

# Reframing the Racial Disparities Issue for State Governments

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**Abstract** Although racial and ethnic disparities in health have been on the federal government's agenda since 1985, no policy reforms have significantly reduced disparities. The question arises whether states can effectively address this issue without waiting for solutions from the national government. The purpose of this article is to propose ways of reframing the disparities issue that might give state policy makers more leverage and might strengthen political will to address the issue. I suggest a moral frame based on a concept of distributive justice in which medical care must be distributed according to need. I explain the rationales for such a frame and consider its strategic advantages and disadvantages. In the last section, I suggest some policies based on this framing that are within the power of state legislatures.

Racial and ethnic disparities in health have been on and off the American political agenda for over a century. In many ways, the issue is a stunning example of what Anthony Downs (1972) has called "the issue-attention cycle": people discover a phenomenon that has been right under everyone's nose, they interpret it as a crisis, they propose and perhaps even implement policies to address the problem, they may even evaluate their progress against the crisis, and then gradually, their attention to the problem wanes and the problem itself fades back into oblivion.

A basic axiom of policy studies is that social problems do not exist "out there," waiting to be discovered by careful empirical observation and analysis. Phenomena become social problems when people perceive and interpret them as problems and come to some shared understanding that they want to change the situation (Elder and Cobb 1983; Gusfield 1981;

Kingdon 1999). Sometimes social movements provide the impetus for reframing an issue as a problem; sometimes interest groups, professional leaders, and political elites provide the impetus (Benford and Snow 2000). Often, an issue comes to be defined as a serious problem warranting government action in the interplay between popular movements and elite leadership. In our article about U.S. policy making on racial disparities in this volume, Vanessa Gamble and I track this striking pattern of interplay among community-led activism, professionally driven research, and elite government response from the early twentieth century onward.<sup>1</sup>

The prime impetus for the current attention to racial and ethnic disparities came from the federal government, specifically, Ronald Reagan's secretary of health and human services, Margaret Heckler. As Senator Edward Kennedy (2005: 453) tells it, "the issue of health disparities did not seriously capture national attention until 1985, when Margaret Heckler, secretary of health and human services, released the *Report of the Secretary's Task Force on Black and Minority Health*, which detailed the many stark differences in health between blacks and whites." The Heckler report is generally acknowledged as the catalyst for a series of federal and state initiatives: creation of a federal Office of Minority Health and eventually similar state offices, numerous scientific and governmental reports, increased governmental data collection, designation of a Center for Health Disparities Research within the National Institutes of Health, and perhaps most notably, public vows by the Clinton administration in 1998 to eliminate racial and ethnic disparities by the year 2010 (U.S. Department of Health and Human Services 1998).

Yet, as John McDonough and his colleagues note, despite official embrace of the issue, "the elimination of racial and ethnic health disparities has not yet attained the status and priority necessary to improve the health and well being of tens of millions of Americans. . . . legislative proposals are few, and none has resulted in significant new public resources" (McDonough et al. 2004: 3). As a former Massachusetts state legislator and a policy scholar and activist, McDonough himself has been a leader in articulating a strong role for states and in putting health disparities on states' policies agendas. McDonough understands that in order for states to tackle any problem, they need not only knowledge and action plans, but above all, they need political will. As part of a project to develop the knowledge base, action plans, and political will for states to address racial and ethnic disparities, McDonough asked me to think about how

1. For a historical perspective, see Gamble and Stone, this issue.

state policy makers might frame the issue for maximum political leverage. Thus, my purpose in this article is not to propose specific state policies that might remedy disparities—McDonough and colleagues have already done that (*ibid.*)—but rather to propose ways of framing disparities as a political issue that might strengthen political will.

At the outset, I should note that I believe, as does McDonough, that many of the large, system-level problems of American health care must be addressed on a national level, because states are relatively weak agents when it comes to wielding power over health care financing, medical technology, and the medical-industrial complex (Stone 1992). That said, however, states do have important scope for leadership on this issue. They have substantial authority over education and licensing for the health professions and substantial discretion over their own Medicaid and State Children's Health Insurance Programs (SCHIPs) within the parameters of federal guidelines and federal budgeting. They operate public health departments and community health centers. State leaders also wield many of the usual instruments of political issue—definition: they can hold hearings, stage press conferences, issue press releases, make speeches, and engage in a variety of symbolic politics, all of which help shape media coverage and through media, shape public perception and political support. And perhaps most important, in the context of American federalism, states can and do serve as incubators of ideas, laboratories of innovation, and modelers of new pathways for solving national problems.

Given a set of resources and powers at any level of government, one of the most important jobs of political leadership is to help define a problem in conjunction with larger political forces and to persuade a broad public beyond the immediately affected citizens and interest groups that it *is* a problem and warrants political attention. This is the essence of political will. Policy makers need a persuasive moral rationale to guide their own efforts and to mobilize a broader public. In this article, I sketch how racial and ethnic disparities in health care are an aspect of distributive justice, and I suggest a view of distributive justice that offers a strong rationale for correcting racial and ethnic disparities.

In framing an issue, policy makers also need a persuasive causal story, because problems come onto the political agenda on the backs of causal stories.<sup>2</sup> Causal stories do several kinds of work to move a problem onto the public agenda and shape the alternative policy responses that politi-

2. Material in this section draws on Stone 1986.

cians consider. Causal stories cast a problem as the result of human agency, not mere accidents or fate. If something is the result of chance or of nature (weather is the classic), there is nothing humans can do about it, with or without government. To describe a problem as amenable to human action is to make it a problem worthy of human attention. Causal stories also identify particular people, behaviors, or choices as the cause of a problem. The stories may be right or wrong, but they function something like accusations—they place blame and assign responsibility. Finally, causal stories usually embody fixes. They designate how the responsible parties must change their behavior and who might be in a position to bring about such change.

To stimulate political will requires tapping into deep moral values and cultural ideals that transcend policy arenas and legal jurisdictions. Although I conceived this article in the context of state policy making, I believe that the same issue frames that are most likely to strengthen political will at the state level are most likely to work at the national level, too. In the last section, I consider how state policy makers might use the frames I suggest to support programs within their power to accomplish, but as an exercise in framing, this article is addressed to national policy makers as well. By reframing the issue of racial and ethnic disparities, I hope to increase its political salience, give it higher priority on state and national policy agendas, and mobilize political support for the heretofore missing legislative proposals and new public resources.

### **Narrowing the Problem**

In thinking about how to frame the disparities issue for state action, the first question is how to simplify it. Issue framing entails moral visions and causal stories, but perhaps even more fundamentally, framing serves to simplify the complicated reality of a social issue to something more manageable by the human mind.

There is overwhelming evidence of racial and ethnic disparities in health status, access to insurance, and medical care itself.<sup>3</sup> These are three different, though related, problems. One preliminary issue is whether policy makers want to address all three of them, and if not, which one to address first. At a very practical level, it makes sense to narrow the problem because smaller, well-defined problems are easier to solve than bigger,

3. The most comprehensive summary of the research data is probably the Institute of Medicine's report, *Unequal Treatment* (Smedley, Stith, and Nelson 2003, esp. 38–77).

ill-defined ones. But practicality is not the only reason for narrowing the problem. Health status and health insurance have certain characteristics that limit their power to generate political will.

Health status is professional jargon for what laypeople simply call good or bad health. Ultimately, good health is the goal we care about, whether as citizens, health professionals, or policy makers, and likewise, eliminating racial and ethnic disparities in health is the end goal for public policy. Disparities in access to insurance and in medical care are troubling mainly because we believe insurance and care are means to better health. Yet for reasons I will argue below, eliminating disparities in health status is not the most effective way to frame the problem, even though it is the end goal.

Professionals measure health status by indicators of longevity and morbidity and, as doctors and researchers never tire of pointing out, the correlates and causes of even these more precise measures are enormously complex. If it is hard for researchers to sort out the complex determinants of health status, it is even harder for laypeople to grasp the causal mechanisms underlying their own health. Complexity does not bode well for political issue framing. Problems for which there is no understandable causal story are hard to sell; people feel helpless without a causal story to guide them (Fairclough and O'Connell 2003).<sup>4</sup>

For about two decades, the public health establishment has emphasized lifestyle factors as important determinants of health. Many policy makers believe that the best way to address disparities in health status is to educate people about lifestyle risk factors and other preventive health measures. The lifestyle theory does indeed offer a relatively simple causal story—individual behavioral choices determine health status—and it is one that accords with the current conservative emphasis on personal responsibility for well-being (as in the name of the legislation that ended the entitlement to welfare assistance, the Personal Responsibility and Work Opportunity Reform Act). But lifestyle factors are only one determinant of health. Infectious disease, accidents and physical injuries, genetic make-up, diseases whose causes no one understands, and differential access to preventive and curative medicine are also important determinants. Health promotion through education about healthy behavior is a good thing, but

4. Shanto Iyengar (1989, 1991) argues, based on his public opinion research, that people's interpretations of issues with which they have little personal experience are primarily shaped by "attributions of responsibility" embedded in media framing, and that these attributions entail two dimensions of causal stories as I have theorized: "causal responsibility" and "treatment responsibility."

by itself, it will not eliminate or even significantly reduce racial and ethnic disparities without addressing the other determinants. Moreover, health promotion and prevention activities are relatively cheap; they can easily tempt state politicians to fund prevention as a symbolic gesture, without putting necessary resources into financing treatment for people who do get sick and for whom preventive screening identifies serious problems.

There is one more reason for state policy makers to avoid the lifestyle/health status framing if they want to strengthen their own political will. Bluntly, state and local governments have strong financial interests in promoting unhealthy lifestyles. Since the tobacco settlement in 1998, state governments have become heavily reliant on cigarette taxes and tobacco-settlement money to square their budgets and finance borrowing. This means they depend on their citizens' continued high rates of smoking for tax revenues, and they depend on the fiscal prosperity of the tobacco industry for their yearly lump-sum payments. With such fiscal dependence on an unhealthy lifestyle choice, states cannot afford to aggressively promote healthy lifestyles.<sup>5</sup> At the local level, school districts increasingly depend on revenues from soft drink and fast food companies to meet their budgets, especially as states curb their aid to schools (Nestle 2002; U.S. General Accounting Office 2002). Exclusive contracts with soft drink and fast food companies provide significant revenue and in-kind resources—often the only resources—for sports, computers, and extracurricular activities. While many states have tried to pass legislation limiting advertising and sale of junk food in schools, school administrators fiercely defend these revenue sources and have stymied or watered down the legislation (Winter 2001). Many health advocates have pointed out the contradictions between teaching healthy nutrition in the classroom and promoting unhealthy nutrition in the hallways and on the sports fields. But in this era of economic slump and massive state budget deficits (Ku and Nimalendran 2003), states are too weak to use financial and political instruments to promote healthy lifestyles. Thus, addressing disparities with programs to change individual lifestyle choices could easily become cynical symbolic politics, because the lifestyle-choice frame gives state

5. Some states are still aggressively fighting smoking with such measures as banning smoking in public places (New York) and antismoking ad campaigns (California). But since the tobacco settlement in 1998, states have rallied to the defense of cigarette manufacturers that lose trials and are faced with major financial penalties. Sixteen states have passed laws limiting the size of bonds tobacco companies must post when they appeal adverse decisions. Twenty-two states have passed laws that help the big companies stay afloat by squeezing low-priced cigarette makers out of the market. At best, then, states have mixed motives in their efforts to reduce smoking.

and local governments a fig leaf and permits them to deny their tacit participation in promoting unhealthy lifestyles.

Disparate access to health insurance presents a different set of problems as an issue frame. Since health insurance is how most people pay for medical care, racial disparities in access to health insurance are also an important contributing factor to disparities (Hargraves and Hadley 2003). For a long time, many researchers and advocates believed that if access to insurance were equalized, equal access to medical care would follow. Recent studies have demonstrated that racial disparities in treatment remain, even when insurance status is held constant and even in some cases when black and white patients are members of the same insurance or managed care plan (Gornick et al. 1996; Gaskin and Hoffman 2000; Schneider, Zaslavsky, and Epstein 2002). Clearly something else is at work. If the goal of equalizing access to insurance is equalizing access to medical care, we need to address care more directly.

Another reason health insurance is a politically difficult route to addressing racial disparities is that insurance inhabits the realm of economics. Insurance is a financial product, in industry jargon, and infused with all the cultural norms surrounding products that are made and distributed in markets (Stone 1993). Most economists cast medical care as a consumption good, something that people choose to buy after comparing their options, pondering their tastes, and juggling their budgets. In economic theory, disparities in distribution of consumption goods are not at all troubling, because disparities by definition reflect different consumer preferences and different values. Ability to pay is supposed to have some bearing on distribution. Thus in the American political economy that so highly prizes market distribution, it is much harder to get people morally outraged or politically exercised about disparities, even racial disparities, when the good in question is viewed as a consumption good.

Of the three types of racial and ethnic disparities in health, medical treatment disparities are most amenable to becoming a hot-button political issue. Access to medical treatment is the reason we want health insurance; no one wants or needs health insurance in itself, just to have an unreadable document in their drawer. People want health insurance because it is a ticket to medical care. And they want medical care because they believe it can make a difference in their health and can probably make more of a difference than anything else they might be able to do.

To be sure, economists have also recast medical care itself, not only health insurance, as a consumption good, with an entire public discourse about medical consumers and providers, consumer choice, competition

among sellers for patients, comparison shopping by patients among plans, and so forth. But as I will argue below, although the market frame dominates American political culture, there is still strong philosophical support for the idea that medical treatment is essential to life and well-being, rather than an optional good or marginal enhancement to lifestyle (Daniels 1985).

Finally, the concept of disparities in medical treatment is a potentially effective political framing because it consists of palpable human interaction. When people hear of disparities in medical treatment, they get images of doctors, nurses, receptionists (“Do you have health insurance?”), and billing clerks. You can hear, see, feel, and smell medical treatment. You can conjure up an image of a place and a person whose behavior and whose decisions affect you. There’s somebody there. And ultimately, any policy reform needs somebody there, somebody whose behavior and decisions policy can change. Policy needs human agency.

The notion of disparities in medical treatment accords closely with the legal concept of disparate treatment that has been so powerful in civil rights reform. In the American political landscape, it makes sense to focus on intentional human behavior. An issue frame that highlights inequalities in the way medical services are provided to minorities harnesses the power of the civil rights idea as an engine of reform in the United States. Focusing on medical care frames the disparities problem as an injustice by highlighting human relationships and the way people treat each other.

Within the realm of medical care, there are significant racial and ethnic disparities in diagnostic tests, therapies and procedures, and preventive measures (Smedley, Stith, and Nelson 2003; Geiger 2003). Plausible alternative explanations have been ruled out. Racial disparities in medical care remain even after accounting for differences in insurance, income, and education; even after accounting for clinical differences in severity of disease and complications; and even after accounting for the possibility of inappropriate overuse of some procedures by whites (Smedley, Stith, and Nelson 2003, chap. 1).

Moreover, disparities in medical care are not uniform across the fifty states. One study of ten states (Gaskin and Hoffman 2000) found significant racial and ethnic disparities in the likelihood of being hospitalized for a preventable condition, which itself is an indicator of limited access to primary care. Moreover, in this study, there were significant differences among states in their levels of disparities. Racial and ethnic disparities were greatest in large urban states with large minority populations and greater poverty (California, New York, Florida, and New Jersey) than

in rural states and states with smaller minority populations (Virginia, Missouri, South Carolina, and Pennsylvania). Perhaps the most disturbing indicator of racial disparities in treatment is the index of segregation developed by David Barton Smith (2001). According to Smith's research, despite the end of de jure racial segregation in hospitals, a large proportion of blacks insured by Medicare (a uniform federal benefit plan) receive their hospital care in facilities that are de facto segregated. States in the Midwest and Northeast that have large minority populations show greater segregation than states in the South, where federal officials once mounted a concerted legal campaign to end segregation (*ibid.*).

### **Framing a Rationale for Government Action**

The first finding of the Institute of Medicine's *Unequal Treatment* (Smedley, Stith, and Nelson 2003: 62) declares, "Racial and ethnic disparities in healthcare exist and, because they are associated with worse outcomes in many cases, are unacceptable." Political leaders, if they hope to make an issue of racial disparities in medical care, must provide a persuasive answer to the question, Why are they unacceptable? After all, we tolerate significant racial and ethnic disparities in the distribution of other valuable social resources, notably income, housing, education, and access to natural and cultural riches. We also tolerate racial and ethnic disparities in the distribution of "bads," notably imprisonment, capital punishment, and exposure to environmental toxins. These disparities are also associated with "worse outcomes" (such as standard of living and socioeconomic mobility) but that is not enough to persuade the political system that they are unacceptable. It would be hard to imagine an expert committee commissioned by Congress making an unequivocal statement that income disparities between racial groups are unacceptable. Is there then something special about health and medical care that enables the Institute of Medicine committee and others to assume that racial disparities in this realm are unacceptable? Is there a reason state policy makers should take on this issue ahead of other distributive disparities across racial and ethnic groups?

To answer these questions, we need to inquire into the broader standards of distributive justice that govern American political life, recognizing that these standards themselves are always an area of intense political dispute. There are very few social distributions in which everyone receives exactly equal portions (absolute equality). As Michael Walzer (1986) showed in *Spheres of Justice*, in every culture, people tend to believe that different

goods require different standards of distribution, depending on the meaning of the goods in the particular culture. To argue that any distributive outcome is inequitable and morally unacceptable, one has to make a convincing case that the distribution violates the standard that best applies to a particular sphere in a particular culture. In our democratic polity, for example, we believe political power ought to be distributed absolutely equally among adult citizens (excepting felons and the mentally retarded), so we use a rule of one person, one vote. We believe professional jobs and honors ought to be distributed in proportion to achievement, and so (in theory) we use a rule of merit-based allocation. Any political contest over distributive justice, therefore, involves as a first step showing which standard, among several legitimate ones, ought to apply to the resource in question.

There are at least five major standards of distributive justice that have a claim to legitimacy in American political ideology and that in practice govern some important area of our collective life. Importantly, these standards all coexist. Although the United States has a market economy, by no means do we believe everything should be distributed according to market principles. Importantly, too, our ideal of distributive justice starts from a premise that all humans are fundamentally equal in moral worth (this is the natural rights tradition in eighteenth-century philosophy that gave us our *causus belli*: “All men are created equal”). This tradition allows for deviations from a standard of absolute equality, but it requires that every distribution made according to some other standard be justified with a principled rationale (Stone 2001: 39–60). The natural rights tradition is also the basis for the principle that race, ethnicity, gender, nationality, and religion are not legitimate criteria for distribution of anything (with the possible exception of salvation in the latter case).

The principle of absolute equality comes directly out of the natural rights tradition. Absolute equality is the classic same-size slice of cake for everyone. We can see this principle in the one person, one vote rule, as well as in the apportionment of voting districts for the House of Representatives. In a sense, one might say that the guarantee of public education for every child distributes educational opportunity according to the absolute equality principle (though if one considers the amount of spending per pupil as a measure of educational value, the absolute equality principle is violated).

Despite the rhetorical commitment to equal moral worth, however, perhaps the dominant ideal of distributive justice in American political ideology is *individual merit or desert*. People should receive shares of

goods (meaning both material goods and income, as well as intangible goods such as educational opportunity and honors) in proportion to their achievements or their deservingness. Thus, for example, college and professional school admissions, as well as jobs and promotions, are theoretically based on merit. Meritocracy is the ideal (or myth, depending on your viewpoint) of distributive justice at the heart of American political development. According to the ideal, our founders came here rejecting the principle of distribution according to hereditary bloodlines and caste to establish instead a society in which individuals could rise and fall on their talents and accomplishments. According to James Morone (2003) in *Hellfire Nation*, the Puritan founders in fact made moral desert the primary criterion of distributive justice, and elite evaluations of *group moral worth*, rather than individual merit, continue to drive public policy. Nevertheless, equal moral worth combined with differential individual achievement remains the moral standard at the heart of civil rights law, and the merit standard is the strongest basis for rejecting immutable traits (race, ethnicity, gender) as determinants of a distribution.

Heredity does have a place in American principles of distributive justice. Our tax laws enable families to pass on at least some of their acquisitions and the tax code implicitly declares that hereditary descendants are legitimately entitled to benefit from such assets that they did not earn themselves. University admissions policies that give priority to children of alumni reveal a similar sense of legitimacy about hereditary distribution.

Distribution according to willingness and ability to pay is obviously the primary principle of market economies. Consumer goods, housing, and to a large extent education and medical care are distributed according to ability to pay. Without going into an extended philosophical discussion of market ideals of justice, suffice it to say that many people interpret market distribution as a variation on merit, since earnings and assets might be understood as the fruits of labor and talent.

The last major principle of distributive justice is need. Need is the principle associated with socialism (“From each according to his ability, to each according to his need”), but it is a principle with strong legitimacy in capitalist economies as well. The gamut of social assistance programs variously dubbed *safety net* or *welfare state* are premised on need as a standard of justice. All the public sector income or means-tested programs, such as food stamps, Medicaid, income assistance, and Supplemental Security Income, use need-based distribution. Importantly, although a need standard will result in an unequal distribution of goods or services—each person will ideally receive the amount he or she needs and people’s

shares will therefore differ—in many spheres of life, need, rather than absolute equality, is considered the appropriate standard of equity.

### **Rationales for a Need Standard of Justice in Medical Care**

To make racial disparities in medical care a problem of injustice, we have to argue that medical care is one of those goods that ought to be distributed purely and only according to need, and specifically medical need. Everyone who needs an appendectomy should get one and no one who does not should. In fact, I believe this is and always has been the core argument for universal access. No one is troubled by the prospect of some people getting appendectomies and others never getting one, but we are all (I trust) troubled by the prospect of someone with an inflamed appendix not being able to have surgery.

There are three major arguments why medical care ought to be distributed according to medical need. First, medical care is often said to be a right because health is a prerequisite to everything else we value in life. Many philosophers consider good health to be what John Rawls (1971) called a “primary good,” something fundamentally and universally important to human well-being and capacity (Green 1976; Daniels 1985). Just as equal starting resources are necessary for the textbook ideal of free-market competition, basic health is necessary for a fair meritocracy. Health enables people to learn, work, contribute, and achieve; people cannot earn, merit, or deserve if they cannot function in the first place. If medical care were not distributed according to medical need, all merit-based distributions would be suspect (and in fact are suspect to many of us).

Second, in our modern scientific culture, health is not understood as primarily a matter of individual choices and effort. Classically, sickness is not sin. The notion that people ought to receive medical care in accordance with their moral deservingness strikes most of us as bizarre. In fact, insurance provisions that exclude self-inflicted illnesses and injuries from coverage highlight that we believe most medical problems are not self-inflicted or somehow earned by our actions. Obviously, the lifestyle theory of disease causation that has been a prominent feature of public health since the late 1970s modifies the earlier germs-and-accidents causal story about disease and transforms at least some sickness into sin. Meanwhile, however, genetic research has significantly diminished the types of illness for which individual responsibility is a reasonable causal story.

And although smoking, poor diet, lack of exercise, and other unhealthy behaviors *are* sometimes viewed as personal irresponsibility, policy proposals based on this idea usually call for charging irresponsible people higher prices for medical insurance or care, but rarely (if ever) for withholding medical care from them if they are sick enough to need it.

The third reason to distribute medical care according to medical need is that medicine is a science. We understand science to be a realm of expertise and objectivity, right and wrong answers, and remedies that can be proven effective or not. This means that a standard of need can be arbitrated clearly and fairly. What care people receive can and should be determined by experts. To be sure, medicine is as much art as science, and there are many clinical situations for which science has no clear-cut answers and even large, randomized controlled trials fail to answer clinical questions definitively. But modern notions of outcome measurement and evidence-based medicine are predicated on the assumption that clinical medicine can and should be practiced as a science. The kinds of diagnostic and treatment disparities that *Unequal Treatment* identifies and that most people find so troubling are ones in which racial and ethnic minorities receive care that does not meet a scientific consensus on standards of quality. Although medicine is still full of internal disputes about the best treatments for a given problem, our cultural concept of illness and medical care holds strongly to medical expertise as the appropriate determinant of who should get what care.

### **Advantages of Framing the Medical Disparities Issue as a Deviation from the Need Standard**

This way of framing the disparities problem has some significant advantages. First, it accords with the dominant cultural paradigm of medicine as a scientific field and draws on the considerable cultural capital embedded in science. This enables policy makers to use the authority of science and the aura of apolitical objectivity that medicine still enjoys, despite numerous highly political controversies such as stem cell research or the safety of anti-inflammatory drugs. This is a lesson we can draw from the history of Social Security Disability Insurance. In passing the original legislation for federal assistance to the permanently and totally disabled, legislators were able to overcome fears of malingering, cheating, corruption, and excess utilization by framing disability as a medical construct and assigning disability determination to physicians (Stone 1984). Responses to

*Unequal Treatment* suggest that indeed, medical science may play a similar role in the politics of disparities. According to Risa Lavizzo-Mourey, a member of the study committee and now president of the Robert Wood Johnson Foundation, the report was “incredibly powerful because it put in one place, with the power of the IOM behind it, data that were compelling to people who had not been previously compelled to believe that this was an important issue” (IOM 2003).<sup>6</sup> Race, needless to say, is an extremely contentious and fractious issue in American politics. If some small part of the issue can be hived off and made amenable to more reasoned, less emotive deliberation, so much the better.

Second, framing the racial disparities issue as a problem of deviation from need-based distribution accords with the common, nearly universal value on good health. This framing enables policy makers to draw on the strong popular consensus around the desirability of good health and good medical care.<sup>7</sup> It also undercuts one of the main excuses for tolerating or ignoring racial disparities, the argument that racial and ethnic minorities have cultural preferences for foregoing some kinds of tests or treatments and therefore choose not to utilize them.<sup>8</sup>

Third, this framing could potentially defuse some of the explosive energy that attaches to racial politics. Remedial policies to address racial disparities in other areas—notably school desegregation and affirmative action in higher education and employment—have invariably stimulated bitter and divisive backlash. National attention to racial and ethnic disparities has already provoked a backlash against the very suggestion of racial and ethnic bias in health care (Satel 2002; Satel and Klick 2005; Epstein 2005). Wrapping the racial disparities issue in the larger rubric of deviations from medical need may help avoid some of the backlash that has

6. Risa Lavizzo-Mourey was a member of the IOM committee that produced the report. The Robert Wood Johnson Foundation is one of the largest health care foundations in the United States. The quotation is from a statement made at the Institute of Medicine meeting, “Unequal Treatment One Year Later,” March 19, 2003, in Washington, DC. The Web broadcast of the statement was available on March 19, 2003, at [www.kaisernetwork.org/healthcast/iom/19March2003](http://www.kaisernetwork.org/healthcast/iom/19March2003).

7. I say “nearly universal” mindful that parts of the disability rights movement challenge the widely held value. As part of its effort to overcome society’s stigmatization of disability, the movement seeks to elevate disability to a desirable state. Much of the disability rights literature objects to language and descriptions that cast disability as an undesirable state, and some is devoted to showing that disability is an experience and a culture to be prized. Thus, even one of the culture’s (and my own) most basic premises about medical care is subject to political challenge.

8. Research that offers this explanation for racial and ethnic disparities is reviewed (not terribly critically) in Smedley, Stith, and Nelson 2003: 136–138.

followed other remedial racial policies. By focusing on deviations from a standard of medical need, policy makers would have warrant to address other factors that contribute to racial and ethnic disparities in addition to stereotypes, bias, and prejudice, particularly income and insurance. Most analysts believe that low income exacerbates and contributes indirectly to racial disparities and that to correct racial disparities, we must also address medical disparities that are generated by income disparities. For example, as economist Tom Rice (2003) and many others have shown, because racial and ethnic minorities are disproportionately low-income, cost-sharing requirements disproportionately hinder their ability to obtain care. Any level of patient co-payment presents a higher burden to a person with a lower income. In addition, blacks, Hispanics, and certain other ethnic groups have higher rates of certain diseases and therefore greater needs for medical services. Higher need for care multiplies the impact of cost sharing. As Rice (2003: 452) says, “Simply put, cost-sharing results in *de facto* discrimination.” Cost sharing is only one of many policies and administrative regulations that contribute to racial disparities in medical care through a differential effect on low-income groups. I use it only to illustrate the larger point: Framing medical disparities as a deviation from the medical-need standard enables policy makers to address some of the underlying causes and contributory factors that are not specifically racial but that contribute to racial and ethnic disparities.

A fourth advantage of framing the issue this way is that it allows policy makers to avoid treating medical care as an ordinary consumption good. This is an important advantage, because as we have seen, in American political philosophy, ordinary consumption goods fall under a market standard of justice, which means people should get only what they are able and willing to pay for. In the market sphere, disparities of access are morally permissible, all the more so if they attach to disparities of income or ability to pay. When medical care is viewed as a consumption good, economists typically divide it into two categories—essential goods and luxury goods. Care in the essential category—emergency, life saving, ability saving, or prevention of terrible disease and disability—is treated as falling under a need standard and therefore ought to be made available to everyone. Care in the luxury category—the more elective, health- and function-improving kind—is treated as a matter of personal preference, something for which individuals have to take responsibility in their own budgeting. Considering all (or almost all) medical care as an essential good, properly distributed according to medical need, recognizes that

most medical care affects people's ability to achieve and therefore to merit or deserve. Medical care is opportunity-creating and so it fits with the principle of equal opportunity.

Finally, framing the racial disparities issue as deviation from a medical-need standard allows us to treat medical disparities as error rather than discrimination, prejudice, or bias.<sup>9</sup> (This is a disadvantage, too, which I'll discuss below, but here let me state the case for why it is an advantage.) All the evidence in the medical disparities literature points to a significant component of personal prejudice, stereotyping, and biased decision making on the part of some providers (Smedley, Stith, and Nelson 2003: 162–174; Schulman et al. 1999; van Ryn and Burke 2000). But in the context of American racial politics, prejudice is a fighting word, a loaded accusation. Many people would sooner hear that they made mistakes, even grave mistakes, than that they were prejudiced. And most supervisors would sooner have to correct an employee's grave mistakes than have a conversation about racial prejudice, much less discipline someone for it. Framing racial bias as a medical mistake is a way to meet it face to face by slipping in the side door.

### **Disadvantages of Framing the Racial Disparities Issue as a Deviation from Need Standard**

This framing of the racial disparities issue is not without its problems. Perhaps the most important critique is that it diminishes and even hides the evil of racial oppression by lumping racial disparities together with all other deviations from the medical need standard. It offers no reason why racial disparities are morally worse than any other disparities. Racial and ethnic disparities in medical care replicate the legal oppression of blacks and other minorities in earlier times and perpetuate their second-class citizenship. Arguably racial disparities are worse than income or geographic disparities because race was the fault line of our most undemocratic moment. Arguably it was a long moment, and arguably, too, the moment is not over (Klinkner and Smith 1999; Massey and Denton 1993; Bowser 2001). Historical subjugation of blacks and other ethnic minorities undoubtedly contributes to their relative concentration at the bottom of the income distribution and in poor residential areas. Still, by focusing

9. I take this idea from Sidney Watson (2001: 203), who argues that "differences based on race and ethnicity rather than medical need are medical mistakes."

on deviations from the medical need standard, regardless of whether those deviations are partly attributable to racial discrimination, income inequality, or geographic residence, the medical need framing cuts to the core of a complex web of causation to address the outcome that matters.

A second concern is that by not casting the racial and ethnic disparities as a scientific mistake rather than as a civil rights issue, this framing loses the potential power of civil rights claims in American politics. Yet given the contemporary backlash against racial justice and especially against race-conscious remedies, a soft-pedaling race may be strategically valuable. And race does not disappear in this framing. To define racial and ethnic disparities as deviations from a medical-need standard is to merge the race consciousness of the civil rights perspective with the science consciousness of the medical perspective. This framing thus activates both trajectories that have historically made racial disparities a public issue in the United States—the grassroots, activist route and the professional, scientific route (Gamble and Stone, this issue).

A third critique is that this framing neglects, and perhaps downplays, the role of personal prejudice, bias, stereotyping, and discrimination. There is no question that medical encounters sometimes entail such prejudice and discrimination<sup>10</sup> or that such attitudes and behavior have to be addressed if racial disparities are to diminish. But as noted earlier, sneaking up on prejudice by charitably interpreting it as medical error may be easier and more effective than confronting it as abhorrent, immoral, and stigmatized behavior.

### **Causal Theories and State Leverage Points**

As I read the scientific and popular literature on racial and ethnic disparities in medical care, there are two major kinds of causal story: the simple story of personal discrimination and the complex story of structural, legal, regulatory, and contextual determining factors. The Institute of Medicine report, *Unequal Treatment*, makes abundantly clear that both kinds of causes are operative.

In the discrimination story, disparities are caused by providers' behavior. Their diagnostic and treatment decisions are influenced by bias, prejudice, and stereotyping. Some physicians, for example, assume that black patients are less intelligent, less likely to comply with treatment regimens,

10. See generally Smedley, Stith, and Nelson 2003, esp. chap. 3; Schulman et al. 1999; and van Ryn and Burke 2000.

and more likely to be substance abusers (Schulman et al. 1999; van Ryn and Burke 2000). Stereotyping may be done out of ignorance, or it may be done semideliberately as a mental shortcut, a process now sometimes called “statistical discrimination” or “heuristics” (Schauer 2003). A considerable literature, including *Unequal Treatment*, describes plausible scenarios in which physicians, operating under conditions of high uncertainty and time pressure, unconsciously use stereotypes as mental shortcuts for rational decision making. In this framing, race- or ethnicity-based decision making may be the result of clinicians’ reliance on heuristics or rules of thumb, rather than bias or personal animus (Smedley, Stith, and Nelson 2003: 160–179).<sup>11</sup> Although the discrimination story has many variations with more or less intentional, deliberate, or conscious behavior on the part of health care providers, what they all share is an identifiable “perp”—someone who intentionally or unintentionally treats racial and ethnic minorities worse than whites. With enough investigation (so the premise of this story), we can identify the perps and catch them in the act.

The other story I will call the complex story for lack of a better term (although Kitchen Sink might do just as well). It includes many variations: the patterned effects of income disparities that work themselves out as racial disparities; institutional rules that are race neutral on their face but have disparate impact on minorities; and historic patterns of unequal treatment, residential segregation, and educational denial whose aftereffects add up to medical disadvantage. Although these stories are even more varied than the discrimination stories, I lump them together because they share an important political feature: they lack an identifiable perp. If there is human agency in these stories, it is more deeply hidden. Nevertheless these stories do create identifiable victims of injustice, and in that they offer potential impetus for grassroots mobilization.

If state policy makers want to address racial disparities in medical care, they have to milk these causal stories to see where and how they coincide with the political authority and organizational capacity of state governments. No matter how earnest their intent, state policy makers can only do what they have the power to do. Here I will suggest the most potent state leverage point for each causal story.

Discrimination is a matter of individual decision making by health personnel. Obviously, state attorneys general, civil rights offices, and anti-

11. This section of *Unequal Treatment* is based on the work of one of the IOM panel members, M. Gregg Bloche. See Bloche 2001, esp. pp. 103–106, and Bloche 2005, esp. pp. S56–S58.

discrimination commissions have the authority to pursue discrimination as civil rights violations. However, civil rights litigation is adversarial, narrowly targeted, and unlikely to reach any but the most egregious cases of intentional discrimination, and then only after the fact. States might be better advised to use their power over medical education and professional discipline, which is limited but holds some possibility of getting at the root sources of discrimination by health professionals. Medical and nursing schools and allied professional programs largely answer to national curricula and accrediting associations, but states at least have some power to influence the content of curricula through their power to set the requirements for licensure. States have authority to examine, license, monitor, and discipline health personnel. In practice, states delegate that authority to professional boards, but state legislatures empower these boards and set parameters on professional licensing through state practice acts. Conceivably, the responsible state legislative committees could work with state licensure boards to develop broad standards of medical education about race and ethnicity to be included on licensure exams.

What sort of reforms to medical education might states pursue? Already, there is a minor industry dedicated to inculcating cultural competence in health care personnel and institutions. (In fact, several states have considered bills to require some form of cultural competence training for health professionals as a means of addressing the disparities issue; Ladenheim and Groman, this issue). *Cultural competence* is a loose phrase that means, roughly, awareness of and sensitivity to cultural beliefs, attitudes, and practices concerning health and illness. Cultural awareness might help clinical decision makers understand patients who are of a different race or ethnicity than themselves, but it is hard to see how clinicians might incorporate this knowledge in their diagnostic and therapeutic decision making. Indeed, the concrete policy recommendations that emerge from the cultural competence literature rarely address clinical decision making. Most often, they center on providing foreign language and American Sign Language interpreter services and recruiting more health personnel from minority communities on the assumption that people of like backgrounds can communicate better (Brach and Fraser 2000; Betancourt, Green, and Carillo 2002).

Framing disparities as deviation from a scientific standard of quality care suggests a different tack to reforming medical education to address racial and ethnic disparities. Medical education might take an evidence-based approach to teaching about race. In this approach, students would learn how to evaluate race as they would any other factor in a patient's

history—by supplementing hunches, best guesses, and intuitions with observations and assessments of actual symptoms and behavior. Race or ethnicity could be presented as one more red herring in diagnostic and therapeutic decision making. Just as students are taught to be alert for other kinds of misleading clues, they could be taught how race and ethnicity can function as red herrings to distort clinical judgment. Clinicians would use their knowledge of cultural beliefs and practices to guide their history taking, help them present diagnostic information and therapeutic recommendations to patients, and where relevant, to frame their own course of action in the context of the patient's family and community-support network. This kind of evidence-based approach might be more effective at reducing stereotyping and prejudice than softer, cultural-competence approaches that teach students to appreciate alternative value systems and cultural practices, but do not directly enhance doctors' scientific decision-making skills. Moreover, teaching clinicians how to use information about race and ethnicity in scientifically valid ways should improve care for all minority patients, no matter what their income or insurance status.

Turning now to complex causal stories, states can use their power over public health information to reveal patterns of disadvantage, injustice, or victimization to publicize the problem of racial disparities and to build political support for redress. By collecting and reporting data on racial disparities, public health agencies can bring the problem into the sunshine (Marshall et al. 2000). State data collection on black and minority health has been encouraged and somewhat standardized by the federal Office of Minority Health, and most states already do such reporting (Trivedi et al. 2003). However, current state reporting largely uses measures of health status and measures of access. These measures describe population groups who probably need better health care, but they do not pinpoint exactly where in the health system change needs to happen. Using the frame of deviation from a medical-need standard, state reporting would focus on well-defined clinical indicators (such as recommended vaccinations for infants and children, protocols for managing diabetes and high blood pressure, or recommended diagnostic work-ups for chest pain) and seek to identify racial and ethnic disparities in adherence to these standards.

Financing is a major factor in the complex causal story, and financing (or lack of it) is thought to play a big role in generating racial and ethnic disparities. If states are to address disparities with an honest acknowledgment of their agency in contributing to the problem, they have to consider those aspects of health care financing in which they have a great deal

of choice. The two obvious ones are Medicaid and the State Children's Health Insurance Programs. They are joint federal-state programs. The federal government sets some parameters on state programs (and foots a good portion of the bill), but states have wide latitude to establish eligibility criteria, benefit packages, and provider reimbursement rates.

Each of these choices has strong effects on the likelihood that minorities will receive equal treatment with whites. States can choose to make *eligibility* more or less restrictive and thus to insure more or fewer people. Since Medicaid is means-tested and minorities are disproportionately low income, stringent eligibility criteria affect minorities more heavily. In setting the design of *benefit packages*, states implicitly determine whether people insured by Medicaid will have access to the same tests and treatments as people insured by other plans. Again, since minorities are disproportionately insured by Medicaid, disparities in the benefit package translate into some racial disparities in medical treatment. In setting *provider reimbursement rates*, states determine whether physicians, physical therapists, hospitals, home health agencies, and nursing homes will be paid as much for treating Medicaid patients as they receive for treating patients insured by other plans. Lower rates—and Medicaid rates are notoriously low—discourage providers from accepting and treating Medicaid patients. Minorities, because they are disproportionately insured by Medicaid, will have access to a far narrower range of providers. They may be excluded altogether from providers who are especially well-trained, experienced, or have highly specialized and unique skills. Moreover, Medicaid patients famously have difficulty finding obstetricians and other specialists willing to treat them.

State policies on other aspects of financing health care are important as well. When states cut back funding and eligibility for Medicaid, leaving more people uninsured, or when they fail to address the problem of uninsured, those decisions affect the quality of care hospitals can provide to all patients. They also affect whether hospitals will survive or whether they will fold or abandon low-income communities. Hospitals with high shares of Medicaid or uninsured patients tend to be ones that serve communities with disproportionately high minority populations. Just as cost-sharing requirements in personal health insurance affect minorities disproportionately, so stringency in state reimbursement to providers affects providers in minority communities disproportionately.

State policy makers (at least those who pay attention to health policy) know all these things about financing. But framing the disparities issue in terms of deviation from a medical-need standard, as opposed to a budget

issue, may help generate political support to overcome the mentality of fiscal crisis and restraint.

### **Concluding Thoughts**

When all is said and done, the most clever, sophisticated, strategic issue framing comes to nothing if there is no political will to solve the problem. Do states have the political will to address the racial disparities issue? To frame the issue of racial disparities in a way that states *can* or might be able to do something about it is to identify those choices already made by state actors that contribute to the problem. In a sense, states have to be willing to look their own policies in the eye and say, "Mea culpa." States made the Medicaid rules, for example. Do they want to raise taxes to generate more revenues to be able to increase provider reimbursements? Do they want to increase the number of citizens covered or the richness of the benefit package, either of which requires more state funding? Do they have the political clout to fund new initiatives to insure the uninsured at a time when states are struggling to keep their budgets somewhere near the black line? The point of this framing exercise is precisely to strengthen political will and political clout.

If eliminating racial and ethnic disparities in medical treatment means distributing all care according to medical need, health professionals also have to look themselves in the mirror and own up to subtle forms of discrimination where they exist. States can foster this kind of professional renewal in two ways. They can prod schools and licensure boards to educate providers about scientifically valid uses of race and ethnicity as clinical information. States can make it easier for professionals to distribute their services according to need by ensuring that providers get paid the same amount for the same treatment, regardless of the identity of the patient. Ultimately, state actors have to believe and be willing to proselytize that medical disparities are wrong and that a state's government and citizenry are morally obliged to correct them, even at greater cost to themselves.

Admittedly, this framing of medical disparities as a distributive justice issue creates some uncomfortable trouble for state policy makers, because if deviation from medical need is wrong, then any kind of deviation from it is morally unacceptable, whether based on racial, income, geographic (rural versus urban), or jurisdictional (Mississippi citizens versus Massachusetts citizens) groupings. If medical care should be distributed strictly according to medical need, then state policy makers have to face up to this

question: Why are disparities across states morally permissible? Surely medical need has little to do with which state a person happens to inhabit, so why should state residence determine a person's access to medical care or a person's health outcomes? Why are disparities across rural and urban areas within a state acceptable? Why are disparities across neighborhoods within a metropolitan area acceptable?

The medical-need standard for judging disparities calls into question the decentralization of authority over public health that is a cornerstone of American health policy. Just as courts reformed malpractice law thirty-five years ago to recognize that professional standards of care are national and do not vary from state to state (*Canterbury v. Spence*, 464 F.2d 772), perhaps it is time to bring this concept of national clinical standards to bear in medical education and delivery of care. National clinical standards could be a powerful tool for diminishing racial and ethnic disparities.

Ultimately, radical as this framing is, it has the advantage of showing state policy makers that the disparities problem transcends their jurisdictions and requires solutions that transcend their fiscal and political capacities. This framing gives states a common interest in collaborating and even pressing for tougher federal policies and better federal financing to help them address the disparities issue. To be sure, federalism is not "the answer." Neither the national enforcement of civil rights law in the 1960s and 1970s nor the national insurance pool of Medicare succeeded in eliminating differential treatment according to race—but federal law enforcement and federal money surely help.

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