of public health through gathering and sharing personal information. We will closely examine their meaning, scope, and weights. Surveillance and notification of others at risk, such as an HIV-infected individual's sexual partners, are two areas of public health practice that, in some cases, require determining whether and when it is justifiable to override privacy and confidentiality.

We will not devote specific sections of this chapter to the last three GMCs in **Table 2.1**: (#7) keeping promises and commitments, (#8) disclosing information as well as speaking honestly and truthfully (often grouped under transparency), and (#9) building and maintaining trust. Instead, we will note their implications at different points in this chapter.

Three other preliminary notes: First, we refer to these general moral considerations in various ways: as *GMCs*, sometimes as *norms*, *principles*, or *values*, and, occasionally, as *rules*. Second, we refer to the moral requirements they entail both as *obligations* or *duties*, from the standpoint of the

agents, and as *rights*, from the standpoint of those affected. For most moral obligations or duties in this volume, there are generally correlative rights. So, for the most part (but not always), we can say either (1) “A” has an *obligation* or *duty* to “B,” or (2) “B” has a *right*, by which we mean a *justified claim*, against “A.” Third, we do not develop these clusters of GMCs in a systematic moral, social, or political theory. Rather, we will view these as embedded in our liberal, democratic society (where “liberal” refers to the commitment to liberty). We focus mainly on obligations to pursue public health within a country without developing our important responsibilities for global public health. Within a liberal, democratic society, such as the U.S., particular public health programs and interventions must satisfy principles of utility, justice, and the others we examine in this chapter.

## UTILITY: BALANCING PROBABLE BENEFITS, COSTS, AND RISKS

### Utility

The principle of utility has had various interpretations over the last few centuries, as philosophers and others have filled out the normative phrase: “do the greatest good” or “do the greatest good for the greatest number.” It provides a way to determine right and wrong, or justified and unjustified, policies, practices, and actions by determining whether they “do the greatest good.” However, there are sundry interpretations of the values that enable us to appraise a state of affairs as good or bad. Historically, many utilitarians have appealed to subjective values, such as pleasure, happiness, or satisfaction of desires, but some have appealed to objective values viewed as intrinsically good, such as health, knowledge, and beauty.<sup>1</sup> Categories like welfare may have subjective or objective formulations. We do not need to attempt to resolve these debates but only to stress the importance of attending to the values operative in different assessments of states of affairs, effects, and consequences.<sup>2</sup>

In this chapter, the principle of utility is understood as the principle of producing the maximal balance of good over bad effects or maximum net benefits. We will examine a few

<sup>1</sup> These debates about values have led many in recent years to prefer the label consequentialism to utilitarianism, enabling them better to separate the disputes about value from the judgments about producing the net balance of good over bad consequences. But the question of value has still to be resolved. See Driver J, “The History of Utilitarianism,” *The Stanford Encyclopedia of Philosophy* (Summer 2009 Edition), Zalta EN (ed). <http://plato.stanford.edu/archives/sum2009/entries/utilitarianism-history/> and Sinnott-Armstrong W, “Consequentialism,” *The Stanford Encyclopedia of Philosophy* (Winter 2012 Edition), Zalta EN (ed). <http://plato.stanford.edu/archives/win2012/entries/consequentialism/>

of the controversies about defining and measuring benefits when we consider how public health benefits are specified through such measures as lives or life-years or quality-adjusted life-years.

Recognizing the GMC—norm or principle—of utility does not commit us to utilitarianism as an overall framework. Utilitarians tend to make utility the foundational principle from which all other moral norms are derived or the dominant principle that overrides all other moral considerations. It is not necessary to affirm either of these views in order to use the principle of utility as we do—that is, as one among several principles that must be considered in making ethical judgments in public health.

Utility-based judgments about policies, practices, and actions in public health from the standpoint of the principle of utility may proceed informally or formally. We make informal judgments about balancing benefits, costs, and risks all the time, but sometimes we use formal analytic techniques in balancing them. We will start with the latter.

### Cost-Effectiveness and Cost-Benefit Analyses

In public health, health policy, and health care, considerations of utility are often specified and applied through tools of formal analysis, especially cost-effectiveness analysis (CEA) and cost-benefit analysis (CBA).<sup>2,3,4</sup> We are viewing all of these as efforts to maximize societal welfare, often expressed as the principle of utility.

In public health policy and practice, formal, analytic, economic methods have been employed as a way to improve decision making particularly when trade-offs are involved, for instance, between costs and benefits. Their proponents contend that these tools can aid decisions by providing more systematic, quantitative, comparative input about programs and interventions. These tools enable us to state more formally and systematically what we ordinarily consider in less formal and systematic ways.

CEA, CBA, and similar assessments can play important roles in setting and determining how best to pursue specific public health goals. A good example comes from the debate over several years about whether the human papillomavirus (HPV) vaccine should be recommended for males as well as for females in order to reduce the HPV-associated conditions for both. (The societal debate about the HPV vaccine is discussed elsewhere.) At one point, after reviewing further data about the effects of HPV infections on males, the Advisory Committee on Immunization Practices considered the cost-effectiveness of a strategy of adding HPV vaccinations for males to the programs then targeted at females. Following is its assessment:

Mathematical modeling suggests that adding male HPV vaccination to a female-only HPV vaccination program is not the most cost-effective vaccination strategy for reducing the overall burden of HPV-associated conditions in males and females when vaccination coverage of females is high (>80%). When coverage of females is less than 80%, male vaccination might be cost-effective, although results vary substantially across models. Because the health burden is greater in females than males, and numerous models have shown vaccination of adolescent girls to be a cost-effective use of public health resources, improving coverage in females aged 11 and 12 years could potentially be a more effective and cost-effective strategy than adding male vaccination.<sup>5</sup>

Reproduced from Licensure of Quadrivalent Human Papillomavirus Vaccine (HPV4, Gardasil) for Use in Males and Guidance from the Advisory Committee on Immunization Practices (ACIP). Morbidity and Mortality Weekly Report. 2010;59:630–632.

CEA is obviously not the only consideration in setting a vaccination policy but it is, in our judgment, a relevant one. However, considerations of justice are also important in setting vaccine policy regarding males and females.

One major difference between CEA and CBA is how each presents the benefits that are incorporated into its analysis. CEA states the benefits it measures in various ways. For instance, public health officials might use measures such as years of life (life-years or LYs), quality-adjusted life-years (QALYs), number of cases prevented, or number of persons screened for the outcomes of its programs and interventions. CEA eschews the use of money in stating the benefit that is being balanced against costs. Its conclusions appear in formulations such as “cost per QALY.” Public health officials can use CEA to compare different public health programs or interventions only if they have the same endpoint, such as life-years saved. It is not possible to compare different public health programs or interventions if their endpoints are different—for instance, life-years saved versus reduction in the days of work lost to influenza.

By contrast, CBA may begin with nonmonetary quantitative units, such as cases prevented, statistical deaths, or QALYs, but it typically moves beyond these units. It attempts to restate the benefits in ways that will facilitate a direct comparison between the benefits and the costs as well as between different programs and interventions that may have different outcomes such as saving life-years or reducing days lost from work. CBA accomplishes this by using monetary figures for

both the benefits and the costs. Hence, it can present benefit-cost ratios that can then be compared.

Both of these methods have their defenders and their detractors. A major line of defense focuses on their value in providing quantitative input for decision makers in public health and elsewhere. This defense holds that these methods can reduce the need to rely on assigning intuitive weights to different options and can help avoid the vagaries of a political process marred by conflicting ideologies, competing interest groups, and an unformed public. Critics, however, charge that these techniques sometimes are used as a way to bypass rather than inform democratic public engagement. In such cases, they may be employed by persons with technical expertise but with only a narrow vision and limited understanding of the legitimate ethical, legal, social, and political constraints on the use of such methods. Furthermore, critics charge, these methods are not broad enough to capture the entire range of relevant values and options and, in particular, may not adequately consider and may even conflict with principles of justice.

Many of the harshest criticisms are directed at CBA's effort to translate the range of possible goals and benefits being sought into dollar figures. It appears to reduce what is valuable and valued to dollar amounts—even to state the value of life in monetary terms—and thus to screen out much that is important in public health as well as in the society at large. It might appear useful to develop consistent valuations of human life across different programs, such as public health, environmental protections, and transportation, but it is not easy to do. In particular, all of the methods used to assign a dollar value to life seem unsatisfactory and perhaps even seriously flawed.<sup>6</sup> This is one reason CBA is generally less important than CEA in public health. In addition CEA also requires less time and fewer resources, is generally clearer and easier to grasp, and, as a result, is better suited to informing decision making.<sup>7</sup>

It is beyond our task in this chapter to offer a full-scale evaluation of CEA and CBA from an ethical standpoint. Since CEA is more widely used in public health, we will attend to some of its limitations. One concern is that it tends to focus on the costs and benefits that can be measured fairly easily.<sup>8</sup> Ethically, it is important to attend to the range of relevant benefits and costs in conducting analyses of programs and interventions. For instance, the Varicella (chickenpox) vaccine was not deemed to be cost saving for the healthcare system when only the cost per life-year gained was considered; however, on a broader analysis that considered the loss of parental work time in caring for children, it turned out to be cost effective.<sup>8</sup>

At first glance it might appear implausible to challenge one premise of QALY-based CEA—that a healthy life-year has equal value for everyone. The CEA slogan is that a QALY is a QALY whoever possesses it. Nevertheless, there are legitimate challenges, particularly from the standpoint of justice. First, CEAs based on QALYs may in fact discriminate against older persons because, in general, an intervention that prevents the death of younger people will probably produce more QALYs than an intervention that prevents the death of older people. Other things being equal, older people will have fewer life-years ahead of them to be saved. Sometimes it is justifiable to give priority to younger people over older people in allocation decisions, but by focusing on life-years, QALY-based CEAs tend to hide this trade-off rather than enabling us directly to wrestle with it. Second, public health programs and interventions built on CEAs based on QALYs or life-years may not give enough attention to the number of different individual lives that could be saved. After all, if the goal is production of QALYs, then there is no ethical difference between an intervention that saves one person with 60 expected QALYs and another intervention that saves three different people each with 20 expected QALYs. This runs counter to our ordinary ethical intuitions about and expectations regarding public health policies—it lets a mathematical approach trump human solidarity, beneficence, and justice. In short, the preference of QALY-based CEA for life-years over individual lives and for the number of life-years over the number of individual lives is ethically problematic.<sup>6</sup> Finally, and also problematically, QALYs operate with an assumption that there is “a lower utility to society of prolonging life for individuals with preexisting disability than for people without disability.” This raises another justice question about discrimination against persons with disabilities.<sup>8</sup>

Graham and colleagues stress an “obvious but sometimes forgotten” point—CEA is not the only consideration in decision making in public health and other areas: “Other important factors include notions of justice, equity, personal freedom, political feasibility, and the constraints of current law.”<sup>9</sup> As we will see in the next section, how much value is attached to the reduction of particular risks, for example, may depend on the nature of those risks, such as whether they are voluntarily assumed or out of our control. For all their problems, these formal analytic methods can be ethically used not to make ethical decisions but, within limits, to inform such decisions. While recognizing that “CEA methods pose ethical challenges,” Grosse and colleagues are right to stress that “excluding cost-effectiveness as a consideration is also ethically problematic.”<sup>8</sup> We should use these methods within limits and without assuming that they will produce complete answers for public health policy and practice.

## Risk Assessment

In addition to examining public health programs and interventions through a systematic analysis of their costs, effectiveness, and benefits, another important application of utility focuses on risks and benefits. Sometimes benefits themselves are construed in terms of risk reduction—for instance, a public health program may be designed to achieve the goal (benefit) of reducing the risk of an outbreak of an infectious disease.

Risk assessment features the analysis and evaluation of probabilities of certain negative outcomes, particularly harms. (Following Feinberg, we understand harms as “set-backs to interests.”<sup>10</sup>) The process of risk assessment involves several stages.<sup>11</sup> The first is *identifying* risks through locating dangers or threats, for instance, of an outbreak of a deadly avian influenza. Second is the task of *estimating* the risk, which entails determining, to the greatest extent possible, the probability and the magnitude of the harms associated with those dangers or threats. To continue the example of avian influenza: Based on early reports about recent cases, public health officials will seek to estimate the probability of pandemic influenza, in light of what is known about the ease of bird-to-human transmission and human-to-human transmission, as well as the severity (morbidity and mortality) of the infections that have occurred. A third step is *evaluating* the risk. This evaluation seeks to determine whether the identified and estimated risks are acceptable. Acceptability may hinge on balancing the risks and probable benefits of different courses of action in this context.<sup>6</sup> Risk is an inherently probabilistic term, whereas benefits need to have qualifiers to indicate they are not certain or definite. Examining risks, that is, the probability and severity of harms, in relation to various objectives may involve *risk-benefit analysis* (RBA).

These three stages of risk assessment may be followed by a fourth stage involving actions to control and manage risks depending on the cost-effectiveness ratios of different possible actions to reduce risks. Risk-reduction itself may be viewed as a benefit and various interventions may be evaluated in light of their effectiveness and cost-effectiveness in reducing risks of morbidity and mortality from, say, an avian influenza outbreak (Figure 2.1).

## Variations in Risk Perception

Public health policies and practices are often contested because of significant variations in people’s perceptions of risk. It is tempting to assume that expert risk analysts and the general public will have substantially different perceptions of risks, in part because the general public may not adequately appreciate statistical probabilities. This may in part be true,

**FIGURE 2.1** Risk Analysis and Assessment

	Severity of Harm	
	Trivial	Serious
Low	1	2
High	3	4

but differences can also be expected across both groups because a number of factors influence perceptions of risk, both the probability of harm’s occurrence (low to high) and the severity of that harm (trivial to serious). Perceptions of risk reflect several factors beyond the relevant numbers, such as the harm’s severity in terms of morbidity and mortality or its statistical probability. For instance, risk perceptions may be influenced by whether the agent voluntarily assumes the risks rather than having them imposed by others, and whether he or she has some control over them (for example, by driving an automobile rather than flying commercially). They may also be influenced by whether the risks are new rather than familiar, and whether they are dreaded because of some associated conditions such as stigmatization.<sup>12,13</sup> The stigma associated with HIV infection in its early years led people to fear the risks associated with accidental HIV infection more than other comparable risks, such as accidental infection with hepatitis B prior to the development of an effective vaccine.

The public’s perception of risk, even if its estimate of probabilities or severities is distorted, forms an important part of the context of public health policies and practices. The complexities indicate both the necessity and the difficulties of public communication and engagement around perceived risks and risk reduction strategies.

## DISTRIBUTIVE JUSTICE

In the context of public health, justice is one of the core GMCs, which we stated as distributing benefits and burdens fairly (distributive justice) and ensuring public participation, including the participation of affected parties (procedural justice).

Justice is one of the most widely invoked and protean principles in public health ethics. A cluster of terms appears in formulations of justice, terms such as equality, equity, fairness, and impartiality.<sup>14,15</sup> However defined, justice frequently indicates one important basis of public health, as reflected in the goal of just health. For most frameworks of justice, public health is not only a maximization model, such as might develop from the standpoint of the principle of utility, which, on some interpretations, seeks the maximization of public or population health without regard to its distribution. Distributive justice approaches attend to whose health is involved, i.e., how health is distributed in a society, its patterns of distribution. In a public health context, it frequently attends to the vulnerable and disadvantaged as well as to the social determinants of health. Principle #4 of the *Principles of the Ethical Practice of Public Health* stresses both the egalitarian thrust and the concern for the vulnerable: “Public health should advocate and work for the empowerment of disenfranchised community members, aiming to ensure that the basic resources and conditions necessary for health are accessible to all.”

Historically, the term justice has had both broad and narrow meanings. For instance, in the Biblical context, justice is usually viewed as roughly equivalent to righteousness. Instead of viewing justice as covering all of morality, we define it as giving each person his or her due and each group its due. Then it becomes necessary to determine the criteria for specifying what is due to persons and groups.

### Formal Justice and Material Justice

One place to start is the distinction between formal justice and material justice or between a formal criterion of justice and material criteria of justice. At least since Aristotle, the formal criterion of justice has been to treat equals equally, or similar cases similarly. At first glance, this might not appear to be very helpful, since as a formal criterion, it is empty—it does not specify the relevant respects in which people must be equal or cases similar. Nor does it indicate how those who are equal in relevant respects should be treated, only that they should be treated equally. Nevertheless, the formal criterion of justice plays an important role in challenging various forms of discrimination and unequal treatment based on arbitrary differences.

Because of the emptiness of formal justice, it is necessary to specify material criteria that identify relevant characteristics for determining equals and unequals. These material criteria may be specified in different ways in different contexts of justice. They may look different depending on whether we are considering, for instance, distributive justice, retributive or

criminal justice, commutative justice (contracts), or compensatory justice (rectifying past injustices). Our primary focus is distributive justice, that is, justice in the distribution of benefits and burdens, costs, and risks, coupled with justice in procedures and processes, such as public participation, often crucial in specifying what is due individuals and groups under conditions of scarcity, such as a public health crisis (which we will focus on in the excursus that follows this section).

Examples of material criteria include “to each according to his/her need,” “to each according to achievement,” “to each according to effort,” “to each according to ability to pay,” and so forth. These and other material criteria are defensible in certain contexts but not others. The just distribution of grades in an academic course should track students’ achievements, rather than their need or their ability to pay. However, the distribution of expensive automobiles justly follows the material criterion of ability to pay. In the context of health care, distribution according to need is recognized as an important requirement of justice, but it may be combined with other criteria as well, such as the probability of a successful outcome; or, in a two-tiered system, such as operates in the U.S., ability to pay (or to have insurance pay) may play a role as well.

Consistent with our overall approach, we are not going to develop a full-blown theory of justice to compete in the marketplace of theories of justice, but we will identify several contending theories that take specific material criteria (sometimes in combination) as largely determinative of what is due individuals and groups. These theories are useful as “ideal types” that indicate the presuppositions and implications of taking one or more material criteria as far as they can be taken in a systematic framework. Hence, they provide helpful points of reference in societal conversations about what is due individuals and groups, what constitutes just public health. Readers will recognize versions of these theories in those conversations.<sup>b</sup>

## Theories of Distributive Justice

### *Libertarian Justice Theory*

As its name suggests, a libertarian theory of justice, influenced by philosophers such as John Locke and Robert Nozick, focuses on individuals’ liberties, and so emphasizes our duties to respect others’ liberties and the state’s duty to protect our liberties, conceived as rights, when they are threatened. This often leads to a conception of the “minimal state,” sometimes

<sup>b</sup> We are largely limiting our attention to the public health within the United States rather than globally. Global responsibilities are important, but beyond the scope of our discussion here, other than in passing.

**TABLE 2.2** Types of Theories of Distributive Justice

Libertarian
Utilitarian
Egalitarian
Communitarian

called the “night watchman state,” designed to prevent or punish transgressions of individual boundaries, including individuals’ property rights. Taxation, as emphasized by the Tea Party in the U.S., is generally opposed as an unjust violation of liberty rights, especially if it goes beyond what is necessary for the minimal state to protect liberty rights. On this view, health care is not a right, but people may voluntarily choose to act charitably and contribute to health care for others and may within a community even voluntarily consent to some form of healthcare distribution. Public health may be legitimate particularly if it focuses on protecting individuals against contagious diseases—a form of boundary violation—rather than on broader conceptions of health promotion that mark much contemporary public health.

### Utilitarian Justice Theory

Utilitarian theories of justice, historically shaped by such figures as Jeremy Bentham and John Stuart Mill, ground conceptions of justice in the principle of utility, which requires, as we saw in the previous section, actions, policies, or rules that produce maximal net benefits. According to Mill, “justice is a name for certain moral requirements, which, regarded collectively, stand higher in the scale of social utility, and are therefore of more paramount obligation, than any others; though particular cases may occur in which some other social duty is so important, as to overrule any one of the general maxims of justice.”<sup>16</sup> (p. 259) Justice, which involves correlative duties and rights, is not independently warranted but is rather derivative from utility. In this framework, duties and rights in just health care or just public health presuppose a foundation in net social utility. Health care and public health can be valued at least to the extent that they contribute to net social utility.

### Communitarian Justice Theory

Like utilitarian theories, communitarian theories of justice, drawing on a number of philosophical perspectives, do not assign independent significance to individual rights, such as liberty, in contrast to libertarians (and to proponents of

egalitarian justice). Rather, their conception of just health care and public health depends on the community’s conception of the good of health, in relation to other goods, and the contributions of health care and public health to all those goods, not simply to health. Daniel Callahan, a representative of this perspective, approaches the allocation of health care from a putative shared substantive consensus about the good society. Hence, his questions for judging just allocations in health care and public health focus on their contributions to a good society: “Just what is it that good health brings to a society and how much and what kind of it are necessary for a good society? What is the common good it will bring us, and what is the public interest that it serves?”<sup>17</sup> (p. 105–106) However elusive a substantive consensus may be—and it appears to be more elusive in a pluralistic society than Callahan and many communitarians suppose—this approach resonates with public health ethics, in viewing the community as both a *source* of insight into values and as a *target* (beyond the aggregation of individuals) for just health care and public health.

### Egalitarian Justice Theory

Egalitarian theories of justice draw on philosophical and religious perspectives that recognize the equality of persons in at least some respects and the importance of treating them as equals in certain respects. Although there are a number of different versions of egalitarian theories, many of those in the last several decades have been influenced by the magisterial theory of justice propounded by John Rawls.<sup>14</sup> These generally recognize equalities in certain basic social goods but allow for other inequalities as well, and most of them recognize the possible legitimacy of a two-tiered system, with the lowest tier being a decent minimum or adequate level of health care (to be set in a deliberative democratic way). Among those influenced by Rawls’ work, Norman Daniels, building on Rawls’ conception of “fair equality of opportunity,” argues that justice requires a society to remove or reduce obstacles that prevent fair equality of opportunity. This includes providing programs that compensate for persons’ disadvantages such as their health disadvantages.<sup>18,19</sup> Egalitarian theories differ depending on whether they emphasize more equal opportunities, more equal capabilities, more equal welfare, or some combination of these.<sup>20,21</sup>

Certainly if we focus on opportunities and seek to ensure fair equality of opportunity, in combination with the formal criterion of justice, this will provide a reason for criticizing the use of several characteristics as bases for distributing benefits and burdens. We can start with obvious characteristics that are not relevant to the distribution of health care or health and that are not under the control of individuals—these include gender, race, and ethnicity. Their use as criteria

in public health is generally discriminatory (unless, perhaps, as correctives to counter previous discrimination). Studies indicate that there are numerous racial and ethnic disparities in health care for a range of medical conditions and that these disparities lead to worse health outcomes for individuals and groups—a situation that an Institute of Medicine report rightly labels “unacceptable.”<sup>22</sup>

At a broad level, egalitarian principles of justice feature equal regard for all persons and the treatment of each person as an equal, according to fair procedures, in the distribution of goods. This does not preclude rationing health care and other contributors to good health but sets constraints on how that rationing can proceed. It will regularly require fair participation in decisions that affect the distribution of such goods, and it will generally require fair procedures, such as ways to appeal adverse decisions. In the excursus that follows, we will consider whether and how egalitarian justice (in distribution, procedures, and participation) can be combined with utility in triage in a public health crisis.

### EXCURSUS: JUST CARE IN A PUBLIC HEALTH CRISIS: UTILITY AND EGALITARIAN JUSTICE

What is just care in a public health crisis? We continue to explore the principles of utility and egalitarian justice by considering their place in the allocation of resources in a public health crisis. Several societal macro-allocation decisions determine, by default if not by design, how many doses of vaccine and antiviral medications and how many ventilators and intensive care beds will be available in a crisis. They thus determine the extent of scarcity of needed resources in a public health crisis and the intensity of the dilemmas that arise. In this section we will not focus on such macro-allocation decisions but instead will examine just care in a public health emergency or crisis, such as a deadly pandemic influenza or bioterrorist attack.

#### Triage in a Public Health Crisis

Let’s imagine a public health crisis of the magnitude of the 1918–1919 pandemic influenza, which is estimated to have killed over half a million people in the U.S. and as many as 40 million worldwide. In such a crisis, which criteria and procedures should we use to allocate vaccines (if a vaccine is ready for use), antiviral medications, ventilators, and access to intensive care? We will consider several proposals based on utility and see whether and how far they can satisfy the requirements of egalitarian justice, and where they may need to be modified or rejected from that standpoint. The perspective of egalitarian justice, as we interpret it, requires that each person be treated as an equal but not necessarily

identically; that unequal distributions of goods, including medical care, can sometimes be justified, particularly in public health crises; but that the criteria and processes of distribution in such contexts must themselves be fair, provide fair equality of opportunity, sometimes represented in lotteries, recognize the transcendence of persons over their social roles and functions, and involve the participation of affected stakeholders. Not all utility-based systems of allocation are equally problematic or satisfactory from an egalitarian perspective.

Several different terms have been used to describe and direct the process of distributing scarce preventive, prophylactic, and therapeutic resources in a public health crisis. These include distribution, (micro)allocation, selection, triage, rationing, and the like. However much they point to the same process, some of their connotations are different enough to affect public communication and public justification. “Selection” evokes conflicting images. On the one hand, it seems neutral and descriptive; on the other hand, many recall its use in Nazi Germany’s extermination programs. The terms “distribution” and “allocation” offer more neutral descriptions and do not immediately evoke the harsh circumstances and hard choices suggested by “rationing” and “triage.” “Triage” usually implies systematic “rationing” using classifications and categories that are efforts to “do the greatest good for the greatest number” (utility). It is often used to describe rationing medical and other goods in military contexts, civilian emergency responses—for example, to earthquakes or a mass casualty shooting—and emergency units in hospitals. A system of triage grades people according to needs and probable outcomes, and it seeks to maximize utility.<sup>23,24</sup> We will use the terms “triage” and “rationing” most of the time.

#### Types of Utility-based Triage

When we presented the principle of utility earlier in this chapter, we did not stress that it is often applied within certain boundaries rather than universally. For instance, when we talk about utility in public health, we often are thinking within our national boundaries, even though the principle’s logic is universal. In approaching triage or rationing in a public health crisis, several possible boundaries of utility need attention.

*Health or medical utility* focuses on what would produce the greatest benefit among those already suffering from the serious effects of a natural or human-made public health crisis or at high risk of suffering such effects. The first step in triage is to determine medical utility, but it often extends beyond medical utility to include *social utility*, sometimes characterized as the social value or worth of the individuals who might be salvaged. It is very important to draw distinctions within

**TABLE 2.3** Utility-Based Triage in a Public Health Crisis

Health or medical utility
Social utility
<ul style="list-style-type: none"> <li>• Narrow social utility</li> <li>• Broad social utility</li> </ul>

social utility, between what we might characterize as *broad social utility* and *narrow social utility*. Broad social utility considers the overall value or worth of the individual to the society. By contrast, narrow social utility focuses on specific valuable (and perhaps essential) social roles that an individual fills or social functions that he or she discharges.<sup>24</sup>

Rationing based on medical utility does not necessarily violate the requirements of egalitarian justice. Take, for instance, medical utility focused on saving lives. As Derek Parfit notes, we try to save more lives “[b]ecause we do give equal weight to saving each. Each counts for one. That’s why more count for more.”<sup>25</sup> Here judgments of utility and egalitarian justice overlap, but we will raise some questions later about efforts to further specify and operationalize medical utility.

Social utility is more complicated. Both broad and narrow versions of social utility are in tension with egalitarian justice, but it may be possible to justify one but not the other in a public health crisis. In our view, it is not justifiable to ration resources in such a crisis by appeal to broad social utility, worth, or value, based on a judgment of people’s lives viewed as a whole. However, a limited appeal to narrow social utility in triage—to save lives, to protect the fabric of the social order—in a public health crisis may be ethically acceptable. In recognizing limited, narrow social utilitarian exceptions to his egalitarian framework, ethicist Paul Ramsey focused on specific functions highly valued by the community in an emergency or crisis, such as an earthquake, and considered such functions similar to those performed by sailors on a lifeboat after a shipwreck—it is ethically justifiable to save some sailors in order to increase the chances of the lifeboat’s endurance until help can arrive.<sup>26</sup> In such contexts, rationing by narrow “comparative social worthiness” can be ethically justified.

### Applications of Medical and Social Utility

We can further explore the distinction between medical and social utility (both broad and narrow) by considering a proposal by Pesik, Keim, and Iserson for the ethical allocation of emergency care following a terrorist attack with weapons of mass destruction. Their arguments are not limited to such

**TABLE 2.4** Acceptable and Unacceptable Criteria for Allocating Scarce Medical Care in an Emergency Following a Terrorist Attack

Should Consider	Should Not Consider
Likelihood of benefit	Age, ethnicity, or sex
Effect on improving quality of life	Talents, abilities, disabilities, or deformities
Duration of benefit	Drug or alcohol abuse
Urgency of the patient’s condition	Antisocial or aggressive behaviors
Direct multiplier effect among emergency caregivers	Socioeconomic status, social worth, or political position
Amount of resources required for successful treatment	Coexistent conditions that do not affect short-term prognosis

Modified from Pesik N, Keim ME, Iserson KV. Terrorism and the ethics of emergency medical care. *Annals of Emergency Medicine* 2001;37:642–646 with permission from Elsevier.

terrorist attacks but extend to other public health crises too.<sup>27</sup> Following are their lists of acceptable and unacceptable criteria for allocating scarce medical care in that context.

As indicated in this table, Pesik and colleagues identify a range of factors that should and should not be considered in rationing scarce resources in such an emergency. All the criteria they propose for use rest on judgments of medical utility and one criterion also incorporates narrow social utility—“direct multiplier effect among emergency caregivers” because of their ability to help others.<sup>27</sup> By contrast, the criteria they oppose generally reflect broad social utility—stated in either positive or negative terms—or, independently of broad social utility, violate standards of egalitarian justice: discrimination based on age, ethnicity, or sex, or on talents, abilities, disabilities, or deformities, or on coexistent conditions that do not affect short-term prognosis. In general, their list is reasonable. However, as we will see below, it overlooks some potentially important social functions that probably should receive priority in some public health crises.

Triage systems based on medical utility generally attend to persons’ degrees of need and probabilities of successful treatments. Not surprisingly, Pesik and colleagues’ material criteria focus, specifically, on likelihood of benefit, effect on quality of life, duration of benefit, and urgency of need. They also incorporate a criterion of amount of resources required. This criterion, which is sometimes called a “principle of conservation,” recognizes that it is important not to exhaust large

amounts of limited resources on a few persons. Pesik and colleagues state the point this way: “the likelihood of benefit using minimal resources takes precedence [in order] to maximize the efficient use of scarce medical supplies.”<sup>27</sup> Moreover, “practitioners must prioritize intervention to those who will benefit most from the fewest resources.”<sup>27</sup> These criteria are ethically justifiable from the standpoint of medical utility.

The criterion of “direct multiplier effect among emergency caregivers” clearly seeks to maximize medical utility, but insofar as it attends to the value of a specific social function, it also represents narrow social utility or instrumental value. Triage in military and civilian disaster contexts has often included narrow social utility, along with medical utility. For instance, it has been common to include in conceptions of salvageability in military triage not only saving individual lives but also “returning the wounded to duty and the earlier the better.”<sup>23</sup> (p. 11)

In a severe public health crisis, stemming from pandemic influenza or a bioterrorist attack, social functions other than the one Pesik and colleagues identified probably will also be important, whether to save more lives or maintain the social order. These crucial social functions almost certainly will not favor only those of higher socioeconomic status or broad social value. Many of the crucial social functions will include tasks such as transportation, supplying food, providing security, maintaining electrical power, and burying the dead.

We may be able to identify some crucial social roles and functions with confidence in advance of a particular public health emergency, but it may be difficult to predict with great precision which social roles and functions will be essential and will lack sufficient personnel. Hence, some ethicists suggest that we publicly debate the ethical rationale for the narrow social utility or instrumental value exception and then “hold it in reserve” depending on the circumstances that emerge.<sup>28</sup> Nevertheless, it is reasonable to assign priority for distribution of vaccinations to workers in vaccine production and to physicians and healthcare professionals with direct patient contact because of the multiplier effect we noted previously. However, the criterion of narrow social utility or instrumental value will probably not be appropriate in the distribution of ventilators in an influenza pandemic because of the difficulty of restoring persons who require ventilator use to functional capacity during the pandemic.<sup>28,29</sup>

### Public Participation, Public Trust, and Social Stability

Social utilitarian systems of allocation, according to some ethicists, are so unstable by their very nature that they cannot endure if they are transparent but, instead, will require either

deception or coercion.<sup>30</sup> They believe that at-risk individuals simply will not consent to a social utilitarian system, but only to one based on egalitarian justice. They may be right about this for a strictly social utilitarian system. However, a richer and fuller interpretation of utility is available. We are proposing a system that combines medical utility with narrow social utility, tempered throughout by egalitarian concerns for equal respect, fair procedures, and fair opportunity. We believe that such a system for a public health crisis can be ethically justified to the public and can garner public support.

There have been several efforts to formulate ethically justifiable and operational systems of triage in advance of a public health crisis. These usually involve multiple criteria, including specifications of what we have called medical and narrow social utility along with egalitarian considerations. Specifications of medical utility have taken several directions, some of them evident in our discussion of utility earlier in this chapter. The specification of medical utility in terms of saving lives, in the context of decisions about ventilator use, has too often been limited to survival to discharge from the hospital.<sup>28</sup> Countering this tendency is one reason Pesik and colleagues emphasized duration of benefit. If duration is emphasized, then it may be useful to focus on life-years, rather than on lives; but as we saw earlier in this chapter, this also raises serious questions of distributive justice—even more so if these life-years are adjusted for quality or disability. Still another approach stresses the life-cycle criterion, which calls for providing each individual with an equal or fair opportunity to live through the various stages of life.<sup>31</sup> According to White and colleagues, even though this criterion gives priority to the young, it does not unjustly discriminate against older people; rather, it “is inherently egalitarian because it seeks to give all individuals equal opportunity to live a normal life span.”<sup>28</sup>

Recent proposals for allocation systems in a public health emergency have rightly recommended several substantive or material criteria. These multi-criteria systems do not yield algorithms for decision making, and the criteria frequently require further specification and balancing. White et al propose an allocation system that “incorporates and balances multiple morally relevant considerations.”<sup>28</sup> These considerations are (1) saving the most lives, (2) maximizing the life-years saved, and (3) prioritizing young patients who have not had an opportunity to live a full life.<sup>28</sup> In another multi-criteria proposal, Persad et al recommend what they call a “complete lives system” for “very scarce medical interventions.” This system gives priority to younger people who have not yet had the opportunity to live a complete life, but it also incorporates other criteria: prognosis (potential life-years), saving the most

lives, lottery, and instrumental value (narrow social utility).<sup>32</sup> The first several are morally relevant in all allocation decisions, while the last (instrumental value) could be justifiable in situations such as pandemic influenza.

Such multi-criteria proposals, involving ethicists and professionals, help us see more clearly the ethical issues involved in different systems of triage. As helpful as these proposals are, we need public engagement and participation in developing, specifying, balancing, and implementing multi-criteria systems for triage for several reasons. First, throughout we have emphasized not only the public's right to justification—that is, to publicly articulated reasons for triage decisions—but also the importance of public participation in the process of setting allocation standards and procedures. Second, among the basic GMCs identified as foundational to public health ethics is the concept of building and maintaining public trust. This is important throughout public health ethics, but it is particularly important here. According to Bailey and colleagues, “In working towards a just distribution, we must engage the public. What will and will not be accepted by our communities will largely depend upon whether individuals understand the basis for the schemes, and whether they agree with the ethical underpinnings.”<sup>33</sup> The public's trust cannot be blind; it *must* be informed and engaged trust. And without public trust, a society will not be able to handle a public health crisis very well.

In a time of crisis, public health and other public officials, as well as healthcare professionals, understandably may consider members of the public to be (at best) passive nonparticipants or (at worst) major obstacles to an effective public health response. Hence, they may be reluctant to be transparent, to communicate effectively, and to engage the public. A more defensible approach views the public as a capable partner and ally. Glass and Schoch-Spana contend that “generally effective and adaptive collective action” is possible, and that “failure to involve the public as a key partner in the medical and public-health response could hamper effective management of an epidemic and increase the likelihood of social disruption.”<sup>34</sup> They propose several guidelines for integrating the public into planning responses to an epidemic resulting from a bioterrorist attack; these guidelines, with appropriate modifications, apply to other public health crises too.

This last guideline is very important for public engagement and public trust, not only in specifying and balancing criteria of medical utility but also, and perhaps especially, in specifying and balancing criteria of narrow social utility—these cannot stray too far from the affected populations'

**TABLE 2.5** Guidelines for Integrating the Public into Planning for Public Health Crises

Treat the public as a capable ally in the response to an epidemic
Enlist civic organizations in practical public health activities
Anticipate the need for home-based patient care and infection control
Invest in public outreach and communication strategies
Ensure planning that reflects the values and priorities of affected populations
Data from Glass TA, Schoch-Spana M. Bioterrorism and the people: how to vaccinate a city against panic. <i>Clinical Infectious Diseases</i> 2002;34:217–223.

“values and priorities,” or trust and cooperation will evaporate. And, at minimum, the public's trust and cooperation are essential. In particular, the public needs to have confidence in the procedures and standards of triage because some, perhaps many, will not receive the vaccination, prophylaxis, or treatment they need and want. Hence, it is crucial that the criteria be developed in public with public participation and justified publicly, in advance of the crisis and as it continues to evolve.

We are emphasizing public participation as a corrective, intended to counter the tendency to exclude the public or to involve the public too little and too late.<sup>28</sup> In no way do we minimize the indispensable participation of public health professionals, physicians, other healthcare professionals, and the like, in planning for a public health crisis. Decisions in a public health crisis must be made in light of the best available scientific evidence at the time and revised in light of the developing information.<sup>33</sup>

## FAIR PROCEDURES AND PROCESSES

In a number of works, Norman Daniels, sometimes in collaboration with James Sabin, has argued for the importance of fair procedures and processes in priority setting in health care and public health. Fair process is a form of procedural justice. One of Daniels' articles is entitled “Establishing a fair process for priority setting is easier than agreeing on principles.”<sup>35</sup> He emphasizes that “the moral legitimacy of limits and priorities ... involves not just who has moral authority to set them, but how they are set.” Moral legitimacy or authority is not equivalent to legal authority, though it often presupposes legal authority. “In the absence of consensus on principles, a fair process allows us to agree on what is legitimate and fair.”<sup>35</sup>

**TABLE 2.6** Conditions of Fair Process: Accountability for Reasonableness

Publicity Condition
Relevance Condition
Revisability and Appeals Condition
Regulative Condition
Data from Daniels N. <i>Just Health: Meeting Health Needs Fairly</i> . Cambridge, UK: Cambridge University Press, 2008, pp. 118–119.

Following is a table of Daniels' four conditions of fair process, which are designed to ensure accountability for reasonable decisions in priority setting.

The *publicity condition* requires a transparent process with publicly available rationales that articulate the grounds for priorities. The *relevance condition* requires that stakeholders affected by priority decisions concur that the grounds—normative, scientific, empirical—for priorities be recognized as relevant to fair decisions. The third condition, the *revisability and appeals condition*, provides for a way to revisit and revise decisions as new evidence and arguments emerge, and for an appeals process for those who believe they merit an exception to the priority policies. Finally, the *regulative condition*, which Daniels also calls the enforcement or regulation condition, requires some mechanism to ensure that the first three conditions are being met.<sup>36</sup>

Another important question is how much consistency there must be across geographical areas even within the same country. Obviously, fair processes in particular communities may produce considerably different approaches to rationing—this was certainly evident in the criteria and methods for rationing influenza vaccine in the U.S. in 2004–2005. While operating within some broad federal guidelines, different communities supplemented their priority schemes based on risks to the individual and risks the individual might create for others with lotteries and first-come, first-served. Moreover, some formal and informal prioritization occurred on the basis of social function. That particular crisis was overblown, but the question remains how much variation can be tolerated in rationing schemes in a national public health crisis. To be more specific: during a public health crisis, how much variation can a community of, say, 100,000 people tolerate in the criteria employed for access to intensive care and ventilators by a community hospital versus the criteria used by a university-based tertiary care hospital?

Ultimately, the public health crisis, whatever it is, will pass. Whether and how the pieces can be picked up and public life can resume will depend in part on how tragic choices were handled. As Calabresi and Bobbit remind us, when societies confront tragic choices that involve fundamental social-cultural values, they must “attempt to make allocations in ways that preserve the moral foundations of social collaboration.”<sup>37</sup> (p. 18)

## RESPECT FOR AUTONOMOUS CHOICES AND LIBERTIES

One of the basic GMCs in public health ethics is *respecting autonomous choices and actions, including liberty of action*. This is a presumptive principle or value, but one that can sometimes be rebutted in the name of public health. It is important that public health be specified in particular circumstances, rather than presented as a vague, univocal goal that trumps all principles and values that might set limits on means to realize it. Yes, some public health goals will override autonomous choices and liberties, but not all will, especially the goals that are largely if not exclusively paternalistic. Hence, specification is required to determine exactly which goals in which circumstances will triumph over these presumptive constraints. In any event, as we show in this section, many interventions in the name of public health do not seriously compromise autonomous choices and liberty of action, and, because of the importance of respect for autonomy and liberty, they should have priority in the selection of interventions. Nevertheless, in some circumstances, coercive and other measures that restrict or eliminate individuals' choices in the name of public health can satisfy the justificatory conditions we have sketched: effectiveness, necessity, least infringement, proportionality, and impartiality in the context of public justification.

### The Intervention Ladder

In its important report on public health ethics, the Nuffield Council on Bioethics proposed what it called an “intervention ladder” to help us think through the various ways public health policies and practices can affect people's choices.<sup>38</sup> The report contends that interventions “higher up the ladder are more intrusive and therefore require a stronger justification.”<sup>38</sup> Following are the steps or rungs of the “intervention ladder.”

This proposed Intervention Ladder is a helpful starting point, but it is problematic in some ways and incomplete in others. The steps or rungs are not always separate and even the lower interventions may be unjustifiable in some circumstances. Much again will depend on the public health goal that is sought as well as on the other GMCs. In using the

**TABLE 2.7** Intervention Ladder

Intervention Ladder
8. Eliminate choice
7. Restrict choice
6. Guide choice by disincentives
5. Guide choice by incentives
4. Guide choice by changing the default policy
3. Enable choice
2. Provide information
1. Do nothing

Data from: the Nuffield Council on Bioethics report, *Public Health: Ethical Issues* (London: Nuffield Council, November 2007) Available at: <http://www.nuffieldbioethics.org/sites/default/files/Public%20health%20-%20ethical%20issues.pdf> Accessed January 17, 2013.

Intervention Ladder for heuristic or exploratory purposes, we will also indicate possible expansions of or developments off different rungs.

The language of the first step, “do nothing,” is potentially misleading because taking no specific action against the threat does not preclude the possibility of monitoring the situation. Monitoring, surveillance, and the like can provide data that may be useful in taking other steps. Even though the justificatory burden increases as we climb the Intervention Ladder, doing nothing or only monitoring can also require ethical justification, for instance, in view of the deaths that occur as a result of not intervening to get motorcyclists to use helmets. Moreover, we should note, doing nothing or simply monitoring the situation also affects individuals’ choices; it is part of what is called “choice architecture,” which we will discuss below, and it influences individual choices.<sup>39</sup>

The second step involves providing information—for instance, about the value of exercise or certain diets. It is hard to see ethical problems with providing accurate, truthful information to make informed choices possible and even to shape personal choices in the direction of a public health goal, such as a healthier diet. This rationale, for example, is behind labels providing information about calories in different foods. In its simplest formulation (provide information), this step may not adequately stress the place and value of rational persuasion—i.e., the provision of reasons to try to persuade the individual to act in the desired ways. Whether the information is provided in a neutral way to create the possibility of informed choices, or in a persuasive way with reasons offered for the benefits of certain actions, this step in no way compromises autonomy.

In addition to rational persuasion, there is also the possibility of presenting both information and reasons in graphic ways to appeal to the public’s imagination and emotions. So, for instance, in addition to providing information about the health impact of smoking cigarettes, and offering reasons individuals should not start smoking or should stop if they have started, the government and private groups could present images that graphically depict the terrible health consequences for many smokers. Such a presentation of information attempts to stoke viewers’ imaginations and emotions in order to lead them to the desired behaviors.<sup>40</sup> **Figure 2.2** is one example from the Centers for Disease Control and Prevention’s campaign to warn people about the terrible health effects of smoking.

Such advertisements go well beyond the provision of information to ensure informed choices and beyond efforts at rational persuasion. They seek to change behavior by appealing to the imagination and the emotions through graphic and powerful images. In combination with other efforts, they also seek to alter social norms, in part by stigmatizing and shaming conduct. In a 2013 opinion piece in *The New York Times*, Richard Reeves writes: “New York is deploying a powerful weapon to reduce teen pregnancy: shame. New advertisements around the city dramatize the truncated life chances of children born to teenagers; in one, a tear-stained toddler stares out, declaring: ‘I’m twice as likely not to graduate high school because you had me as a teen.’”<sup>41</sup> Critics of this campaign against teen pregnancy decry the effort to shame communities and individuals as ineffective, counterproductive, and hurtful to communities and individuals. By contrast, Reeves defends it on the grounds that even in a liberal society, shame can function as “a form of moral regulation, or social ‘nudge,’ encouraging good behavior while guarding individual freedom.”<sup>41</sup>

Even though stigmatizing conduct can be effective in some contexts, it raises important ethical issues. Its use requires thoughtful justification, and it must be used in ways that are likely to be effective without being harmful. This will require attention to other factors; for instance, in a campaign against teen pregnancy, both education and the availability of contraception will also be important. Furthermore, Reeves emphasizes, “it is equally important that shame not be used as an excuse for lack of support. Once prevention, including moral pressure, has failed, and a child is born to a teenager, the overriding priority must be to provide as much help as possible.”<sup>41</sup>

It is also important to distinguish stigmatizing *conduct* from stigmatizing *persons* who engage in that conduct. This is at best very difficult. Campaigns against smoking, as

**FIGURE 2.2** A Tip from a Former Smoker (CDC advertisement)

In March 2012, the Centers for Disease Control and Prevention (CDC) “launched the first-ever paid national tobacco education campaign—*Tips From Former Smokers (Tips)*.” This campaign seeks to get people to quit smoking “by highlighting the toll that smoking-related illnesses take on smokers and their loved ones.” These “hard-hitting ads showed people living with the real and painful consequences of smoking. Many of the people featured in the ads started smoking in their early teens, and some were diagnosed with life-changing diseases before they were age 40. The ads featured suggestions or ‘tips’ from former smokers on how to get dressed when you have stoma or artificial limbs, what scars from heart surgery look like, and reasons why people have quit smoking.” The accompanying print advertisement—there are also videos—presents Terrie, age 52, from North Carolina, whose throat cancer is blamed on smoking that led to a laryngectomy. According to the CDC, the effect of the *Tips* campaign was “immediate and intense.”

See <http://www.cdc.gov/tobacco/campaign/tips/about/campaign-overview.html>



Reproduced from: CDC. *Tips From Former Smokers: Terrie's Story*. <http://www.cdc.gov/tobacco/campaign/tips/resources/ads/tips-2-ad-terrie-full.pdf>. Accessed June 27th, 2013.

represented in the advertisements noted above and in policies such as increased taxation of cigarettes, often have the effect, if not the intention, of stigmatizing smokers as well as smoking, and this can lead to smokers becoming targets of resentment and hostility.<sup>42</sup> In the U.S., smoking is more prevalent among lower socioeconomic groups, and ethical questions, including questions of justice, arise about stigmatization of socially vulnerable persons. Similar points apply to teen pregnancies, where there is the additional problem of effectively stigmatizing the conduct of males—the focus has been primarily on teen girls who become pregnant.

For all efforts to persuade or motivate through the presentation of information, in whatever form, a fundamental ethical requirement is truthfulness, a component of one of our GMCs (#8). Indeed, one possibility not included in the Intervention Ladder would not be ethically justifiable in the pursuit of public health—the manipulation of information through deception or lying. Some manipulations that might be effective would simply not be ethical. For instance, exaggerating risks could motivate behavior. Or, to take an even more dramatic example, manipulating persons' memories, by creating false beliefs, may be effective in behavior modification in some contexts. One team of researchers found that

it could get individuals to avoid certain foods by manipulating them to believe a lie—that those foods had actually made them sick when they were young. It could also lead individuals to eat asparagus by convincing them to believe falsely that they had once really liked asparagus.<sup>43</sup> These experiments thus involved creating false bad memories of unhealthy foods to avoid and false good memories of healthy foods. In one experiment, Loftus and colleagues had 131 students complete forms that indicated their food experiences and preferences; these forms included some questions about strawberry ice cream. These students then received a fake computer analysis of their forms that allegedly indicated what they really and truly liked and disliked. However, the computer reports for 47 of the students indicated, again falsely, that they had been sickened by eating strawberry ice cream when they were young. Later, close to 20% of these students indicated on a questionnaire that strawberry ice cream had made them sick, and that they were not going to eat it in the future.<sup>43</sup> However, for whatever reason, researchers were not able to engender false beliefs about the consumption of chocolate chip cookies and potato chips!<sup>43</sup> Moreover, it is not known how long such false memories endure. However useful the creation of false memories might be in engendering healthy

behavior, it transgresses important ethical barriers and violates respect for persons, their dignity, and their autonomy. It would be morally perilous for a democratic society even to contemplate such manipulations as options.

The third rung on the Intervention Ladder is to enable choices. Individuals may not pursue healthy options for themselves or for others because of the difficulties of doing so, perhaps because of a lack of capacity or resources to carry them out or because of the costs of doing so. Consider a person who has tuberculosis and for whom the recommended approach is Directly Observed Therapy (DOT) for treatment until noncontagious or cured. One way to secure the person's compliance with DOT may be to enable his or her choice by providing vouchers for transportation to a center for DOT. Reducing parents' out-of-pocket costs for their children's recommended vaccinations has also been effective in the U.S. Other examples include providing free fruits in school cafeterias, funding participation in "stop smoking" programs, and building lanes for bicycles.<sup>38</sup> This rung on the Intervention Ladder poses no ethical concerns from the standpoint of respect for autonomous choices and liberties; however, it may raise important issues of utility and distributive justice.

Guiding choices by altering the defaults (step #4 on the Intervention Ladder) is an often effective way to shape conduct without undermining individuals' liberty to choose.<sup>44</sup> It is a "nudge" that leaves the final choice with the individual. In *Nudge: Improving Decisions about Health, Wealth, and Happiness*, Thaler and Sunstein define a "nudge" as "any aspect of the choice architecture that alters people's behavior in a predictable way without forbidding any options or significantly changing their economic incentives."<sup>39</sup> (p. 6)

More broadly, "choice architecture" organizes "the context in which people make decisions," and it is ubiquitous and never purely neutral.<sup>39</sup> In reviewing and evaluating a proposed policy that would affect persons' decisions in one direction or the other, we may worry about whether a nudge is warranted. However, even if unnoticed, the existing policy itself constitutes a "choice architecture" that affects individuals' decisions. For instance, if the U.S. were to attempt to increase the supply of organs available for transplantation by adopting an "opt-out" policy, it would not be establishing a "choice architecture" where none existed. Rather, it would be replacing one kind of "choice architecture" with another.

The current U.S. policy for obtaining organs for transplantation is an "opt-in" policy: If individuals while alive do not take steps, such as signing a donor card or checking "donor" on their driver's license or entering a donor registry, they will not be considered donors (although U.S. law

allows the next of kin to donate the decedent's organs if he or she did not indicate an objection to donation). By contrast, in an "opt-out" system, which is common in Europe, an individual's nonobjection to organ donation while alive will be counted as consent to organ donation after his or her death. In both systems, a little effort will be required to take an action that differs from the default. In an "opt-in" system, the default is nondonation unless the individual takes an action to signify donation; in an "opt-out" system, the default is donation unless the individual takes an action to indicate objection to donation. In either system, the final decision about organ donation rests with that individual—he or she has the liberty to say "yes" or "no" to organ donation. An Institute of Medicine Committee on Increasing Rates of Organ Donation held that in order for an "opt-out" policy of organ donation to be ethically acceptable, there must be public understanding and clear, easy, nonburdensome, reliable, and widely available ways for individuals to indicate their refusal.<sup>45</sup>

In this regard, Thaler and Sunstein argue that if an intervention is to count as a "mere nudge," it "must be easy and cheap to avoid."<sup>39</sup> (p. 6) While placing fruit at eye level in a school cafeteria nudges students to select the fruit, rather than something else that is also available, a school's ban on junk food would not count as a nudge.<sup>39</sup> Furthermore, "nudges"—e.g., guiding behavior by changing the default policy—need to be distinguished from interventions that significantly change individuals' "economic incentives."<sup>39</sup> (p. 6) Hence, there is often an important distinction between changing the default option and taking the next two steps on the Intervention Ladder: guiding choice by incentives or by disincentives, at least if these incentives or disincentives are significant. To be sure, setting the defaults in certain directions works in part because of the "costs" involved in taking the nondefault option, such as signing a donor card or registering as a nondonor. Often there are also cognitive and psychological costs, but they too must be low for the altered default to count as a nudge.<sup>39</sup>

The next rung (#5) on the Intervention Ladder is guiding choices by incentives. For instance, in securing the compliance with DOT by a person with tuberculosis, it might be possible not only to enable his choice by providing vouchers for transportation but also to motivate compliance by providing incentives, such as money he can spend however he chooses. In addition, there is evidence (discussed elsewhere) that incentive awards to clients or families can effectively increase rates of vaccination.

While some view the use of incentives as potentially coercive ("Cash might coerce some people into changing behavior...."<sup>46</sup>), others insist that providing incentives

cannot be considered coercive because it expands rather than restricts options.<sup>47</sup> We take the latter perspective, but we concede that providing incentives can still be morally problematic in some circumstances. On the one hand, if the amount of the incentive falls below an acceptable threshold it may be exploitative in that it takes unfair advantage of a person's situation. On the other hand, if the amount is too large, it may constitute an undue inducement.

Still another concern is the stigmatization associated with conditional cash transfers—i.e., conditional on behavioral changes—directed at disadvantaged persons. Some also argue that cash payments can change behavior without making behavioral change a condition for the transfer; they contend that payments to poor mothers generally end up being used for their children's health and well-being.<sup>46</sup> Even defenders lay down some stringent requirements for justification of incentives for people to care for their health: "They should be used only when the program is likely to do more good than harm to disadvantaged individuals, taking account of compliance costs, stigma, and stress to recipient; the behavior change is sufficiently verifiable to deter fraud and gaming; and the program is likely to be cost effective, taking account of all benefits and costs, including administration and monitoring."<sup>48</sup>

Critics also register their concern about the deleterious impact of incentives on a person's character. Incentives are directed at conduct not character, but some worry that they may also damage character. "Incentive programs," Ruth Grant argues, "ought to come with a 'caution' label" because they "have been shown repeatedly to undermine motivation and performance, as well as to corrode character."<sup>49</sup> (p. 122) Furthermore, their effects tend to be limited to the short term.<sup>49</sup> However, if the short-term public health goal is to get parents to have their children vaccinated, then the use of effective financial incentives may be more important (for the children and for others) than strengthening the parents' character or other long-term goals.

The next rung on the Intervention Ladder is guiding choices through disincentives, especially but not only financial disincentives. Obvious examples include increasing taxes on cigarettes to discourage smoking, or fining people for failing to get recommended vaccinations—the last was the penalty in the famous early 20th century case *Jacobson v. Massachusetts*. Depending on the kind and level of the disincentive involved, disincentives can be effective in some circumstances. In the U.S. we do use (and generally find acceptable) the non-monetary disincentive or sanction of not allowing children to attend school if they have not had certain vaccinations. In addition to being a disincentive or sanction, this also functions to protect other children in the school context.

Elsewhere, we will consider the use of monetary sanctions, such as the distribution of fewer food vouchers, following parental or guardian failures to adhere to the schedule for their children's vaccinations. While there is some evidence that these disincentives were effective in the short run, major concerns arose about justice and fairness in the distribution of burdens and benefits and about the harm to the children who may have been deprived of needed food (see Chapter 7).

The Intervention Ladder's penultimate rung is restricting choice. The Nuffield Council gives examples of regulating so as to restrict the options available to consumers by requiring the removal of unhealthy ingredients from foods.<sup>38</sup> Another example is New York City Mayor Michael Bloomberg's proposed ban on the sale of sugared drinks over 16 ounces in certain contexts. This ban would restrict and constrain individuals' choices about drinks but, in the final analysis, would not totally rule out those choices, because individuals could simply buy more than one smaller-size beverage. However, they would end up paying more—another disincentive. The final rung on the Intervention Ladder is eliminating choice. One example is forcible quarantine of people who have been exposed to certain infectious diseases or forcible isolation of people who have begun to show the symptoms of those diseases.

The Nuffield Council's Intervention Ladder does not use the label of coercion for any of its steps, and most of the interventions listed are not properly considered coercive. Some of them may be ethically problematic or even wrong in some circumstances for other reasons. Nevertheless, some forms of the final three interventions are or may be coercive. The paradigm situation of coercion is evident when the robber confronts the victim: "Your money or your life." Years ago, a notoriously stingy comedian could garner some laughs by saying, "Let me think about it." This is a coercive situation, but many of the actions that influence choices one direction or another are not coercive, even though careless discussants may label them as such.

The term "coercion" has been overused and overextended in critiques of different interventions in public health as well as in critiques of policies, practices, and actions in therapy and research. Hawkins and Emanuel offer a helpful examination of this often misused concept. For them, "coercion involves a threat that makes a certain choice irresistible."<sup>47</sup> Their further explication softens the notion of irresistibility: "A person is coerced when her choices are unfavorably narrowed by someone who is trying to get her to do something she would not otherwise do."<sup>47</sup> An intervention can be unsuccessfully coercive or incompletely coercive—in that the coerced choice turns out not to be an irresistible one after all.

Coercive acts, Hawkins and Emanuel argue, have two features. The first is the type of choice a coerced individual faces: narrowed, constricted options. This feature is not sufficient for coercion because not all situations of narrowed, constricted choice are coercive. For instance, an individual may face a set of choices that are *all* bleak or dire, such as deciding among (choice 1) extreme radiation or (choice 2) massive chemotherapy for a cancer that is likely to be deadly without treatment (choice 3)—certainly a narrow set of options, but the individual may still make his or her own choice about which treatment to undertake, if any. A second feature is thus also indispensable for a situation to be coercive: others' purposeful actions created the situation of narrowed, constricted choice.<sup>47</sup> An example might be confinement (or the threat of confinement) of a person who is not complying with the therapeutic requirements for tuberculosis; such tactics represent a coercive effort to get him or her to comply.

The top three rungs of the Intervention Ladder need to meet a higher bar of justification in light of the justificatory conditions we identified (effectiveness, necessity, least infringement, proportionality, impartiality, all to be met in the context of public justification). And they can be met under certain conditions, as the examples suggest. We have also attempted to show in this section that many of the other interventions are often ethically justified but that they also frequently raise ethical issues that need to be addressed.

Moreover, we should not overemphasize the limits placed on public health interventions by respect for autonomous choices and various liberties. These are important presumptive limits that may direct public health officials to find ethically preferable interventions rather than limiting potentially effective interventions. Furthermore, it is often important in public health to *express community* rather than merely to *impose community*. Certainly the imposition of community, in the sense of imposing communal obligations in the name of protecting or promoting public health, is ethically justifiable in some circumstances. Forcible isolation of an uncooperative patient with tuberculosis who is putting others at risk is a good example, as we have seen. However, in many contexts, expressing community and solidarity by providing resources and support may also be as effective—or even more effective—than imposing community through manipulation or coercion.<sup>50</sup>

### Paternalistic Interventions

Our examination of the Intervention Ladder used a variety of examples and arguments for and against different interventions in those examples. We did not distinguish the several types of reasons for those interventions: public health,

population health, financial and other costs to the society, and the individual's own welfare. The heading for this section is “paternalistic interventions,” but an equally good heading would be “paternalistic reasons for interventions.”

Paternalistic actions have two characteristic features: (1) they aim to protect or promote the welfare of individuals themselves (rather than others or the society), and (2) they seek to accomplish this goal by overriding some of the individuals' choices and actions.<sup>51,52</sup> The metaphor back of paternalistic actions is that of father-child relationships, particularly as those relationships were portrayed in the late 19th century, when the term paternalism appeared. This metaphor was alive in the language of “paternal government” that John Stuart Mill and others used to criticize governmental policies even before the term “paternalism” came on the scene.<sup>53 (p. 94)</sup> It still accurately describes the rationale for some interventions by public health officials, physicians, and others, but it is normatively problematic because it highlights the value of benefiting the individual while obscuring or downplaying the principle of respecting their autonomous choices and liberties.

We need to distinguish *weak* and *strong* paternalism, a distinction apparently first drawn by Feinberg and subsequently developed by others.<sup>54</sup> (The terms *soft* and *hard* are also sometimes used in their place.) In strong paternalistic actions, the intended beneficiary is a person who is considered to be autonomous or substantially autonomous but whose choices and actions put him or her at risk. Such actions infringe the intended beneficiary's autonomy, and, hence, are at least presumptively wrong. As Ronald Dworkin suggests, paternalistic interventions are disrespectful, demeaning, and insulting to the beneficiary whose autonomy they violate.<sup>55 (pp. 262–63)</sup> There are also consequentialist reasons to challenge such paternalistic interventions. According to John Stuart Mill, “[t]he strongest of all the arguments against the interference of the public with purely personal conduct, is that when it does interfere, the odds are that it interferes wrongly, and in the wrong place.”<sup>53 (p. 78)</sup> For all these reasons, it is hard to justify taking the final three steps on the Intervention Ladder—the three steps that most compromise autonomy—to secure health and other benefits for the autonomous individual who resists those interventions. By contrast, it is justifiable to take those steps under some conditions to protect or promote public health, as distinguished from the health of the autonomous individual. However, the “libertarian paternalism” advocated by Thaler and Sunstein accepts interventions below the top three rungs, which leave the individual free to resist and which can be more easily justified even for paternalistic reasons.<sup>39</sup>

In *weak* paternalism, by contrast, the intended beneficiary is considered to be nonautonomous or substantially nonautonomous. Consequently, his or her choices and actions do not warrant the respect and noninterference the autonomous person can claim. The principle of respect for autonomous choices and actions does not stand in the way of interventions to protect or promote the interests of the nonautonomous or substantially nonautonomous person, who may have significant mental deficiencies, serious psychiatric problems, drug addiction, and so forth. Justice and fairness as well as public beneficence warrant such interventions. However, it is not easy in public health policy and practice to determine when people are substantially nonautonomous and thus may be coerced for their own benefit—for instance, is a person’s obesity the result of substantially autonomous or substantially nonautonomous choices?

Proponents of governmental interventions into personal choices and actions rarely defend those interventions as paternalistic, or at least as purely paternalistic. Usually, they argue that the interventions are also necessary to protect other individuals, the public health, public resources, particularly financial resources, and so forth. It is sometimes plausible, in view of public expenditures on health care and other goods and services, to point to the societal impact of individuals’ actions that may initially appear only to harm themselves.

The debates about laws that require motorcyclists to wear helmets are instructive. Some arguments for mandatory helmet laws are clearly paternalistic—the goal is to protect the motorcyclists themselves. Other arguments seek, sometimes with difficulty, to demonstrate that motorcyclists who do not wear helmets increase risks and costs to others. For instance, they may create hazards for passing vehicles and may impose excessive burdens on rescue teams, physicians, nurses, and other health professionals as well as on medical institutions. The public may also complain about bearing some or all of the costs of the motorcyclist’s care.

One report indicates that in 2010, “helmet use saved the lives of 1,544 motorcyclists, and an additional 709 lives might have been saved if all motorcyclists had worn helmets. . . . Helmets are proven to save lives and money, and universal helmet laws are the most effective way to increase helmet use.”<sup>56</sup> Another study similarly concludes: “Examination of individual state experiences with motorcycle helmet legislation demonstrates that universal motorcycle helmet laws effectively promote helmet use compliance, reduce morbidity and mortality in motorcycle crashes, and lower the healthcare costs and associated societal burdens of these crash victims.”<sup>57</sup> It is important to consider, in view of the best available evidence,

the strengths and weaknesses of different arguments about protecting individuals’ best interests, public and population health, and the public treasury. Most often paternalistic arguments will be mixed with other kinds of arguments as this example indicates—the reasons for intervention, in this case a coercive intervention, are directed at the individuals affected and at the impact their actions have on other individuals or on the society.

## PRIVACY AND CONFIDENTIALITY

In the context of public health as well as health care, the protection and nondisclosure of individuals’ personal information is an important—though nonabsolute—ethical obligation. Disclosures of a patient’s personal information by healthcare professionals without the patient’s authorization may be decried as a breach of privacy, or as a breach of confidentiality, or both. There is a close relationship between privacy and confidentiality, but it is also essential to distinguish them. Despite their partial overlap in protecting personal information, their differences also need attention. Privacy emerged centuries after confidentiality became prominent, but we will start with privacy because it is the broader category.

### Privacy

We define privacy as a state or condition of limited access, including nonaccess, to a person.<sup>6</sup> Access to a person may occur in any one of a number of ways—for instance, through looking at, listening to, or touching the person, or through receiving information about the person from others’ reports or from laboratory data. We follow Anita Allen’s characterization of four dimensions of privacy, each of which involves limited access to a person, and we add a fifth dimension: relational or associational privacy (**Table 2.8**).<sup>58</sup>

*Informational* privacy, which is most commonly emphasized in public health ethics, particularly in the context of surveillance, involves limited access or nonaccess to personal

**TABLE 2.8** Dimensions of Privacy

Informational privacy
Physical privacy
Decisional privacy
Propriety privacy
Relational/associational privacy

Data from Allen A. Genetic privacy: emerging concepts and values. In: Rothstein MA (ed). *Genetic Secrets: Protecting Privacy and Confidentiality in the Genetic Era*. New Haven, CT: Yale University Press, 1997:31–59.

information and protection and nondisclosure of any personal information acquired by public health officials. *Physical* privacy concerns access to persons and their personal spaces, *decisional* privacy encompasses personal choices and zones or spheres of such choices, and *propriety* privacy includes property interests, such as interest in a person's DNA or image.<sup>58</sup> The fifth dimension of privacy, which we have added to Allen's list, is *relational* or *associational* privacy. This last dimension includes various personal relations or associations with others as well as individuals' decisions with others in those relations or associations. Examples include family life and friendship as well as less intimate associations. While identifying these various dimensions is useful, the lines between them are far from clear cut and impermeable. And there is substantial overlap between some of these dimensions of privacy and other moral notions, for instance, between decisional privacy and autonomy.

Another valuable distinction is between *having privacy* and *having a right to privacy*. A person may have privacy—in the sense that others do not access that person in any of the several ways noted—without having a right to privacy, that is, a justified claim against others that they not infringe that person's privacy. Conversely, a person may have a right to privacy but still lack privacy if others violate her right. Many factors may determine whether a person has privacy—perhaps others are indifferent to her or have no effective way to access her, or perhaps they respect her enforceable right to privacy. Whatever the reason for a person's state or condition of limited access, that person has privacy whether or not she has a right to privacy.

Several dominant metaphors for public health surveillance, an indispensable tool in public health, suggest its risk to privacy, especially informational privacy. Whether surveillance is viewed as “the eyes of public health” or the “radar” for public health or a way to keep “a finger on the pulse of the health of a community,” it involves access to individuals or at least to information about them. Surveillance thus entails the reduction or loss of privacy at least to some extent.

The distinction between anonymous (or anonymized) information and personally identified (or identifiable) information is crucially important in analyzing and evaluating uses of surveillance as a tool in public health. Anonymous information does not sacrifice individual privacy, and thus does not create psychosocial or other risks for individuals from whom it is derived. Similarly, informational privacy is not threatened if personal identifiers have been removed and there is adequate security for the anonymized information. Data for epidemiological purposes, such as determining pockets of influenza in different communities, may not need

personal identifiers, but public health surveillance sometimes requires individuals' names or other personal identifiers for effective action. Tracking persons exposed to an infectious disease is one example.

How strong or weighty are privacy and the right to privacy? As important as privacy and the right to privacy are in our society, they represent only one value or moral consideration among many. In considering public health tools and interventions, privacy and the right to privacy set only presumptive, though nonetheless important, limits, and can be overridden when the justificatory conditions we have identified are met.

### Confidentiality

Confidentiality overlaps with informational privacy—both involve limited access to information about a person. While informational privacy has a more recent pedigree, emerging a little over a century ago, confidentiality is arguably one of the oldest and most prevalent rules in medical ethics. Confidentiality can be viewed as a way to protect informational privacy within a specific set of relationships.

Suppose a person seeks health care and voluntarily enters into a relationship with one or more healthcare professionals. That person willingly surrenders much of his or her privacy in order to gain the benefits of that relationship through accurate diagnosis, informed prognosis, and efficacious treatment. In a confidential relationship in health care, the information generated about a patient is protected, within limits, by rules of confidentiality. A patient has reasonable and legitimate expectations that the information generated in this relationship (generally) will not be disclosed to others without his or her consent or authorization. Of course, these expectations are set in different ways by different institutions, societies, and legal systems. For instance, a patient seeking care in a hospital can expect—and may even have explicitly or implicitly consented to—further disclosures of personal information to a variety of health professionals and ancillary staff contributing to her care. In addition, the law sets certain limits on these expectations, requiring healthcare professionals to disclose, depending on the state, epilepsy, gun-shot wounds, suspected child abuse, certain contagious diseases, and the like. Moreover, the Privacy Rule implementing the Health Insurance Portability and Accountability Act of 1996 (HIPAA) allows the disclosure of personally identifiable health information for public health purposes even if the individual has not specifically authorized it.<sup>59</sup>

One big ethical question is where the legal and policy boundaries should be set for protected information in health care. Physicians and other health professionals have

considerably more latitude to disclose information without personal identifiers than information with personal identifiers, such as name, social security number, etc. As we noted above, much public health surveillance, particularly for epidemiological purposes, can be conducted without personal identifiers. However, sometimes it is crucial to have access to personal identifiers—for instance, to determine the source of an outbreak of food poisoning.

A further clarification of the distinction between privacy and confidentiality may be useful. Only someone who is in a confidential relationship with another person can infringe, breach, or violate that person's right to confidentiality. Years ago, when newspaper columnist Jack Anderson reported that the well-known and controversial lawyer Roy Cohn was enrolled in a National Institutes of Health experimental trial of the drug AZT for the treatment of AIDS, critics charged that some healthcare professionals had violated Cohn's rights of confidentiality and privacy by passing on this information to Anderson, who in turn had violated Cohn's right to privacy by publishing it. Only those in a confidential relationship with Cohn could have violated his right to confidentiality or failed to protect his confidentiality; others not involved in a confidential relationship may have violated his privacy, but they could not have violated the confidentiality of the relationship.<sup>60</sup>

In short, “[c]onfidentiality is present when one person discloses information to another, whether through words or other means, and the person to whom the information is disclosed pledges, implicitly or explicitly, not to divulge that information to a third party without the confider's permission.”<sup>60</sup> (p. 318) If the patient from whom the information was derived consents to the release of that information to third parties, there is no breach of confidentiality. Consent to disclosure cancels the obligation to respect confidential information at least to the extent of the consent.

The presumptive duty to protect confidential information thus hinges in part on the implicit or explicit pledge by the health professional or the larger context in which the care is provided, such as institutional or legal requirements. So it in part rests on promise-keeping. There are also other possible grounds for this duty. One of these is already evident: patients' autonomy and their privacy rights. Another is based on the probable consequences of having rules of confidentiality that patients can rely on when they seek help. Without a reasonable and legitimate expectation of confidentiality, within certain limits, people would be reluctant to yield their privacy to health professionals because of fears of harm, such as embarrassment and stigmatization, from unauthorized disclosures of their personal information. This reluctance would compromise effective health care.

This consequentialist argument does not establish how narrow or broad, how strong or weak, or how exception-less rules of confidentiality need to be in order to ensure effective health care. A version of the debate about such questions was evident in the legal decisions in the famous *Tarasoff* case and in the commentary surrounding that case.<sup>61</sup> In this case, a male patient in therapy confided in his therapist that he wanted to kill a young woman who had rebuffed his romantic interest in her. The therapist was concerned enough that he alerted the university police, who, after talking with the young man, determined that he was not a sufficient threat to require further detention. The therapist's patient killed the young woman when she returned to the area. Her family filed a lawsuit contending that the therapist did not do enough to prevent their daughter's death and that he should also have warned the intended victim of his patient's threatened violence.

This lawsuit eventually led to a California Supreme Court decision on the bases and limits of rules of confidentiality.<sup>61</sup> In an important, precedent-setting opinion, the majority held that therapists have an affirmative obligation to warn the intended victims of a patient's or client's threatened violence, while the minority opinion rejected such an affirmative obligation. Both opinions appealed to consequentialist/utilitarian arguments in assessing a rule that would require therapists to warn third parties based on information gained in the therapeutic relationship, thus breaching the confidential relationship. The consequentialist/utilitarian questions about rules of confidentiality include: Would requiring therapists to warn prospective victims in such cases save more lives? Or would a stronger protection of confidentiality save more lives by encouraging and enabling troubled individuals to disclose their deepest, darkest desires and fantasies so they could be effectively addressed in the therapeutic relationship? It is by no means clear which side has stronger evidence for these speculative consequences.

A similar debate has surrounded rules of confidentiality in the care of HIV-infected patients who have sometimes been reluctant or even refused to disclose their positive HIV status to their sexual partners. On the one hand, there are concerns that specific, identifiable individuals might become infected because they do not know their partner's positive HIV status and thus are unaware of some of the risks involved in the relationship. On the other hand, there are concerns that requiring healthcare professionals to warn sexual partners in such cases could lead people to avoid testing and thus prevent them from obtaining information, counseling, etc., that could help them protect their partners as well as themselves. In short, the debate concerns which rule of confidentiality would save the most lives. This debate has shifted more in the direction of disclosure as

HIV/AIDS has come to be viewed as a “chronic” disease rather than a “lethal” disease as a result of advances in antiretroviral treatment—because of the need to start treatment as early as possible, because the disease is less stigmatized, and so forth.

Physicians and other healthcare professionals may, in effect, find themselves in a public health role, with a public health task to discharge, when their patients are exposing others to significant risks, that is, a high probability of serious harm. They may, and sometimes should, breach confidentiality in order to protect identifiable third parties at risk—for instance, in the case of a recalcitrant patient who refuses to inform his sexual partner of his positive HIV status and refuses to engage in safer sexual practices. The strategy proposed by American Medical Association’s Council on Ethical and Judicial Affairs for such a case is a reasonable one: “Physicians must honor their obligation to promote the public’s health by working to prevent HIV-positive individuals from infecting third parties within the constraints of the law.” It then indicates three interrelated steps the physician *should* take “if an HIV-positive individual poses a significant threat of infecting an identifiable third party.”<sup>62</sup>

Two of these steps—(a) and (c)—depend on what the law requires or permits and so raise again the question about which laws and policies are ethically justifiable. The other step (b)—“attempt to persuade the infected patient to cease endangering the third party”—does not indicate how far the physician must go to confirm the patient’s cessation of endangerment.

## CONCLUSIONS

This chapter has explored four major clusters of GMCs: utility; distributive justice; respect for autonomous choices and actions, including liberty; and privacy and confidentiality,

**TABLE 2.9** Steps Physicians Should Take when an HIV-Infected Patient Endangers a Third Party: Recommended by the AMA

- |     |   |
|-----|---|
| (a) | notify the public health authorities, if required by law;   |
| (b) | attempt to persuade the infected patient to cease endangering the third party; and                                |
| (c) | if permitted by state law, notify the endangered third party without revealing the identity of the source person. |

Data from *Recommendations in Code of Medical Ethics of the American Medical Association*, 2010–2011 Edition. Chicago, IL: American Medical Association, 2010;2:23 (issued June 2008), p. 127.

along with ample illustrations of their implications for goals and means, programs and interventions, in public health. Some of these GMCs (e.g., utility and justice) serve as grounds for public health, while some serve as potentially limiting principles (e.g., respecting autonomous choices and actions and privacy and confidentiality). The latter should not be viewed as mere obstacles, because in many contexts public health can best be protected and promoted by respecting autonomous choices, including liberty of action, or by guarding privacy and confidentiality. As the Intervention Ladder suggests, these presumptive obstacles may even lead us to find alternative interventions that are effective but that do not seriously compromise autonomy or liberty (or privacy or confidentiality, for that matter). Nevertheless, in some cases these GMCs remain obstacles, presumptive rather than absolute ones, which can sometimes be justifiably overridden in the name of public health, not as a vague category but as a specific set of concrete and important goals.



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## Discussion Questions

- Do you believe that utility and egalitarian justice can be successfully combined in a system of substantive criteria and processes for triage in a public health emergency? If so, how? If not, what alternative do you propose?
  - Do you find any moral issues in the lower rungs of the Intervention Ladder? Do you agree that the higher rungs of the Intervention Ladder must meet a higher burden of justification?
  - What is your view about the use of stigmatization and shaming in the context of campaigns to reduce teen pregnancies and cigarette smoking?
- Define a paternalistic intervention and distinguish strong and weak versions. Can you think of cases in which strong paternalistic interventions would be ethically justified?
  - What is the distinction between privacy and confidentiality? How much weight should they have when information about individuals could protect other individuals or public health?

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