THE RIGHT TO EQUAL TREATMENT

An Action Plan to End Racial and Ethnic Disparities in Clinical Diagnosis and Treatment in the United States

A Report by the Panel on Racial and Ethnic Disparities in Medical Care Convened by Physicians for Human Rights

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ABOUT PHYSICIANS FOR HUMAN RIGHTS

Physicians for Human Rights (PHR) promotes health by protecting human rights. PHR believes that respect for human rights is essential for the health and well-being of all people.

Since 1986, PHR members have worked to stop torture, disappearances, and political killings by governments and opposition groups and to investigate and expose violations, including: deaths, injuries, and trauma inflicted on civilians during conflicts; suffering and deprivation, including denial of access to health care, caused by ethnic and racial discrimination; mental and physical anguish inflicted on women by abuse; exploitation of children in labor practices; loss of life or limb from landmines and other indiscriminate weapons; harsh methods of incarceration in prisons and detention centers; and poor health stemming from vast inequalities in societies. Over 400 health professionals are part of PHR's Asylum Network, providing medical evaluations for hundreds of asylum seekers over the past decade. PHR also works to protect health professionals who are victims of violations of human rights and to prevent medical complicity in torture and other abuses. PHR works to educate health professionals and medical and public health students and organize them to become active in supporting a movement for human rights and creating a culture of human rights in the medical and scientific professions. As one of the original steering committee members of the International Campaign to Ban Landmines, PHR shared the 1997 Nobel Peace Prize.

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I. EXECUTIVE SUMMARY

Introduction

While the health status of all American population groups has improved dramatically over the past six decades, the gaps between whites and minorities—African Americans, Hispanics, Native Americans and some Asian subgroups—have persisted and, on some indicators, widened. These racial and ethnic minorities have continued to experience deeply troubling annual rates of excess morbidity and mortality: in sum, to live sicker and die younger. These disparities in health *status* are the consequence of environmental factors (social, physical, biological and economic), behavioral risk factors, and lack of access to medical care. They have long been the focus of increasingly intense governmental, professional and health policy concern, and are the targets of such recent interventions by the Department of Health and Human Services as *Healthy People 2000* and *Healthy People 2010*.

Only relatively recently, however, has attention been focused on a second category of health gap—racial and ethnic disparities in health *care*, in the quality, intensity and comprehensiveness of diagnostic procedures and treatment choices afforded minority patients. Once an isolated issue, the last few decades have seen the peer-reviewed publication of hundreds of health services and epidemiological research studies, marked by increasingly sophisticated control of such confounding variables as health insurance, income, education, age, sex, and disease severity, documenting such disparities. At least eight major and independent reviews have affirmed these findings, most notably the landmark 2002 publication by the Institute of Medicine, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare*. That report examined the complex question of causation and raised the possibility that institutional practices and provider bias and stereotyping, often below the level of conscious awareness but reflective of persistent and divisive forces in the nation's social structure, were significant contributors to racial and ethnic disparities in health care.

Purpose of the Study

In recognition of the human rights implications of these disparities, Physicians for Human Rights (PHR) has carried out a four-part effort to contribute to the goal of eliminating racial and ethnic differences in medical care. Over the past four years, its components were:

1. As a resource for policy makers and researchers, the creation of a comprehensive bibliography of relevant studies of racial/ethnic disparities in care, and of issues related to causation; and
2. A compilation of more than 400 detailed annotations, critically analyzing and summarizing a selection of key research studies across a wide spectrum of disease categories, prepared by a staff of clinicians, health services researchers, and epidemiologists;

These are available on the enclosed CD-ROM and are posted on the PHR website (www.phrusa.org).

3. The preparation of commissioned papers on civil and human rights, cultural competency education for health care providers, and stereotyping in clinical decision making; and
4. Convening a distinguished Panel on Racial and Ethnic Disparities in Medical Care [the Panel], to review this evidence and make specific recommendations for action.

Summary of Findings

The Panel's review of this massive body of research data affirms and extends the conclusions of the Institute of Medicine's *Unequal Treatment* report. It finds the evidence of racial and ethnic disparities in medical care to be widespread, occurring across the full spectrum of disease categories and medical and surgical procedures. The evidence is robust, beyond reasonable doubt, of a pervasive and troubling finding in the health care system, and a cause for deep concern. It shows that these disparities are imbedded in two aspects of the nation's larger social and health care structures: the persistence of negative racial and ethnic

stereotyping and bias, reflected in repeated national surveys, and the inequities of a system that leaves more than 40 million Americans without health insurance. The Panel recognizes multiple patient, provider and institutional factors as the causes of racial and ethnic disparities in care, but notes that the question of bias is central to human rights concerns, and defines bias in health care as a double violation: of the egalitarian commitments and ethics of medicine and of the democratic principles of the larger society. It concludes that racial and ethnic bias and stereotyping by providers make significant contributions to the disparities that have been so thoroughly documented in the American health care system, mandating both further research and targeted interventions to affect change.

Civil and Human Rights Perspective

The Panel's report is unique in its invocation of a civil and human rights perspective and its emphasis on the obligations of government to eliminate discrimination. Responsibilities to end all forms of racial discrimination are set out in an international treaty that the United States has joined, the Convention on the Elimination of all Forms of Racial Discrimination. At its disposal under domestic law is the familiar and powerful tool of Title VI of the Civil Rights Act of 1964.

Title VI of the Civil Rights Act

Title VI of the Civil Rights Act requires that recipients of federal financial assistance may not discriminate on the basis of race, color or national origin. Since virtually all providers of health services receive federal payments under some federal program, Title VI now applies to most health care activities in the United States and makes clear that lower quality health services that are a product of provider attitudes or institutional practices that are biased on account of race or ethnicity violate Title VI. The law also applies to systematic discrimination or a "pattern or practice" of discrimination and also bans policies or practices that, while apparently not based on race or ethnicity, have a discriminatory impact on minorities and lack a substantial justification.

Unfortunately addressing discrimination in health care services has been the forgotten frontier of civil rights enforcement and, as a result, the tremendous potential of Title VI to address racial and ethnic disparities in health care remains untapped. The federal agency principally responsible for assuring compliance with Title VI in the area of health services, the Office of Civil Rights(OCR) of the Department of Health and Human Services (HHS), has lacked the resources, the competence and the commitment to address disparities in the quality of health services that are based on race. The Panel stresses that OCR already has the mandate to collect and analyze data on disparities in the quality of health services, to foster collaboration to secure voluntary compliance, to engage in investigation and, where voluntary efforts fail, to take enforcement action against entities that engage in intentional discrimination or whose policies and practices have a disparate impact on minorities without substantial justification. But OCR has done little to identify and address disparities in the quality of health care received by minorities in the United States. The Panel emphasizes that with the necessary staff, financial resources and expertise, OCR can offer powerful leadership. It can educate and provide effective technical assistance to recipients of federal funds to encourage voluntary compliance, develop consistent policy guidelines to disseminate throughout the agency and engage in investigations and enforcement clearly within its jurisdiction when voluntary compliance fails.

International Convention on the Elimination of All Forms of Racial Discrimination (CERD)

Achieving compliance with everyone's right to quality treatment, not compromised or limited by attitudes about race and ethnicity, is not simply a matter of enforcing complaint-driven civil rights law by federal agencies or the courts. The human rights at stake require far more concerted leadership and action by the federal government. That is why commitments the United States has made to abide by international human rights law play so large a role in the Panel's analysis. That body of law requires not simply judicial remedies for violations of civil rights, but comprehensive and effective steps that will bring discrimination to an end regardless of individual complaints.

These obligations are contained in the International Convention on the Elimination of All Forms of Racial Discrimination (CERD), adopted in 1965

by the UN General Assembly and ratified by the United States, in 1994. The Convention sets out the elements of government responsibility to end discrimination. The basic requirement of CERD, set out in Article 2, is that "States Parties condemn racial discrimination and undertake to pursue by all appropriate means and without delay a policy of eliminating racial discrimination in all its forms and promoting understanding among all races." It then sets out specific activities governments agree to undertake to eliminate discrimination. These include not engaging in discrimination itself; not taking actions to "sponsor, defend or support racial discrimination by any persons or organizations;" reviewing laws and policies and eliminating any that have the effect of creating or perpetuating discrimination; and prohibiting and bringing to an end "racial discrimination by any persons, group or organization." In other words, CERD obliges governments to take steps not merely to respond to instances of racial discrimination through enforcement activities, but to take vigorous and thorough steps to eliminate racial discrimination in society. The treaty also makes clear that discrimination encompasses practices that have a disparate impact as well as those that are a result of intentional discrimination.

The Role of the Federal Government

The Panel places special emphasis on the critical role the federal government needs to play in systematically identifying and monitoring disparities in the quality of health services throughout the United States. As in other areas where civil rights are at great risk, the federal government should assure that data on race and ethnicity (and primary language) is collected in all clinical records and that federal health agencies analyze these data regularly so that disparities may be identified in communities and institutions across the nation. Once disparities are identified, administrators of health plans and facilities, health professionals, and community organizations can ascertain the reasons for the disparities and work proactively to end them. The Panel notes that not all statistical disparities amount to discrimination, but an identified disparity would nevertheless need to be explored and explained to determine where there exists a non-discriminatory reason for the disparity.

There exist two dimensions tothis task. The first is to assure that federal policies that require collection of race and ethnicity (and primary language) data in clinical and administrative records in the United States health care system are consistently followed and enforced; currently, the experience is to the contrary. The second requirement is to analyze data regularly, using accepted quality assurance measures, to detect disparities based on race and ethnicity. Federal action to establish a system within federal health agencies to collect data on race and ethnicity and regularly provide analysis is the only way to identify disparate treatment and then to provide effective remedies.

Summary of Recommendations

Collection and monitoring of the quality of health services by race and ethnicity is simply the start, however. The Panel endorses the Institute of Medicine's 21 general recommendations for change and asserts that what is required now is to translate each of these principles into recommendations for specific actions by identifiable and accountable stakeholders—government agencies, public and private sector institutional providers of care, health professionals and their organizations, quality assurance agencies, educational institutions and accrediting authorities, community-based advocacy groups and civil rights monitors and human rights organizations.

To these ends, the Panel offers some 24 detailed policy recommendations and 11 research recommendations—the core of this report—as the agenda for a sustained advocacy campaign to reduce and eliminate racial and ethnic disparities in health care, and as yardsticks to measure progress toward that goal. The Panel recommendations attempt to indicate both what needs to be done and who should do it.

These detailed recommendations are contained in the last chapter of this report. They should be understood as part of a concerted plan to meet the United States' obligations under international human rights law, particularly treaty obligations under the Convention on the Elimination of All Forms of Racial Discrimination to end "racial discrimination in all its forms and promot[e] understanding among all races." Specific actions taken

should be included in the United States report due bi-annually under the Convention to the treaty monitoring committee. In sum, the Panel recommends the following actions.

To the Federal Government:
The federal government, through actions by Congress and the executive branch, should:

- Strengthen the capacity of civil rights enforcement agencies to investigate disparities in the quality of care based on race or ethnicity through increased funding for the Office of Civil Rights (OCR) in the Department of Health and Human Services (HHS), establishing an Office of Health Disparities within OCR, and creating a Health Section in the Civil Rights Division of the Department of Justice.

- Assure that the Department of Health and Human Services, its agencies, and all private health providers receiving federal funds collect data on race, ethnicity and primary language in clinical patient records according to standards established by the Office of Management and Budget. HHS should create an outreach campaign to assure understanding of the reasons for such data collection and to protect against its misuse. Congress should provide financial assistance to states to enable them to meet federal standards in programs they administer.

- Assure that the Centers on Medicare and Medicaid Services and other federal agencies that finance health care services engage in systematic, periodic analysis of racial disparities in clinical care programs they support, using standard quality assurance measures. The Agency for Healthcare Research and Quality should provide technical assistance in this analysis. Congress should also provide financial incentives to encourage private health care providers and plans to engage in such analysis and provide support for additional quality assurance measures. Each year the Department of Health and Human Services should sponsor an annual conference on progress in eliminating racial and ethnic disparities in the quality of health care.

- Assure adequate and sustained funding for federal agencies monitoring and seeking to end racial and ethnic disparities in the quality of care. These agencies include the Office of Minority Health and the National Center on Minority Health and Health Disparities, among others.

- Assure funding for programs designed to increase diversity in the health workforce.

- Take steps to make access to health care available to all Americans, since universal coverage is essential to achieve equity and quality.

To National Organizations of Health Care Professionals:
National organizations of health care professionals should:

- Continue to expand programs in cultural competence and increase awareness of unconscious biases in clinical treatment decisions, and collaborate with community-based organizations in eliminating racial and ethnic disparities in the quality of health care. Boards that certify health professionals in specialties should require cultural competency training and emphasize evidence-based practice for quality assurance purposes.

To Educational Institutions for Health Professionals:
Educational institutions for health professionals should:

- Include cultural competency training at all levels of curriculum and training programs, engage in affirmative action to diversify the health workforce and develop tools to encourage self-assessment regarding racial and ethnic disparities in quality of care at both individual and institutional levels.

To Licensing Agencies:
Licensing agencies should:

- Include measures of cultural competence, measures of evidence-based practice and awareness of evidence of racial and ethnic disparities in their standards.

To Accreditation Agencies:
Accreditation agencies should:

- Include requirements related to the assessment and elimination of racial and ethnic disparities in standards for institutions they certify.

To Community-Based and Minority Advocacy Organizations:
Community-based and minority advocacy organizations should:

- Collaborate with health professional organizations in efforts to end racial and ethnic disparities in the quality of health care.

To the Research Community, including Funding Agencies:
The research community, including funding agencies, should:

- Support and engage in a range of research activities to better understand the causes of racial and ethnic disparities in the quality of health care, including the nature and impact of stereotyping, patient mistrust of providers, and other factors; the effectiveness of various interventions in eliminating these disparities; and the relationship of factors like socio-economic status to disparities in the quality of care.

II. INTRODUCTION

Almost sixty years have passed since the publication of *An American Dilemma*, Gunnar Myrdal's comprehensive examination of the conflict between America's commitments to equality and its racial practices. In a chapter on race and health status, Myrdal wrote: "Area for area, class for class, Negroes cannot get the same advantage in the way of prevention and cure of disease that the whites can…Discrimination increases Negro sickness and death both directly and indirectly, and manifests itself both consciously and unconsciously."[1] It is an astonishingly prescient statement, validated now by thousands of studies presenting evidence of racial and ethnic disparities in both health status and medical care, and it is as relevant—and also applicable to Hispanic Americans, Native Americans, and Asian/Pacific Islander American subgroups—as when it was written. But the statement has a larger significance. *An American Dilemma* was, at its core, a major human rights document, and it included health status and health services as appropriate arenas of human rights attention and concern.

Over the ensuing six decades, the legal, political, economic and social structures of American society have, of course, changed profoundly. But while the health status of all population groups has improved dramatically, the gaps between whites and minority groups have persisted and, on some indicators, widened. Racial and ethnic minorities continue to live sicker and die younger. At present, for example, in comparison with the white majority, there are 130,000 *excess* African American deaths annually. Classic public health research demonstrates that the poorer health status of minorities in the United States is primarily due to environmental factors—social, physical, biological and economic—as well as to lack of access to medical care. These disparities in health status have been a focus of increasingly intense governmental, professional and health policy concern since the 1985 publication by the US Department of Health and Human Services (HHS) of the Secretary's Task Force on Black and Minority Health,[2] culminating in the elaboration of specific programs and goals for the elimination of such differentials in *Healthy People 2000* and *Healthy People 2010.*[3]

A significant contribution to poorer health status may also be made by racial and ethnic disparities in medical care itself—differences in the quality, intensity and comprehensiveness of diagnostic processes and treatment choices that can profoundly affect quality of life, morbidity and mortality. Yet even after the end of *de jure* segregation in medical care, and until relatively recently, such racial and ethnic differences in treatment remained an isolated issue, rather than a focus of concern.

Well into the 20th century, observations of differences were presented as evidence that African Americans were fundamentally different from (and inferior to) whites in physiology and susceptibility to disease. More scientific (but scattered) studies focusing on disparities in treatment began to appear in the peer-reviewed literature in the 1960s, especially during the civil rights struggles of that decade. Their number grew steadily during the 1970s and 1980s, and—facilitated by access to computerized databases and the development of multi-center and system-wide studies—appeared by the hundreds in the 1990s. These studies were, furthermore, marked by increasing sophistication in the control of such confounding variables as health insurance coverage, income, education, age, sex, disease severity and concomitant morbidity. Yet it was not until 2000, in the pioneering work of

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[1] Myrdal G. *An American Dilemma*. Vol 1. New York: Harper & Brothers Publishers; 1944.

[2] US Department of Health and Human Services, *Report of the Secretary's Task Force on Black and Minority Health*. Washington, DC: USDHHS; 1985.

[3] US Department of Health and Human Services, *Healthy People 2010: Understanding and Improving Health*. Washington, DC: USDHHS; 2000.

[4] Mayberry RM, Mili F, Ofili E. Racial and ethnic differences in access to medical care. *Medical Care Research and Review. 2000*; 57, Suppl 1:108-145.

Mayberry, Mili and Ofili,[4] that the first attempt at comprehensive review and analysis was published.

Multiple theories of causation were offered, but these studies cumulatively raised the possibility that racially discriminatory clinical decisions by physicians, often below the level of conscious awareness, and the institutional cultures of hospitals and other organized providers of care were major contributing factors. If so, this is more than a routine medical quality assurance issue. It is a double violation: of the egalitarian commitments and ethics of medicine and of the democratic principles of the larger society. It is thus an issue of unique concern to Physicians for Human Rights (PHR). A human rights perspective is especially important because of its emphasis on the responsibility of government to end all elements of racial and ethnic discrimination.

In recognition of the human rights implications of these disparities, PHR has, over the past four years, carried out a four-part effort to contribute to the goal of eliminating racial and ethnic differences in the quality of medical care. With support from the Ford Foundation, the W. K. Kellogg Foundation, the Commonwealth Fund, the Josiah Macy, Jr., Foundation, and the Robert Wood Johnson Foundation, its components were:

1. As a resource for policy makers and researchers, the creation of a comprehensive bibliography of relevant studies of racial/ethnic disparities in care and of issues related to causation, from more than two decades of the peer-reviewed literature;

2. A compilation of more than 400 detailed annotations, critically analyzing and summarizing a selection of key research studies examining racial/ethnic disparities in care across a wide spectrum of disease categories and medical and surgical procedures;

3. The preparation of commissioned papers on civil and human rights, cultural competency education for health care providers and stereotyping in clinical decision-making;

4. Convening a distinguished Panel on Racial and Ethnic Disparities in Medical Care, to review this evidence and make specific recommendations for action.

The bibliography and annotations are included on the enclosed CD-ROM and posted on the PHR website (www.phrusa.org). It should be noted that in all documents (the report, CD and website), as in the research studies upon which they draw, the term "race" refers to perceived or self-identified race, a social category, and does not imply a scientifically established biological category.

While this work was in progress, a substantial number of relevant reviews, foundation reports, and a wide variety of governmental and private-sector programs have contributed to the recognition of the racial/ethnic disparities problem in the quality of treatment and offered proposals for change. These efforts culminated, just over a year ago, in the landmark publication by the Institute of Medicine, National Academy of Sciences, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare*, a massive review of the evidence, scholarly discussions of related issues, and a series of recommendations for ongoing efforts to reduce and eliminate such differences.

This PHR report is presented in the hope of building on those efforts, and as a step in accord with the Panel's primary conclusion: that a sustained campaign, shaped by an action plan widely involving government, the private health care sector, professional medical and health care organizations and providers, academic medical centers, and community-based and minority advocacy organizations in legislative, regulatory, educational and administrative reforms, will be required to eliminate racial and ethnic disparities in American health care. The danger—all too familiar in human rights and civil rights efforts—is that reports and recommendations will be allowed to fade on the shelf. The need is for an informed, committed and insistent campaign for medical justice.

III. THE CONTEXT OF DISPARITIES IN HEALTH CARE

In "pre-civil rights America," William Finnegan has noted, "the second-class citizenship of black people was a settled fact, in education, political enfranchisement, housing and employment."[5] It was a time, in Gerald Thomson's description, "when the United States was generally willing to deny proper health care on the basis of race" and health care "was embedded in intense racism and discrimination."[6] North and South alike, *de jure* and *de facto* segregation meant exclusion from hospitals, clinics, and physicians' offices, or care in separate and unequal facilities. Both access to and quality of care were profoundly affected. As one scholar summarized the evidence, in the pre-civil rights era, "discrimination was everywhere, including among the medical and health professionals who furnished care and ultimately determined the structure, design, and operation of the health system."[7] No clearer evidence could be offered that, despite ethical obligations to equality, the institutions of medical care (and many of its practitioners) were not immune to the prevailing racial attitudes and beliefs of the majority. The civil rights legislation of the mid-1960s, and in particular Title VI of the Civil Rights Act of 1964, dramatically changed that landscape, but the issue of continuing racial and ethnic differences in medical care must still be viewed in the context of the larger society and its current views of race and ethnicity.

Even after the two federal laws that forced the desegregation of many aspects of medical care, the Civil Rights Act of 1964 and the Medicare Act, the legacy of generations of discrimination continued to be felt, not only in practice – such as the effective exclusion of African American and other minority practitioners from hospital admitting privileges – but also in laws that continue to allow individual health care providers to choose whom to serve. As Myrdal had noted decades earlier, both restricted access *to* care and differences *in* care were the result.

But these are symptoms of a larger injustice. Multiple national studies of majority beliefs about minorities affirm that negative racial and ethnic characterizations, though often subtler in open expression, continue to be both widely held and stubbornly resistant to change. In a national social survey in 1990, for example, 29% of white respondents characterized blacks and Hispanics as "unintelligent"; 44% said blacks were "lazy" and 33% said the same of Hispanics; 56% and 42%, respectively, said blacks and Hispanics "prefer welfare," and 50% and 38%, respectively, believed blacks and Hispanics were "violence-prone." Five years later, a similar study reported almost identical responses, including a judgment by 60% of white respondents that "most blacks just don't have the motivation or willpower to pull themselves up out of poverty." In 2001, a Washington Post/Kaiser Family Foundation/Harvard University survey offered substantial evidence of majority desensitization or denial of the consequences of commonly held views of minorities: 51% of whites asserted that African Americans have "about the same opportunities in life as whites have," and 49% said the same of Hispanics. And with regard to access to health care, 50% of whites said African Americans are "just about as well off as the average white person," and 44% said the same of Hispanics.[8]

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[5] Finnegan W. "The Fire Last Time." *New York Times Book Review*. March 23, 2003.

[6] Thomson GE. Discrimination in health care. *Annals of Internal Medicine* 1997; 126: 910-912.

[7] Rosenbaum S, Markus A, and Darnell J. US civil rights policy & access to health care by minority Americans: implications for a changing health care system. *Medical Care Research and Review*. 2000; 57 (Supp 1): at 237.

[8] These findings reflect an ideological fantasy: that racism has been conquered, and American society is already "colorblind." The achievement of colorblindness, in this view, can be affirmed by simply prohibiting official identification of individuals by race or ethnicity. Such so-called "racial privacy" initiatives in several states are efforts to "establish" colorblindness by denying the continuing reality of everyday racism.

Racial and Ethnic Characterization by Physicians

Physicians do not generally perceive bias in the health care system. A Kaiser Foundation National Survey of Physicians conducted in March 2002 found that 55% of doctors asserted that the health care system "rarely" treats people unfairly based on racial or ethnic background; an additional 10% said "never." Similar denials were found of unfair treatment based on gender, or on fluency in English. Less than one third of physicians believed that the health care system "at least sometimes" treats people unfairly because of their race or ethnic background. (The responses of African American and Latino physicians differed sharply: 77% and 52%, respectively, said this occurs at least somewhat often.) Despite these overall perceptions of the health care system, however, 65% of respondents correctly disagreed with the statement that "African Americans are just as likely as whites who have heart disease to get specialized medical procedures and surgery," and 57% correctly agreed that "whites with HIV or AIDS are more likely than African Americans with HIV or AIDS to get the newest medicines or treatments." It is noteworthy that white physicians were less likely than the general public to believe that unfair treatment on the basis of race or ethnicity occurs at least "somewhat often" (29% vs. 47%).

On the causes of unfair treatment, provider bias was not cited as a contributor. Doctors were more likely to believe that unfair treatment based on race/ethnicity was largely due to "too few doctors being available in minority communities (58%), but 52% also agreed that it occurs because "many doctors are not skilled in communicating with people from different racial or ethnic backgrounds."

Race and ethnicity (as well as social class and primary language) thus remain powerful and often divisive markers for differential experience in American society, and such differences are manifested not only by such traditional indices as residential segregation, educational resources, employment opportunity, or access to mortgage loans, but also within the health care system.

Inequity in Access to Care

Within the health care system, racial and ethnic disparities are imbedded in a larger structure of inequity. More than 40 million Americans have no health insurance, and more than 60 million lacked such insurance for at least part of a recent year. Those numbers are currently growing rapidly as states facing fiscal crises reduce Medicaid eligibility (and often limit benefits, a less visible limitation of insurance coverage, as well). Proposals to convert Medicaid into block grants to states—and free them from federal eligibility requirements—are likely to exacerbate these trends. There are continuing imbalances between urban and rural areas in hospital resources and the availability of other medical providers and managed care organizations, as well as between the supplies of primary care physicians and specialists.

Collectively, these factors limit and distort access to care. They often result in postponement of physician visits, reliance on home remedies or over-the-counter medications, presentation at later stages of disease, lack of access to specialty services, limitations on the comprehensiveness of care, and reliance on emergency rooms. Lack of a continuous relationship with a primary care physician or what has been termed a "medical home" may increase distrust in the health care system among all such access-limited patients, but particularly among minority patients. These are powerful structural determinants of quality of care.[9] Although nominally race-neutral, these barriers to equal health care and treatment access have a disproportionate effect on minority populations. While they neither explain nor justify the findings of differences by race/ethnicity in the care of similarly insured and situated patients described in the next section of this report, they clearly affect the health status of disadvantaged populations.[10]

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[9] Bloche, G. Race and Discretion. *Yale Journal of Health Policy, Law, and Ethics*, Spring 2001; 1: 95-131.

[10] See, for example, Shavers VL, Shankar S, Alberg AJ. Perceived access to health care and its influence on the prevalence of behavioral risks among urban African Americans. *Journal of the National Medical Association*. 2002;94:952-962.

IV. THE EVIDENCE AND ITS IMPLICATIONS

The possibility that the quality, intensity and comprehensiveness of medical care varies by race and ethnicity raises two essential questions:

1. Is there consistent, credible and robust evidence, in studies properly designed and appropriately controlled for major confounding variables, of differences by race and ethnicity in diagnostic procedures and therapeutic interventions?

2. If such compelling evidence exists, what is known about its causes?

What the Evidence Shows

The answer to the first question is affirmative, and is beyond reasonable doubt. There are by now literally hundreds of competent studies and the overwhelming majority have found that, overall, African Americans, Hispanic Americans, and (to a less well documented extent) Native Americans and Asian American/Pacific Islander subgroups receive less care, and less intensive care, than comparable white patients. This pattern has been found not only for such high-technology interventions as angioplasty and coronary artery bypass grafting, advanced cancer chemotherapy, renal transplantation, advanced therapy for HIV/AIDS, diagnostic and treatment procedures for cerebrovascular and peripheral arterial disease, and glaucoma surgery, but also for such bread-and-butter processes as general medical and surgical procedures, and the treatment of asthma, diabetes, congestive heart failure and pneumonia. Disparities in care have been found even for such basic elements of clinical care as the adequacy of history-taking, physical examination, and routine laboratory and radiological procedures. In one of the essential elements of care—control of pain—studies have found that Hispanic patients with long-bone fractures and African American patients with colon cancer are substantially less likely than their white counterparts to receive adequate pain medication, and this is not due to any difficulty by physicians in accurately estimating the intensity of pain in minority patients.

In the management of coronary artery disease, the subject that has been most intensively studied, there is good evidence that denial of appropriate treatment has included African American patients who were most seriously ill and were most likely to have benefited, and that this contributed to significant differences in subsequent five-year mortality rates. There is ample, though by no means universal, evidence in this and other disease categories of similar effects on outcomes. Such differences in care are found after health insurance status, age, sex, income, education and other measures of socioeconomic status, hospital type and resources, stage and severity of disease, and presence or absence of concomitant disease have been accounted for. It should be noted that these racial/ethnic differences in care have been found in all hospital types—teaching and non-teaching, voluntary and public, as well as in the Veterans Affairs hospital system in which care is free, insurance coverage and physicians' fees are not relevant, and the socioeconomic spectrum of patients is narrower.

In the last three years, at least eight major reviews—two in the Institute of Medicine report alone, totaling more than 130 pages of description and analysis of peer-reviewed studies—have summarized this evidence. In a disease-categorical review by the American College of Cardiology Foundation, for example, 67 of 81 competent studies were found to show racial/ethnic differences in diagnostic procedures, treatment choices, or both. Many studies are based on detailed examination of clinical records and, in general, the more rigorous the criteria, the greater the likelihood of positive findings. The Institute of Medicine, for example, listed the 13 studies (among the hundreds cited) that met the most definitive methodological standards for design, data sources, and control of confounding variables; 11 of the 13 found significant racial/

ethnic differences in care. There is not absolute uniformity of results in surveys of large bodies of peer-reviewed research, and of course any single study has limitations of one sort or another. But the consistency of findings across a wide range of study types—retrospective and prospective—and of data sources, both administrative and clinical, is impressive. The American College of Cardiology review of cardiovascular studies, titled "The Weight of the Evidence," has been posted on the Web at www.kff.org/whythedifference, and there are plans to follow with studies in other disease categories.

To this already substantial body of work, Physicians for Human Rights has now added a major bibliography of relevant research literature citations covering studies in 17 different disease and treatment categories, ranging from asthma, cardiovascular disease and cancer, to diabetes, ophthalmic disease and end of life care, and also including studies of such related issues as patient trust, cultural competency, clinical trials and research methods (see Table I). In addition, in many of these categories, selected studies of particular importance are annotated and analyzed in detail. Approximately 400 such annotations are included, and abstracts of hundreds of other studies were included for the Panel's review and for subsequent use by the growing number of health disparities researchers. This effort involved a search of numerous databases and careful attention to the adequacy of study designs, sample sizes and nature, control of confounding variables, and the strengths and limitations of study conclusions. Each study selected for annotation was reviewed independently by a physician and a doctoral-level epidemiologist or health services researcher. This body of work confirms and extends the weight of the evidence establishing racial and ethnic disparities as a pervasive and troubling finding in the health care system, and a cause for deep concern.

Causes of Racial/Ethnic Disparities

The question of causation is much more complex, and it is far from resolved.

Most of the studies documenting racial/ethnic disparities in care include rather cursory discussions of possible causes—and many of those discussions are speculative, since retrospective studies drawn from administrative data sets record demographic data and information on the diagnostic and therapeutic processes chosen and on outcomes, but do not contain information on the factors that influenced or determined clinical decision-making. Studies based on detailed clinical records are a far more useful but not uniform source of such information. Prospective studies, much smaller in number, provide an opportunity for qualitative interviews with both patient and physician, but that is infrequently an element of the study design. Until recently, much of the data relevant to possible causes came from studies of the opinions, feelings, or reported experiences of patients, minority focus groups, health professional students, and physicians, and from observations of physician-patient interactions and communication. In general, however, these were not associated with information on the care received and thus could not shed light on causation in specific clinical cases. Only a small number of prospective studies, so far, have empirically examined factors that might account for the racial/ethnic disparities observed in a series of specific cases.

Theories of causation fall into three broad categories: patient factors, provider factors, and (less well-defined) institutional factors. Patient factors frequently cited to explain disparities in care include patient choice or preference (usually implying a patient's refusal to accept a physician's recommendation); cultural beliefs about health and medical care thought to be held by members of different minority groups; minority mistrust of the health care system (based at least in part on high reported rates of perceived instances of past discrimination); language barriers; difficulties in cross-racial/ethnic physician-patient communication; alleged biological differences in clinical presentation or responses to treatments and medications; and unmeasured aspects of socioeconomic status assumed to be associated with race or ethnicity.

Provider factors frequently cited include lack of cultural competency, physicians' practice styles, clinical uncertainty about the findings in the medical history or symptom presentation of minority patients, and both conscious and unconscious racial/ethnic bias and negative stereotyping that influence clinical decisions. Institutional factors may include such items as lack of familiarity with a diverse racial/ethnic case mix, or policies, nominally independent of race/ethnicity, with regard to

the treatment of uninsured patients which have a selective effect on the care of minorities because of their higher rates of lack of insurance.

It is important to distinguish between these putative causes of disparities in health care and those that are primary causes of the health status of minority groups but do not explain differences in the diagnosis or treatment of similarly insured and similarly diseased patients who differ only by race or ethnicity. Lack of health insurance and consequently impaired access to both general and specialty health care, for example, can cause initial presentation at advanced stages of disease. Socioeconomic factors like income and education show strong independent associations with morbidity and mortality. Behavioral choices and lifestyle factors are important influences on health status, but careful studies of attributable risk show that they account for less than a third of the observed gaps between the health status of minority and white populations in the United States.[11] Residential segregation profoundly exacerbates poverty, exposure to environmental hazards, and diminished access to medical, educational, occupational and other mainstream resources.[12]

There is some evidence in published studies for each of the proposed causes of racial/ethnic disparities in diagnosis and treatment. There is growing agreement that causation is multifactorial, and that each of these causes requires both further research and targeted corrective interventions. While physician behaviors—and their own awareness of the evidence and possibilities of bias—have properly been a major focus of attention, such other factors as minority mistrust must also be addressed. Recently proposed models suggest that the multiple factors may interact with each other: patient mistrust or cultural belief, for example, may induce changes in physician behavior and communication, which in turn may be perceived as discriminatory and influence patient preference.

Mistrust of Physicians

Among these contributing causes, the question of mistrust of physicians deserves particular attention. Recent surveys have revealed alarming levels of suspicion among all patients, but especially among African American patients. In one such study,[13] 63% of African Americans and 38% of whites believed their physicians often prescribed medication as a means to experiment on people without their consent; 25% of African Americans and 8% of whites believed that their doctor had actually given them an experimental treatment without their consent. More than 45% of African Americans and approximately 35% of whites said they believed that their doctor might expose them to unnecessary risks. In the same study, the role that mistrust may play in the physician-patient encounter is illustrated by findings that some 15% of African Americans did not feel they could freely question their doctors, a rate almost double that of whites. These results were consistent across all educational and income levels. Such findings of mistrust are particularly intense with regard to participation in clinical trials and medical research[14] but are by no means limited to those aspects of care. The record of similar studies extends back over three decades or more, and are consistent with the detailed descriptions of qualitative studies of minority and white focus groups. Mistrust obviously affects compliance with prescribed regimens and may interact with cultural

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[11] Lantz PM, House JS, Lepkowski JM, Williams DR, Mero RP, Chen J. Socioeconomic factors, health behaviors, and mortality: results from a nationally representative prospective study of US adults. *Journal of the American Medical Association*. 1998;279:1703-1708.

[12] Williams DR, Collins C. Racial residential segregation: a fundamental cause of racial disparities in health. *Public Health Reports*. 2001;116:404-416. The authors conclude that effective efforts to eliminate racial disparities in health status must seriously confront segregation and its pervasive consequences. For classic studies of residential segregation and its effects, see Massey DS, Denton NA. *American Apartheid: Segregation and the Making of the Underclass*. Cambridge, MA: Harvard University Press, 1993, and more recently, Irons P. *Jim Crow's Children: The Broken Promise of the Brown Decision*. New York: Viking Penguin, 2002.

[13] Corbie-Smith G, Thomas SB, St George DM. Distrust, race, and research. *Archives of Internal Medicine*. 2002;162:2458-2463.

See also Deuscher MP, Saver GB, Franks P, Fiscella K. Racial and ethnic disparities in perceptions of physician style and trust. *Archives of Family Medicine*. 2000;9:1156-1163.

[14] Shavers VL, Lynch CF, Burmeister LF. Racial differences in factors that influence the willingness to participate in medical research studies. *Annals of Epidemiology*. 2002;12:248-256. Also, by the same authors: Knowledge of the Tuskegee study and its impact on the willingness to participate in medical research studies. *Journal of the National Medical Association*. 2000; 92:563-572;

Corbie-Smith G. The continuing legacy of the Tuskegee Syphilis Study: considerations for clinical investigation. *American Journal of Medical Science*. 1999;317:5-8. See also Gamble VN. Under the shadow of Tuskegee: African Americans and health care. *American Journal of Public Health*. 1997;87:1773-1778.

beliefs: if physicians are not regarded as reliable, alternative theories of causation and of appropriate treatment may seem more credible.

The cultural competence of physicians and other health care professionals—that is, the ability to interact comfortably and appropriately with racially and ethnically diverse patients, to understand culturally determined health beliefs and value systems, to invite participation in clinical decision-making, and to explain diagnostic and treatment recommendations in terms that are understandable across social class and cultural lines—is now increasingly regarded as an essential component of a physician's knowledge and skills. Both patient "styles" and physician "styles" of verbal and nonverbal behavior in the clinical encounter may affect the adequacy of the medical history, the physician's understanding of the illness, the patient's satisfaction, and the outcome. And these problems are compounded by language barriers and the absence of skilled interpreters. As van Ryn has noted,[15] all these factors may interact to produce disparities in care. Our understanding of these processes is still far too limited, and that prompts the research recommendations that will follow in this report.

In many studies, no single factor has been found likely to account for all of the racial variance in care. For example, minority patient preferences may be identified as a contributor, but not as nearly sufficient to explain the observed disparities. Similarly, although many studies have found an association between patient demographic factors and health beliefs, there is a lack of evidence of an association between those beliefs and subsequent care received. Effective change will thus require the participation and involvement of minority communities – the populations most affected by disparate treatment – as well as that of physicians, their organizations, hospitals and other organized settings of care.

The Question of Bias

The question of bias, however, is central to human rights concerns. Among many discussions of this possibility, two studies in recent years are particularly useful in illustrating its role in clinical decision-making. In one, the projection of classic negative racial stereotypes onto African American patients with coronary artery disease was associated with physicians' decisions to deny a recommendation for angioplasty or bypass grafting even in some cases in which standard clinical criteria defined the need as urgent.[16] In the other, a review of clinical decisions by a group of Veterans Affairs cardiologists who were given all of the appropriate clinical information about patients with coronary artery disease—but were effectively blinded to each patient's race—found no significant difference in the treatment decisions made for African Americans and whites.[17] Removing that single variable from clinical awareness was associated with care that differed only by clinical characteristics, not race.

It is important to understand that negative social stereotyping—indeed, many forms of stereotyping—may occur below the level of conscious awareness. This phenomenon has been extensively studied and scientifically validated in research in cognitive psychology; stereotyping is a common cognitive shortcut. These studies have found that negative stereotyping may occur in persons who are not consciously prejudiced. While direct evidence of negative social stereotyping by health care providers is limited, other studies have established that stereotyping is facilitated by time pressure and situations of cognitive complexity—both of which characterize many clinical encounters.

Of all the putative causes of racial/ethnic disparities in care, the allegation of provider bias is the most disturbing to physicians, even when it is explained that most negative racial stereotyping occurs below the level of conscious awareness. It conflicts with their own conscious commitments and a deep-seated belief that patients should be treated fairly and equally. The weight of the present evidence, however, not only in peer-reviewed studies but also in the consistently reported experiences of minority patients and scattered but objective reports of openly expressed negative racial attitudes,[18] is already sufficiently compelling, and

[15] van Ryn M, Fu SS. Paved with good intentions: do public health and human service providers contribute to racial/ethnic disparities in health? *American Journal of Public Health*. 2003;93:248-255.

[16] van Ryn M, Burke J. The effect of patient race and socioeconomic status on physicians' perceptions of patients. *Social Science and Medicine*. 2000;50:813-828.

[17] Okelo S, Taylor AL, Wright JT, Gordon N, Mohan G, Lesnefsky E. Race and the decision to refer for coronary revascularization: The effect of physician awareness of patient ethnicity. *Journal of the American College of Cardiology*. 2001;38:698-704.

justifies a definitive statement. The Panel concludes that racial and ethnic bias and stereotyping by providers, operating most often below the level of conscious awareness, make one of the several types of significant contributions to the disparities in diagnosis, treatment and outcomes of minority patients that have been so thoroughly documented in the American health care system. It mandates both further research and targeted interventions to affect change.

[18] See, for example, Finucane TE, Carrese JA. Racial bias in presentation of cases. *Journal of General Internal Medicine*.1990;5:120-121, and Anderson MR, Moscou S, Fulcohn C, Neuspel DR. The role of race in the clinical presentation. *Family Medicine*. 2001;33:430-434, and South-Paul H. Racism in the examining room: Myths, realities and consequences. *Family Medicine*. 2001;33:473-475.

V. RACIAL DISPARITIES IN CLINICAL CARE: CIVIL RIGHTS AND HUMAN RIGHTS LAW PERSPECTIVE

The existence of racial and ethnic disparities in treatment is, of course, a problem of quality of care. Initiatives by many health care organizations and associations to eliminate disparities address a core dimension of quality. The recognition by the Institute of Medicine that the measurement and elimination of disparities belongs in the forefront of quality assurance/quality improvement is therefore of critical importance. Integrating the effort to eliminate disparities with quality improvement programs will sustain attention to racial and ethnic disparities over the long term and benefit from the application of existing quality improvement mechanisms. Recommendations for furthering this integration are included in Chapter VIII of this report.

It also follows that, in the first instance, the responsibility for monitoring and eliminating race- and ethnicity-based disparities in clinical care lies with the organizations providing care and the bodies that review their quality. These organizations should be encouraged and supported whenever they make a commitment to address these issues together. At the same time, the existence of such disparities—especially given the evidence that bias and stereotyping play a role in their perpetuation—is a civil rights and human rights concern that requires robust responses from a government committed to the protection of civil and human rights. Indeed, the United States has an obligation under both domestic and international law to eliminate racial and ethnic discrimination in this country and is responsible for having both policies and compliance tools that will assure that all its citizens in similar circumstances are treated equally. It must provide the leadership, support, training and technical assistance to secure voluntary compliance to end disparities and the enforcement tools to protect rights when voluntary efforts are not forthcoming. In these areas the US has fallen short.

International human rights law has special applicability here. This body of law, which includes both customary law and treaties, has to date received little attention in connection with civil rights concerns in the United States. That is because it is new to the US—the Senate only ratified the international treaty governing racial discrimination, the International Convention on the Elimination of all Forms of Racial Discrimination, in 1994—and because the Senate's ratification did not incorporate the provisions of the convention into domestic law. Nevertheless, because of its focus on the proactive steps governments must take to eliminate racial and ethnic discrimination, the Convention sets out the expectations for how a government that embraces the ideal of racial justice, as the United States committed to do in ratifying the Convention, must approach the problem – and how it should be held accountable for its inaction.[19]

US Law – Title VI of the Civil Rights Act

Congress passed the Civil Rights Act of 1964 to eradicate racial discrimination in the US. Title VI of this act prohibits discrimination on the basis of race, color, or national origin in any program or activity receiving federal financial assistance. It states:

> *No person in the United States shall, on the ground of race, color, or national origin, be excluded from participation, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance.*[20]

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[19] International human rights law also includes the right "to the highest attainable standard of health," which is contained in Section 12 of the International Covenant on Economic, Social and Cultural Rights. The United States has signed, but not ratified, this treaty. The right to the highest attainable standard of health requires both assuring access to and quality of health care services and guaranteeing non-discrimination in health care services. See United Nations, Committee on Economic, Social and Cultural Rights, *General Comment 14, The Right to the Highest Attainable Standard of Health*, 11/08/2000. E/C.12/2000/4.

[20] As amended, 42 U.S.C. § 2000d –7 (1994).

Title VI doesn't mention health care at all, but rather is drafted to apply to all activities and programs that receive federal financial assistance. With the enormous growth of the federal role in health care, however, and judicial and congressional clarifications of the reach of Title VI, it now applies to most health care activities in the United States. The expanding role of federal programs in medical services in the United States is such that virtually every hospital, clinic, health plan, and other health organization comes within its bounds. Roughly twenty-seven federal agencies grant an estimated $900 billion in financial assistance annually to over one thousand programs.[21] Programs or activities that receive federal financial assistance have been interpreted to include hospitals and other institutional entities that receive Medicare and Medicaid funding (except for individual Medicare providers not associated with organizations like HMOs) or are recipients of maternal and child health or other federal health grants. Programs or activities also include all of the operations of the relevant entity *any part of which* is extended Federal financial assistance.[22]

Individual health care providers who receive payments for services under Medicaid and other federal programs other than Medicare Part B (physician payments) are also subject to the requirements of Title VI. The Medicare exclusion is an anomaly, dating back to the inception of the program,[23] and does not apply if the services are provided through an HMO or similar entity. Moreover, some state civil rights laws apply to these providers.

Title VI bars many forms of intentional discrimination in health, including services or plans that deny enrollment, apply different enrollment, eligibility, admission or membership standards, or engage in other exclusionary practices where the entity is aware of the complainant's race, color or national origin and acts on account of it.[24] A person who receives lower quality health services because of provider attitudes that are biased on account of race or ethnicity clearly is covered by Title VI; acting according to stereotypes, even unconscious stereotypes, is evidence of such bias. Intent, of course is not always explicit, and Title VI allows inferences of discriminatory intent from the circumstances of the exclusion such as the events leading up to the decision in question, the historical background of these events, a departure from standard procedure, legislative or administrative history, a past history of discriminatory or segregated conduct and, importantly, statistical evidence of unexplained disparities.[25] Title VI, moreover, applies not simply to individual exclusions but to systematic discrimination or "pattern or practice of discrimination," or standard operating procedure.[26]

Statistical evidence, though not dispositive, is especially important in determining the existence of racial disparities in clinical treatment, since it is very difficult to discern bias in individual clinical judgments. By contrast, evidence of significant statistical differences in treatment, such as non-referral for kidney transplants among minority patients, could establish a basis to believe — a prima facie case under the law – that discrimination was occuring. Not all statistical disparities, of course, amount to discrimination. Other factors could be at work, but the disparity would nevertheless need to be explored and explained to determine where there exists a non-discriminatory reason for the disparity.

There are undeniable hurdles in determining whether statistical disparities amount to discrimination, for example, in figuring out whether individuals with varying clinical presentations are "similarly situated" and in establishing legally that the judgments of different clinicians practicing in a facility or plan, each presumably exercising independent clinical judgment, can be considered together. Courts and administrative agencies have not begun to grapple with these and other problems of determining a civil rights violation in cases of racial disparities in treatment.

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[21] US Commission on Civil Rights. 1996. Federal Title VI Enforcement to Ensure Nondiscrimination in Federally Assisted Programs at 12.

[22] See 42 U.S.C. § 2000d-4a(3)(A)(ii).

[23] Rosenbaum, supra note 1 at 246.

[24] However, "the record need not contain evidence of bad faith, ill will or any evil motive on the part of the [recipient]." Elston v. Talladega County Bd. Of Educ., 997 F.2d 1394 (11th Cir.), reh'g denied 7 F.3d 242 (11th Cir. 1993) at 1406, quoting Williams v. City of Dothan, Alabama, 745 F. 2d 1406, 1414 (11th Cir. 1984).

[25] See Arlington Heights v. Metro Housing Redevelopment Corp., 429 U.S. 252, 266-68 (this case is an evaluation of intentional discrimination under the Fourteenth Amendment but as stated above the analysis is the same for intentional discrimination under Title VI.)

[26] See International Brotherhood of Teamsters v. United States, 431 U.S. 324, 336 (1977).

There are already well-documented examples in the medical literature that would be subject to civil rights review, for example, the systematic failure of Hispanic and African American patients to be given adequate (or any) pain medication for long-bone fractures, as compared to similarly injured white patients, or the relative exclusion of African American patients in a diabetes clinic from receipt of a glucometer and instruction in its use. Perhaps the most compelling cases are provided by numerous peer-reviewed published studies documenting the relative failure of clinicians to recommend angioplasty or coronary artery bypass surgery for African American patients, as compared to white patients–even when standardized and widely accepted clinical criteria indicated that the procedure was urgently needed–and the significant increase in subsequent mortality among the African American subjects.

The regulations promulgated by the Department of Health and Human Services under Title VI also address the impact of practices or policies that make reference to no members of racial or ethnic groups but have a discriminatory impact on them, for example, employment tests that tend to exclude women or African-Americans but are not job-related. The question of discriminatory impact focuses on results rather than intent.[27] The Title VI regulations prohibit, among other things, the use of criteria, the location of services, or the establishment of standards and requirements in a manner that have the effect of denying people equal enjoyment of certain privileges or benefits that are enjoyed by others or a different race.[28] Discrimination attributable to socio-economic status alone, however, is not a violation of Title VI.

To conclude that this type of discrimination is at work, there must be evidence that the disparate impact, i.e., the health outcome, is causally related to the recipient's facially neutral policy. Disparate impact will not be considered discrimination, however, if the practice has a "substantial legitimate justification," is necessary to meet an important goal that is integral to mission of the entity, and that the justification has a demonstrable relationship to the policy or decision in question; in other words, the practice is acceptable if it is rationally related to a legitimate purpose.[29]

Discriminatory impact analysis in instances of disparities in quality of clinical treatment would focus on apparently neutral clinical criteria that disproportionately harm members of minority groups. For example, criteria for kidney transplantation in renal failure that depend on the estimated strength of patients' social support systems might be questioned as having a discriminatory impact on African Americans that is justified neither by clinical need nor by a proven relationship to outcome.

Assuring Compliance

The principal responsibility for assuring compliance with Title VI lies with agencies of the federal government; at the Department of Health and Human Services, it is the Office of Civil Rights (OCR). OCR can take enforcement action against both intentional discrimination and policies and practices that have a disparate impact on minorities. It has a significant sword—withdrawal of federal financial assistance. Indeed, the enactment of Medicare and Medicaid in the 1960's and the enormous federal dollars they released into the healthcare system were instrumental in desegregating health care institutions.[30] Most of the energy of OCR, however, is designed to be devoted to assuring voluntary compliance, through investigating complaints and seeking fair resolution, data collection and analysis, outreach, education and technical assistance.[31] The Department of Justice also plays a role, coordinating implementation and enforcement of Title VI and the regulations issued by each agency.[32] It may also bring cases in court against recipients for non-compliance with Title VI and can seek injunctive relief, specific per-

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[27] Title VI allows Federal agencies to enact regulations to implement its objectives. All entities which receive Federal financial assistance must enter into binding agreements in which they certify that they will comply with these regulations. HHS has promulgated regulations under Title VI which prohibit both intentional and disparate impact discrimination. The Supreme Court has determined that these regulations are valid and apply even if the actions or practices are not intentionally discriminatory. See Guardians; Alexander v. Choate supra note 23; Villanueva v. Carere, 85 F.3d 481 (10th Cir. 1996).

[28] 45 C.F.R. §80.1-80.13.

[29] See e.g., Bryan v. Koch , 627 F.2d 612 (2d Cir. 1980); NAACP v. Wilmington Med. Ctr., 657 F.2d at 1322 (3d Cir. 1981)

[30] D.B. Smith. *Health Care Divided: Race and Healing a Nation*. Ann Arbor: University of Michigan Press. 1999.

[31] US Commission on Civil Rights, *Health Care Challenge: Acknowledging Disparity, Confronting Discrimination and Ensuring Equality* 1999 [UCCCR Report] Volume II. at 139.

formance and other equitable relief once a matter has been formally referred to it by another agency.

Although the structure and procedures for enforcement seem to hold the promise of obtaining voluntary compliance with enforcement of Title VI where necessary and therefore the progressive elimination of discrimination and disparities in health care, the opposite has held true. In a scathing review of OCR's enforcement of Title VI in 1999, the United States Commission on Civil Rights criticized OCR's ability to carry out its mandate. It found that the Office had inadequate staffing, inadequate training for the staff it had, lacked technical medical staff available to assist in the investigation of complaints, lacked adequate resources[33] and failed to collect and monitor data relating to its mandate in contravention of regulations of the Department of Justice requiring it to do so.[34]

One of the most significant findings of the Commission was that HHS was not gathering the information on which all compliance reviews and enforcement had to be predicated. It noted that HHS did not monitor or review the racial/ethnic data its state recipients collected in order to measure their compliance with Title VI. A judicial decision, however, has interpreted the obligation to collect these types of data to give the agency considerable discretion. In *Madison Huges v. Shalala,*[35] the plaintiffs sought to enforce a regulation that HHS collect certain data from its recipients so that Title VI could be effectively enforced. They sought to require the Health Care Financing Administration (now the Centers for Medicare and Medicaid Services) to collect race/ethnicity data on every claim made on Medicare patients. The appellate court stated that "HHS is entitled to require different types of racial data, depending on the type of review or investigation it is conducting." The court went on to state that it must defer to the discretionary framework for data collection set out in the HHS regulations and how best to use such data to implement Title VI.[36] This case essentially removes judicial review of HHS' data-collection activities in an environment in which it is clear that OCR has interpreted its data collection responsibilities minimally. On the other hand, it is not realistic to believe that OCR can develop the competence and staffing to collect and analyze data on health disparities from the millions of episodes of health care; this task instead should be assigned to people or agencies with expertise in analysis of health data; other agencies should be mandated to collect such data.[37] Instead, OCR needs to develop competence in evaluation and follow-up of reports on disparities made by health agencies.

The Commission on Civil Rights also singled out the lack of policy development as a major flaw in OCR's enforcement efforts. Clear guidelines and policy directives effectively disseminated among highly trained staff are important to ensure consistent and effective compliance and enforcement of any regulatory regime. This becomes more important in an environment where there is little consistent judicial pronouncement on appropriate standards and definition of relevant terms. The Commission expressed its concern about OCR's dereliction of its rule-making and policy development duties:

> *OCR's general failure to use regulations and policies to implement civil rights laws has had a devastating effect on the agency's ability to conduct the thorough, comprehensive enforcement needed to ensure equal access to quality health care in a complex and ever-changing environment. As such discrimination in health care has been allowed to persist.*[38]

More broadly, compared to the history of discrimination and its continuing legacy in an industry that consumes vast resources and affects every

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[32] Congress vested the President with the power to approve rules, regulations and orders issued by these agencies and to coordinate them. Pursuant to Executive Order 12,250, the President delegated his Title VI coordinating function to the Attorney General who was also given the responsibility to oversee and coordinate the implementation and enforcement responsibilities of the Federal agencies. See DOJ Manual supra note 7 at 14

[33] For example, in 1999, the OCR budget was only 0.0054% of the total HHS budget. Commission report p. 44

[34] USCCR Report supra note 41 at 143

[35] 80 F.3d 1121 (4th Cir. 1996)

36 It should be noted that there is no doubt that HHS has the authority to collect such data. The so-called Racial Privacy Initiative in California would seek to preclude data collection on the state level, would undermine civil rights enforcement under state law, but would have no bearing on federal authority.

[37] See recommendations in the next section on data collection and analysis.

[38] USSCR Report supra note 41 at 66.

American, administrative enforcement is startlingly weak. One astute observer comments:

> *Despite the fact that hundreds of billions of dollars are pumped into the health system annually by the federal government, the nation is probably further than it has been in two generations from a workable and ongoing data mechanism for monitoring the racial performance of federally funded providers.*[39]

In the years since the report was issued, OCR has sought to bring the health disparities in clinical treatment into its work. It faces enormous impediments to that goal. Although in recent years it has finally received very modest budget increases, that decision follows about two decades of essentially flat funding. Moreover, OCR has been assigned principal responsibility for new National Standards to Protect the Privacy of Personal Health Information, a task that will inevitably consume huge agency resources.

So OCR is engaged in some training and technical assistance activities addressing racial and ethnic disparities in quality of health care, but almost no investigation and enforcement. In a statement to Congress in 2002, the agency said it was expanding its training activities and its enforcement. OCR indeed has engaged in a number of training, outreach and educational activities, but except for actions concerning access to health services, it has engaged in no investigation, voluntary compliance or enforcement activities regarding racial and ethnic disparities in health.[40] It is not systematically collecting data on racial and ethnic disparities in health, nor does it have the institutional capacity to do so. Neither is it evaluating data produced by other sources containing evidence of racial disparities in clinical care. For this it would need more staff, access to expertise from epidemiologists, health quality assurance experts, and statisticians, and a sophisticated understanding of the relationship between disparities and discrimination.

Individual Enforcement

Apart from compliance activities by federal agencies, Title VI permits individual enforcement through a lawsuit by an individual against an entity that receives federal financial assistance.[41] In 2000, however, the Supreme Court held that enforcement of disparate impact cases is restricted to the Office of Civil Rights,[42] leaving private lawsuits available only for cases of intentional discrimination. Even where intentional discrimination is alleged, individual enforcement poses significant challenges to individuals subjected to discrimination. Disparate treatment in clinical health services is often not evident to the patient. Even when an individual suspects that discrimination is at work in diagnosis or treatment options, disparate treatment is enormously difficult to show because individual clinical care depends on a host of variables about the patient, including age, history, co-occurring disorders, severity of symptoms, and much more; bringing a case would thus be complex and expensive. Indeed, even determining that a particular individual is "similarly situated" based on clinical presentation in a particular diagnostic or treatment setting is often complex.

Of course individuals, like federal agencies, can rely on data on patterns of racial and ethnic disparities in quality of the particular service to identify disparities. Moreover, supportive evidence can be brought to bear as well, such as recent research elucidating a role of *non-clinical* factors in such clinical decision-making, related to stereotypic assumptions on the part of the provider. The hurdles to such enforcement, however, combined with the overwhelming need to work with providers, health plans and institutions to secure rigorous cooperative efforts to end disparities in treatment, underscores the need for a more robust and energetic Office of Civil Rights.

International Human Rights Law

The need for leadership by the federal government in ending racial disparities based on race and ethnicity is reinforced by obligations the United States has agreed to through its ratification of an important treaty, the International Convention on the Elimination of all Forms of Racial Discrimination (CERD).

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[39] Rosenbaum et al, note 8.

[40] Statement of Robinsue Frohboese, Principal Deputy and Acting Director, Office of Civil Rights on The HHS/OCR's Role in Eliminating Racial and Ethnic Disparities in Health before the Congressional Black Caucus, the Congressional Hispanic Caucus, and the Congressional Asian Pacific Islander American Caucus, April 12, 2002 Caucus. http://www.hhs.gov/asl/testify/t020412c.html.

[41] Cannon v. University of Chicago, 441 U.S. 677 (1979) this case relates to another civil rights law based on receipt of federal financial assistance, and its reasoning applies to Title VI as well.

[42] Alexander v. Sandoval, 121 S. Ct. 28 (2000).

Introduction

International human rights law has developed exponentially since the end of the Second World War. The significance of the international protection of human rights is set out in the preamble of the UN Charter where the United Nations states its determination to "reaffirm faith in fundamental human rights, [and] in the dignity and worth of the human person." Freedom from racial discrimination has been codified in several treaties and is also a tenet of customary international human rights law.

At the same time, international human rights law is rarely brought to bear on analysis of racial discrimination in the United States. In part, this is a product of the fact that civil rights law in the United States is so extensive and detailed, and subject to thousands of judicial decisions and administrative interpretations. Equally important, international human rights law has not been incorporated into the fabric of American law. The human rights treaties the United States has ratified are not "self-executing," that is, they cannot be enforced within US courts without legislative authorization,[43] and Congress has rarely done so. Moreover, Congress often includes a "reservation," "declaration" or "understanding" in ratifying human rights treaties that state that the treaties offer no greater rights or protections than American law.

International human rights treaty obligations thus appear at first glance to add little either to substantive civil rights law or to enforcement mechanisms for the protection of minority rights in the United States. Yet having signed and ratified CERD, the United States has binding obligations to take affirmative steps to end racial discrimination. That of course includes all discrimination, and thus encompasses racial disparities in clinical treatment that are a product of discrimination.

The Obligations of the United States to Address Racial Disparities under International Human Rights Law

The prohibition on racial discrimination has been a centerpiece of treaties, UN General Assembly resolutions and UN human rights conferences since the inception of the United Nations. The principle of non-discrimination and equality of all persons is enshrined in Article 1(3) of the UN Charter. It states that one of the purposes of the UN is to achieve "international co-operation in promoting and encouraging respect for human rights and for fundamental freedoms for all *without distinction as to race*, sex, language, or religion …"[44] This principle has also been established in the International Bill of Rights. One of the components of the International Bill of Rights, the International Covenant on Civil and Political Rights, which the United States has ratified, states,

> *All persons are equal before the law and are entitled without any discrimination to the equal protection of the law. In this respect, the law shall prohibit any discrimination and guarantee to all persons equal and effective protection against discrimination on any ground such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.*[45]

Because of the importance of the elimination of racial discrimination, a treaty exclusively focused on such discrimination, the International Convention on the Elimination of Racial Discrimination (CERD), was adopted in 1965 by the UN General Assembly and entered into force in 1969.[46] It has been joined by 165 states, including the United States, which did so in 1994, subject to certain reservations.[47]

Human rights treaties approach human and civil rights quite differently than American law. American civil rights laws address the subject by reciting the protection individuals have from discrimination (language such as "no person shall be subject to discrimination" or as the Fourteenth Amendment does, "no person …shall be denied… the equal protection of the law") or stating that certain entities are prohibited from engaging in discrimination. International human rights treaties take a different approach. Because they are agreements by governments, they set forth commitments and obligations those government have agreed to fulfill. The obliga-

[43] See, for example, Senate Ratification of Convention on the Elimination of all Forms of Racial Discrimination, Section III, available at http://untreaty.un.org/ENGLISH/bible/englishinternetbible/partI/chapterIV/treaty2.asp.

[44] Emphasis added

[45] International Covenant on Civil and Political Rights Article 26.

tions may and indeed do include requirements to enact legislation that protects individuals from discrimination, like US civil rights laws and also by setting out the elements of the responsibility of government to end discrimination.

Thus the basic requirement of CERD, set out in Article 2, is that "States[48] Parties condemn racial discrimination and undertake to pursue by all appropriate means and without delay a policy of eliminating racial discrimination in all its forms and promoting understanding among all races." It then sets out specific activities governments agree to undertake to eliminate discrimination. These include not engaging in discrimination itself; not taking actions to "sponsor, defend or support racial discrimination by any persons or organizations;" reviewing laws and policies and eliminating any that have the effect of creating or perpetuating discrimination; prohibiting and bringing to an end "racial discrimination by any persons, group or organization." In other words, CERD obliges government to take steps not merely to respond to instances of racial discrimination through enforcement activities, but to take vigorous and thorough steps—"all appropriate means"—to eliminate racial discrimination in society.

The treaty also makes clear that discrimination encompasses practices that have a disparate impact as well as those that are a result of intentional discrimination. Article 1 of CERD defines discrimination as

> *… any distinction, exclusion, restriction or preference based on race, colour, descent, or national or ethnic origin which has the purpose or effect of nullifying or impairing the recognition, enjoyment or exercise, on an equal footing, of human rights and fundamental freedoms in the political, economic, social, cultural or any other field of public life.*

The reference to the "effect" of discrimination makes the application to actions that have a disparate impact clear, and is reinforced by the overarching goal to enable individuals of all racial groups to be "on an equal footing" in society.[49] The effort to achieve substantive equality is also signaled by CERD's explicit allowance of "special and concrete measures" to ensure protection of certain racial groups or individuals belonging to these groups and to ensure their equal enjoyment of human rights and fundamental freedoms.

Finally, the obligations of governments under CERD extend beyond ending officially sanctioned discrimination. As noted above, the purpose of the Convention is to prohibit and bring to an end "racial discrimination by any persons, group or organization" and the definition of discrimination extends to "the political, economic, social, cultural or any other field of public life." The scope of what is meant by "public life" is somewhat ambiguous, though the rest of the Convention makes it clear that it is a reference to services open to the public, whether they are public or private. Article 5(f) of the Convention describes one of the rights protected under the Convention as "The right of access to any place or service intended for use by the general public, such as transport, hotels, restaurants, cafés, theatres and parks." Article 5 also includes the obligation of governments "to prohibit and to eliminate racial discrimination in all its forms and

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[46] 660 U.N.T.S. 195, 5 I.L.M. 352 (1966). This convention was adopted by the UN General Assembly on December 21, 1965 G.A. Res. 2106, 21 GAOR, Supp 14, U.N. Doc. A/6014, at 47

[47] A reservation is a unilateral statement made by a state when signing, ratifying, acceding to, accepting or approving a treaty whereby it purports to exclude or vary the legal effect of certain provisions of the treaty in their application to the State. Reservations are permitted unless the treaty prohibits them, the reservation is beyond those allowed by the treaty, the reservation is incompatible with the object and purpose of the treaty, or if it seeks to modify rules of law derived from customary international law. For a discussion of United States reservations in CERD, see McDougall, G, Toward a Meaningful International Regime: The Domestic Relevance of International Efforts to Eliminate All Forms of Racial Discrimination, 40 Howard L.J. 571 (1997).

[48] The word "States" in international treaties refers to national governments.

[49] The United States did not enter a Reservation, Declaration or Understanding with respect to this definition of discrimination in CERD that includes disparate impact or seeking to put individuals "on an equal footing." When the Senate ratified the International Covenant on Civil and Political Rights in 1992 it included an Understanding that "The United States understands distinctions based upon race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or any other status - as those terms are used in article 2, paragraph 1 and article 26 - to be permitted when such distinctions are, at minimum, rationally related to a legitimate governmental objective." The Understanding also included the position that "the prohibition in paragraph 1 of article 4 upon discrimination, in time of public emergency, based `solely' on the status of race, colour, sex, language, religion or social origin, not to bar distinctions that may have a disproportionate effect upon persons of a particular status." The Understanding can be found at http://untreaty.un.org/ENGLISH/bible/englishinternetbible/partI/chapterIV/treaty6.asp

to guarantee the right of everyone, without distinction as to race, colour, or national or ethnic origin, to equality before the law, notably in the enjoyment of the following rights: the right to public health, medical care, social security and social services."[50]

Part of the responsibility of signatories to CERD is to submit reports to the treaty monitoring committee on compliance every two years. The reporting requirement is important as an accountability mechanism because it represents a formal and public means both of identifying problems of racial discrimination and of setting out the steps the government has taken to remedy them. Nongovernmental organizations may submit "shadow" reports to the Committee. After the committee reviews the report, it may make concluding observations and suggestions for how to achieve compliance.

These obligations reflect a large, even visionary objective. The goal is not mere prohibition of discrimination, but its elimination. To achieve it, all public authorities and public institutions, both national and local, must act in conformity with this obligation. States are also bound to take effective measures to review policies and to amend, rescind or nullify any laws and regulations that have the effect of creating or perpetuating racial discrimination. The approach of CERD, in short, calls for effective action on a variety of fronts to end racial discrimination in all its forms. Civil rights enforcement of course plays a role, but it is the proactive efforts to eliminate discrimination, including the engagement of private entities such as health care organizations and practitioners, that will be at the center of a human rights approach.

The implications for the problem of racial disparities in clinical care are clear. Since the goal of CERD is to place all people on "an equal footing" regardless of race, the United States must take effective action to end those disparities in clinical care. The precise cause of these disparities, whether intentional, the product of stereotyping or unconscious bias, or the application of supposedly neutral rules, is beside the point. So long as the health of African Americans, Hispanics, Native Americans and some Asian subgroups suffer on account of practices and judgments that bring them a lower quality of clinical care than similarly-situated whites, CERD demands assertive and effective action by government. This includes support for improved quality assurance mechanisms, effective monitoring and review of racial disparities, education and training of providers, and compliance and enforcement mechanisms that work and are accessible to all, and using its influence to assure other effective steps in the private sector to achieve the goal of quality of care that does not depend on race or ethnicity.

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[50] CERD, Article 5(e)(iv). The Senate's ratification of CERD included a reservation to limit scope of the meaning of 'public life' to assure that it did not apply to highly private transactions. Senate Ratification of Convention on the Elimination of all Forms of Racial Discrimination, Section III, available at http://untreaty.un.org/ENGLISH/ bible/englishinternetbible/partI/chapterIV/treaty2.asp It therefore entered a reservation that "the United States does not accept any obligation under this Convention to enact legislation or take other measures . . . with respect to private conduct except as mandated by the Constitution and laws of the United States." As the discussion of Title VI above indicates, however, American civil rights law extends into the sphere of private conduct that involves services to the population, including health services. Since the "laws of the United States," particularly Title VI and its implementing regulations, broadly cover health care activities in the United States, the reservation regarding private conduct does not remove the obligations imposed by CERD regarding relationships within health care settings.

VI. IDENTIFYING DISPARITIES AND DISCRIMINATION AND DEVELOPING PLANS TO ADDRESS THEM

The research studies discussed earlier and contained in the bibliography to this report show in select populations the existence of disparities in quality of care based on race and ethnicity. But these studies are no substitute for collecting data at the community or institutional level, and on a continuing basis, that can identify disparities, overcome denial, raise consciousness and most important, provide the basis for actions to end disparities in those communities and institutions. Ongoing data collection, moreover, is essential for documenting change, monitoring progress and demonstrating maintenance of improvement. Indeed, the first step in eliminating racial and ethnic disparities in the quality of medical treatment in communities and institutions where it takes place is to identify them. To accomplish that, data on clinical services must be collected and analyzed. But unlike virtually every other area of civil rights, the existence of patterns of disparities and discrimination in communities, health plans, hospitals, or even regions of the country, is insufficiently known. That is because data on race and ethnicity are not routinely and consistently recorded in clinical and administrative records in the US health care system, thus seriously limiting the ability to detect, understand and limit race and ethnicity-based disparities in medical care. The data that are available are insufficiently analyzed to determine the existence of these disparities.

This omission is in some ways extraordinary. Not only are the data essential for improving the quality of care, but monitoring compliance through data collection and analysis has been at the center of civil rights enforcement since the 1960's. That is because civil rights violations cannot be always detected through the experience of single individuals or groups of individuals. Rather, it is critical to look for patterns where individuals from a minority group are disadvantaged compared to similarly situated individuals in housing, in employment, in lending, in access to health services – or in the quality of clinical care. Only through this collection and analysis of data on large groups of people can patterns of discriminatory conduct be pinpointed and remedies found.

There are, of course, many other reasons to collect and analyze data on disparities in diagnosis and treatment: to improve the quality of health care and consequently the health of the population, to inform consumers of the performance of health care plans and providers, and to gain insight into the factors that are responsible for the disparities. These reasons, however, merely reinforce the need systematically and routinely to collect, analyze and report disparities in clinical health care.

Precedents for data collection, analysis and reporting in civil rights enforcement are well established. Efforts of school districts to end de facto segregation depended on the availability of the racial compositions of their schools. Compliance with non-discrimination mandates in housing, banking, and employment all require constructing large databases that can show patterns within institutions, neighborhoods and communities. Indeed, for years after the Civil Rights Act of 1964 was passed, employers subject to the law were required to report the racial composition of their work force and their applicant pool. In the late 1990's, Congress strengthened a law on mortgage lending and civil rights to assure that a variety of financial institutions analyze and publicly report statistical information on their lending patterns, including information on the race and ethnicity of borrowers and applicants for mortgages.

In the case of identifying and ending racial disparities in health treatment and diagnosis, data collection and analysis is even more critical than in other areas. That is because, as noted above, the experience of discrimination in clinical care is rarely apparent. An African-American applicant for a mortgage with excellent credit may infer that a bank's rejection was a result of racial bias. It is far less likely that an African-American with severe kidney disease will have any basis to believe that non-referral for a renal transplant has anything to

do with race. Indeed, as indicated earlier in this report, even a clinician who engages in disparate treatment based on race in making decisions about renal transplants is unlikely to be aware of it. Moreover, the enormous number of potentially confounding clinical variables, the isolation of clinical encounters from scrutiny, and the centrality of individual clinical judgment in medicine make disparities difficult to detect in single cases or small groups of cases. Indeed, until the Institute of Medicine put its imprimatur on the existence of the phenomenon in its 2002 report, even hundreds of research studies showing racial and ethnic disparities in a large variety of clinical interventions did not convince many skeptics that such disparities in the quality of clinical care existed at all.

At the same time, because data collection and analysis on racial disparities is so closely linked to improvement in quality of clinical care, it should be far less threatening to health providers, hospitals and health plans than data collection in other areas of civil rights enforcement. Data collection has long been central to the quality assurance process, and any reasonable clinical program should respond to evidence that it has a problem with disparate diagnosis or treatment based on race and ethnicity, so that it can identify the cause and take corrective action. As the Institute of Medicine reported, monitoring can not only "help to ensure accountability to enrolled members and payors, improve patient choice, and allow for evaluation of intervention programs," but may even bring about "cost savings that would offset the cost of data collection."[51] These reasons explain why organizations of providers such as the American Association of Health Plans and the American Hospital Association as well as insurers such as Aetna have openly welcomed efforts to develop uniform data collection, analysis and reporting mechanisms so their members and subscribers can offer or receive, as the case may be, higher quality of care through the elimination of racial disparities.

Moreover, in recent years the potential for monitoring racial and ethnic disparities in the quality of health care has risen dramatically. The development of uniform widely-accepted definitions of race and ethnicity by the federal Office of Management and Budget, federal mandates to collect race, ethnic and primary language data in certain programs, the practice of many states and private institutions to collect racial and ethnic data,[52] the increasing sophistication of quality assurance mechanisms to detect racial and ethnic disparities in clinical care (including the ability of some of these mechanisms to distinguish race and ethnicity from socio-economic status), and the standardization of electronic health claims data, all should make analysis of racial disparities in clinical care a relatively straightforward, if technically complex, task.

For example, in 1997 the Office of Management and Budget established uniform definitions, standard categories, and reporting procedures for race and ethnicity,[53] which were embraced in 1999 by the Department of Health and Human Services,[54] used in the 2000 census and now are scheduled for uniform application across the federal government. There are straightforward ways of improving the Social Security Administration's process for gaining racial identifiers in conjunction with the issuance of a Social Security number (used to identify racial and ethnic status in Medicare). And the Centers for Medicare and Medicaid services already has authority to require states to collect racial and ethnic identifiers in the Medicaid and the Children's Health Insurance Programs.

Further, the Office of Minority Health in HHS has established culturally and linguistically appropriate collection standards for federal, state, and national accreditation agencies. These standards ensure that these data are collected and updated in health records and integrated into the organization's management systems. The standards recommend self-identification of patients and suggest that the primary language of patients or caregivers of some minor patients be noted.

At the same time, many of the obstacles to data collection and analysis in this field have been eliminated or shown to be overstated. For example, privacy concerns need not deter data collection so long

[51] *Unequal Treatment* at 216.

[52] For example, the Hospital Cost and Utilization Project uses discharge abstract data from hospitals in 17 states that includes race and ethnicity. Moreover, almost all hospitals collect data on race and ethnicity for birth and death certificates, tumor registries, and reportable conditions like HIV/AIDS.

[53] OMB, Statistical Policy Directive No. 15, Race and Ethnic Standards for Federal Statistics and Administrative Reporting (1997). OMB has also issued guidance entitled Implementation of 1997 Standards for Federal Data on Race and Ethnicity (2000).

as safeguards are in place regarding the use of the data and consumers understand the reason for the collection of the information. As in other areas of civil rights enforcement, concerns about patient privacy, or the misuse of racial and ethnic data, for example, in red-lining, can be addressed in a straightforward way. Indeed, a fair degree of consensus has developed on how best practices in obtaining information on race and ethnicity, for example, on when racial and ethnic data should be collected (at enrollment rather than application or service) and on who should determine race and ethnicity (the consumer). Outreach to consumer groups that explains the purposes for which the data are collected can increase support for it. Just as lending data are collected to eliminate rather than facilitate red-lining, so collection of race and ethnic data in health can be explained to promote equal treatment in the intimate setting of clinical care.

The barriers to collection of data on race and ethnicity are falling in the private sector as well. Aetna Insurance Company, one of the largest insurers and health care corporations in the United States, has begun to collect racial and ethnic data on its 14 million participants.[55] In its first effort to collect the data from prospective beneficiaries voluntarily, 80% of the applicants were willing to provide that information.

Using Quality Assurance Measures to Identify Disparities

Enormous progress has been made as well in the use of quality assurance measures to determine the existence of racial and ethic disparities.56 While more work needs to be done, there already exist quality assurance mechanisms that can be used to assess racial disparities across a range of quality measures. There are a number of advantages to using existing measures, including their familiarity, reliability, availability and widespread acceptance.

One is the Health Plan Employer Data and Information Set (HEDIS). The HEDIS measure, developed by the National Committee on Quality Assurance, is a standardized set of performance measures for a variety of conditions and clinical interventions. Although it applies to only half of the leading causes of morbidity and mortality, for conditions and interventions to which it applies it can be very useful. In particular, HEDIS is likely to be useful for breast cancer screening, cervical cancer screening, Chlamydia screening, control of high blood pressure, beta blocker treatment after a heart attack, cholesterol management after acute cardiovascular events, comprehensive diabetes care, use of appropriate medication for people with asthma, follow-up after hospitalization for mental illness, antidepressant medication management, and possibly others.

The value of HEDIS in assessing racial and ethnic disparities was demonstrated by the recent work of Schneider, Zaslavsky and Epstein, who found that HEDIS can be used to measure racial disparities in four clinical effectiveness measures — breast cancer screening, use of beta blocker medication after myocardial infarction, diabetic eye exams, and follow-up after hospitalization for mental illness — in the Medicare + Choice program.[57] They analyzed data from the Medicare + Choice program, which has required participating health plans to report HEDIS data to the Centers for Medicare and Medicaid Services. Data from 294 health plans representing over 400,000 beneficiaries were analyzed according to the four clinical effectiveness measures. These were matched with demographic data supplied by CMS from 4.7 million beneficiaries in managed health plans that included information both on race and socio-economic indicator based on receipt of Medicaid (an indicator of low income) and zip code of residence. (Census Bureau information contains information on income, educational attainment, and urban/rural status for each zip code.) The authors were able to determine that the quality of clinical care for these Medicare recipients in the four clinical areas was substantially lower for blacks than for whites. Moreover, they were able to determine the extent to which the differences could be explained by socio-economic factors.

Thus even with existing impediments to the collec-

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[54] Department of Health and Human Services, *Improving the Collection and Use of Racial and Ethnic Data in HHS* (1999).

[55] *Wall Street Journal*, March 5, 2003.

[56] Fiscella, K. Using existing measures to monitor the quality of care provided of minorities. Workshop Proceedings on Improving Healthcare Quality for Minority Patients. National Quality Forum. Washington, D.C. June 28,2001.

[57] Eric C. Schneider, M.D., Alan M. Zaslavsky, Ph.D, Arnold M. Epstein, M.D. Racial disparities in quality of care for enrollees in Medicare managed care. *Journal of the American Medical Association* 2001; 287: 1288-1294

tion and analysis of quality of race and ethnic data, it is possible to institutionalize the analysis of quality of clinical care based on race. The authors conclude, "Our analysis demonstrates the Medicare program's HEDIS data collection offers an unprecedented opportunity to assess racial and socioeconomic disparities in quality of care. Reports to health plans about identified disparities could be a powerful lever for change if health plans are able to use this information to target interventions that improve clinical quality for minority enrollees."[58]

Other quality assurance programs can be used in other settings. The Joint Commission on Accreditation of Health Care Organizations, which accredits hospitals, nursing homes and other health care organizations, has a set of measures, called ORYX, that includes measures related to management of myocardial infarctions, heart failure, community-acquired pneumonia and pregnancy-related conditions. The Agency for Health Care Research and Quality has also introduced a revised set of quality indicators for hospitals that target rates of overuse and underuse of key procedures, potentially avoidable adverse hospital outcomes and potentially avoidable hospitalizations.

For HMO's, the Foundation for Accountability has developed measures for HMOs that relate to detection and management of alcohol misuse, breast cancer, asthma, diabetes, depression, HIV, and smoking. The Centers on Medicare and Medicaid Services has a Health Care Quality Improvement Program that, in cooperation with Peer Review Organizations established for Medicare and Medicaid, uses measures for management of myocardial infarction, heart failure, community-acquired pneumonia (similar to ORXY) as well as for diabetes and strokes (similar to HEDIS).

If these are linked to racial and ethnic data and primary language, most of the measures offer a reasonable starting place for assessment of minority health care quality and the disparities between and among racial and ethnic groups.

Other methods of assessing racial disparities have also been proposed and it is evident that progress must continue to improve quality assurance mechanisms and to develop new ones so that they are suitable for analysis and reporting of racial and ethnic disparities. But in this area, the perfect is the enemy of the good. Existing quality assurance mechanisms for assessing the reporting racial and ethnic disparities in clinical care can and should be used even as new ones are developed.

Despite these advances both in methods of collection of data on race and ethnicity and in the means of assessing disparities, however, neither the major public or private entities have taken the steps needed to collect data on racial and ethnic identifiers and engage in the analysis and reporting of disparities in diagnosis and treatment — much less to engage in activities tailored to bring it to and end once identified. Private sector accreditation agencies such as the National Committee for Quality Assurance and the Joint Committee on the Accreditation of Healthcare Organizations, do not include the elimination of racial disparities in care among their mission statements or their standards despite the recognition by the IOM of equity as a core measure of quality.

The Need for Federal Action

The federal government has not used its existing authority to assure standardized collection of racial and ethnic data in its own health programs and those receiving federal support, much less put into place a program for analysis and reporting of those data. It has not used its authority to enforce uniform standards for the collection of this information in state Medicaid and Children's Health Insurance Program. Indeed, as the Institute of Medicine reported, "standardized data on racial and ethnic differences in care are generally unavailable."[59] What's more, the IOM said, "Federal, private and state-supported data collection efforts are scattered and unsystematic, and many health plans, with a few notable exceptions, do not collect data on enrollees' race, ethnicity, or primary language."[60] The federal government has not even included race and ethnic identifiers as required code sets in the electronic transmission of health records, although it had the opportunity to do so. In sum, the IOM found a vacuum of federal leadership, especially within the agency most responsible both for quality of care and civil rights enforcement in health, Department of Health and Human Services. It noted

[58] Id.

[59] *Unequal Treatment* at 169.

[60] *Unequal Treatment* at 215.

that "no single HHS blueprint exists to provide a framework for the department's activities."

A report by Perot and Youdelman for the Commonwealth Fund regarding federal practices on racial and ethnic data collection in health programs found inconsistent policy messages, fears of potential misuse of data, lack of enforcement, lack of uniform standards, lack of centralized authority, and serious technical problems in data collection.[61] Collection of primary language data, which can be critical to identify ethnic group, is rarely required. Other scholars, committees, and officials have identified the same patterns.

Observers often point out that the key to the solution for these problems is straightforward, federal leadership. The US Commission on Civil Rights urged that the Department of Health and Human Services establish a comprehensive minority database;[62] Perot and Youdelman's central recommendation after a review of federal policies and practices on data collection was that the Department of Health and Human Services should have a "written policy and sustained action to ensure the collection and reporting of data necessary to support and facilitate achievement"[63] of the goal of "eliminating racial and ethnic disparities in health." Indeed, the Department of Health and Human Services' own reports reflect the same need for leadership. *Healthy People 2010*, for example, recommends improved data collection and analysis to detect and eliminate disparities. HHS adopted a plan for improved data collection in 1999, but the results have been spotty and uncoordinated.

The Centers for Medicare and Medicaid Services has encouraged data collection by race and ethnicity, but Perot and Youdelman report that "CMS has not formally articulated its own policy rationale for the collection and reporting of these data in a systematic way to assess the quality and quantity of services received or health outcomes experienced by Medicare, Medicaid and [State Child Health Insurance Program] beneficiaries."[64] Moreover, a variety of reporting initiatives by CMS have been undertaken, including charging peer review organizations with disparities reduction, but the initiatives have remained separate and uncoordinated.

To be sure, data collection and analysis in health care is complicated, and conflicting rules, varying purposes, and complex legal requirements have impeded what should be rather straightforward solutions. For example, data on race and ethnicity may be used for a variety of possible purposes beyond the detection of disparities in the quality of clinical care, such as who is accessing health services, the health status of different populations, utilization rates of services to which racial and ethnic groups do have access, the effectiveness of public health interventions among different racial and ethnic groups, and of course racial and ethnic disparities in diagnosis and treatment. The roles of federal, state and local government and various private sector entities such as hospitals and health plans add another level of complexity to the issue.

These complications, however, are hardly excuses, especially when the result is that violations of the rights of African Americans and other minorities guaranteed by the Civil Rights Act of 1964, not only go uncorrected but remain undetected. Similarly, these factors cannot excuse the failure of the United States to live up to its obligations under the Convention to Eliminate all forms of Racial Discrimination. The next section addresses means to fulfill the obligations to identify and end such disparities in health services.

Responding to Identified Disparities

Once disparities are identified, health care institutions can analyze their sources and develop plans to end them. When efforts to end racial and ethnic disparities in clinical diagnosis and treatment enter mainstream quality improvement programs, the institutions, working cooperatively with practitioners, community organizations, professional groups and others, can develop quality improvement plans to end them. There is ample room for innovation in the development of these plans, for example, in providing internal procedures for explicit review mechanisms in those categories of diagnostic exam-

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[61] Ruth T. Perot and Mara Youdelman, *Racial, Ethnic and Primary Language Data Collection in the Health Care System: An Assessment of Federal Policies and Practice*. The Commonwealth Fund. 2001. Available at http://www.cmwf.org/programs/minority/perot_racialethnic_492.pdf

[62] US Commission on Civil Rights, *The Health Care Challenge: Acknowledging Disparity, Confronting Discrimination, and Ensuring Equity*. 1999.

[63] Perot and Youdelman at 5.

[64] Perot and Youdelman at 14-15.

ination or treatment choice in which racial and ethnic disparities have been most frequently found. Such attempts would allow quality assurance programs to make efficient use of the extensive studies, in different disease categories, that have documented the patterns of disparity—a good example of the integration of quality assurance and disparities elimination. The key is to encourage the development of such plans when disparities are found and to provide support to institutions in developing and implementing them.

VII. THE ROAD AHEAD: RECOMMENDATIONS

How can a society that is supposed to be committed to racial justice end the intolerable disparities in an area that is the center of well-being—health care? An initial framework for such an effort is provided by the Institute of Medicine's (IOM) report on *Unequal Treatment*, which offered 21 general recommendations. Two of these addressed the need for both public and provider awareness of the existence and scope of racial and ethnic disparities. Five concerned legal, regulatory and policy interventions, addressing such problems as inadequacies in "low-end" public and private health insurance coverage that lead to disparities in care, the under-representation of minorities in the health professional workforce, the lack of continuity in physician-provider relationships, and protection for the adequacy of services provided in publicly funded managed care programs. Six addressed relevant aspects of the health care system itself, calling for the use of evidence-based guidelines for care, improved reimbursements and provider incentives to assure adequacy of services to minority and low-income patients, overcoming problems in physician-patient communication and patient mistrust, and urging the use of interpretation services, community health workers, and multidisciplinary teams. Two general recommendations urged cross-cultural education in the health professions and patient education and empowerment efforts. Four asserted the necessity of data collection by race, ethnicity, and primary language in records of access and clinical care and in performance measures and monitoring for disparities, and two addressed the need for further research on the causes of disparities, interventions to rectify them, and ethical issues raised by them.

The Panel endorses the IOM framework. What is required now is to translate each of these principles into recommendations for specific actions and responsibilities by identifiable and accountable stakeholders—government agencies, public and private sector institutional providers of care, health professionals and their organizations, quality assurance agencies, educational institutions and accrediting authorities, community-based advocacy groups concerned with equity in health care, civil rights monitors and human rights organizations. These recommendations should serve both as the agenda for a sustained advocacy campaign to reduce and eliminate racial and ethnic disparities in health care, and as yardsticks to measure progress toward that goal. These recommendations are, therefore, attempts to indicate both what needs to be done and who should do it. Some of these steps are already well under way, but need to be sustained and expanded; others are measures that have yet to be initiated but are urgently needed.

Because the Panel approaches this problem from a human rights standpoint, most of the recommendations concern actions by governments. The Panel recognizes, of course, that many other stakeholders have a role in addressing the problem of racial disparities in care, and address them briefly. The Panel also acknowledges the efforts of many professional organizations such as the American College of Physicians and the American College of Cardiology, educational institutions, associations of managed care and health institutions such as the American Hospital Association and American Association of Health Plans, as well as individual health care companies like Aetna, to take racial and ethnic disparities in health care seriously and to develop concerted strategies to address them.

The Panel's recommendations do not, in most cases, directly engage the issues of major structural changes in the health care system itself. They are the focus of ongoing and increasingly urgent policy debates in the American electorate and among its political representatives. It is clear, however, that the present system fails to embody fully the principle of health care as a basic human right, a core responsibility of government, and an essential component of a humane social contract. It is equally clear that such failures contribute to disparities in access, quality of care, and health outcomes, most particularly for the overlapping populations of the

poor and minorities. Even for those among these groups who have some access to care, many must negotiate a baffling labyrinth of fragmented services, complex bureaucratic eligibility requirements, managed care limitations on coverage and benefits, lack of referrals to specialty care, and the financial constraints imposed by deductibles and co-payments.[65] Continuity of relationships with primary care or other physicians may be abruptly disrupted as a consequence of policies (in Medicare and in private health insurance plans) that allow providers to participate in some plans but not all, thus allowing them to avoid serving predominantly poor populations. Providers, in turn, are increasingly affected, in their care for African American, Hispanic and other minority patients, by time constraints that impair cross-cultural communication and explanations, and by financial constraints on the quality of care such as the gross inadequacy of Medicaid reimbursements. Cumulatively, all these structural factors become effective incentives for disparities and disincentives for quality of care; they distort the process.[66] In a very real sense, providers and patients alike are damaged by these structural defects, inefficiencies and inequities—trapped in the same labyrinth.

It is neither moral nor justifiable, however, to conclude that the reduction and elimination of racial/ethnic disparities in medical care must await major structural reform of the organization and financing of the present health care system in the US. To do so would simply prolong one aspect of the double deprivations that are now the daily experience of many minority Americans: first, heightened exposure to health-damaging social, physical and biological environments; second, limitations on the quality and comprehensiveness of both preventive and curative care. Although the Panel has one recommendation on the structure of health care, the recommendations address what can and must be done *now even without structural changes*: changes in equity and quality that are not merely desirable but feasible in the present US health care context.

The recommendations that follow should be part of a concerted plan toward ending racial and ethnic disparities in the quality of clinical treatment in the United States as part of the government's obligation under the Convention on the Elimination of All Forms of Racial Discrimination to end "racial discrimination in all its forms and promot[e] understanding among all races." The specific actions taken should be included in the United States report due bi-annually under the Convention.

RECOMMENDATIONS FOR ACTION

A. To the Federal Government

Strengthen Civil Rights Agencies

In recent decades, health has been a forgotten frontier of civil rights. Compliance with both domestic civil rights law and international human rights obligations of the federal government need to be strengthened. The Office of Civil Rights in the Department of Health and Human Services can educate and provide effective technical assistance to recipients to encourage voluntary compliance, develop consistent policy guidelines to disseminate throughout the agency and, most importantly, engage in investigations and enforcement in this field clearly within its jurisdiction when voluntary compliance fails. A special unit within the Office of Civil Rights can be especially effective in enabling the office to develop the expertise to assess data on disparities in quality of care based on race and ethnicity and to collaborate with hospitals, health plans and providers to determine whether the disparities are the product of discrimination and, if needed, to initiate enforcement.

1. Congress should create an Office on Health Disparities within the HHS Office of Civil Rights. The scope of responsibility should include racial and ethnic disparities in the *quality* of clinical treatment. Skills should include expertise in interpreting health disparities data, including the operations, scope and interpretation of quality assurance mechanisms, for the purpose of a strong investigation and enforcement program.[67]
2. Congress should provide substantial new resources to OCR[68] with an instruction that it devote

[65] Bloche, G. Race and Discretion. *Yale Journal of Health Policy, Law, and Ethics*, Spring 2001; 1: 95-131.

[66] *Unequal Treatment* 80-124.

[67] This is critical because the existence of disparities is not proof of discrimination.

[68] After years of stagnation, OCR's resources have recently increased, but its responsibilities have vastly increased, particularly to administer complex new medical privacy legislation.

resources to engage in investigation activities and enforcement regarding discrimination based on race or ethnicity in clinical settings as required by Title VI. This new staff should be specifically assigned to train health organizations in the relationship of Title VI to the problem of disparities in quality of treatment, foster voluntary compliance and investigate racial and ethnic disparities in clinical care where health organizations are not taking sufficient steps to address them. It should be provided with the resources to gain access to expertise in quality assurance, epidemiology, clinical medicine, statistics and other relevant fields.

3. Congress should establish a section on health care in the Department of Justice Office of Civil Rights Division to match existing sections that deal with discrimination in housing, employment, and education.

Collect Data on Racial, Ethnic and Primary Language Data in Health Plans

An essential component of an effort to end disparities in quality of health care based on race or ethnicity is a requirement that all clinical encounters and records—in hospitals, ambulatory facilities, HMOs and other managed care systems—be recorded by the patient's race or ethnicity and primary language. Without these data, monitoring for racial and ethnic disparities in care cannot be effective, institutional and provider self-assessments, regional and national report cards cannot be produced, and the central medical goal of quality assurance will be constrained. While opposition may be anticipated on ideological, financial and logistical considerations, it is noteworthy that one of the largest health maintenance organizations has already initiated quality assurance by race and ethnicity, and others have successfully used standard quality of care indicators to monitor racial and ethnic parity. In contrast, so-called "racial privacy" initiatives, proposed in some states, must be recognized as assaults on quality of care efforts.

Observers and analysts have uniformly called for federal leadership to obtain and analyze the data needed to identify racial and ethnic disparities in clinical treatment, particularly on leadership from the Department of Health and Human Services. This is an important but limited approach. It is up to Congress to set national policy and lay the groundwork for leadership by agencies, especially in light of bureaucratic failure or judicial interpretations that have severely impeded protection of civil rights.[69] Moreover, to the extent that private sector activities are affected, a Congressional mandate is far stronger than an administrative rule. Finally, because resources are needed to enable entities to do what is required, Congress can provide those resources. This approach is also required by the Convention on the Elimination of all forms of Racial Discrimination.

Finally, federal action is required to assure uniformity. States have differing requirements for collection of race, ethnic and language data. A few states place restrictions on ethnic and racial data collection and reporting in health. In California, a proposed initiative by opponents of affirmative action would effectively prohibit the collection of data on race and ethnicity in all social and educational programs in the state. Congressional action would assure that data collection in health would not be disrupted by the results of such an initiative.

4. Congress should declare that protecting the civil rights of Americans must include ending disparities based on race or ethnicity in the quality of clinical medical treatment. To implement Title VI of the Civil Rights Act of 1964, Congress:

   a. should mandate that the Department of Health and Human Services ensure that all entities offering health services that receive federal financial assistance, including states, health plans, hospitals, nursing homes and other entities, collect and report racial, ethnic and primary language identifiers for recipients of clinical health services they offer according to standards the Department establishes;

   b. should require that racial, ethnic and primary language identifiers be retrievable in clinical records, including those transmitted electronically;

   c. should amend the Health Insurance Portability and Accountability Act to require race and ethnicity data, in a form consistent with standards established by the Office of Management and Budget, in the mandatory code sets for the transmission of electronic clinical records;

[69] See, for example, the Civil Rights Restoration Act, which overturned mistaken interpretations of civil rights laws, including Title VI, by the Supreme Court.

d. should require agencies responsible for setting standards for race and ethnic data collection, including the Office of Management and Budget, assure that the data are not misused to permit or facilitate discrimination and periodically review and update standards to remain consistent with developments in the field;

e. should mandate that HHS determine the feasibility of collecting data on social and economic status at the same time data on race and ethnicity is collected;

f. should mandate and fund an outreach campaign to assure that individuals coming for health services understand the purposes for which racial and ethnic data will be used and the protections against their misuse.

5. With respect to agencies that provide or furnish health care, Congress should require that

   a. the Centers on Medicare and Medicaid Services assure that health care providers seeking reimbursement in programs administered by the agency collect data on racial, ethnic, primary language and social class data in accordance with 1997 OMB standards;

   b. Health Resources And Services Administration (HRSA) be required to ensure that all federally-qualified community and migrant health care centers collect race, ethnicity, and primary language data on all patients according to 1997 OMB standards. Congress should provide adequate funding for these purposes.

   c. HRSA be mandated to require hospitals that receive Hill-Burton loans to implement standards for the collection of these data.

6. Congress should provide technical and financial assistance to states to enable them to meet federal standards for data collection and reporting in federally-supported programs such as Medicaid and the Children's Health Insurance Program.

Assure Analysis of Health Data to Detect Disparities Based on Ethnicity and Race

As critical as it is to assure that data on race and ethnicity are collected, it is insufficient to determine whether racial and ethnic disparities exist. The data must be regularly and systematically analyzed and reported on the smallest appropriate units of analysis feasible. This analysis will advance the purpose of quality assurance efforts and civil rights enforcement. This analysis should apply across all federally-supported efforts, including Medicaid managed care programs, community health centers, VA programs and other programs with substantial numbers of minority patients. Initial attention should be focused on disease categories in which there has been the most extensive documentation of existing disparities in care. Responsibility for conducting the analysis regularly and systematically must be assigned by Congress, and responsibility given to both health agencies and OCR to determine if racial disparities found amount to discrimination. Once data are analyzed, the public, practitioners, financers and institutions can be informed about racial disparities and civil rights investigation and enforcement becomes possible.

7. Congress should mandate that federal agencies that finance health services engage in systematic, periodic analysis of racial and ethnic disparities in clinical care programs they support. Congress should provide adequate funding for these purposes. To implement this mandate, Congress should

   a. require that the Centers for Medicare and Medicaid Services immediately begin to engage in systematic, periodic analysis of racial disparities in clinical care programs it supports, including Medicare, Medicaid and the Children's Health Insurance Program.[70] In doing so, CMS should use standard quality assurance measures, such as HEDIS. Priorities for analysis of data should be based on conditions and interventions where studies to date have indicated the existence of racial disparities in diagnosis and treatment. Analysis should be done in a manner that will promote understanding of racial disparities in particular settings or communities rather than on a nationwide or state-wide basis. This information should be available by the smallest tech-

[70] CMS should not have to wait until all data it receives is consistent with OMB standards. As noted above, racial and ethnic identifiers already exist in the Medicare + Choice program. The Children's Health Insurance Program also requires collection of racial and ethnic identifiers. Medicare has access to racial and ethnic identifiers in its Enrollment Data Base that can be tied to clinical records. Although currently the accuracy of these identifiers beyond "black" and "white" is poor, analysis can begin for disparities involving African Americans.

nically appropriate scale possible (e.g., hospital, group of hospitals) to the public.

b. require that HRSA implement, through its transplantation division, a system to routinely monitor and publicly report transplantations rates and outcomes by race, ethnicity and primary language;[71] this information should be available by the smallest technically appropriate scale possible (e.g., hospital, group of hospitals) to the public.

c. require that the Veterans Administration engage in systematic, periodic analysis of racial disparities in clinical care programs it operates, using standard quality assurance measures. This information should be available by the smallest technically appropriate scale possible (e.g., hospital, group of hospitals) to the public.

8. Congress should encourage private sector health entities subject to Title VI to engage in monitoring of racial and ethnic disparities in quality of health care offered by these entities.

9. To encourage private sector use of quality assurance mechanisms to assess disparities in the quality of clinical care, Congress should appropriate funds to encourage use of quality assurance standards to HMOs, health plans and hospitals nationally. The Agency for Health Care Research and Quality should prepare a series of financial assistance programs intended to stimulate such projects within health plans, insurance companies, hospitals and others. These projects should include the development of quality assurance systems designed to track disparities and quality improvement systems designed to eliminate disparities. It should also offer incentives to these entities that engage in accepted forms of quality assurance that reviews of disparities based on race and ethnicity will be a consideration in an enforcement action by the Office of Civil Rights. [72]

10. Congress should encourage and financially support federal initiatives, undertaken in cooperation with private sector agencies such as the National Committee for Quality Assurance, to develop additional quality assurance measures procedures that can be used to determine racial and ethnic disparities in clinical diagnosis and treatment. Reliable, feasible and valid measures should be developed to monitor and report, inter alia, use of diagnostic and therapeutic cardiovascular and cerebrovascular procedures, joint replacement surgery, curative cancer surgery, and organ transplantation according to race and ethnicity. New measures are also needed to monitor minority health quality regarding diseases including HIV/AIDS and sickle cell anemia. Standards for determining which groups should be included in reporting by particular HMO's and hospitals need to be developed.

11. The Agency for Healthcare Research and Quality should

a. provide technical assistance to other agencies with respect to methods of engaging in annual analyses of racial and ethnic disparities in clinical care, including

- identify appropriate quality assurance mechanisms to assess disparities;
- identify the level at which the analysis should be conducted, e.g., plan, hospital, community; and
- specify the clinical diagnostic and therapeutic measures which should be monitored;

b. provide leadership in developing new quality measures applicable to racial and ethnic disparities.

Provide Needed Resources to Agencies Addressing Race and Ethnic Disparities in Health[73]

Agencies of the federal government are already deeply involved in issues of racial and ethnic disparities,

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[71] Kidney failure disproportionately affects African Americans, American Indians and possibly Latinos and is one of the top ten causes of death of African Americans. There is also extensive and incontrovertible evidence of under-referral of African-Americans for renal transplants.

[72] The assistance programs would be of two types. The first type would be support for institutions to establish Quality Assurance systems to monitor disparities in several areas within their patient or plan member population. The conditions of federal support could require or encourage that these systems be explicitly linked to existing HEDIS or JCAHO measures. The intent of this program would be to demonstrate the feasibility of this approach in the real world and to develop strategies for overcoming institutional implementation barriers. This demonstration project could also be used to guide federal requirements in the future. The second type of program would be action oriented. Institutions would be asked to identify a major disparity within their institution and then to develop and implement a plan to address these disparities. As with most grants, continuing funding would be contingent upon progress towards meeting established goals.

[73] Particular resource needs are discussed in sections that follow.

although their focus in recent years has been more on the elimination of disparities in health status (such as the higher age-specific and disease-specific morbidity and mortality, excess deaths, and diminished life expectancy among minority populations, due primarily to social, economic and environmental factors) than on the problem of variations by race and ethnicity in the quality and comprehensiveness of care. A first requirement is for sustained and adequate funding for both the grant and intramural programs of these agencies devoted to issues of racial and ethnic disparities.

12. Congress must assure adequate and sustained funding for the agencies and programs particularly relevant to the study,[74] monitoring, and rectifying of racial and ethnic disparities in health care. These include such specific components of the Department of Health and Human Services as the Office of Minority Health, the Office of Civil Rights, the Office of the Surgeon General, the Centers for Medicare and Medicaid Services, and the Center for Disease Control and Prevention. At the National Institutes of Health, adequate and sustained funding is essential for the National Center on Minority Health and Health Disparities and centers within the National Cancer Institute and the National Institute for Mental Health. Restoration of adequate funding is crucial for the Agency for Healthcare Research and Quality, which is playing a central role in quality assurance and the monitoring of racial and ethnic disparities in care, and must include its further development of Centers of Excellence and other intramural and extramural programs. These federal agencies are major engines of reform and corrective interventions, and their funding should be specific targets of an advocacy campaign in every budget cycle.

13. Congress, along with the states, should increase funding for "pipeline" programs, integrating efforts by high schools, colleges and health professional schools to increase the diversity of the applicant pools for health workforce careers, together with state loan repayment programs for health professional service, leadership, research, and advocacy in minority health and health care disparities in presently underserved areas.

Promote Equity in Health Services

The contributions of an inequitable and fragmented health care system, with many perverse incentives to provide low quality care, especially to people of low income (of which racial and ethnic minorities represent an enormous percentage) and a population of tens of millions of uninsured people, to racial and ethnic disparities in clinical care is beyond the scope of this report. Nevertheless, it is important to recognize that equity in health services and elimination of racial and ethnic disparities go hand in hand.

14. Congress and state legislatures should take the actions necessary to make access to health care available to all, since universal coverage is essential to equity. In so doing, it should assure that eligibility rules, service structures, reimbursement rates, provider participation rules, and plan management policies do not result in lower quality care for African Americans, Hispanic Americans, Asian and Pacific Islander Americans or Native Americans.

Engage Stakeholders

As in other areas where key civil rights are at stake, stakeholder involvement is crucial.

15. In order to achieve a more appropriate balance in its efforts to eliminate racial/ethnic disparities in both health status and health care, HHS should sponsor an annual conference of stakeholders—professional, institutional and community-based—on the occasion of the publication of the national report card on disparities by the AHRQ.

B. National Organizations of Health Care Professionals

A number of associations of health care professionals have embraced the elimination of disparities in quality of health services based on race or ethnicity as part of their mission. Others should follow their lead and take proactive steps to eliminate disparities within their areas of practice. One key step is to assure that individuals seeking certification in specialty areas of practice are properly trained to be aware of these disparities and to take steps to assure their elimination in their own practices.

16. The American Medical Association, the National Medical Association, Hispanic Medical Association, the professional organizations of Native American and Asian/Pacific Islander physicians, and their

[74] The subjects of study and research include those described in Questions for Further Study at the end of Section III above.

counterpart organizations in nursing, physician assistant, public health, psychology and related disciplines, as well as associations concerned with a particular specialty, have been increasingly active in addressing the problem of racial/ethnic disparities in care. Each of these should

a. initiate, continue or expand programs in cultural competence to include awareness of the existing levels and types of disparities, and to address the problem of unconscious bias,

b. organize sessions on these subjects and on both their quality assurance and human rights dimensions at their annual meetings,

c. assist state medical societies in doing the same, and

d. engage in collaborative efforts with community-based and minority advocacy organizations to address issues of access to care, navigation of the health care system, mistrust, and patient empowerment.

17. Boards that examine and certify practitioners in a speciality in medicine and other disciplines should

a. require cultural competency training and awareness of racial/ethnic disparities evidence to be included in all approved residency programs and in examination for board certification,

b. emphasize disease-specific evidence-based guidelines for quality assurance in diagnostic and therapeutic choices now especially prone to racial/ethnic disparities, and

c. organize sessions at their annual scientific meetings on these topics, and their ethical/human rights implications. Similar programs should be undertaken by such related organizations as the American Cancer Society, the American Heart Association, etc. Many such efforts and programs are already under way; they should be continued and expanded.

C. Educational Institutions

Cultural competency education should occur during all the years of health professional education and post-graduate continuing education. Curricular requirements for such training are already a requirement for the accreditation of medical schools by the Liaison Committee on Medical Education. Similar requirements should be developed for other health professional schools. Parallel efforts should be developed on the individual level for certification by specialty boards in medicine, which also have responsibility for mounting educational programs on cultural competency and awareness of existing problems of disparities in care.

Educational institutions also have a key role in research and in promoting minority representation in the health professions through effective affirmative action programs. Affirmative action and diversity in the health professional workforce are essential components of the effort to achieve racial and ethnic equity in medical care. Minority physicians and other health professionals cannot be presumed to be automatically immune to biases endemic in the larger society or engendered by aspects of professional education, nor is physician-patient racial/ethnic concordance the only pathway to equal treatment, but the evidence is clear that it is strongly associated with patient satisfaction and trust. Efforts to expand the pool of applicants to professional training, like those long maintained by the Association of American Medical Colleges and many individual professional educational centers, are necessary to correct the dramatic under-representation of African Americans, Hispanic Americans and Native Americans in the health professions.

18. Medical and other health professional schools should include cultural competency education at all levels of the curriculum and in residency and fellowship training. Having such programs should be a condition of accreditation.

19. It is essential that programs in affirmative action and related efforts to increase diversity in the health workforce be maintained, to correct the massive under-representation of African Americans, Hispanic Americans, Native Americans and other minorities in the health professions. Premature abandonment of affirmative action at college and graduate professional levels will produce heavy costs in access to care, health professional representation in presently underserved and minority areas, physician-patient continuity of care, and patient satisfaction.

20. Academic Medical Centers should continue and expand regional and multi-center consortia for

data collection, research studies on racial/ethnic disparities, and the development of both institutional and individual provider self-assessment tools to measure equity in clinical practice by race, ethnicity and primary language.

Licensing of Health Professionals

21. State licensing agencies in medicine and other health professional disciplines similarly should include measures of cultural competency, knowledge of evidence-based medicine, and awareness of evidence on racial/ethnic disparities.

D. Accreditation Institutions

The accreditation process is a powerful tool for assuring that institutions offering health services take appropriate actions toward equal treatment.

22. The Council of Teaching Hospitals, the Council on Graduate Medical Education, and their analogues in other health professions should include requirements related to the elimination of disparities in the quality of clinical services, including monitoring such disparities, in their standards and provide guidance in quality assurance steps to end them once they are identified.

23. The National Committee on Quality Assurance and Joint Commission on the Accreditation of Healthcare Organizations should incorporate the goal of eliminating disparities in clinical diagnosis and treatment into their missions statements; contribute to the establishment of standard operating procedures for the collection of race and ethnicity data; and contribute to the development of key quality measures that are stratified by race and ethnicity and require plans or hospitals to report on them. Each should also require participating hospitals or health care plans initially to identify one or two key areas of disparity and develop and implement quality improvement plan to address them.

E. Community-based and Minority Advocacy Organizations

Community-based advocacy organizations are a presently overlooked and underutilized resource for change. These, together with the major traditional national civil rights and other organizations of minority groups, are an essential resource for involvement in issues of racial and ethnic disparities in health care. The survey and focus-group evidence of minority mistrust of health professionals and the health care system is compelling and alarming, and such mistrust plays a role in distorting physician-patient and institution-patient interactions and facilitating the occurrence of disparities in care. Most current efforts have focused on institutional and individual providers, and such programs are important. But "top-down" approaches are incomplete and unlikely to sustain advocacy campaigns without extensive grass-roots involvement. All other stakeholders should engage such organizations in addressing the need to end racial and ethnic disparities in the quality of health services.

24. The HHS Office of Minority Health maintains an extensive list of health-related minority advocacy organizations. Sustained collaborative programs between health professional organizations and community-based groups are needed in an ongoing and candid educational effort to address these problems, and funding should be found for them.

F. Health Care Provider Organizations and their Associations

Certain health providers and plans, such as Aetna, as well as associations like the American Hospital Association and the American Association of Health Plans have already shown leadership in supporting the collection of data based on race, ethnicity and primary language. They have a critical, even primary role, in supporting their members in all aspects of efforts to eliminate racial and ethnic disparities in clinical diagnosis and treatment. A commitment to evidence-based practice, management and payment structures that encourage time with patients, thorough peer review procedures and many more specific actions can help to identify and eliminate disparities.

The Panel recognizes that the ultimate agents of change in the effort to eliminate race/ethnicity-based disparities will always be the individual providers—the doctors, dentists, nurse-practitioners, nurses, physician assistants and others who care for patients. Given the current structures of medical practice, change agents will also include the organizations within which they work, and the larger associations that represent them. Collectively, all these stakeholders will be the primary architects of the quality assurance programs, peer review mechanisms, training and educational programs that are relevant to the problem of disparities. These efforts

will be enhanced by outreach to community-based organizations in joint efforts to confront disparities in care. The government actions recommended will provide the necessary framework for change, but within that context it is the professionalism of providers, and their commitment to equity, that must prevail.

RECOMMENDATIONS FOR RESEARCH

To accept the role of multiple non-clinical factors in clinical decision-making is not to claim that there is adequate understanding of the ways in which they are acquired, how they operate in the nexus of the patient-physician clinical encounter, and how they may be modified. A modest sample of priority needs for further research, would include the following:

1. Intense observational studies of race-discordant and race-concordant physician-patient clinical encounters, in combined or parallel efforts by medical anthropologists and sociologists, cognitive psychologists, clinical educators and quality assurance evaluators;
2. A new round of studies of the culture of medicine, focused on the behaviors and expressed attitudes toward race and ethnicity in ward rounds, medical and surgical residents meetings, and both the overt and the latent content of instruction of medical students, nursing students, and other providers-in-training;
3. An expansion of prospective studies of disparities in care, combining clinical data with qualitative interviews with patients and providers;
4. Studies of what has been termed the natural history of social categorization in medical education and practice. Studies need to explore the prior experiences and racial and social values that students bring to the onset of professional education, the ways in which values and behaviors are acquired or modified in the course of training, and the effect, if any, of education and awareness of the evidence of disparities;
5. Studies of the effectiveness of standard clinical guidelines in reducing disparities in the disease categories most frequently associated with findings of racially differential care;
6. Exploration of health system differences such as the documented lower frequency of racial and ethnic disparities in care in the Department of Defense health care system,[75] in community health centers,[76] and in the End Stage Renal Disease Program. Such studies should explore the role of racial/ethnic diversity in senior clinical and administrative positions, diversity of provider staff, and the effect of physician-patient continuity of care;
7. Evaluation of cultural competency programs and their impact on the attitudes, knowledge, skills and behaviors of health care providers. Further research should identify the most effective content and methods of teaching that prepare providers to be aware of and to address health and health care disparities;
8. Community-participant research, jointly involving professional medical groups and community-based minority organizations, to explore effective methods of reducing distrust and to study the effectiveness of different educational methods or teaching techniques on facilitating active patient participation in clinical decision making. Much greater understanding is needed of the determinants of patient preferences for different treatment options;
9. Further studies of stereotyping, and effective methods of suppressing or controlling it, jointly involving cognitive psychologists, medical educators and clinicians in quality control. One focus should be on what has been called application error—the inappropriate application of epidemiological or genetic data about groups to a particular individual of that group—since the utilization of group-based data in individual risk assessment and therapeutic choice is an integral part of medical training;
10. Studies on appropriate indicators of socio-economic status, and methods for incorporating such indicators in patient records, to permit analysis of this factor as a determinant of disparities in qual-

[75] Dominitz JA, Samsa GP, Landsman P, Provenzale D. Race, treatment and survival among colorectal carcinoma patients in an equal-access medical system. *Cancer*. 1998;82:2312-2320.

[76] Shi, L, Starfield B, Politzer R, Regan J. Primary care, self-rated health, and reduction in social disparities in health. *Health Services Research*; 2002;37:1-22, and Shi L, Regan J, Politizer RM, Luo J. Community health centers and racial/ethnic disparities in healthy life. *International Journal of Health Services*. 2001;31:567-582. Other recent data show a striking reduction in low birth weight rates of urban and rural African American women who are health center patients, as compared to national African American rates.

ity of health services;

11. Interventional studies designed to eliminate disparities. These can be patient targeted, provider targeted or institutionally targeted, conducted in both publicly funded and privately insured programs and sites of care, with special attention to managed care programs, and address both ambulatory and inpatient care.

The need for such studies to increase understanding, however, does not qualify or diminish support for the conclusion stated above, that racial and ethnic disparities in the quality of clinical health care exist.

VIII. CONCLUSION

Each of these recommendations provides a specific target for advocacy and a yardstick for measuring progress. The Panel calls for a sustained and planned campaign of advocacy and action. The historian Philip Klinkner has described the long record of struggles to achieve racial equality in the United States as an unsteady march, characterized by relatively brief bursts of progress and much longer periods of stagnation or regression. Each episode of progress has been the product of a surge from the grass roots, a determination to close the gap between principle and practice that have been so repeatedly described by W.E.B. Dubois, Myrdal, the Kerner Commission, and in the health sector by a succession of Surgeons General and, most recently, by the Institute of Medicine. That surge, and that determination, is what is envisioned now.

TABLE I

Bibliographic Categories

General Medical and Surgical Procedures
Cardiovascular Disease
Cerebrovascular Disease
Cancer
Asthma
Renal Disease
Organ Donation
Maternal and Child Health
Ophthalmic Disease
Mental Health
Diabetes
Emergency Care
End of Life Care
Hip Repair
Prevention
C-Section and Hysterectomy
Clinical trials
Research Methods
Patient Trust
Cultural Competence