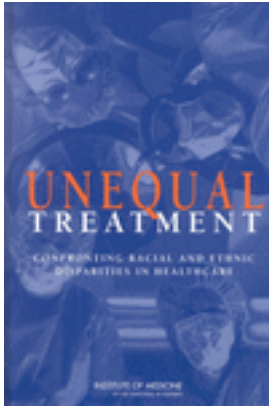


Free Summary



Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care (full printed version)

Brian D. Smedley, Adrienne Y. Stith, and Alan R. Nelson, Editors, Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care
ISBN: 978-0-309-08532-8, 782 pages, 6 x 9, hardback (2003)

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Racial and ethnic disparities in health care are known to reflect access to care and other issues that arise from differing socioeconomic conditions. There is, however, increasing evidence that even after such differences are accounted for, race and ethnicity remain significant predictors of the quality of health care received. In Unequal Treatment, a panel of experts documents this evidence and explores how persons of color experience the health care environment. The book examines how disparities in treatment may arise in health care systems and looks at aspects of the clinical encounter that may contribute to such disparities. Patients' and providers' attitudes, expectations, and behavior are analyzed. How to intervene? Unequal Treatment offers recommendations for improvements in medical care financing, allocation of care, availability of language translation, community-based care, and other arenas. The committee highlights the potential of cross-cultural education to improve provider–patient communication and offers a detailed look at how to integrate cross-cultural learning within the health professions. The book concludes with recommendations for data collection and research initiatives. Unequal Treatment will be vitally important to health care policymakers, administrators, providers, educators, and students as well as advocates for people of color.

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Summary

ABSTRACT

Racial and ethnic minorities tend to receive a lower quality of healthcare than non-minorities, even when access-related factors, such as patients' insurance status and income, are controlled. The sources of these disparities are complex, are rooted in historic and contemporary inequities, and involve many participants at several levels, including health systems, their administrative and bureaucratic processes, utilization managers, healthcare professionals, and patients. Consistent with the charge, the study committee focused part of its analysis on the clinical encounter itself, and found evidence that stereotyping, biases, and uncertainty on the part of healthcare providers can all contribute to unequal treatment. The conditions in which many clinical encounters take place—characterized by high time pressure, cognitive complexity, and pressures for cost-containment—may enhance the likelihood that these processes will result in care poorly matched to minority patients' needs. Minorities may experience a range of other barriers to accessing care, even when insured at the same level as whites, including barriers of language, geography, and cultural familiarity. Further, financial and institutional arrangements of health systems, as well as the legal, regulatory, and policy environment in which they operate, may have disparate and negative effects on minorities' ability to attain quality care.

A comprehensive, multi-level strategy is needed to eliminate these disparities. Broad sectors—including healthcare providers, their patients, payors, health plan purchasers, and society at large—should be made aware of the healthcare gap between racial and ethnic groups in the United States. Health systems should

base decisions about resource allocation on published clinical guidelines, insure that physician financial incentives do not disproportionately burden or restrict minority patients' access to care, and take other steps to improve access—including the provision of interpretation services, where community need exists. Economic incentives should be considered for practices that improve provider-patient communication and trust, and reward appropriate screening, preventive, and evidence-based clinical care. In addition, payment systems should avoid fragmentation of health plans along socioeconomic lines.

The healthcare workforce and its ability to deliver quality care for racial and ethnic minorities can be improved substantially by increasing the proportion of underrepresented U.S. racial and ethnic minorities among health professionals. In addition, both patients and providers can benefit from education. Patients can benefit from culturally appropriate education programs to improve their knowledge of how to access care and their ability to participate in clinical-decision making. The greater burden of education, however, lies with providers. Cross-cultural curricula should be integrated early into the training of future healthcare providers, and practical, case-based, rigorously evaluated training should persist through practitioner continuing education programs. Finally, collection, reporting, and monitoring of patient care data by health plans and federal and state payors should be encouraged as a means to assess progress in eliminating disparities, to evaluate intervention efforts, and to assess potential civil rights violations.

Looking gaunt but determined, 59-year-old Robert Tools was introduced on August 21, 2001, as a medical miracle—the first surviving recipient of a fully implantable artificial heart. At a news conference, Tools spoke with emotion about his second chance at life and the quality of his care. His physicians looked on with obvious affection, grateful and honored to have extended Tools' life. Mr. Tools has since lost his battle for life, but will be remembered as a hero for undergoing an experimental technology and paving the way for other patients to undergo the procedure. Moreover, the fact that Tools was African American and his doctors were white seemed, for most Americans, to symbolize the irrelevance of race in 2001. According to two recent polls, a significant majority of Americans believe that blacks like Tools receive the same quality of healthcare as whites (Lillie-Blanton et al., 2000; Morin, 2001).

Behind these perceptions, however, lies a sharply contrasting reality. A large body of published research reveals that racial and ethnic minorities experience a lower quality of health services, and are less likely to receive even routine medical procedures than are white Americans. Relative to whites, African Americans—and in some cases, Hispanics—are less likely to receive appropriate cardiac medication (e.g., Herholz et al., 1996)

or to undergo coronary artery bypass surgery (e.g., Ayanian et al., 1993; Hannan et al., 1999; Johnson et al., 1993; Petersen et al., 2002), are less likely to receive peritoneal dialysis and kidney transplantation (e.g., Epstein et al., 2000; Barker-Cummings et al., 1995; Gaylin et al., 1993), and are likely to receive a lower quality of basic clinical services (Ayanian et al., 1999) such as intensive care (Williams et al., 1995), even when variations in such factors as insurance status, income, age, co-morbid conditions, and symptom expression are taken into account. Significantly, these differences are associated with greater mortality among African-American patients (Peterson et al., 1997; Bach et al., 1999).

STUDY CHARGE AND COMMITTEE ASSUMPTIONS

These disparities prompted Congress to request an Institute of Medicine (IOM) study to assess differences in the kinds and quality of health-care received by U.S. racial and ethnic minorities and non-minorities. Specifically, Congress requested that the IOM:

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

This Executive Summary presents only abbreviated versions of the study committee's findings and recommendations. For the full findings and recommendations, and a more extensive justification of each, the reader is referred to the committee report. Below, findings and recommendations are preceded by text summarizing the evidence base from which they are drawn. For purposes of clarity, some findings and recommendations are presented in a different sequence than they appear in the full report; however, their numeric designation remains the same.

Defining Racial and Ethnic Healthcare Disparities

The study committee defines *disparities* in healthcare as racial or ethnic differences in the quality of healthcare that are not due to access-

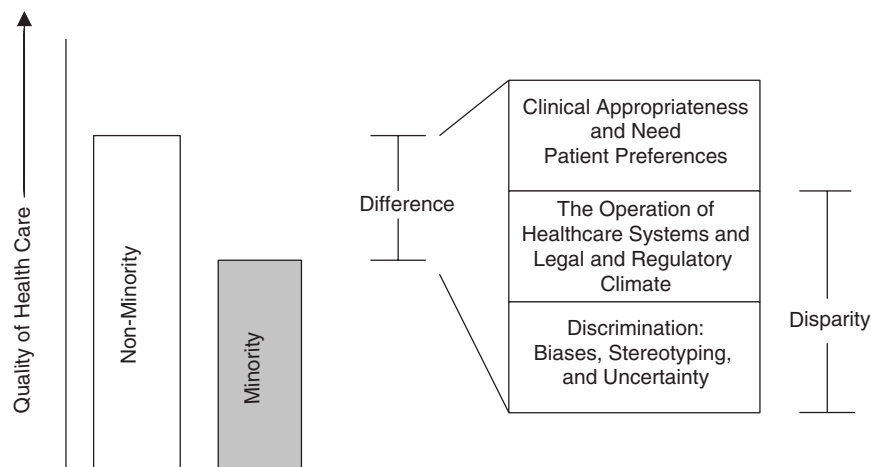


FIGURE S-1 Differences, disparities, and discrimination: Populations with equal access to healthcare. SOURCE: Gomes and McGuire, 2001.

related factors or clinical needs, preferences,¹ and appropriateness of intervention (Figure S-1). The committee's analysis is focused at two levels: 1) the operation of healthcare systems and the legal and regulatory climate in which health systems function; and 2) discrimination at the individual, patient-provider level. Discrimination, as the committee uses the term, refers to differences in care that result from biases, prejudices, stereotyping, and uncertainty in clinical communication and decision-making. It should be emphasized that these definitions are not legal definitions. Different sources of federal, state and international law define discrimination in varying ways, with some focusing on intent and others emphasizing disparate impact.

¹The committee defines patient *preferences* as patients' choices regarding healthcare that are based on a full and accurate understanding of treatment options. As discussed in Chapter 3 of this report, patients' understanding of treatment options is often shaped by the quality and content of provider-patient communication, which in turn may be influenced by factors correlated with patients' and providers' race, ethnicity, and culture. Patient preferences that are not based on a full and accurate understanding of treatment options may therefore be a source of racial and ethnic disparities in care. The committee recognizes that patients' preferences and clinicians' presentation of clinical information and alternatives influence each other, but found separation of the two to be analytically useful.

EVIDENCE OF HEALTHCARE DISPARITIES

Evidence of racial and ethnic disparities in healthcare is, with few exceptions, remarkably consistent across a range of illnesses and healthcare services. These disparities are associated with socioeconomic differences and tend to diminish significantly, and in a few cases, disappear altogether when socioeconomic factors are controlled. The majority of studies, however, find that racial and ethnic disparities remain even after adjustment for socioeconomic differences and other healthcare access-related factors (for more extensive reviews of this literature, see Kressin and Petersen, 2001; Geiger, this volume; and Mayberry, Mili, and Ofili, 2000).

Studies of racial and ethnic differences in cardiovascular care provide some of the most convincing evidence of healthcare disparities. The most rigorous studies in this area assess both potential underuse and overuse of services and appropriateness of care by controlling for disease severity using well-established clinical and diagnostic criteria (e.g., Schneider et al., 2001; Ayanian et al., 1993; Allison et al., 1996; Weitzman et al., 1997) or matched patient controls (Giles et al., 1995). Several studies, for example, have assessed differences in treatment regimen following coronary angiography, a key diagnostic procedure. These studies have demonstrated that differences in treatment are not due to clinical factors such as racial differences in the severity of coronary disease or overuse of services by whites (e.g., Schneider et al., 2001; Laouri et al., 1997; Canto et al., 2000; Peterson et al., 1997). Further, racial disparities in receipt of coronary revascularization procedures are associated with higher mortality among African Americans (Peterson et al., 1997).

Healthcare disparities are also found in other disease areas. Several studies demonstrate significant racial differences in the receipt of appropriate cancer diagnostic tests (e.g., McMahon et al., 1999), treatments (e.g., Imperato et al., 1996), and analgesics (e.g., Bernabei et al., 1998), while controlling for stage of cancer at diagnosis and other clinical factors. As is the case in studies of cardiovascular disease, evidence suggests that disparities in cancer care are associated with higher death rates among minorities (Bach et al., 1999). Similarly, African Americans with HIV infection are less likely than non-minorities to receive antiretroviral therapy (Moore et al., 1994), prophylaxis for pneumocystic pneumonia, and protease inhibitors (Shapiro et al., 1999). These disparities remain even after adjusting for age, gender, education, CD4 cell count, and insurance coverage (e.g., Shapiro et al., 1999). In addition, differences in the quality of HIV care are associated with poorer survival rates among minorities, even at equivalent levels of access to care (Bennett et al., 1995; Cunningham et al., 2000).

Racial and ethnic disparities are found in a range of other disease and

health service categories, including diabetes care (e.g., Chin, Zhang, and Merrell, 1998), end-stage renal disease and kidney transplantation (e.g., Epstein et al., 2000; Kasiske, London, and Ellison, 1998; Barker-Cummings et al., 1995; Ayanian et al., 1999), pediatric care and maternal and child health, mental health, rehabilitative and nursing home services, and many surgical procedures. In some instances, minorities are *more* likely to receive certain procedures. As in the case of bilateral orchiectomy and amputation, however (which African Americans undergo at rates 2.4 and 3.6 times greater, respectively, than their white Medicare peers; Gornick et al., 1996), these are generally less desirable procedures.

Finding 1-1: Racial and ethnic disparities in healthcare exist and, because they are associated with worse outcomes in many cases, are unacceptable.

Recommendation 2-1: Increase awareness of racial and ethnic disparities in healthcare among the general public and key stakeholders.

Recommendation 2-2: Increase healthcare providers' awareness of disparities.

RACIAL ATTITUDES AND DISCRIMINATION IN THE UNITED STATES

By way of context, it is important to note that racial and ethnic disparities are found in many sectors of American life. African Americans, Hispanics, American Indians, and Pacific Islanders, and some Asian-American subgroups are disproportionately represented in the lower socioeconomic ranks, in lower quality schools, and in poorer-paying jobs. These disparities can be traced to many factors, including historic patterns of legalized segregation and discrimination. Unfortunately, some discrimination remains. For example, audit studies of mortgage lending, housing, and employment practices using paired “testers” demonstrate persistent discrimination against African Americans and Hispanics. These studies illustrate that much of American social and economic life remains ordered by race and ethnicity, with minorities disadvantaged relative to whites. In addition, these findings suggest that minorities' experiences in the world outside of the healthcare practitioner's office are likely to affect their perceptions and responses in care settings.

Finding 2-1: Racial and ethnic disparities in healthcare occur in the context of broader historic and contemporary social and economic

inequality, and evidence of persistent racial and ethnic discrimination in many sectors of American life.

ASSESSING POTENTIAL SOURCES OF DISPARITIES IN CARE

The studies cited above suggest that a range of patient-level, provider-level, and system-level factors may be involved in racial and ethnic healthcare disparities, beyond access-related factors.

Patient-Level Variables: The Role of Preferences, Treatment Refusal, and the Clinical Appropriateness of Care

Racial and ethnic disparities in care may emerge, at least in part, from a number of patient-level attributes. For example, minority patients are more likely to refuse recommended services (e.g., Sedlis et al., 1997), adhere poorly to treatment regimens, and delay seeking care (e.g., Mitchell and McCormack, 1997). These behaviors and attitudes can develop as a result of a poor cultural match between minority patients and their providers, mistrust, misunderstanding of provider instructions, poor prior interactions with healthcare systems, or simply from a lack of knowledge of how to best use healthcare services. However, racial and ethnic differences in patient preferences and care-seeking behaviors and attitudes are unlikely to be major sources of healthcare disparities. For example, while minority patients have been found to refuse recommended treatment more often than whites, differences in refusal rates are small and have not fully accounted for racial and ethnic disparities in receipt of treatments (Hannan et al., 1999; Ayanian et al., 1999). Overuse of some clinical services (i.e., use of services when not clinically indicated) may be more common among white than minority patients, and may contribute to racial and ethnic differences in discretionary procedures. Several recent studies, however, have assessed racial differences relative to established criteria (Hannan et al., 1999; Laouri et al., 1997; Canto et al., 2000; Peterson et al., 1997) or objective diagnostic information, and still find racial differences in receipt of care. Other studies find that overuse of cardiovascular services among whites does not explain racial differences in service use (Schneider et al., 2001).

Finally, some researchers have speculated that biologically based racial differences in clinical presentation or response to treatment may justify racial differences in the type and intensity of care provided. For example, racial and ethnic group differences are found in response to drug therapies such as enalapril, an angiotensin-converting-enzyme inhibitor used to reduce the risk of heart failure (Exner et al., 2001). These differ-

ences in response to drug therapy, however, are not due to “race” *per se* but can be traced to differences in the distribution of polymorphic traits between population groups (Wood, 2001), and are small in relation to the common benefits of most therapeutic interventions. Further, as noted above, the majority of studies document disparities in healthcare services and disease areas when interventions are equally effective across population groups—making the “racial differences” hypothesis an unlikely explanation for observed disparities in care.

Finding 4-2: A small number of studies suggest that racial and ethnic minority patients are more likely than white patients to refuse treatment. These studies find that differences in refusal rates are generally small and that minority patient refusal does not fully explain healthcare disparities.

Healthcare Systems-Level Factors

Aspects of health systems—such as the ways in which systems are organized and financed, and the availability of services—may exert different effects on patient care, particularly for racial and ethnic minorities. Language barriers, for example, pose a problem for many patients where health systems lack the resources, knowledge, or institutional priority to provide interpretation and translation services. Nearly 14 million Americans are not proficient in English, and as many as one in five Spanish-speaking Latinos reports not seeking medical care due to language barriers (The Robert Wood Johnson Foundation, 2001). Similarly, time pressures on physicians may hamper their ability to accurately assess presenting symptoms of minority patients, especially where cultural or linguistic barriers are present. Further, the geographic availability of healthcare institutions—while largely influenced by economic factors that are outside the charge of this study—may have a differential impact on racial and ethnic minorities, independent of insurance status (Kahn et al., 1994). A study of the availability of opioid supplies, for example, revealed that only one in four pharmacies located in predominantly non-white neighborhoods carried adequate supplies, compared with 72% of pharmacies in predominantly white neighborhoods (Morrison et al., 2000). Perhaps more significantly, changes in the financing and delivery of healthcare services—such as the shifts brought by cost-control efforts and the movement to managed care—may pose greater barriers to care for racial and ethnic minorities than for non-minorities (Rice, this volume). Increasing efforts by states to enroll Medicaid patients in managed care systems, for example, may disrupt traditional community-based care and displace providers who are familiar with the language, culture, and values of ethnic

minority communities (Leigh, Lillie-Blanton, Martinez, and Collins, 1999). In addition, research indicates that minorities enrolled in publicly funded managed care plans are less likely to access services after mandatory enrollment in an HMO, compared with whites and other minorities enrolled in non-managed care plans (Tai-Seale et al., 2001).

Care Process-Level Variables: The Role of Bias, Stereotyping, Uncertainty

Three mechanisms might be operative in healthcare disparities from the provider's side of the exchange: bias (or prejudice) against minorities; greater clinical uncertainty when interacting with minority patients; and beliefs (or stereotypes) held by the provider about the behavior or health of minorities (Balsa and McGuire, 2001). Patients might also react to providers' behavior associated with these practices in a way that also contributes to disparities. Unfortunately, little research has been conducted to elucidate how patient race or ethnicity may influence physician decision-making and how these influences affect the quality of care provided. In the absence of such research, the study committee drew upon a mix of theory and relevant research to understand how clinical uncertainty, biases or stereotypes, and prejudice might operate in the clinical encounter.

Clinical Uncertainty

Any degree of uncertainty a physician may have relative to the condition of a patient can contribute to disparities in treatment. Doctors must depend on inferences about severity based on what they can see about the illness and on what else they observe about the patient (e.g., race). The doctor can therefore be viewed as operating with prior beliefs about the likelihood of patients' conditions, "priors" that will be different according to age, gender, socioeconomic status, and race or ethnicity. When these priors—which are taught as a cognitive heuristic to medical students—are considered alongside the information gained in a clinical encounter, both influence medical decisions.

Doctors must balance new information gained from the patient (sometimes with varying levels of accuracy) and their prior expectations about the patient to determine the diagnosis and course of treatment. If the physician has difficulty accurately understanding the symptoms or is less sure of the "signal"—the set of clues and indications that physicians rely upon to make diagnostic decisions—then he or she is likely to place greater weight on the "priors." The consequence is that treatment decisions and patients' needs are potentially less well matched.

The Implicit Nature of Stereotypes

A large body of research in psychology has explored how stereotypes evolve, persist, shape expectations, and affect interpersonal interactions. Stereotyping can be defined as the process by which people use social categories (e.g., race, sex) in acquiring, processing, and recalling information about others. The beliefs (stereotypes) and general orientations (attitudes) that people bring to their interactions help to organize and simplify complex or uncertain situations and give perceivers greater confidence in their ability to understand a situation and respond in efficient and effective ways (Mackie, Hamilton, Susskind, and Rosselli, 1996).

Although functional, social stereotypes and attitudes also tend to be systematically biased. These biases may exist in overt, explicit forms, as represented by traditional bigotry. However, because their origins arise from virtually universal social categorization processes, they may also exist, often unconsciously, among people who strongly endorse egalitarian principles and truly believe that they are not prejudiced (Dovidio and Gaertner, 1998). In the United States, because of shared socialization influences, there is considerable empirical evidence that even well-meaning whites who are not overtly biased and who do not believe that they are prejudiced typically demonstrate unconscious implicit negative racial attitudes and stereotypes (Dovidio, Brigham, Johnson, and Gaertner, 1996). Both implicit and explicit stereotypes significantly shape interpersonal interactions, influencing how information is recalled and guiding expectations and inferences in systematic ways. They can also produce self-fulfilling prophecies in social interaction, in that the stereotypes of the perceiver influence the interaction with others in ways that conform to stereotypical expectations (Jussim, 1991).

Healthcare Provider Prejudice or Bias

Prejudice is defined in psychology as an unjustified negative attitude based on a person's group membership (Dovidio et al., 1996). Survey research suggests that among white Americans, prejudicial attitudes toward minorities remain more common than not, as over half to three-quarters believe that relative to whites, minorities—particularly African Americans—are less intelligent, more prone to violence, and prefer to live off of welfare (Bobo, 2001). It is reasonable to assume, however, that the vast majority of healthcare providers find prejudice morally abhorrent and at odds with their professional values. But healthcare providers, like other members of society, may not recognize manifestations of prejudice in their own behavior.

While there is no direct evidence that provider biases affect the qual-

ity of care for minority patients, research suggests that healthcare providers' diagnostic and treatment decisions, as well as their feelings about patients, are influenced by patients' race or ethnicity. Schulman et al. (1999), for example, found that physicians referred white male, black male, and white female hypothetical "patients" (actually videotaped actors who displayed the same symptoms of cardiac disease) for cardiac catheterization at the same rates (approximately 90% for each group), but were significantly less likely to recommend catheterization procedures for black female patients exhibiting the same symptoms. Weisse et al. (2001), using a similar methodology as that of Schulman, found that male physicians prescribed twice the level of analgesic medication for white "patients" than for black "patients." Female physicians, in contrast, prescribed higher doses of analgesics for black than for white "patients," suggesting that male and female physicians may respond differently to gender and/or racial cues. In another experimental design, Abreu (1999) found that mental health professionals subliminally "primed" with African American stereotype-laden words were more likely to evaluate the same hypothetical patient (whose race was not identified) more negatively than when primed with neutral words. And in a study based on actual clinical encounters, van Ryn and Burke (2000) found that doctors rated black patients as less intelligent, less educated, more likely to abuse drugs and alcohol, more likely to fail to comply with medical advice, more likely to lack social support, and less likely to participate in cardiac rehabilitation than white patients, even after patients' income, education, and personality characteristics were taken into account. These findings suggest that while the relationship between race or ethnicity and treatment decisions is complex and may also be influenced by gender, providers' perceptions and attitudes toward patients are influenced by patient race or ethnicity, often in subtle ways.

Medical Decisions Under Time Pressure with Limited Information

Studies suggest that several characteristics of the clinical encounter increase the likelihood that stereotypes, prejudice, or uncertainty may influence the quality of care for minorities (van Ryn, 2002). In the process of care, health professionals must come to judgments about patients' conditions and make decisions about treatment, often without complete and accurate information. In most cases, they must do so under severe time pressure and resource constraints. The assembly and use of these data are affected by many influences, including various "gestalts" or cognitive shortcuts. In fact, physicians are commonly trained to rely on clusters of information that functionally resemble the application of "prototypic" or

stereotypic constellations. These conditions of time pressure, resource constraints, and the need to rely on gestalts map closely onto those factors identified by social psychologists as likely to produce negative outcomes due to lack of information, to stereotypes, and to biases (van Ryn, 2002).

Patient Response: Mistrust and Refusal

As noted above, the responses of racial and ethnic minority patients to healthcare providers are also a potential source of disparities. Little research has been conducted as to how patients may influence the clinical encounter. It is reasonable to speculate, however, that if patients convey mistrust, refuse treatment, or comply poorly with treatment, providers may become less engaged in the treatment process, and patients are less likely to be provided with more vigorous treatments and services. But these kinds of reactions from minority patients may be understandable as a response to negative racial experiences in other contexts, or to real or perceived mistreatment by providers. Survey research, for example, indicates that minority patients perceive higher levels of racial discrimination in healthcare than non-minorities (LaVeist, Nickerson, and Bowie, 2000; Lillie-Blanton et al., 2000). Patients' and providers' behavior and attitudes may therefore influence each other reciprocally, but reflect the attitudes, expectations, and perceptions that each has developed in a context where race and ethnicity are often more salient than these participants are even aware of. In addition, it is clear that the healthcare provider, rather than the patient, is the more powerful actor in clinical encounters. Providers' expectations, beliefs, attitudes, and behaviors are therefore likely to be a more important target for intervention efforts.

Finding 3-1: Many sources—including health systems, healthcare providers, patients, and utilization managers—may contribute to racial and ethnic disparities in healthcare.

Finding 4-1: Bias, stereotyping, prejudice, and clinical uncertainty on the part of healthcare providers may contribute to racial and ethnic disparities in healthcare. While indirect evidence from several lines of research supports this statement, a greater understanding of the prevalence and influence of these processes is needed and should be sought through research.

INTERVENTIONS TO ELIMINATE RACIAL AND ETHNIC DISPARITIES IN HEALTHCARE

Legal, Regulatory, and Policy Interventions

“De-Fragmentation” of Healthcare Financing and Delivery

Racial and ethnic minorities are more likely than whites to be enrolled in “lower-end” health plans, which are characterized by higher per capita resource constraints and stricter limits on covered services (Phillips et al., 2000). The disproportionate presence of racial and ethnic minorities in lower-end health plans is a potential source of healthcare disparities, given that efforts to control for insurance status in studies of healthcare disparities have not taken detailed account of variations among health plans. Such socioeconomic fragmentation of health plans engenders different clinical cultures, with different practice norms, tied to varying per capita resource constraints (Bloche, 2001).

Equalizing access to high-quality plans can limit such fragmentation. Public healthcare payors such as Medicaid should strive to help beneficiaries access the same health products as privately-insured patients. This recommendation is also reflected in the IOM *Quality Chasm* report’s strategies for focusing health systems on quality, in its call to “eliminate or modify payment practices that fragment the care system” (IOM, 2001, p. 13).

Recommendation 5-1: Avoid fragmentation of health plans along socioeconomic lines.

Strengthening Doctor-Patient Relationships

Several lines of research suggest that the consistency and stability of the doctor-patient relationship is an important determinant of patient satisfaction and access to care. Having a usual source of care is associated, for example, with use of preventive care services (Agency for Healthcare Research and Quality, 2001). In addition, having a consistent relationship with a primary care provider may help to address minority patient mistrust of healthcare systems and providers, particularly if the relationship is with a provider who is able to bridge cultural and linguistic gaps (LaViest, Nickerson, and Bowie, 2000). Minority patients, however, are less likely to enjoy a consistent relationship with a provider, even when insured at the same levels as white patients (Lillie-Blanton, Martinez, and Salganicoff, 2001). This is due in part to the types of health systems in

which they are enrolled and the relative lack of providers located in minority communities.

Health systems should attempt to ensure that every patient, whether insured privately or publicly, has a sustained relationship with an attending physician able to help the patient effectively navigate the healthcare bureaucracy. Federal and state performance standards for Medicaid managed care plans, for example, should include guidelines to ensure the stability of patients' assignments to primary care providers (and these providers' accessibility), reasonable patient loads per primary care physician, and time allotments for patient visits.

Recommendation 5-2: Strengthen the stability of patient-provider relationships in publicly funded health plans.

Patient and provider relationships will also be strengthened by greater racial and ethnic diversity in the health professions. Racial concordance of patient and provider is associated with greater patient participation in care processes, higher patient satisfaction, and greater adherence to treatment (Cooper-Patrick et al., 1999). In addition, racial and ethnic minority providers are more likely than their non-minority colleagues to serve in minority and medically underserved communities (Komaromy et al., 1996). The benefits of diversity in health professions fields are significant, and illustrate that a continued commitment to affirmative action is necessary for graduate health professions education programs, residency recruitment, and other professional opportunities.

Recommendation 5-3: Increase the proportion of underrepresented U.S. racial and ethnic minorities among health professionals.

Patient Protections

Much of the political focus on Capitol Hill in the summer of 2001 was devoted to managed care regulation. To one extent or another, the various bills debated would all extend protections to enrollees in private managed care organizations, providing avenues for appeal of care denial decisions, improving access to specialty care, requiring health plans to disclose information about coverage, banning physician "gag" clauses, and providing other legal remedies to resolve disputes. Publicly funded health plans, however, are not addressed in these legislative proposals. Given that many minorities are disproportionately represented among the publicly insured who receive care within managed care organizations, the same patient protections that apply to the privately insured should apply to those in publicly funded plans (Hashimoto, 2001).

Recommendation 5-4: Apply the same managed care protections to publicly funded HMO enrollees that apply to private HMO enrollees.

Civil Rights Enforcement

Enforcement of regulation and statute is also an important component of a comprehensive strategy to address healthcare disparities, but unfortunately has been too often relegated to low-priority status. The U.S. DHHS Office of Civil Rights (OCR) is charged with enforcing several relevant federal statutes and regulations that prohibit discrimination in healthcare (principally Title VI of the 1964 Civil Rights Act). The agency, however, has suffered from insufficient resources to investigate complaints of possible violations, and has long abandoned proactive, investigative strategies (Smith, 1999). Complaints to the agency declined in the early 1990s, but have increased in recent years, while funding has remained level in terms of appropriated dollars but lower in terms of spending power after adjusting for inflation (U.S. Commission on Civil Rights, 2001). The agency should be equipped with sufficient resources to better address these complaints and carry out its oversight responsibilities.

Recommendation 5-5: Provide greater resources to the U.S. DHHS Office for Civil Rights to enforce civil rights laws.

Health Systems Interventions

A variety of interventions applied at the level of health systems may be effective as a part of a comprehensive, multi-level strategy to address racial and ethnic disparities in healthcare.

Evidence-Based Cost Control

In the current era of continually escalating healthcare costs, cost containment is an important goal of all health systems. To the extent possible, however, medical limit setting by health plans should be based on evidence of effectiveness. The application of evidence to healthcare delivery, such as through the use of evidence-based guidelines, can help to address the problem of potential underuse of services resulting from capitation or per case payment methods, as noted in the IOM *Quality Chasm* report (IOM, 2001). Evidence-based guidelines offer the advantages of consistency, predictability, and objectivity that general, discretionary advisory statements do not. In addition, because evidence-based guidelines

and standards directly promote accountability, they also indirectly affect equity of care.

In actual practice, however, a pragmatic balance must be sought between the advantages and limitations of guidelines, such as the tension between the goal of standardization versus the need for clinical flexibility. Disclosing health plans' clinical protocols offers one means of achieving this balance, as it would aid both private sector and public efforts in balancing the virtues of rules and discretion. To achieve this, private accrediting entities and state regulatory bodies could require that health plans publish their clinical practice protocols, along with supporting evidence, thereby opening these protocols to professional and consumer review (Bloche, 2001).

Recommendation 5-6: Promote the consistency and equity of care through the use of evidence-based guidelines.

Financial Incentives in Healthcare

Financial factors, such as capitation and health plan incentives to providers to practice frugally, can pose greater barriers to racial and ethnic minority patients than to white patients, even among patients insured at the same level. Low payment rates limit the supply of physician (and other healthcare provider) services to low-income groups, disproportionately affecting ethnic minorities (Rice, this volume). Inadequate supply takes the form of too few providers participating in plans serving the poor, and provider unwillingness to spend adequate time with patients. This time pressure may contribute to poor information exchange between physicians and members of minority groups.

If appropriately crafted, however, financial incentives to physicians can serve a positive role in efforts to reduce disparities in care. Economic rewards for time spent engaging patients and their families can help physicians to overcome barriers of culture, communication, and empathy. In addition, incentives that encourage physicians to adhere to evidence-based protocols for frugal practice and to engage in age- and gender-appropriate disease screening can promote efficient, quality care and penalize deviations, regardless of race or ethnicity. Further, financial incentives linked to favorable clinical outcomes, where reasonably measurable (e.g. control of diabetes, asthma, and high blood pressure) can also promote equity of care (Bloche, 2001). Again, this recommendation is consistent with the IOM *Quality Chasm* report, which calls for healthcare organizations, clinicians, purchasers, and other stakeholders to "align the incentives inherent in payment and accountability processes with the goal of quality improvement" (IOM, 2001, p.10).

Recommendation 5-7: Structure payment systems to ensure an adequate supply of services to minority patients and limit provider incentives that may promote disparities.

Recommendation 5-8: Enhance patient-provider communication and trust by providing financial incentives for practices that reduce barriers and encourage evidence-based practice.

Interpretation Services

As noted above, many racial and ethnic minorities find that language barriers pose a significant problem in their efforts to access healthcare. Language barriers may affect the delivery of adequate care through poor exchange of information, loss of important cultural information, misunderstanding of physician instruction, poor shared decision making, or ethical compromises (e.g., difficulty obtaining informed consent; Woloshin et al., 1995). Linguistic difficulties may also result in decreased adherence with medication regimes, poor appointment attendance (Manson, 1988), and decreased satisfaction with services (Carrasquillo et al., 1999; David and Rhee, 1998; Derose and Baker, 2000).

Broader use of professional interpretation services has been hampered by a number of logistical and resource constraints. For example, in some regions of the country, few trained professional interpreters are available, and reimbursement for interpretation services via publicly funded insurance such as Medicaid is often inadequate. Greater resources are needed to support professional interpretation services, and more research and innovation should identify effective means to harness new technologies (e.g., simultaneous telephone interpretation) to aid interpretation.

Recommendation 5-9: Support the use of interpretation services where community need exists.

Community Health Workers

Community health workers—often termed lay health advisors, neighborhood workers, indigenous health workers, health aides, *consejera*, or *promotora*—fulfill multiple functions in helping to improve access to healthcare. Community health workers can serve as liaisons between patients and providers, educate providers about community needs and the culture of the community, provide patient education, contribute to continuity and coordination of care, assist in appointment attendance and adherence to medication regimens, and help to increase the use of preventive and primary care services (Brownstein et al., 1992; Earp and Flax,

1999; Jackson and Parks, 1997). In addition, some evidence suggests that lay health workers can help improve the quality of care and reduce costs (Witmer et al., 1995), and improve general wellness by facilitating community access to and negotiation for services (Rodney et al., 1998).

Recommendation 5-10: Support the use of community health workers.

Multidisciplinary Teams

Research demonstrates that multidisciplinary team approaches—including physicians, nurses, dietitians, and social workers, among others—can effectively optimize patient care. This effect is found in randomized controlled studies of patients with coronary heart disease, hypertension, and other diseases, and has extended to strategies for reducing risk behaviors and conditions such as smoking, sedentary lifestyle and obesity (Hill and Miller, 1996). Multidisciplinary teams coordinate and streamline care, enhance patient adherence through follow-up techniques, and address the multiple behavioral and social risks faced by patients. These teams may save costs and improve the efficiency of care by reducing the need for face-to-face physician visits and improve patients' day-to-day care between visits. Further, such strategies have proven effective in improving health outcomes of minorities previously viewed as "difficult to serve" (Hill and Miller, 1996). Multidisciplinary team approaches should be more widely instituted as strategy for improving care delivery, implementing secondary prevention strategies, and enhancing risk reduction.

Recommendation 5-11: Implement multidisciplinary treatment and preventive care teams.

Patient Education and Empowerment

Increasingly, researchers are recognizing the important role of patients as active participants in clinical encounters (Korsch, 1984). Patient education efforts have taken many forms, including the use of books and pamphlets, in-person instruction, CD-ROM-based educational materials, and internet-based information. These materials guide patients through typical office visits and provide information about asking appropriate questions and having their questions answered, communicating with the provider when instructions are not understood or cannot be followed, and being an active participant in decision-making. While evaluation data are limited, particularly with respect to racial and ethnic minority patients, preliminary evidence suggests that patient education can improve pa-

tients' skills and knowledge of clinical encounters and improve their participation in care decisions.

Recommendation 5-12: Implement patient education programs to increase patients' knowledge of how to best access care and participate in treatment decisions.

Cross-Cultural Education in the Health Professions

Given the increasing racial and ethnic diversity of the U.S. population, the development and implementation of training programs for healthcare providers offers promise as a key intervention strategy in reducing healthcare disparities. As a result, cross-cultural education programs have been developed to enhance health professionals' awareness of how cultural and social factors influence healthcare, while providing methods to obtain, negotiate and manage this information clinically once it is obtained. Cross-cultural education can be divided into three conceptual approaches focusing on *attitudes* (cultural sensitivity/awareness approach), *knowledge* (multicultural/categorical approach), and *skills* (cross-cultural approach), and has been taught using a variety of interactive and experiential methodologies. Research to date demonstrates that training

Summary of Findings

Finding 1-1: Racial and ethnic disparities in healthcare exist and, because they are associated with worse outcomes in many cases, are unacceptable.

Finding 2-1: Racial and ethnic disparities in healthcare occur in the context of broader historic and contemporary social and economic inequality, and evidence of persistent racial and ethnic discrimination in many sectors of American life.

Finding 3-1: Many sources—including health systems, healthcare providers, patients, and utilization managers—may contribute to racial and ethnic disparities in healthcare.

Finding 4-1: Bias, stereotyping, prejudice, and clinical uncertainty on the part of healthcare providers may contribute to racial and ethnic disparities in healthcare. While indirect evidence from several lines of research supports this statement, a greater understanding of the prevalence and influence of these processes is needed and should be sought through research.

Finding 4-2: A small number of studies suggest that racial and ethnic minority patients are more likely than white patients to refuse treatment. These studies find that differences in refusal rates are generally small and that minority patient refusal does not fully explain healthcare disparities.

Summary of Recommendations

General Recommendations

Recommendation 2-1: Increase awareness of racial and ethnic disparities in healthcare among the general public and key stakeholders.

Recommendation 2-2: Increase healthcare providers' awareness of disparities.

Legal, Regulatory, and Policy Interventions

Recommendation 5-1: Avoid fragmentation of health plans along socioeconomic lines.

Recommendation 5-2: Strengthen the stability of patient-provider relationships in publicly funded health plans.

Recommendation 5-3: Increase the proportion of underrepresented U.S. racial and ethnic minorities among health professionals.

Recommendation 5-4: Apply the same managed care protections to publicly funded HMO enrollees that apply to private HMO enrollees.

Recommendation 5-5: Provide greater resources to the U.S. DHHS Office for Civil Rights to enforce civil rights laws.

Health Systems Interventions

Recommendation 5-6: Promote the consistency and equity of care through the use of evidence-based guidelines.

Recommendation 5-7: Structure payment systems to ensure an adequate supply of services to minority patients, and limit provider incentives that may promote disparities.

Recommendation 5-8: Enhance patient-provided communication and trust by providing financial incentives for practices that reduce barriers and encourage evidence-based practice.

Recommendation 5-9: Support the use of interpretation services where community need exists.

is effective in improving provider knowledge of cultural and behavioral aspects of healthcare and building effective communication strategies. Despite progress in the field, however, several challenges exist, including the need to define educational core competencies, reach consensus on approaches and methodologies, determine methods of integration into the medical and nursing curriculum, and develop and implement appropriate evaluation strategies. These challenges should be addressed to realize the potential of cross-cultural education strategies.

Recommendation 6-1: Integrate cross-cultural education into the training of all current and future health professionals.

Recommendation 5-10: Support the use of community health workers.

Recommendation 5-11: Implement multidisciplinary treatment and preventive care teams.

Patient Education and Empowerment

Recommendation 5-12: Implement patient education programs to increase patients' knowledge of how to best access care and participate in treatment decisions.

Cross-Cultural Education in the Health Professions

Recommendation 6-1: Integrate cross-cultural education into the training of all current and future health professionals.

Data Collection and Monitoring

Recommendation 7-1: Collect and report data on health care access and utilization by patients' race, ethnicity, socioeconomic status, and where possible, primary language.

Recommendation 7-2: Include measures of racial and ethnic disparities in performance measurement.

Recommendation 7-3: Monitor progress toward the elimination of healthcare disparities.

Recommendation 7-4: Report racial and ethnic data by OMB categories, but use subpopulation groups where possible.

Research Needs

Recommendation 8-1: Conduct further research to identify sources of racial and ethnic disparities and assess promising intervention strategies.

Recommendation 8-2: Conduct research on ethical issues and other barriers to eliminating disparities.

DATA COLLECTION AND MONITORING

Standardized data collection is critically important in the effort to understand and eliminate racial and ethnic disparities in healthcare. Data on patient and provider race and ethnicity would allow researchers to better disentangle factors that are associated with healthcare disparities, help health plans to monitor performance, ensure accountability to enrolled members and payors, improve patient choice, allow for evaluation of intervention programs, and help identify discriminatory practices. Unfortunately, standardized data on racial and ethnic differences in care are generally unavailable. Federal 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.

A number of ethical, logistical, and fiscal concerns present challenges to data collection and monitoring, including the need to protect patient privacy, the costs of data collection, and resistance from healthcare providers, institutions, plans and patients. In addition, health plans have raised significant concerns about how such data will be analyzed and reported. The challenges to data collection should be addressed, as the costs of failing to assess racial and ethnic disparities in care may outweigh new burdens imposed by data collection and analysis efforts.

Recommendation 7-1: Collect and report data on healthcare access and utilization by patients' race, ethnicity, socioeconomic status, and where possible, primary language.

Recommendation 7-2: Include measures of racial and ethnic disparities in performance measurement.

Recommendation 7-3: Monitor progress toward the elimination of healthcare disparities.

Recommendation 7-4: Report racial and ethnic data by federally defined categories, but use subpopulation groups where possible.

NEEDED RESEARCH

While the literature that the committee reviewed provides significant evidence of racial and ethnic disparities in care, the evidence base from which to better understand and eliminate disparities in care remains less than clear. Several broad areas of research are needed to clarify how race and ethnicity are associated with disparities in the process, structure, and outcomes of care. Research must provide a better understanding of the contribution of patient, provider, and institutional characteristics on the quality of care for minorities. Research has been notably absent in other areas. More research is needed, for example, to understand the extent of disparities in care faced by Asian-American, Pacific-Islander, American Indian and Alaska Native, and Hispanic populations, and to better understand and surmount barriers to research on healthcare disparities, including those related to ethical issues in data collection.

Recommendation 8-1: Conduct further research to identify sources of racial and ethnic disparities and assess promising intervention strategies.

Recommendation 8-2: Conduct research on ethical issues and other barriers to eliminating disparities.

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UNEQUAL TREATMENT

CONFRONTING RACIAL AND ETHNIC
DISPARITIES IN HEALTH CARE

Brian D. Smedley, Adrienne Y. Stith, and
Alan R. Nelson, Editors

Committee on Understanding and Eliminating
Racial and Ethnic Disparities in Health Care

Board on Health Sciences Policy

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NOTICE: The project that is the subject of this report was approved by the Governing Board of the National Research Council, whose members are drawn from the councils of the National Academy of Sciences, the National Academy of Engineering, and the Institute of Medicine. The members of the committee responsible for the report were chosen for their special competences and with regard for appropriate balance.

Support for this project was provided by the Office of Minority Health, U.S. Department of Health and Human Services. Additional support for data collection activities was provided by The Commonwealth Fund and the Henry J. Kaiser Family Foundation. The views presented in this report are those of the Institute of Medicine Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care and are not necessarily those of the funding agencies.

Library of Congress Cataloging-in-Publication Data

Unequal treatment : confronting racial and ethnic disparities in health care / Brian D. Smedley, Adrienne Y. Stith, and Alan R. Nelson, editors ; Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care, Board on Health Sciences Policy, Institute of Medicine.

p. ; cm.

Includes bibliographical references and index.

ISBN 0-309-08265-X (hardcover with CD-ROM); ISBN 0-309-08532-2 (hardcover)

1. Discrimination in medical care. 2. Health services accessibility. 3. Minorities—Medical care. 4. Race discrimination. 5. Racism—Cross-cultural studies. 6. Social medicine.

[DNLM: 1. Health Services Accessibility—United States. 2. Ethnic Groups—United States. 3. Minority Groups—United States. 4. Quality of Health Care—United States. WA 300 U515 2002] I. Smedley, Brian D. II. Stith, Adrienne Y. III. Nelson, Alan R. (Alan Ray) IV. Institute of Medicine (U.S.). Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care.

RA563.M56 U53 2002

352.1'089—dc 21

2002007492

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Willing is not enough; we must do.”*
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This report has been reviewed in draft form by individuals chosen for their diverse perspectives and technical expertise, in accordance with procedures approved by the NRC's Report Review Committee. The purpose of this independent review is to provide candid and critical comments that will assist the institution in making its published report as sound as possible and to ensure that the report meets institutional standards for objectivity, evidence, and responsiveness to the study charge. The review comments and draft manuscript remain confidential to protect the integrity of the deliberative process. We wish to thank the following individuals for their review of this report:

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Although the reviewers listed above have provided many constructive comments and suggestions, they were not asked to endorse the conclusions or recommendations nor did they see the final draft of the report before its release. The review of this report was overseen by **HAROLD C. SOX**, Editor, *Annals of Internal Medicine*, Philadelphia, PA, appointed by the Institute of Medicine, and **ELAINE L. LARSON**, Professor of Pharmaceutical & Therapeutic Research, Columbia University School of Nursing, New York, NY. Appointed by the NRC's Report Review Committee, these individuals were responsible for making certain that an independent examination of this report was carried out in accordance with institutional procedures and that all review comments were carefully considered. Responsibility for the final content of this report rests entirely with the authoring committee and the institution.

Acknowledgments

Many individuals and groups made important contributions to the study committee's process and to this report. The committee wishes to thank all of these individuals and organizations, but recognizes that attempts to identify all and acknowledge their contributions would require more space than is available in this brief section.

To begin, the committee would like to thank the sponsors of this report. Core funds for the committee's work were provided by the Office of Minority Health, U.S. Department of Health and Human Services, in response to a Congressional request. The committee thanks Joan Jacobs and Olivia Carter-Pokras of this office, who served as the Task Order Officers on this grant. Additional funding for data collection efforts was provided by the Henry J. Kaiser Family Foundation of Menlo Park, California, and The Commonwealth Fund, a New York City-based private, independent foundation. The committee thanks Marsha Lillie-Blanton of the Henry J. Kaiser Family Foundation, and Karen Scott Collins and Dora L. Hughes of The Commonwealth Fund for their support.

The committee found the perspectives of many individuals and organizations to be valuable in understanding the complex problem of racial and ethnic disparities in healthcare. Several individuals and organizations provided important information at open workshops of the committee. These include, in order of appearance, Nathan Stinson, Ph.D., M.D., M.P.H., Deputy Assistant Secretary for Minority Health, U.S. Department of Health and Human Services; Charles Dujon, Legislative Assistant, Office of the Honorable Jessie Jackson, Jr., U.S. House

of Representatives; Rodney Hood, M.D., National Medical Association; Adolph Falcon, M.P.P., National Alliance for Hispanic Health; Jeanette Noltenius, Ph.D., Latino Council on Alcohol and Tobacco, representing the Multicultural Action Agenda for Eliminating Health Disparities; Yvonne Bushyhead, J.D., and Beverly Little Thunder, R.N., National Indian Health Board; H. Jack Geiger, M.D., City University of New York; Deborah Danoff, M.D., Assistant Vice President, Division of Medical Education, American Association of Medical Colleges; Paul M. Schyve, M.D., Senior Vice President, Joint Commission on Accreditation of Healthcare Organizations; Sindhu Srinivas, M.D., President, American Medical Student Association; Mary E. Foley, R.N., MS, President, American Nurses Association; Randolph D. Smoak, Jr., M.D., President, American Medical Association; Terri Dickerson, Assistant Staff Director, U.S. Commission on Civil Rights; Carolyn Clancy, M.D., Agency for Health Care Research and Quality; James Youker, M.D., President, American Board of Medical Specialties; Ray Werntz, Consumer Health Education Council; Vickie Mays, Ph.D., Chair, National Committee on Vital and Health Statistics Subcommittee on Populations; Robyn Nishimi, Ph.D., Chief Operating Officer, National Quality Forum; Lovell Jones, Ph.D., Intercultural Cancer Council; David Satcher, M.D., Ph.D., U.S. Surgeon General; Richard Epstein, J.D., James Parker Hall Distinguished Service Professor of Law, University of Chicago Law School; Clark C. Havighurst, J.D., Wm. Neal Reynolds Professor of Law, Duke University School of Law; Marsha Lillie-Blanton, Dr. P.H., Vice President in Health Policy, The Henry J. Kaiser Family Foundation; June O'Neill, Ph.D., Director, Center for the Study of Business and Government, Baruch College of Public Affairs; Thomas Perez, J.D., M.P.P., Assistant Professor and Director of Clinical Law Programs, University of Maryland Law School; and Thomas Rice, Ph.D., Professor and Vice-Chair, Department of Health Services, UCLA School of Public Health.

The committee also gratefully acknowledges the contributions of the many individuals who participated as members of one of four liaison panels, which were assembled to serve as a resource to the committee, to provide advice and guidance in identifying key information sources, to provide recommendations to the study committee regarding intervention strategies, and to ensure that relevant consumer and professional perspectives were represented. These individuals are listed in Appendix A. Similarly, the committee thanks the many individuals who provided input to study staff during "roundtable discussions" held at the Asian and Pacific Islander American Health Forum (APIAHF) conference on April 27 and 28, 2001, and the Indian Health Service (IHS) Research Conference on April 22 and 23, 2001. The committee extends its gratitude to Gem Daus of APIAHF and Leo Nolan, William Freeman, and Cecelia Shorty of IHS for their assistance in arranging these roundtable discussions.

Data from focus group discussions involving racial and ethnic minority healthcare consumers and healthcare providers helped to put a “human face” on the problem of disparities in care. The committee extends its gratitude to the many individuals who participated in these focus group discussions and shared their experiences, which included both positive as well as negative experiences in healthcare systems. These focus groups were convened and conducted by Westat, Inc., and a summary of the major themes is presented in Appendix D. Tim Edgar and Meredith Grady of Westat deserve special thanks for their work to convene these groups and provide a synthesis of the data.

Joe R. Feagin of the University of Florida, Nicole Lurie of RAND, Vickie Mays of UCLA, and Richard Allen Williams of UCLA and the Minority Health Institute served as technical reviewers on aspects of the report. These individuals provided technical comments only, and are not responsible for the final content of the report. Ruth Zambrana of the University of Maryland also provided valuable assistance regarding health care needs of Hispanic populations, and Elizabeth Marchak of the *Cleveland Plain Dealer* provided the study committee with informative and well-researched news articles from her research on healthcare disparities. Michael Sapoznikow designed the graphic illustration that appears as Figure 3-1 in Chapter 3. The committee thanks each of these individuals.

Finally, the committee would also like to thank the authors whose paper contributions contributed to the evidence base that the committee examined. These include H. Jack Geiger of the City University of New York; W. Michael Byrd and Linda A. Clayton of the Harvard School of Public Health; Lisa A. Cooper and Debra L. Roter of Johns Hopkins University; Jennie R. Joe, with the assistance of Jacquetta Swift and Robert S. Young of the Native American Research and Training Center, University of Arizona; Mary-Jo DelVecchio Good, Cara James, Byron J. Good, and Anne E. Becker, Department of Social Medicine, Harvard Medical School; Sara Rosenbaum of the School of Public Health and Health Services, George Washington University; Thomas Perez of the University of Maryland Law School; Madison Powers and Ruth Faden of the Kennedy Institute of Ethics, Georgetown University; and Thomas Rice of the Department of Health Services, UCLA School of Public Health.

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