

Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care (with CD)

Brian D. Smedley, Adrienne Y. Stith, and Alan R. Nelson, Editors, Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care
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A

Data Sources and Methods

In an effort to provide a comprehensive response to the study charge, the study committee examined various sources of data to assess the scope of disparities in healthcare, explore sources of these disparities, and generate strategies to eliminate them. These data sources included a review of recent scientific literature, commissioned papers, public input from professional societies and organizations, input from technical liaison panels, and focus group/roundtable input. The committee received these data over the course of the 17-month study period. The study timeline is depicted in Figure A-1.

Study Committee

A 15-member study committee was convened to assess these data. Membership of the committee included individuals with expertise in clinical medicine, economics, healthcare services research, health policy, health professions education, minority health, psychology, anthropology and related fields. The committee was convened for five two-day meetings held in December 2000, February 2001, May 2001, July 2001, and September 2001.

Literature Review

The literature review included, but was not limited to, seminal articles published in peer-reviewed journals within the last ten years, with an emphasis on the most recent publications. In selecting literature to re-

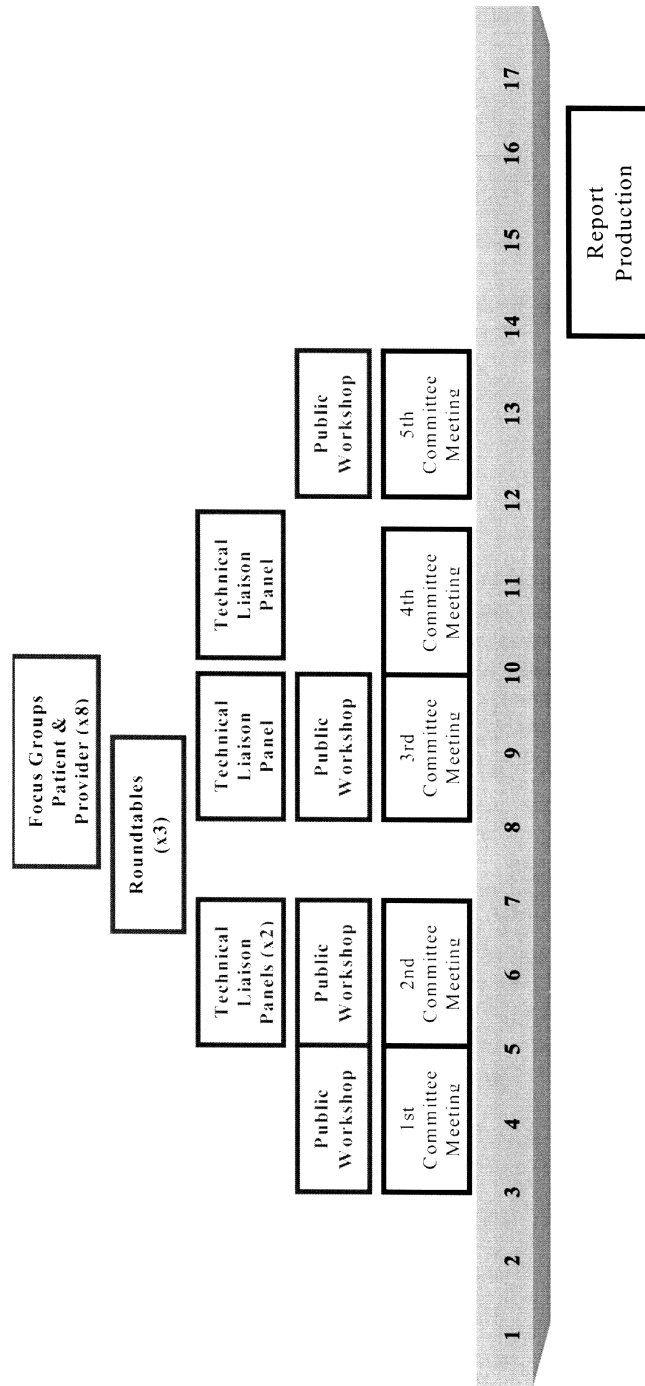


FIGURE A-1 Study components and timeline.

view, the committee identified only peer-reviewed studies that assessed racial and ethnic variation in healthcare while controlling for differences in access to healthcare (either by studying similarly insured patients or by statistically adjusting for differences in insurance status) and socioeconomic differences. This body of literature, however, represents only a fraction of the published studies that investigate racial and ethnic differences in access to and use of healthcare services.

Commissioned Papers

The study committee commissioned seven papers. These papers were intended to provide in-depth information on selected topic areas (e.g., legal aspects of healthcare discrimination, studies on patient-provider interaction, extensive literature review). Topics and paper authors were determined by the study committee. It should be noted that the commissioned paper contributions do not serve to substitute for the committee's own review and analysis of the literature, as described above and in Chapter 1. Much of the committee's own analysis was conducted independently, prior to receiving the draft commissioned papers.

Public Workshops

The study committee hosted four workshops to gain additional information from the public on aspects of the study charge. These workshops occurred during open portions of the committee's scheduled meetings. The topics and nature of the workshops were determined by the study committee. They were intended to allow the committee to gain additional perspectives on potential sources of bias in clinical settings; institutional or system-based obstacles that may differentially affect service provision to racial and ethnic minority patients; other potential sources of healthcare disparities; and explore potential interventions to eliminate disparities in health service delivery. Content included the perspectives of racial and ethnic minority and non-minority health professions organizations (e.g., American Medical Association), and government agencies, as well as programs and strategies employed by organizations to address disparities. In addition, at the fourth workshop selected commissioned papers served as topic areas for a discussion of legal and ethical perspectives. At each public workshop meeting, individuals and groups were invited to present information to the study committee in a roundtable setting to facilitate discussion and interaction. Agendas from public workshops and lists of participants are listed in Boxes A-1 through A-4.

BOX A-1

**INSTITUTE OF MEDICINE
COMMITTEE ON UNDERSTANDING AND ELIMINATING
RACIAL AND ETHNIC DISPARITIES IN HEALTHCARE**

**NATIONAL ACADEMY OF SCIENCES,
2101 CONSTITUTION AVENUE, NW
ROOM 150**

**AGENDA
TUESDAY, DECEMBER 19, 2000**

- 1:00 p.m. **WELCOME AND INTRODUCTIONS**
Alan Nelson, M.D.
Chair
IOM Committee on Understanding and Eliminating Racial
and Ethnic Disparities in Healthcare
- 1:15 p.m. **OVERVIEW FROM STUDY SPONSOR**
Nathan Stinson Ph.D., M.D., M.P.H.
Deputy Assistant Secretary for Minority Health,
U.S. Department of Health and Human Services
- 1:35 p.m. **CONGRESSIONAL PERSPECTIVE**
Charles Dujon
Legislative Assistant, Office of the Honorable Jessie Jack-
son, Jr. U.S. House of Representatives
- 2:00 p.m. **PRESENTATIONS FROM OTHER INTEREST GROUPS
AND STAKEHOLDERS**
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., & Beverly Little Thunder, R.N.
Indian Health Board
- 3:00 p.m. **UNDERSTANDING AND ELIMINATING RACIAL AND
ETHNIC DISPARITIES IN HEALTHCARE — WHAT IS
KNOWN AND WHAT NEEDS TO BE KNOWN?**
H. Jack Geiger, M.D.
City University of New York
- 4:00 p.m. **ADJOURN**

BOX A-2

**INSTITUTE OF MEDICINE
COMMITTEE ON UNDERSTANDING AND ELIMINATING
RACIAL AND ETHNIC DISPARITIES IN HEALTHCARE**

**NATIONAL ACADEMY OF SCIENCES
CECIL AND IDA GREEN BUILDING, 2001 WISCONSIN AVENUE, NW
ROOM 126**

**AGENDA
TUESDAY, FEBRUARY 20, 2001**

- 9:00 a.m. **WELCOME AND INTRODUCTIONS**
Alan Nelson, M.D.
Chair
IOM Committee on Understanding and Eliminating Racial
and Ethnic Disparities in Healthcare
- 9:15 a.m. ***Deborah Danoff, M.D.***
Assistant Vice President, Division of Medical Education
American Association of Medical Colleges
- 9:45 a.m. ***Paul M. Schyve, M.D.***
Senior Vice President
Joint Commission on Accreditation of Healthcare
Organizations
- 10:15 p.m. ***Sindhu Srinivas, M.D.***
President
American Medical Student Association
- 10:45 a.m. ***Mary E. Foley, R.N., M.S.***
President
American Nurses Association
- 11:15 a.m. ***Randolph D. Smoak, Jr., M.D.***
President
American Medical Association
- 11:45 a.m. ***Terri Dickerson***
Assistant Staff Director
U.S. Commission on Civil Rights
- 12:15 p.m. **PUBLIC WORKSHOP ADJOURNS**

BOX A-3

**INSTITUTE OF MEDICINE
COMMITTEE ON UNDERSTANDING AND ELIMINATING
RACIAL AND ETHNIC DISPARITIES IN HEALTHCARE**

**NATIONAL ACADEMY OF SCIENCES
CECIL AND IDA GREEN BUILDING, 2001 WISCONSIN AVENUE, NW
ROOM 126**

**AGENDA
TUESDAY, MAY 15, 2001**

- 1:00 p.m. ***Carolyn Clancy, M.D.***
Agency for Healthcare Research and Quality
- 1:45 p.m. ***James Youker, M.D.***
President, American Board of Medical Specialties
- 2:15 p.m. ***Ray Wertz***
Consumer Health Education Council
- 2:45 p.m. ***Vickie Mays, Ph.D., Chair***
National Committee on Vital and Health Statistics
Subcommittee on Populations
- 3:15 p.m. **QUESTIONS AND COMMENTS**
- 3:30 p.m. **PUBLIC WORKSHOP ADJOURNS**

WEDNESDAY, MAY 16, 2001

- 9:00 a.m. ***Robyn Nishimi, Ph.D.***
Chief Operating Officer, National Quality Forum
- 9:30 a.m. ***Lovell Jones, Ph.D.***
Intercultural Cancer Council
- 10:00 a.m. **PUBLIC WORKSHOP ADJOURNS**

BOX A-4

**INSTITUTE OF MEDICINE
COMMITTEE ON UNDERSTANDING AND ELIMINATING
RACIAL AND ETHNIC DISPARITIES IN HEALTHCARE**

**NATIONAL ACADEMY OF SCIENCES,
2101 CONSTITUTION AVENUE, NW
MAIN BUILDING—LECTURE ROOM**

**PUBLIC WORKSHOP
“RACE, THE MEDICAL MARKETPLACE, AND HEALTHCARE DISPARITIES”**

**AGENDA
THURSDAY, SEPTEMBER 6, 2001**

8:30 a.m. **WELCOME AND INTRODUCTIONS**
Alan Nelson, M.D.
Chair, IOM Committee on Understanding and Eliminating Racial and Ethnic Disparities in Healthcare

8:35 a.m. **OPENING REMARKS**
David Satcher, M.D., Ph.D.
U.S. Surgeon General

8:55 a.m. **PANEL DISCUSSION**
M. Gregg Bloche, J.D., M.D.
Moderator, IOM Committee on Understanding and Eliminating Racial and Ethnic Disparities in Healthcare

PARTICIPANTS:

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

Thomas Rice, Ph.D.
Professor and Vice-Chair, Department of Health Services, UCLA
School of Public Health

11:00 a.m. **ADJOURN**

Technical Liaison Panels

Four liaison panels 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. Liaison panels were composed of individuals with relevant experience or expertise on the study charge. Nominations for individuals invited to the panels were sought from over 100 stakeholder groups. Panel members included patient advocates, providers of health-care services, payer groups, as well as representatives from ethnic minority professional organizations and federal agencies. Each liaison panel was convened by study staff in Washington, D.C. for a half-day meeting. Panelists were asked to provide recommendations regarding potential sources of data, intervention strategies, and other recommendations relevant to the study charge. Discussion content and recommendations from the liaison panels were presented by staff to the study committee at its meetings. The agenda for panel meetings is presented in Box A-5. Lists of participants for each of the four panels are presented in Boxes A-6 through A-9.

Focus Groups and Roundtable Discussions

A series of focus groups were conducted by the Westat Corporation, Rockville, MD, for the study committee (see Appendix E). Information gathered at focus group discussions was intended to afford the study committee greater insight into the experiences and perceptions of patients and providers, supplementing data from the empirical literature, and providing a richer context for data interpretation. Qualitative data gathered during focus group discussions were used to illustrate and expand upon findings and recommendations provided in the committee report.

Six groups, composed of 8-10 individuals each, were conducted with healthcare consumers with participants from various racial and ethnic backgrounds. Two groups were conducted with African Americans: one in Los Angeles, CA, and the other in Rockville, MD. The third group was conducted in Los Angeles with Hispanics who were fluent in English, and the fourth was conducted in Washington, DC, with Hispanics who identified themselves as primary Spanish-speaking with little or no English fluency. The fifth group was conducted with American Indians in Albuquerque, New Mexico. The final group was conducted in Los Angeles with Chinese Americans who identified themselves as primarily Mandarin-speaking with little or no English fluency. Participants were asked to comment on the quality of healthcare they received and experiences encountered when seeking medical care in a variety of public and private

BOX A-5

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AGENDA—LIAISON PANEL

- 12:00 p.m. **LUNCH**
- 12:15 p.m. **INTRODUCTIONS**
Daniel J. Wooten, M.D.
IOM Scholar in Residence
Panel Chair
- 12:30 p.m. **OVERVIEW OF IOM STUDY**
Brian Smedley, Ph.D.
Adrienne Stith, Ph.D.
IOM study staff
- 12:45 p.m. **CURRENT INITIATIVES AND RESOURCES FOCUSED ON
REDUCING HEALTHCARE DISPARITIES**
- 1:30 p.m. **BREAK**
- 1:45 p.m. **DISCUSSION OF FACTORS THAT CONTRIBUTE TO
INEQUITIES IN HEALTHCARE**
- 2:30 p.m. **PANEL INPUT—RECOMMENDATIONS TO STUDY
COMMITTEE**
- Recommendations for Intervention Strategies
 - Policy Recommendations
 - Research Recommendations
- 4:00 p.m. **ADJOURN**

BOX A-6

**INSTITUTE OF MEDICINE
COMMITTEE ON UNDERSTANDING AND ELIMINATING
RACIAL AND ETHNIC DISPARITIES IN HEALTHCARE**

**TECHNICAL LIAISON
FEDERAL PANEL**

FEBRUARY 12, 2001

Jonca Bull, M.D., Food and Drug Administration

Denice Cora-Bramble, M.D., Health Resources and Services
Administration

Marsha Davenport, M.D., Center for Medicare and Medicaid Services

Carole Brown, Office for Civil Rights, Office of the Secretary of Health
and Human Services

LTC Willie L. Hensley, Department of Veterans Affairs

****Joan Jacobs***, Office of Minority Health, Office of the Secretary of Health
and Human Services

Camara Phyllis Jones, M.D., M.P.H., Ph.D., Centers for Disease Control
and Prevention

Raynard Kington, M.D., Ph.D., National Institutes of Health

Yvonne T. Maddox, Ph.D., National Institutes of Health

Beverly Malone, Ph.D., Office of Public Health and Science, Office of
the Secretary of Health and Human Services

George A. Mensah, M.D., Centers for Disease Control and Prevention

Leo J. Nolan III, Indian Health Service

Delores L. Parron, M.D., Planning and Evaluation Program, Department
of Health and Human Services

Capt. Adam M. Robinson, Jr., M.D., Department of Defense

Craig Vanderwagen, M.D., Indian Health Service

*observer from sponsoring office

BOX A-7

**INSTITUTE OF MEDICINE
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RACIAL AND ETHNIC DISPARITIES IN HEALTHCARE**

TECHNICAL LIAISON PANEL

FEBRUARY 14, 2001

Joseph A. Berry, M.D., United Healthcare

Zora Brown, Breast Cancer Resource Committee

Gina Gregory-Burns, M.D., Kaiser Permanente

Mary Lou de Leon Siantz, R.N., Ph.D., National Association of Hispanic Nurses

Gary C. Dennis, M.D., Howard University Hospital

Richard Levinson, M.D., DPA, American Public Health Association

Joseph Quash, M.D., Association of Black Cardiologists

Rene F Rodriguez, M.D., Interamerican College of Physicians and Surgeons

Cynthia A. Warrick, Ph.D., Howard University

Donald A. Young, M.D., Health Insurance Association of America

BOX A-8

**INSTITUTE OF MEDICINE
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RACIAL AND ETHNIC DISPARITIES IN HEALTHCARE**

LIAISON PANEL

MAY 4, 2001

David Baines, M.D., Seattle Indian Health Board

Henry Chung, M.D., Pfizer Pharmaceuticals Groups

Tom Chung, Ph.D., Commonwealth of Massachusetts, Executive Office
of Elder Affairs

Carolyn M. Clancy, M.D., Agency for Health Research & Quality

Gem P. Daus, M.A., Asian and Pacific Islander American Health Forum

Lucille Davis, Ph.D., R.N., Southern University School of Nursing, Baton
Rouge, LA

Pete Duarte, M.D., Thomason Hospital, El Paso, TX

Alicia C. Georges, Ed.D., Department of Nursing, Herbert H. Lehman
College, Bronx, NY

Robert D. Gibson, Pharm.D., Sc.D., American Pharmaceutical Association

Miya Iwataki, Los Angeles County Department of Health Services

Anita Moncrease, M.D., M.P.H., Health Resources and Service
Administration

Tom Perez, J.D., Maryland University School of Law

Elena Rios, M.D., M.S.P.H., National Hispanic Medical Association

Richard Allen Williams, M.D., University of California at Los Angeles
and Minority Health Institute

**Violet Ryo-Hwa Woo, M.S., M.P.H.*, Office of Minority Health

* observer from sponsoring office

BOX A-9

**INSTITUTE OF MEDICINE
COMMITTEE ON UNDERSTANDING AND ELIMINATING
RACIAL AND ETHNIC DISPARITIES IN HEALTHCARE**

LIAISON PANEL

JUNE 21, 2001

Dennis Andrulis, Ph.D., M.P.H., State University of New York Downstate Medical Center

Deborah Bohr, M.P.H., Health Research and Educational Trust

Cindy Brach, M.P.P., Agency for Healthcare Research and Quality

Deborah Danoff, M.D., Association of American Medical Colleges

Leonard G. Epstein, M.S.W., Bureau of Primary Health Care, Health Resources Services Administration

George Flouty, M.D., Pfizer, Inc.

Candice Mathew Healy, M.P.A., State University of New York Downstate Medical Center

Laura Hernandez, M.P.I.A., Centers for Medicare and Medicaid Services (formerly the Health Care Financing Administration)

Charlene Landis, M.A., Pfizer, Inc.

Ed Martinez, M.S., National Association of Public Hospitals

***Guadalupe Pacheco, M.S.W.**, Office of Minority Health, DHHS

Rea Panares, M.H.S., Washington Business Group on Health

Carlos Vidal, Ph.D., State University of New York Stonybrook

Malcom Williams, M.P.P., Grantmakers in Health

VIDEO CONFERENCE PARTICIPANTS

Niels Agger-Gupta, Ph.D., California Healthcare Interpreters Association

Sakinah Carter, M.P.H., The California Endowment

Tessie Guillermo, Asian and Pacifica Islander Health Forum

Melba Hinojosa, M.A., RN, MediCal Managed Care, California Department of Health Services

Vivian Huang, California Primary Care Association

Wendy Jameson, M.P.P., M.P.H., California Health Care Safety Net Institute

Beatriz Solis, M.P.H., LA Care Health Plan

Jai Lee Wong, The California Endowment

* observer from sponsoring office

settings, either for themselves or for a child or other family member. All participants had private health insurance, Medicare, Medicaid/MediCal, or Indian Health Service coverage.

In addition, two focus groups were conducted by telephone with African American and Hispanic healthcare providers throughout the United States: one was conducted with nurses, the other with physicians. Participants were asked to provide their opinions and comments on the quality of healthcare services that minority patients receive. They also discussed how their race or ethnicity affected their medical training or professional careers. Providers' perspectives added a rich content for understanding patients' experiences with racism in healthcare, addressing some of the institutional factors that affect quality of care.

An experienced facilitator, who possessed knowledge of cultural and linguistic differences of ethnic minority groups, led each of the nine groups. Facilitators for the consumer groups were matched with regard to race, ethnicity, and primary language. Study staff were present at Washington, DC area and phone-based focus groups.

To supplement qualitative information on the experiences and perceptions of racial and ethnic minority patients, advocates, and their healthcare providers, roundtable discussions were held at two national conferences (the Asian American and Pacific Islander Health Forum [AAPIHF] conference in Alameda, CA and the Indian Health Service [IHS] Research conference in Albuquerque, NM) where racial and ethnic minority health issues were discussed. At both conferences, study staff solicited participants from among conference attendees and invited them to participate in small group discussions (up to 20 people) to discuss participants' perceptions of racial and ethnic healthcare disparities and strategies to eliminate them. At the Indian Health Service Research Conference, a member of the study committee (Dr. Jennie Joe) facilitated a small group discussion that including American Indian tribal leaders, healthcare providers, and IHS staff. At the AAPIHF conference, study staff facilitated three small discussion groups, including representatives of advocacy and community groups, healthcare providers, and others.