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Serving as Adviser to the Nation to Improve Health

CONFRONTING THE NATION'S HEALTH DISPARITIES

The evidence was mounting—and it was troubling. During the waning years of the past century, one study after another reported that members of racial and ethnic minority groups in the United States, including African Americans, Hispanics, and American Indians, generally had higher rates of morbidity and mortality than did white people. Moreover, numerous studies suggested that minorities, even when they had equal access to health care, were receiving lower-quality care, from routine medical procedures to treatments for life-threatening conditions.

Alarmed by the apparent disparities, Congress in 1999 asked the Institute of Medicine (IOM) to assess the kinds and quality of healthcare received by population groups nationwide. *Unequal Treatment:*

Confronting Racial and Ethnic Disparities in Healthcare, issued in 2002, confirmed the problems in no uncertain terms. “Disparities in the healthcare delivered to racial and ethnic minorities are real and are associated with worse outcomes in many cases,” said Alan Nelson, M.D., a retired physician and noted health professional who chaired the study committee. “The real challenge lies not in debating whether disparities exist, because the evidence is overwhelming, but in developing and implementing strategies to reduce and eliminate them.”

Widely heralded as a national wake-up call, the report documents that minorities tend to receive a lower quality of health care across a broad range of diseases and clinical procedures—and that this is true even when their insurance coverage, income, age, and severity of conditions are comparable with white counterparts. For example, minorities with cardiovascular disease are less likely to receive cardiac medications or to undergo bypass surgery; those with kidney disease are less likely to receive dialysis or transplants; and those with cancer are less likely to receive appropriate diagnostic tests, treatments, and pain medications. By contrast, minorities in some cases are more likely to receive less-desirable procedures, such as lower limb amputation for diabetes.

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A number of factors, often working together, contribute to this health gap. Some of them are systemic, involving the way that healthcare systems are organized and operate. For example, hospitals and health plans trying to cut costs sometimes adopt policies and practices that come at the expense of patients who are least educated about their treatment options and least likely to push their doctors for more services. Patients' attitudes and behaviors also play a role. Some minority patients do not follow their doctor's instructions exactly, while others, often out of distrust of the medical community, put off seeking care until their illness is too far along to be treated effectively. In addition, there is evidence that healthcare providers' biases, prejudices, and uncertainties when treating minorities can lead to unequal treatment. And the conditions under which many clinical encounters take place, which are characterized by time pressures and cognitive complexity, may enhance the likelihood that care will be poorly matched to minority patients' needs.

An important first step to bridging the health gap, according to the report, is to raise awareness among key stakeholders—healthcare providers, their patients, insurance companies, state and federal policymakers, and the general public—that significant racial and ethnic disparities exist. The massive media attention that *Unequal Treatment* generated marked an important step toward this goal. The IOM also distributed report summaries to healthcare providers, health system administrators, and consumers.

Among other recommendations, the report calls on health systems and insurers to adopt evidence-based guidelines, based on the best available science, for making decisions about which procedures to order or pay for. Health systems also should make sure that financial incentives for physicians do not disproportionately burden or restrict minority patients' access to care. In communities where large numbers of people prefer to use languages other than English, health systems should provide translation services to make sure that their patients' needs are understood and met.

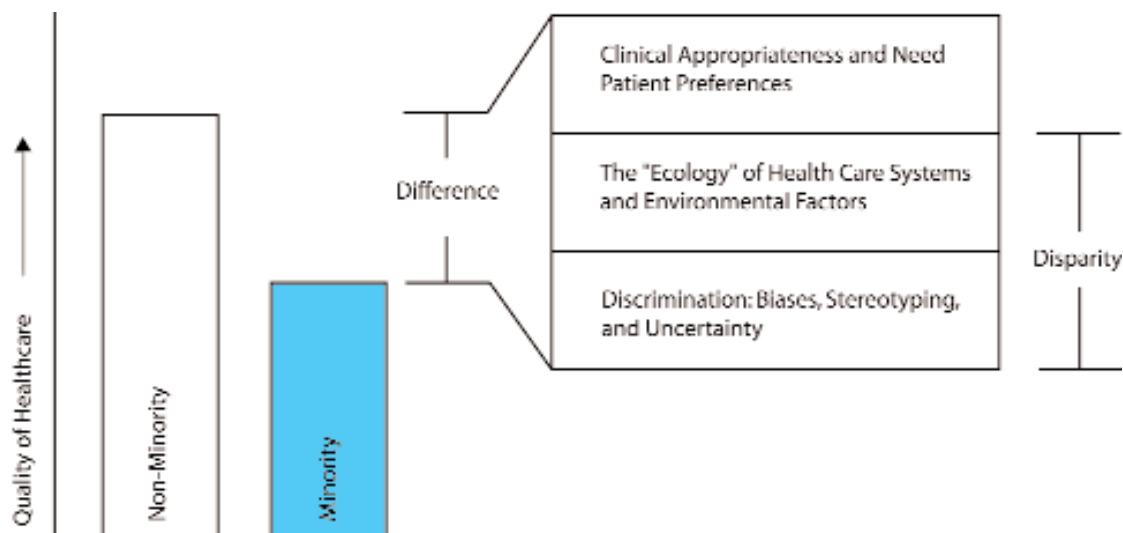


FIGURE 1. Differences, disparities, and discrimination: populations with equal access to health care. SOURCE: Gomes and McGuire, 2001.



When patients are able to ask questions and get answers they understand, they are better able to participate in making decisions about their treatment.

And health systems should work with federal and state government agencies on education programs to provide ethnic and minority patients with information about how to access care and ask the right questions during clinical encounters. Outreach programs can draw on a host of tools, including books and pamphlets, computer-based materials, personal contacts, and electronic communications via the Internet. When patients are able to ask questions and get answers they understand, they are better able to participate in making decisions about their treatment.

The report also stresses the importance of increasing substantially the proportion of racial and ethnic minorities among health professionals. These providers not only may be more likely to choose to work in medically underserved communities, but they also can help health systems in efforts to reduce cultural and linguistic barriers. Federal and state health agencies and policymakers, working with representatives of medical schools and other academic institutions, have important roles to play in fostering such recruitment efforts. Similarly, all health professionals should receive cross-cultural education, during their formal training and beyond, that will help them to better interact with patients who have different cultural points of view and different attitudes about health care.

Ensuring Diversity in the Healthcare Workforce

Several other IOM reports have highlighted the need to bring more members of racial and ethnic

minority groups into the U.S. healthcare workforce. *The Right Thing to Do, The Smart Thing to Do; Enhancing Diversity in the Health Professions* (2001) summarizes the proceedings of a major symposium organized in conjunction with the American Association of Medical Colleges and the Association of Academic Health Centers. The report identifies barriers to recruiting and training underrepresented minority students and proposes steps for overcoming these obstacles. Efforts will be needed at all stages of the academic pipeline, beginning with programs to help minority students perform better in science and mathematics in grade school and high school. Promising students must be encouraged to pursue these fields during undergraduate and professional training, and they must be provided with a variety of tools and support to ensure their success. Academic institutions and health professional organizations can help smooth the educational pathway, especially at the undergraduate level, by rewarding faculty for serving as mentors to students.

In the Nation's Compelling Interest: Ensuring Diversity in the Health-Care Workforce (2004) provides an even more in-depth examination of institutional and policy-level strategies to address this pressing need. Commissioned by the W. K. Kellogg Foundation, the report says that health professions educational institutions—HPEIs for short—should begin by developing and implementing clear mission statements that recognize the value of diversity to their own environments as well as to the larger healthcare

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A LETTER FROM IOM PRESIDENT, HARVEY FINEBERG, M.D., PH.D.



Many burdens of disease and failures to gain access to needed care fall disproportionately on racial and ethnic minorities. The Institute of Medicine has highlighted these disparities in recent years through reports such as *Unequal Treatment* (2002), which documented the persistence of racial and ethnic disparities in U.S. healthcare, and *In the Nation's Compelling Interest* (2004), which outlined ways to improve and maintain diversity in the national healthcare workforce.

The IOM has provided guidance to federal agencies seeking to implement their own remedies to health disparities. For example, in *The Unequal Burden of Cancer* (1999) the IOM examined NIH research on ethnic minorities, and a new project that began last fall is reviewing the NIH's strategic research plan to reduce and eliminate health disparities. Similarly, when Congress mandated that the Agency for Healthcare Research and Quality (AHRQ) begin producing an annual report on health disparities, AHRQ turned to the IOM for advice on this project, leading to our *Guidance for the National Healthcare Disparities Report* (2002).

Disparities in health care and outcomes are intimately connected to other shortcomings in our health system. This inter-dependency is illustrated, for example, by our six-part study of uninsurance, our reports on health literacy and health communication, and our ongoing series on quality of care that began with *To Err Is Human* (2000) and *Crossing the Quality Chasm* (2001). While differences in variables like insurance, access to care, and appropriate utilization of services cannot entirely account for disparities in health, they are frequently exacerbating factors.

The linkage between disparities and poor quality runs in both directions. The quality chasm cannot be crossed while disparities persist, and measures to reduce disparities contribute to the overall quality of care. Indeed, the six dimensions of quality that were identified in the *Quality Chasm* report—healthcare that is safe, effective, patient-centered, timely, efficient, and equitable—include an explicit recommendation that the nation strive for care that "does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location, and socioeconomic status."

As the IOM continues to identify and find ways to eliminate health disparities, we seek to build on the strengths of past reports, to integrate the lessons learned in these distinct yet interwoven areas, and to know that achieving quality healthcare means achieving quality for all. For the health system to succeed, we need to put the "e" in front of quality.

—Harvey V. Fineberg, M.D., Ph.D.



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professions. Additionally, HPEIs should base their admissions on a comprehensive review of each applicant, including an assessment of both qualitative factors that may be relevant to enhancing diversity (such as race or ethnicity, background, and multilingual abilities) and quantitative data that speaks to academic skills (such as prior grades and standardized test scores).

Other recommendations call for evaluating federal programs designed to support minority and ethnic students in HPEIs, and then expanding those programs that are found to be successful in recruiting and graduating students. (Most such programs are conducted by the Health Resources and Services Administration through the Public Health Service Act.) State and local groups, often working with HPEIs, also should explore ways for overcoming the financial constraints that too often have prevented underrep-

resented students from pursuing careers in the health professions. Possible activities include reimbursing tuition payments and forgiving or repaying educational loans.

Promoting Health Communications and Health Literacy

As the United States becomes culturally and ethnically more diverse, efforts to reach all segments of the population with needed health information become more important—and more challenging. Health professionals know that whole ranges of behaviors ultimately make a difference in how people feel and how they maintain their health. But how do they communicate the language of good health so that it is uniformly received—and accepted—by people from different cultures and backgrounds?

Speaking of Health: Assessing Health Communications Strategies for Diverse Populations (2002) addresses this question and offers some

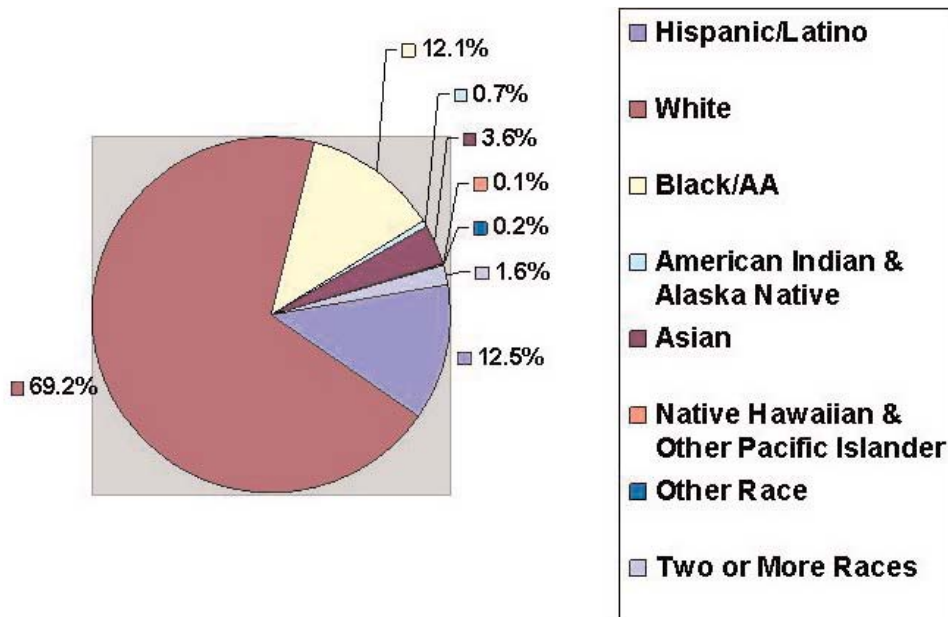


FIGURE 2. U.S. population by race and Hispanic or Latino origin: all ages. SOURCE: U.S. Census, 2000.



WHAT IS HEALTH LITERACY?

Health literacy is the degree to which individuals can obtain, process, and understand the basic health information and services they need to make appropriate health decisions. But health literacy goes beyond the individual. It also depends upon the skills, preferences, and expectations of those health information providers: our doctors, nurses, administrators, home health workers, the media, and many others.

creative strategies and guidelines to help achieve sustained health gains across cultural groups. For example, successful communication programs seem to have certain attributes in common. These conditions include a strong science base for recommended behaviors, a realistic possibility that recommendations can be implemented by the target population, coordination with other programs addressing related issues, and sufficient resources to get the message to the intended audiences often enough to be effective. Many key questions remain, however, and the report provides a coordinated research agenda to help fill the missing knowledge gaps. This means supporting research that improves current understanding of how information is received by culturally diverse groups, expanding evaluations of communication programs to determine their effectiveness, and paying more attention to the ethical and social concerns that must be appreciated and respected in designing communication campaigns, among other activities.

Of course, clear communication is critical to successful health care for all Americans. Yet nearly half of the adult population—90 million people—are known to have difficulty understanding and acting on health information, according to *Health Literacy: A Prescription to End Confusion* (2004). People with limited health literacy have a higher rate of hospitalization and make greater use of emergency services. Health literacy is defined as the degree to which individuals have

the capacity to obtain, process, and understand the basic information and services they need to make appropriate health decisions. But health literacy goes beyond the individual. It also depends on the skills, preferences, and expectations of the providers of healthcare and health information: doctors, nurses, administrators, home health workers, the media, and many others.

Health literacy also goes beyond mere education levels. A person who has finished high school or college may still not be able to navigate the health system. Health literacy comes from a convergence of education, cultural and social factors, and health services. While reading, writing, and math skills make up part of the basis of health literacy, many other skills and abilities also are important, such as speaking, listening, having adequate background information, and being able to advocate for oneself in the health system.

Commissioned jointly by a number of government, industry, and philanthropic organizations, *Health Literacy* proposes a concerted action plan to help people of all races and ethnic groups, ages, and income levels become better able to manage their health. Efforts will be needed by the public health and healthcare systems, the education system, the media, and healthcare consumers. Among specific actions, the Department of Health and Human Services should take the lead in developing uniform standards for addressing health literacy; and government and private funders should support the development



and use of culturally appropriate new measures of health literacy, as well as multidisciplinary research on the extent, associations, and consequences of limited health literacy. Educators should take advantage of opportunities to incorporate health-related tasks, materials, and examples into their lesson plans. Professional schools and continuing education programs in the health fields should incorporate health literacy into their curricula and areas of competence. And health-care systems should develop and support demonstration programs to establish effective approaches to reduce the negative effects of limited health literacy.

Health and the Uninsured

Members of ethnic and minority groups are more likely to lack health insurance or to be insufficiently insured than are white Americans—

although many of them lack insurance as well. The IOM has issued a series of reports exploring the health consequences of going without insurance. The uninsured receive only about half of the medical care of people with insurance. They are less likely to see a doctor on a regular basis, and they receive fewer preventive services and less care for chronic conditions. As a result, the uninsured suffer from poorer health, and they are more likely to die prematurely, with roughly 18,000 unnecessary deaths occurring each year because of lack of health insurance.

The final report in the series, *Insuring America's Health: Principles and Recommendations* (2004) builds on earlier reports and lays out a set of core principles that can be used to design new strategies for improving health insurance coverage. Health coverage should be universal, with everyone in the United States covered, and it

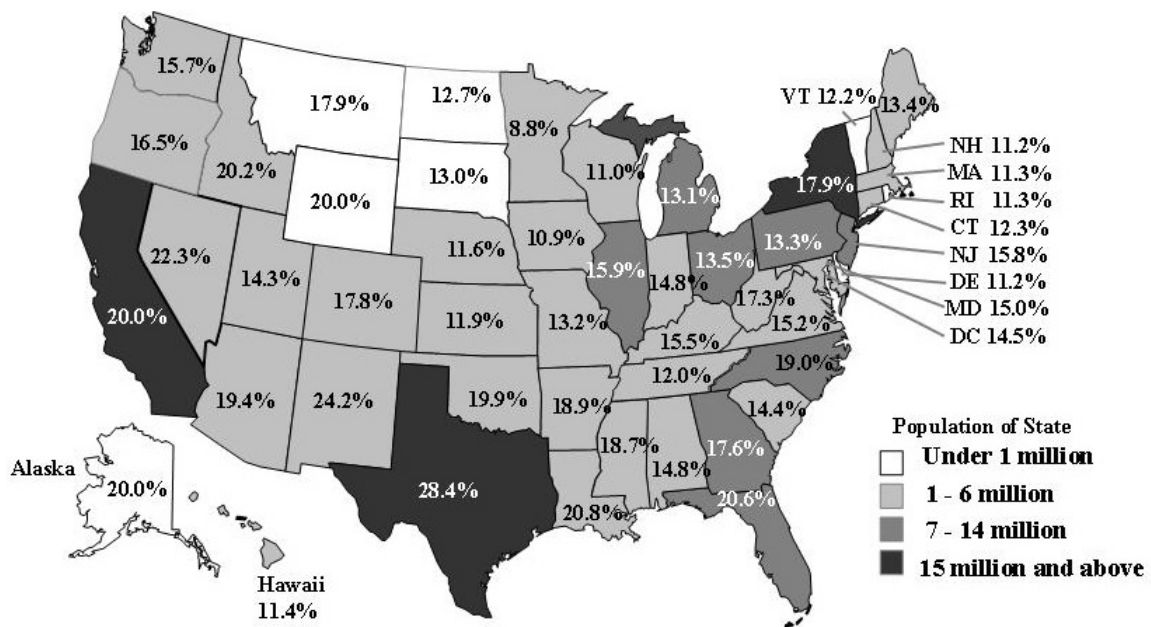


FIGURE 3. Uninsured rates by state in the U.S.

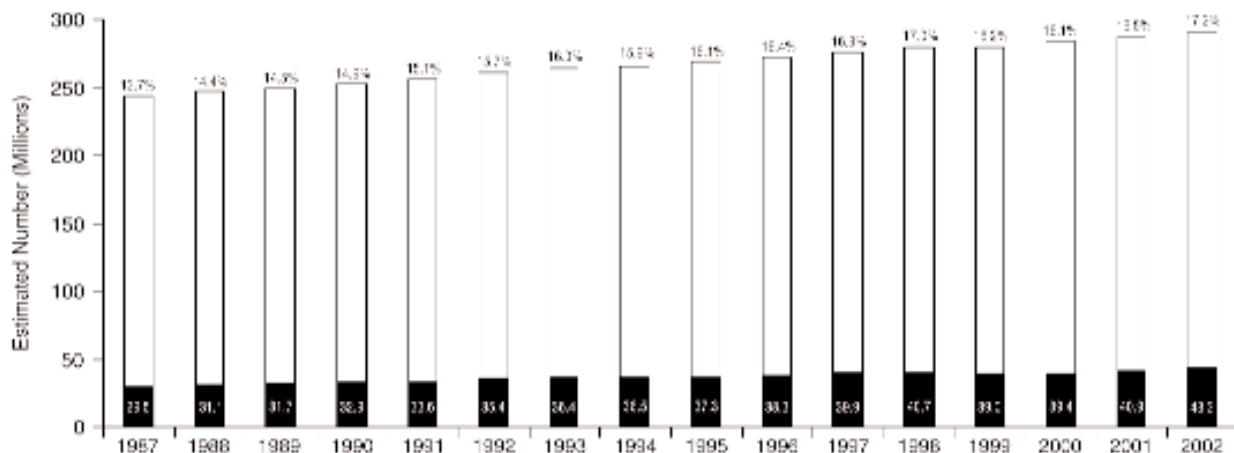


FIGURE 4. Uninsured persons under age 65, number and proportion of general population under age 65, 1987-2002. NOTE: Estimates for 2000, 2001, and 2002 are Census 2000-based weights. SOURCES: Fronstin, 2002; Mills and Bhandari, 2003.

should be continuous, from birth onward. Coverage should be affordable to individuals and families, and the overall health coverage strategy should be affordable and sustainable to society. And health insurance should enhance health and well-being by promoting access to high-quality care that is effective, efficient, safe, timely, patient-centered, and equitable. Until health coverage meeting these principles is in place, the federal and state governments should continue supporting the programs, institutions, and providers that form the nation's healthcare "safety net."

Informing Government Health Care and Research Programs

We know more about cancer prevention, detection, and treatment than ever before—yet not all segments of the U.S. population, including poor people and members of some racial and ethnic minority groups, have benefited to the fullest extent possible from these advances. *The Unequal Burden of Cancer: An Assessment of NIH Research*

and Programs for Ethnic Minorities and the Medically Underserved (1999) documented the gaps that existed at that time in cancer prevention, treatment, and research specific to cancer in minorities. The report, requested by the National Institutes of Health, also offered a slate of recommended improvements. The NIH responded with several major changes, including development of a comprehensive strategic plan to address minority health disparities and establishment of the National Center on Minority Health and Health Disparities to serve as the focal point for coordinating minority health research efforts.

The IOM also has helped the Agency for Healthcare Research and Quality (AHRQ) in its efforts to produce a new annual report, requested by Congress, that would document racial, ethnic, socioeconomic, and geographic healthcare disparities nationwide. The National Healthcare Disparities Report would inform both policymakers and the public on the extent of disparities and focus their attention where action is most needed.



Guidance for the National Healthcare Disparities Report (2002) offered advice on a variety of technical issues and made suggestions on proposed funding plans. The AHRQ built on the report's concepts, and in early 2004 the agency issued the first healthcare disparities report.

In current work, the IOM is assessing the NIH's strategic plan for addressing minority health disparities. The NIH developed the plan in collaboration with its various institutes and centers and with the National Center on Minority Health and Health Disparities. The public also

supplied substantial input. The IOM study committee is now evaluating how well the strategic plan advances scientific understanding of the causes of health disparities and the means to reduce them, whether it provides for adequate research infrastructure, and whether it pays sufficient attention to the dissemination and application of research findings to reduce and ultimately eliminate health disparities among minority and ethnic populations. The committee expects to issue its report in November 2005.

HIGHLIGHTED ACTIVITIES

Cancer Survivorship: Improving Care and Quality of Life

This project will examine the long-term medical and social consequences of cancer treatment and survival and assess the quality of care provided to cancer survivors, individuals living beyond their primary cancer treatment. The report will define quality care for cancer survivors and propose solutions to enhance access to such care; explore social and economic hardships facing cancer survivors related to, for example, under-insurance and employment discrimination, and propose policies to ameliorate such problems; and describe how we can improve what we know about the quality of care and quality of life for cancer survivors and their families. The report will recommend policies to improve the quality of care and life for cancer survivors. Additional information is available at <http://www.iom.edu/project.asp?id=4931>.

Redesigning Health Insurance Benefits, Payment and Performance Improvement Programs

This project will identify options for redesigning insurance benefits, provider payment policies, and performance improvement programs in ways that will encourage and reward improvements in health and health care delivery. The primary focus is on the Medicare program, but the findings and recommendations will likely have broad applicability to all public and private insurance programs. The committee will produce three major reports: a quality-based benefits report, a performance and payment report, and a performance improvement programs report. For more additional details about this project, go to <http://www.iom.edu/project.asp?id=19805>.



WHAT'S NEW AT THE IOM?

The following are newly initiated studies at the Institute of Medicine (IOM). Additional information can be found on the IOM website (www.iom.edu).

Assessment of the U.S. Drug Safety System,

David Blumenthal (Co-Chair),
Sheila Burke (Co-Chair)

Gulf War and Health: Physiologic, Psychologic, and Psychosocial Effects of Deployment Related Stress,

(Chair to be named)

Sleep Medicine and Research,

Harvey R. Colten (IOM), (Chair)

Mineral Requirements for Cognitive and Physical Performance of Military Personnel,

(Chair to be named)

Progress in Preventing Childhood Obesity,

Jeffrey P. Koplan (Chair)

Identifying and Preventing Medical Errors,

Linda R. Cronenwett (Co-Chair),
Lyle Bootman (Co-Chair)

President's Emergency Plan for AIDS Relief (PEPFAR) Implementation Evaluation,

Jaime Sepulveda (Chair)

IOM PRESIDENT RESPONDS TO LETTER IN *NATURE MEDICINE*, ADDRESSING THE FDA DRUG SAFETY STUDY

In the April 2005 issue of *Nature Medicine*, Dr. Bernard J. Carroll questions whether the Institute of Medicine (IOM) can undertake a credible study of the Food and Drug Administration's post-marketing drug safety system because some IOM members are employed by pharmaceutical companies, serve on the boards of these companies, or serve as Deans in academic institutions that receive substantial funds from pharmaceutical firms. Dr. Harvey Fineberg writes, "Dr. Carroll's reasoning is flawed because he fails to take account of the actual procedures and policies followed by the Institute of Medicine in conducting its studies." For the full article, please go to: <http://www.iom.edu/news.asp?id=26522>.



RECENTLY RELEASED REPORTS

Integrating Employee Health:

A Model Program for NASA

Food and Nutrition Board (May 8)

WIC Food Packages: Time for a Change

Food and Nutrition Board (April 27)

Healers Abroad: Americans Responding to the Human Resource Crisis in HIV/AIDS

Board on Global Health (April 19)

Making Better Drugs for Children with Cancer

National Cancer Policy Board (April 18)

Cord Blood: Establishing a National Hematopoietic Stem Cell Bank Program

Board on Health Sciences Policy (April 14)

Assessing the Quality of Cancer Care:

An Approach to Measurement in Georgia

National Cancer Policy Board (April 7)

Review of the HIVNET 012 Perinatal HIV Prevention Study

National Cancer Policy Board (April 7)

Implications of Genomics for Public Health: Workshop Summary

Board on Health Promotion and Disease Prevention
(April 5)

Spinal Cord Injury: Progress, Promise, and Priorities

Board on Neuroscience and Behavioral Health
(April 5)

Federal Agency Roles in Cancer Drug Development from Preclinical Research to New Drug Approval: The National Cancer Institute and The Food and Drug Administration

National Cancer Policy Board (March 30)

Implications of Nanotechnology for Environmental Health Research: Workshop Summary

Board on Health Sciences Policy (March 25)

Veterans and Agent Orange: Update 2004

Board on Health Promotion and Disease Prevention (March 4)

The Smallpox Vaccination Program: Public Health in an Age of Terrorism

Board on Health Promotion and Disease Prevention (March 3)

Economic Models of Colorectal Cancer Screening in Average-Risk Adults: Workshop Summary

National Cancer Policy Board (February 22)

Vaccine Safety Research, Data Access, and Public Trust

Board on Health Promotion and Disease Prevention (February 17)

Rebuilding the Unity of Health and the Environment, The Greater Houston Metropolitan Area: Workshop Summary

Board on Health Sciences Policy (February 3)

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