PART I

Ideas and Concepts

Chapter 1

Values in Health Policy: Understanding Fairness and Efficiency

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Deborah Stone introduces us to the two most important values in health care. We cannot have all we want of both fairness and efficiency, so we have to think about trade-offs between them. In the process, we learn a more fundamental lesson: How to think about values in health policy?

Two powerful ideals—fairness and efficiency—drive health-policy debates. These ideas unite us around lofty goals, only to divide us the minute we get down to details. That's not only because there is an inherent tension between fairness and efficiency, but also because each ideal has multiple meanings. Different interpretations of fairness and efficiency define different kinds of community. They draw different boundaries, boundaries that include or privilege some people while excluding or disadvantaging others. Inside these grand ideals lurk many dilemmas for those who would use them as yardsticks for policy evaluation.

EFFICIENCY

Let's start with efficiency, for though it is less inspiring than fairness, it is more often taken for granted as an objective standard and an incontrovertible value in health policy.

Efficiency is another word for a bargain. It is getting the most for the least or, in slightly more economic terms, producing the most output for a given input. All policy reformers promise to give the country a bargain. Every person with a program to peddle promises that this program will save more than it costs. Efficiency is one of those motherhood values that everybody is *for*, so long as no one spells out exactly what it means—but it papers over a lot of conflicts.

The idea behind efficiency is engagingly simple: First, we measure the costs and benefits of any program, proposal, or procedure. Then, with measurements in hand, we compare them and choose the course of action with the highest ratio of benefits to costs. That's all efficiency is: getting the most we can for a given cost. A smart policy analyst or manager should be able to determine the most efficient way of accomplishing a goal. Who could be against efficiency? It is obviously a universal good.

Or is it? I want to challenge the assumption that efficiency is an empirically measurable fact. I want to suggest, instead, that efficiency is a concept that always comes from a point of view. Efficiency can be judged only from a particular vantage point, and just as there are multiple vantage points in society,

so there are multiple efficiencies. From a political science perspective, efficiencies are like politicians—they are tied to constituencies. And if we understand efficiency this way, it will be easy to see why someone might be against a policy reform that promises efficiency. Let me illustrate with five examples.

The Waiting Room

A physician's waiting room is set up to be efficient. With long training and very expensive expertise, a physician is a valuable resource. A physician can't know in advance how much time each patient will need, so to use the resource most efficiently, the receptionist schedules patients so that there are always several waiting in the waiting room and often two or three in different examining rooms. The physician never has an unused minute. The patients kill a lot of time. (You know the drill—how much time have *you* killed in physicians' waiting rooms? I'll bet it's more time than you have bought yourself by watching your cholesterol.)

The waiting room game is efficient only if we regard it from the physician's point of view. The physician, as a resource, is being used to the max. His or her time is never wasted. Now look at it from the patients' point of view. Some of their time is always wasted. In order to say that the waiting room system produces the most medical care for the least expenditure of time, we have to ignore all the patients' wasted time or value patients' time much less than the physician's time, or both.

The point is simple. One person's efficiency is another person's waste. Even if we think that organizing medical care so that patients wait for physicians is the most efficient use of medical resources for society as a whole, we still buy societal efficiency at the cost of lots of wasted time for lots of people. Somebody is hurt. The physician's waiting room is a good metaphor for the core notion of efficiency itself—every gain and every loss belongs to somebody.

The Million-Dollar Catheter Lab

Under the headline "Doctors Say They Can Save Lives and Still Save Money," the *New York Times* touted the Geisinger Foundation in Minnesota as the wave of the future because it had figured out how to increase efficiency in medical care. Among its tricks was a grand version of the waiting room game. The health plan avoided "duplication of costly equipment" by doing all cardiac catheterizations at one hospital. "This does mean," the reporter allowed, "that some patients have to travel up to 100 miles for major procedures that in a less efficient system might be available at a community hospital."[1]

It might be more efficient to have only one cardiac catheterization lab for the entire community served by a specialty provider, but we should't leap to that conclusion before we tally up all the costs of centralization. First, there are the costs of patients' time; second, the time of their spouses, friends, or whomever accompanies them; third, the travel and lodging costs for all the people who have to travel so far from home. There are the emotional costs of making this procedure into an even bigger deal than it already is by embedding it in a trip away from home. There may be still more costs associated with leaving home—paying someone else to mind the kids, for example, or the burden to yet another relative who comes into the home to mind the kids. One can imagine an infinite chain of disturbance: John needs a cardiac catheterization, his wife Janice goes with him, her sister Janeen takes time off from work to mind their kids, Janeen's colleagues work harder to fill in for her, and some of Janeen's work doesn't get done, with attendant costs to her employer.

A full efficiency calculus has to take into account the points of view of *all* the people affected by the remote location of catheterization labs. Tracing out such chains of consequences is rather like doing genealogy: We can decide to go only so far as our great-grandparents, but drawing any limit is an arbitrary decision. This represents what I call the boundary problem in efficiency measurement. How do we know where to draw the boundaries in assessing the ripple effects of any way of organizing medical care? There are no natural or correct or obvious boundaries because people live embedded in social networks, just as they are born into unbounded genealogical trees.

The Paycheck

Every paycheck is an expenditure to a hospital and a livelihood to an employee, and therein lies a tale. Whether a paycheck goes on the output side or the input side of an efficiency ratio depends on who is doing the accounting.

We could adopt the point of view of a hospital CEO and measure the cost of providing hospital care. How much input does it take to produce our output? To the CEO, a paycheck is input. The CEO wants to write as few paychecks as possible and to keep each one of them as low as possible.

But the hospital is also a community institution and a major local employer. To the governor, the mayor, and even the neighbors, the hospital's role is not only to make sick people

well but also to provide economic stability to the neighborhood. From the point of view of the local community, each hospital payroll check is output many times over. It means a livelihood to a hospital employee and her family. Because employees will spend most of their paychecks, each check also means revenue to local businesses and, in turn, paychecks for those businesses' employees.

Economies produce not only goods and services but also jobs. In standard market models, labor counts as an "input" to production. But from the point of view of the Secretary of Labor, President, and for that matter, most elected politicians, employment is also an economic output that citizens expect their governments to deliver. Societies whose economies produce more employment for their members are usually better off than those whose economies produce less, and politicians who preside over declining employment had better watch their electoral backs.

Thus, reformers like Bill Clinton and Barack Obama are only half right when they say, "We can't fix our economy without doing something about health care costs." The half they forget is that the health care system is the strongest part of our economy in terms of generating jobs. Between 2000 and 2010, the US economy lost 3.2 million jobs. Every sector of the economy experienced job loss, except for two—education and health, whose annual rates of job growth were 2.9 and 2.8%, respectively. Looking into the future, between 2010 and 2020, jobs in health care, home health care, and personal care are expected to account for almost half of all job growth.[2]

There is a nasty double bind here. Health care expenditures are eating up our gross national product (GNP) and raising the cost of American goods, but every health care expenditure is income to someone employed in the health sector or to someone employed by someone who makes things for the health sector. We can't get a handle on health care costs unless we are willing to put a lot of people out of work.

There is another wrinkle to the paycheck story. Jobs, on balance, probably contribute to people's health: Paychecks feed families and pay medical bills. Jobs give people pride, satisfaction, and a sense of worth. For the lucky employees of large businesses, jobs provide health insurance and access to medical care. To be sure, not all jobs provide decent wages, stress-free work, or even safe and healthy work, much less health insurance. But to the extent that jobs do provide these things, reducing the input side of health production by reducing paychecks doesn't necessarily increase the ratio of output (health) to input (dollars).

Only from the vantage point of someone whose vision stops at the hospital walls does cutting staff increase efficiency.

The Leaky Bladder

During the 1990s, New York had the most extensive, generous, and costly Medicaid home health care program in the nation. To save money, the state department of social services decided to make home care more efficient. The department devised a system to define precise client needs such as feeding, toileting, and bathing and then designated an amount of time necessary for an aide to complete each task. The goal was to pay home care workers only for the time necessary to do these instrumental tasks and to cut out the unproductive or "dead time." Dead time is time a home care worker spends chatting with the client—schmoozing, joking, just being together in a human relationship, or, as is so often necessary in home care, coaxing adults to feel okay about being treated like children who cannot bathe, toilet, or feed themselves.

Under the new system, an elderly woman whose chief problem was incontinence would have her care allotment reduced from having a full-time, live-in attendant to having someone come in for 10.5 hours per week. (You figure out how many times a day the woman might be able to have her clothes and sheets changed and the maximum amount of time she might spend sitting in her own urine.) The department thought of paying for her care in the same way an auto mechanic would figure out how much time it takes to service a car with a leaky gas tank. The pursuit of instrumental efficiency reduced this woman to a leaky container that needed mopping up.[3]

To talk about making health care more efficient requires us to think of health care production like widget production. Economists traditionally measure productivity in manufacturing as output per labor hour—how many widgets does each worker produce in an hour? In the service sector, this definition becomes something like "number of people processed per hour of labor," since handling people is what service industries do. If physician productivity is measured as number of patients treated per hour (and it often is), the most efficient physician becomes the one who spends the least time with patients. In hospitals, more personnel such as

nurses and aides no doubt add to patients' comfort and sense of well-being, and maybe even to their health, but they lower productivity statistics because now there are more workers spread over the same number of patients.

If we adopt the point of view of consumers, patients, and families instead of CEOs and budget directors, productivity looks very different. In choosing a hospital or a nursing home for a relative, you would look for a *high* staff-to-patient ratio. In choosing a physician for yourself, you probably want one who will take time to listen to your concerns, explain things well, invite your questions, and preserve your sense of dignity and hope in difficult situations. The very qualities that make hospitals and healers more attractive and helpful to consumers make them less productive in efficiency statistics.

In health care, it is hard to tell what efficiency is because we don't know what "output" is in the first place. Those intangible qualities of good doctoring or home care that patients really value are hard to define precisely, let alone observe, measure, and put a price on. For example, when considering whether insurance should cover hip transplants for people over age 80, we know what the price tag is, and we can average it out over their life expectancy—but how should we value the benefit to them and their families of being independent and not having to use a wheelchair for the rest of their lives? Like hip transplants, all health care goods and services have known prices, but like independence, most of what people value about their health doesn't carry a price tag. In fact, most of what the health system produces is not so easily definable and measurable—things such as better functioning, lowered risk of future disease, reduced pain, education about caring for oneself, and, let us not forget, reassurance, hope, and a sense of well-being.

Our inability to measure intangible values makes calculating efficiency devilishly difficult and leads those who try calculating it to omit the things they can't easily measure and thereby omit the things that matter most. Worse, when payment systems reward providers for scoring well on efficiency measures, the measurable drives out the unmeasurable. Suppose, for example, we could provide an incontinent woman with three changes a day instead of more frequent changes without any increase in skin problems or urinary tract infections. The outcome data and the cost of the new protocol would look like an efficiency gain—until, that is, we count her increased discomfort and humiliation and her friends' reluctance to visit her because of the odor. An efficiency-driven home care program would likely be blind to such human costs as lost dignity and eroded social networks.

The Cost-Ineffective TB Program[4]

Paul Farmer, physician, anthropologist, and international medical activist, was troubled by the large number of cases of drug-resistant tuberculosis in Haiti and Peru. When he and his colleague Dr. Jim Yong Kim tried to interest the World Health Organization (WHO) in funding public health campaigns against MDR-TB (multidrug-resistant tuberculosis, as the disease is nicknamed), they learned that WHO had deemed treating the disease in developing countries as not cost-effective. Indeed, it did cost about $15,000 a year to treat one person with MDR-TB. Treating the simpler forms of TB that do respond to standard antibiotics was much cheaper. And so, in the deadly jargon of policy analysis, WHO had declared in one of its manuals: "In settings of resource constraint [read: poor countries], it is necessary for rational resource allocation to prioritise TB treatment categories according to the cost-effectiveness of treatment of each category."[5] In other words, physicians like Farmer and Kim were supposed to ignore patients with MDR-TB because they could cure more people by putting all their resources into treating those with ordinary TB.

With WHO's seal of disapproval for treating MDR-TB in developing countries, it was nearly impossible for Farmer and Kim to raise money to support their programs. They were so committed to treating the disease, though, that they went ahead treating a small number of patients, begging and borrowing the money and drugs to do it. (At one point, they were "found out" by Brigham and Women's Hospital; they had taken $92,000 worth of drugs from its pharmacy to Haiti and Peru. But they never intended to steal; they had a philanthropist in their corner who wrote a check to the hospital, with a note saying he thought the hospital "ought to be more generous toward the poor.") They were determined to prove that at least the disease was curable. And they were incensed by the way that cost-effectiveness analysis, as they saw it, "rationalized an irrational status quo: MDR treatment was cost-effective in a place like New York, but not in a place like Peru."

Farmer and Kim had been buying some drugs to treat MDR-TB in different places. They noticed that one of the drugs,

manufactured by Eli Lilly, cost $29.90 per vial at the Brigham and Women's Hospital in Boston, $21.00 per vial in Peru, and only $8.80 per vial in Paris. When their Paris supplier suddenly refused to sell them any more drugs, a light bulb went on: The price of drugs is set by the pharmaceutical manufacturers, and they set radically different prices for different markets. If that were true—and it still is—then the "cost" of treating MDR-TB was not a given cost. The "cost" in cost-effectiveness analysis was an artifact of the drug manufacturer's pricing policies.

Dr. Kim, Dr. Farmer, and their allies browbeat, jawboned, and negotiated. They persuaded some manufacturers to lower their prices for the MDR-TB drugs, and persuaded one of them, Eli Lilly, which had a patent on one of the most effective drugs, to donate large amounts of its drug. Suddenly, the cost of curing a case of drug-resistant TB plummeted from $15,000 a year to $1,500 a year, and cure rates were very high.

But it wasn't enough to get one or two companies to lower prices for a small amount of drugs. Farmer and Kim set about trying to change the market for MDR-TB drugs, to change the entire system of supply and demand. They knew they needed to get someone to manufacture large quantities of these drugs for less money. They joined forces with other nonprofit organizations to stimulate smaller drug manufacturers to make generic versions of MDR-TB drugs. In order to convince generic manufacturers to develop and produce the drugs, they had to show that there was a market for them, meaning that a lot of TB projects would use (and buy) them. They masterminded a plan to get MDR-TB drugs listed on WHO's official list of "essential drugs," a list that in itself symbolically signaled a market demand. If a drug were on WHO's essential list, then firms should manufacture it regardless.

Farmer's and Kim's public-health coup turns cost-effectiveness analysis inside out. Cost-effectiveness and cost-benefit analyses depend on knowing the cost of whatever outcome you are trying to produce. You've got to plug *some* price into your equation. But if cost is simply a matter of what a supplier charges, then it, in turn, depends on the power relationships between buyers and sellers. When the WHO evaluated the cost-effectiveness of treating MDR-TB in developing countries, it took the price of drugs as a given—something fixed and unchangeable. Implicitly, then, WHO also took as a given the political economy of pharmaceuticals—the dominant market position of large American pharmaceutical companies, the monopoly pricing permitted by American patent protection, the power of manufacturers to dictate prices, and WHO's power to dictate what diseases public-health programs would treat and therefore which drugs they would purchase.

If, instead, we regard the cost of inputs as themselves outputs of a political-economic system, then they are not objective measures, and the cost-benefit analysis that derives from them is no more objective. Prices and cost-effectiveness judgments are captives of the political status quo, and cost-effectiveness analysis is a recipe for preserving the current distribution of resources.

These five stories illustrate some of the traps that await health care efficiency experts. Without carefully specifying *whose* costs count, what kinds of costs we want to control, and what kinds of output we want from the medical system, efficiency-driven reforms could merely shift costs to people and places where they are less visible and produce health services that give people less value for their money instead of more.

FAIRNESS

Elsewhere in the world, medical insurance is called "sickness insurance," and it covers sick people. In the United States, we have "health insurance," and as befits its name, insurers strive to weed out sick people and cover only the healthy. This is about as perverse a system as one can imagine, and one that poses an extraordinary puzzle: Why and how does a country's political system produce a health system whose result is absolutely antithetical to its public purpose? The result can best be explained as a long history of political conflict between worldviews about fairness and equity. This conflict is vividly illustrated—quite literally, illustrated with photographs—in the advertising campaigns of health insurance companies.

In the late 1980s, the trade associations of the health and life insurance industry sponsored an advertising campaign to persuade the public that "paying for someone else's risks" is a bad idea.[6] In one of these ads, a photo of a worker in a hard hat and tool belt straddling the girders of a steel tower was captioned "If you don't take risks, why should you pay for someone else's?" Another ad showed a young man and woman playing basketball one on one, and asked "Why should men and women pay different rates for their health

and life insurance?" The choral refrain at the bottom of each ad in the series went "The lower your risk, the lower your premium," and the small print explained the relevant facts. For example,

> Women under 55 normally incur more health care expenses than men of the same age, so they pay more for individual health insurance than men. After age 55, women generally have lower claims costs, so they normally pay less for individual health insurance than men of the same age.
>
> That's why insurers have to group people with similar risks when they calculate premiums. If they didn't, people with low risks would end up subsidizing people with high risks. And that wouldn't be fair.

In 1991, with Bill Clinton running on a platform of universal access to health care, larger companies began to distance themselves from the trade association's "bear-your-own-risk" campaign. For example, the Prudential Insurance Company of America ran a full-page ad featuring a chest X-ray captioned, "Because he works for a small company, the prognosis isn't good for his fellow workers either." The ad went on to decry the industry practice of not insuring small companies with one or a few very sick workers. Another Prudential ad showed a drawing of a heart under the headline: "If you ever need one, there's an insurance company that has one." Still, despite the more moderate tone of some ads trying to change the insurance industry's image, the industry continued to deny coverage to people with any "preexisting condition" and to charge higher premiums to those with high risk of needing medical care.

By the time of Barack Obama's first presidential run, *preexisting condition*, once a little-known term of industry legalese, had became a household word and the emblem of popular anger against industry unfairness. In his stump speeches, Obama did not need to define it. Of his many heart-rending stories about people denied access to medical care, the one about his mother grabbed the nation most. She had died of breast cancer and spent her last months fighting "her" insurance company that deemed her cancer a preexisting condition and refused to pay for her treatment. In the summer of 2009, as Obama's health reform got seriously underway, the chastened and worried trade association of health insurers, now renamed America's Health Insurance Plans, ran a TV ad calling for a strikingly different concept of fairness:

> Let's Fix Health Care. . . . If everyone's covered, we can make health care as affordable as possible. And the words "pre-existing condition" will become a thing of the past.[7]

Indeed, only two weeks after Obama's victory in 2008, seeing the handwriting on the wall, the trade association of health insurers announced in a press release that it would give up the "lower-your-risk/lower-your-premium" principle "as part of a universal participation plan in which all individuals were required to maintain health insurance."[8] Without directly saying so, the industry was calling for a mandate to buy health insurance. If everyone has to buy it, insurers wouldn't have to worry that only sick people will buy it. (And insurers would get a lot of new customers, to boot.)

These ads and stories have many layers of meaning. On the surface, the issue is how commercial insurers ought to price their health insurance policies. Below the surface, these narratives offer competing visions of community. They suggest how Americans should think about what ties them together and what they owe each other. In one view, no one should feel an obligation to pay for the medical care of those who get injured while doing constructive work for society. Similarly, though women of childbearing age are exhorted daily to ensure the health of their babies, even those not yet born, the men with whom they create the next generation have no obligation to help finance their extra medical care. Alternatively, said the Prudential ad, Obama, and the health insurance trade association in 2009, we should not abandon those who are sick or attached to people who are sick; sick and healthy, we are all one community.

At still another level, the ads reflect the long-running political struggle over health insurance reform. The underlying question is whether medical care should be distributed as a right of citizenship or as a market commodity. If, as the lower-your-risk the lower-your-premium principle commends, we charge people as closely as possible for the medical care they need and consume, then we are treating medical care like other consumer goods distributed through the market. If, like President Obama, we are unwilling to throw sick people out of the insurance lifeboat,

if we think that the healthy should help pay for the care of the sick, then medical care becomes more like things we distribute as a basic right, such as education. These ads and stories symbolize two very different logics of insurance: the actuarial fairness principle and the solidarity principle.

Actuarial fairness—people paying for their own risk—is more than an idea about distributive justice. It is also the business strategy used by the private insurance industry, which provides coverage for well over half of people under age 65 who have health insurance.[9] The driving aim behind the Affordable Care Act (ACA) of 2010 was to restructure American health insurance according to the solidarity principle, and much of the conflict over implementing the act is best understood as a struggle between these two principles of fairness as the basis for health policy.

The Solidarity Principle

Social insurance operates by the logic of *solidarity*. Its purpose is to guarantee that certain agreed-upon individual needs will be paid for by a community or group. This is the logic of mutual aid societies and fraternal associations, as well as government social insurance programs. Having decided in advance that some need is deserving of social aid, a society undertakes to guarantee that the need is met for all its members. The argument for financing medical care via social insurance rests on the belief that medical care should be distributed according to medical need.

If medical care were financed like most market goods, by charging people for exactly the goods and services they consume, medical care would be distributed only partially according to need. Only those who are sick and need care would seek to purchase it, but only those who could also afford to pay would actually receive it. In addition, some who are not sick but who have plenty of resources might purchase more care than they need. People who could not afford to buy care would not receive any, regardless of their need for it.

Social insurance unties the two essential connections of the market: first, the link between the amount one pays for care (or any good) and the amount one consumes; and second, the link between the amount of care one buys and one's ability to pay. Under a social insurance scheme, individuals are entitled to receive whatever care they need, and the amounts they pay into the scheme are totally unrelated to the amount or cost of care they actually use. (Of course, to the extent there are coinsurance and deductibles in a social insurance scheme, the amount a person pays is partially related to the amount one consumes.)

Even social insurance doesn't guarantee that medical care will be distributed exactly according to medical need, however. Need, after all, is a rather elusive concept, all the more so in medicine. Unlike most consumer goods, the value of medical care depends on it being customized. Whether someone can benefit from a particular medical procedure doesn't hinge on personal tastes and preferences, as economic theory would have it, but rather on a correct match between a medical procedure and a person's pathology. The degree to which social insurance results in allocation of care according to need is mediated by the professional skill of medical personnel in matching procedures to pathologies. Many other factors unrelated to medical need influence the distribution of care, such as local professional norms about the appropriate use of procedures, the supply of medical facilities and personnel, and financial incentives for providers to offer diagnostic tests and treatments (or not).[10] All of these factors mean that even under a system of pure social insurance, medical care will not be perfectly distributed according to medical need. But the *ideal* of the solidarity principle is that we should strive to distribute medical care according to medical need and to limit the influence of ability to pay.

The solidarity principle doesn't require that medical care be distributed equally in the sense that everyone gets the same amount. Social insurance is not a fixed-shares arrangement, where each contributing member gets an equal slice of the pie. When people pool their risks and their savings in a social insurance program, they are taking their chances that they may never become sick or need expensive care, and that most of their contributions will go to help the members who *do* incur a need for expensive care. As in any lottery, they pay into the pot, regardless of whether they ultimately get to draw out of it.

In fact, only some members of a risk pool will get sick enough to need care. Since only those who get seriously sick will receive a payout, the others necessarily pay to help them. Thus, redistribution from the healthy to the sick is built into insurance. Health-policy analysts and corporate benefits managers frequently discover with great alarm that a small portion of insured people accounts for a huge proportion of claims expenditures, as though this skewing means that something is

amiss. But subsidy from the vast majority of insured people to a small minority is precisely what is supposed to happen in insurance. Such skewing is what people agree to when they join a social insurance risk pool. They accept it because they don't know, when they join, whether they will be on the giving end or the receiving end, and they want to protect themselves in case they are part of the unlucky minority. They accept it, too, because they believe that sickness is one of those contingencies when society should rally around the individual.

Actuarial Fairness

Commercial insurers—that is, private firms selling insurance as a profit-making venture—operate on a deep contradiction. They provide for pooling of risks and mutual aid among policyholders, much as social insurance does; yet they select their policyholders, categorize them into groups with similar risks and medical needs, and price their policies according to market logic. When they speak of equity, commercial insurers espouse the principle of actuarial fairness: Premium rates should be differentiated so that "each insured [person] will pay in accordance with the quality of his risk."[11] By quality of risk, insurers mean the likelihood a person will incur whatever loss he or she is insured against, say, fire for fire insurance or accidents for auto insurance. Health insurers are interested in factors that affect or predict a person's use of medical care. These include one's occupation, hobbies (since some are very dangerous), personal medical history, and any medical information such as family history or a genetic marker that predicts disease, even if the disease hasn't yet occurred.

Insurers assert that actuarial fairness requires them to seek the most complete risk information on applicants. They must assess applicants' risk by looking at their medical records, and then "create classifications to recognize the many differences which exist among individuals." Ultimately, an insurer has the "responsibility to treat all its policy holders fairly by establishing premiums at a level consistent with risk represented by each individual policyholder."[12] "Medical underwriting" is the name for this process of examining people's medical history, categorizing their risk, and pricing their insurance according to their risks or refusing to insure them at all. According to the actuarial fairness principle, people who have diseases or serious risks to their health are getting a more valuable insurance policy than those with lesser risks, so they ought to pay more for the extra value. Or, to see the matter another way, if insurers did *not* identify people with higher risks, separate them from the general pool of policyholders, and charge them more, insurers would be causing a "forced subsidy from the healthy to the less healthy."[13] "An applicant presenting a low risk of loss to the insurer should not be required to subsidize another applicant who presents a higher degree of risk."[14]

Here is the crux of the conflict: The very redistribution from the healthy to the sick that is the essential purpose of medical insurance under the solidarity principle is anathema to commercial insurers under the actuarial fairness principle. Tellingly, insurers virtually never use the word *subsidy* without a pejorative modifier such as *coerced*, *forced*, or *unfair*. Although all insurance entails a subsidy from the lucky to the unlucky (whether luck concerns car accidents, diseases, or fires), commercial insurers eschew subsidy from one "class" of policyholders to another. *Class*, in insurance jargon, means risk class, or a group of people with similar probabilities of becoming sick (or perhaps more accurately, with similar probabilities of generating costs to the insurer). To commercial insurers, subsidy is not what they pursue but the *unwanted result* of their failure to segregate people into homogeneous risk classes.

If the actuarial fairness principle could be perfectly implemented, if we had perfect predictive information and precise ratings, each person would pay for himself. This, of course, would be the antithesis of insurance. In fact, in a world of perfect predictive information, there would be no need and no market demand for insurance because no one would stand to gain by "beating the odds." Since each insurance policy would be priced according to the medical care actually consumed by each policyholder, people would do better to pay for their care directly and avoid paying for insurance companies' administrative and marketing expenses, not to mention profits. And since the price of insurance would be the same as the price of needed medical care, those who couldn't afford to pay for their own care couldn't afford to pay for insurance either.

Actuarial Fairness and the Politics of Exclusion

To put the matter simply, the United States got a "health insurance" system instead of a "sickness insurance" system because unlike the governments of other industrialized countries, our government fostered privatization of the social welfare function

from the beginning. Because government allowed the private sector to provide the first line of defense against illness, and because the private sector operated on the logic of actuarial fairness, the door was open for a politics of exclusion.

The first battles over insurance company underwriting practices concerned race, specifically, life insurers' use of race as an underwriting criterion. As early as the 1880s, several states tried to prohibit life insurance companies from charging higher rates to blacks than whites.[15] Insurers found it quite easy to avoid public interference with their "scientific principles." In 1900, Frederick Hoffman, then chief statistician of Prudential, complained that many states had passed laws "compelling Industrial [life insurance] companies to accept Negro risks at the same rates as those charged the white population. Fortunately," he boasted, "the companies cannot be compelled to solicit this class of risks, and very little business of this class is now written by Industrial companies, practically none by the Prudential."[16] (Translation: You try to make us charge the same rates to blacks and whites; we just won't sell to blacks.)

In the ensuing 130 years, the public and private sectors have skirmished many times over the way insurers use race and other social groupings. Civil rights agencies have fought against "redlining" by banks—using a borrower's race and the racial composition of a neighborhood in deciding whether to issue home insurance and mortgages. In the 1970s, activists challenged the use of gender as a factor in pricing life, disability, and auto insurance. Disease-based interest groups (notably Tay-Sachs disease, sickle cell anemia, and DES mothers and daughters) challenged the use of "their disease" as a criterion in underwriting life and health insurance and succeeded in winning protections in several states. In the late 1980s, insurers' use of sexual orientation as a proxy for AIDS risk and then HIV tests became a contentious issue, followed quickly by the use of genetic tests for hereditary diseases. Various states and the federal government have tried to curb many of these practices but with little success against an industry that fiercely defends its right to use them.

Commercial insurers have been able to preserve their actuarial practices in part by capturing public regulators and in part by making substantial campaign contributions to state and federal legislators. Most state insurance departments and commissions are controlled by men and women who come from commercial insurance and will return to lucrative jobs there. They share the insurers' worldview in which equity means actuarial fairness. In the 1980s, when the battle over HIV testing by health and life insurers was largely perceived as a struggle about taking gays aboard the insurance lifeboat, a state commissioner told the Office of Technology Assessment (emphasis added):

> We encourage insurers to test where appropriate because *we don't want insurance companies to issue policies to people who are sick, likely to be sick, or likely to die*.[17]

When public regulators see their job as protecting private health insurers from covering sick people, we get a system of "health insurance" instead of "sickness insurance."

Insurers have been able to block state and federal legislative restrictions on their underwriting criteria, either by defeating bills and regulations or by inserting narrow language to permit the use of criteria that are "actuarially sound." For example, the Genetic Information Nondiscrimination Act of 2008 prohibits health insurers from adjusting premiums based on genetic information but allows them to increase premiums or deny coverage based on the actual presence of a genetic disease. The law forbids insurers from requesting, requiring, or buying genetic information about individuals who want to enroll in a group plan, but if insurers happen to obtain genetic information "incidentally" in the process of requiring or buying other medical information, they cannot be held in violation of the law.[18]

Whatever risk classification and actuarial pricing insurers cannot accomplish through direct medical underwriting, they can often accomplish through targeted marketing or pricing. Health maintenance organizations (HMOs) and other managed care plans feature their maternity and fitness club benefits in their advertising as a way of attracting the young and healthy. Some health plans quietly avoid contracting with physicians in minority neighborhoods, an indirect way of making their insurance inaccessible to populations against whom they cannot discriminate outright. If all else fails, insurers can play hardball with legislators who try to curb actuarial practices that exclude sick people or price them out of the market. Prudential's strategy of simply "not soliciting" Negro business was the prototype. During the first year of the ACA, health insurers stopped offering policies to children rather than comply with the prohibition on preexisting condition exclusions. In order to make good on its promise of insurance for children with cancer, autism, heart defects, and other serious illnesses, the Obama administration had to back down and permit insurers to price policies according to health status.[19]

CONCLUSION

The ACA goes farther than any other federal or state legislation in restraining health insurers' use of the actuarial fairness principle and strengthening the solidarity principle.[20] But eradicating actuarial rating remains an elusive goal. Under the new law, most health insurance for people under 65 will still be provided by private companies, steeped in their beliefs about actuarial fairness and lured by its profit potential. The law permits certain kinds of actuarial rating, notably, pricing according to age and tobacco use. Because the states will offer multiple insurance plans with different benefit levels and prices, there will inevitably be some self-sorting into plans, with healthy and wealthy people choosing plans with very high deductibles, and sick or high-risk people seeking plans with low deductibles and co-payments. The act provides an elaborate and complicated system of "risk adjustment" whereby plans with relatively healthy members will subsidize plans with relatively sick members. However, past experience with risk adjustment suggests that it only weakly compensates for the ability of some private insurers to avoid the sick.[21]

From an efficiency perspective, the ACA might look like a bad bargain. The cost of gathering data and administering risk adjustment depletes the amount of people's premiums that comes back in the form of medical care. And yet, one might argue that the Rube Goldberg contraption that is the health reform was the only politically feasible one, and if it substantially mitigates exclusion of the sick from health insurance, it was a grand bargain after all.[22]

Efficiency and fairness are fine aspirations for public programs, but no one should be lulled into thinking they are neutral criteria for judging the virtues of health care systems or reform proposals. The words are more like empty packages, gift-wrapped with glitter and bows, tempting us to imagine their contents. Stakeholders in the complex world of health insurance conduct much of their politics by offering visions of what might be in these boxes under different political and economic scenarios. When the boxes are finally opened, some people will find useful and lucrative gifts; others will go away empty-handed. Every conception of efficiency and equity has winners and losers.

STUDY QUESTIONS

1. What is a key assumption behind the view that policy efficiency entails simply choosing the course of action with the highest ratio of benefits to costs?
2. What does Stone think about a "universal" concept of efficiency as "what is best for society as a whole"?
3. If we assume that the most efficient system is to have patients wait for physicians, what seems to be undervalued?
4. What is the boundary problem of efficiency measurement?
5. Suppose efficiency is considered to be the ratio of benefits (the numerator) to expenditures (the denominator). Should hospital staff paychecks be counted as benefits or expenditures?
6. What are the two different perspectives on health care labor productivity?
7. How and why did the message of health insurers' advertising change between the 1980s and 2009?
8. Which two health insurance schemes and underlying principles does Stone contrast?
9. How do social insurance and solidarity hold medical care ideally be distributed?
10. Would it be remarkable in a social insurance scheme for a small portion of the insured people to account for a huge proportion of claims expenditures?

11. According to Stone, what is the basic contradiction in commercial insurance?
12. What is actuarial fairness?
13. Why does Stone think the United States has a health insurance system rather than a sickness insurance system?

ENDNOTES

1. Eckholm, 1991.
2. Henderson, 2012, table 1, p. 66.
3. This story is from Bennett, 1992.
4. I take the details of this story from Kidder, 2003. All quotations in this section are from this book unless otherwise noted.
5. World Health Organization, *Treatment of Tuberculosis: Guidelines for National Programmes*, 2nd ed., Geneva, 1997, quoted in Kidder, 2003, p. 141.
6. Stone, 1994, gives a longer analysis of health insurance industry ads through up to and during Clinton's health reform.
7. You can see the ad on YouTube at http://www.youtube.com/watch?v=R36YJl8SagU (viewed May 8, 2012).
8. America's Health Insurance Plans, 2008.
9. Cohen and Martinez, 2012.
10. Hillman et al., 1990, 1604–08.
11. Bailey, Hutchinson, and Narber, 1976.
12. Clifford and Iuculano, 1987.
13. Clifford and Iuculano, 1987.
14. Hoffman and Kincaid, 1986–1987.
15. James, 1947.
16. Hoffman, 1900.
17. Statement made at a meeting (February 17, 1987) of the Advisory Panel to the Office of Technology Assessment for its study, *Medical Testing and Health Insurance* (US Congress, 1988). I was a member of this panel.
18. Associated Press, 2008; U.S. Congress 2008, Pub. L. 110–233, *Genetic Information Nondiscrimination Act*, Title I.
19. Pear, 2011.
20. Kaiser Family Foundation, 2012.
21. Weiner, Trish, Abrams, and Lemke, 2012.
22. Jacobs and Skocpol, 2010.

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Eyewitness

Adventures with Informed Consent

Deborah Stone

In a report from the real world of patients and medicine, Deborah Stone shows us how impenetrable bureaucracy, overworked staff members, and defensive legalism wipe out our privacy and bury the patient's right to know.

A few years ago, I had a mole removed from my forehead. I'd had a preliminary consultation with the dermatologist—even such simple things are never done on the spot. On the day I returned for the actual excision, the receptionist gave me a form to sign, saying, "We need this form in order to biopsy it."

Of course, I thought to myself, they have to get my consent, if only so my insurer will pay. Nevertheless, I always read forms before signing. The part she was asking me to sign read: "I understand that Medicare will not pay for a pap smear test for one of the following reasons (there were four boxes that could be checked, but none of them was). I agree to be personally responsible for all the charges."

"I don't understand," I said. "I'm not on Medicare and I'm not having a Pap smear."

"You're reading too much into it," the receptionist snapped. "It has nothing to do with Medicare. We need your signature in order to biopsy it," and then, after a pause meant to suggest my impending stupidity, she drawled, "unless you don't *want* it biopsied."

"Well then," I asked, "is this saying that I will have to pay for the biopsy?"

"No," she said, still exasperated. "Your insurance will cover it."

Well-informed patients and strictly regulated consent procedures are the foundations of the medical marketplace and the supposed guarantees that medicine will treat patients right. In practice, informed consent is a sham. Medical staff administer these forms as if they are a royal nuisance, and by and large, they brook no questions from patients. "Shut up and sign" is the prevailing attitude.

Most people don't even read medical consent forms before signing, and the clinical staff don't *expect* patients to read them. When someone like me comes along, someone who actually reads forms and asks questions, the staff get flummoxed, annoyed, or both.

Once, on admission to a hospital for a breast lump biopsy (it was benign), the admitting clerk handed me a consent form saying, "This just allows us to bill your insurance company." I read it over. Billing my insurer was only one of about six or seven things for which the form asked my permission. Most notable to me was authorization for the hospital and its physicians to do anything to me they deemed necessary while I was in their custody.

Given that I was going in for a breast biopsy and given the history of breast cancer treatment—namely, radical mastectomies performed at the surgeon's discretion without consultation with the woman—I found this consent form horrifying, no matter that I had discussed this very issue with my surgeon and that she had assured me she *never* did surgical treatment or even lymph node dissections at the same time as the initial biopsy.

I pointed out to the admitting clerk that the form was about more than permission to bill my insurer. "Oh, really?" She professed surprise.

Each time I have visited that same hospital for mammograms and follow-up care, the admitting clerk has handed me a consent form with the same cheery line, as if she's offering me a special deal: "This just allows us to bill your insurance company." I practically know the form by heart. It's a HIPAA (Health Insurance Portability and Accountability Act) form, now ubiquitous in the medical world. You can't walk into a clinic or office anymore without being asked to sign that you've received a notice of the institution's "privacy practices." This particular form does indeed say that I authorize the hospital to disclose my health information to my insurer. It also says I've seen the hospital's "notice of privacy practices," which is a separate form—six pages, single spaced—listing myriad ways "we may use or disclose your protected health information."

The form tells me that the hospital may share my health information both inside and outside the conglomerate Boston health system of which it is a part. It may use my information for medical research and for training new health care workers. The health system may use my health information to contact me not only about "patient care issues, treatment choices, and follow-up instructions," but also "with other health related benefits and services that may be of interest to you"—in other words, marketing. And also, "for fundraising to

support [the system] and its mission of excellence, provided, however, that such information is limited to demographic information only." Bill my insurance company, indeed.

By signing the HIPAA form, I'm authorizing a mega-hospital system to include me in its research, business operations, and marketing and fundraising databases, not to mention that I'm giving it permission to turn over my "protected health information" to law enforcement, public health, and other government authorities. These HIPAA "notices of privacy" are grossly misnamed. They're notices of publicity. All the paperwork in the name of privacy masks how patient privacy has been gutted, and it's all carried out through the rituals of informed consent—we give you a notice; you read it, understand it, agree to its provisions, and pen your signature to signify your consent.

As if to underline how vacuous and absurd the HIPAA process has become, one diagnostic imaging center I've used keeps a wastebasket by the door with a prominent sign, "Please Discard Unwanted Privacy Notices Here." Both times I've been there, the basket was full. In another physician's office where I have an annual checkup, the receptionist greets me with something like, "You probably don't want a copy of our privacy notice, but I need you to sign this paper saying you've received it."

Most medical visits now begin with this parody of consent: The patient is asked to sign one piece of paper saying they've received another piece of paper. No one cares whether they've read or understood the paper that provides the important information. This inane ritual inures people to the very idea of consent as a useful and informative procedure.

With the advent of electronic medical records, the ritual has become even more of a shell game. When my dental clinic went electronic, the receptionist informed me I had to sign all my various forms again using the new electronic signature pad, much like the credit card pads in stores. The forms, she reminded me, included the notice of privacy, the right to bill my insurer, the consent to treatment, and the "no guarantee of success" disclaimer. I stood at a counter looking at the back of her computer monitor.

Receptionist: "This is the such-and-such form. Now sign on the line."

Me: "But I can't see what I'm signing."

Her: "That's because it's on my screen"

Me: "I want to see what I'm signing."

Her: "There's a copy on the counter right in front of you. I told you those are the forms you will be signing. That's why they're there. Right now you're signing the one marked 'A'."

Me, thinking to myself: I could be signing a $500,000 mortgage.

Me to her: "Can I look at the screen?"

Her: "I'm sorry, it doesn't turn around."

Defeated, I signed four times. The bank hasn't yet come after me for a mortgage payment, but by now I've had the same experience in several medical establishments: I'm asked to sign my name on an electronic pad with absolutely no idea what I might be signing. So much for "informed."

Okay, maybe privacy and billing notices aren't so important, but surely good information about potential risks and benefits of any medical treatment is essential for wise decision making. For another surgery I needed, the consent form warned me of many potential, if unlikely, risks of this procedure, including death. My surgeon had discussed the "1%" chance of cutting the nerves to my vocal cords, leaving me unable to speak, but he hadn't mentioned death. I raised my eyebrows and uttered some sort of startled exclamation about not expecting to meet my maker quite so soon. "Oh, we have to say that for everything," the admitting clerk assured me. "If I were you, I'd just sign it, because you have to in order to have the surgery."

There's something cynical and duplicitous about making patients sign off on every risk, including death, no matter how remote the possibility. Another form I had to sign to have my mole excised, a procedure for which I would be having Novocain, warned me that "all forms of anesthesia involve risk and the possibility of complications, injury, and sometimes death." Crying wolf undermines the credibility of all warnings, including the most serious ones, to the point that even the people administering informed consent forms tell patients not to believe the information.

When the oncologists informed my cousin about a rigorous (their word) and brutal (his wife's word) lymphoma treatment protocol, they softened the terrifying potential consequences by saying, "Legally we have to mention anything that has ever happened in any of the patients who have undergone this protocol, even if the problems were unrelated to the cancer treatment." With their verbal assurances of how unlikely the worst consequences were, they all but contradicted the written forms. What's a patient to believe when informed consent gives such mixed messages?

A key principle of the law of contract, the principle that underlies informed consent in medicine, is the idea that parties to a contract must give their consent voluntarily. Coerced consent, consent obtained under duress, is not consent and cannot make a valid contract. In practice, there's coercion in every act of medical informed consent. There's subtle coercion in the staff's perfunctory presentation of consent documents, in their impatience with people who actually read them, and in their outright misrepresentation of what these documents say. And there's brute coercion in the situation: As the admitting clerk said to me, unless you sign, we won't treat you.