National Institutes of Health

Strategic Research Plan and Budget to Reduce and Ultimately Eliminate Health Disparities Volume I

Fiscal Years 2002-2006

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

FY 2002

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Foreword

Medical and scientific advances have introduced new opportunities for the continued improvement of health for all Americans. However, in spite of notable improvements gained as a result of the advancement of knowledge through basic and applied research, diagnostics and treatment, there continues to be an alarming disproportionate burden of illness among minority and medically underserved populations. NIH's mission of "uncovering new knowledge that will lead to better health for everyone" lays the foundation for the overall goal of understanding the causes of health disparities and for developing effective interventions to eliminate these disparities.

All of us who have been privileged to participate in this age of scientific discovery have a responsibility to ensure that the new knowledge generated in our laboratories and our clinics benefits all of our citizens and all of our communities. Our aim at the NIH is to promote the development and transfer of research-based information from the biomedical, behavioral, and social sciences for use by health professionals, communities, and others in working toward the elimination of health disparities.

In order to address the constant and confounding problem of health disparities experienced by the affected communities including the medically underserved population, the NIH is committed and remains vigilant in supporting research to understand biological, socioeconomic, cultural, environmental, institutional, and behavioral factors affecting health disparities. Research is but only one solution in a multifaceted effort. In addition to devoting resources toward the application of research programs, the NIH is also planning and conducting education and training programs and increasing outreach activities, to translate new knowledge from research into improved health outcomes for all Americans.

This strategic plan, NIH Strategic Research Plan and Budget to Reduce and Ultimately Eliminate Health Disparities, is the first step in implementing Public Law (P.L.) 106-525, The Minority Health and Health Disparities Research and Education Act of 2000, and represents NIH's assurance and commitment to this effort. The plan was developed through an open process with substantial input from the public, particularly from representatives of groups who disproportionately experience disparities in health, in addition to those in academia and health care professionals. It describes the activities underway and planned to bring the full strength of NIH's research, training and outreach programs to bear on the challenge of eliminating domestic health disparities, increasing participation by minorities in clinical research, and increasing the number of minority clinical and basic medical scientists who are essential to the success of our efforts.

While the diversity of the American population remains one of our Nation's greatest assets, the discrepancies in health status described here represent a challenge to better understand these disparities, and to reduce and ultimately eliminate them.

Public Law 106-525 requires the NCMHD to report to the Congress by December 2003 recommendations for the methodology the NIH will use to determine the amount of NIH resources dedicated to the conduct and support of health disparities research.

The budget data for health disparities activities contained within the budget table in Volume I of this version of the NIH Strategic Research Plan and Budget to Reduce and Ultimately Eliminate Health Disparities used a definition of minority health and health disparities research that the NIH is currently refining in accordance with Public Law 106-525.

Because of concerns about current definitions, we are unable to provide the Congress with valid and reliable data on minority health disparities research in this report. In order to overcome this problem for our next report, and to further improve the quality of data, we submit to Congress, NIH has established an NIH Committee on Minority Health and Health Disparities Research Definitions and Application Methodology. The Committee is developing new definitions and a revised application methodology that will be used by the NIH for future reporting purposes. The Committee will develop a uniform NIH Guidance that:

- Provides NIH operational definitions, based on Public Law 106-525, for minority health and health disparities research,
- Provides a consistent methodology for applying the definitions,
- Contains the criteria necessary to identify both minority health and health disparities population groups and diseases, and
- Serves as the foundation for identifying, coding, tracking, and reporting on NIH activities and resources.

The NIH will be updating the Strategic Research Plan and Budget each year. Accordingly, the budget figures to be contained within the next iteration (2003) of the NIH Strategic Research Plan and Budget will be more precise, based upon the revised definitions and application methodology.

Elias A. Zerhouni, M.D. Director National Institutes of Health John Ruffin, Ph.D. Director National Center on Minority Health and Health Disparities, National Institutes of Health

Executive Summary

Over the last two decades the overall health of the Nation has improved significantly. Yet there continue to be striking disparities in the burden of illness

and death experienced by African Americans, Hispanics, Native Americans, Alaska Natives, Asians, and Pacific Islanders. The most striking disparities include shorter life expectancy as well as higher rates of cardiovascular disease, cancer, infant mortality, birth defects, asthma, diabetes, stroke, sexually transmitted diseases, and mental illness. These disparities are believed to be the result of the complex interaction among biological factors, the environment, and specific health behaviors. Inequalities in income and education also appear to underlie many health disparities in the United States. Disparities in income and education levels are associated with differences in the occurrence of illness and death, including heart disease, diabetes, obesity, elevated blood lead level, and low birth weight.

Overcoming persistent health disparities and promoting health for all Americans rank as our Nation's foremost health challenge. To overcome this challenge, the National Institutes of Health (NIH) is supporting and conducting a wide range of research, and seeking new knowledge, strategies, and methodologies about disease and disabilities. This new knowledge has and will continue to lead to innovative diagnostics, treatments, and preventative strategies to reduce, and eventually eliminate, health disparities.

MISSION

The NIH mission on minority health and health disparities is to support and promote biomedical and behavioral research, research training, research capacity, and research information dissemination, with the goal of improving the health status of minorities and other health disparity populations.

VISION

A time when all Americans have the opportunity for long, healthy, and productive lives regardless of race, ethnicity, or socioeconomic status.

Within the NIH, the National Center on Minority Health and Health Disparities (NCMHD) serves as the focal point for planning and coordinating minority health and other health disparities research. According to P.L. 106-525, the NCMHD was established by Congress to foster, coordinate, and assess the progress of all NIH-sponsored research activities involving minority health and other health disparities by working in collaboration with NIH's Institutes and Centers (ICs) and other program offices within the NIH Office of the Director (OD).

The initiatives described in this plan represent the major priorities and broad range of activities that the NIH will undertake to reduce and ultimately eliminate health disparities. The plan is not merely a compilation of all the activities of the NIH entities, but an aggregation of primary areas of emphasis and activities conducted across the NIH. This plan is the first step of an evolving process by which the strategic plan will be revised on a yearly basis based on public comments received, public health need, scientific opportunity, changes in available funds, and other factors. The plan will be posted on the NCMHD website on a continuing

basis and public comments on the plan will be encouraged and considered at any time. The strategic plan follows a methodological planning model, which presents mission, vision, goals, objectives, and programs for reducing and eventually eliminating health disparities.

The Strategic Plan is focused on three major goals:

- Research to advance the understanding of the development and progression of diseases and disabilities that contribute to minority health and other health disparities
- Research Infrastructure to increase minority health and health disparity research training, career development, and institutional capacity
- Public Information and Community Outreach to ensure the public, healthcare professionals, and research communities are informed and educated concerning the latest advances in minority health and health disparities research.

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Specific initiatives to support each objective are highlighted in Section IV of this plan. The programs presented are a representative sampling, selected for their depth of activities and breadth of scope in addressing minority health and health disparities. They do not represent the totality of the NIH program. Further information about each of the initiatives and a complete list of all IC initiatives, can be found in Volume II of this strategic plan.

All of these many initiatives cut across a variety of areas representing a myriad of diseases, disabilities, and organizational boundaries. These initiatives represent a trans-agency commitment to exploring and solving many of the health disparities problems our citizens and our Nation face. Much needs to be done, but we are confident that the medical research community working with, and informed by, the public, patients, health care providers, policymakers, and others will continue to develop new knowledge that will lead to improvements in the prevention, diagnosis, and treatment of diseases and disabilities that contribute to health disparities among minority and medically underserved populations.

Section I: Introduction

Despite notable improvements in the overall health of the Nation in the last two decades, there continue to be striking disparities in the burden of illness and death among African Americans, Hispanics, Native Americans, Alaska Natives, Asians, and Pacific Islanders and underserved groups such as disadvantaged rural Whites. Overcoming such persistent health disparities, and promoting health for all Americans ranks as one of our Nation's foremost challenges.

According to P.L. 106-525, the Minority Health and Health Disparities Research

and Education Act of 2000, health disparity populations refer to "a population where there is a significant disparity in the overall rate of disease incidence, prevalence, morbidity, mortality, or survival rates in the population as compared to the health status of the general population." To meet this challenge, the NIH is focusing its efforts on minority health disparities as well as other health disparity populations. Health disparity efforts transcend the bounds of gender, except in certain instances of specialized research (i.e. lupus in women, cervical cancer in Vietnamese women).

Minority Health Disparities

Diseases, disorders, and conditions that disproportionately afflict individuals who are members of racial and ethnic minority groups

Other Health Disparity Populations

Population groups who suffer from health disparities when compared to the general population

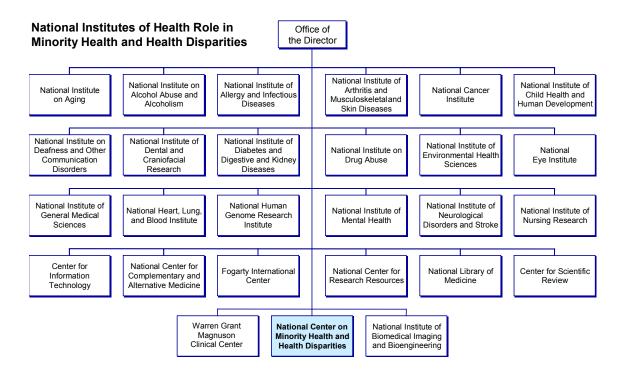
Research activities may include basic and applied research, research and development with respect to products, behavioral research, social sciences research, cultural research, and linguistic research.

It is imperative that the Nation make a concerted effort to reduce health disparities. The National Institutes of Health (NIH) has a unique and central role in this endeavor. By supporting and conducting a wide range of research, the NIH seeks new knowledge, strategies, and methodologies about disease and disabilities. This new knowledge has, and will continue to, lead to innovative diagnostics, treatments, and preventive strategies to reduce, and eventually eliminate, health disparities.

NIH Organizational Structure

The mission of the NIH is to improve the Nation's health by uncovering new knowledge about the prevention, detection, diagnosis, and treatment of diseases and disabilities. NIH's mission is, thus, central to expanding national efforts to address differences in incidence, prevalence, morbidity, mortality and burden of diseases and other adverse health conditions that exist among specific population groups in the United States.

The NIH, comprised of twenty-seven Institutes and Centers (ICs) and other program offices in the Office of the Director (OD), has long been committed to addressing and eliminating health disparities. The National Center on Minority Health and Health Disparities (NCMHD) serves as the focal point for planning and coordinating minority health and other health disparities research across the NIH.



NCMHD Role

According to P.L. 106-525, the NCMHD was established by Congress to work in collaboration with other NIH IC's to foster, coordinate, and assess the progress of all NIH-sponsored research activities involving minority health and other health disparities.

The NCMHD leads the federal effort at the National Institutes of Health to stimulate new research, improve the health status of minority Americans and other underserved groups across their lifespan and promote programs aimed at expanding the participation of underrepresented minorities in all aspects of biomedical and behavioral research.

Specific priorities for the Center include:

- Developing an integrated, cross-disciplinary national research agenda on health disparities
- Promoting and supporting research capacity-building activities in the minority and medically underserved communities

- Establishing broad aspects of two-way communication and outreach with the Center's many stakeholders
- Collaborating with NIH research partners to sponsor activities involving minority health and health disparities
- Assessing, tracking, and monitoring the results of NIH minority health and health disparities research progress

NCMHD's effort cuts across disease areas and organizational boundaries and involves a trans-agency commitment. It coordinates and augments the efforts of each Institute, Center, and program office in the NIH Office of the Director. Furthermore, the Center functions as the central repository for minority health and health disparity research information and fosters knowledge sharing among the IC's. More information regarding NCMHD's mission, vision, and strategic objectives can be found in the NCMHD's section in Volume II.

Objectives of the Strategic Plan

In response to P.L. 106-525, the five-year Trans-NIH Strategic Plan describes an ambitious approach to reduce and ultimately eliminate health disparities among racial and ethnic minorities and other health disparity groups. The scope of the problem of health disparities among minorities and other populations, the specific objectives for solving the problem, and the means for advancing those objectives are the substance of this strategic plan. The initiatives described here represent the major priorities and the broad range of activities that the NIH will undertake to reduce and ultimately eliminate health disparities.

Objectives of the Trans-NIH Strategic Plan

- Present NIH's role in minority health and health disparities, including the function of the NCMHD
- Discuss the methodology used to develop the Trans-NIH Strategic Plan
- Examine factors that contribute to minority health and health disparities
- Outline Department of Health and Human Services (HHS) and NIH efforts to reduce and ultimately eliminate health disparities
- Present the structured planning model used to support minority health and other health disparities activities; including the mission, vision, goals, objectives and sample programs that support reducing and eliminating minority health and other health disparities

This plan allows for the evaluation of NIH's progress and the extent to which NIH meets its projected goals. The plan is not merely a compilation of all the activities of the relevant NIH entities, it aggregates the primary areas of emphasis and activities conducted across the agency and provides the reader with an understanding of the cross-cutting nature of disease and scientific discovery.

This plan is an evolving document. It will be updated and revised on a yearly basis based on public comments received, public health need, scientific opportunity, changes in available funds, and other factors.

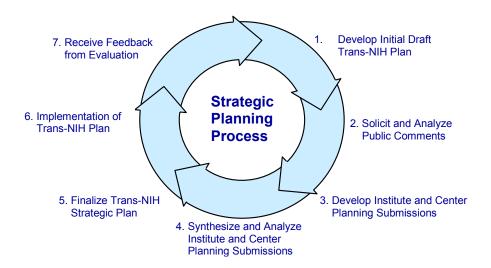
Organization of the Strategic Plan

This strategic plan sets forth NIH's goals for reducing and, ultimately, eliminating health disparities among racial and ethnic minorities and other populations and describes some of the many initiatives that will be expanded or created to meet these goals. Volume I contains background on minority health and health disparities, future initiatives to address these issues, and NIH long-term goals and objectives. Volume II includes strategic plan submissions from all the IC's, as well as from NIH's Office of AIDS Research (OAR) and Office of Behavioral and Social Sciences Research (OBSSR).

SECTION	TOPICS				
VOLUME I					
I. Introduction	Describes the NIH organizational structure, the objectives of the Trans-NIH Strategic Plan, the organization of the plan, and the methodology used to develop the strategic plan.				
II. Background on Minority Health and Health Disparities	Presents the factors that contribute to the problem of minority health and other health disparities				
III. Department of Health and Human Services (HHS) and NIH Efforts to Reduce and Ultimately Eliminate Health Disparities	Describes HHS, and NIH efforts to address minority health and other health disparities and the coordination of the interdisciplinary approach				
IV. Strategic Planning Model	Presents the strategic planning model; including the mission, vision, goals, objectives, and sample programs established to support reducing and eventually eliminating health disparities among minorities and other populations. In addition, the NIH Minority Health and Health Disparities Budget and the conclusion are presented in this section.				
VOLUME II					
Individual IC, OAR, and OBSSR Strategic Plan Submissions	Provides IC, OAR, and OBSSR strategic areas of emphasis, objectives, action plans, timelines and performance measures to reduce and ultimately eliminate health disparities in the United States.				

Development of the Strategic Plan

The NIH followed a structured strategic planning model in developing this strategic plan. The initial draft five-year Trans-NIH Strategic Plan incorporated the efforts of a Trans-NIH working group, which consisted of each NIH Institute and Center Director. The draft was published on October 6, 2000 for technical and public review. The plan was developed through an open process with substantial public input, particularly from representatives of groups who disproportionately experience disparities in health. Comments were received and archived up until February 23, 2001. Next, each IC, the OBSSR, and the OAR developed a mission-specific submission for the strategic plan that sets forth in greater detail ongoing and future efforts to reduce health disparities among minority and other health disparity populations. The NCMHD synthesized and analyzed all IC submissions to develop the Trans-NIH Strategic Plan.



This strategic plan incorporates input from the public, professional and patient advocacy groups, health care organizations, academic institutions, ethnic/minority groups, federal agencies, and the scientific community. The input from these stakeholders is reflected throughout the plan.

During the implementation of the Strategic Plan, the NCMHD will seek additional public comment to aide in revising the plan. The Center also will provide support to the other ICs to assist them in convening workshops that will include outside experts to assess their health disparities agendas, progress and outcomes in health disparities research. This process will enable further refinement of the IC submissions to the Trans-NIH Strategic Plan in future years.

Section II: Background on Minority Health and Health Disparities

The health disparities that afflict ethnic and racial minorities as well as other underserved populations are not limited to one or two disease categories. They apply to a broad spectrum of disease types that encompass infectious diseases, vascular diseases, endocrine diseases, arthritic diseases, connective tissue diseases, malignancies, mental illness and others. Health disparities also exist within different geographic regions of the United States. Consequently, "health disparity" is an issue that is relevant to the work of every NIH Institute and Center, and certain offices within the NIH Office of the Director. A brief sample of relevant diseases follows:

- Infant Mortality Over the last decade, the infant mortality rate remains more than twice as high among African Americans as compared to Whites, even when controlling for socioeconomic factors. American Indians and Alaska Native infants also have a death rate almost double that of Whites.
- Heart Disease and Stroke Coronary heart disease mortality is 20 percent higher for African Americans than Whites. Fewer African Americans survive severe cardiomyopathy as compared to Whites a difference that is attributed to both biological and socioeconomic factors. The incidence of stroke is disproportionately high in African Americans, where the mortality rate is nearly 27.5 percent higher than in Whites.
- Cancer Minority groups suffer disproportionately from cancer, and disparities exist in both mortality and incidence rates. African Americans have both a higher overall incidence and a higher death rate than any other racial or ethnic group. The difference in cancer mortality is about 12% higher for Hawaiian men and 20% higher for Hawaiian women than that of white Americans.

The mapping of U.S. Cancer incidence and mortality rates indicate distinct regions of the country where disparities in cancer exist. NCI's *Atlas Of Cancer Mortality in the United States* map geographic mortality distribution by county and by race for all major cancers. By mapping cancer rates, disparities by region have been identified for further study. These regions include the Mississippi Delta Region, and the Appalachia Region. The average cervical cancer mortality rate among African American women is more than double that of white women and the national average for all women. Rates are particularly high among black women in the rural South, primarily in the Mississippi Delta region that encompasses 235 counties and parishes within the states of Alabama, Arkansas, Illinois, Kentucky, Louisiana, Mississippi, Missouri and Tennessee. Cervical cancer mortality is higher than average among Latina women living on the Texas-Mexico border, among white women

in Appalachia, rural New York State, and northern New England. Mortality from the disease also is higher than average among Vietnamese and some Native American and Native Alaskan women. (NCI sponsored registry of the *Surveillance, Epidemiology, and End Results (SEER)* program.)

While incidence rates for all cancer sites in the Appalachia Region compared to the national SEER population was similar, incidence of reported lung, colon, rectal and cervical cancer was each substantially higher in the Appalachian region which includes regions within thirteen states. In rural Appalachia, incidence of lung and cervical cancer was approximately one-third higher than the national average. In addition, the ratio of unstaged cancers at all sites was elevated for rural Appalachia. (Central cancer registries of Kentucky, Pennsylvania, and West Virginia established by the *Appalachia Cancer Network Surveillance Task Force.*)

- Mental Health Disease burden associated with mental disorders falls disproportionately on ethnic minority populations. Native American and Alaska Natives not only suffer disproportionately from depression, but this population also experiences a higher rate of suicide.
- Diabetes The prevalence of diabetes in African Americans is twice as high than in whites. Certain racial and ethnic communities, including African Americans, Hispanic Americans, American Indians and Certain Pacific Islander and Asian American populations as well as economically disadvantaged or older people, suffer disproportionately compared to white populations.
- HIV and AIDS AIDS incidence for African Americans is disproportionately higher than for other populations. African American females are diagnosed with AIDS at a rate that is nearly 4 times higher than for Hispanic American females, 10 times higher than for American Indian or Alaska Native females and 24 times more often than white females. African American males experience a rate of AIDS incidence that is almost 3 times higher than for Hispanic American males, nearly 6 times greater than for American Indian or Alaska Native males and nearly 8 times higher than for white males.

The table that follows further describes, in quantitative terms, health disparities of certain conditions in selected populations. It is clear from this overview that the nature of the disparity may vary significantly from group to group, and that for certain groups there is a paucity of data to adequately assess the problem. This data was compiled from the following resources: "Health, United States 2002"; "Trends in Racial and Ethnic-Specific Rates for the Health Status Indicators: United States, 1990-98"; "HIV/AIDS Surveillance Report 2001"; "Healthy People 2010: Understanding and Improving Health"; and National Vital Statistics Reports, "Deaths: Leading Causes for 2000".

HEALTH DISPARITIES OF CERTAIN CONDITIONS IN SELECTED POPULATIONS					
	INDEX IN SELECTED POPULATIONS				
HEALTH CONDITION AND SPECIFIC EXAMPLE	WHITE	AFRICAN AMERICAN	HISPANIC or LATINO	ASIAN or PACIFIC ISLANDER	AMERICAN INDIAN or ALASKA NATIVE
Infant mortality rate per 1000 live births ¹	5.9	13.9	5.8	5.1	9.1
Cancer mortality rate per 100,000 ²	199.3	255.1	123.7	124.2	129.3
Lung Cancer - age adjusted death rate ³	38.3	46.0	13.6	17.2	25.1
Female Breast Cancer age adjusted death rate	18.7	26.1	12.1	9.8	10.3
Coronary Heart Disease mortality rate per 100,000 ²	206	252	145	123	126
Stroke mortality rate per 100,000	58	80	39	51	38
Diabetes diagnosed rate per 100,000	36	74	61	DSU	DSU
End-Stage Renal Disease rate per million ²	218	873	DNA	344	589
AIDS – diagnosed rate per 100,000 ⁴					
Female	2	48	13	1	5
Male	14	109	43	9	19

DSU = Data are statistically unreliable

DNA = Data have not been analyzed

¹ Chartbook on Trends in the Health of Americans. Excerpted from Health, United States 2002. Department of Health and Human Services. National Center for Health Statistics. DHHS Publication No. 1232-1. August 2002.

² Healthy People 2010. Understanding and Improving Health (Second Edition). Department of Health and Human Services. November 2000.

³ Keppel, Kenneth, Jeffrey Pearcy and Diane Wagener. Trends in Racial and Ethnic-Specific Rates for the Health Status Indicators: United States, 1990-98. Statistical Notes. Number 23. January 2002, pgs. 1-16.

⁴ HIV/AIDS Surveillance Report. U.S. HIV and AIDS Cases Reported Through December 2001 Year-End Edition. Slides 13 &14. (Available at URL: http://www.cdc.gov/hiv/graphics/surveill.htm)

⁵ National Vital Statistics Reports. 2002 Deaths: Leading Causes for 2000. Vol. 50:16:1-41.

Multifactorial Basis of Health Disparities

The genesis of health disparities is multifactorial and hence will require a coordinated and interdisciplinary approach to eliminate them. Below we present one author's perspective of the various factors contributing to the disproportionate burden of morbidity and mortality suffered by racial and ethnic minorities. Other schema and classifications could be created as well, however they would have in common many of the factors cited below. With the exception of race, many of these factors apply to non-ethnic underserved populations as well. The common denominator in the latter case is related to low socio-economic status and the protean effects of poverty on health.

HEALTH PRACTICES Smoking Alcohol Nutrition BIOLOGICAL FACTORS PSYCHOLOGICAL STRESS Family Stress Financial Stress CULTURAL FACTORS ENVIRONMENTAL SOCIO-ECONOMIC RACE BIOLOGICAL HEALTH **FACTORS** Residential Stress PROCESSES OUTCOMES Occupational Stress RACISM PSYCHOSOCIAL RESOURCES Social Ties Perceptions of Control POLITICAL FACTORS MEDICAL CARE Need

A Framework for Understanding the Relationship Between Race and Health 1

Not only are there multiple factors, there is great overlap between them that produces a destructive synergy. We describe several of these factors in greater detail below:

Socioeconomic Status/Education Level. An extensive body of literature has demonstrated a strong association between health and socioeconomic status. (The highest educational level achieved is often considered one of the best measures of socio-economic status.) For instance Marmot and colleagues have shown that illness and mortality decreased in British civil servants as measures of socioeconomic status rose. Low socioeconomic status and poor health were most closely correlated with a perception of reward imbalance and lack of control in

¹ King G. and William D.R., 1995. Race and Health: A multidimensional approach to African American Health. In: Amick BC, Levine S, Tarlov AR, Walsh DC, eds. Society and Health: New York: Oxford University Press (Taken from Workshop Summary: Pharmacokinetics and Drug Interactions in the Elderly, National Academy Press

the work place. This also correlated with an increase in fibrinogen, a biological marker of inflammation and certain chronic disease states. The negative health effects of depressed socioeconomic status are relevant to many racial and ethnic minorities, as well as to underserved white populations.

Biology. Even after controlling for socioeconomic status there seem to be factors that further influence disease states in racial and ethnic populations. Some of this residual effect may be biological in nature. For instance differences in socioeconomic status do not completely explain the higher rates of hypertension, glaucoma and lupus in African Americans. "Thrifty genes" and other predisposing genetic factors have been proposed to explain the epidemic of obesity and diabetes in Pima Indians. Biological differences seem responsible for different rates of drug metabolism in various populations. This may help explain why immunosuppressive agents may not be as effective in African Americans.

Access and Quality of Health Care. Health care access and quality are often substandard in the same populations that suffer from health disparities. Lack of access may result in failure to prevent disease, delayed detection and inadequate treatment of disease. In the United States racial minorities and other health disparity groups suffer from barriers to medical care for multiple reasons i.e., lack of insurance, which is in turn related to unemployment or employment in the small business sector; language barriers; travel barriers; immigration status; and issues related to culture, trust and discrimination. Among racial and ethnic minorities Hispanics seem to face particularly high barriers to access, though disadvantaged whites who are unemployed or work in the small business sector are frequently uninsured and face many of the same issues. However, equalizing access will not be sufficient to eliminate health disparities. Even in countries that have optimized and equalized access, for example Britain and Finland, health disparities persist and closely track socioeconomic status.

Racial and Ethnic Discrimination. Racial and ethnic discrimination creates additional barriers to care. Even if discrimination is not overt, perceived discrimination that occurs as a consequence of insensitivity or a lack of cultural competence can create further barriers to care and an ineffective therapeutic relationship. The struggle to "advance and achieve" in the face of discrimination creates stress that may manifest itself in disease. This phenomenon, known as John Henryism, has been thought to contribute to the disproportionate degree of hypertension in African Americans. Hypertension is a major risk factor for stroke, which is also disproportionately elevated in African Americans.

Cultural Issues. Culture may be interpreted in the traditional sense as applying to a racial or ethnic group, or more broadly to include socioeconomic status, urban, rural or suburban lifestyles, as well as geographic location and other

factors. Cultural practices may influence diets and other behaviors that influence health status. In addition cultural factors may include alternative methods of healing that may conflict with mainstream medicine. Many racial and ethnic minority patients who employ traditional methods of healing often feel uncomfortable informing non-ethnic caregivers of these modalities, which may include pharmacologically active herbs. African Americans may be less likely to be fully engaged in a therapeutic relationship with a psychiatrist when it is involuntary than when it is based on self-referral.

Coordination of an Interdisciplinary Approach

While this list of factors is not meant to be exhaustive, it is illustrative of the complexity of the problem and points to the need for a coordinated interdisciplinary approach if we are to reduce and ultimately eliminate the "health gap". The coordination must occur within the NIH as well as among the other federal agencies devoted to this objective. The goal of the coordinated interdisciplinary approach is to promote synergies and reduce redundancy in this formidable effort. This has implications for the trans-NIH plan on multiple levels:

- Many of the disease complexes that afflict health disparity groups cut across boundaries of several Institutes and Centers (IC's). Examples include coronary artery disease, diabetes, obesity, anger and depression, and behavioral factors that contribute to all these. This suggests a need for enhanced collaboration among the Institutes and Centers in conducting health disparity research. In addition, IC's that are traditionally biological must develop an increased awareness of, and an integration with, the non-biological factors contributing to disease. For instance establishing more extensive correlation between disease states and educational status, or using surveys and other instruments that are more tailored to minority populations.
- It is important to build infrastructure for health disparity research by supporting minority-serving institutions that may not have adequate resources, increasing the number of minority researchers, and increasing the scope and depth of research that focuses on health disparities. Sharing "best practices" in attracting minority researchers is an obvious way different IC's can collaborate.
- It is essential that the IC's develop new and innovative ways to reach health disparity populations so that the fruits of research can benefit the target populations. This outreach must go beyond mere information dissemination. It must strive to influence behaviors that are relevant to health. Collaboration between biologically focused and behaviorally

focused IC's and offices is important in this effort. Once again establishing and sharing best practices in this regard would be highly beneficial.

■ Finally, in order to achieve the Congressionally mandated goal of reducing and ultimately eliminating health disparities, it is important that we establish interim goals and objectives with outcomes that are, where possible, quantifiable. This is a challenging task and IC's can learn from each other in establishing best practices in measuring outcomes related to the reduction of health disparities.

Congress established the NCMHD to play the central role in leading, coordinating and monitoring this effort and one of the first steps was to produce this trans-NIH plan to reduce and ultimately eliminate health disparities in the United States.

Section III: Department of Health and Human Services (HHS) and NIH Efforts to Reduce and Ultimately Eliminate Health Disparities

HHS Efforts

In developing the Trans-NIH Strategic Plan, a review of existing Department of Health and Human Services (HHS) activities to address minority health and other health disparities was undertaken to ensure the Trans-NIH Strategic Plan is aligned with similar HHS efforts and to ensure that the NIH is leveraging the full breadth and depth of programs and activities directed toward minority health and other health disparity populations. Two key cross cutting initiatives, the HHS *Initiative to Eliminate Racial and Ethnic Disparities in Health* and *Healthy People 2010*, were considered given that aspects of their goals and objectives are related directly to this Plan.

- The *Initiative to Eliminate Racial* and *Ethnic Disparities in Health* was initiated by the HHS to eliminate the disparities in six areas of health status experienced by racial and ethnic minority populations.
- Complementing the *Initiative to* Racial Eliminate and Ethnic Disparities in Health is another HHS initiative, Healthy People 2010, a national health promotion and disease prevention initiative involving several federal agencies such as the U.S. Department of Agriculture and the U.S. Department of Education. Healthy People 2010 sets forth the Nation's health objectives for the next decade, which include a major goal for eliminating health disparities among different segments of the population.

Initiative to Eliminate Racial and Ethnic Disparities In Health

- Infant Mortality
- Cancer Screening and Management
- Cardiovascular Disease and Stroke
- Diabetes
- HIV/AIDS Rates
- Child and Adult Immunization Levels

Healthy People 2010

- Conduct New Outreach Campaign
- Develop New Approaches to Build on Existing Successes to Address Racial and Ethnic Health Disparities
- Major New Foundation/Public Sector Collaboration to Address Disparities
- Develop more Effective Ways to Target Existing Federal Programs to Address Health Disparities
- Involve Communities, Foundations, Advocacy Organizations, and Businesses to Develop Ways to Target Racial and Ethnic Health Disparities

The Trans-NIH Strategic Plan is consistent with these HHS-wide efforts and furthers the objectives of HHS to prevent disease, promote health, and deliver care to the US population, especially the racial, ethnic and other health disparity populations.

The coordination of HHS health disparities research activities will be further enhanced by NIH participation in the HHS Research Coordination Council.

NCMHD Efforts

The NCMHD co-funds projects with other NIH Institutes and Centers, and various Federal Offices and Agencies to improve the quality and efficiency of NIH health disparities research.

For example, the Center provides support to increase the number of funded meritorious programs through the Centers for Disease Control and Prevention's *Racial and Ethnic Approaches to Community Health (REACH 2010)* and the Agency for Healthcare Research Quality's *Excellence Centers to Eliminate Racial and Ethnic Health Disparities (EXCEED)* programs.

In addition, the Center and the Office of Minority Health, Office of Public Health and Science, co-fund several projects to support other organizations, including:

Interamerican College of Physicians and Surgeons (ICPS) - The National Hispanic Youth Initiative in Health, Biomedical Research and Policy Development includes a rigorous curriculum and comprehensive approach to increasing Hispanic manpower in health care and biomedical research. It comprises a series of lectures and round table/group discussions on health care issues and scientific research, academic preparation, and opportunities in the health sciences and research, health legislation and public policy, the health status of Hispanic communities, and clinical and scientific preceptor ships. This program contributes to retaining students in the academic pipeline and serves as a pre-college program to increasing the number of Hispanic youth pursuing careers in the health sciences and/or scientific research arenas.

National Medical Association (NMA) - The National African American Youth Initiative in Health and Policy Development Scholars Program increases the awareness of African American youth on national health issues, scientific research, public policy and the role and impact of the Federal Government in the development of health policy. The Youth Initiative prepares, motivates, and encourages young African Americans to pursue careers in the health and scientific fields.

American Indian Youth Initiative - This project will recruit promising high school students into biomedical careers and further expansion of the Indian Health Network, an on-line electronic service designed to link isolated tribes and urban organizations with physicians and other providers, health facilities, and educational institutions to enhance the health of all Indian communities.

The Asian and Pacific Island American Health Forum - This project will establish and maintain a national on-line Asian and Pacific Islander (A/PI) Health Information Network to expand and enhance health promotion and disease prevention, health advocacy, mental health and substance abuse, education, health services research opportunities, and cultural competency. NIH can use this information network to target information about research opportunities and clinical trials to A/PI communities.

NIH Efforts

The NIH occupies a unique place in the federal effort to eliminate health disparities among minorities and the medically underserved. The NIH works with the public, health care providers, scientists, and policymakers to identify the relevant issues; develop the research plans to address these issues; and support and conduct a broad range of studies in this area. These studies include epidemiological; biological, behavioral, and social science research; as well as health services research. In addition, the NIH provides support for the infrastructure that underpins the research enterprise, such as training, instrumentation, and research facilities. The NIH carries out public information and community outreach programs to communicate research findings to individuals, organizations, and other entities that can put the research results into practice.

While NIH-funded research yields information important to addressing the complex problems among racial and ethnic minorities and other underserved populations, it is only a part of a multi-faceted effort to prevent disease, promote health, and deliver appropriate care to these communities.

Section IV: Strategic Planning Model for Reducing and Ultimately Eliminating Health Disparities

The strategic plan follows a methodical planning model, which presents the mission, vision, goals, objectives, and programs for reducing and eventually eliminating health disparities among minorities and other populations - elements of the model that will guide the remainder of this volume.

Captures the enduring focus of the organization - the organization's grand Mission purpose; why it exists and what needs it fulfills. Captures the desired end state of the organization and describes future direction. Provides unity of direction and long-term focus. Vision Identifies how the vision will be realized. Goals are longer term in nature, and are broad statements describing a desired future condition or achievement. Goals Provides additional specificity about how the goals will be accomplished. Objectives are more near term and measurable, and clearly describe an intended outcome. **Objectives** Identifies programs to support meeting the objectives. **Programs**

Strategic Planning Model

Mission to Reduce and Ultimately Eliminate Health Disparities

The mission is to promote minority health and to lead, coordinate, support, and assess the NIH effort to reduce and ultimately eliminate health disparities. In this effort the NCMHD will conduct and support basic, clinical, social, and behavioral research; promote research infrastructure and training; foster emerging programs; disseminate information; and reach out to minority and other health disparity communities.

Vision to Reduce and Ultimately Eliminate Health Disparities

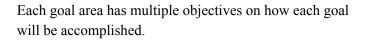
The vision to support minority health and health disparities is to envision an America in which all populations will have an equal opportunity to live long, healthy and productive lives.



Goals and Objectives to Reduce and Ultimately Eliminate Health Disparities

The Strategic Plan is focused on three major goals:

- Research
- Research Infrastructure; and
- Public Information and Community Outreach





Research. Research to advance our understanding of the development and progression of diseases and disabilities that contribute to health disparities in minority populations is central to this effort. Research includes advancing the understanding of diseases and disabilities. In addition, it includes developing new and improved approaches for detecting, diagnosing, preventing, treating or delaying onset or progression of diseases and disabilities that contribute to health disparities.

OBJECTIVES
 Advance understanding of the development and progression of diseases and disabilities that contribute to health disparities
 Develop new or improved approaches for detecting or diagnosing the onset or progression of diseases and disabilities that contribute to health disparities
 Develop new or improved approaches for preventing or delaying the onset or progression of diseases and disabilities that contribute to health disparities
 Develop new or improved approaches for treating diseases and disabilities that contribute to health disparities

Research Infrastructure. Just as a building is only as solid as its foundation, the success of the biomedical research enterprise depends on a solid infrastructure. Broadly defined, research infrastructure includes biomedical researchers and personnel and the means and resources for supporting and training them, as well as research facilities, equipment, and supportive services. The NIH recognizes that our ability to reduce health disparities through the research proposed in this plan requires a strong commitment to training and supporting investigators in these areas. Our ability to sustain and even increase the momentum of recent scientific progress and our international leadership in medical research depends upon recruitment, training, support, and retention of biomedical investigators from diverse population groups. To ensure this, the NIH has identified five research infrastructure objectives:

GOAL	OBJECTIVES
Research Infrastructure	 Expand opportunities in research training and career development for, and provide research supplements to, research investigators from minority and other special populations experiencing health disparities
	 Increase funding support for construction and renovation of research facilities across the nation aimed at enhancing the ability of these institutions to conduct health disparities research
	 Provide increased funding at institutions across the country for resources, new equipment and shared equipment programs for use in health disparities research
	■ Increase representation in peer review from minority and ethnic populations
	 Improve research data collection systems and enhance data quality regarding health disparities

Public Information and Community Outreach. Communicating the scientific and health information gained from research into health disparities is of paramount importance. These efforts extend beyond dissemination of the results of research to other scientists, and include the transmission of all information that may improve the health of minorities to the general public, patients, advocacy groups, health care providers, media, and policymakers. Additionally, this includes a comprehensive and aggressive outreach to those groups whom the research is intended to help and their health care providers. These messages must be tailored to the communities at highest risk for the adverse consequences of the health disparity in question. The efforts must also include producing health information that is culturally applicable, ensuring that it is disseminated to the appropriate communities, and assessing the effectiveness of these communication efforts. In the arena of public information and community outreach, our objectives include the following:

GOAL	OBJECTIVES			
Public Information and Community	 Provide the latest research-based information to healthcare providers to enhance the care provided to individuals within populations experiencing health disparities 			
Outreach	 Facilitate the incorporation of science-based information into the curricula of medical and allied health professions schools, and into continuing education activities of health professionals 			
	 Maintain ongoing communication linkages and dialogue with minority, ethnic, and other special populations, including the underserved, who experience health disparities 			
	 Develop computer databases and internet resources to disseminate current information about scientific research and discoveries and other activities regarding health disparities 			
	 Develop targeted public health education programs focused on particular disease areas in order to reach those individuals within minority, ethnic, and other special populations who experience health disparities within these disease areas 			

Overview of NIH Programs to Reduce and Ultimately Eliminate Health Disparities

This section highlights a number of the NIH programs related to minority health and health disparities research, research infrastructure, and public information and community outreach. The specific programs presented in this section are a representative sampling, selected for their depth of activities and breadth of scope in addressing minority health and health disparities. They do not represent the totality of the NIH program.



Each program outlines how objectives will be accomplished and identifies specific examples of how program performance will be measured through performance measures and/or outcome measures. Further information about each of the initiatives listed below, and a complete list of all IC initiatives and corresponding performance/outcome measures, can be found in Volume II of this strategic plan.

Sample Programs – Research. The research programs listed below are a representative example of the variety of ongoing and new research studies that NIH supports as part of its strategic plan for understanding and reducing health disparities among ethnic and racial minorities and other populations. The ultimate goal of these research efforts is to develop improved means for prevention, diagnosis, and treatment of diseases and disabilities that disproportionately affect specific populations. The table below outlines sample ongoing research programs and provides selected examples of program performance measures:

Selected Examples of Ongoing Programs: Research

IC PROGRAMS
 Multi-Ethnic Study of Atherosclerosis, Specialized Centers of Research (SCOR) on Ischemic Heart Disease in Blacks Glucose Tolerance and Risk for Cardiovascular Disease in the Elderly African America Diabetes Mellitus Study (AADM) African American Hereditary Prostate Cancer Study Network (AAHPC), Barbados Prostate and Breast Cancer Study Study of Hereditary Hemochromatosis and Iron Overload Disease in Diverse Populations
■ Inner-City Asthma Study
 National Household Survey on Drug Abuse Behavioral Therapy Development Program National Drug Abuse Treatment Clinical Trials Network (CTN)
■ Diabetes Prevention Program (DPP)
 National Institute of Mental Health's Child and Adolescent Research Consortium, the American Psychological Association, and Fordham University's Center for Ethics Education

Selected Examples of Measuring Program Performance

- Track the number of articles published in scientific journals
- Percentage increase mechanisms for healthcare providers to better diagnose, prevent, and treat minority health and health disparities
- Percent of studies which are "targeted studies"
- Percent of studies that are "Inclusion studies"
- Percent of total research budget spent on addressing minority health and health disparities
- Percentage research that influence policy
- Track rates of health disparity indicators and project a percent reduction of the those rates over a set period of time

Sample Programs – Infrastructure. Ongoing research infrastructure programs provide selected examples of the variety of ongoing and new research infrastructure activities that the NIH will support as part of its strategic plan for understanding and reducing health disparities among ethnic and racial minorities. The ultimate goal of these efforts is to support research, expand opportunities in training, foster career development, and increase research funding for health disparities research. The table below outlines sample ongoing research infrastructure programs in this area and provides selected examples of program performance measures:

Selected Examples of Ongoing Programs: Infrastructure

IC INFRASTRUCTURE OBJECTIVES	IC PROGRAMS
NIAID Provide training opportunities for minority scientists	Introduction to Biomedical Research ProgramBridging the Gap ProgramTraining Grants Program
NHLBI Expand the opportunities in research training and career development for underrepresented minorities.	 Historically Black Colleges and Universities (HBCU) Research Scientist Award NHLBI Mentored Development Award for Minority Faculty Biomedical Research Training Program for Underrepresented Minorities NHLBI Minority Institution Research Scientist Development Award
NIDDK Expand the genetic/familial studies of diabetic nephropathy to include more minority patients	 FIND Study – Family Investigation in Nephropathy of Diabetes
NINR Enhance research infrastructure allowing for an increased emphasis on projects relating to health disparities Enhance mentorship, training and research opportunities for minority students and researchers	 Center for Health Promotion and Risk Reduction in Special Populations Mentored Research Scientist Development Award for Minority Investigators (RFA: NR-00-002) Research Supplements for Underrepresented Minorities (RSUM)
NCI Increase the number of minority scientists in biomedical research and enhance the careers of those already in the field	 Center to Reduce Cancer Health Disparities (CRCHD) Comprehensive Minority Biomedical Program (CMBP) Continuing Umbrella of Research Experiences (CURE)
NCRR Increase research competitiveness through Institutional Development	 Institutional Development Award (IDeA) Biomedical Research Infrastructure Networks (BRIN) Centers of Biomedical Research Excellence (COBRE)

Selected Examples of Measuring Program Performance

- Monitor number and progress of minorities entering training programs (% increase in minorities entering training programs over previous years and number completing training programs)
- Increase and track the number of minority scientists engaged in research (establish targets)
- Increase and track minority subjects enrolled in research and clinical trails
- Percentage increase in partnerships with minority institutions
- Increase number of research projects addressing minority health and health disparities
- Track the number of articles published in scientific journals by minority investigators
- Number of minority faculty, post doctoral fellows, and graduate students trained while conducting research
- Number of competitive grants issued to minority researchers

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Sample Programs – Outreach. NIH is continuing its efforts to translate highly technical research advances into clear, culturally relevant explanations of the steps individuals can take to improve their health. The matrix below describes sample programs for enhancing communications and outreach related to the goal of reducing health disparities and provides selected examples of program performance measures:

Selected Examples of Ongoing Programs: Public Information and Community Outreach

IC OUTREACH OBJECTIVES	IC PROGRAMS
NIDCR Ensure the development, collection, and distribution of proven oral health communication and education methods/materials for populations associated with health disparities, to oral health education program planners Ensure the integration of science-based oral health messages and materials into existing federal health communication and education programs for racial/ethnic minorities and the underserved	 Health Communication and Information Dissemination Research: Opportunities in Oral Health Health Information National Trends Survey (HINTS) Administration for Children and Families' Head Start program USDA's Women, Infants, and
NHLBI Expand and strengthen our programs of outreach and education for minority populations.	 Children program (WIC) Asian American and Pacific Islander (AAPI) ASPIRE Project Strengthening the Heartbeat of American Indian/Alaska Native Communities
NIDA Put research into practice in minority communities by providing science-based prevention and treatment information to service providers serving these populations	■ NIDA Toolkit Program
NLM Explore the use of new information technologies to enable diabetes patients, especially patients from minority and medically underserved populations, to manage their disease and avoid or delay the onset of costly and debilitating complications	 Naomi Berrie Diabetes Center at Columbia/Presbyterian Hospital in New York City to study Type 1 diabetes Children's Hospital in Los Angeles Project

Selected Examples of Measuring Program Performance

- The number of materials developed or adapted for minority and underserved populations
- Linkages with minority organizations
- Collaborative relationships with federal, state and local agencies to improve communication to minority and underserved populations
- Research on communication methods that are effective for minority and underserved populations
- Utilization of published materials by schools and institutions
- Greater participation in, and awareness of, health disparity studies

NIH Minority Health and Health Disparities Budget

Table I provides total health disparities research budget figures for each NIH Institute and Center. These financial resources demonstrate the commitment of the NIH to help close the health disparity gap among ethnic minority populations and those living in rural areas. In order to make notable progress in the overall health of the nation, this funding will be used for conducting and supporting research, addressing the national need for minority scientists and health professionals and providing information to the relevant communities for improving health conditions.

Public Law 106-525 requires the NCMHD to report to the Congress by December 2003 recommendations for the methodology the NIH will use to determine the amount of NIH resources dedicated to the conduct and support of health disparities research.

The budget data for health disparities activities contained within the budget table in Volume I of this version of the NIH Strategic Research Plan and Budget to Reduce and Ultimately Eliminate Health Disparities used a definition of minority health and health disparities research that the NIH is currently refining in accordance with Public Law 106-525.

Because of concerns about current definitions, we are unable to provide the Congress with valid and reliable data on minority health disparities research in this report. In order to overcome this problem for our next report, and to further improve the quality of data, we submit to Congress, NIH has established an NIH Committee on Minority Health and Health Disparities Research Definitions and Application Methodology. The Committee is developing new definitions and a revised application methodology that will be used by the NIH for future reporting purposes. The Committee will develop a uniform NIH Guidance that:

- Provides NIH operational definitions, based on Public Law 106-525, for minority health and health disparities research,
- Provides a consistent methodology for applying the definitions,
- Contains the criteria necessary to identify both minority health and health disparities population groups and diseases, and
- Serves as the foundation for identifying, coding, tracking, and reporting on NIH activities and resources.

The NIH will be updating the Strategic Research Plan and Budget each year. Accordingly, the budget figures to be contained within the next iteration (2003) of the NIH Strategic Research Plan and Budget will be more precise, based upon the revised definitions and application methodology.

NATIONAL INSTITUTES OF HEALTH

Health Disparities (Dollars in millions)

Participating	FY 2001	FY 2002	FY 2003
ICs	Actual	Estimate	Estimate
NCI	\$350.3	\$392.4	\$439.4
NHLBI	218.2	240.0	256.8
NIDCR	19.0	21.7	23.3
NIDDK	126.0	145.0	157.0
NINDS	33.7	36.5	39.4
NIAID	579.5	659.5	743.9
NIGMS	149.8	169.4	180.4
NICHD	242.9	276.4	301.3
NEI	36.3	41.5	45.0
NIEHS	30.4	34.0	41.1
NIA	73.3	83.3	90.2
NIAMS	38.8	44.0	47.7
NIDCD	4.5	3.4	3.7
NIMH	160.0	181.1	196.3
NIDA	26.9	29.5	32.1
NIAAA	33.4	36.4	41.5
NINR	28.9	31.2	33.2
NHGRI	10.2	14.9	16.0
NIBIB**	n/a	n/a	n/a
NCRR	64.9	72.3	78.2
NCCAM	12.5	13.8	14.5
NCMHD	125.1	149.9	178.5
FIC	1.1	1.2	1.2
NLM	3.0	3.9	4.8
CC***	[1.2]	[1.2]	[1.2]
OD	2.8	2.6	2.6
NIH	2371.5	2683.9	2968.1

Figures for FY 2002 and FY 2003 are the most current estimates available and do not reflect final FY 2002 awards or FY 2003 Congressional action. Figures will be updated when the new definitions are available.

^{**} New Institute to be included in future reporting.

*** Clinical Center figures for FY 2002 and FY 2003 were not included in original estimates in the FY 2002 President's Budget and are therefore shown as non-add.

Conclusion

This document describes an ambitious plan being undertaken by the NIH for reducing and ultimately eliminating the increased burden or disease and premature mortality suffered by minority and medically underserved populations. This effort cuts across disease areas and organizational boundaries and involves a transagency commitment. It augments the efforts of each Institute and Center, and relevant program offices in the NIH Office of the Director in this important arena. As in many areas of research, more remains to be done. The medical research community working with, and informed by, the public, patients, health care providers, policymakers, and others has and will continue to develop new knowledge that leads to improvements in the prevention, diagnosis, and treatment of diseases and disabilities that contribute to health disparities.

In fiscal year 2001, the NIH spent over \$2 billion on research, research infrastructure, and public information and community outreach efforts to reduce health disparities. This provided a strong basis for further investments over the longer term – investments that promise substantial progress in reducing the incidence, prevalence, severity, and social and economic burdens of diseases and disabilities that affect racial and ethnic minorities and other health disparity populations.