

U.S. Policy on Health Inequities: The Interplay of Politics and Research

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Abstract What is the relationship between scientific research and government action in addressing health inequalities in the United States? What factors increase the impact of scientific research on public policy? To answer these questions, we focus on racial and ethnic disparities in health status and health care in the United States. We first review the history of the disparities issue to elucidate how the continual and persistent interplay between political action and scientific research drives government policy. We then analyze two recent government-sponsored reports about racial and ethnic disparities to understand the strategic consequences of issue framing. We draw lessons about how disparities research can have a greater impact on public policy.

W. E. B. DuBois, a towering figure of twentieth-century social and political thought, asserted in his 1903 classic, *The Souls of Black Folks*, “The problem of the Twentieth Century is the problem of the color line—the relationship of the darker to the lighter races of men” (DuBois 1903: 13). Three years later, in *The Health and Physique of the Negro American*, DuBois (1906) and his colleagues documented racial inequalities in health. Yet despite a century of activism and research on the problem, inequalities persist.

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With the recent resurgence of interest in health inequality among researchers in the United States and other countries, one pressing question is how scientific research can best contribute to reducing health disparities. This article grew out of an international conference on the relationship between scientific research and government action in addressing health inequalities.¹ The conference included participants from six countries who were asked to consider three questions: First, what is or are the major axis/axes of inequality in the distribution of health and health care in each country? Second, what can researchers do to package and disseminate their research so that it is more likely to be translated into action? And third, what structural modifications to government receptor agencies might maximize the likelihood of research uptake by government? The conference participants were asked to select a research report that had had or was likely to have a major impact on policy and to reflect on the characteristics of the report that contributed to its effectiveness.

As participants representing the United States, we chose to focus on racial and ethnic disparities in health. Race and ethnicity are not the only dimensions of health inequality, and indeed, *Healthy People 2010*, the decennial goal-setting document of the U.S. Department of Health and Human Services, calls for the elimination of all health disparities including differences that occur by race or ethnicity, gender, education or income, disability, geographic location, or sexual orientation (U.S. Department of Health and Human Services 1998). We chose our focus on race and ethnicity for historical, political, and philosophical reasons. Because of the U.S. history of slavery and subsequent de jure and de facto racial segregation and discrimination, race has long been a strong determinant of access to care and health status. Therefore, racial and ethnic disparities as a political and research issue in the United States have a long history. For over one hundred years, minority communities have responded to their poor health status and limited access to health care with research and activism. Racial and ethnic disparities in access to medical care and in those aspects of health that are amenable to human intervention violate the American concept of justice. Finally, racial and ethnic diversity in the United States is growing and issues of race and ethnicity are not going away. With this demographic change, racial and ethnic disparities in health take on a new urgency.

1. Sponsored by AcademyHealth, the Rockefeller Foundation, and the Nuffield Trust, the conference included participants from Great Britain, Netherlands, South Africa, Chile, China, and the United States.

In thinking about the role of research in U.S. policy making, we realized that the conference framework assumed a certain model of the relationship between research and policy change: a research community discovers and documents health inequities and packages and disseminates its findings, and then the research is either successfully taken up by government or not. We question such a model on both theoretical and historical grounds, because it neglects the role of political action as a catalyst for both research and policy.

Theoretically, thirty years of scholarship on agenda setting and issue framing have shown that social problems do not become policy issues just because they exist as problems or even because careful scientific research has documented that they *are* problems (Elder and Cobb 1983; Gusfield 1981; Kingdon 1999; Gamson 1992; Benford and Snow 2000). Problems such as health disparities must be converted into political issues by leaders (grassroots, community, political, religious, and intellectual). Then they must be defined in a way that government can do something about them with the kinds of tools it has at hand (legislation, regulation, taxation, financing, and public education). Only then does a problem begin to make its way through the political process as something to which government develops a specific policy response. Thus, to be effective, research must not only reveal problems but also frame them in a way that they are perceived as bad situations and moral wrongs that government can and should fix.

Historically, major changes in the access of minority Americans to health care came as a result of political action. Most notably, desegregation of medical institutions (though still not fully accomplished) came about as part of the broader civil rights movement (Smith 2001). But as we will show, in the case of racial disparities in the United States, the mainspring of policy change has always been political action. Some of that activism generated scientific research and government reports. We will show that policy progress on racial disparities in the United States grew from the interplay of scientific research and political activism.

In this article, we first review very briefly the nature of racial and ethnic disparities in health. Second, we present a chronological history of the disparities issue to demonstrate how the continual and persistent interplay between political action and scientific research drives government policy. Third, we compare two recent government-sponsored reports on health disparities: *The Health Care Challenge: Acknowledging Disparity, Confronting Discrimination and Ensuring Equality*, produced by the U.S. Commission on Civil Rights in 1999, and *Unequal Treatment: Confront-*

ing *Racial and Ethnic Disparities in Health Care* (Smedley, Stith, and Nelson 2003), issued by the Institute of Medicine (IOM) in 2002. We chose these two reports because they frame the issue of racial disparities very differently and represent the politics-research dichotomy that we wished to explore. The U.S. Commission on Civil Rights report framed racial inequalities in health primarily as a problem of political action and law enforcement; the Institute of Medicine report framed them primarily as a problem of understanding the causes of disparities through scientific research. We compare the strategic advantages and disadvantages of each framing for mobilizing government action. Last, we draw lessons from our analysis about how disparities research can have a greater impact on public policy. We emphasize that research must go beyond documenting inequalities to developing the political will to redress them.

The Nature of Racial and Ethnic Disparities

First, a word about our terminology. Disparity is a *descriptive* term that refers to differences between population groups in health status or access to medical care. It carries no moral loading and no connotation of right or wrong. Inequity is a *normative* term. Inherent in its meaning is a critique of differences as unfair, unjust, or morally wrong.² Three leading U.S. health researchers have defined equity as “an ethical value that may be operationally defined as striving to reduce systematic disparities in health between more and less advantaged social groups within and between countries” (Braveman, Starfield, and Geiger 2001: 679; see also Braveman and Gruskin 2003). Elsewhere in this issue, Deborah Stone attempts to combine descriptive and normative concepts by defining health disparities as deviations from a clinical standard of need.

The choice of terms is a matter of political strategy as well as meaning. Some researchers feel that as scientists, they should not use terms with moral connotations to describe empirical phenomena. Some advocates feel that as political activists, they should not strip their language of its moral and political impact. Other advocates believe that using a term that is neutral and less politically charged is tactically preferable. Although we believe that the term *inequities* is the most appropriate, we will use the term *disparities* because that is the word that has been most widely incorporated into the American policy and research lexicon.

2. See Stone 2001, chapter 2, “Equity,” for an extended analysis of the meanings of equity in political contests and policy making.

Although *disparities* is now a buzzword in U.S. health care research and policy and a keyword in medical indexing, there is no agreed upon definition of the term *health disparities*. One recent article identified eleven different definitions of health disparities and noted that each definition carries with it implications for research, policy, and monitoring (Carter-Pokras and Baquet 2002). Thus, for example, the National Institutes of Health (in *ibid.*: 430) defines health disparities as “differences in the incidence, prevalence, mortality, and burden of diseases and other adverse health conditions that exist among specific population groups in the United States.” The Institute of Medicine (whose report we will analyze in depth) defines disparities as “racial or ethnic differences in the quality of healthcare that are not due to access-related factors or clinical needs, preferences, or appropriateness of intervention” (Smedley, Stith, and Nelson 2003: 3–4). The Health Resources and Services Administration, the principal primary-health-care service agency of the federal government, defines disparity as “a population-specific difference in the presence of disease, health outcomes, or access to care” (Carter-Pokras and Baquet 2002: 430).

Research and policy reports generally note three types of racial and ethnic health disparities: disparities in health status, access to care, and quality of care. The following statistics from *Healthy People 2010* (U.S. Department of Health and Human Services 1998) provide a snapshot of the disparities in health status. The infant mortality rate among African Americans is more than double that of whites. That of American Indians and Alaska Natives is almost double. Heart disease death rates are more than 40 percent higher for African Americans than for whites. The death rate for all cancers is 30 percent higher for African Americans than for whites; for prostate cancer, it is more than double that for whites. The death rate from HIV/AIDS for African Americans is more than seven times that for whites; the rate of homicide is six times that for whites. Hispanics living in the United States are almost twice as likely to die from diabetes as are non-Hispanic whites and have higher rates of high blood pressure and obesity. American Indians and Alaska Natives also have disproportionately high death rates from unintentional injuries and suicide. Women of Vietnamese origin suffer from cervical cancer at nearly five times the rate for white women. New cases of hepatitis and tuberculosis also are higher in Asians and Pacific Islanders living in the United States than in whites.

African Americans and Hispanics generally have less access to medical care than whites. First, they are much less likely than whites to have

health insurance. African Americans are almost twice as likely as non-Hispanic whites to be uninsured (22.8 percent compared to 12.7 percent for whites); Hispanics are almost three times as likely to be uninsured (35 percent compared to 12.7 percent for whites) (Smedley, Stith, and Nelson 2003: 83–87). Second, minorities are less likely than whites to have access to regular primary care and chronic care. African American children use emergency rooms as their primary source of care at twice the frequency of white children. African American and Hispanic adolescents and adults are less likely than whites to have had any physician contact during a year, even controlling for income and health status. Elderly African American hospital patients are more likely to be discharged to home than to a nursing home, and even when they are discharged to nursing homes, they encounter longer discharge delays than white patients, even after accounting for clinical and demographic characteristics.³

With respect to quality of care relative to whites, African Americans, and in some cases Hispanics, are less likely to receive appropriate cardiac procedures, less likely to receive hemodialysis and kidney transplantation, and less likely to receive state-of-the-art HIV/AIDS care and early-stage lung cancer care, even when variations such as insurance status, income, age, disease severity, and coexisting conditions are taken into account. Similarly, they are less likely to receive appropriate preventive services, such as breast and cervical cancer screening and immunizations. Even when African American women receive prenatal care, they are less likely than whites to receive amniocentesis, ultrasound, and counseling about tobacco and alcohol use.⁴ One recent study found that for the most part, black and white Medicare beneficiaries receive their primary care from different physicians. Not only is care largely segregated by race, but physicians who treat black patients are less likely to be board certified than those who treat white patients and are more likely to report that they face difficulties obtaining high-quality subspecialty referrals, diagnostic imaging, and nonemergency hospital admission for their patients (Bach et al. 2004).

3. For a comprehensive review of literature on disparities in access to medical care, see Mayberry, Mili, and Ofili 2000.

4. For a comprehensive review of literature on disparities in quality of care, see Smedley, Stith, and Nelson 2003: 48–74, and Geiger 2003.

Disparities, Research, and Action: The Historical Context

For much of the twentieth century the color line in medicine was so rigidly drawn that hospitals and medical institutions could, and routinely did, exclude African Americans. The racially exclusionary practices of hospitals often had tragic consequences, as the November 1931 death of Juliette Derricotte, Dean of Women at Fisk University, vividly demonstrates (*Crisis* 1932; Lerner 1972: 384–396). It also illuminates the limits of individual actions in the context of institutional restrictions. Miss Derricotte died after she was refused hospital care following an automobile accident in Dalton, Georgia. According to witnesses, she received medical treatment from a white physician at the scene and later at his office. According to witnesses, the physician provided good and compassionate care, but because of racial discrimination he could not admit her to the local hospital. Consequently she was moved to the private home of a black woman who had no medical or nursing training. Apparently the residence, which witnesses described as filthy, was where black patients received medical care in the town. Derricotte remained at the private home for several hours and died after she was transferred fifty miles to the black ward of a Chattanooga hospital. The National Association for the Advancement of Colored People (NAACP) publicized the death in black and white newspapers nationwide. By putting a human face on hospital discrimination, the civil rights organization hoped to galvanize support for efforts to desegregate hospitals. African Americans believed that their exclusion from hospitals as patients and health professionals played a major role in their poor health status.

Historically, progress in addressing racial disparities has resulted from the interplay of research and political action. Indeed minority community leaders sometimes deliberately transformed their knowledge about disparities and injustices into scientific research projects to gain recognition for their political claims. As the work of W. E. B. DuBois demonstrates, research became a form of protest, as well as a resource for future protest and political action.

In 1906 DuBois, a sociologist and civil rights activist, published the monograph, *The Health and Physique of the Negro American* (DuBois 1906), one of a series of research studies published under the auspices of Atlanta University, a historically black institution. DuBois used data such as census reports, vital statistics, and insurance company records to document the poor health status of African Americans in comparison to

white Americans. DuBois contended that these disparities stemmed from social conditions and not from inherent racial traits. "With improved sanitary conditions, improved education, and better economic opportunities," he declared, "the mortality of the race may and probably will steadily decrease until it becomes normal" (ibid.: 73). One of the major objectives of *The Health and Physique of the Negro American* was to refute the theories of Frederick L. Hoffman, a statistician at Prudential Life Insurance. In his influential 1896 treatise *Race Traits and Tendencies of the American Negro*, Hoffman attributed the poor health status of African Americans to inherent susceptibility and racial inferiority.

The Health and Physique of the Negro American served as the basis for the Eleventh Conference for the Study of Negro Problems. On May 29, 1906, scholars, health professionals, and activists gathered at Atlanta University to review DuBois' findings. At the end of the meeting they adopted several resolutions. They called for the formation of local health leagues to provide information about preventive medicine and urged existing health organizations to institute programs to address the health care needs of African Americans. The latter recommendation might have been developed to remind white Americans that germs have no color line and that self-interest mandated that they not neglect black health needs. Conference attendees also reaffirmed DuBois' stance about the importance of social factors in determining health. They passed a resolution stating that they "did not find any adequate scientific warrant for the assumption that the Negro race is inferior to other races in physical build or vitality. The present differences in mortality seem to be sufficiently explained by conditions of life" (DuBois 1906: 110). In their final resolution they emphasized the connection between research and social reform. It stated, "The Conference above all reiterates its well known attitude toward . . . social problems: the way to make conditions better is to study the conditions" (ibid.).

The African American community also attempted to address health inequities by creating its own institutions such as hospitals, medical schools, and professional societies.⁵ They also initiated self-help activities such as the National Negro Health Movement. The origins of the movement can be traced to 1915 when the Virginia affiliate of the National Negro Business League established a health week to call attention to the high morbidity and mortality rates of black Virginians and to develop programs to attack them. The league had become interested in health

5. For an extended discussion of this issue, see Gamble 1995.

issues because its members believed that the poor health status of African Americans was a “source of economic loss to the race and a hazard to the general welfare of the state” (Moton n.d.). The goal of the health week was to teach African Americans about the principles of public health and hygiene to help them become stronger and more effective citizens. Its activities included lectures in churches and schools and the formation of brigades to clean neighborhoods.

The activities in Virginia attracted the attention of Booker T. Washington, one of the most prominent black leaders of the late nineteenth and early twentieth centuries. In 1915, Washington, the principal of Tuskegee Institute and president of the National Negro Business League, moved the program to Tuskegee to give it a national focus. Washington (n.d., quoted in Smith, 1995: 38) saw the effort as critical for the advancement of African Americans because “without health . . . it will be impossible for us to have permanent success in business, in property getting, [and] in acquiring education. . . . Without health and long life all else fails.” In 1923 an official of the National Urban League, an organization that promotes economic opportunity and social welfare for African Americans, stated, “the Negro’s struggle for health might be considered an effort of the race to survive” (Jones 1923: 72).

Black Americans readily embraced health week. Between 1915 and 1930, African Americans in thirty-two states participated in health week activities. In 1935, 2,200 communities from across the nation sent in reports of their health week activities. In memory of Booker T. Washington, who died shortly after the initiation of the national program, National Negro Health Week was held during the first week of April—his birthday week. Although many health care efforts were concentrated in this week, the organizers of National Negro Health Week saw beyond this annual event and worked to establish the improvement of black health as an ongoing effort. They successfully worked to bring the problem of black health to the attention of the federal government and organizations such as the American Social Hygiene Association, the American Red Cross, and the Rockefeller Foundation. According to historian Susan L. Smith (1995: 34), “Black health activists turned National Negro Health Week into a vehicle for social welfare organizing and political activity in a period when the vast majority of African Americans were without formal political and economic power.”

In 1930 the United States Public Health Service (USPHS) assumed operation of National Negro Health Week and it subsequently became a year-round activity. The Tuskegee organizers welcomed this shift because

they saw it as a step toward placing black health care on the nation's public health agenda.⁶ Two years later, the USPHS established the Office of Negro Health Work under the direction of Dr. Roscoe G. Brown, a black dentist. The creation of this office represented the first time since the end of the Civil War that black health care issues were institutionalized within a federal bureaucracy.⁷ The office served as the center of the federal government's black health efforts. Its activities included coordinating health week, developing educational materials, and publishing *National Negro Health News*, a quarterly journal on black health issues.

The Office of Negro Health Work operated until 1950. Its demise reflected major changes in American race relations—the rise of integrationism as a strategy for black advancement and with it, the rejection of separate programs and facilities for African Americans. Physician-activist W. Montague Cobb contended that “the idea of a special ‘Negro Health Week’ has become outmoded” because it represented segregationism (Cobb 1950: 8). The federal government decided to close the office because it was “in keeping with the trend toward integration of all programs for the advancement of the people in the fundamentals of health, education, and welfare” (Smith 1995: 78).

After World War II the campaign to desegregate medical facilities and dismantle separate institutions for African Americans gained momentum. Medical civil rights activists accurately maintained that a segregated health care system led to inferior medical care for black Americans. In addition, they charged that the separate-but-never-equal facilities of the black medical ghetto could never adequately meet the health and professional needs of African Americans.

Armed with the precedent set by the 1954 Supreme Court decision *Brown v. Topeka Board of Education*, which struck down segregation in public education, the medical civil rights activists began a judicial assault on hospital segregation. *Simkins v. Moses H. Cone Memorial Hospital* proved to be the pivotal case. In February 1962, black physicians, dentists, and patients from Greensboro, North Carolina, brought suit to stop the racially discriminatory practices at two voluntary hospitals that had received close to \$3 million under the Hill-Burton Act, a federal hospital construction program. The plaintiffs in *Simkins* challenged the constitutionality of a “separate-but-equal” clause in the legislation. Although the

6. More comprehensive information on National Negro Health Week can be found in Brown 1937 and Smith 1995: 34–57.

7. After the Civil War, the Freedmen's Bureau maintained a medical department to address the medical needs of the newly emancipated slaves.

district court ruled against them, the Court of Appeals found in their favor in November 1963, and its decision stood because the Supreme Court refused to hear the case on appeal (Beardsley 1987: 245–272; Halperin 1988: 59–63; *Journal of the National Medical Association* 1962; *Journal of the National Medical Association* 1963; Harty 1964; *Hospitals* 1964).

The *Simkins* decision represented a significant victory in the battle against racial discrimination in health care. Its authority, however, was limited to those hospitals that received Hill-Burton funds. A 1964 federal court decision, *Eaton v. Grubbs*, broadened the prohibitions against racial discrimination to include voluntary hospitals that did not receive such funds (Halperin 1988; *Modern Hospital* 1964; *Hospitals* 1964; *Journal of the National Medical Association* 1957; *Journal of the National Medical Association* 1961). The 1964 Civil Rights Act supplemented these judicial mandates and prohibited racial discrimination in any programs that received federal assistance. The 1965 passage of the Medicare and Medicaid legislation made most hospitals potential recipients of federal funds and thus obligated them to comply with federal civil rights legislation (Parker 1964; *Journal of the National Medical Association* 1965).⁸

In March 1966, Reverend Dr. Martin Luther King, Jr., the civil rights leader, went to Chicago to plan direct action against the city's hospitals because of their racially discriminatory practices. He hoped that his efforts would dramatize the health problems of black Americans. "Of all forms of discrimination and inequalities, injustice in health is the most shocking and inhuman," Dr. King declared (*Chicago-Sun Times* 1966: 12). King's comments vividly illustrate how African Americans throughout the twentieth century saw health care inequities as inextricably linked to the struggle for civil rights. Various segments of the black community—health care professionals, politicians, activists, newspaper reporters—called attention to the community's poor health status and developed multipronged strategies to improve it, including activism, self-help, research, and legal suits.

During the 1970s and 1980s it became increasingly clear that, despite the significant impact of the civil rights movement in securing access of minority Americans to the nation's medical institutions, disparities continued to persist between the health of white and minority Americans. In January 1984, Margaret Heckler, President Ronald Reagan's secretary of health and human services (1983–1985), sent *Health, United States, 1983* to the U.S. Congress. This annual report card on the health status of Americans documented significant gains. But Heckler (U.S. DHHS

8. For an extensive discussion of the medical civil rights movement, see Smith 1999.

1985: ix) pointed out, it also “signaled a sad and significant fact; *there was a continuing disparity in the burden of death and illness experienced by Blacks and other minority Americans as compared with our nation’s population as a whole*” (Heckler’s emphasis). She noted that although there had been steady gains in the health status of minority Americans, “the stubborn disparity remained—an affront both to our ideals and to the ongoing genius of American medicine” (ibid.: 185).

In response to this “national paradox,” Heckler established the Secretary’s Task Force on Black and Minority Health to conduct a comprehensive and coordinated study of these disparities (ibid.: 2). The nineteen-member task force of senior scientists and officials of the Department of Health and Human Services conducted its work over the course of a year. Its activities included analyzing existing morbidity and mortality data, examining the factors underlying these disparities, and consulting with experts in minority health from outside of the federal government.

The task force released its ten-volume report in October 1985. Its most significant accomplishment was its extensive documentation of the extent of the health disparities between the health status of blacks, Native Americans, Hispanics, and Asian/Pacific Islanders compared to those of whites. The task force decided that the statistical technique of *excess deaths* best defined disparities in mortality. It described excess deaths as the difference between the number of deaths observed in the minority populations and the number that would have been expected if the minority population had the same age- and sex-specific death rates as the nonminority population. The task force used the concept of excess death to graphically illustrate the magnitude of racial and ethnic disparities in America. It found that 60,000 excess deaths occurred each year in minority populations—deaths that probably would not have occurred had the persons been white. The task force identified six causes of death—cancer, cardiovascular disease and stroke, cirrhosis, diabetes, homicide and accidents, and infant mortality—that together accounted for more than 80 percent of the excess deaths observed in minority populations.

The task force recognized that the factors underlying the health disparity between minority and white Americans are “complex and defy simplistic solutions” (ibid.: 7). “Health status,” it contended, “is influenced by the interaction of physiological, cultural, psychological, and societal factors that are poorly understood for the general population and even less so for minorities” (ibid.). In its report, the task force did not discuss these factors at great length. Its primary goal was to accurately document the problem of racial and ethnic disparities.

The task force made eight main recommendations to the secretary (*ibid.*: 8). Strikingly, the recommendations focused entirely on information strategies—improving education, research, data, and communications among agencies—but were silent on the question of politics and political will, as if knowledge deficiencies were the only cause of disparities. Indeed, Dr. Edith Irby Jones, the president of the National Medical Association, a black medical society, criticized the report's emphasis on health education and lifestyle changes. She argued that the Heckler report implied, "If black people would only 'behave' their health problems would be solved. . . . as black Americans, we know it is not as simple as all that" (Jones 1985: 486).

The release of the Heckler report pushed minority health issues onto the national research and health policy stage. In response to the report, the Department of Health and Human Services swiftly established in 1985 the Office of Minority Health (OMH). In January 1986, Dr. Otis Bowen, Heckler's successor, appointed Dr. Herbert Nickens, a black psychiatrist, as the office's first director. Thirty-five years after the demise of the Office of Negro Health Work, the federal government once again had an office dedicated to improving minority health. Its broadened mandate—minority health, rather than black health—reflected the recognition of disparities in other minority groups and the changing demography of the American population. OMH was given responsibility for implementing the task force recommendations, as well as planning, coordinating, and monitoring activities across the U.S. Department of Health and Human Services that relate to disease prevention, health promotion, service delivery, and research concerning racial and ethnic minorities. In 1990, five years after the establishment of the OMH, the NIH created an Office of Research on Minority Health to coordinate the development of NIH policies, goals, and objectives related to minority research and research training programs. By 2004, thirty-five states and territories had established some kind of office, commission, council, or advisory panel on minority health. The Heckler report can be credited with stimulating the formation of this infrastructure (McDonough et al. 2004: 11).

After the release of the Heckler report, research analyzing racial and ethnic disparities in health status, quality of care, and access proliferated, although the issue did not attract much political attention and, indeed, it remained very much a research issue. In 1990, the American Medical Association—not known as a particularly progressive organization—responded to the growing research on racial and ethnic disparities in treatment. Its Council on Ethical and Judicial Affairs released a report that

called these disparities “unjustifiable.” It contended that patient characteristics such as income, education, and cultural beliefs played probable roles in these disparities. However, it did not let physicians off the hook. It recognized that “disparities in treatment decisions may reflect subconscious bias. . . . The health care system like all of society has not eradicated this [racial] prejudice” (Council on Ethical and Judicial Affairs 1990: 2346). Thus, the American Medical Association, however gingerly, applied a civil rights frame to the disparities issue.

In 1999, the *New England Journal of Medicine* addressed the issue of physician bias head-on with an article from a team of researchers led by Dr. Kevin A. Schulman (Schulman et al. 1999). For this study, the researchers developed a standardized computer program to survey primary care physicians’ recommendations about chest pain. The computer program included videotaped interviews with patients (white males, white females, African American males, and African American females) about the nature of their chest pain. Unbeknownst to the physicians taking part in the study, the patients were actually identically dressed actors reading from identical scripts. The researchers had also standardized most aspects of the patients’ medical and social histories—age, cardiac risk factors, health insurance, and job. The only variables were the race and gender of the “patients.” The study found that African Americans and women with chest pain had relative odds of referral for cardiac catheterization that were 60 percent of the odds for whites and men. African American women faced the greatest disparity—relative odds that were 40 percent of those for white men. The researchers attributed the disparate care to “subconscious perceptions rather than deliberate actions or thoughts” on the part of physicians (ibid.: 624).

Schulman’s research design incorporated a variation of a traditional civil rights strategy—the use of testers. Civil rights activists have long used this strategy to determine whether the treatment afforded to white and black people in the same situation varies. For example, black and white testers with identical credit histories and perhaps résumés are sent to rent an apartment, apply for a mortgage, or purchase insurance. If blacks with the same characteristics as whites are turned down while whites are accepted, it is likely that race was the decisive factor. The tester strategy is a powerful civil rights enforcement technique because it figuratively catches people in the act of discriminating. The Schulman study combined elements of political action and scientific research and essentially brought a testing program to medicine.

The Schulman study received widespread media attention. Most major

newspapers covered it (Goldstein 1999; *Wall Street Journal* 1999; Rubin 1999; *New York Times* 1999), and it was a feature story on *Nightline*, a highly regarded television news program (*ABC News Nightline* 1999). The study provoked strong responses because it told a powerful story of discrimination at the hands of physicians. Perhaps because of its wide media exposure, this study became a lightning rod for discussions about racial discrimination and racial and ethnic disparities in health care. Six months after the publication of the Schulman study, an article in the *New England Journal of Medicine* harshly criticized the study's methodology and called its findings "overstated" (Schwartz, Woloshin, and Welch 1999: 279). But as Thomas Perez, the former director of the Office of Civil Rights in the Department of Health and Human Services, has noted, attempts to dismiss the Schulman study "miss the mark, and ignore the wide body of research, both before and after the Schulman study, suggesting that race continues to matter in health care, and racial bias may contribute to racial and ethnic disparities in health status" (Perez 2003: 633).

The Schulman study was released a year after Dr. David Satcher assumed the positions of U.S. surgeon general and assistant secretary of health. Satcher, an African American physician who had dedicated his career to improving the health of minority and underserved patients, praised the study on ABC's *Good Morning America* (1999) as "the best that we have documenting subconscious prejudice." During his tenure as the nation's top public health and health policy adviser, Satcher once again pushed the issue of health disparities onto the nation's health policy and research agenda. His efforts led to the development of the Initiative to Eliminate Racial and Ethnic Disparities in Health and the inclusion of the elimination of health disparities as one of the two major objectives of *Healthy People 2010* (U.S. Department of Health and Human Services 1998).

In November 2000, President Bill Clinton signed the Minority Health and Health Disparities Research and Education Act of 2000 (Public Law 106–525). One of its major provisions was the elevation of the NIH Office of Minority Health to the Center for Minority Health and Health Disparities. This move was not without controversy (Healy and Brainard 1999; Brainard 1999). Dr. Harold Varmus, then NIH director, opposed the elevation because he believed that the creation of the center would confine research on minority health to one center. However, African American political and medical leaders believed that the change in status would give the office more clout because, as a center, it could award its own grants. They passionately supported the change and gathered bipartisan support,

including that of Senator Bill Frist of Tennessee, to push the legislation. Frist, currently Senate majority leader, is a cardiothoracic surgeon who wields great influence on health policy issues. Frist agreed to support the legislation after provisions were included that would also cover poor white Americans. Thus the act was not just a minority health bill, but one that also recognized health disparities in white, economically disadvantaged Americans. Another provision of the act directed the Agency for Health Care Research and Quality, the agency in the federal government primarily responsible for health quality and health services research, to conduct and support research on health disparities. In the years since the Heckler report, the federal government has expanded its support of research to eliminate racial and ethnic disparities in health, and the pace of research is accelerating. Although disparities research has gained momentum in the United States, questions still remain as to how to create political will to sustain the issue and how to translate research into action.

A Tale of Two Reports

Whether research successfully bridges to policy depends on two broad factors. First is the external political environment. The success of any research report depends to a large extent on whether the political soil is fertile—as was the case with the Schulman study. No matter what the quality or content of the research, it does not stand a chance of shaping policy if leaders and coalitions in power do not tangibly support the broad goals of eliminating disparities. This is what we mean by *political will*. In this sense, the bridge between research and policy is politics.

Racial and ethnic health disparities in the United States occur in a larger political context in which race has been a singularly divisive force. Over more than two centuries and continuing into the present, widespread popular resistance to racial integration and racial equality has been fierce—at times more muted, at other times more strident—but no one can think realistically about addressing health disparities without attending to this perennial resistance. Researchers *as researchers* can do little about the broader political climate and structures of power, except to take advantage of good opportunities when they arise. However, they can (and should) recognize the external political environment, try to understand it, and address their research and recommendations to specific audiences and political actors.

The second broad factor determining the policy impact of research is *issue framing*. Issue framing is the way advocates define a problem and

its causes. As we noted in the introduction, social problems do not automatically get on the political agenda just because they are problems, even widely recognized problems. Advocates or issue leaders have to conceptualize the problem as something caused by human actions and decisions and amenable to human agency. If a problem is perceived as a matter of fate or nature—such as, “It’s the natural condition of African Americans to be sicker than whites because they have weaker constitutions”—then there is not much, if anything, that government can do about it. Framing a problem as a political issue entails telling a causal story that locates the cause of the problem in human action, thereby blaming somebody for the problem and suggesting somebody else as the appropriate fixer.⁹ Issue framing in research reports is largely a matter of rhetorical strategy, in the broadest sense. While researchers cannot control the political environment, they can and do control the way they frame issues in their own reports; in fact they frame issues and tell implicit causal stories whether they are conscious of doing so or not.

To illustrate and analyze how these two factors affect the translation of research into policy, we compare two recent government-sponsored reports on health disparities: *The Health Care Challenge: Acknowledging Disparity, Confronting Discrimination and Ensuring Equality* (U.S. Commission on Civil Rights 1999) and *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care* (Smedley, Stith, and Nelson 2003), issued by the Institute of Medicine in 2002.¹⁰ Both reports are so recent that it is too soon to assess what impact they have had. We chose them as the focus of our case study because they both have promise of being extremely influential, because they occupy the two poles of the disparity issue we have been describing (political action and science), and because they illustrate a certain maturation in American policy-oriented disparities research.

Twenty-five years ago, in 1981, the Institute of Medicine produced a report called *Health Care in the Context of Civil Rights* that combined and foreshadowed the separate trajectories of the two recent reports. The Office for Civil Rights of the Department of Health, Education, and Welfare commissioned this report. It asked the Institute of Medicine (1981: vii) to assemble data on “observable disparities or inequalities in health care” affecting “social/ethnic minorities” and “handicapped persons.”

9. For a fuller elaboration of this idea, see Stone 1989.

10. Because their titles are so long and so hard to keep straight, we will refer to these reports as the Commission on Civil Rights (CCR) report and the Institute of Medicine (IOM) report.

Historian and health policy analyst Rosemary Stevens, who chaired the committee, noted that the Office for Civil Rights specifically asked the committee “not to draw conclusions as to whether and in what respects members of these groups were subject to . . . discrimination,” but, she added, “arraying available evidence about disparities in health and health care . . . is the beginning of a process of discussion and debate . . . out of which health and civil rights policies can be more openly addressed” (IOM 1981: vi–vii). The two reports we have chosen for our case study emphasize respectively civil rights enforcement and data gathering as means of stimulating public awareness, debate, and action.

The U.S. Commission on Civil Rights is an independent, bipartisan agency of the executive branch, with no enforcement powers of its own. Rather, it is a fact-finding agency. The commission’s members are appointed, some by the president and some by Congress, for term appointments (that is, they are not political appointees). As befits the report’s origins, it adopts the civil rights strategy for understanding, framing, and remedying disparities. In this strategy, discrimination is considered an important root cause of racial and ethnic disparities, and while not the only cause, it is a critical one to address because so long as discrimination persists, eradicating the other causes will not eliminate disparities (Perez 2003). Research plays an important role in this strategy just as it does in the science strategy, but here research is focused on understanding how and where discrimination happens and on how antidiscrimination law is enforced.

The Institute of Medicine is a scientific body that is part of the National Academy of Sciences. The National Academy of Sciences is a private, nonprofit agency, but it is quasi-governmental in the sense that it is chartered by Congress and receives a great deal of its funding from the federal government. It remains an independent scientific body whose purpose is to advise Congress and executive branch agencies by providing scientific data to inform policy.¹¹ Members of the institute (as well as of the National Academy) are elected on the basis of their scientific scholarship, expertise, and reputations. The Institute of Medicine convenes ad hoc panels of experts to conduct each study requested by government. Thus, *Unequal Treatment* was the product of a panel of experts drawn primarily from the

11. Scholars have noted that the National Academy of Sciences and its component institutes such as the Institute of Medicine are not totally free of government influence, since they are beholden to Congress for annual appropriations and for their work in the form of requested studies and advice.

world of public health and medicine. It illustrates the scientific-research strategy for understanding, framing, and remedying disparities. In this strategy, the causes of disparities are seen as multiple and complex, and adequate scientific research is necessary to untangle causal factors before we can know exactly how to address the problem. Science becomes a prerequisite to effective policy action.

External Political Environment and the Effectiveness of Research Reports

The federal government commissioned both reports, but the difference between their approaches is evident from the charges given to the respective bodies. The civil rights commission is authorized by Congress to investigate deprivations of civil rights.¹² Within that broad mandate, it selects, plans, and conducts its own investigations. In presenting *The Health Care Challenge*, Mary Frances Berry, then chair of the commission, described the commission's purpose to examine "the efforts of the U.S. Department of Health and Human Services (HHS) Office for Civil Rights (OCR) in enforcing Title VI of the Civil Rights Act of 1964, Title IX of the Education Amendments of 1972, the requirements under the Hill-Burton Act of 1946, and the nondiscrimination provisions of the community block grant programs administered by HHS" (U.S. Commission on Civil Rights 1999: vii). Without going into each of these laws, it is still easy to see that the commission's congressional authorization determined the way it would frame the issue of health disparities—namely, as a question of discrimination and enforcement (or nonenforcement) of antidiscrimination laws already on the books. The causal story was taken for granted: "Disparities persist in part because of inadequate enforcement of Federal civil rights laws relating to health care by the Department of Health and Human Services" (*ibid.*). The commission's mandate and *raison d'être* was to focus on this one part of the causal story.

The Institute of Medicine's charge for *Unequal Treatment* was included in the Congressional Appropriations Bill of 1999 and was sponsored by Representative Jesse Jackson, Jr. of Illinois, who is a prominent member of the Congressional Black Caucus and a key player in the passage of the Minority Health and Health Disparities Research and Education Act of

12. Public Law 103-419 reauthorized the commission in 1994 and reiterated its power and purpose as investigating deprivations of civil rights and designing and evaluating advertising campaigns to discourage discrimination.

2000. Congress charged the Institute of Medicine with three tasks quite different from those of the civil rights commission:

- 1) Assess the extent of racial and ethnic disparities in health care that are not otherwise attributable to known factors such as access to care (e.g., ability to pay or insurance coverage);
- 2) Evaluate potential sources of racial and ethnic disparities in health care, including the role of bias, discrimination, and stereotyping at the individual (provider and patient), institutional and health system level;
- 3) Provide recommendations regarding interventions to eliminate healthcare disparities. (Smedley, Stith, and Nelson 2003: 3)

The more scientific, objective-research-based approach can be seen in this charge, which asks the IOM to use the scientific method of controlling for confounding variables (“not otherwise attributable to”) and to elucidate causal mechanisms (“evaluate potential sources”). The second part of the charge makes clear that the IOM was to consider multiple causal mechanisms (“potential *sources*,” plural). The third part of the charge was to recommend *interventions*, a medical metaphor that suggests more diffuse but perhaps broader approaches than civil rights law enforcement.¹³

Comparison of the charges suggests some other differences in the political environment of the two reports and the way each would ultimately be able to influence authoritative political institutions capable of changing policy. The civil rights commission’s self-imposed charge was narrower than the Institute of Medicine’s. It aimed to evaluate each of the offices and agencies responsible for enforcing civil rights law in health care. The civil rights commission identified five target audiences—the president, Congress, Department of Health and Human Services, state and local health care agencies, and beneficiaries of federally funded health care—and set forth goals for how it would assist each one to help eliminate disparities (U.S. Commission on Civil Rights [CCR] 1999: 6–7). From the beginning, then, the civil rights commission knew *whose* behavior it should try to change—the sine qua non of effective policy implementation.

Not surprisingly, the CCR report named names and did not mince words. For example, it documented that the Office on Women’s Health at the Department of Health and Human Services (part of the Public Health Service, also under the Department of Health and Social Services) had not

13. *Intervention* is also a military metaphor, but given the background of members of the IOM study committee, they probably had the more benign medical imagery of intervention in mind.

collaborated with the Office for Civil Rights, even though it was responsible for improving the health of all women, minorities included. The report revealed that the Office on Women's Health director, Wanda Jones, was "unaware of the function of OCR nor did she know who the director was" (ibid.: 120). In its recommendations, the civil rights commission named specific offices and agencies and suggested very specific actions they could take. For example, it said the Office for Civil Rights should monitor the activities of operating divisions, such as the Office on Women's Health and the Office of Minority Health. It should train staff of these divisions "at its headquarters . . . on their civil rights responsibilities. Each women's health and minority health office in HHS should have a senior civil rights analyst on staff who would be responsible for overseeing civil rights implementation" (ibid.: 213). The findings and recommendations—over thirty pages of them—go on with this level of specificity. For example, to enhance collaboration between the Office for Civil Rights and operating divisions, OCR should "distribute information with photographs and telephone numbers of each of its staff members" (ibid.: 216).

The Institute of Medicine committee was not asked to identify actors who should carry out its recommended interventions, and as a result, it addressed its recommendations to no one in particular. Each recommendation is cast in the grammatical imperative form, a verb with no subject. For example:

- Avoid fragmentation of health plans along socio-economic lines (Recommendation 5–1).
- Strengthen the stability of patient-provider relationships in publicly funded health plans (Recommendation 5–2).
- Increase the proportion of underrepresented U.S. racial and ethnic minorities among health professionals (Recommendation 5–3).

Commands uttered to no one in particular will likely not fall on *any* ears, let alone deaf ones. Moreover, several of the recommendations fly in the face of current federal policy direction, making them likely to fall on deaf ears if they fall anywhere. For example, because the United States lacks universal health insurance and relies on means testing as the principal eligibility criterion for safety-net programs, health insurance plans are quite deliberately fragmented along socioeconomic lines. Calling on leaders to avoid this kind of fragmentation is whistling in the wind. Current government policy toward the two largest public insurance programs, Medicare and Medicaid, promotes giving insured people choice among competing plans and letting them police quality of care by voting with their feet.

This model of consumer-driven market competition in health care actually promotes instability of patient-provider relationships. Recommendations such as the IOM committee's that contradict broad national policy direction stand little chance of being implemented.¹⁴ The third illustrative IOM recommendation above—increasing minority representation among health professionals—is ineffective because it takes the form of exhortation, with no specific steps to achieve the goal. By comparison, the civil rights commission makes the same recommendation but suggests several concrete mechanisms and names which part of government should carry out each one (U.S. Commission on Civil Rights 1999: 196).

The civil rights commission is part of the executive branch. While it is not an enforcement agency itself, it advises executive agencies on enforcement of civil rights law mainly by providing information. In some sense, the CCR report had a better shot at translating its research into action because it did not need to recommend passage of new laws or programs to eliminate disparities. It had only to recommend enforcing laws already on the books, ones to which Congress had already assented. Not that civil rights enforcement is without controversy and resistance, but at least that first hurdle of statutory authority was already cleared.

Paradoxically, however, the civil rights commission's political strength was also its weakness. The fact that it is embedded in the executive branch and therefore aimed its report exclusively at reforming executive agencies' performance meant that implementation of its recommendations was highly dependent on the political will of the chief executive and his party. When the executive branch changed political hands, as it did in the election of 2000, political appointees were replaced by people who share the president's and the Republican Party's distaste for aggressive civil rights enforcement. Lacking commitment from the top officials, civil rights enforcement was drastically attenuated and the report's audience was less receptive.

The Institute of Medicine is not technically part of government; it serves government in an advisory capacity and has absolutely no implementation or enforcement responsibilities. The very fact that Congress asked a medical research organization to perform this study, instead of, say, an

14. At a meeting to consider the impact of the IOM report one year later, Alan R. Nelson, chair of the committee, said that as a result of the report, the Centers for Medicare and Medicaid Services (which administers Medicare and Medicaid) have "recognized the need for steps to strengthen the stability of patient-provider relations in publicly funded programs" (Institute of Medicine 2003b). Whether this verbatim repetition of the report's recommendation is more than lip service remains to be seen.

executive branch agency or a private law institute, meant that the report would focus on the medical care delivery system. It would take a systemic approach and examine how various elements of the system contribute to disparities. Paradoxically, some of its political weaknesses might turn out to be strengths. The scientific evidence gathered by the study panel is now available for advocates to pick up and use at any time. Similarly, the recommendations offer general guidance to those who would take the initiative to translate them into concrete programs that might be acceptable under a given political administration. And the IOM report offers ideas on what medicine can do to get its own house in order, without government intervention. The IOM report stamps the disparities issue with the imprimatur of the scientific establishment. In the United States, science carries enormous cultural authority that stands above partisan and ideological politics. For this reason, the IOM report could become a valuable political resource, without itself taking much of a political stand.

Issue Framing and the Effectiveness of Research Reports

The different modes of issue framing—civil rights versus scientific research—are evident in the style and formatting of the two reports. The CCR report uses the legal style of footnotes at the bottom of the page and is structured like a legal brief—it comes on like gangbusters, firing off its arguments at the very beginning before presenting any evidence. The key argument is presented in the first paragraph of the preface and again on page 1 of the Introduction: Health disparities persist because the government, specifically the Office for Civil Rights of the Department of Health and Human Services, has failed to enforce antidiscrimination laws. The first words of the preface are strong and forthright: “Equal access to quality health care is a crucial issue. . . . For too long, too many Americans have been denied equal access to quality health care on the basis of race, ethnicity and gender” (ibid.: vii). The report uses the politically charged language of equality.

The Institute of Medicine report conveys the judicious restraint of scientific writing. It uses the scientific style of citation with references in parentheses in the text and a bibliography at the end. Its introductory chapter is a literature review. In the first few sentences, it rehearses a few notable racial and ethnic health disparities and then takes a distinctly agnostic and cautious stance on the causes: “The reasons for these health status disparities are *complex and poorly understood*, but *may* largely reflect socioeco-

conomic differences in health-related risk factors, environmental degradation, and direct and indirect consequences of discrimination” (Institute of Medicine 2003a: 25; emphasis added). The report adheres to the neutral terminology of science—disparities, differences, percentages, and probabilities. The introduction sets forth definitions—of health care, health services, and quality of care; of different racial and ethnic populations; and of the term *disparities*. These definitions and terminologies give the report a technocratic and didactic feel, but also an air of considered judgment and dispassionate analysis. The CCR report, by contrast, nowhere defines disparities, health care, or discrimination, its central concepts. It assumes a commonly understood meaning. It attempts to mobilize people to its cause by stimulating moral outrage and assumes that its audience shares common conceptions of justice and injustice.

Even the nature of the research differs notably between the two reports. The civil rights commission staff interviewed key officials in civil rights enforcement and the legal community, and its report makes extensive use of direct quotations from individuals speaking in the first person, as well as specific anecdotes from published documents and government memoranda. Often a section of text is preceded by one of these quotations in italics. This device mimics the legal device of taking testimony from witnesses and, not incidentally, also the religious tradition of bearing witness to important life-changing events. Personal quotations and anecdotes put a personal face on evidence, which is a key to mobilizing people into action, but it is a reporting style that is often disparaged in the scientific tradition as merely anecdotal.

The Institute of Medicine report, by contrast, is replete with statistical tables and bar graphs.¹⁵ These aggregate data convey the sense that certain disparities in treatment have been scientifically proved by valid scientific techniques. The data, though dry and impersonal, get their persuasive power from this sense that they are the result of careful, unbiased study design and observation, not merely the personal observations of interested parties. Although the CCR report discusses aggregate data about disparities and relies on many of the same scientific studies cited in the IOM

15. Ironically, the executive summary of the IOM report starts with an anecdote—a news story about a black man who received the first fully implantable artificial heart. This beginning is ironic for two reasons: First, anecdotes are not an important part of the report’s style and evidence, so it is strange to lead off the executive summary with one. Second, this anecdote, the very first words of the report after the abstract, tells a story of *equal* access, not unequal treatment, which is the subject of the report.

report, because of its liberal use of direct quotations and anecdotes, the entire report has a more concrete and personal feel.

The IOM style is probably more persuasive to skeptics and people who do not already believe that disparities exist. At a meeting to assess the impact of the report one year later, Dr. Risa Lavizzo-Mourey, president of the Robert Wood Johnson Foundation and a member of the IOM committee that issued the IOM report, stated that *Unequal Treatment* 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” (Institute of Medicine 2003b).¹⁶ The CCR report is patently advocacy research and therefore less persuasive to nonsupporters (in fact two members of the commission filed a dissenting statement to the report), but it is written in a style that is more accessible to people who are not scientifically trained, and therefore it is more likely to stir moral outrage among the believers. And moral outrage is a prerequisite to political action when redistribution to the have-nots is at stake.

Another difference between the two reports is their depiction of human agency and responsibility in causing health disparities. The Institute of Medicine report, beholden to a complex-systems model of causation, generally either hides human agency by using the passive voice or attributes agency to vague abstract entities. Thus, for example, in its initial section on causes of disparities (called *potential sources*, a less active notion than cause), “racial and ethnic disparities in care *may emerge, at least in part, from a number of patient level attributes*” (Institute of Medicine 2003a: 6, emphasis added). “*Aspects of health-systems—such as ways in which systems are organized, financed, and the availability of services—may exert different effects on patient care, particularly for racial and ethnic minorities*” (ibid.: 7, emphasis added). And “*Three mechanisms might be operative in healthcare disparities from the provider’s side of the exchange: bias (or prejudice) against minorities; greater clinical uncertainty when interacting with minority patients; and beliefs (or stereotypes) held by the provider about the health of minorities*” (ibid.: 8, emphasis added). Notice how the last statement characterizes bias, prejudice, and stereotyping as *mechanisms that operate from a place* (“the provider’s side”) instead of as human (physician) attitudes and actions. Reports that characterize causation as “disparities emerging from attributes,” “aspects of systems exert-

16. The Robert Wood Johnson Foundation is one of the largest health care foundations in the United States.

ing effects,” and “mechanisms being operative in disparities” are not well crafted to generate policy change because they fail to identify who should change what behavior.

Like all government documents, the CCR report has its share of passive constructions and abstractions as responsible agents, but as we have shown, it is not afraid to name names and pin responsibility. The report begins by blaming the Department of Health and Human Services and specifically its Office for Civil Rights for not taking specific actions: “The failure of HHS/OCR to play an active role in the monitoring and regulation of health care has resulted in the continuance of policies and practices that, in many instances, are either discriminatory or have a disparate impact on minorities” (U.S. Commission on Civil Rights 1999: 9). Moreover, in succeeding chapters, the report casts discrimination in the active voice, with specific actors behaving in specific ways: “Private facilities have used specific, identifiable tactics to avoid treating poor people of color altogether or limiting their numbers. . . . For example, some facilities relocate from African American or Latino communities to predominately white communities. Other facilities close or move the typical paths of entry for poor people—emergency and obstetrical care units” (U.S. Commission on Civil Rights 1999: 76; quoted in Engleman Lado 1994: 246–247).

The Lessons

Eliminating racial and ethnic health disparities is an issue of distributive justice. It entails redistributing valuable material resources (health care) and opportunities (good health). Redistribution is perhaps the most contentious and charged issue in all of politics. A nation’s commitment to any kind of redistribution is principally a matter of political will. Research is necessary, but to be effective in influencing policy, it has to be initiated and translated in ways that account for the political environment, and it has to be framed in ways that will mobilize the “have-nots” and be most persuasive to the “haves.”

We certainly cannot draw strong conclusions about the impact of research on policy from the two reports we analyzed, in part because the reports are too recent and in part because a report’s impact probably has more to do with the political environment at the time it appears than with its internal characteristics (about which we say more below). Nevertheless, we can make a few inferences about how research can most effectively bridge to policy and about the relationship between research and political action in stimulating policy reform.

In terms of framing and packaging research, first, researchers should focus their efforts on the causes of health disparities and developing intervention strategies. We know that racial and ethnic disparities exist in numerous areas of diagnosis, treatment, and preventive care, even when income, insurance status, and other socioeconomic factors are held constant. The data documenting the existence and types of disparities are overwhelming. The information needed to reduce and eliminate these disparities is information about how they come about and how to intervene, not more information that they exist.

Second, researchers should seek to understand the causes of disparities in terms of human agency. They should try to identify specific decisions of specific individuals that generate disparities. Much attention (too much in our opinion) has been focused on lifestyle choices and health behaviors of minorities themselves. The IOM report made clear that decision making by health care providers and rules and policies of health care programs create and perpetuate disparities. Researchers, therefore, should seek to identify clinical and institutional decision-making rules that create or perpetuate disparities and explain the underlying causal mechanisms by which such rules contribute to disparities. Researchers should avoid attributing responsibility and agency to abstractions such as systems and mechanisms.

Third, researchers should recognize the structure of political authority and target political actors with authority and power to change the causes of health disparities. Before beginning research, researchers should specify their objectives in terms of whose behavior they seek to change. They should identify a target audience or audiences and not just assume that if they put out their findings and recommendations, someone will take them up. They should name these audiences often in reporting their results and make sure they recommend concrete steps that are within the legal authority or competence of the target. They should frame the issue in such a way as to gather broad political support.

Fourth, researchers should be willing to use moral language. The scientific community tends to define the disparities issue in technocratic language. The term *disparities* itself exemplifies this technocratic turn. Through the 1970s, when the issue was fought in the United States directly as a civil rights issue, the language of equality prevailed. We have said that eliminating racial and ethnic disparities is a matter of political will. Political will comes from moral passion; people are moved to action by moral outrage, by personal stories that tell of injustice and oppression. U.S. researchers would do well to take home one lesson from abroad (though it

is a lesson we should have learned from our own civil rights movement): Abandon the term *disparities* and name the issue health inequity or health inequality, terms with greater moral valence.

These framing strategies, we recognize, are helpful but not necessarily effective. Our review of the history of the disparities issue in the United States suggests that political leadership is a crucial ingredient for catapulting racial and ethnic inequality to a prominent place on the national agenda. Like so many issues, this one rose and fell many times over decades. Arguably, it rose highest when a prominent and effective leader was committed to promoting the issue: W. E. B. DuBois, Martin Luther King, Jr., Margaret Heckler, Mary Frances Berry, and David Satcher. In the cases of Heckler and Satcher, both high-level government officials, their agencies did not function so much as receptors of scientific reports, but quite the opposite: they commissioned scientific reports, framed the inquiry, and even appointed the staff. Similarly, both the civil rights commission and the Institute of Medicine reports were initiated by government request. The civil rights commission undertook its report as part of its mission to enforce civil rights law; the Institute of Medicine undertook its study at the request of Congress. Thus, contrary to the model of scientific influence in which a scientific community uncovers a problem and brings its findings to government, on the health inequality issue, a political community recognized a problem and enlisted the help of researchers to define and document it, to give it visibility, and to generate political support for addressing it. One might even say that this is the same path started by W. E. B. DuBois, who was first a political leader committed to raising the political status of black citizens and who used his own scientific background to both advance knowledge and to enlist the help of a larger scientific community in the service of the political goal.

As mentioned above, we certainly cannot draw strong conclusions about the impact of research on policy from the two reports we analyzed, in part because the reports are too recent, and in part because a report's impact probably has more to do with the political environment at the time it appears than with its internal characteristics. In the case of the IOM report, it entered the American political arena during a period of intense backlash against remedial racial policies in general. During the same years the IOM's study committee was working, conservatives were mounting a major effort to eliminate affirmative action in higher education, an effort that culminated in two 2003 U.S. Supreme Court decisions (*Grutter v. Bollinger* and *Gratz v. Bollinger*) that preserved but weakened affirmative action. Not surprisingly, then, the IOM report generated

a strong backlash against efforts to remedy racial and ethnic inequalities in health and health care.

The backlash occurred in both the scientific and the political arenas. Within the academy, prominent scholars published articles debunking the IOM's findings of racial and ethnic disparities.¹⁷ In the political arena, the (second) Bush administration was notably hostile to affirmative action policies and even to acknowledging racial and ethnic inequality. In December 2003, two days before Christmas and during the congressional recess, Health and Human Services Secretary Tommy Thompson released the first *National Health Care Disparities Report* (U.S. Department of Health and Human Services, Agency for Health Care Research and Quality 2003). One of the goals of this congressionally mandated report was to provide Congress with objective and accurate scientific research with which they can make policy and budgetary decisions regarding health decisions (Bloche 2004). However, the report soon found itself deeply embroiled in partisan politics.

The report downplayed the problem and appeared to overturn almost one hundred years of research on health inequities. What was not widely known at the time of the report's release was that it was a drastically altered version of an original report that had been prepared in June 2003 by researchers from the Agency for Health Care Quality and Research. The revisions had been made by political appointees at the Department of Health and Human Services. The revised report eliminated the researchers' conclusion that national disparities are "national problems," substituted a discussion of the social costs of disparities with a discussion of policy "successes" in reducing disparities, and replaced examples of the most egregious racial and ethnic disparities with much milder examples and those health problems or medical access areas where minorities did better than whites (U.S. House of Representatives, Committee on Government Reform—Minority Staff Special Investigations Division 2004). For example, the report noted that American Indians and Alaska Natives were less likely to have their cholesterol checked (a milder example of a health disparity) and had a lower death rate from all cancers. It neglected to mention that these minority groups had significantly lower overall life expectancies and significantly higher infant mortality rates (*ibid.*: 2).

The revised report went so far as to eliminate most uses of the widely accepted but politically mild term *disparities*. In the executive summary

17. For an overview of this backlash, see Bloche 2005. For examples of the scientific backlash, see Satel 2002; Satel and Klick 2005; and Epstein 2005.

of the original report, the researchers had used the term *disparity* or *disparities* over thirty times. In the revised version, the terms were only used twice and only in reference to the Department of Health and Human Services policy on disparities, not to the data contained in the report (ibid.: 6). The authors of the revised report preferred the term *difference*. In the executive summary of the revised report they wrote, “Where we find variation among populations, this variation will simply be described as a ‘difference.’ By allowing the data to speak for themselves, there is no implication that these differences result in adverse health outcomes or imply prejudice in any way” (U.S. Department of Health and Human Services, Agency for Health Care Research and Quality 2003: 5). This contention directly refuted the findings of the IOM report.

Disturbed by this distortion of research findings, Department of Health and Human Services staff members leaked copies of the original report. The revelation of the tale of these two reports provoked charges of the politicization of science by Democrats and led to an investigation by the Special Investigations Division of the minority staff of the House Government Reform Committee. In February 2004, as the result of political pressure, Secretary Thompson acknowledged that revising the report had been a mistake and issued the researchers’ original report.

This imbroglio over the National Health Disparities Report makes plain a long-standing historical fact—the influence of research in eliminating disparities is inextricably linked to political climate, political dynamics, and the moral commitments of scientists as well as political leaders. The writing and framing of reports, as well as the research itself, are important and have some impact on generating public and research interest and concern, but without strong political will that forces commitment from political leaders, the power of research is greatly diminished. Indeed, politics is the bridge between research and policy.

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