Since the late 1960s, federal civil rights enforcement initiatives in health have been half-hearted and ineffective. The historical failure of the federal government to address the possible role of racial discrimination has taken place despite considerable evidence that, for a number of services, racial and ethnic minorities continue to receive inferior treatment to that accorded to whites. In many cases, these treatment differences remain even after controlling for socioeconomic and insurance statuses, and standard covariates such as patient age, health status, and gender.\(^1\)

Health care consumed 15.3 percent of GDP in 2003. Public funds covered 43.8 percent of health expenditures in 2003, with Medicare and Medicaid accounting for 36.4 percent of all health outlays.\(^2\) This is significant in a civil rights context because enforcement is typically most effective when the government has the financial leverage to secure compliance. Early forays into civil rights enforcement in health were quite successful. In the six months prior to the launch of the Medicare program, the federal government undertook a massive effort to ensure that hospitals did not receive funds if they practiced racial discrimination. When the Medicare program began in July 1966, all but ten percent of the nation’s hospitals were in compliance with Title VI of the 1964 Civil Rights Act, which prohibits the provision of federal funds to entities that discriminate. Two years later, only two percent of hospital and health

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facilities that had applied for Medicare payments were deemed noncompliant. Compared to other areas of civil rights, hospital desegregation was smooth and effective. Moreover, the data required to monitor racial discrimination should be relatively easy to collect, given that hospitals and managed care organizations gather all sorts of information about their patients. The Department of Health and Human Services (HHS) has the clear legal authority to mandate racial data collection from its funding recipients.

Why, then, has the federal government done so little in this area? In seeking to answer this question, I center my attention on administrative efforts by the federal government. I ask specifically why the Office for Civil Rights (OCR)—first in the Department of Health, Education and Welfare (HEW), and then, after 1980, in the Department of HHS—has accomplished so little in the fight against racial discrimination. One key factor is that the mission of fighting racial discrimination in health has, for historically shifting reasons, never been a central priority for any single government agency. The reasons for the low priority of civil rights enforcement in health were sometimes accidental and sometimes the result of conscious choices by political actors. While priority of mission is not the sole condition required for success—which I define as the production of outcomes that are consistent with a stated agency mission—effective agency activism does require knowledgeable and committed actors operating within a favorable institutional context. I limit the scope of this article to issues of differential treatment (whether intentional or unintentional) of patients by providers on the basis of race, ethnicity, or primary language. I do not discuss efforts by the federal government to ensure a diverse group of patients in clinical trials, or to encourage training of more physicians of color. The former, in my view, is primarily a matter of sound scientific practice, and the latter falls more squarely within the category of outreach than of antidiscrimination policy.

Examining Administrative Enforcement

Focusing attention on OCR is important for several reasons. Most fundamentally, the federal government is required to correct discriminatory practices in areas of the health-care system receiving federal funds. Title VI of the Civil Rights Act of 1964 prohibits intentional discrimination in federally funded programs and activities, while federal Title VI regulations also incorporate an “effects” standard. These regulations proscribe recipients of federal aid from “utiliz[ing] criteria or methods of administration which
have the effect of subjecting individuals to discrimination because of their race, color, or national origin, or have the effect of defeating or substantially impairing accomplishment of the objectives of the program as respect individuals of a particular race, color, or national origin.” With regard to site location, applicants or recipients “may not make selections with the effect of excluding individuals from, denying them the benefits of, or subjecting them to discrimination under any program to which this regulation applies, on the ground of race, color, or national origin.”

The federal government has brought few civil rights suits in the health field. Tellingly, the Department of Justice’s Civil Rights Division does not even have a unit devoted to health, as it does in areas such as employment, education, housing, and voting. The importance of OCR leadership increased with a 2001 Supreme Court decision, Alexander v. Sandoval (121 U.S. 1511), which found that private litigants have no right of action under Title VI regulations. That is, private plaintiffs must prove intentional discrimination to win such suits, though federal regulations only require that discriminatory effects be established. OCR and other federal agencies retain the right to pursue cases under the effects standard.

Even before the Alexander case, lawsuits contending discrimination faced several obstacles. Because Title VI bars racial but not economic discrimination, “proving discrimination where the affected population is both minority and uninsured probably would be virtually impossible.” Racial treatment differentials of similarly insured patients—for example, Medicare patients of different racial/ethnic backgrounds—have attracted little legal attention. Such instances would appear to represent the most transparent example of discrimination prohibited under Title VI.

Health-related cases based on Title VI of the 1964 Civil Rights Act fall into several categories: (1) cases challenging practices that deny care to one or more groups of minority patients (for example, refusal to participate in Medicaid, denial of care to patients without a personal physician, or the requirement of large pre-admission deposits); (2) cases targeting differential treatment within a hospital (mainly with regard to Medicaid patients); and (3) cases contesting closure or relocation of hospitals. Cases in this third category almost always fail. Plaintiffs have had better luck pursuing cases challenging explicit limitations that disproportionately affect racial and ethnic minority patients within a health-care market. For example, in Linton v. Carney, affirmed by the 6th Circuit in 1995, the court found that the state of Tennessee could not continue to limit the number of nursing-home beds available for Medicaid patients in specific facilities. On the whole, successful civil rights suits in health have been relatively uncommon. Pressing a civil rights case in health requires considerable
expertise and resources, and most civil rights expertise in the legal field has been developed in employment and education rather than health. These factors, combined with the likelihood that defendants will have considerable financial resources, suggest unpromising prospects for the potential of private litigation to foster meaningful change.10

For better or for worse, then, OCR bears most of the responsibility for policing racial (and other forms of) discrimination in health care. To assess why OCR has been less aggressive in enforcing antidiscrimination laws in health than have civil rights agencies in other fields, such as employment and education, several common explanations merit investigation: (1) physicians’ cultural prestige and political power made the government unwilling to enforce civil rights aggressively; (2) racial discrimination in this field is particularly hard to identify and address; and (3) Congress designed OCR to be an impotent agency.

Explanations for Limited Civil Rights Enforcement

Smith argues that because physicians were a powerful political force and reluctant participants at the Medicare program’s inception, “imposing any kind of Title VI requirements on medical practices was inconceivable.”11 To exempt physicians from compliance with the 1964 Civil Rights Act, HEW’s General Counsel defined doctors as private contractors, rather than federal funding recipients, under Part B of the Medicare program. At the behest of some southern senators, Congress had excluded federal insurance or guaranty from coverage under Title VI so that the provision could not be used to fight discrimination in housing, an industry in which the Federal Housing Administration and Veterans Administration insured bank mortgages.12 Congress did, however, clearly intend that hospitals and other health-care providers be covered under Title VI.

Title VI regulations are more encompassing. According to Rosenbaum and Teitelbaum, “In their prohibition of discrimination either directly or through contractual arrangements, the regulations would appear to apply not only to traditional entities such as hospitals, nursing homes and other ‘brick and mortar’ institutions, but also to modern managed care entities that function as insuring intermediaries with contractually networked providers.”13 Thus, the professional dominance of physicians does not account for the fact that OCR did little after the mid-1960s to assure the compliance of other health-care providers, such as hospitals and nursing homes, which are highly regulated in areas such as safety and costs (e.g., Medicare reimbursement)
and receive much of their funding from government. Hospitals, for example, received 58 percent of their funding from public sources in 2003. These brick-and-mortar entities, if monitored more rigorously for civil rights compliance, in turn would have the incentive to analyze the admission and practice patterns of their physicians more closely.

Judging from OCR’s own administrative records, the civil rights office did not fail to press enforcement in health because its staffers feared repercussions from providers. The experiences of other civil rights agencies lend credence to the notion that these agencies do not typically buckle under political pressure from the entities they regulate. The Equal Employment Opportunity Commission (EEOC) offers the clearest example of a civil rights agency acting aggressively despite possessing little formal authority against powerful targets of regulation—in this instance, big business. When it created the EEOC in the Civil Rights Act of 1964, Congress did not foresee a confrontational agency that a decade later would wring a $38 million settlement from one of the nation’s most powerful employers, AT&T. Nevertheless, after a plodding start in its first few years of operation, the EEOC developed powerful tools to monitor the racial and gender makeup of a company’s workforce, and to pressure some of these firms to change their hiring and promotion practices. In the wake of the settlement, a U.S. Chamber of Commerce attorney commented that “fear is not too strong a word to use about the way companies feel about the EEOC now.” The EEOC seemed to encourage this response, with one staff attorney commenting that the settlement showed other employers that “we can take on some of the nation’s biggest employers and beat the socks off them.” The EEOC went on to file more than three hundred lawsuits in less than two years, concentrating on large corporations such as General Motors, General Electric, and Sears, Roebuck.

With a shared sense of mission, EEOC employees developed innovative approaches to fight discrimination. Some observers felt strongly that these approaches extended well beyond the intent of the law. Fortunately for the agency, the courts offered their support, most dramatically in the Supreme Court’s Griggs v. Duke Power Co. (1971) decision. As Eleanor Holmes Norton, EEOC head under President Carter, recalled about the agency’s early years: “The courts . . . were not much interested in whether the EEOC was a true regulatory agency or had enforcement power. Lacking precedents in the American experience for civil rights enforcement, the courts accepted the expertise of the Commission and its view of the law. Never in the history of administrative law has an agency done so much with so little.”
If the story of weak civil rights enforcement is due to the cultural and political strength of the regulated, affirmative action in employment is a perplexing case. Few private-sector actors have had the cultural and political strength of large corporations such as AT&T. EEOC employees were uninhibited about confronting these companies because, as unelected officials, they were politically insulated from direct pressure by these corporations. Moreover, by working at an agency with the singular mission of fighting discrimination in the workplace, EEOC staffers largely were able to avoid internal squabbles over agency priorities that plagued multiple-mission agencies such as HEW and HHS.

During the heyday of civil rights enforcement in the late 1960s and early 1970s, civil rights agencies were typically more responsive to lobbying by civil rights organizations than by the entities they regulated. Civil rights organizations have not lobbied as vigorously for antidiscrimination enforcement in health as in other areas. One likely reason for this relative neglect is that most health advocacy groups have been concerned primarily with issues of access; differential treatment of insured patients can almost seem like a “luxury,” in the description of one advocate with whom I spoke. Traditional civil rights groups tend to seek government intervention in numerous areas, but they must prioritize these goals. With the Office for Civil Rights in HEW responsible for both education and health until 1980, civil rights groups lobbied most vigorously for school desegregation rather than health issues.

Pinpointing Discrimination

Initial civil rights compliance efforts largely addressed situations of explicitly segregated health facilities. Most of these facilities faced substantial financial incentives from the newly created Medicare and Medicaid programs to end practices of blatant segregation. After this successful initial wave of compliance activity, HEW’s job became substantially more difficult. Potential new targets of enforcement, such as nursing homes, were much less reliant on federal funds than were hospitals. Discriminatory treatment by hospitals became more subtle, and thus harder to detect by agency officials and patients themselves. For example, the Justice Department found in a 1970s review of Title VI implementation that “complaint procedures may have little use in the context of state-administered health and welfare programs for aside for segregation as such, it is difficult for a beneficiary to know whether he has been ‘discriminated against.’”
Even if individuals feel that they are suffering discrimination, they might be reluctant to “test their civil rights on an operating table,” Rep. Charles Rangel (D-N.Y.) observed in a 1973 hearing on Title VI enforcement in the Medicare and Medicaid programs. At the same hearing, a witness from the General Accounting Office observed that many patients may not know how to register a complaint. “I guess, if you happen to know of a civil rights organization, they might give you assistance, or if you are familiar with the provisions of title VI and your rights under that . . . [you might go] to the regional office of OCR. If you do not know these things, it might be difficult.” In addition, patients believing that they have been mistreated might be inclined to pursue a more lucrative malpractice case rather than filing a civil rights claim.

Health-related claims historically have constituted a small percentage of Title VI complaints. This situation creates disincentives within government agencies and Congress to allocate resources for civil rights enforcement in health. According to the U.S. Civil Rights Commission, numbers of complaints “served to justify certain policies, such as the priority which was given to particular field investigations and particular programs at the expense of others. They also served to justify, by their absence, inactivity in other areas.” While HEW received a sizable number of complaints from 1964 to 1968 alleging discrimination in health facilities, volume dropped sharply after 1968. More recently, Title VI complaints have declined as a percentage of overall civil rights complaints at HHS. For example, in 1981, 350 of the 1,222 complaints received by HHS were Title VI claims; a dozen years later, Title VI complaints remained basically flat at 340, while overall complaints had increased markedly to 2,094 (see Table 1).

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<td>DOE</td>
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<td>350 (1222)</td>
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Source: USCCR 1996.

This reliance on complaint volume to prioritize enforcement activities may have the effect of privileging some policy areas over others, but complaint tallies may not reflect the actual extent of discrimination. As previously noted, in a highly complex area such as health care, individuals may have little way of knowing whether they are suffering discrimination. Encounters with the health-care system are also more likely
to involve gravely serious situations, even matters of life and death, than encounters in the housing or job market. With respect to differential treatment based on race, many individuals may have little or no hard evidence to confirm their suspicions that they are receiving inappropriate care because of their race; only large-scale studies documenting treatment differentials traceable to race are likely to prove discrimination. Such an approach would resemble the strategies used in affirmative action in employment and race-conscious college admissions, where the focus is on a broad statistical patterns of fairness, rather than individual acts of discrimination.

The Changing Landscape of Federal Civil Rights Enforcement in Health

One might also attribute OCR’s failure to confront racial discrimination to the intentions of Congress, which lagged behind other branches of government in addressing the issue. President Truman’s 1948 executive orders (9980 and 9981) banning racial discrimination in federal employment and segregation in the armed services led to the complete desegregation of Veterans Administration hospitals by 1954. Under President Kennedy, the federal government began to make research grants and contracts to medical schools and their hospitals contingent upon racial desegregation of their facilities.25

Judiciary action also preceded the Civil Rights Act of 1964 in *Simkins v. Moses H. Cone Memorial Hospital* (1963). In this case, a group of black physicians, dentists, and patients brought legal action against two hospitals in Greensboro, North Carolina, that received funds under the federal Hill-Burton hospital construction program. The Hill-Burton health-facilities construction program, created in 1946, allowed private medical institutions to apply through the state for federal construction funds. Recipients of Hill-Burton grants, loans, or loan guarantees were required to provide assurance that they would provide a reasonable volume of care to individuals unable to pay, and that they would make their services available to all persons in the service areas without regard to race, creed, or color. The law, however, exempted facilities from the nondiscrimination requirement if they promised “equitable provision for separate population groups”—that is, “separate but equal” facilities.26 Between 1946 and 1962, under the Hill-Burton Act, over $36 million in federal grants were made for the construction of eighty-nine racially segregated medical facilities.
The plaintiffs in Simkins v. Cone maintained that the Greensboro hospitals’ refusal to grant staff privileges to black physicians or to admit black patients violated their rights to equal protection under the Fourteenth Amendment. The Court of Appeals for the Fourth Circuit agreed that the acceptance of Hill-Burton funds by the hospitals was state action and deemed the separate-but-equal provision unconstitutional. On March 2, 1964, the Supreme Court denied certiorari, upholding the Appeals Court decision. Congressional supporters of the civil rights legislation “repeatedly referred to the Simkins decision in justifying the need for Title VI,” indicating that they fully expected health discrimination to be addressed upon passage of the law.27

Prior to these decisions, HEW policy specified that admission could be denied on the basis of race in parts of the facility that did not receive Hill-Burton funds, patients could be segregated within a facility, and individual medical practitioners could be denied staff privileges or employment on account of race. New regulations changed these provisions but limited the reach of the revised rules to pending and future applications. Even after publication of the implementing regulations for Title VI of the 1964 Civil Rights Act, HEW continued to apply the nondiscrimination provisions only to pending and future applications. As Wing observes: “It was not until the implementation of Medicare and Medicaid, which brought almost all hospitals and nursing homes within the purview of the Title VI regulations, that discrimination in these health facilities was effectively prohibited.”28

The federal funding available through the Medicare and Medicaid programs provided a sizable incentive for hospitals to discontinue their explicitly segregationist policies. For HEW, the responsibility to ensure that recipients of federal funding did not discriminate presented a host of complex organizational and logistical challenges. Initially, individual program agencies had primary responsibility for implementing Title VI. Within HEW, five departmental units—the Office of Education, the Public Health Service, the Surplus Property Division, the Vocational Rehabilitation Administration, and the Welfare Administration—had Title VI obligations. This arrangement meant that each of these agencies was asked to convey grants and to refuse to do so if justified. An internal history of the department noted that HEW’s “grant administrators had in past years demonstrated a general coolness to the idea of grant conditioning; now, in 1965, the function of conditioning grants was assigned to the agencies whose operations were conducted by these same administrators.”29 This arrangement did not bode well for rigorous civil rights enforcement.
The HEW assistant secretary was directed to evaluate and supervise Title VI activities within the agencies, and to represent the department in government-wide Title VI activities. The assistant secretary, with a staff of two, was responsible also for other civil rights obligations (including those stemming from two executive orders covering equal employment opportunities), air and water pollution control, international affairs, and patent policy. James M. Quigley, the assistant secretary at the time, quickly became troubled by the uneven handling of Title VI compliance across HEW’s component agencies. “Let’s quit acting like the Balkans and start performing like a Department,” he scolded the agencies. He proceeded to offer department-wide, procedural guidance on Title VI compliance.

According to HEW estimates circa 1969, the department was responsible for monitoring racial discrimination in approximately two hundred state agencies administering continuing programs under as many as four hundred or five hundred state plans, roughly ten thousand hospitals, about twenty-three thousand public school districts, and about two thousand colleges. The Office of Equal Health Opportunity was formed within the Public Health Service in January 1966, assigned with the task of ensuring compliance by a maximum number of hospitals when Medicare took effect on July 1. President Johnson did not want the big splash of Medicare diminished by southern outrage over denial of funds. On the day Medicare was implemented, around ten percent of ninety-two hundred hospitals were barred from funding because of noncompliance with Title VI. By 1968, HEW could report that 98 percent of all hospital and health facilities that had applied to receive Medicare payments were in compliance with the Civil Rights Act of 1964; even assuming some exaggeration, “the result was surprisingly good.”

In summer 1967, Congress attempted to assert greater control over how agency funds were spent by instructing a reluctant HEW to shift its Title VI responsibilities from its constituent programs to a new Office for Civil Rights that was accountable directly to the secretary. While some civil rights organizations initially believed the reorganization signified a retreat from the government’s commitment, HEW’s internal history maintains that “the relationship between the new centralized Office for Civil Rights and the program agencies showed substantial improvement. There was no longer presence in the program agencies of a unit which program administrators saw as an irritant and a block to their desire to distribute the funds so generously endowed on them by the Congress.” It continues: “Through the centralization in the Office of the Secretary, [OCR Director F. Peter] Libassi was able to exert more
influence directly through the Secretary and from a more responsible hierarchical position high in the bureaucracy, rather than from a position of what can almost be termed subservience to the program directors.” The centralization effort stemmed from a concern within Congress that agency school desegregation initiatives—not those in health—were more far-reaching than originally envisioned. The unintended effect was that civil rights attention would go to the highly publicized issue of school desegregation.

Competing Agency Missions

This relegation of health concerns to secondary status within OCR had tremendous consequences for the vigor with which enforcement was carried out.

High prioritization of civil rights are no guarantor of effective action, but if civil rights is a minor concern or an afterthought, rigorous antidiscrimination measures are virtually impossible. Unlike the EEOC in employment, civil rights efforts in health and education did not have the advantage of a stand-alone agency. Nevertheless, the U.S. Commission on Civil Rights observed that “HEW, by virtue of the nature and scope of its programs, is the most important Federal department or agency to be affected by Title VI. To a large extent, the success or failure of that law is measured by the success or failure of HEW’s effort.” By 1969, HEW had more than one hundred thousand employees, and comprised “some 250 separate programs under hundreds of authorizations supported by approximately 100 appropriations categories.” HEW’s 1969 expenditures of $45 billion represented nearly one-fourth of total federal expenditures. Moreover, the agency’s civil rights compliance program, beginning in the summer and fall of 1964, “was to occupy more space in the public print, more Presidential attention, and more political controversy for the ensuing decade than any other HEW program.” Consequently, the agency’s legitimacy would hinge on the way it carried out its civil rights program. HEW became best known—and in some circles, most reviled—for its work in the area of school desegregation.

The General Accounting Office found in a 1973 report that “HEW has significantly reduced its title VI compliance staff [for health-related matters] to the point where the staff’s principal duties are to prevent hospitals, ECFs [extended-care facilities], and nursing homes from reverting to previous overt discriminatory policies and practices.” At a congressional hearing that same year, recently appointed
OCR director Peter Holmes acknowledged that civil rights enforcement in the Medicare and Medicaid programs has “not received the same level of emphasis or attention by the Office for Civil Rights as has the elementary and secondary education program. That is an admission on the record by me of that fact. And we are trying to do something about it.” At the time of Holmes’s testimony, OCR had no full-time health expert on its staff. The situation did not improve in subsequent years. In 1976, the acting director of OCR’s Health and Social Services Branch testified that the number of professional staff positions—which had declined from eighty-seven in 1973–74 to less than nineteen in the 1977 operating plan—meant that the branch could do a “less than minimum [job]. . . . It is just not adequate in any sense of the word to meet our responsibilities.”

Judicial mandates also played a major role in OCR’s emphasis on education. Most important in this regard is the *Adams* litigation, filed in 1970. The litigation charged HEW with failure to enforce Title VI of the 1964 Civil Rights Act by granting federal funds to numerous school districts and state higher education systems in the seventeen southern and border states that were discriminating against African Americans on the basis of race. The U.S. District Court and the Court of Appeals issued orders in 1973, 1975, 1976, and 1977 obligating HEW to adopt strict time frames for complaint processing and other procedures in order to assure compliance with Title VI. Because the *Adams* orders were limited to educational institutions, OCR “was required to give priority attention to education activities,” resulting in “almost total neglect of health and human service policy development activities and greatly reduced compliance efforts.” OCR also used considerable staff resources clarifying bilingual education requirements for schools.

During the 1970s, budgetary constraints forced OCR to face new responsibilities with reduced staffing and resources. Congress placed new obligations on the agency in prohibiting discrimination in federally assisted programs against the physically or mentally disabled (Section 504 of the Rehabilitation Act of 1973), against women in federally assisted education programs (Title IX of the Education Amendments of 1973), and against the aged (employment excepted). Section 504 states: “No otherwise qualified handicapped individual in the United States . . . shall, solely by reason of his handicap, be excluded from participation in, be denied benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance.” HEW did not issue regulations on Section 504 compliance for its own activities until 1977, four years after passage of the legislation.
A memo from the Ford administration’s outgoing head of HEW/OCR to Jimmy Carter’s presidential transition team, describing issues that would face the civil rights staff in coming months, illustrates HEW’s juggling act. The list of fifteen items includes: (1) development and issuance of final regulations to implement Section 504 of the Rehabilitation Act of 1973; (2) development and issuance of Title VI standards on higher education admissions policies; (3) adherence to workload and time frames specified in the Adams orders; (4) creation of strategies for complaint handling and conflict resolution; (5) promulgation of standards for equal educational opportunity in state higher education systems; (6) elimination of language barriers in public schools; and (7) development of policy positions for Title IX issues. Not a single priority item pertains to the health and social services area. As overall federal commitment began to decline in the mid-1970s, even priority areas of civil rights enforcement lapsed, leaving little political possibility for secondary areas to gain added resources and attention.

Reasons for Optimism in the Carter Era

The election of Jimmy Carter to the presidency evoked tempered optimism from advocacy groups who viewed the Nixon and Ford administrations as hostile to aggressive civil rights enforcement. A July 1977 memo from Carter to all executive departments and agencies reminded them that “there are no exceptions” to the requirement in Title VI that government not support discriminatory programs. “No matter how important a program, no matter how urgent the goals, they do not excuse violating any of our laws—including the laws against discrimination,” Carter noted pointedly.

In October 1979, HEW was divided into two agencies, the Department of Education and the Department of Health and Human Services (HHS). The administration had argued for this split largely on the grounds that “the health and welfare programs, which are closely related and account for 92 percent of HEW’s budget of nearly $200 billion, dominate the HEW Secretary’s time and attention.” The reverse was true with respect to civil rights. David Tatel, the OCR director at HEW from 1977 to 1979, recalled that “99 percent of our energies” went into education. A 1980 OCR report to HHS Secretary Patricia Harris stated that, “as recently as 1977, only 4 percent of OCR’s compliance effort was devoted to health and human services issues, with most of the health compliance staff assigned to education activities.”
To the limited extent that Congress considered the civil rights ramifications of the Education Department proposal, most discussion concerned the effect a reorganization would have on desegregation of educational institutions. Even the U.S. Commission on Civil Rights—the federal government’s watchdog on discrimination—failed to mention health care as a major civil rights issue in its 1980 report, which identified housing, education, employment, voting rights, police practices, and immigration as the most prominent issues facing the nation in the coming decade. Echoing the congressional testimony of other witnesses, Phyllis McClure, the director of the Washington office of the NAACP Legal Defense and Educational Fund, asserted that putting “enforcement of these laws in the hands of the educational establishment will jeopardize the civil rights of children.”53

Despite the hesitation about the split among civil rights supporters, the proposed reorganization brought the possibility that OCR within the new HHS would prioritize antidiscrimination enforcement in health and welfare. When OCR at HEW was divided into two separate offices—one in Education and one in HHS—the latter office was allocated one-third of the staff, budget, and other resources, despite the fact that the HHS compliance program covered “65 percent of the recipients formerly funded by HEW and 59 percent of the beneficiaries.”54

The division of resources between the two OCRs came with “no assessment” of what future responsibilities of the offices would be, according to a former OCR director of Divisional Analysis; instead, the split was based on existing allocations.55

The new OCR in HHS began operations in May 1980. Six months later, Ronald Reagan was elected president. Though more successful in some areas than others, Reagan sought to loosen federal civil rights oversight across the board.56 This retrenchment, just at the time when new direction and momentum seemed possible for civil rights in health care, probably forestalled a more sustained attack on discrimination in this area. In the case of OCR at HHS, the failure to establish a more proactive policy direction during this pivotal time reverberates to the present day. Scholars of social policy have mined extensive historical evidence to show that the trajectory of policy development is shaped in important ways by the political and institutional origins of a given policy.57 The tendency for policies to continue along a well-trodden path does not occur in a mechanistic sense. Instead, because interests and institutions congeal around particular policies, political actors seeking reversals of past policies—for example, renewed civil rights enforcement in health during a time of retrenchment—face particularly imposing obstacles when trying to create the impetus for change.58
During the Reagan administration, many civil rights staffers became profoundly disillusioned. For example, in the Justice Department’s Civil Rights Division, seventy-five division attorneys—more than half of its lawyers—signed a statement opposing the policies of William Bradford Reynolds, the assistant attorney general for civil rights. One attorney in the division reported: “When we—that is, the division—lose in court, all the attorneys go up and down the hall cheering because we feel we really won.” Similar divisions developed between political appointees and longtime staffers at OCR in HHS. Hal Freeman, a former regional manager at OCR, who resigned in February 1986 after eighteen years in the agency, reported that year that “there is widespread demoralization in the agency . . . and a general feeling that there is no commitment on the part of this agency to fully implement the laws. The agency is as busy as it ever has been, but it’s busy doing make work, changing forms, changing formats, and not really doing the substantive work of the agency.”

Clearer Missions, but in a More Hostile Political Environment

In this context of severe civil rights retrenchment, HHS released its Report of the Secretary’s Task Force on Black and Minority Health. Published in 1985, the report represented the first attempt by the federal government to raise awareness about gaps between the health status of whites and various racial and ethnic minority groups. The federal government continues to assess racial and ethnic health disparities. In 1998, HHS launched the Initiative to Eliminate Racial and Ethnic Disparities in Health, and included the elimination of racial health disparities as a primary goal in HHS’s Healthy People 2010 initiative. One Healthy People 2010 publication claims that racial and ethnic health disparities “are believed to be the result of the complex interaction among genetic variations, environmental factors, and specific health behaviors.” Notably, the agency does not acknowledge the possibility that racial discrimination plays a role in maintaining these disparities. This is a troubling omission, given the growing body of evidence suggesting that differential treatment by providers is a contributing factor to racial health disparities.

Perhaps the most puzzling aspect of the federal sluggishness in civil rights enforcement is the failure to collect racial and ethnic data from recipients of federal funds. HHS’s Title VI regulations specify that federal funding recipients should collect and submit information that “the responsible Department official or his designee may determine to be necessary to enable him to ascertain whether the recipient has complied”
with civil rights statutes. “For example,” the regulation states, “recipients should have available for the Department racial and ethnic data showing the extent to which members of minority groups are beneficiaries of and participants in Federally-assisted programs.” Despite the usefulness of this information, HHS does not require data on race, ethnicity, and language preference from funding recipients. According to Thomas Perez, director of OCR during the Clinton administration, “mandating data collection boils down to a question of political will.”

In a comprehensive study of federal policies related to data collection, Perot and Youdelman find that the racial and ethnic data collection policies of HHS and other federal departments with health-related responsibilities are “inconsistent and sometimes contradictory.” The authors urge HHS to take the lead in data collection efforts. Among their suggestions, they recommend that the agency ensure the accuracy of Medicare racial and ethnic data (which is now rife with inaccuracies); enforce state collection of racial, ethnic, and primary-language data for Medicaid and State Children’s Health Insurance Program (SCHIP) enrollees; and mandate data collection as a condition of receiving funds in areas such as block grants.

The Institute of Medicine’s 2003 report, Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare, appears to have focused greater attention on the role of racially disparate treatment in the existence of health disparities. Alan Nelson, a past president of the American Medical Association and the chair of the IoM Committee that produced the report, stated: “My first impulse [in responding to the IoM report’s findings] was to say ‘This couldn’t be.’” But, given that humans share the adaptive strategy of using categorizing and generalizing techniques to simplify a complex world, coupled with the time pressure and complexity that physicians face, “the expectation that physicians be immune [to employing stereotypes] is unrealistic.” This recent willingness to assess provider treatment decisions with respect to race, ethnicity, and language access may reflect a broader trend toward monitoring physician behavior, particularly by managed care organizations.

The AMA deemed the IoM report a “wake-up call” for the medical profession. In December 2002, the association launched a program to confront racial and ethnic disparities, noting that “racial and ethnic minority patients experience a lower quality and intensity of health care and receive fewer diagnostic and preventive health care services.” Two months later, the AMA announced an outreach effort, in collaboration with the Henry J. Kaiser Family Foundation, the Robert Wood Johnson Foundation, and leading heart organizations, to publicize evidence on
racial differences in cardiac care and seek out physicians to help address this problem.\textsuperscript{68} The Kaiser Family Foundation and the American College of Cardiology Foundation reviewed research on racial and ethnic differences in cardiac care, finding that 84 percent of the studies deemed methodologically sound identified racial/ethnic differences in cardiac care for at least one of the minority groups studied. (Most of the studies compare African Americans to whites.) The review panel concludes that while factors such as varying insurance benefits, patient preferences, and availability of high-tech equipment may account for some of these differences, “other factors may be more directly within the physician’s control such as patient-provider communication, practice location decisions, or biases in the diagnostic or referral processes.”\textsuperscript{69} Without a better understanding of the role that provider behavior plays in the existence of these disparities, the causes will remain murky.

Private-sector efforts to address treatment disparities are encouraging, but they can go only so far. With respect to the federal government, there seem to be no major legal or political impediments to requiring more uniform data from providers directly, or from states that collect data from health-care entities. HHS’s civil rights office has been chronically underfunded and understaffed. In its 1996 report on federal Title VI activities, the U.S. Commission on Civil Rights reported that HHS distributed $225 billion in federal financial assistance to seven hundred thousand recipients, while the Department of Education dispersed $30 billion in funds to twenty-five thousand recipients. Despite the much broader reach of health and social services programs, in 1995 Education had 868 civil rights staffers and a civil rights budget of $56.4 million; in comparison, HHS had 309 civil rights staffers and a civil rights budget of $22 million (see Table 2). OCR’s staff has decreased by more than 50 percent over the last two decades. Not every analysis of OCR considers this

<table>
<thead>
<tr>
<th>Agency</th>
<th>FFA</th>
<th>Number of recipients</th>
<th>CR budget</th>
<th>CR staff</th>
</tr>
</thead>
<tbody>
<tr>
<td>DOE</td>
<td>$30B</td>
<td>25,000</td>
<td>$56.4M</td>
<td>868</td>
</tr>
<tr>
<td>HHS</td>
<td>$225B</td>
<td>700,000</td>
<td>$22.2M</td>
<td>309</td>
</tr>
<tr>
<td>HUD</td>
<td>$18.7B</td>
<td>26,358</td>
<td>$63.5M</td>
<td>726</td>
</tr>
</tbody>
</table>

FFA=Federal financial assistance
HUD resources include budget and staffing for fair housing as well as civil rights for federally assisted programs.

office to be the helpless victim of a stingy Congress. For example, the U.S. Commission on Civil Rights found that HHS/OCR has done a remarkably poor job of making its case for increased resources.70

OCR’s consistently inadequate performance has led some observers to suggest that civil rights responsibilities be stripped from this “weak and dysfunctional agency,” and that civil rights compliance should be woven into the broader and better-regulated set of requirements related to program performance and overall health quality. “If the federal government and other health purchasers can insist on accountability in health quality on the part of hospitals, nursing homes, and even physicians in private practice,” Rosenbaum and Teitelbaum argue, “then it is difficult to see why measures of racial justice in performance are any more controversial.”71

The very limited power of the civil rights office in health has been mirrored in some respects by the Office of Fair Housing and Equal Opportunity (FHEO) in the Department of Housing and Urban Development (HUD), an agency that has operated primarily to aid rather than monitor the private housing market. Like its counterpart in health, FHEO has tried unsuccessfully to ensure that agency contractors are in meaningful compliance with civil rights laws. Sara Pratt, the director of the Office of Enforcement in HUD’s Office of Fair Housing and Equal Opportunity (FHEO) from 1993 to 1999, maintains that the most viable long-term solution to developing adequate fair-housing enforcement is to reassign these obligations to a new agency devoted to this issue.72 With HUD’s wide array of issues, including regulating and working with the housing industry, addressing programmatic and political issues, and acquiring and allocating resources, it is difficult to get civil rights “to the top of the heap [at HUD] even with the most committed leadership,” Pratt notes.

In health, as in housing, the poor performance is all but certain to continue until federal aid recipients get the message that civil rights are central to overall program compliance with federal standards—whether these standards are administered through a separate civil rights office or a larger program compliance office within the existing agency. In either case, civil rights staffers must have authentic decision-making authority to withhold funds. When enforcement takes place through a marginalized, stand-alone agency or a weak office within a massive bureaucracy, it is virtually guaranteed to fail.

The missed opportunities for the federal government to monitor discrimination in health cannot be dismissed as mere historical accidents, as this would imply that no one bears political responsibility for these failures. However, there is not a single culprit through time. For instance, Congress clearly intended for the Civil Rights Act of 1964 to be applied
to health, so we cannot attribute the weakness of civil rights enforcement in health to conscious congressional design. At the same time, if members of Congress felt strongly that OCR must address discrimination in health, surely they could have followed through to ensure that the objective was achieved. One can say something similar about recent presidential administrations and of OCR itself: surely they could have done more if they believed civil rights enforcement in health to be important.

Conclusion

In this article, I have attempted to account for the weakness of federal civil rights enforcement in health care. Often-cited factors such as the cultural prestige of physicians and the difficulty of pinpointing discrimination in health are important parts of this story. However, other civil rights agencies (such as the EEOC) have confronted powerful corporations, which are prestigious in their own right, and effective civil rights enforcement has focused on identifying broad patterns of disadvantage, rather than individual acts of discrimination. Congressional intentions do not explain this weakness either, as members expected that OCR would address discrimination in health. Indeed, in the late 1960s and early 1970s, many members of Congress would have welcomed OCR devoting more attention to discrimination in health and less to the explosive issue of school desegregation. The story of anemic enforcement is incomplete without assessing the institutional weakness of the civil rights mission in health. This institutional weakness of the civil rights mission in health is not an explanation by itself, but it provides a framework for understanding how and why OCR acted as it did, and how various governmental and private interests responded to these actions.

Until 1980, civil rights enforcement in health was usurped by efforts in education, which consumed nearly all civil rights attention in the Department of Health, Education and Welfare. Throughout the 1970s, HEW’s civil rights staff was assigned a number of new and divergent responsibilities, without commensurate funding or staffing increases. Court orders mandating specific civil rights actions in education left very few resources for enforcement in health and social services. With declining overall funding for civil rights, less prominent civil rights goals stood little chance of receiving increased resources and attention.

Shortly after the creation of a separate civil rights office within HHS, the Reagan administration assumed power, quickly revealing an aversion to aggressive civil rights enforcement. Thus, the opportunity to create new
momentum for antidiscrimination initiatives in health was truncated. The beginning of government attention to racial health disparities during this time was nevertheless a promising development. Unfortunately, the federal government has not followed up with a real commitment to identifying the causes of disparities.

HHS has the unique capability to require the collection of uniform data on race, ethnicity, and language by providers and other levels of government. Without this information, it is nearly impossible to draw firm conclusions about the extent of differential treatment. More than twenty-five years ago, the Leadership Conference on Civil Rights asserted: “Federal civil rights compliance has never had the advantage of adequate data to help plan and monitor enforcement approaches, and to help identify potential problem areas. Instead it has been ruled by guesswork and the principle of giving attention where the immediate crisis seems greatest.” Surprisingly little has changed since that time. While the growing concern in the private sector about the need to assess the causes of racial and ethnic health disparities is noteworthy, leadership from HHS is an essential piece to this puzzle. Numerous studies of government bureaucracies have revealed that once specific policy orientations and ways of doing business become entrenched, they are quite resistant to change. As one frustrated HUD political appointee noted as he departed the agency in 1971, “Changing the bureaucracy’s direction is like trying to turn a battleship around.” Civil rights supporters should push Congress to assign a greater role to OCR within HHS, or build a separate, more responsive office for civil rights enforcement from scratch. The latter option holds greater promise. Though reorganization is not a simple formula for greater effectiveness (witness the Department of Homeland Security), congressional action to reassign civil rights enforcement in health to a stronger, more functional office would alert providers that racial fairness is an integral part of compliance with federal regulations. A reinvigorated enforcement effort would not require that the new office try to “beat the socks off” the entities it regulates, as the EEOC did in its heyday. Providers receiving federal dollars already provide considerable data to the federal government. Requiring health entities to include racial and ethnic data would be a reasonable first step without undue political risks and would contribute to a greater understanding of health disparities. Such a move also would indicate that the federal government is ready, at last, to enforce the Title VI requirements written into law more than four decades ago.

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Notes


5. This article draws on primary documents that include: a microfilm collection of official HEW documents; the Jimmy Carter Presidential Materials (Carter Presidential Library, Atlanta, Georgia); the papers of former OCR chief Patricia Roberts Harris, stored at the Library of Congress (Washington, D.C.); and the papers of several civil rights groups (also at the Library of Congress). In addition, I incorporate congressional testimony, judicial decisions, and secondary sources. Last, with the aid of a research assistant, I interviewed present and former federal civil rights officials, as well as a number of staffers for advocacy groups; some of these interviews were conducted for background purposes, while others were for attribution.


9. One of the best-known civil rights cases in health is NAACP v. Medical Center, Inc. (1981), in which the plaintiffs challenged the hospital’s plan to move a number of its services from the largely African American, inner-city of Wilmington, Delaware, to a predominantly white suburb. At the district court’s behest, HEW undertook a civil rights investigation, concluding that the proposed plan would violate Title VI of the 1964 Civil Rights Act and Section 504 of the Rehabilitation Act of 1973. HEW negotiated a settlement with the Wilmington Medical Center in which the hospital agreed to provide free shuttle-bus transportation between the two centers and to make investments in the Wilmington plant. See also Bryan v. Koch (1980). A 1990 Circuit Court decision, Women’s Equity Action League v. Cavazos, concluded that the procedures used by HHS to enforce the law are the agency’s exclusive discretion and are not reviewable by the courts (Smith, Health Care Divided).


11. Smith, Health Care Divided, 162.

12. David Barton Smith, “Racial and Ethnic Health Disparities and the Unfinished Civil Rights Agenda,” Health Affairs, March–April 2005. Smith contends that one major consequence of this exemption was the federal failure to collect data on discriminatory medical treatment, despite the regulatory authority to do so.

16. DeWitt, "Labor Report," 913. Many firms were particularly concerned about findings of sex discrimination, which was a relatively new area of scrutiny.
17. Ibid., 920.
19. See Smith, Health Care Divided; Miles, The Department of Health, Education, and Welfare; and Quadagno, "Promoting Civil Rights Through the Welfare State."
24. For earlier data, see Wing, “Title VI and Health Facilities.” For data from the 1980s and 1990s, see U.S. Commission on Civil Rights, Federal Title VI Enforcement to Ensure Nondiscrimination in Federally Assisted Programs.
25. Smith, "Racial and Ethnic Health Disparities and the Unfinished Civil Rights Agenda."
26. Wing, “Title VI and Health Facilities,” 144.
28. Wing, “Title VI and Health Facilities,” 146.
30. Memorandum, James M. Quigley to staff of OS and agencies, 8 February 1965, Reel 2, part 1, chap. 3, p. 51, HEW.
32. Reel 2, part 1, chap. 4, p. 28, HEW.
34. With this new arrangement, direct Title VI appropriations were made by Congress. Under the prior approach, no separate Title VI funds were allocated to the various agencies within HEW. See "OCR Title VI Report," Reel 2, part 1, chap. 5, p. 2, HEW.
35. Reel 2, part 1, chap. 5, p. 3–4, HEW.
36. The other major enforcement agency in employment, the Office for Federal Contract Compliance, monitors the civil rights compliance of federal contractors. Though not a stand-alone agency, the OFCC had the power to cut off funding to federal contractors that did not comply with antidiscrimination requirements and the support of the Department of Labor (in which it was situated) to use this authority. See Hugh Davis Graham, “The Politics of Clientele Capture: Civil Rights Policy and the Reagan Administration,” 103–19, in Redefining Equality, ed. Neal Devins and Davison M. Douglas (New York, 1998).
37. U.S. Commission on Civil Rights, HEW and Title VI, vi.
38. “The Department of Health, Education, and Welfare During the Administration of President Lyndon B. Johnson,” Reel 1, part 1, pp. 1–2, HEW.
41. HJC 1973, 166.
43. Letter, Law Offices of Rauh, Silard and Lichtman to Patricia Roberts Harris, 10 August 1979, Box 53, Folder: OCR 1979, Patricia Roberts Harris Papers, LoC.
45. Graham, “Civil Rights Policy in the Carter Presidency.”
49. “Memorandum for the Heads of Executive Departments and Agencies,” 20 July 1977, box 4, Civil Rights Act of 1964 Title VI, Martha (Bunny) Mitchell Papers, CPM. The memo also notes that “administrative proceedings leading to fund terminations are the preferred method of enforcing Title VI, and this sanction must be utilized in appropriate cases. . . . The effective use of the sanctions provided by Title VI is an essential element of this Administration’s effort to guarantee that Federal funds do not flow to discriminatory programs.”
51. Author telephone interview with David Tatel, former OCR Director, 28 January 2003.
53. The AFL-CIO also opposed creation of a separate Education Department, arguing that “a coordinated health, welfare, and education approach” was best suited to tackle the problems of “poverty, equal educational opportunity, welfare, youth unemployment and health security. Labor has been instrumental in building coalitions around these issues. A fragmentation of their administration will only encourage narrow thinking and a fragmentation of the political voice that now speaks for all of them.” Statement on “Separate Department of Education” adopted by the Twelfth Constitutional Convention, AFL-CIO, December 1977; reprinted in House Government Operations/ Legislation and National Security Subcommittee, “Establishing a Department of Education” (17, 20, and 21 July 1978, 1 and 2 August 1978), 321.
55. Author telephone interview with Peter Jacobson, former OCR director of Divisional Analysis, 11 November 2002.
56. See, for example, Pierson, Dismantling the Welfare State! (New York, 1994); and Steven A. Shull, The President and Civil Rights Policy: Leadership and Change (New York, 1989).
57. See, for example, Pierson, Dismantling the Welfare State!; Skocpol, Protecting Soldiers and Mothers (Cambridge, Mass., 1992); and Margaret Weir, Politics and Jobs (Princeton, 1992).
60. House Government Operations/Intergovernmental Relations and Human Resources Subcommittee, “Oversight of the Office for Civil Rights at the Department of Health and Human Services” (6 and 7 August 1978), 84.
63. HHS Title VI Regulation, 45 CFR 80.6.
64. Perez, “The Civil Rights Dimension of Racial and Ethnic Disparities in Health Status,” 651. It was not until 1974 that OCR tried to gather data systematically from hospitals to monitor compliance with Title VI—and then only in response to a consent decree from a case regarding segregation in New Orleans hospitals. The findings from this initiative, finally released in 1977, represented “the only systematic effort ever conducted to evaluate the impact of the Civil Rights Act and the enforcement of Title VI in the Medicare program on racial segregation in hospital care in a metropolitan area” (Smith, Health Care Divided, 174).
66. Michelle van Ryn and Jane Burke, “The Effect of Patient Race and Socio-Economic Status on Physicians’ Perceptions of Patients,” Social Science and Medicine 50 (2000): 813–28. Van Ryn and Burke analyzed data from 618 post-angiogram physician-patient encounters in New York State, finding that the race of patients is associated with physicians’ assessment of patient intelligence, feelings of affiliation toward the patient, expectations of noncompliance, and beliefs about patients’ likelihood of high-risk behaviors. These differences persisted after adjusting for socioeconomic status and standard covariates, including patient age, sex, and health-risk status, and physician age, race, sex, and specialty.
68. “AMA announces new program to tackle health care disparities,” 11 December 2002, accessed 3 April 2003 at www.ama-assn.org/ama. At the same site, see also
“Perception vs. Reality” and “AMA collaborates with others in new health disparities initiative,” 17 February 2003.

69. See Kaiser Family Foundation, “Racial/Ethnic Differences in Cardiac Care: The Weight of the Evidence (Summary Report)” (Menlo Park, Calif., 2002). While racial differences in cardiac care appear to be the best documented, there is good reason to believe that unequal treatment occurs across many categories of treatment. In one of the two main reviews of the literature on disparate treatment, Geiger finds that “the preponderance of the evidence strongly suggests that among the multiple causes of racial and ethnic disparities in American health care, provider and institutional bias are significant contributors—a possibility raised repeatedly, if reluctantly, by many researchers.” As he observes, compared to (important) efforts to target “differences in the social, physical and biological environments—incomes, education, occupation, housing and nutrition—which are themselves determined in part by persistent racism . . . provider and institutional bias are far more directly (though not easily) remediable, and represent an opportunity for more rapid change.” H. Jack Geiger, “Racial and Ethnic Disparities in Diagnosis and Treatment: A Review of the Evidence and a Consideration of Causes,” Papers in Institute of Medicine, Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare (Washington, D.C., 2002). The same argument is made in David Barton Smith, “Eliminate the Disparities in Treatment: The Link to Healing a Nation,” Journal of Healthcare Management 47, no. 3: 156–60. The other primary literature review in this area, by Mayberry et al., finds that the evidence for racial disparities in treatment varies according to disease category and service type. They find the evidence for disparate treatment to be relatively strong in the area of heart disease and stroke, and somewhat less conclusive in areas such as cancer, HIV/AIDS, diabetes, and mental health. Mayberry and his colleagues urge further research into the causes of racial health disparities, which remain “poorly understood.” See Robert M. Mayberry, Fatimi Mili, and Elizabeth Ofili, “Racial and Ethnic Differences in Access to Medical Care,” Medical Care Research and Review 57, supplement 1 (2000): 131.


73. Leadership Conference on Civil Rights, “Position Paper on Administration of Civil Rights Programs,” box 164, Civil Rights/Liberities–Minorities (General), Domestic Policy Staff Files: Eizenstat, CPM.

74. Memo, Albert A. Applegate to George Romney, box 41, George Romney Papers, Bentley Historical Library, Ann Arbor.

75. Such an office also might be responsible for assuring compliance with existing health-quality standards. See Rosenbaum and Teitelbaum, “Civil Rights Enforcement in the Modern Healthcare System.”