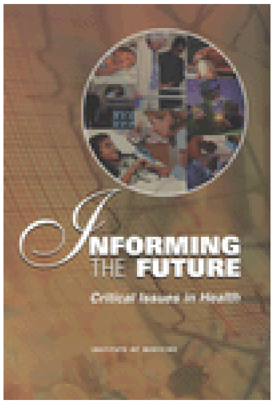

Informing the Future: Critical Issues in Health

Institute of Medicine

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THE NATIONAL ACADEMIES
Advisers to the Nation on Science, Engineering, and Medicine

Informing the Future

Critical Issues in Health

INSTITUTE OF MEDICINE
Washington, D.C.

INSTITUTE OF MEDICINE · **2101 Constitution Avenue, N.W.** · **Washington, DC 20418**

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The **Institute of Medicine** was established in 1970 by the National Academy of Sciences to secure the services of eminent members of appropriate professions in the examination of policy matters pertaining to the health of the public. The Institute acts under the responsibility given to the National Academy of Sciences by its congressional charter to be an adviser to the federal government and, upon its own initiative, to identify issues of medical care, research, and education. Dr. Kenneth I. Shine is president of the Institute of Medicine.

The **National Academy of Sciences** is a private, nonprofit, self-perpetuating society of distinguished scholars engaged in scientific and engineering research, dedicated to the furtherance of science and technology and to their use for the general welfare. Upon the authority of the charter granted to it by the Congress in 1863, the Academy has a mandate that requires it to advise the federal government on scientific and technical matters. Dr. Bruce M. Alberts is president of the National Academy of Sciences.

The **National Academy of Engineering** was established in 1964, under the charter of the National Academy of Sciences, as a parallel organization of outstanding engineers. It is autonomous in its administration and in the selection of its members, sharing with the National Academy of Sciences the responsibility for advising the federal government. Dr. William A. Wulf is president of the National Academy of Engineering.

The **National Research Council** was organized by the National Academy of Sciences in 1916 to associate the broad community of science and technology with the Academy's purposes of furthering knowledge and advising the federal government. The Council has become the principal operating agency of both the National Academy of Sciences and the National Academy of Engineering in providing services to the government, the public, and the scientific and engineering communities. The Council is administered jointly by both Academies and the Institute of Medicine. Dr. Bruce M. Alberts and Dr. William A. Wulf are chairman and vice chairman, respectively, of the National Research Council.

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Contents

The Institute of Medicine: A Unique National Resource

Unprecedented opportunities and challenges face the nation and the world as we seek to improve human health through research, prevention, and clinical care. The federal government plays a pivotal role in shaping the opportunities and meeting the challenges through the policies it establishes, the programs it funds, and the leadership it provides. Over the next 4 years, scientific and policy issues both predictable and unpredictable will confront the administration and Congress.

The health sector now constitutes more than 14% of the nation's Gross Domestic Product (GDP)—a level projected to rise to 16% within the next few years. Approximately half this amount is spent through the public sector, a share that will also rise in the coming decade. Policymakers face difficult decisions about how to obtain the best value for these large and growing expenditures.

For science-based advice about these issues, the nation's leaders often turn to an institution that was created specifically for this purpose: the Institute of Medicine (IOM) of The National Academies. The IOM—a nonprofit organization chartered in 1970 as a component of the National Academy of Sciences (NAS)—provides a public service by working outside the framework of government to ensure independent guidance on matters of science and medicine. The IOM's mission is to advance and disseminate scientific knowledge to improve human health. The Institute provides objective, timely, authoritative information and advice concerning health and science policy to government, the corporate sector, the professions, and the public.

The Institute and The National Academies use an unusual process to obtain the most authoritative, objective, and scientifically balanced answers to difficult questions of national importance. Our work is conducted by committees of volunteer scientists—the country's leading experts—who serve without compensation. Committees are carefully composed to assure the requisite expertise and to avoid bias or conflict of interest. Every report produced by our committees undergoes extensive review and evaluation by a group of experts who are anonymous to the committee, and whose names are revealed once the study is published. The results of these committee deliberations have been relied upon for 30 years to provide policymakers with objective advice.

The Institute's work centers principally on committee reports or studies on subjects ranging from HIV prevention to how to provide clinical care in extended space flight; from research opportunities at the National Institute of Health (NIH) to protecting the nation's food supply. We also conduct Roundtables, workshops or symposia that provide an opportunity for public- and private-sector experts to openly discuss contentious issues in an environment that facilitates evidence-based dialogue. Additionally, for 26 years, the IOM has managed The Robert Wood Johnson Health Policy Fellowships Program, which is designed to develop the capacity of outstanding mid-career health professionals in academic and community-based settings to assume leadership roles in health policy and management (for more information, see page 95). The majority of our studies and other activities are requested and funded by the federal government. However, private industry, foundations, and state and local governments also initiate studies, as does the IOM itself.

The objective in all of these activities is to improve decision-making by identifying scientifically sound evidence to inform the deliberative process. Over its history, the IOM has become recognized through its projects as a national resource of judgment and veracity in the analysis of issues relating to human health. Depending on the request, studies may be narrow in scope, designed to answer very specific and technical questions, or they may be broad-based examinations that span myriad academic disciplines, industries, and even international borders. Many of today's major news reports concern issues that we have previously addressed; others, like tobacco harm reduction, are currently under study.

IOM MEMBERS

The Institute of Medicine is both an honorific membership organization and a policy research organization. The Institute's members, elected on the basis of their professional achievement, serve without compensation in the conduct of studies and other activities on matters of national policy for health. Election to active membership is both an honor and a commitment to serve in Institute affairs. On reaching the age of 66, members automatically are transferred to senior status.

The bylaws of IOM specify that no more than 60 new active members shall be elected annually. The announcement of newly elected members occurs at the IOM Annual Meeting in October. The number of regular and senior members plus foreign associates currently stands at 1,375.

An unusual diversity of talent among Institute members is assured by the charter stipulation that at least one-quarter of them be selected from professions other than those primarily concerned with medicine and health. More than a hundred of the regular members are in the natural, social, and behavioral sciences, law, administration, and engineering. They, together with the health professionals in the membership, bring a breadth and depth of competence necessary for studies of today's health problems, which have many more dimensions than the traditional concerns of medicine.

FOR THE PUBLIC GOOD

This booklet provides a brief look at the work of the Institute—and highlights some of the policy areas that we believe will be important in the next several years. It is organized into three sections. The first section illustrates a number of reports that have provided a basis for developing or negotiating policy over a range of scientific issues; the second section samples work that we have recently completed or have under way, organized into areas of continuing national concern; and the third section provides a comprehensive bibliography of IOM reports published over the past several years.

Highlighted Reports

To Err Is Human: Building a Safer Health System

Perhaps the best example of the Institute of Medicine's potential for shaping and guiding health care policy is *To Err Is Human: Building a Safer Health System,* a report on preventable errors in the health care delivery system.

. . . it would be irresponsible to expect anything less than a 50 percent reduction in errors over 5 years.

The IOM Quality of Health Care in America Committee was formed in June 1998. Its charge: Develop a 10-year national strategy to effect a threshold improvement in quality. The committee's first report, *To Err Is Human,* was intended to break the cycle of inaction on medical errors. Given current knowledge about the magnitude of the problem, it would be irresponsible to expect anything less than a 50 percent reduction in errors over 5 years.

To Err Is Human argues for a comprehensive approach to improve patient safety. It does not focus on a single solution because there is no "magic bullet" that will reduce errors; and, indeed, no single recommendation in the report should be considered as the answer.

In developing its recommendations, the committee sought to strike a balance between regulatory and market-based initiatives, and between the roles of professionals and organizations. The report offers a four-part plan to improve safety: expand the knowledge base about errors and safety, implement mechanisms to learn about and prevent errors, raise oversight standards related to safety and implement safe practices at the local delivery level.

The combination of activities proposed in the report offers a roadmap toward a safer health system. The committee recommended that the proposed program be evaluated after 5 years to assess progress in making the health system safer.

Despite the difficulty of its subject, *To Err Is Human* is positive and optimistic. Its Executive Summary concludes: “With adequate leadership, attention, and resources, improvements can be made. It may be part of human nature to err, but it is also part of human nature to create solutions, find better alternatives, and meet the challenges ahead.”

“It may be part of human nature to err, but it is also part of human nature to create solutions. . . .”

The response to the report has been rapid and far-reaching, with activities occurring at the national, state, and local levels to address different aspects of the four-part plan. On December 7, 1999, President Clinton signed an executive order inaugurating a major federal initiative to improve patient safety in federally funded health care programs. The Agency for Health Care Research and Quality has developed a research agenda for patient safety and awarded several grants in FY 2000 to improve understanding about how to prevent errors. Numerous congressional hearings were held and bills that would provide up to $40 million for patient safety research have been introduced.

At the state level, activities have focused on creating consistent approaches for learning about errors rapidly to prevent their recurrence. Accrediting organizations and large purchasers are considering how they can strengthen their standards for patient safety. The Leapfrog Group, a consortium of Fortune 500 companies sponsored by the Business Roundtable, has made a commitment to use their purchasing power to put forth stronger safety standards, such as the use of computerized physician order entry for medications. Several professional societies have increased their attention to error prevention through conferences and journals and are developing strategies for continuing education. At the local level, health care organizations look for new ways to improve safety within their own institutions, with hospitals particularly focused on improving medication safety as a starting point. Media coverage on television, radio, and in newspapers and magazines has alerted consumers to the actions they can take to improve the safety of the care they receive by asking questions and staying informed.

Calling the Shots: Immunization Finance Policies and Practices

In June 2000, IOM released *Calling the Shots: Immunization Finance Policies and Practices*. This study, originally requested by the U.S. Senate Appropriations Committee, examines the finance requirements of the U.S. national immunization system and offers a comprehensive analysis of the public and private health care systems that support the purchase and delivery of vaccines for children and adults in the United States.

The study committee concluded that the infrastructure that supports the U.S. immunization system is weakening, even though coverage rates for young children have reached record highs. The addition of new vaccines; the shift in services between public and private health care systems; the increased needs for surveillance, education, and safety efforts; and the data requirements of the immunization system have all placed extraordinary demands on state public health systems. As a result, states are unable to exercise new responsibilities in such areas as performance assessment and assurance, nor are they able to engage effectively in policy development with public and private health finance systems.

. . . the infrastructure that supports the U.S. immunization system is weakening, even though coverage rates for young children have reached record highs.

The committee recommended that the federal government increase its investment in immunization infrastructure by $75 million per year, which would increase annual state grant awards to a total of $200 million. State governments were also urged to increase their levels of expenditure for immunization infrastructure by $100 million per year. The committee further recommended that the federal government spend an additional $50 million per year on adult vaccines, focusing on the needs of high-risk adults between 18 and 65 years of age who are ineligible for other forms of health care assistance.

Congress and the Centers for Disease Control and Prevention (CDC) have acted swiftly in response to the report's recommendations. The CDC has indicated that the report provides an excellent blueprint to guide its state grant award system in the future. The FY 2001 appropriations bill for the Department of Health and Human Services (DHHS) includes half of the recommended increase for infrastructure ($37.5 million), with the remaining half scheduled for support in FY 2002. State governments are now considering increasing their own investments. A series of regional briefings with state-level legislative, budgetary, and health officials will be organized in 2001 to consider ways in which these recommendations could be implemented.

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Organ Procurement and Transplantation: Assessing Current Policies and the Potential Impact of the DHHS Final Rule

In the fall of 1998, Congress asked the IOM to review the potential impact that a DHHS regulation (known as the "Final Rule") would have on various aspects of organ procurement and transplantation. These areas included access for low-income and minority populations, organ donation rates, waiting times for transplants, patient survival rates, and costs. The area of most concern to DHHS, Congress, and the transplant community was liver transplantation. An implicit issue, underlying the tension between DHHS and its contractor, the United Network for Organ Sharing, was the appropriate scope of federal oversight. The thrust of the report was to support—through a rigorous statistical analysis that had not been done previously—the conclusion that broader sharing of organs would save and improve lives, and that there was a clear need for stronger federal oversight. The report's recommendations were integrated into the Final Rule and were instrumental in facilitating its enactment.

The thrust of the report was to support—through a rigorous statistical analysis that had not been done previously—the conclusion that broader sharing of organs would save and improve lives, and that there [is] a clear need for stronger federal oversight.

The Unequal Burden of Cancer: An Assessment of NIH Research and Programs for Ethnic Minorities and the Medically Underserved

This congressionally requested study examined the range of research and training programs supported by the NIH that address racial and ethnic disparities in cancer incidence, morbidity, and mortality. The study committee notes that while NIH, and in particular the National Cancer Institute (NCI), has funded an impressive array of programs designed to increase knowledge of the impact of cancer in ethnic minority communities, no blueprint or strategic plan appeared to guide this activity. In addition, funding for research and training programs to meet the specific needs of ethnic minority communities appeared insufficient to address the unequal burden of cancer.

The report's recommendations included suggestions that NCI expand surveillance programs to provide a more complete understanding of the burden of cancer among ethnic minority and medically underserved populations, provide greater authority and funding to the NCI Office of Special Populations Research, expand behavioral and social science research regarding cancer risk factors and population-based intervention strategies, and increase public participation in the NIH research priority-setting process. In response to these recommendations, NIH has developed a comprehensive strategic plan to address minority health disparities and is establishing a center to coordinate and focus minority health research efforts. A similar legislative proposal to establish a Center for Health Disparities is pending before Congress. In addition, NCI's National Cancer Advisory Board has reviewed NCI funding of research and training programs relevant to minority and medically underserved populations and has recommended several changes in the institute's accounting procedures to provide more accurate information regarding funding for these programs.

Benefits Coverage: Extending Medicare Reimbursement in Clinical Trials

. . . clinical trials are integral to modern medical care and to the progress of medical science.

The Balanced Budget Act of 1997 directed the Health Care Financing Administration (HCFA) to commission a study of payment of routine patient care costs for Medicare beneficiaries enrolled in approved clinical trial programs. A committee was established under the aegis of the National Cancer Policy Board to explore this subject. In December 1999, the committee issued *Extending Medicare Reimbursement in Clinical Trials*. The IOM concluded that clinical trials are integral to modern medical care and to the progress of medical science. HCFA has issued little explicit policy on payment for care of patients in trials, although Medicare law has been widely interpreted to exclude such payment. The IOM report noted, however, that bills for payment are usually submitted, and paid, without disclosing or recognizing patient participation in trials. The report recommended that clinical trials should be encouraged, that patients should be reassured that costs will be covered as they would absent a trial, and that an explicit decision should be issued by HCFA to implement such policies and eliminate any confusion.

On June 7, 2000, President Clinton issued an executive memorandum directing the Secretary of Health and Human Services to "explicitly authorize (Medicare) payment for routine patient care costs . . . and costs due to medical complications associated with participation in clinical trials," and his memorandum cited the IOM report as a prominent basis for this directive. By September 2000, HCFA issued a proposed National Coverage Decision which required coverage of care costs of patients in clinical trials for "all items and services that are otherwise generally available to Medicare beneficiaries...except the investigational item or service, itself, items provided solely to satisfy data collection needs, . . . and items and services provided by the trial sponsor without charge." This decision applies to both fee-for-service Medicare and Medicare+Choice. In January 2001, the National Cancer Policy Board will begin examining how HCFA is disseminating this coverage decision and ensuring that providers, trial sponsors, and patients are fully informed of Medicare's support of clinical trials.

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Leading Health Indicators for Healthy People 2010

"Healthy People" is the nation's agenda for health promotion and disease prevention. The report, prepared by the Office of the Surgeon General, has been revised on a regular basis since 1979 and is in its fourth iteration, as *Healthy People 2010*. Over the past 20 years, the Healthy People agenda has grown from 15 strategies supporting five primary health goals to approximately 1,000 health objectives. The DHHS, the agency responsible for implementing the agenda, asked the IOM to develop a set of leading indicators to engage the public's attention and motivate actions at the individual and community levels in a small number of health objectives. In response to this request, IOM published two interim reports and a final report, *Leading Health Indicators for Healthy People 2010.* Through the series of reports, IOM recommended a framework for identifying a science-based framework around which sets of leading indicators could be organized. These efforts resulted in the development of three sets of leading health indicators in the areas of health determinants and health outcomes, life course determinants, and prevention-oriented indicators. IOM's framework for selecting indicators and proposed final set of indicators was used by DHHS to prioritize the nation's Healthy People 2010 agenda.

Scientific Opportunities and Public Needs: Improving Priority Setting and Public Input at NIH

This study, requested by Congress, charged the IOM with examining four issues related to setting priorities at NIH: allocation criteria, the decision-making process, mechanisms for public input, and the impact of congressional directives. The report's recommendations address each of these charges, but there is a single theme that runs through them. It was that NIH should revamp its approach to public input and outreach—at every level—without delay. The report's recommendations have been acted upon by NIH and have helped NIH to strengthen the priority-setting process, including a realization that openness is as important to the process as such other valued qualities as expertise, innovation, and objectivity. Enacting the recommendations has also helped to enhance the public's understanding of the complexities of decision-making at NIH. Implementing the report's recommendations gave Congress confidence that it can delegate priority setting to NIH leadership knowing that a broader range of views will be sought and welcomed before decisions are made.

The report's recommendations . . . have helped NIH to strengthen the priority-setting process, including a realization that openness is as important to the process as such other valued qualities as expertise, innovation, and objectivity.

Ensuring Quality Cancer Care

The National Cancer Policy Board reviewed evidence on the quality of cancer care, from early detection to end-of-life care, and concluded that many individuals with cancer do not receive care known to be effective for their condition. In the report, *Ensuring Quality Cancer Care*, the Board outlined steps that could be taken to improve quality, highlighting the need for accountability systems to ensure the translation of research into practice. The federal response to the report has been heartening. A Quality of Cancer Care Committee has been established within the Department of Health and Human Services to provide interagency opportunities for collaborative action, and the National Cancer Institute has launched new research initiatives in key areas outlined in the report. The report was featured in a congressional hearing of the Senate Coalition on Cancer, cochaired by Senators Diane Feinstein and Connie Mack in September 1999, with promise of more congressional attention in 2000 and beyond. The American Society of Clinical Oncology, concerned about the report's findings, has initiated a large quality-of-care study to test the feasibility of building and implementing a national cancer quality monitoring system. In 2000, the Board issued *Enhancing Data Systems to Improve the Quality of Cancer Care* focusing on the important role of data systems to quality improvement. The Board will continue to follow up on important issues identified in the quality-of-care report. In 2001, the Board will examine further the policy implications of the volume-outcome relationship in cancer care and review the state of end-of-life care for individuals with cancer.

. . . the National Cancer Institute has launched new research initiatives in key areas outlined in the report.

Ensuring Safe Food: From Production to Consumption

At the request of Congress, the IOM was asked to identify ways in which the food safety system in the United States could be improved. The resulting report presented two major recommendations: change federal food statutes to foster and enhance science-based strategies for food safety; and invest in one individual, who should report to a cabinet-level federal official or to the president, the statutory responsibility and budgetary authority to coordinate federal food safety efforts and speak on food safety issues. Immediately following the release of the report, the president appointed a federal Food Safety Council, composed of the Secretaries of Health and Human Services and of Agriculture, the Administrator of the Environmental Protection Agency, and the Director of the Office of Science and Technology Policy of the White House. The president directed the Food Safety Council to provide a report within 6 months regarding efforts to improve the coordination of federal food safety activities, and to respond to the findings and recommendations of the IOM/NRC report.

Veterans and Agent Orange

IOM assessments and conclusions have been used by the Secretary of Veterans Affairs to make determinations about compensation policy . . .

In response to the concerns voiced by Vietnam veterans and their families, Congress called upon the IOM to review the scientific evidence on the possible health effects of exposure to Agent Orange and other herbicides. Since 1993 the IOM has published several reports that synthesize the developing literature on dioxin, an unintentional contaminant of one of the herbicides used in Vietnam, and a number of cancer and non-cancer health outcomes: *Veterans and Agent Orange: Health Effects of Herbicides Used in Vietnam (1994); Veterans and Agent Orange: Update 1996*; and *Veterans and Agent Orange: Update 1998*. The IOM reports concluded that there is sufficient evidence of an association between exposure to herbicides/dioxin and four diseases: soft-tissue sarcoma, non-Hodgkin's lymphoma, Hodgkin's disease, and chloracne. The reports also concluded that there is limited/suggestive evidence of an association for six classes of diseases, three cancers—respiratory (larynx, lung—bronchus, and trachea) cancer, prostrate cancer, and multiple myeloma and three other health outcomes—spina bifida in children of veterans, acute and subacute peripheral neuropathy, and porphyria cutanea tarda. IOM assessments and conclusions have been used by the Secretary of Veterans Affairs to make determinations about compensation policy for the Department of Veterans Affairs. As a result, veterans are now compensated for these conditions. The IOM is currently conducting a review to assess new research on the topic. The results of this work will be published in the upcoming *Veterans and Agent Orange: Update 2000*.

HIV/AIDS

The IOM's long-standing interest and involvement in AIDS policy-making has spanned over a decade and is marked by significant contributions. *Confronting AIDS: Directions for Public Health, Health Care, and Research* (1986) was one of the first published reports to provide a comprehensive scientific and policy analysis of efforts to address the epidemic. It also proposed strategies for meeting the scientific, public health, and social challenges that arise in developing rational AIDS policy. *Confronting AIDS: Update 1988* was published as a supplement to the original report and provided an assessment of the nation's progress in the intervening years. Both reports are credited with stimulating a number of federal legislative and public policy options to increase federal spending for AIDS research and other AIDS-related prevention, public health, and health care programs.

Two subsequent reports—*HIV Screening of Pregnant Women and Newborns* (1991) and *Reducing the Odds: Preventing Perinatal Transmission of HIV in the United States* (1999)—were influential in fostering a dialogue and critical examination of perinatal HIV-screening policies and have provided guidance to federal agencies, such as the Centers for Disease Control and Prevention and to states in developing policies for HIV counseling and testing of pregnant women. IOM's recent report *No Time to Lose: Getting More from HIV Prevention* (2000) challenges the nation to implement a new strategy to avert as many new HIV infections as possible. The strategy includes developing a more accurate surveillance system, allocating resources based on HIV incidence and cost-effectiveness principles, directing prevention services to HIV-infected persons, improving the translation of prevention research findings into action at the community level, investing in the development of new prevention tools and technologies, and striving to overcome social and policy barriers that impede HIV prevention. The report's recommendations are currently under consideration by the CDC as it develops its HIV Prevention Strategic Plan through 2005.

***No Time to Lose . . .* challenges the nation to implement a new strategy to avert as many new HIV infections as possible.**

Selected Recommendations for Health Care Delivery . . .

- **Reduce Medical Errors:** Establish a Center for Patient Safety within the Agency for Healthcare Research and Quality. Encourage the development of voluntary reporting systems for errors that do not result in serious harm by extending peer-review protections to the data and information in these systems. Establish a nationwide mandatory reporting system administered by the states to collect standardized information about adverse events that result in death or serious harm. (*To Err Is Human: Building a Safer Health System*)
- **Improve End-of-Life Care:** Revise payment systems so they encourage rather than impede good end-of-life care and sustain rather than frustrate coordinated systems of excellent care. For cancer care, take steps to ensure quality of care at the end of life, in particular, the management of cancer-related pain and timely referral to palliative and hospice care. (*Approaching Death: Improving Care at the End of Life; Ensuring Quality Cancer Care*)
- **Improve the Quality of Long-Term Care:** Congress should require a 24-hour presence of registered nurse coverage in nursing homes. Payment levels for Medicare and Medicaid should be adjusted to enable such staffing to be achieved, and the Health Care Financing Administration should develop minimum staffing levels (number and skill mix) for direct care based on case-mix adjusted standards. (*Nursing Staff in Hospitals and Nursing Homes: Is It Adequate?*)
- **Reform Medicare Laboratory Payment:** Medicare payments for outpatient clinical laboratory services should be based on a single, rational, national fee schedule. (*Medicare Laboratory Payment Policy: Now and in the Future*)

NOTE: Also see recommendations concerning health insurance and the health care safety net in the Demographic Trends section.

The Changing Health Care Delivery System

The purpose of the health care system must be to continuously reduce the impact and burden of illness, injury, and disability, and to improve the health and functioning of the people of the United States.

Advisory Commission on Consumer Protection and Quality, 1998

Today, more than four out of every five workers are enrolled in managed care plans.

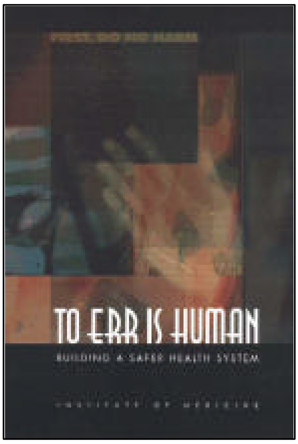
The U.S. health care system has experienced a remarkable transformation over the past decade. Managed care plans now enroll more than 80 million Americans. Ninety-one percent of employees with health insurance were enrolled in managed care plans in 1999, up from 27 percent in 1988. This shift to managed care has brought both opportunities and problems that touch how physicians practice medicine and how other health professionals, such as nurses and dentists, provide their services. We are presented, for example, with opportunities for more fully integrating medicine and public health, and for introducing into the health care system sophisticated techniques for collecting, handling, and assessing data that will prove valuable in quality assurance, cost containment, and research. Yet while some progress is evident, most of these opportunities remain unrealized. On the other hand, many of the problems are highly visible. They include a destabilization of academic medicine, growing anger among consumers over denial of care and other restrictions, renewed escalation in health care costs, and increasing concerns that cost-containment efforts are affecting quality of care.

In moving toward a system that meets the challenge of efficiently and effectively improving people's health, the nation must be guided by a single organizing principle—improving the quality of health care. While keeping costs in mind is certainly important, focusing foremost on reducing costs, which too often has been the case in the past, cannot and will not suffice. The systems by which health care is delivered and financed must be designed to ensure that care is safe, effective, efficient, equitable, and tailored to each individual's specific needs and circumstances.

The systems by which health care is delivered and financed must be designed to ensure that care is safe, effective, efficient, equitable, and tailored to each individual's specific needs and circumstances.

QUALITY OF HEALTH CARE SERVICES

The Institute of Medicine has a history of conducting studies to improve the quality of health care, as well as to identify the changes in education and training necessary to achieve that goal.



We launched our most ambitious effort in June 1998, with the creation of the Committee on Quality of Health Care in America. The committee was charged to provide the nation with a roadmap for changes that could transform the health care system into one that is safe, efficient, and consumer-centered. Among its attributes, this new system will provide a better working environment for physicians and other health care professionals, and it will allow individuals to participate in and, to the degree possible, help direct the care they receive. The committee's first report, *To Err Is Human: Building a Safer Health System* (2000), argues that safety—freedom from accidental injury during medical treatment—is a critical first step in improving quality of care. Each year, there are an estimated 98,000 avoidable deaths among hospitalized patients. The report con-

LEADING CAUSES OF DEATH[1]

Diseases of the Heart	**726,974**
Cancer (malignant neoplasms)	**539,577**
Cerebrovascular Disease	**159,791**
Chronic Obstructive Pulmonary Disease	**109,029**
Medical Errors[2]	**44,000–98,000**
Accidents and Adverse Effects (motor vehicle accidents = 43,458; all others = 52,186)	**95,644**
Pneumonia and Influenza	**86,449**
Diabetes	**62,636**
Suicide	**30,535**
Kidney Disease	**25,331**
Liver Disease	**25,175**

SOURCES: 1. Centers for Disease Control and Prevention, 1997. 2. IOM, *To Err Is Human: Building a Safer Health System,* 2000.

cludes, in particular, that errors can best be prevented by designing systems that make it harder for health care professionals and other health care workers to make mistakes and easier for them to do the right thing. Even well-trained, conscientious people working in poorly designed and managed systems will sometimes commit serious errors. Medical errors will be reduced and patient safety increased by focusing on the design and management of good systems. The report details a comprehensive strategy for designing safety into the health system at all levels, and it explains how patients themselves can influence the quality of care they receive.

. . . errors can best be prevented by designing systems that make it harder for health care professionals and other health care workers to make mistakes and easier for them to do the right thing.

In early 2001, the IOM will release several related reports. *Crossing the Quality Chasm: A New Health System for the 21st Century* is the culminating report of the Committee on Quality of Health Care in America. It proposes a strategy and action plan for improving the organization, delivery, and financing of health care in order to address serious shortcomings in the quality of care. *Envisioning a National Quality Report* examines what aspects of quality should be measured and tracked over time in order to determine whether the nation's health care delivery system is improving in its capacity to provide high-quality care. The report lays out a conceptual framework for monitoring quality and provides examples of the types of measures that might be included in a national quality tracking system.

Over the years, a number of studies have suggested that "higher-volume settings"—that is, hospitals, physicians, and other types of providers who handle larger numbers of patients—typically produce better health outcomes than do smaller settings. The Committee on Quality of Health Care in America, in conjunction with the National Cancer Policy Board, explored this apparent link. The resulting report, *Interpreting the Volume–Outcome Relationship in the Context of Health Care Quality* (2000), presents evidence on the relationship between hospital and physician volume and achieving better quality of care and patient outcomes in eight clinical areas, and it assesses the potential policy implications of using volume as a quality indicator. For example, higher-volume providers may have greater experience and more sophisticated facilities, and they may use better organized systems of care and multidisciplinary team approaches. However, volume alone is an imprecise indicator of quality: Some low-volume providers have excellent outcomes, while some high-volume providers have very poor outcomes. Furthermore, the performance gap appears to narrow with time as procedures become well established, which suggests that volume may be most pertinent when a new technology is beginning to diffuse into general practice.

. . . volume alone is an imprecise indicator of quality: Some low-volume providers have excellent outcomes, while some high-volume providers have very poor outcomes.

In 1997, the Veterans Health Administration implemented a new national formulary—the official list of drugs, devices, and supplies that may be used in treating patients at all of the agency's facilities. The goal, in part, was to reduce costs. However, many veterans expressed concern that the new formulary was overly restrictive and thus compromised clinical care. *Description and Analysis of the VA National Formulary* (2000) concluded that it is not overly restrictive and does appear to be reducing costs without demonstrable adverse effects on quality of care. But the report stressed that there are manifold opportunities to improve the policies and procedures that comprise the system for managing the VA National Formulary.

QUALITY OF LONG-TERM CARE

With the aging of the U.S. population, more people are facing questions about long-term care, for themselves or family members. At the same time, the quality of long-term care has raised concerns among local, state, and national policymakers and the public, including the users of these services and their families. *Improving the Quality of Long-Term Care* (2000) concludes that strengthening quality measurement and accountability programs for various long-term-care options—including nursing homes, residential care facilities, and home-based services—will be critical to serving an increasingly diverse mixture of people who have varying clinical and personal needs and preferences. The report recommends actions that federal and state governments, as well as private providers, can take to improve the quality of long-term care and to meet the needs of an increasingly diverse clientele. Consumers can play an important role in encouraging and assuring quality of care. Federal and state governments should encourage and support programs that provide consumers with information on long-term care options, on the compliance of individual care providers with state standards, on complaint resolution mechanisms, and on other quality-related issues.

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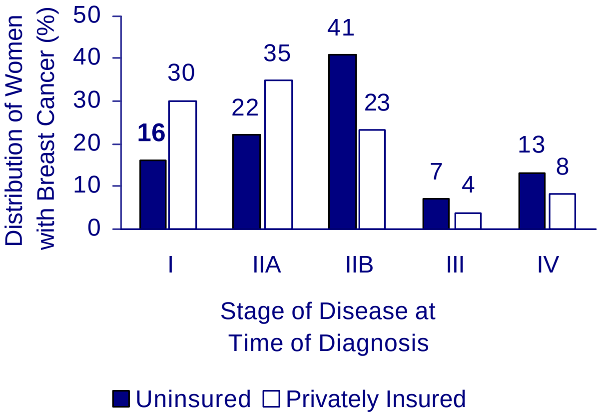
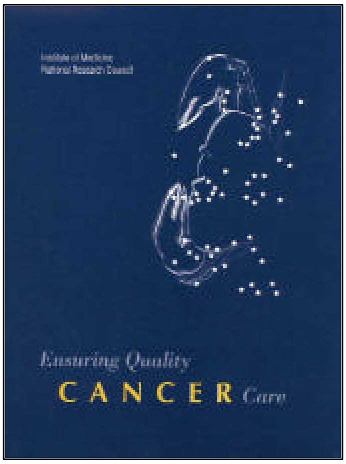


Distribution of women with breast cancer by disease stage at time of diagnosis. SOURCE: *Ensuring Quality Cancer Care,* 1999; page 52.

QUALITY OF CANCER CARE

Each year, more than 8 million Americans, or 3 percent of the population, require treatment for cancer. Even as new methods for fighting cancer are emerging from the nation's laboratories, some already proven therapies are not reaching all of the people who might benefit. Many cancer patients may be getting the wrong care, too little care, or too much care, in the form of unnecessary procedures. Lack of medical coverage, social and economic status, patient beliefs, physician decision-making, and other factors can stand between the patient and the best possible care. *Ensuring Quality Cancer Care* (1999), prepared by the National Cancer Policy Board, examines how cancer care—from early detection to measures for easing the end of life—is delivered in various regions of the nation. The conclusion: for many Americans with cancer, there is a wide gulf between what might be considered the ideal treatment and the reality of their experience with cancer care. The report defines quality care and recommends how to monitor, measure, and extend such care to all people with cancer.



Breast cancer is the most common cancer, and perhaps the most feared disease, among women in the United States. Almost 180,000 new cases are diagnosed annually, and about 44,000 women die from breast cancer each year. Until more is known about breast cancer prevention, the best hope for reducing its toll is early detection. X-ray mammography (imaging of breast tissues) and physical examination of the breast are now the mainstays for detection, but new technologies are emerging. In addition to overcoming the high costs of these new technologies, their expanded use also depends, in the case of devices, on approval by the Food and Drug Administration; on their being adopted by health plans and providers; on developing systems to support payment for screening and follow-up; and on how readily private firms bring the technologies to market. Experience from current mammography and breast self-examination programs also shows that success will depend on providing outreach to women, enhancing education of women and providers, and increasing convenient access to facilities and services. The National Cancer Policy Board is currently assessing the potential of these new technologies, and its report, *Mammography and Beyond: Developing Technologies for the Early Detection of Breast Cancer*, will be released in 2001.

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HEALTH INSURANCE

As the shape of the nation’s health care delivery system continues to shift, knowledge about health insurance status and the effects of having or not having insurance becomes increasingly critical. The IOM has studied selective aspects of this issue and continues to engage in related activities. Information on our examinations of children’s health insurance status, on the effects of not having insurance, and on the increasingly worrisome state of the country’s health care safety net can be found in the next section of this publication, in the section on Demographic Trends.

Selected Recommendations Related to Demographic Changes. . .

- **Health Care Safety Net:** Federal and state policymakers should explicitly address the full potential impact of any changes in Medicaid policies on the viability of safety net providers and the populations they serve. Federal programs and policies targeted to support the safety net and the populations it serves should be reviewed for effectiveness in meeting the needs of uninsured people. The nation's capacity to monitor the changing structure and financial stability of the safety net must be improved. (*America's Health Care Safety Net: Intact but Endangered*)
- **Children:** All children should have health insurance. Public and private insurers should be encouraged to develop affordable products that address the specific needs of children, including children with chronic conditions and special health care needs. Nonfinancial barriers to care should also be reduced. (*America's Children: Health Insurance and Access to Care*)
- **Minority Health:** Research and research funding relevant to cancer among ethnic minority and medically underserved populations should be more adequately assessed and should be increased. (*The Unequal Burden of Cancer: An Assessment of NIH Research and Programs for Ethnic Minorities and the Medically Underserved*)
- **Nutrition and Elderly People:** Nutrition therapy provided by registered dieticians should be a reimbursable service under Medicare. Availability of nutrition services should be improved in home health care settings, and standards for nutrition services should be strengthened in long-term-care facilities. (*The Role of Nutrition in Maintaining Health in the Nation's Elderly: Evaluating Coverage of Nutrition Services for the Medicare Population*)

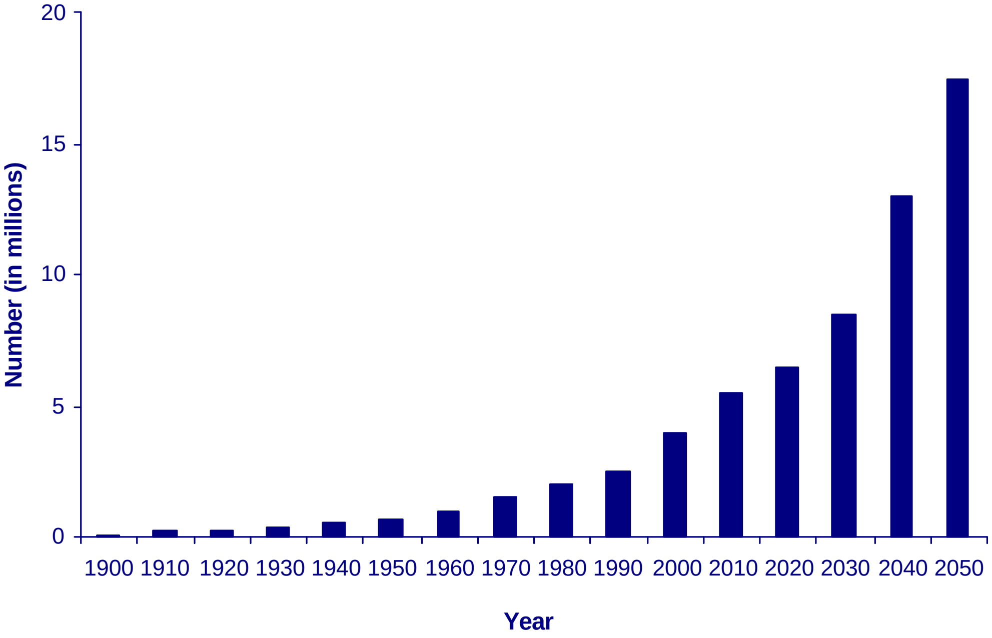
Demographic Trends

America's health in the 21st Century must wrestle successfully with equity among the young and the aged and among social and ethnic groups.

Lincoln Chen, *2020 Vision: Health in the 21st Century.*
Institute of Medicine 25th Anniversary Symposium

The U.S. population is in the midst of major changes. In the next few decades, Americans will be getting older and living longer. Increasing ethnic and racial diversity will make the issue of diversity more pronounced, especially in those regions with higher concentrations of these populations. One decade from now, fully one-third of the U.S. population will be composed of ethnic and racial minorities; this growth is driven by both higher birth rates among minority groups and significant levels of immigration. Uninsurance rates are likely to be negatively affected by these trends as the two highest in populations of uninsured—children and young adults—grow as part of the increase in minorities and immigrants. National and local health care policies need to be sensitive to these changes and the nature of the populations they address.

New Census Bureau projections anticipate that the over-65 age group, which now stands at roughly 35 million, will increase by nearly 5 million during the coming decade and double, to 70 million, by 2030. The over-85 age group will likewise double, to almost 9 million, by 2030. This unprecedented cohort of older people will



Number of people 85 years old and older in the United States, 1900–2000. The population aged 85 and older is the fastest growing age group in the country. SOURCE: *Nursing Staff in Hospitals and Nursing Homes: Is It Adequate?,* 1996; page 33.

make equally unprecedented demands on the health care system. More than 85 percent of people age 65 and older have hypertension, diabetes, or blood lipid disorders due to chronic disease. Already, the issue of access to prescription drugs is a national concern. Spending for pharmaceuticals and other costly new services and products will fuel growth in health expenditures and increase pressure on public and private insurance arrangements. Chronic disease prevention and management will become more important, as will long-term care and other assisted-living services.

More than 85 percent of people age 65 and older have hypertension, diabetes, or blood lipid disorders due to chronic disease.

The nation's population also is becoming increasingly diverse. Census projections anticipate that the minority population will increase by nearly 20 million during the next decade, reaching 140 million by 2030, when minorities will constitute 40 percent of the total population. Increasing diversity will likely contribute to a growth in the number of uninsured among the nonelderly population and widen health disparities between whites and minorities (related, in part, to levels of uninsurance among minorities). Currently, an estimated 44 million Americans are uninsured. More than one-third of Latinos, the fastest growing ethnic group in the country, lack public or private health insurance. Although most poor families are white, higher proportions of minority families are poor or have very low incomes—a fact that has significant implications for health.

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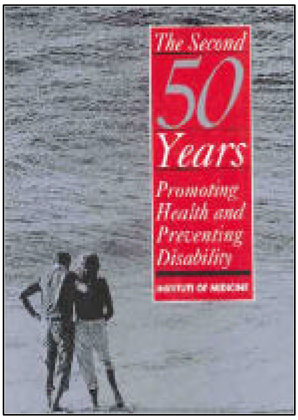
The Institute of Medicine conducts a variety of studies that address critical health issues that arise as the nation's population grows older and shifts in composition.

HEALTH CARE NEEDS OF AN AGING POPULATION

Who uses long-term care? How have the characteristics of this population changed? What paths do people follow in long-term care? How can this care be improved? As mentioned in the previous section, *Improving the Quality of Long-Term Care* (2000), a study sponsored by the Robert Wood Johnson Foundation, provides a comprehensive look at the quality of care and quality of life in a variety of settings, including nursing homes, residential care facilities, home health agencies, and private residences where family members provide or direct most of the services. The report highlights the degree to which long-term care is changing to meet the needs of an increasingly diverse clientele and to satisfy consumer desires to have more control over the location and kinds of services that are provided. It identifies critical problems and offers recommendations for federal and state policymakers on setting and enforcing standards of care, strengthening the caregiving workforce, reimbursement issues, and expanding the knowledge base to guide organizational and individual caregivers in improving the quality of care.

Older individuals and their families enter the health care system with their own unique set of problems, conditions, and values. How can the needs and desires of each person be appropriately assessed and addressed in a rapidly changing health care environment? Health outcomes research, which studies the end results of the structure and processes of health care on the health and well-being of patients and populations, has the potential of providing the measurement tools to make that assessment and the analytic knowledge to suggest ways of addressing the challenges posed. *Health Outcomes for Older People: Questions for the Coming Decade* (1996) considers what the future is likely to bring for America's older population and its health care system. The report proposes an agenda for health outcomes research and recommends the development of a "toolbox" of reliable, valid, and practical measurement tools for use in a variety of elderly populations, covering both health-related quality-of-life issues as well as satisfaction with care. The eventual goal is to provide older people with practical information to assist in making important health choices.



Many older people are never counseled to stop smoking, start exercising, or take other measures commonly urged on the young, despite clear evidence that such measures help older people. When health professionals fail to offer such care, they may be dooming elderly people to years of discomfort, isolation, or disability. *The Second 50 Years: Promoting Health and Preventing Disability* (1992) provides a framework for protecting the quality of life for people over age 50. Taking its title from the second 50 years of the roughly 100-year human life span, the report focuses on 13 major health threats to the elderly, examining how each affects the older person and how those effects might be mitigated. It presents wide-ranging, practical advice for health care providers,

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policymakers, and other sectors of society. Recommendations range from changing national policies to changing the way elderly patients are interviewed in the doctor's office, and from encouraging city planners to redesign the nation's urban environments to encouraging older persons to exercise, even providing them with specific exercises to help in becoming and remaining fit.

ADVISING ON MEDICARE

Many elderly people do not fully understand what the traditional Medicare program covers, let alone what the newer health care delivery options add to the mix. *Developing an Information Infrastructure for the Medicare+Choice Program* (1999) describes the best ways to help Medicare beneficiaries with their information needs in an environment of choice. The Health Care Financing Administration (HCFA), which administers Medicare, has primary responsibility for educating its nearly 40 million beneficiaries about the Medicare+Choice Program, which offers enrollees a wide range of health care options. The report outlines how HCFA, working with other government agencies and private-sector organizations, can organize education and marketing strategies to build an information infrastructure that elderly beneficiaries will find helpful, customized to their needs, and trustworthy.

The nation's health care delivery system is being challenged to accommodate the needs of the growing numbers of Americans with serious or complex medical problems. Of particular concern are strategies to finance the long-term provision of complicated arrays of health and other services required by these patients. Issues have arisen about ensuring access to care and quality of care for individuals with persistent, disabling, or progressively life-threatening medical conditions. *Definition of Serious and Complex Medical Conditions* (1999) provides guidance to caregivers and health plans in identifying patients with particularly complicated medical conditions, and it recommends a strategy for identifying individuals enrolled in

The nation's health care delivery system is being challenged to accommodate the needs of the growing numbers of Americans with serious or complex medical problems.

health plans who would benefit from receiving intensive services. To provide efficient, high-quality care for these individuals, health care delivery systems must be able to deal with a diverse array of clinical, social, mental, and functional health issues, and they also must be capable of working effectively with other community and social support systems.

Congress in recent years has broadened Medicare coverage to include some preventive services, such as breast-cancer screening, but cost concerns have often limited further extensions. Three IOM reports examine both the evidence for extending coverage and the cost to Medicare of doing so:

. . . Medicare should cover dental care that is effective in reducing infections and other complications associated with serious medical conditions and their treatment.

- *Extending Medicare Coverage for Preventive and Other Services* (2000) assesses skin-cancer screening, dental services for patients with certain medical conditions, and eliminating the time limit on coverage of immunosuppressive drugs for transplant patients; it also identifies those areas in which the evidence supports expansion of Medicare coverage. There is a solid case that Medicare should cover dental care that is effective in reducing infections and other complications associated with serious medical conditions and their treatment. The report also concludes that the evidence for removing the current time limitation on coverage of immunosuppressive drugs is strong. However, lack of evidence precludes other clear recommendations.

- *The Role of Nutrition in Maintaining Health in the Nation's Elderly: Evaluating Coverage of Nutrition Services for the Medicare Population* (2000) concludes that individualized nutrition counseling could improve health for many Medicare beneficiaries. Poor nutrition is a major problem for many older Americans, and one that can contribute to common chronic illnesses, such as cardiovascular disease, hypertension, and diabetes. Nutrition therapy should be a reimbursable Medicare benefit upon referral from a physician, and registered dietitians should be the primary professionals to qualify for reimbursement for such services. The report offers a series of recommendations to eliminate the administrative barriers that now prevent wider use of nutrition therapy.

- *Extending Medicare Reimbursement in Clinical Trials* (2000) provides a medically and fiscally responsible framework for Medicare to pay for routine care necessary during a beneficiary's participation in clinical trials. Drugs, devices, and procedures that are effective at preventing, diagnosing, or treating disease are the backbone of high-quality health care, and clinical trials are the means of finding out whether those interventions work and are safe. The report concludes that since Medicare has a stake in ensuring that medical interventions it pays for are effective, it would be sound policy to remove any disincentives to the participation of Medicare recipients in clinical trials.

ADOLESCENT HEALTH

Adolescents comprise another segment of the population that is undergoing dramatic changes, both increasing in number and racial/ethnic diversity. To help them grow and develop, young people need the support of their families, neighborhoods, and communities. However, changing societal and economic factors have had a significant impact on the ability of families at all income levels to provide such supervision and guidance. Maintaining and promoting adolescent health is further challenged by the increasing number of young Americans—an estimated 7 million (one-quarter of adolescents 10- to 17-years old)—that engage in behaviors that put them at high risk for negative health and developmental outcomes, such as alcohol and other drug abuse, unintended pregnancy and fatherhood, or infection with a sexually transmitted disease, including HIV. Recent years have seen the escalation of youth violence, both in exposure and involvement. What strategies and approaches can help guide youth away

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from unhealthy behaviors and unsafe practices and engage them in health promoting behaviors? The search for answers has revealed many gaps in understanding how teenagers negotiate critical transitions from childhood to adulthood. Why are some youths—even in communities struggling with the problems of poverty, crime, drugs, and other negative influences—able to connect with social and economic networks that can help them become successful and productive adults, while others never gain access to or turn away from such networks?

The Board on Children, Youth, and Families currently has a project under way to review community-level programs to promote positive youth development. The committee report will be published in 2001 and provide findings and conclusions framed around the essential elements of adolescent well-being and healthy development and linked to program features that contribute to a successful transition from adolescence to adulthood. The report will examine what we know about the current landscape of development programs for America's youth, as well as how these programs are meeting their diverse needs—with particular attention to racial, ethnic, and socioeconomic considerations. It will offer recommendations for policy, practice, and research to ensure that programs are well designed to meet young people's developmental needs and evaluated according to the best theory and practice.

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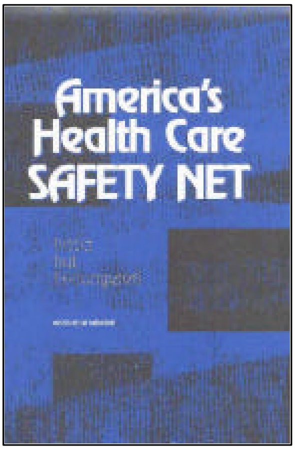
LOW-INCOME AND MINORITY POPULATIONS

Even in this time of unprecedented prosperity and budget surpluses, there are many groups in the United States that fall outside the economic and medical mainstreams—particularly the millions of low-income individuals with limited or no health insurance, as well as many Medicaid beneficiaries and people who need special services. To address at least the basic health needs of these groups, the nation



has long relied on an institutional safety net system, a patchwork of hospitals, clinics, financing, and programs that varies dramatically from community to community and state to state. This system has never been financially robust, but has continued to survive. Recently, however, a series of changes in the structure and financing of the U.S. health care system has inadvertently caused serious problems for the safety net system. *America's Health Care Safety Net: Intact but Endangered* (2000) recommends steps to buttress the system in order to ensure access to care for disadvantaged and underserved populations. Of key importance, there needs to be an independent, expert oversight body that will monitor the status of the safety net system and its ability to meet the needs of those who rely on its services. Such enhanced tracking capability will help to promote public accountability, as well as a more coordinated approach to data collection, technical assistance, and the application and dissemination of best practices.

The IOM has a study under way to document the health effects of being uninsured in the United States. Sixty percent of today's 44 million uninsured live in families with incomes below 200 percent of the federal poverty line. Roughly 84 percent of the uninsured live in families headed by workers. Even among the poorest, those in families with incomes less than the federal poverty line, fewer than half (47.6 percent) of nonelderly Americans have publicly sponsored health insurance. Assuming the continuation of current trends in the availability and cost of employment-based health insurance, immigration, and income support programs, the fraction of the population that is uninsured will continue to rise over the next decade. This group is at risk for poorer health, financial hardship, and significant strains on the family. Local and national communities also face health threats, burdens on public services and health care institutions, and distortions in labor and

Assuming the continuation of current trends in the availability and cost of employment-based health insurance, immigration, and income support programs, the fraction of the population that is uninsured will continue to rise over the next decade.

The Safety Net Serves a Wide Range of Vulnerable Populations

- Uninsured and underinsured

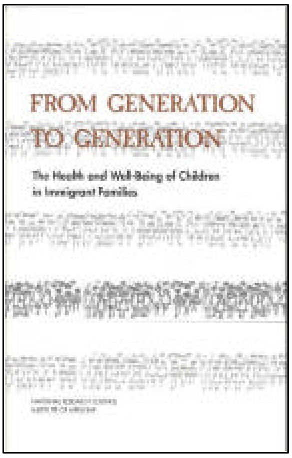
  - Working poor whose employers do not offer insurance
  - Non-Medicaid-covered unemployed poor
  - Children who are not included in parents' coverage
  - Adults who cannot afford employer-sponsored coverage

- Medicaid beneficiaries
- Chronically ill individuals
- People with disabilities
- Mentally ill individuals
- People with communicable diseases (e.g., HIV infection/AIDS or tuberculosis)
- Legal and undocumented immigrants
- Minorities
- Native Americans
- Veterans
- Homeless people
- Substance abusers
- Prisoners

SOURCE: *America's Health Care Safety Net: Intact but Endangered,* 2000; page 51.

health care markets. These burdens are not uniformly dispersed across the nation, but are concentrated in communities that are disproportionately poor, minority, and immigrant. The particular contribution of health insurance coverage to an individual's access to quality health care and the consequent differences in health status and quality of life is not widely understood. The IOM is beginning a 3-year study, sponsored by the Robert Wood Johnson Foundation, that will produce a series of reports to improve understanding of the consequences of uninsurance.

The children of today offer a preview of the nation's future citizens, workers, and parents. One of every five children under age 18 living in the United States—14 million, all told—is an immigrant or has immigrant parents. Available evidence suggests that on many



measures of health and well-being, these children perform as well as or better than U.S.-born children with U.S.-born parents. Over time and across generations, however, as immigrant children become part of the American society, many of these advantages do not appear to be sustained. *From Generation to Generation: The Health and Well-Being of Children in Immigrant Families* (1998) examines the many factors—family size, fluency in English, parent employment, acculturation, delivery of health and social services, and public policies—that shape the outlook for the lives of these children and youth. Among the findings, immigrant children experience a somewhat higher poverty rate, are more likely to live in overcrowded housing, and are three times as likely to lack health insurance coverage than are children in U.S.-born families. Immigrant children also are considerably less likely to visit a doctor on a regular basis. The report recommends improved research and data collection that will advance knowledge about these children and, as a result, increase their visibility in current policy debates.

Concerns about the health and well-being of children and adolescents who live in poverty have grown as the nation has embarked on a major restructuring of welfare, income support, social service policies, and the health care delivery system. As such decisions are made, it is critical that public and private policymakers consider the most current research regarding the effects of poverty and welfare dependency on children. The association between poverty and poor child health outcomes has been well documented, but less is known about the mechanisms through which poverty operates and about which aspects of poverty are most damaging. *New Findings on Poverty and Child Health and Nutrition: Summary of a Research Briefing* (1998) examines what has been learned about the specific ways in which poverty affects the health of children and youth, and it considers next steps for research that will inform debates about welfare policy and health outcomes for poor children and adolescents.

The association between poverty and poor child health outcomes has been well documented, but less is known about the mechanisms through which poverty operates and about which aspects of poverty are most damaging.

Children without insurance are of special concern because lack of access to health services may have lifetime consequences. *America's Children: Health Insurance and Access to Care* (1998) highlights the need to reduce both financial and nonfinancial barriers so that all children can have health insurance. Public and private insurers should be encouraged to develop affordable products that address the specific needs of children, including children with chronic conditions and special health care needs. Yet even having health insurance will not guarantee utilization of proper care, and other steps, such as providing assistance with child care and transportation, offering culturally appropriate services, and making use of information technology, will also be necessary to reach some populations with necessary services.

Public and private insurers should be encouraged to develop affordable products that address the specific needs of children, including children with chronic conditions and special health care needs.

To help address this problem, the federal government in 1997 created the State Children's Health Insurance Program (SCHIP) to allow states to provide child health assistance to uninsured, low-income children "in an effective and efficient manner." States liked SCHIP for the flexibility it offered in providing coverage and services in ways that reflect each state's unique circumstances and characteristics. Yet with so much variation possible, how will we know whether SCHIP is effective? *Systems of Accountability: Implementing Children's Health Insurance Programs* (1998) examines the responsibilities of Congress, the federal government, and state governments to assure accountability for the quality of services provided to children under SCHIP. The report concludes that SCHIP offers an unprecedented opportunity to move from the traditional monitoring and compliance models of health care, which focus on financial performance, to a quality-improvement model that can better improve access for uninsured children to appropriate health care services. Reaching this goal will require developing a performance monitoring system at the federal level, as well as continuing support of efforts to improve indicators of children's health and well-being, including indicators for children with special health care needs.

Despite rapid improvements in the overall health of the U.S. population, racial and ethnic minorities generally experience higher rates of morbidity and mortality than nonminorities. African-Americans, for example, experience the highest rates of mortality from heart disease, cancer, diabetes, and HIV/AIDS of any other racial or ethnic group. The reasons for these health status disparities are poorly understood, but may largely reflect socioeconomic differences and inadequate access to health care. African Americans, Hispanics, and Asian Americans are less likely than whites to have health insurance, have more difficulty getting health care, and have fewer choices in where to receive care. Even at equivalent levels of access to care, however, minorities are less likely to receive even routine medical procedures and more likely to experience a lower quality of health services. For example, African Americans are less likely than whites to receive appropriate cardiac medication or to undergo coronary artery bypass surgery; they are less likely to receive hemodialysis and kidney transplantation; and, among patients hospitalized for pneumonia, they are less likely to receive such clinical services as radiographs and intensive care. The IOM is now conducting a study to assess the extent of differences in the kinds and quality of health care received by racial and ethnic minorities and nonminorities, evaluate the potential sources (e.g., provider attributes, patient attributes, or institutional and system attributes) of racial and ethnic differences in health care, and recommend policies and practices to reduce health care disparities.

Despite rapid improvements in the overall health of the U.S. population, racial and ethnic minorities generally experience higher rates of morbidity and mortality than nonminorities.

ASSESSING DISEASE TRENDS

We know more about cancer prevention, detection, and treatment than ever before—yet not all segments of the U.S. population have benefited to the fullest extent possible from these advances. Some racial and ethnic minorities experience more cancer than the majority population, and poor people—no matter their ethnicity—often lack access to adequate cancer care. *The Unequal Burden of Cancer: An Assessment of NIH Research and Programs for Ethnic Minorities and* *the Medically Underserved* (1999) documents the gaps existing in prevention and treatment and the absence of adequate research to understand risk factors specific to cancer in minorities. The report offers recommendations regarding improving the collection of cancer-related data, particularly among ethnic minorities and the medically underserved; ensuring that clinical trials supported by the National Institutes of Health include participation by these special populations; disseminating research results to health professionals serving these groups; and increasing sensitivity to the issues of cancer survivorship.

The United States is at a critical juncture in fighting tuberculosis (TB). On the one hand, we have regained control of TB, which had reemerged in the late 1980s and early 1990s, after being brought under tighter control by the 1960s. On the other hand, we are particularly vulnerable—again—to the complacency and neglect that can come with declining numbers of cases. *Ending Neglect: The Elimination of Tuberculosis in the United States* (2000) details an action plan for federal and state governments, as well as the private sector, to develop and implement intensified TB prevention and treatment programs. Eliminating TB also will require accelerated research to identify new tools for managing the disease. And given the global face of tuberculosis, the United States must increase its engagement with other nations' efforts to control TB—for both altruistic reasons and to help reduce the total "reservoir" of infection.

. . . given the global face of tuberculosis, the United States must increase its engagement with other nations' efforts to control TB—for both altruistic reasons and to help reduce the total "reservoir" of infection.

Selected Recommendations for Consumers. . .

- **Care at the End of Life:** Policymakers, consumer groups, and purchasers of health care should work with practitioners and researchers to develop better strategies for improving care at the end of life and to hold health care organizations accountable for such care. A continuing public discussion is essential to develop a better understanding of the modern experience of dying and the options available to patients and families. (*Approaching Death: Improving Care at the End of Life*)
- **Information for Medicare Beneficiaries:** Special and major efforts are needed to build the needed consumer-oriented information infrastructure for Medicare beneficiaries. (*Letter Report to the Administrator of HCFA on Developing an Information Infrastructure for the Medicare+Choice Program*)
- **Managed Mental Health Services:** Health Care Purchasers must be responsive to consumers and families and develop means of ensuring their meaningful participation in treatment decisions. (*Managing Managed Care: Quality Improvement in Behavioral Health*)
- **Long-Term Care:** Federal and State governments should encourage the development of effective consumer advocacy and protection programs by providing support for consumer education and information dissemination and for complaint resolution programs. (*Improving the Quality of Long-Term Care*)
- **Breast Implants:** A national model of informed consent for women undergoing breast implantation should be developed, and the continuing effectiveness of the informed consent model should be monitored. (*Safety of Silicone Breast Implants*)

* * *

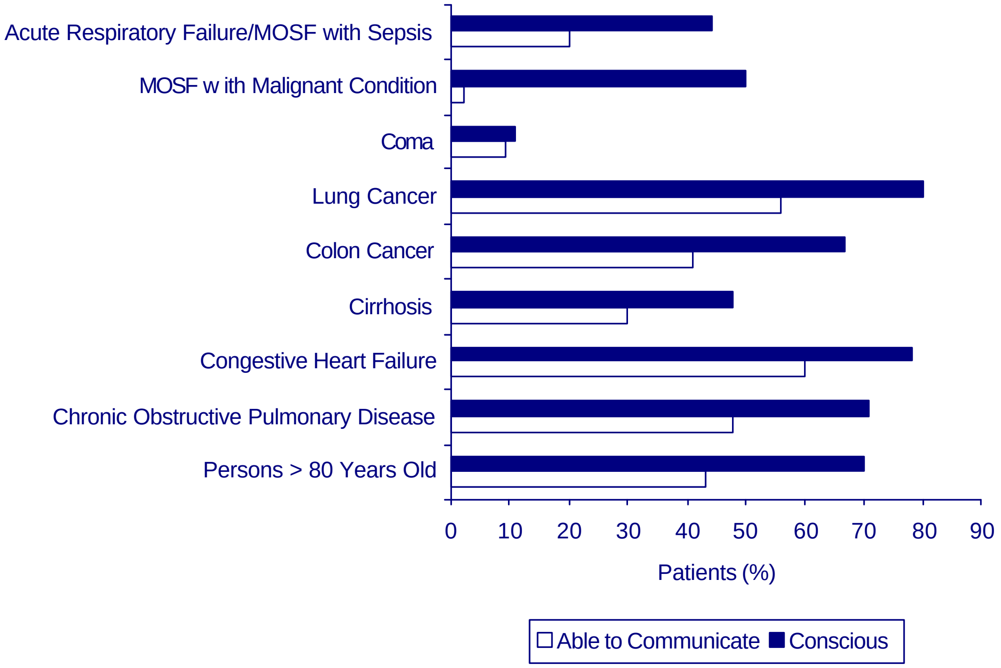
Changing Consumer Attitudes

The empowerment of certain groups in U.S. society, from minorities to women, from gays and lesbians to health care consumers and patients, has contributed new and distinct voices to the debate surrounding advances in medicine and health policy.

Society's Choices: Social and Ethical Decision Making in Biomedicine (1995)

As patients, purchasers of health care and health products, and subjects of clinical research, consumers are becoming activists. They demand and use information about medical treatments, drugs, and dietary supplements, as well as about the standards that are applied to protect their health through regulatory policies or other government actions. Activism will increase as education levels rise and the Internet democratizes access to information—some scientifically sound, some unreliable. Growing numbers of consumers also are becoming wary of institutions and health professionals and distrustful of government. These changes in public attitudes and actions offer both opportunities and challenges to public officials—at the national, state, and local levels—who will shape and manage health care programs.

The Institute of Medicine conducts studies that directly assist consumers by providing authoritative advice on pressing, and often confusing, health issues. Consumers also benefit indirectly, as our reports guide health professionals, institutions providing health care services, and federal agencies in designing and managing programs that offer high-quality care and support informed choice.

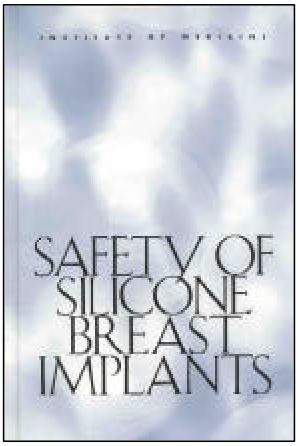


Rates of consciousness and the ability to communicate in the 3 days before death as reported by family members of severely ill hospitalized patients. A patient's cognitive abilities may have a significant effect on caregivers, including their inclination to deny impending death or to become more emotionally distant. MOSF = multiple organ system failure. SOURCE: *Approaching Death: Improving Care at the End of Life,* 1997; page 43.

SUPPORTING CONSUMER CHOICE

Just as more people are paying attention to the quality of their lives, they also are becoming increasingly concerned about how they may die.

Just as more people are paying attention to the quality of their lives, they also are becoming increasingly concerned about how they may die. *Approaching Death: Improving Care at the End of Life* (1997) focuses on the numerous complex issues that face people who are dying, their families, and their caregivers. The report presents what we know about care at the end of life, what we have yet to learn, and what we know but do not adequately apply. It seeks to build understanding of what constitutes good care for the dying and offers recommendations to policymakers that address specific barriers to achieving good care.



More than 1.5 million women in the United States have silicone breast implants. Most of these women say they are very satisfied with their implants, but some women have experienced complications that require surgery or even removal of the implants. Others claim that their implants have caused even more serious health problems. *Safety of Silicone Breast Implants* (2000) evaluates the evidence for associations of these devices with human health conditions. Implants do not appear to cause major diseases of the whole body. Problems with implants appear to be local, but not life-threatening, complications. During the early years of breast implants, women considering surgery often were not given much information about possible complications or the likelihood that the implants would not last forever.

Can marijuana relieve health problems? Is it safe for medical use? Public opinion on the medical value of marijuana has been sharply divided, with proponents on both sides citing “scientific evidence” to support their views. *Marijuana and Medicine: Assessing the Science Base* (1999) reviews the science behind marijuana’s actions and examines the efficacy of therapeutic uses of marijuana. The report finds that cannabinoid drugs—that is, drugs that act in ways similar to the primary active ingredient in marijuana—may have a role to play in medicine in such areas as pain relief and appetite stimulation. Yet, for several reasons, the future of cannabinoid drugs lies not in smoked marijuana but in chemically defined drugs whose actions can be better controlled. To cover the period until such drugs are available, the report calls for continued basic research and for clinical trials under limited circumstances and with strict oversight.

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For each of these three reports, the IOM has produced consumer-oriented summaries to help members of the general public—especially individuals and their families who face or expect to face such issues—understand the scientific facts and the available options.

PROVIDING AUTHORITATIVE ADVICE

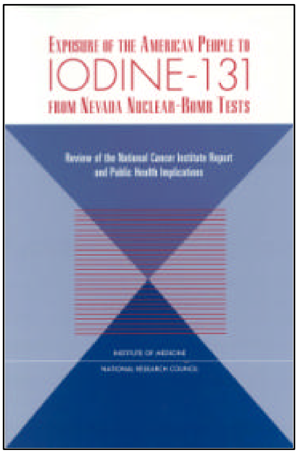
Better information about food and nutrition can help improve consumer choices. Numerous reports by our Food and Nutrition Board have established the recommended daily intake levels of vitamins and minerals and the maximum levels of nutrients which pose no risk of adverse effects due to overconsumption. Changes in food labeling laws, the use of nutrient recommendations in determining minimum levels of foods provided in public and private programs, and other recent developments point to a need for a comprehensive approach to reviewing current dietary recommendations. A series of IOM reports on Dietary Reference Intakes (DRIs) provide quantitative estimates of nutrients individuals need to optimize their health, prevent disease and deficiencies, and avoid adverse affects due to consuming too much of a nutrient. DRIs have been developed for a variety of vitamins and minerals; macronutrients, such as protein, fat, and carbohydrates; trace elements, such as iron and zinc; and antioxidants, such as selenium. DRIs for water and electrolytes, such as sodium and potassium, and for other food components, such as fiber and phytoestrogens, are in the process of being reviewed and developed.

Better information about food and nutrition can help improve consumer choices.

The number of Americans who use complementary and alternative medical therapies has grown rapidly in recent years. With increased use comes increased need for scientific investigation and understanding of whether these therapies are safe and effective. The IOM is reviewing complementary and alternative therapies used by the American public. In addition to examining issues of safety and effectiveness, the report will explore whether people using these therapies delay seeking conventional treatments, differences in how diverse cultural and ethnic groups use these therapies, how often and under what conditions physicians make referrals for these therapies, and the extent that insurance companies pay for them.

Of the many interventions that appear to be important in preserving and maintaining physical and mental health in older women, hormone replacement therapy has attracted the greatest interest. The IOM plans to review the current science related to hormone replacement therapy. The resulting report will address issues regarding dosage, delivery mechanisms, and timing of initiation and cessation of therapy to maximize health outcomes and reduce adverse effects. It also will examine the role of hormone replacement therapy as part of a comprehensive health promotion and disease prevention program, when combined with other healthy behaviors, such as diet, exercise, and weight control.

For nearly 50 years, public concern and scientific debate have surrounded the program of aboveground nuclear weapons testing that the United States conducted in Nevada during the period from 1951 to 1962. Concern about radioactive fallout north and east of the Nevada Test Site began to emerge soon after weapons testing began. During the late 1980s, the National Cancer Institute (NCI) began assessing the level of radiation exposure that Americans may have received from radioactive iodine released during atomic bomb tests, and NCI later issued a report with this information. The IOM/NRC report *Exposure of the American People to Iodine-131 from Nevada Nuclear-Bomb Tests: Review of the National Cancer Institute Report and Public Health Implications* (1999) provides an evaluation of the soundness of the methodologies used by the NCI to estimate past radiation doses, detect possible health consequences of exposure to iodine-131, identify implications for clinical practice, and construct possible public health strategies to respond to the exposures, such as systematic screening for thyroid cancer. The report also provides an evaluation of the NCI estimates of the number of thyroid cancers that might result from the nuclear testing program and offers guidance on approaches the U.S. government might use to communicate with the public about iodine-131 exposures and health risks.



EXPOSURE RISK ASSESSMENTS

Congress, veterans groups, and other interested parties have relied upon the IOM to provide authoritative assessments of these risks and what is known about their consequences.

Veterans, their relatives, and their representatives have long been an active voice arguing for more information and for a larger say on issues that affect their health. The IOM has conducted a number of studies designed to assess the health effects on military personnel and civilians of exposure to toxic substances during deployment in theatres of war or proximity to nuclear weapons testing. These studies not only provide the government agencies that request them with the latest scientific information and evaluations, but also serve as unbiased sources of information for the individuals whose health may have been jeopardized by their service or by defense weapons production. A legacy of cold war secrecy is the continuing distrust of the government's honesty in assessing and revealing these risks. Congress, veterans groups, and other interested parties have relied upon the IOM to provide authoritative assessments of those risks and what is known about their consequences.

Among the studies, *Veterans at Risk* (1993) assessed the long-term health consequences among World War II veterans of exposure to mustard agents. A series of studies, beginning with *Veterans and Agent Orange: Health Effects of Herbicides Used in Vietnam* (1993), has focused on exposure to herbicides (and their contaminants, notably dioxin) used during the Vietnam War. We currently are working on *Update 2000*, the fourth volume in this series. *Gulf War Veterans: Measuring Health* (1999) examined the evidence of adverse health effects from exposure to certain chemicals, drugs, and vaccines known to be present during the war in the Persian Gulf. Much remains unknown about such effects, and we now have a major study under way to assess exposures to 33 toxic agents that Gulf War veterans may have encountered during their service.

All U.S. military personnel now are vaccinated against anthrax. The first service-related vaccinations occurred in 1990–1991, when reports that Iraq had produced weapons containing anthrax spores during the Gulf War fueled fears of the potential use of anthrax as a biological weapon. Since vaccination became the official military policy in 1998, some soldiers and other observers have expressed concern about the safety of receiving the vaccine. The IOM has two studies under way to evaluate the health risks associated with anthrax vaccine. *The Safety and Efficacy of Anthrax Vaccine for the U.S. Military*, requested by the Department of Defense, will examine such issues as the types and severity of adverse reactions, including gender differences; long-term health implications; efficacy of the vaccine against all known anthrax strains; validation of the manufacturing process; and gaps in existing research. *Review of the CDC Anthrax Vaccine Safety and Efficacy Collaborative Research Program* will advise the Centers for Disease Control and Prevention on the completeness and appropriateness of its proposed plan for assessing the range of issues related to ensuring safe and efficient use of the vaccine.

Since vaccination [against anthrax] became the official military policy in 1998, some soldiers and other observers have expressed concern about the safety of receiving the vaccine.

Selected Recommendations for Behavioral and Social Science . . .

- **Investments in Young Children:** The president should establish a task force to review all public investments in childcare and early childhood education, with the goal of making the most of scientific knowledge about early childhood. The task force should be charged to develop a 10-year plan that focuses on ways to foster sustained relationships between preschoolers and qualified caregivers; that addresses the special needs of children with developmental disabilities or chronic health conditions; and that ensures that all child-care settings are safe, stimulating, and responsive to families' concerns. Further, the major current sources of funding for childcare and early education should support initiatives aimed at increasing the qualifications, pay and benefits of child-care professionals. (*From Neurons to Neighborhoods: The Science of Early Childhood Development*)
- **Interdisciplinary Research and Training:** Because behavioral change is complex, successful intervention efforts are similarly complex and require the contributions of behavioral and social sciences, clinical medicine, and genetics, as well as other fields such as education. Advances in the behavioral and social sciences depend upon research that draws on multiple disciplines. Training programs need to provide scientific breadth to encourage work across disciplinary boundaries. The NIH and other federal research agencies should implement peer-review procedures that facilitate cross-disciplinary efforts and require universities to implement supportive policies for scientists working across disciplines. (*Bridging Disciplines in the Brain, Behavioral, and Clinical Sciences*)
- **Focus on Minorities:** The newly established program of behavioral and social science research at NCI addresses an area of research that has been neglected in the past. The program should identify as one of its highest priorities a focus on cancer prevention, control and treatment needs of ethnic minority and medically underserved groups. (*The Unequal Burden of Cancer: An Assessment of NIH Research and Programs for Ethnic Minorities and the Medically Underserved*)
- **Social and Behavioral Determinants of Health:** Social and behavioral factors have a broad and profound impact on health across a wide range of conditions and disabilities. A better balance is needed between the clinical approach to disease, presently the dominant public health model for most risk factors, and research and intervention efforts that address generic social and behavioral determinants of disease, injury, and disability. (*Promoting Health: Intervention Strategies from Social and Behavioral Research*)

Behavioral and Social Science

We know that the greatest improvements in the nation's health will result from a better understanding of social and behavioral factors that affect health.

S. Leonard Syme, Chair, IOM Committee on Promoting Health:
Intervention Strategies from Social and Behavioral Research

Approximately half of all deaths in the United States, as well as the majority of diseases and disabilities, are linked to behavioral and social factors. Some of these factors—such as smoking, poor diet, excess alcohol use, and sedentary lifestyles—relate directly to the choices and actions of individuals. Other factors, such as poverty and exposure to environments that discourage healthy behavior, involve society at large. All of these factors are amenable to change, but research tells us that achieving change at the individual or environmental level is difficult. Yet, less than 5 percent of the approximately $1 trillion spent annually on health care nationwide is devoted to reducing risks posed by behavioral and social factors. Greater investments are needed to address the fundamental behavioral and social causes of disease, disability, and mortality.

Approximately half of all deaths in the United States, as well as the majority of diseases and disabilities, are linked to behavioral and social factors.

Health and Behavior: Frontiers of Research in the Biobehavioral Sciences (1982) brought national attention to the important role of behavior in health. The report reviewed research on the role of behavior in the prevention and treatment of a variety of diseases, described psychosocial and behavioral risk factors and prevention efforts, discussed the relationship of mental health care with primary care, and recommended directions for research on health and behavior. The report was one of the first to recognize the contributions of the behavioral sciences to medical practice and to promote multidisciplinary research on known behavioral risk factors for disease.

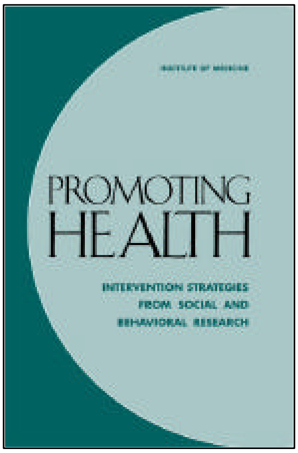
The charge to society is to blend the skepticism of a scientist, the passion of an advocate, the pragmatism of a policymaker, the creativity of a practitioner, and the devotion of a parent—and to use existing knowledge to ensure both a decent quality of life for all our children and a productive future for the nation.

From *Neurons to Neighborhoods: The Science of Early Childhood Development* (2000)

Progress since 1982 has been disappointingly slow. Today, such research comprises a small but growing segment of the National Institutes of Health's portfolio, while also receiving support from the Centers for Disease Control and Prevention and several foundations. However, major barriers remain in the design, funding, and conduct of research to develop reliable interventions to change individual and population-level patterns in such areas as diet, smoking, and exercise. Even when effective interventions are known, communicating them to diverse populations presents a major challenge. *Healthy People 2010*, the national health agenda developed by the Office of the Surgeon General, with input from the IOM, offers a roadmap for achieving major improvements in the nation's health and for reducing health disparities among diverse populations. Successful navigation of this roadmap depends on continued progress in the behavioral and social sciences, as well as on incorporation of the resulting knowledge into education, clinical practice, and population-level health interventions.

The IOM continues to play an important role in assessing needs in the behavioral and social sciences and in the translation of research findings into practice.

ADVANCING THE FIELD



A key to helping people enjoy longer, healthier lives is to understand how to promote behavioral change and to create healthier environments. *Promoting Health: Intervention Strategies from Social and Behavioral Research* (2000) summarizes what has been learned in behavioral and social research that is of value in improving health at different stages of life. The report acknowledges that health, disease, and well-being are complex states that develop and change over the entire life course. In addition, behavioral and social influences on health are complex, and no single intervention, or set of interventions, is likely to address all of these factors. Thus, health experts must use multiple approaches (e.g., education, laws, social support systems, and programs designed to help people change their destructive behaviors), and they must address multiple levels of influence simultaneously (e.g., individuals, families, communities, states, and the nation as a whole).

For example, efforts to reduce the number of people who smoke should take into account not only the physiological and psychological effects of nicotine addiction, but also such larger issues as the influence of friends and colleagues who smoke, the availability of tobacco products, and the number of public places where smoking is allowed. The report also notes that children should be a major focus of intervention efforts, since many of the risk factors observed in adults, such as being overweight and shunning physical activity, can be detected—and changed—in childhood. And, in designing intervention programs for people of all ages, public health practitioners and researchers should seek community involvement and work closely with the individuals who are targeted for participation.

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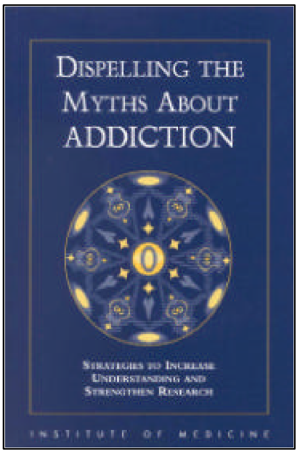
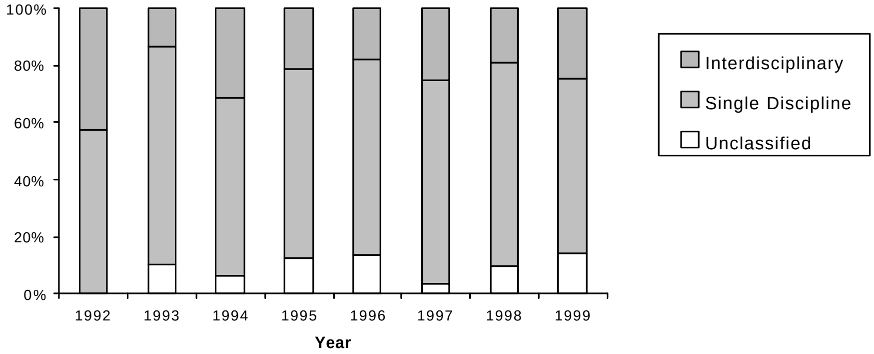
Health and Behavior: The Interplay of Cells, Self, and Society (2001) reviews the evidence linking biological, psychological, and social risk factors to medical disease. For example, the relationships between cardiovascular disease and the neuroendocrine system, stress, individual behavior, social networks, and socioeconomic status are explored. The report also describes the variety of interventions that have been used at the levels of the individual, the family or social network, the organization, the community, and society, and it evaluates the limitations and potential of these approaches. The recommendations for future directions in research could help federal agencies and foundations make decision about priorities for funding.



Behavioral and social science research provides a frame of reference to better understand drug and substance abuse. *Dispelling the Myths about Addiction* (1997) describes the psychosocial factors, as well as the biological factors, that influence an individual's potential for drug use and addiction. Beliefs and attitudes, many of which are learned from role models at home, in the community, or in the media, have a strong influence on drug use. The report notes that cognitive and behavioral research on the psychosocial factors related to drug initiation and use can lead to the development of new and effective prevention interventions.

WORKING ACROSS DISCIPLINES

Providing answers to the complex health questions facing today's society requires an integrated approach that melds multiple disciplines. A recently released report, *Bridging Disciplines in the Brain, Behavioral, and Clinical Sciences* (2000), examines the needs, obstacles, and strategies for interdisciplinary research and training in these fields. Its findings may be broadly applicable in other fields of scientific research and training as well. The report concludes that while interdisciplinary training programs are growing in number, barriers persist. For example, disciplinary jargon and cultural differences among scientists inhibit easy interactions. Some believe that interdis-

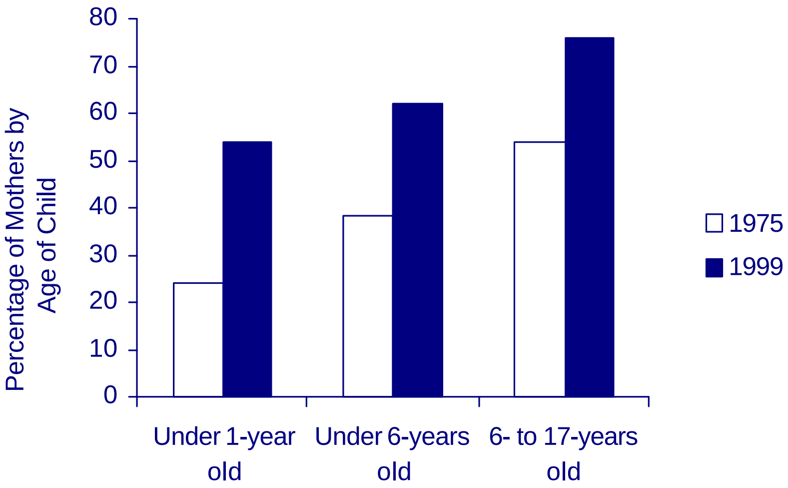


Annual distribution of Requests for Applications (RFAs) at the National Institutes of Health. RFAs are posted to encourage research in fields of special interest. The importance of interdisciplinary research at NIH is clear, as an average of 23% of all RFAs issued in 1992–1999 by NIH institutes addressed interdisciplinary research. SOURCE: *Bridging Disciplines in the Brain, Behavioral, and Clinical Sciences,* 2000; page 48.

ciplinary research reduces the likelihood of receiving funding or achieving "first authorship" of publications, recognition that traditionally has been essential in gaining tenure. The duration and cost of interdisciplinary education also can be discouraging.

Interdisciplinary research should supplement, not displace, single-discipline efforts. . . .

Among the proposed remedies, government funding agencies can implement peer-review procedures that reward scientists working across disciplines, fund shared core facilities, and require universities to endorse interdisciplinary efforts. For their part, universities can take preemptive steps to ensure that appointment, promotion, and tenure policies do not impede interdisciplinary research and teaching; develop ways allocate appropriate credit for interdisciplinary efforts; and to support the types of shared facilities that are needed when bridging disciplines. Interdisciplinary research should supplement, not displace, single discipline efforts, but interdisciplinary training opportunities should be available at all stages of a scientist's career.



Trends in the proportion of mothers in the labor force, by age of child, 1975–1999. NOTE: since 1975 data for mothers with children under 1 year of age are not available, the data for this column are from the June 1977 Current Population Survey. SOURCE: *From Neurons to Neighborhoods: The Science of Early Childhood Development,* 2000; page 270.

TRANSLATING KNOWLEDGE INTO PRACTICE

As a nation, we are not taking full advantage of what is known about early childhood development, between birth and age 5. Such inattention could not come at a worse time. Despite the unprecedented national prosperity, financial hardship is not uncommon. In fact, preschoolers today are more likely to be from poor families than they were 25 years ago. Many parents work long hours out of economic necessity, and often outside the typical 9-to-5 time frame, an increased workload that has left many parents straining to balance making a living with family time. Record numbers of women with young children work outside the home, resulting in increased reliance on childcare for infants and toddlers.

Despite the unprecedented national prosperity, financial hardship is not uncommon. In fact, preschoolers today are more likely to be from poor families than they were 25 years ago.

From Neurons to Neighborhoods: The Science of Early Childhood Development (2000) takes a comprehensive look at the interactions among a child's genetic inheritance, early environment, and personal experiences, and provides science-based advice about the interventions that can make a difference in a child's cognitive, physical, and emotional development. The report notes, for example, that a child's early relationships are critical, and that a child who lacks at least one loving and consistent caregiver, whether a parent or attentive child-care provider, may suffer from severe and long-lasting developmental problems. Yet, the nation's policies and practices regarding childcare and early childhood education are often based on little or no evidence that they actually promote children's well-being. The report calls for a Presidential task force to review all public investments in child care and early childhood education, with the goal of making the most of scientific knowledge. The task force would be charged with developing a 10-year plan focused on ways to foster sustained relationships between preschoolers and qualified caregivers; that addresses the special needs of children with developmental disabilities or chronic health conditions; and that ensures all child-care settings are safe, stimulating, and responsive to families' concerns. The report also recommends that the major funding sources for child care and early education should support improvements in qualifications, pay, and benefits of child-care professionals.

. . . the nation's policies and practices regarding childcare and early childhood education are often based on little or no evidence that they actually promote children's well-being. . . .

Encouraging the adoption of healthy behaviors and avoidance of risky ones, requires useful information on specific health issues and clear incentives to change. In culturally and demographically diverse populations, many factors magnify this challenge. For example, cultural differences in the perception of health and disease, differences in health literacy, and differences in social norms, as well as social and system barriers interfere with adoption of recommended behavior changes. In this regard, diversity is not limited to race, ethnicity, gender, or age. Socioeconomic status, education, religious affiliation, sexual preference, health status, and geographic location often exert greater influence over the processes of health communication and behavior change than do the more easily identified characteristics. The upcoming report *Speaking of Health: Assessing Health Communication Strategies for Diverse Populations* (2001) will review recent advances in research on health communication and health behavior change, offer specific examples of public health interventions, and evaluate the characteristics of individuals, social networks, and communities that influence the effectiveness of public health campaigns. Promising strategies will be identified for public health interventions to achieve a sustained change in the behaviors in diverse populations.

Selected Recommendations for Public Health Policy . . .

- **HIV Prevention:** The nation urgently needs a comprehensive, effective, and efficient strategy for prevention of HIV. The organizing principle should be to avert as many new HIV infections as possible within the resources available for HIV prevention. It will be necessary to improve the way the epidemic is monitored, change how prevention resources are allocated and how activities are prioritized and conducted, foster interactions between the public and private sectors to promote new prevention tools and technologies, and reduce or eliminate social barriers to HIV prevention. (*No Time to Lose: Getting More from HIV Prevention*)
- **Food Safety:** Develop a comprehensive food safety plan that includes a unified, science-based food safety mission; integrates federal, state, and local food safety activities; allocates funding in accordance with science-based assessments of risk and benefit; and provides adequate support for research and surveillance. Congress should establish a unified and central framework for managing federal food safety programs, one that is headed by a single official with the responsibility and control of resources for all federal food safety activities. (*Ensuring Safe Food: From Production to Consumption*)
- **Tobacco Policy:** Congress should enact a comprehensive regulatory statute delegating to an appropriate agency the necessary authority to regulate tobacco products, for the dual purpose of discouraging consumption and reducing the morbidity and mortality associated with use of tobacco products. The agency should be authorized to regulate the design and constituents of tobacco products, with the purpose of setting and gradually reducing ceilings on their nicotine content. (*Growing Up Tobacco Free: Preventing Nicotine Addiction in Children and Youths*)
- **Sexually Transmitted Diseases:** Sexually transmitted diseases (STDs) are at epidemic levels in the United States, with tremendous health and economic consequences. Congress and the administration should collaborate to develop and support a national system for STD prevention. Major components of this system will closely parallel an effective strategy for HIV prevention and thus have multiple payoffs. (*The Hidden Epidemic: Confronting Sexually Transmitted Diseases)*
- **Tuberculosis:** The opportunity exists to virtually eliminate tuberculosis in the United States over the next decade through relatively modest investments in prevention efforts. The opportunity should not be lost. IOM recommends a series of actions from fully funding the TB Strategic Plan to increased professional training, and from mandated completion of therapy to vaccine development. (*Ending Neglect: The Elimination of Tuberculosis in the United States*)

* * *

Rediscovery of Public Health

Public health is what we, as a society, do collectively to assure the conditions for people to be healthy. This requires that continuing and emerging threats to the health of the public be successfully countered.

The Future of Public Health, 1988

The boundaries between public health and medicine are again undergoing significant redefinition. The roots of public health are often traced to the case of John Snow, an English physician of the 19th century. During the 1854 cholera epidemic in London, Snow observed that the disease mainly afflicted people who used water from the Broad Street Pump. Snow, who had spent years researching the causes and transmission of cholera, convinced the government to remove the pump handle, thus averting future outbreaks of cholera. Until the early 20th century, public health and medicine were closely intertwined. However, as clinical interventions became more effective, the fields of medicine—focused on the care and treatment of the individual—and public health—focused on populations—diverged. The previous decade has brought a growing realization that individual and population-level interventions must be joined to improve health. We now recognize that each person's health and well-being are shaped by the inter-

. . . each person's health and well-being are shaped by the interaction of genetic endowment, environmental exposures, lifestyle and food choices, income, and medical care.

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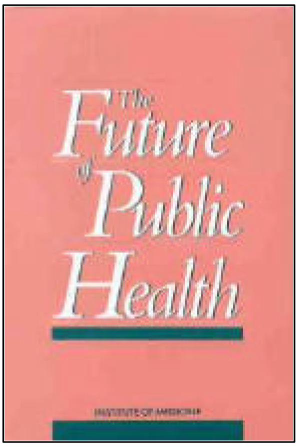


The *Future of Public Health* (1988) documented a public health system in disarray, characterized by inadequate capacity in the field, organizational fragmentation, and disjointed decision-making.

The Institute of Medicine has played a significant role in the rediscovery of population-level health. *The Future of Public Health* (1988) documented a public health system in disarray, characterized by inadequate capacity in the field, organizational fragmentation, and disjointed decision-making. The report was a wake-up call to the nation that an essential set of activities was in a precarious condition. It offered a new vision of public health and presented an action plan to strengthen public health capability throughout the nation. This reinvigorated system—oriented toward disease prevention and health promotion—would engage entire communities for science-based action. While parts of this new public health system have come to fruition, other aspects remain unrealized, and investments in population-level health are still poorly supported in comparison with biomedical research or clinical medicine.

Since the 1988 report, the IOM has continued to play an important role in advancing public health and guiding public policy to support its application. We are beginning a major new study to create an action plan for population-level health in the 21st century.

PROMOTING HEALTH AT THE NATIONAL LEVEL

“Healthy People” is the nation’s game plan for improving the health of the American people. Now in its third decade, Healthy People establishes national goals for improving health and preventing disease and details strategies and interventions to be utilized in reaching those goals. As mentioned above, the Department of Health and Human

A METAPHOR FOR PUBLIC HEALTH

"Public health agencies are a lot like fire departments. They teach and practice prevention at the same time that they maintain readiness to take on emergencies. They are most appreciated when they respond to emergencies. They are most successful—and least noticed—when their prevention measures work the best.

In another respect, the two are different. Everyone knows what a fire department does; few know what a public health department does. The very existence of health departments is testament to the fact that, when legislators, county commissioners, and other policymakers understand what those departments do, they support them. It is a rare person who, once familiar with the day-to-day activities of a public health department, would want to live in a community without a good one."

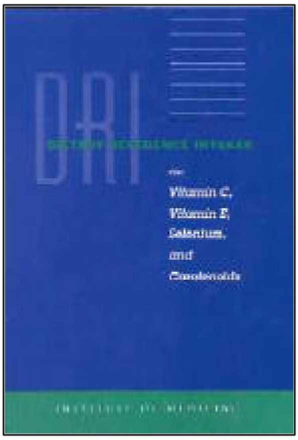
SOURCE: Washington State Department of Health, as quoted in *Healthy Communities: New Partnerships for the Future of Public Health,* 1996; page 40.

Services has called upon the IOM for assistance in developing each decade's plan. In developing *Healthy People 2010,* the Department asked the IOM to recommend leading indicators or core objectives that focus on and monitor the nation's progress in achieving the nation's goals.

At the community level, effective public health—including the realization of Healthy People goals—requires active participation by a host of parties. However, limited guidance has been available to prioritize and assess community efforts. Two IOM reports address this challenge. *Healthy Communities: New Partnerships for the Future of Public Health* (1996) provides a framework for the partnerships between governmental health agencies and managed care organizations—and between public health agencies and communities—that will be necessary to revitalize the nation's public health system. *Improving Health in the Community: A Role for Performance Monitoring* (1997) advises communities on how to develop and use a variety of measurement tools to assess local public health threats and measure progress in reducing them. The report recommends that ac-

At the community level, effective public health . . . requires active participation by a host of parties.

countability for actions to improve public health collaborating be established—not unilaterally assigned. Performance monitoring is the tool that communities can use to hold groups or individuals accountable for meeting their commitments.



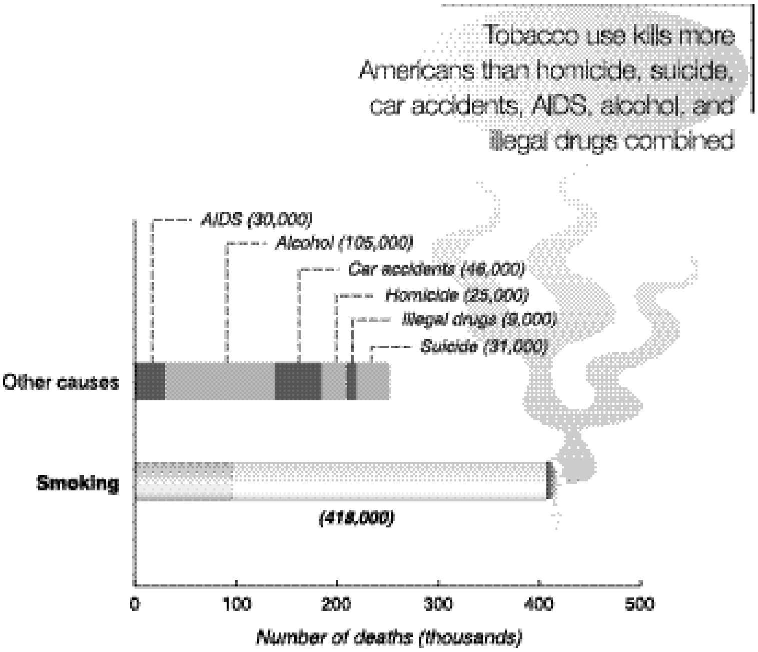
The DRIs will help individuals optimize their health, prevent disease, and avoid consuming too much of a nutrient.

Most Americans know that they should eat more healthful foods—although their success at doing so is uneven. Barriers include school, work, and other environments that do not offer healthful choices, as well as a fast-food industry that supplies tasty, high-calorie foods and thus shapes eating habits. Improved information about food and nutrition can help consumers make better choices. Since 1941, the IOM's Food and Nutrition Board has provided scientifically based information on the role nutrients and other food components play in health, from deficiency to chronic disease. The reports on Recommended Dietary Allowances (RDAs) are important to a variety of users, from individual consumers to government agencies. The U.S. Food and Drug Administration uses the RDAs as the basis for developing "percent daily values"—those numbers that must appear on the labels of everyday food products. The reports are also used to guide food fortification and nutrition assistance programs such as WIC, and for estimating the extent of nutrition-related problems in vulnerable population groups in the United States. Beginning in 1998, the IOM has introduced a series of reports on Dietary Reference Intakes (DRIs), as an expanded approach for providing quantitative estimates of nutrient requirements that expand upon the RDAs. The DRIs will help individuals optimize their health, prevent disease, and avoid consuming too much of a nutrient.

REDUCING PUBLIC HEALTH THREATS

Tobacco

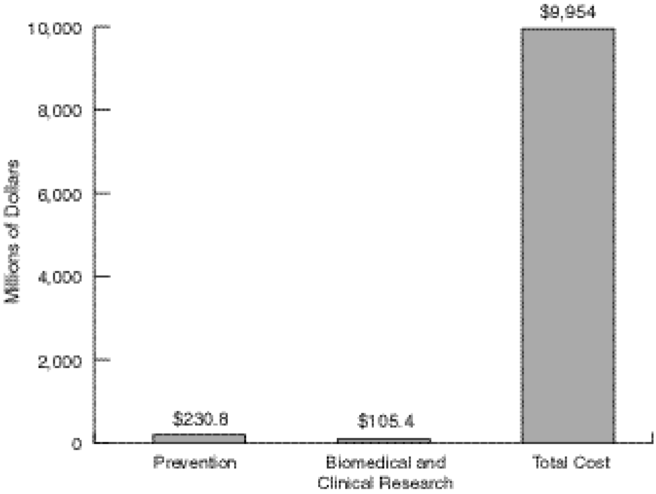
Tobacco is the nation's leading health threat. Several IOM reports have been important in shaping public opinion and national policy



SOURCE: *State Programs Can Reduce Tobacco Use,* 2000; page 2.

regarding efforts to curtail its use. *Growing Up Tobacco Free: Preventing Nicotine Addiction in Children and Youths* (1994) established the elements of a tobacco control policy centered on reducing smoking among young people. The report called on Congress to increase federal excise taxes on tobacco products, and it called for the elimination of all features of advertising and promotion of tobacco products that encourage tobacco use among children and youths. The National Cancer Policy Board built on this foundation. In *Taking Action to Reduce Tobacco Use* (1998) and *State Programs Can Reduce Tobacco Use* (2000), the board called for strengthening federal regulation of the design and composition of tobacco products, conducting research to determine which tobacco control measures are most effective, and eliminating government policies that contribute to increased smoking in other countries. *Clearing the Smoke: Assessing the Science Base for Tobacco Harm Reduction*, to be issued in early 2001, assesses products that claim to reduce the consequences of tobacco use and recommends policies to regulate their marketing and use.

The estimated total costs associated with STDs were more than 43 and 94 times greater than the national public investment in STD prevention and research, respectively, in 1994



Comparison of estimated annual direct and indirect costs for selected STDs and their complications in 1994 versus national public investment in STD prevention and research in federal Fiscal Year 1995. The estimate for investment in STD prevention provided here represents public funding for all interventions—behavioral, curative, or otherwise—that are needed to reduce the spread of infection in a population. SOURCE: *The Hidden Epidemic: Confronting Sexually Transmitted Diseases,* 1997; page 211.

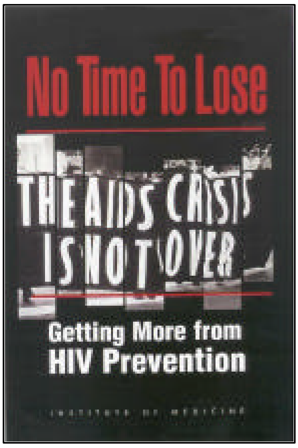
Infectious Disease

The world faces a serious, growing threat from infectious diseases. *Emerging Infections: Microbial Threats to Health in the United States* (1992) attracted attention to this problem and mobilized action in the public and private sectors. The IOM's Forum on Emerging Infections provides a venue for ongoing deliberation regarding these threats. The Forum includes academic researchers, government officials, industry scientists, and consumer representatives. *Antimicrobial Resistance: Issues and Options* (1998) identifies ways for policymakers, health officials, and the pharmaceutical industry to deal with the increasing numbers of disease-causing bacteria that are becoming resistant to drugs. *Public Health Systems and Emerging Infections: Assessing the Capabilities of the Public and Private Sectors* (2000) discusses the core capability of the public health system for infectious disease surveillance, response, prevention, and control. The report considers approaches to communication and collaboration between the scientific and policy-making communities, among professional organizations, and among public health officials and the public.

The United States leads the industrialized world in overall rates of sexually transmitted diseases (STDs), with 12 million new cases annually. About 3 million teenagers contract an STD each year, and many will suffer long-term health problems as a result. In addition, people who have STDs are at increased risk of acquiring and transmitting HIV/AIDS. *The Hidden Epidemic: Confronting Sexually Transmitted Diseases* (1997) challenged the country to recognize the explosive rise in STDs—an increase that was swamping the capacity of the nation's public health system. The unwillingness of the general public and government officials to deal with issues regarding sexuality (e.g., the reluctance to promote condom use or to provide comprehensive sex education for teenagers) is identified as a main contributing factor to the rise in STDs. Issues discussed in the report continue to be prominent, including the key elements of effective, culturally appropriate programs to promote healthy sexual behavior by adolescents and adults.

The United States leads the industrialized world in overall rates of sexually transmitted diseases, with 12 million new cases annually.

The IOM has advised the nation on HIV/AIDS science and policy for more than a decade, starting with our 1986 report *Confronting AIDS: Directions for Public Health, Health Care, and Research.* This and succeeding IOM reports challenged the federal government and the public to recognize the threat posed by HIV, recommended scientifically based policies to reduce new infections, proposed ways to reduce the spread of HIV via blood transfusions, and addressed ways to reduce mother-to-child HIV transmission. Public and private efforts to thwart the spread of HIV have slowed the growth of the epidemic in the United States, but the number of people who become infected each year remains unacceptably high.



Our most recent report, *No Time to Lose: Getting More from HIV Prevention* (2000), recommends a national strategy based on an explicit policy of taking actions necessary to prevent the maximum number of new infections. This strategy would include better tracking of HIV infections, coupled with funding the most cost-effective prevention programs, and could significantly cut the rate of new infections. Prevention efforts must address the epidemic's "new face," as the number of new HIV/AIDS cases among women, minorities, and adolescents has increased dramatically in recent years. Other key needs include making HIV-prevention services for at-risk and infected individuals routine in all clinical and other health-care settings, and abolishing laws and policies that block the use of proven prevention strategies, such as needle exchange programs and comprehensive sex education in schools.

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Bioterrorism

Terrorist attacks, both in the United States and abroad, are of increasing concern. *Chemical and Biological Terrorism: Research and Development to Improve Civilian Medical Response* (1998) assesses the state of the art for detecting potential chemical and biological agents and for protecting both the targets of attack and the health care providers who will be vital in responding to such attacks. The report recommended that every state and major metropolitan area needs a system to ensure that medical facilities, including the state epidemiology office, receive information on actual, suspected, and potential terrorist activity, and called for an improved surveillance infrastructure within the U.S. Centers for Disease Control and Prevention, and state and local government agencies. The report's recommendations are being implemented in approximately 100 cities, and a new study is under way to provide the Department of Health and Human Services with methods to evaluate their effectiveness.

Safe Food

The United States is considered by many to have one of the world's safest food supplies. Yet as many as 81 million illnesses and 9,000 deaths have been attributed each year to food-related hazards. *Ensuring Safe Food: From Production to Consumption* (1998) evaluated the organizational structure and scientific underpinnings of the nation's system for assessing food safety. The conclusion: The system is facing tremendous pressures, with at least 12 federal agencies responsible for various segments. To guide improvement efforts, the report identified five major attributes of an effective food safety system. (1) It should be science-based, with a strong emphasis on risk analysis. (2) It should be grounded on a national food law that is clear, rational, and scientifically based. (3) It should have a unified mission and a single official who is responsible for food safety at the federal level and who has the authority and the resources to implement science-based policy in all federal activities related to food safety. (4) It should be organized to be responsive to and work in true partnership with nonfederal partners. And (5), it must be supported by funding adequate to carry out its major functions and mission—to promote the public's health and safety.

The United States is considered by many to have one of the world's safest food supplies. Yet, as many as 81 million illnesses and 9,000 deaths have been attributed each year to food-related hazards.

Selected Recommendations for Large-Scale Biology

- **National Institutes of Health Research Priorities:** Congress should use its authority to mandate specific programs and entities at NIH only when other approaches have proven inadequate. In turn, NIH should periodically report on the structure of NIH in light of changes in science and the health needs of the public. Congress could adjust the levels of funding for research management and support so that NIH can improve the priority setting process. (*Scientific Opportunities and Public Needs: Improving Priority Setting and Public Input at the National Institutes of Health*)
- **Confidentiality of Health Information:** DHHS, other federal departments, and private organizations should continue or expand educational efforts regarding the protection of the confidentiality of personally identifiable health information in research. Organizations that furnish health services researchers with personally identifiable health information should ensure that the data are prepared in a manner that protects confidentiality. (*Protecting Data Privacy in Health Services Research*)
- **Definition of Special Populations:** NIH should develop and implement across all institutes a uniform definition of "special populations" with cancer. This definition should be flexible, but should be based on disproportionate or insufficiently studied burdens of cancer, as measured by cancer incidence, morbidity, mortality and survival statistics. Emphasis should be on ethnic groups rather than race in surveillance and other population research. This implies a conceptual shift away from the emphasis on fundamental biological differences among "racial" groups to an appreciation of the range of cultural and behavioral attitudes, and lifestyle patterns that may affect cancer risk. (*The Unequal Burden of Cancer: An Assessment of NIH Research and Programs for Ethnic Minorities and the Medically Underserved*)
- **Clinical Trials:** NIH and other federal agencies (particularly HCFA) should continue to coordinate to address funding for clinical trials, particularly to address the additional diagnostic costs associated with prevention trails and third-party payment barriers associated with clinical trials. (*The Unequal Burden of Cancer*)
- **Marijuana and Medicine:** Clinical trials of cannabinoid drugs for symptom management should be conducted to develop rapid-onset, reliable, and safe delivery systems. (*Marijuana and Medicine: Assessing the Science Base*)
- **Rehabilitation Research:** Rehabilitation science and engineering should receive greater financial support, and should serve as the basis for developing new opportunities in multidisciplinary research and education related to disability. (*Enabling America: Assessing the Role of Rehabilitation Science and Engineering*)

Large-Scale Biology

It is important that we, as a society, continue to have access to such [health services] research in order to inform policy making in both private and governmental arenas. At the same time, it is important that we, as a society, protect the privacy of individuals and of vulnerable groups, and the confidentiality of information that patients share with health care providers.

Protecting Data Privacy in Health Services Research, 2000

Mapping the human genome, the cell's complete set of genetic instructions that guides each person's basic life processes, will revolutionize disease diagnosis and treatment. At the same time, the convergence of genomics, structural biology, and informatics, coupled with related changes in the research environment, is transforming biomedical research and public health. The scale, complexity, and costs of research are simultaneously increasing. There are other challenges as well. In virtually every scientific area, privately funded research and development is increasing as fast as publicly funded research. These trends create a series of problems in managing a public–private interface that does not yet have a well-articulated set of rules to match the new science. Problems involving conflict of interest, control of the research agenda, and the free flow of information are increasingly important. Predictably, science is developing much faster than the ethical and legal structures to guide its application.

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Clinical research, a multifaceted area that focuses on assessing potential health improvements and moving them into everyday use, is under particular pressure. Stress on the existing systems for regulating, financing, and managing clinical research is growing. The explosion in privately funded clinical research has introduced complex issues of conflict of interest regarding investigators who also have a financial stake in their projects. Public trust and confidence in clinical research has eroded, complicating the challenges of holding clinical trials and finding sufficient subjects to participate in them. The framework of regulatory controls and ethical guidelines covering clinical research must be updated to more adequately protect patient interests and to rebuild public trust.

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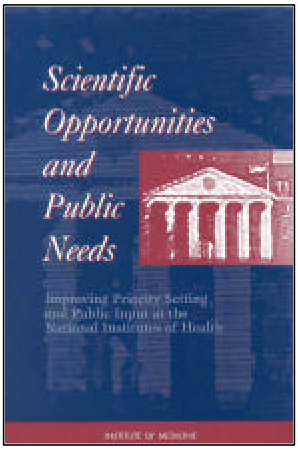
The Institute of Medicine conducts numerous studies at the interface where “big biology” meets public policy and clinical applications.

CHALLENGES IN RESEARCH

A number of IOM reports and other activities address important policy issues in research management and neglected areas of scientific opportunity.

Setting Priorities for Biomedical Research in the Public Sector

The federal government is the single largest sponsor of medical research in the United States, principally through the National Institutes of Health (NIH). Understandably, both the constituencies concerned with specific diseases and those focused on particular fields of research want to ensure that their interests are given fair consideration in establishing funding priorities. In the mid-1990s, concerns about the allocation of NIH research funds came to a head, with extensive debate about congressional earmarking of funds for particular diseases, about NIH's ability to properly balance the social burden of disease with scientific and technical opportunity, and about the adequacy and fairness of public input into the appropriations process and NIH's allocation processes. *Scientific Opportunities and Public Needs: Improving Priority Setting and Public Input at the National Institutes of Health* (1998) recommended criteria for funding allocation, the internal NIH decision-making process, and mechanisms for public participation in that process. A single theme ran throughout the recommendations: that NIH should revamp its approach to public participation and outreach, at every level and without delay. In publicly funded research, openness is as important to the process as such other valued qualities as expertise, innovation, and objectivity. NIH has fully implemented the report's recommendations, one of which was to establish a Director's Council of Public Relations—an advisory group made up of citizens who are patients, family members of patients, or advocates of patients—that meets regularly and facilitates interactions between NIH and the general public.



Addressing the Crisis in Clinical Research

Translating the flood of new discoveries in basic research into effective treatment requires a robust clinical research system. Clinical research is the funnel through which basic research must travel on its way into clinical application. Increasingly, the funnel threatens to become a bottleneck. Among the other forces at work, reimbursement changes by managed care and federal insurance programs have significantly reduced funds available to conduct clinical research. At the same time, the costs of conducting clinical trails in emerging fields, such as genomics, are much higher and entail complex ethical issues that add to their difficulty. In this era of

Clinical research is the funnel through which basic research must travel on its way into clinical application. Increasingly, the funnel threatens to become a bottleneck.

PRIVACY DEFINITIONS

- **Informational privacy:** The right of individuals to control access to, and the use of, information about themselves.
- **Data privacy:** Informational privacy, especially when the information in question is stored in a database.
- **Health information privacy:** Informational privacy, especially when the information in question pertains to the health or medical condition of the individual in question.
- **Confidentiality:** The manner of treating private information, which has been disclosed by the individual subject of the information to a particular person or persons for a specific purpose, such that further disclosure of the information will not be allowed to occur without authorization.

SOURCE: *Protecting Data Privacy in Health Services Research,* 2000; page 23.

remarkable scientific opportunity, fewer young physicians are electing to train for clinical research.

At the request of the leading scientific and professional organizations concerned with clinical research, the IOM has established a Clinical Research Roundtable that meets quarterly to discuss these and other challenges facing clinical research. The Roundtable explores ways to create a more hospitable environment for the conduct of high-quality clinical research. It does so by serving as a forum for leaders from the academic health community, federal agencies, private organizations that sponsor clinical research, health plans and insurance companies, corporate purchasers of health care, foundations, and patient advocacy groups to explore approaches for resolving both acute and long-term issues affecting clinical research. Specific topics addressed thus far include health and professional education and training and public confidence and participation.

Addressing Concerns About Privacy and the Protection of Human Subjects

While anxious to receive the benefits of medical breakthroughs, the public is increasingly uneasy about a range of issues touching upon medical records privacy and the adequacy of protections for human subjects in research. Protecting the privacy of personal health information while enabling improvements in clinical care and research has been intensely debated and is still far from resolved. There is no comprehensive federal statute protecting the privacy of health-related information. Limited federal and state statutes and regulations protect certain types of information under specific circumstances. Finding approaches that can adequately protect privacy without crippling legitimate research and public health practice will be one of the most important policy issues of the next few years. *Protecting Data Privacy in Health Services Research* (2000) examines the procedures followed by Institutional Review Boards (IRBs) and identifies those practices and principles that best protect the privacy, confidentiality, and security of personally identifiable health information.

There is no comprehensive federal statute protecting the privacy of health-related information.

Institutional Review Boards are at the heart of the current system for protection of human research subjects. Each institution that conducts research has its own IRB (or group of IRBs) that reviews protocols proposing clinical research and determines whether the risks to human subjects are reasonable in the light of expected benefits to the subjects and the knowledge to be gained. Consensus is strong that the IRBs as currently constituted are ill equipped to perform their mission. The IOM is conducting a two-phase study of the framework for protecting the interests of those involved in research. Phase I is a fast-track study (release expected in April 2001) that will provide recommendations for accreditation standards to regulate the performance of IRBs. The second phase of the study will examine the entire role of IRBs and consider alternative means of protecting human subjects in research.

Identifying Research Opportunities

The IOM is occasionally asked to look intensely at a specific field of research and to offer recommendations to guide grants and other investments. A report requested by the NIH, *Lesbian Health: Current*

Assessment and Directions for the Future (1999), provided research recommendations for the NIH Office of Women's Health. *Multiple Sclerosis: Current Status and Strategies for the Future* (2000) provides an agenda for basic and clinical research to accelerate scientific discovery and improve clinical treatment of this disease. Sponsored by the National Multiple Sclerosis Society, the report offers a strategic vision for research and training, suggesting ways to engage scientific fields that may not previously have focused on the disease.

Also of increasing importance in the design and conduct of basic, applied, and clinical research is understanding the biological basis of sex and gender differences and their determinants. Research in these areas is of particular interest due to a renewed focus on women's health issues and to the historical lack of research on conditions that are more prevalent in women or that manifest themselves differently in males and females. To further advance the field, the IOM is reviewing the current state of knowledge pertaining to the science base of sex and gender differences and determinants. The report, authored by the Committee on Understanding the Biology of Sex and Gender Differences, will make recommendations on how to facilitate scientific endeavors, take advantage of new opportunities in basic and applied research, and fill identified research gaps to improve the understanding of sex and gender differences and determinants.

VACCINES AND IMMUNIZATION

Immunization represents one of the world's primary public health and medical triumphs. However, several advocacy organizations in the United States have raised concerns about the possibility that some vaccines can cause adverse long-term health consequences, especially on the immune system and the central nervous system, and have pushed for a halt to mandated vaccinations during childhood. Since the mid-1970s, the IOM has addressed a variety of issues regarding immunization, with several reports focused specifically on vaccine safety. Their conclusion: There is little evidence

Immunization represents one of the world's primary public health and medical triumphs.

linking vaccines to many of the purported untoward health events. However, public concern remains high, and media coverage of suspected adverse events has resulted in growing numbers of individuals who refuse vaccination. As the biotechnology revolution develops a new generation of vaccines, public confidence in the safety of these products cannot be assumed.

The IOM plays an important role in providing objective scientific advice about the safety and efficacy of vaccines. Our Immunization Safety Review Project meets quarterly to assess emerging information and to recommend appropriate responses including research regarding putative adverse events involving vaccines. We also study vaccine development, as many diseases, even cancer, may be promising targets for immunization. *Vaccines for the 21st Century: A Tool for Decisionmaking* (2000) provides an analytic framework and quantitative model for comparing potential new vaccines. The report outlines a cost-effectiveness approach for assessing vaccine candidates on the basis of their anticipated impact on morbidity and mortality, as well as on their anticipated costs in terms of development, use, and related health care requirements. Such analysis can help clarify trade-offs in decisions to invest in the development of one vaccine as compared to another, thus simplifying a complicated picture in which vastly different forms of illness and health benefits must be balanced against a variety of costs. The results of such comparisons, of course, will have to be incorporated with other value judgments in targeting particular vaccines for development.

Selected Recommendations Related to Military Personnel and Veterans . . .

- **Health of Deployed Forces:** The Department of Defense should include immunization data, ambulatory care data, and exposure data with immediate medical implications in the individual medical records, and link those records to other information about deployment exposures. Implement a joint system for recording and retrieving information on the locations of service members units during operations. (*Protecting Those Who Serve: Strategies to Protect the Health of Deployed U.S. Forces*)

  DoD should clarify the leadership authority and accountability for coordination of preventive medicine and environmental and health surveillance. The efforts of environmental surveillance, preventive medicine, clinical, and information technology personnel should be integrated. (*Strategies to Protect the Health of Deployed U.S. Forces: Medical Surveillance, Record Keeping, and Risk Reduction*)

  DoD should implement, as quickly as possible, a deployment disease and non-battle injury surveillance system. A lifetime computer-based patient record for service members should be a high priority for development. (*Protecting Those Who Serve*)

- **Military Deployment Research:** Establish a National Center for Military Deployment Health Research that will focus on the health of active, reserve, and guard forces, and veterans and their families. (*National Center for Military Deployment Health Research*)

- **Radiation Exposure in Military Operations:** Whenever possible, soldiers should be accorded the same level of protection as civilians. Military personnel should receive appropriate training in both radiation effects and protection. A program of measurement, recording, maintenance, and use of dosimetry and exposure information is essential. (*Potential Radiation Exposure in Military Operations: Protecting the Soldier Before, During, and After*)

- **VA Formulary:** VA should examine drugs newly approved by FDA in a timely manner. Drugs providing significant improvement in treatment options should be given priority review and serious consideration for the National Formulary. (*Description and Analysis of the VA National Formulary*)

- **Gulf War and Health:** Further research is needed on the long-term health effects of biological and chemical agents including depleted uranium, sarin, pyridostigmine brominde and anthrax and botulinum toxoid vaccines. (*Gulf War and Health: Volume1. Depleted Uranium, Pyridostigmine Bromide, Sarin, and Vaccines*)

Military Personnel and Veterans

If the work that we have done here serves to assist in resuscitating even one casualty that would have otherwise been lost, as we believe it will, then this will have been a successful and worthwhile endeavor.

David E. Longnecker, Chair, IOM Committee on
Fluid Resuscitation: State of the Science for Treating
Combat Casualties and Civilian Injuries

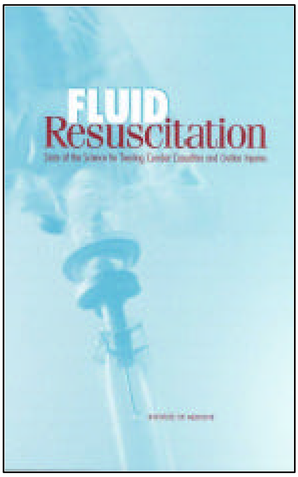
The nation's armed services face complex challenges in assuring the health of military personnel, whether on routine assignments or when deployed in combat or in other remote, extreme situations. The military also faces challenges in protecting and promoting the health of the families of active-duty personnel, whether posted with the service members or remaining in the United States, and in providing health services to military retirees and their families.

In modern warfare, troops are exposed to a variety of conditions and toxic agents that may have long-term health effects not discernable before discharge, hence difficult to establish as causally related to military experiences.

The Institute of Medicine conducts a wide range of studies to advise the Department of Defense (DoD) on how to maintain optimum health status of active-duty personnel, retirees, and their families. We also are very active in addressing issues relating to the health of veterans. In modern warfare, troops are exposed to a variety of conditions and toxic agents that may have long-term health effects not discernable before discharge, hence difficult to establish as causally related to military experiences. The Congress and many veterans groups rely on the IOM to provide objective analyses of health effects associated with military deployments. The deployments may be as recent as the Persian Gulf conflict, or as long ago as World War II.

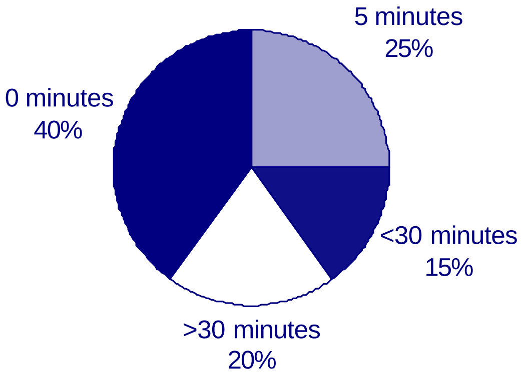
PROMOTING HEALTH AND REDUCING THE RISK OF DISEASE

One of history's greatest generals, Napoleon Bonaparte, observed that "an army marches on its stomach." Good nutrition is as important in readiness today as it was in 1812. Since World War II, the DoD has relied on our Food and Nutrition Board (FNB) for advice on military nutrition. Studies conducted by the FNB's Committee on Military Nutrition Research have answered such questions as how to make meals-ready-to-eat (MREs) more palatable and nutritious, and what healthy body weights, or "body compositional standards," are best suited to the various physical performance expectations for active duty personnel. Because body weight is a serious problem for the military, we are also developing criteria for weight management programs designed specifically for service members. In addition we have made recommendations related to standards for female service members during pregnancy and lactation.



PROTECTING AND TREATING COMBAT TROOPS

The U.S. military has long emphasized troop safety as a top priority, as is evident in military strategy and tactics, and in the development of sophisticated technology to decrease risk to personnel. The commitment also is evident in DoD-sponsored research. One of the most important safety goals involves the immediate resuscitation of wounded soldiers in the field, to improve their survival during transport to a field hospital for advanced treatment. *Fluid Resuscitation: State of the Science for Treating Combat Casualties and Civilian Injuries* (1999)



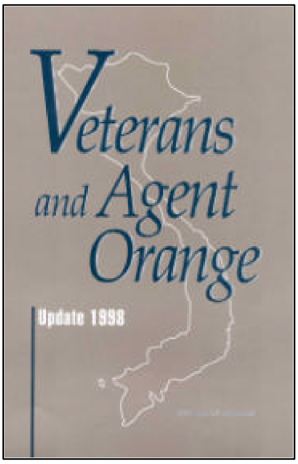
Time from injury to death of battlefield casualties. The single major cause of death in potentially salvageable battlefield casualties is massive bleeding. It is reasonable to expect that with immediate, appropriate care, a significant number of these patients could be saved. SOURCE: *Fluid Resuscitation: State of the Science for Treating Combat Casualties and Civilian Injuries,* 1999; page 11.

recommends an entirely new approach to addressing the leading cause of death in potentially salvageable battlefield casualties—hemorrhage. The report identifies which of today's technologies are best suited for acute treatment of massive blood loss on the battlefield, provides direction for longer-term research that might lead to advances in the knowledge about hemorrhagic shock and care for combat casualties, and offers suggestions for technologies or approaches that would apply to civilian emergency trauma care as well. Other studies have provided advice on such subjects as maintaining cognitive performance during extended combat operations and in extreme, high-altitude environments.

One of the most important safety goals involves the immediate resuscitation of wounded soldiers in the field, to improve their survival during transport to a field hospital for advanced treatment.

DEPLOYMENT-RELATED HEALTH EFFECTS

Many veterans and their families attribute varied chronic and life-threatening diseases to the effects of service in specific theaters of war or presence at weapons test sites. The IOM conducts studies to assess evidence of short-term and long-term health effects that may support or disprove these connections. A number of reports have focused on Agent Orange and other herbicides (including their contaminants, notably dioxin) used during the Vietnam War. *Veterans and Agent Orange: Health Effects of Herbicides Used in Vietnam* (1994) provided



the first comprehensive, unbiased review of the scientific evidence regarding a link between herbicide exposure and such adverse health effects as cancer, reproductive problems, and neurological disorders. This study, and updates in 1996, 1998, and 2000, provides the scientific basis upon which the Department of Veterans Affairs (VA) awards disability compensation to Vietnam veterans. The reports also recommend research that could provide more definitive conclusions about potential health effects.

Almost 700,000 U.S. troops participated in the war in the Persian Gulf, including a large number of reserve units. Most returned home within a few months and resumed their normal activities. Within a relatively short time, a number of reservists and active duty personnel began to report health problems they believed to be connected to their deployment. *Gulf War Veterans: Measuring Health* (1999) concludes that no single diagnosable illness or set of symptoms with a known etiology characterizes either Gulf War veterans in general or a subset of veterans who are experiencing some kind of health problem. Yet, there does seem to be a higher prevalence of some symptoms—such as fatigue, memory loss, headache, and muscle and joint pain—among Gulf War veterans than among nondeployed veterans. Major uncertainties remain, however, and the report recommends that the federal government sponsor a range of research activities, including population studies, health services research, and clinical and biomedical investigations, to address fundamental questions about the health of Gulf War veterans. IOM committees are now studying the potential health effects of up to 33 toxic agents that Gulf War veterans may have encountered during their service. As in the case of Agent Orange, the VA will rely upon our reports to determine disability compensation for these veterans.

. . . no single diagnosable illness or set of symptoms with a known etiology characterizes either Gulf War veterans in general or a subset of veterans who are experiencing some kind of health problem.

Stressors of the Persian Gulf War

Chemical	Environmental	Combat Related
Oil fire smoke	Sand	Rapid mobilization leading to unexpected disruption of lives, particularly for Reserve and Guard units
Diesel and jet fuel	Fleas and other insects	Waiting for combat to begin
Solvents and other petrochemicals	Extreme heat	Potential cumulative effect of repeated deployments to conflict
Insect repellents	Relatively primitive living conditions	Rapid demobilization, particularly for Reserve and Guard units
CARC paint	Unfamiliar character of region	SCUD missile attacks
Depleted uranium	Prohibition against interaction with indigenous population	Multiple chemical alarms
Anthrax and botulinum vaccines	Exposure to dead and mutilated bodies	
Pyridostigmine bromide pills	Exposure to dead animals	

SOURCE: *Gulf War Veterans: Measuring Health,* 1999; page 13.

IOM committees are now studying the potential health effects of up to 33 toxic agents that Gulf War veterans may have encountered during their service.

The Agent Orange and Gulf War studies, along with others examining the health effects of radiation exposures during 1950s atomic tests, highlighted the absence of reliable information about the exact location of individuals during deployments, their exposure levels to various dangerous substances, and other factors necessary to adequately assess potential harm. Discussion of these issues with the DoD resulted in a request by the Department for comprehensive recommendations about how to better protect deployed forces in future combat or peacekeeping operations. *Strategies to Protect the Health of Deployed U.S. Forces: Medical Surveillance, Record Keeping, and Risk Reduction* (1999) recommends urgent action to improve procedures for recording health problems experienced by military personnel in the field, documenting troop locations during deployments, and communicating with military commanders about environmental and medical hazards that may exist in war zones. While achieving the mission of a military operation always will be the paramount objective, soldiers must know that their health and well-being are taken seriously. Failure to incorporate improved procedures may erode the traditional trust between the service member and the military leadership, impair morale, and accelerate early departures from the services.

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Many people within and beyond the military have begun to ask whether there are health consequences of service in military conflicts beyond the obvious war injuries and, if so, whether there are ways to prevent or at least mitigate the consequences of war-related illnesses and deployment-related health effects. Investigations of the health of Gulf War veterans have generated information suggesting that such problems may be experienced by some veterans of all military conflicts. In response to this emerging information, Congress asked the IOM to advise the VA on creating a national facility devoted to war-related illnesses and postdeployment health issues. *National Center for Military Deployment Health Research* (1999) makes recommendations to help the VA in developing the center, which will be responsible for compiling the comprehensive knowledge base necessary for moving the nation forward in protecting all individuals who will participate in future military deployments.

Selected Recommendations for Global Health . . .

- **Global Health:** The U.S. Government should form an Interagency Task Force on Global Health to anticipate and address global health needs and to take advantage of opportunities in a coordinated and strategic fashion. (*America's Vital Interest in Global Health: Protecting Our People, Enhancing Our Economy, and Advancing Our International Interests*)
- **Infectious Disease Surveillance:** The U.S. Government, along with the private sector, should facilitate the development of an effective global system for surveillance of infectious diseases. Along with that, the capacity of developing countries in biomedical surveillance and communications should be fostered. The international infectious disease surveillance activities of the U.S. government should be coordinated by the Centers for Disease Control and Prevention (CDC). CDC should continue leading the development of strategies that strengthen state and federal efforts in surveillance. (*Emerging Infections: Microbial Threats to Health in the United States*)
- **Infectious Disease Research and Training:** National Institutes of Health-supported research on the agent, host, vector, and environmental factors that lead to the emergence of infectious diseases should be expanded and coordinated. Department of Defense infectious disease laboratories should continue to be supported. (*Emerging Infections: Microbial Threats to Health in the United States*)
- **Tuberculosis Control:** The United States should expand and strengthen its role in global tuberculosis control efforts, contributing through bilateral and multilateral international efforts. (*Ending Neglect: The Elimination of Tuberculosis in the United States*)

Global Health

Health, like education, is an investment in human capital, and targeted health investments can help to break cycles of poverty and political instability around the world and contribute to national and global economic development.

America's Vital Interest in Global Health (1997)

Health and disease are universal human concerns. The health of all people is profoundly affected by scientific, technical, economic, social, educational, and behavioral factors that are changing at an unprecedented rate as the world economy becomes increasingly interconnected. Globalization has brought benefits to people in many countries, but it has also created risks that cannot be addressed within traditional national borders. More than 2 million people each day move across national borders, and the growth of international commerce inevitably leads to an increased transfer of health risks. Obvious examples of these risks include infectious diseases, contaminated foodstuffs, pollutants and toxic wastes, and useful but potentially dangerous commercial products such as pesticides.

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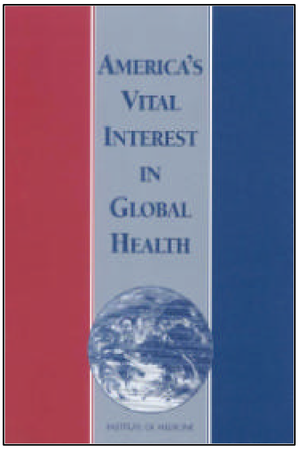
For the United States, distinctions between domestic and international health problems are losing their usefulness and can be misleading. Indeed, the direct interests of the American people are best served when the nation acts decisively to promote health around the world.

The Institute of Medicine produces reports that provide a scientific basis for improving health globally as well as nationally. To ensure that our reports reflect the requisite international perspective and expertise, scientists, policymakers, and other distinguished individuals from foreign countries—both developed and developing—frequently serve on our study committees.

AMERICA'S INTEREST IN GLOBAL HEALTH



Worldwide, there is a growing demand for access to new interventions to diagnose and treat disease, as well as for access to effective ways to prevent disease and promote good health. The knowledge base required to meet these needs is not only technical, derived from experiments of researchers, but also draws from the experiences of governments in allocating resources effectively and efficiently to improve human health. *America's Vital Interest in Global Health: Protecting Our People, Enhancing Our Economy, and Advancing Our International Interests* (1997) was instrumental in demonstrating that the nation will best fulfill its responsibility for protecting Americans' health, enhancing U.S. economic interests, and projecting U.S. influence internationally by exerting leadership in global health. Of critical importance, the United States should lead from its strengths in medical science and technology. The report calls on the federal government to establish an Interagency Task Force on Global Health to address health needs and opportunities. The various U.S. agencies with statutory responsibilities in this area will need to act in a coordinated fashion, and the federal government will need to form partnerships with the nation's

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The 10 Major Causes of Death in Developed and Developing Countries—1990

Cause of Death	Deaths (thousands)		
	Developed	Developing	World
Cardiovascular disorders	5,245	9,082	14,327
Infectious and parasitic diseases	163	9,166	9,329
Malignant neoplasms	2,413	3,611	6,024
Respiratory infections	389	3,992	4,380
Unintentional injuries	552	2,682	3,233
Respiratory disorders	500	2,435	2,935
Perinatal disorders	82	2,361	2,443
Digestive disorders	424	1,426	1,851
Intentional injuries	282	1,569	1,851
Genitourinary disorders	167	568	735

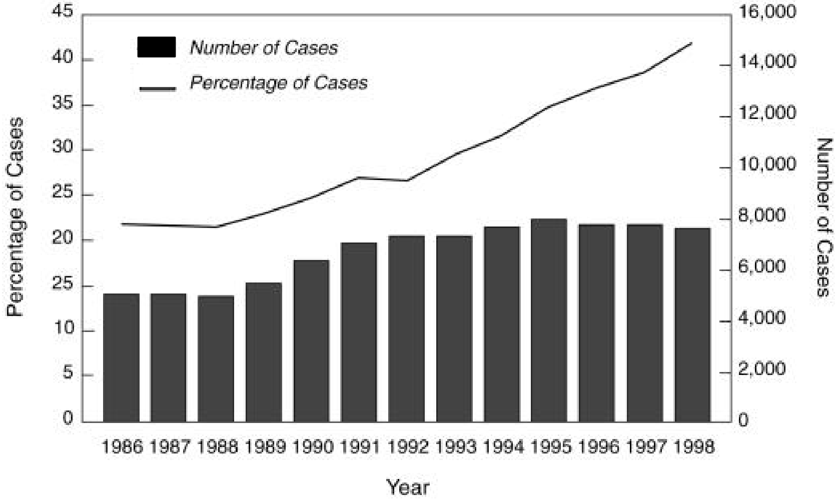
SOURCE: *Control of Cardiovascular Diseases in Developing Countries: Research, Development, and Institutional Strengthening,* 1998; page 18.

academic community, industrial sectors, and nongovernmental organizations, as well as with other nations and international organizations, to most effectively advance human health around the world.

THREATS FROM EMERGING INFECTIONS

The spread of HIV, the emergence of new diseases, and the resurgence of diseases once thought to be under control are together causing almost half of all deaths worldwide among people under the age of 45. The result is a humanitarian crisis with broad social and economic implications. *Emerging Infections: Microbial Threats to Health in the United States* (1992) points to major challenges for the public health and

The spread of HIV, the emergence of new diseases, and the resurgence of diseases once thought to be under control are together causing almost half of all deaths worldwide among people under the age of 45.



Trends in tuberculosis cases among foreign-born people in the United States (the 50 states, the District of Columbia, and New York City), 1986–1998. SOURCE: *Ending Neglect: The Elimination of Tuberculosis in the United States,* 2000; page 36.

medical care communities in detecting and managing infectious disease outbreaks and monitoring the prevalence of endemic diseases. The report promotes early prevention as a cost-effective and crucial strategy for maintaining public health in the United States and worldwide, and it presents an action plan for enhancing surveillance systems, fostering vaccine and drug development, improving methods for controlling the organisms that spread disease, promoting public education aimed at behavioral change, expanding research and training, and strengthening the U.S. public health system.

We have a new study under way to review these issues and present a comprehensive 10-year plan for addressing the continued threat of emerging infections. Our Forum on Emerging Infections also provides an ongoing venue, in a neutral setting, for discussion among scientists and policymakers in government, industry, and academia on problems in prevention, detection, management, and research on infectious diseases. Forum workshops focus on such issues as directions for research to better understand and prevent emerging infections, education and training needs for the medical and public health communities, and opportunities for strengthening partnerships between the public and private sectors.

Tuberculosis (TB) is the leading infectious cause of death worldwide—even though the disease is both preventable and, in most cases, treatable. In the United States, recent years have seen a resurgence in TB, which in the mid-1960s had been under fairly tight control. Particularly troubling has been the appearance of cases of multidrug-resistant tuberculosis, which is difficult and costly to treat, at best, and often proves fatal. *Ending Neglect: The Elimination of Tuberculosis in the United States* (2000) demonstrates that promoting global tuberculosis control not only will help improve the well-being of millions of people around the world, but also is strongly in the U.S. national interest. The proportion of foreign-born patients with tuberculosis in the United States has been steadily increasing—in 1988, 41 percent of all TB patients were foreign-born. As a blueprint for eliminating TB in the United States, the report details a number of intertwined steps that involve all levels of government, international agencies, as well as the private sector. Underlying these steps, there must be a concerted effort to build and sustain the public and political support necessary to ensure that sufficient resources are made available for what must be a long-lasting effort. As the number of TB cases declines, such "social mobilization" by countless groups and individuals may be all that prevents a shift of attention and resources to other perceived needs—and thus all that prevents the onset of yet another period of neglect.

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Smallpox was one of the most deadly diseases the world has ever known, and its elimination in the late 20th century represents a public health triumph. Its elimination also left a question: What should be done with the two known stocks—one in the United States and the other in Russia—of variola virus, which causes the disease? In 1986, the World Health Organization (WHO) proposed that the two remaining stocks of variola be destroyed in June 1999. In *Assessment of*

Criteria for Setting Research Priorities for Cardiovascular Diseases in Developing Countries

There are four criteria to be used in setting priorities for investing in CVD R&D in developing countries:

1. Investments should have a large-scale impact on populations that include men and women, all socioeconomic groups, and various regions of a country. Incremental implementation may be necessary in many countries.
2. Investments in a country should involve methods and processes (but not necessarily results) that are broadly transferable to other low- and middle-income countries.
3. Investments should yield results within a time frame of 5–10 years, although evaluation may be desirable over a longer term.
4. Investments should focus on measurable data that use, for the most part, established epidemiologic, health policy, economic, and social behavioral methodologies.

SOURCE: *Control of Cardiovascular Diseases in Developing Countries: Research, Development, and Institutional Strengthening,* 1998; page 45.

the Future Scientific Needs for Live Variola Virus (1999), an IOM committee concludes that there are important scientific reasons—such as aiding in vaccine development and studies of the human immune system—for maintaining small quantities of the virus and that the most compelling need for long-term retention is to protect against a reemergence of smallpox due to accidental or intentional release of the virus.

HEALTH IN DEVELOPING COUNTRIES

Cardiovascular diseases (CVDs) have reached epidemic proportions in developing countries. Of the 52 million deaths reported worldwide in 1990, 15 million were from CVDs. Moreover, their incidence is increasing—CVDs are projected to become the developing world's leading cause of death over the next decade. Contributing to the problem is the fact

Cardiovascular diseases have reached epidemic proportions in developing countries.

that some of the interventions that have reduced CVD mortality in developed countries are not practical or available in the developing world. *Control of Cardiovascular Diseases in Developing Countries: Research, Development, and Institutional Strengthening* (1998) recommends strategies to reduce the CVD burden in these locations, along with research to monitor these efforts and develop new strategies as needed. Of key importance, U.S. government agencies and other organizations, both public and private, need to work with their counterparts in developing countries in implementing programs to reduce the prevalence of CVD risk factors, such as tobacco use, high blood pressure, and dietary intakes high in fat, salt, and sugar.

Micronutrient malnutrition affects approximately 2 billion people worldwide. People who consume too little iron, vitamin A, iodine, and other micronutrients can suffer a variety of profound effects, including premature death, blindness, stunted growth, mental retardation, learning disabilities, generally poor health, and low work capacity. *Prevention of Micronutrient Deficiencies: Tools for Policymakers and Public Health Workers* (1998) provides a conceptual framework for policymakers and public health workers to improve prevention programs globally. The report serves as a guide for international and national funding in the tailoring of programs that use multiple strategies—such as nutrient supplementation and fortification, food-based approaches, and public health measures—to ensure that people in all countries consume healthful diets.

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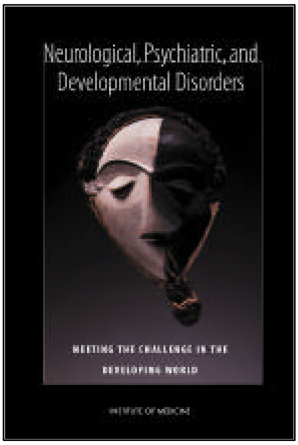
Brain disorders affect at least 250 million people in the developing world, and this number is expected to increase as more people live to old age. These disorders affect the highest human faculties and, left untreated, can destroy a person's dignity, productivity, and autonomy. Yet, public and private health systems in developing countries have paid scant attention to brain disorders, concentrating instead on the major communicable diseases. *Neurological, Psychiatric, and De-*



velopmental Disorders: Meeting the Challenge in the Developing World (2001) presents a comprehensive plan for reducing the toll exacted by these disorders. The report focuses on six representative disorders that are prevalent in developing countries: developmental disabilities, epilepsy, schizophrenia, bipolar disorder, depression, and stroke. The good news is that there are effective and affordable ways to treat or even prevent many forms of these brain disorders—approaches that have proved their value in the industrialized world. The report highlights strategies and interventions to be considered by local, national, and international policymakers in bringing these successes to more and more people in the developing world.

INTERNATIONAL ASSISTANCE

The United States has close ties with six island jurisdictions in the Pacific Basin, and the health and well-being of their citizens is of considerable American interest. The U.S.-Associated Pacific Basin consists of three U.S. flag territories (American Samoa, Commonwealth of the Northern Mariana Islands, and Guam) and three independent countries that are freely associated with the United States (Federated States of Micronesia, Republic of the Marshall Islands, and Republic of Palau). Most health indicators for the islanders are worse than those for mainland Americans. The jurisdictions' health systems must deal with conditions normally seen in both developing countries (malnutrition, tuberculosis, dengue fever, and cholera) and developed countries (diabetes, heart disease, and cancer). Each year, the United States provides approximately $70 million in funding for health care in the region. Several U.S. health agencies, wanting to improve health conditions in the islands, asked for our help in assessing the health needs of the region. *Pacific Partnerships for Health: Charting a New Course* (1998) examines the strengths and

The United States has close ties with six island jurisdictions in the Pacific Basin, and the health and well-being of their citizens is of considerable American interest. Most health indicators for the islanders are worse than those for mainland Americans.

weaknesses of the region's health-related systems and details a strategic plan for improving the islanders' health. The plan has four components: adopting and supporting a system of community-based primary care and preventive services, improving coordination within and between the jurisdictions and the United States, increasing community involvement and investment in health care, and promoting the education and training of the local health care workforces.

Robert Wood Johnson Health Policy Fellowships Program

The Robert Wood Johnson Health Policy Fellowships Program is designed to develop the capacity of outstanding mid-career health professionals in academic and community-based settings to assume leadership roles in health policy and management. This career development program provides an opportunity to gain an understanding of the health policy process and to contribute to the formulation of new policies and programs. The program, initiated in 1973, is funded by The Robert Wood Johnson Foundation and managed by IOM. Six Fellows participate each year in a year-long program of orientation and full-time work experience in Washington, D.C. Fellows are selected from: (1) academic faculties in medicine, dentistry, the biomedical sciences, nursing, public health, health services administration, the allied health professions, economics, and other social sciences; and (2) related organized, community-based providers, and institutions in the health care system, such as health maintenance organizations.

The September-to-August program begins with an 8-week orientation period arranged by the IOM. Fellows meet with key White

House advisers, including officials of the Office of Management and Budget; top administrators of agencies responsible for health activities; congressional committee staff members; and representatives of health interest groups. Also included in this period are seminars on health economics, the congressional budget process, and the politics and process of federal decision-making.

In subsequent weeks the Health Policy Fellows join with the American Political Science Association Congressional Fellows for sessions with senators, representatives, and other experts on the national political and governmental process. During this period, Fellows contact congressional offices that have an active interest in health issues and, in consultation with the program director, negotiate their working assignments. Assignments in the executive branch are also possible.

The work assignments begin in December and end in August. During these assignments, Fellows help develop legislative proposals, arrange hearings, brief legislators for committee sessions and floor debates, and participate with staff in House and Senate conferences. They take part in all areas of the policy process, not as onlookers, but as working participants.

For more information, visit the program's website at www.iom.edu/rwj.

Senior Nurse Scholar Program

The Institute of Medicine, in collaboration with the American Academy of Nursing (AAN) and the American Nurses Foundation (ANF), manages a Senior Nurse Scholar-in-Residence Program. The purpose of the program is to encourage and assist a prominent nurse leader in the articulation and assessment of health policy issues of national concern. The Senior Nurse Scholar selects a specific health policy issue consistent with the priority activities of the IOM and the nursing profession. The Scholar is located at the IOM, attends selected orientation meetings with key officials the in federal agencies as well as congressional committees with other IOM Fellows, and attends forums and meetings of the Institute, the National Academy of Sciences, the AAN, the ANF, and the American Nurses Association. The Scholar works with mentors who assist the individual in refining the selected topic and bridging the gap between academia and the service and health policy sectors. As part of the residency program, the Scholar is required to submit a peer-reviewed paper before the end of the program that should be published and disseminated to a broad audience. The paper is expected to translate and frame academic or experiential knowledge into policy-relevant recommendations on a specific topic.

Recent and Upcoming Reports

This chapter first lists reports released by the Institute of Medicine from 1996 through 2000 and older reports mentioned in the text, grouped by subject area, then reports expected to be released through June 2001. A "🏛" denotes a congressionally mandated study.

RECENT REPORTS (1996–2000)

Aging and the Elderly

Approaching Death: Improving Care at the End of Life, Health Care Services, 1997.

Health Outcomes for Older People: Questions for the Coming Decade, Health Care Services, 1996.

Pharmacokinetics and Drug Interactions in the Elderly and Special Issues in Elderly African-American Populations: Workshop Summary, Neuroscience and Behavioral Health and Health Sciences Policy, 1997.

NOTE: The Board on Global Health was previously known as the Board on International Health; the Board on Neuroscience and Behavioral Health was previously known as the Board on Biobehavioral Sciences and Mental Disorders.

The Role of Nutrition in Maintaining Health in the Nation's Elderly: Evaluating Coverage of Nutrition Services for the Medicare Population, Food and Nutrition Board, 2000.

The Second Fifty Years: Promoting Health and Preventing Disability, Health Promotion and Disease Prevention, 1992.

Working Together: We Can Help People Get Good Care When They Are Dying, Health Care Services, 2000.

Child/Youth Health

Adolescent Decision Making: Implications for Prevention Programs. Summary of a Workshop, Board on Children, Youth, and Families, IOM/NRC, 1999.

Adolescent Development and the Biology of Puberty: Summary of a Workshop on New Research, Board on Children, Youth, and Families, IOM/NRC, 1999.

America's Children: Health Insurance and Access to Care, Health Care Services and Board on Children, Youth, and Families, IOM/NRC, 1998.

The Best Intentions: Unintended Pregnancy and the Well-Being of Children and Families, Health Promotion and Disease Prevention, 1995.

Children of Immigrants: Health, Adjustment, and Public Assistance, Board on Children, Youth, and Families, IOM/NRC, 1999.

Early Childhood Intervention: Views from the Field. Report of a Workshop, Board on Children, Youth, and Families, IOM/NRC, 2000.

Educating Language-Minority Children, Board on Children, Youth, and Families, IOM/NRC, 1998.

Emergency Medical Services for Children, Health Care Services, 1993.

From Generation to Generation: The Health and Well-Being of Children in Immigrant Families, Board on Children, Youth, and Families, IOM/NRC, 1998.

From Neurons to Neighborhoods: The Science of Early Childhood Development, Board on Children, Youth, and Families, IOM/NRC, 2000.

Frontiers of Research—The Development of Human Potential in the 21st Century: Opportunities at the Intersection of Families and Communities, Board on Children, Youth, and Families, IOM/NRC, 1998.

Longitudinal Surveys of Children: Report of a Workshop, Board on Children, Youth, and Families, IOM/NRC, joint with the NRC Committee on National Statistics, 1998.

New Findings on Poverty and Child Health and Nutrition: Summary of a Research Briefing, Board on Children, Youth, and Families, IOM/NRC, 1998.

Paying Attention to Children in a Changing Health Care Environment: Summaries of Workshops, Board on Children, Youth, and Families, IOM/NRC, and Health Promotion and Disease Prevention, 1996.

Protecting Youth at Work: Health, Safety, and Development of Working Children and Adolescents in the United States, Board on Children, Youth, and Families, IOM/NRC, 1998.

Rational Therapeutics for Infants and Children: Workshop Summary, Health Sciences Policy, 2000.

Reducing the Odds: Preventing Perinatal Transmission of HIV in the United States, Health Promotion and Disease Prevention and Board on Children, Youth, and Families, IOM/NRC, 1998.

Research to Improve Intergroup Relations Among Youth, Board on Children, Youth, and Families, IOM/NRC, 1999.

Revisiting Home Visiting: Summary of a Workshop, Board on Children, Youth, and Families, IOM/NRC, 1999.

Risks and Opportunities: Synthesis of Studies on Adolescence, Board on Children, Youth, and Families, IOM/NRC, 1999.

Schools and Health: Our Nation's Investment, Health Sciences Policy, 1997.

Sleep Needs, Patterns, and Difficulties of Adolescents: Summary of a Workshop, Board on Children, Youth, and Families, IOM/NRC, 2000.

Systems of Accountability: Implementing Children's Health Insurance Programs, Health Care Services and Board on Children, Youth, and Families, IOM/NRC, 1998.

Violence in Families: Assessing Prevention and Treatment Programs, Board on Children, Youth, and Families, IOM/NRC, 1998.

Diseases and Conditions (for HIV/AIDS, see Public Health)

Bridging the Gap Between Practice and Research: Forging Partnerships with Community-Based Drug and Alcohol Treatment, Neuroscience and Behavioral Health, 1998.

Changing Health Care Systems and Rheumatic Disease, Health Care Services, 1996.

Clearing the Air: Asthma and Indoor Air Exposures, Health Promotion and Disease Prevention, 2000.

Control of Cardiovascular Diseases in Developing Countries: Research, Development, and Institutional Strengthening, International Health, 1998.

Developing Technologies for Early Detection of Breast Cancer: A Public Workshop Summary, National Cancer Policy Board, IOM/NRC, 2000.

Diet and Health: Implications for Reducing Chronic Disease Risk, Food and Nutrition Board, 1989.

Disability in America: Toward a National Agenda for Prevention, Health Sciences Policy, 1991.

Dispelling the Myths About Addiction: Strategies to Increase Understanding and Strengthen Research, Neuroscience and Behavioral Health, 1997.

Eat for Life: The Food and Nutrition Board's Guide to Reducing Your Risk of Chronic Disease, Food and Nutrition Board, 1992.

Enabling America: Assessing the Role of Rehabilitation Science and Engineering, Health Sciences Policy, 1997.

Ending Neglect: The Elimination of Tuberculosis in the United States, Health Promotion and Disease Prevention, 2000.

Enhancing Data Systems to Improve the Quality of Cancer Care, National Cancer Policy Board, IOM/NRC, 2000.

Marijuana and Medicine: Assessing the Science Base, Neuroscience and Behavioral Health, 1999.

Marijuana as Medicine?: The Science Beyond the Controversy, Neuroscience and Behavioral Health, 2000.

New Partnerships for a Changing Environment: Why Drug and Alcohol Treatment Providers and Researchers Need to Collaborate, Neuroscience and Behavioral Health, 1999.

Pathways of Addiction: Opportunities in Drug Abuse Research, Neuroscience and Behavioral Health, 1996.

Prevention of Micronutrient Deficiencies: Tools for Policymakers and Public Health Workers, International Health and Food and Nutrition Board, 1998.

The Role of Co-Occurring Substance Abuse and Mental Illness in Violence: Workshop Summary, Neuroscience and Behavioral Health, 1999.

Veterans and Agent Orange: Herbicide/Dioxin Exposure and Type 2 Diabetes, Health Promotion and Disease Prevention, 2000.

Drugs, Devices, and Biologics

Assessment of Future Scientific Needs for Live Variola Virus, Global Health, 1999.
An Assessment of the Safety of the Anthrax Vaccine: Letter Report, Health Promotion and Disease Prevention and Medical Follow-Up Agency, 2000.
Assuring Data Quality and Validity in Clinical Trials for Regulatory Decision Making: Workshop Report, Health Sciences Policy, 1999.
Blood and Blood Products: Safety and Risk, Health Sciences Policy, 1996.
Blood Banking and Regulation: Procedures, Problems, and Alternatives, Health Sciences Policy, 1996.
Calling the Shots: Immunization Finance Policies and Practices, Health Care Services, 2000.
Chemical and Biological Terrorism: Research and Development to Improve Civilian Medical Response, Health Sciences Policy, 1998.
Detecting and Responding to Adverse Events Following Vaccination: Workshop Summary, Health Promotion and Disease Prevention, 1997.
Improving Civilian Medical Response to Chemical or Biological Terrorist Incidents: Interim Report on Current Capabilities, Health Sciences Policy, 1998.
Interactions of Drugs, Biologics, and Chemicals in U.S. Military Forces, Medical Follow-Up Agency, 1996.
Marijuana and Medicine: Assessing the Science Base, Neuroscience and Behavioral Health, 1999.
Marijuana as Medicine?: The Science Beyond the Controversy, Neuroscience and Behavioral Health, 2000.
Rational Therapeutics for Infants and Children: Workshop Summary, Health Sciences Policy, 2000.
Research to Identify Risks for Adverse Events Following Vaccination: Biological Mechanisms and Possible Means of Prevention. Workshop Summary, Health Promotion and Disease Prevention, 1997.
Vaccines for the 21st Century: A Tool for Decisionmaking, Health Promotion and Disease Prevention, 2000.
Urgent Attention Needed to Restore Lapsed Adenovirus Vaccine Availability: A Letter Report, Medical Follow-Up Agency, 2000.

Environmental and Occupational Health

Clearing the Air: Asthma and Indoor Air Exposures, Health Promotion and Disease Prevention, 2000.

Environmental Medicine: Integrating a Missing Element into Medical Education, Health Promotion and Disease Prevention, 1995.

Exposure of the American People to Iodine-131 from Nevada Atomic Bomb Tests: Review of the National Cancer Institute Report and Public Health Implications, Health Care Services, joint with the NRC Board on Radiation Effects Research, 1998.

Gender Differences in Susceptibility to Environmental Factors: A Priority Assessment, Health Sciences Policy, 1998.

Nursing, Health, and the Environment, Health Promotion and Disease Prevention, 1995.

Protecting Youth at Work: Health, Safety, and Development of Working Children and Adolescents in the United States, Board on Children, Youth, and Families, IOM/NRC, 1998.

Rebuilding the Unity of Health and the Environment: A New Vision of Environmental Health for the 21st Century, Health Sciences Policy, 2000.

Reducing the Burden of Injury: Advancing Protection and Treatment, Health Promotion and Disease Prevention, 1998.

Reducing Stress Fracture in Physically Active Military Women, Food and Nutrition Board, 1998.

Review of the Disability Evaluation Study Design: Third Interim Report, Health Care Services, 1999.

Role of the Primary Care Physician in Occupational and Environmental Medicine, Health Promotion and Disease Prevention, 1998.

Safe Work in the 21st Century: Education and Training Needs for the Next Decade's Occupational Safety and Health Personnel, Health Sciences Policy, 2000.

Toward Environmental Justice: Research, Education, and Health Policy Needs, Health Sciences Policy, 1999.

Toxicology and Environmental Health Information Resources: The Role of the National Library of Medicine, Health Promotion and Disease Prevention, 1997.

Food, Nutrition, and Diet

Assessing Readiness in Military Women: The Relationship of Body Composition, Nutrition, and Health, Food and Nutrition Board, 1998.

Diet and Health: Implications for Reducing Chronic Disease Risk, Food and Nutrition Board, 1989.

Dietary Reference Intakes: Applications in Dietary Assessment, Food and Nutrition Board, 2000.

Dietary Reference Intakes for Calcium, Phosphorus, Magnesium, Vitamin D, and Fluoride, Food and Nutrition Board, 1997.

Dietary Reference Intakes: A Risk-Assessment Model for Establishing Upper Intake Levels for Nutrients, Food and Nutrition Board, 1998.

Dietary Reference Intakes for Thiamin, Riboflavin, Niacin, Vitamin B6, Folate, Vitamin B12, Pantothenic Acid, Biotin, and Choline, Food and Nutrition Board, 1998.

Dietary Reference Intakes for Vitamin C, Vitamin E, Selenium, and Carotenoids, Food and Nutrition Board, 2000.

Eat for Life: The Food and Nutrition Board's Guide to Reducing Your Risk of Chronic Disease, Food and Nutrition Board, 1992.

Emerging Technologies for Nutrition Research: Potential for Assessing Military Performance Capabilities, Food and Nutrition Board, 1997.

Enhancing the Regulatory Decision-Making Approval Process for Direct Food Ingredient Technologies: Workshop Summary, Food and Nutrition Board, 1999.

Ensuring Safe Food: From Production to Consumption, Food and Nutrition Board, joint with the NRC Board on Agriculture, 1998.

Evaluating Food Assistance Programs in an Era of Welfare Reform: Summary of a Workshop, Board on Children, Youth, and Families, IOM/NRC, with the NRC Committee on National Statistics, 1999.

Food Chemicals Codex, Fourth Edition, Food and Nutrition Board, 1996.

Food Chemicals Codex: First Supplement to the Fourth Edition, Food and Nutrition Board, 1997.

Food Chemicals Codex: Second Supplement to the Fourth Edition, Food and Nutrition Board, 2000.

Food Labeling: Toward National Uniformity, Food and Nutrition Board, 1992.

Military Strategies for Sustainment of Nutrition and Immune Function in the Field, Food and Nutrition Board, 1999.

New Findings on Poverty and Child Health and Nutrition: Summary of a Research Briefing, Board on Children, Youth, and Families, IOM/NRC, 1998.

Nutrition During Lactation, Food and Nutrition Board, 1991.

Nutrition During Pregnancy: Part 1: Weight Gain, Part 2: Nutrient Supplements, Food and Nutrition Board, 1990.

Nutrition Labeling: Issues and Directions for the 1990s, Food and Nutrition Board, 1990.

Nutritional Needs in Cold and in High-Altitude Environments: Applications for Military Personnel in Field Operations, Food and Nutrition Board, 1996.

Prevention of Micronutrient Deficiencies: Tools for Policymakers and Public Health Workers, International Health and Food and Nutrition Board, 1998.

Reducing Stress Fracture in Physically Active Military Women, Food and Nutrition Board, 1998.

The Role of Nutrition in Maintaining Health in the Nation's Elderly: Evaluating Coverage of Nutrition Services for the Medicare Population, Food and Nutrition Board, 2000.

The Role of Protein and Amino Acids in Sustaining and Enhancing Performance, Food and Nutrition Board, 1999.

Seafood Safety, Food and Nutrition Board, 1991.

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