# NATIONAL INSTITUTES OF HEALTH U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

NIH Health Disparities Strategic Plan Fiscal Years 2004-2008 Volume I

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#### **Forward**

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. The National Institutes of Health's (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.

The NIH provides institutional support to a wide variety of institutions, including minority-serving institutions. Such support benefits all students/faculty/others associated with the grantee institutions, not just minority students. 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.

To address the constant and confounding problem of health disparities experienced by affected communities, including the medically underserved population, the NIH is committed to and remains vigilant in supporting research to understand biological, socioeconomic, cultural, environmental, institutional, and behavioral factors affecting health disparities. Research is only one solution in a multifaceted effort. In addition to devoting resources toward the application of research programs, the NIH also is 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 updated version of the strategic plan NIH Health Disparities Strategic Plan, Fiscal Years 2004-2008 continues the NIH commitment toward implementing Public Law (P.L.) 106-525, The Minority Health and Health Disparities Research and Education Act of 2000. 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 plans to bring the full strength of NIH's research, training, and outreach programs to bear on the challenge of eliminating domestic health disparities by fostering the participation of a diverse biomedical and behavioral scientific workforce, which is essential to the success of our efforts.

Although 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 required the National Center on Minority Health and Health Disparities (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.

In October 2002, the NIH Director and the Director, NCMHD, established an NIH Committee on Minority Health and Health Disparities Research Definitions and Application Methodology, which developed new definitions and a revised application methodology that were used by the NIH in developing this updated version of the NIH Strategic Plan. The Committee developed uniform NIH Guidelines that:

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

Accordingly, the NIH budget figures contained within this revised iteration of the NIH Strategic Plan are based upon the NIH Guidelines. The NIH will continue to implement the plan and revise it based upon scientific opportunities and public input from affected communities.

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## **Executive Summary**

During the last 2 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, American Indians and Alaska Natives, Asian Americans, and Native Hawaiians and other Pacific Islanders, as well as low socioeconomic status (low-SES) populations and rural populations. 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 (including Human Immunodeficiency Virus [HIV] infection), 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

#### **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 racial and ethnic minorities and other health disparity populations.

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 ranks 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 will continue to lead to innovative diagnostics, treatments, and preventive strategies to reduce, and eventually eliminate, health disparities.

#### **VISION**

A time when all Americans have the opportunity for long, healthy, and productive lives.

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), and in consultation with the National Advisory Council on Minority Health and Health Disparities.

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. An evolving process, the strategic plan has been and will continue to be revised 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 web site 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 health disparities in racial and ethnic minority populations and other health disparity populations, including the medically underserved, by increasing and diversifying biomedical, behavioral, social science, and health services research, as well as cultural, linguistic, and social epidemiology research conducted and supported by the NIH.
- Research Capacity to create a culturally competent workforce by expanding opportunities for research training, career development, and institutional research capacity and infrastructure.
- Community Outreach, Information Dissemination, and Public Health Education to ensure the public, health care professionals, and research communities are informed and educated concerning the latest advances in minority health and health disparities research.

The objectives below, associated with each of these overarching goals, have been expanded in response to public comments received regarding the NIH Strategic Research Plan and Budget to Reduce and Ultimately Eliminate Health Disparities, Fiscal Years 2002-2006.

#### RESEARCH RESEARCH CAPACITY **OUTREACH OBJECTIVES OBJECTIVES OBJECTIVES** ■ Increase the number of ■ Provide the latest research-based Advance participants in clinical trials understanding of information to health care providers to the development from racial and ethnic enhance the care provided to and progression minority populations and individuals within racial and ethnic of diseases and other health disparity minority populations and other health populations and groups disparity populations and groups disabilities that Expand opportunities in ■ Facilitate the incorporation of sciencecontribute to research training and career based information into the curricula of health disparities Develop new or development in health medical and allied health professions improved disparities research schools, theological education approaches for ■ Increase the number of institutions, and public health schools, and into continuing education detecting or researchers conducting health activities of health professionals diagnosing the disparities research onset or Increase funding support for ■ Maintain ongoing communication progression of construction and renovation of linkages and partnerships with diseases and research facilities across the community-based and faith-based organizations, health care associations, disabilities that Nation aimed at enhancing the contribute to ability of these institutions to foundations, and academic institutions, health disparities conduct health disparities and foster dialogue with racial and Develop new or research ethnic minority populations and other improved health disparity populations and Provide increased funding at approaches for institutions across the country groups, including the underserved preventing or for resources, new equipment, Develop computer databases and

- 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
- In partnership with other agencies of the Department of Health and Human Services, advance understanding of the multifactorial causes of health disparities, including nonbiological bases of disease incidence and progression

- and shared equipment programs for use in health disparities research
- Increase representation in peer review from racial and ethnic minority populations and other health disparity populations and groups
- Promote the development of inter-institutional partnerships to develop a more diverse, culturally competent workforce
- Improve research data collection systems, enhance data quality regarding health disparities, and develop uniform data systems that facilitate strategies for the elimination of health disparities
- In collaboration with schools and programs of public health, state and local health departments, and academic health departments, support and promote community-based participatory research

- 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 to reach those individuals within racial and ethnic minority populations and other health disparity populations who experience health disparities within these disease areas
- Facilitate, document and disseminate practical strategies responsive to the health care needs, and appropriate to the cultural and linguistic needs, of communities throughout the United States
- Collaborate with public health and other health-oriented policy centers to translate research findings into policy documents that can be used by policy groups and other stakeholders to explain new discoveries from a policy perspective to decision makers

Specific initiatives to support these objectives are highlighted in Section IV, Volume I of the 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 IC initiatives can be found in Volume II of this strategic plan and reflect the broad continuum of this endeavor as ICs frequently review and update their plans.

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, American Indians and Alaska Natives, Asian Americans, Native Hawaiians and other Pacific Islanders, and underserved groups such as disadvantaged rural Whites. Overcoming such persistent health disparities and promoting health for all Americans rank among our Nation's foremost challenges.

The findings section of P.L. 106-525, the Minority Health and Health Disparities Research and

Education Act of 2000, notes the impact of health disparities upon minorities and upon the medically underserved across the nation:

# "(1) Despite notable progress in the overall health of the Nation, there are continuing disparities in the burden of illness and death experienced by African Americans, Hispanics, Native Americans, Alaska Natives and Asian Pacific Islanders, compared to the United States population as a whole.

White individuals, and many of them have the same health care access problems as do members of minority groups."

Section 485(d)(2) of the law states that the Director, National Center for Minority Health and Health Disparities (NCMHD), "shall give priority consideration to determining whether minority groups qualify as health disparity populations..."

The law defines the term "minority group" by reference to Section 1707 of the Public Health Service (PHS) Act, which states at paragraph (g):

- "(3) The term 'racial and ethnic minority group' means American Indians (including Alaska Natives, Eskimos, and Aleuts); Asian Americans; Native Hawaiians and other Pacific Islanders; Blacks; and Hispanics.
- (4) The term 'Hispanic' means individuals whose origin is Mexican, Puerto Rican, Cuban, Central or South American, or any other Spanish-speaking country."

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

In October 2003, the NIH Director and the Director, NCMHD, established an NIH Committee on Minority Health and Health Disparities Research Definitions and Application Methodology, which developed new definitions and a revised application methodology that were used by the NIH in developing this updated version of the NIH Strategic Plan. In January 2004, the Committee provided uniform NIH Guidelines that:

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.

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

The health disparity populations included in the NIH Guidelines and covered by the NIH Health Disparities Strategic Plan, Fiscal Years 2004-2008 are the minority groups delineated within Section 1707(g), PHS Act, above, as well as low socioeconomic status (low-SES) populations and rural populations. Hence, race and ethnicity as risk factors for disease are a scientific issue that must be addressed.

The Congress recognized, however, that the NIH Health Disparities Strategic Plan should be an evolving document and required that the Plan be reviewed annually and updated as appropriate. In this way, the Congress also foresaw that additional health disparity populations may be identified and provided in Section 485(d)(1) of the law a vehicle for the designation of additional health disparity populations as follows:

"A population is a health disparity population if, as determined by the Director of the Center after consultation with the Director of the Agency for Healthcare Research and Quality, 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."

In the future, as the *NIH Health Disparities Strategic Plan* is revised and updated over the years, and based upon the Institute of Medicine (IOM) Report described below, the NCMHD will work with the Agency for Healthcare Research and Quality to determine whether other populations meet this definition and should be designated as health disparity populations. Thus, future iterations of the plan will reflect the evolution of the development of health disparity populations.

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 led and will continue to lead to innovative diagnostics, treatments, and preventive strategies to reduce, and eventually eliminate, health disparities.

#### PUBLIC COMMENT

From late October 2003 to early January 2004, to receive public comment, the NCMHD posted on its web site the *NIH Strategic Research Plan and Budget to Reduce and Ultimately Eliminate Health Disparities*, *Fiscal Years* 2002-2006. Several major themes emerged from the public comments:

■ Increase the number of health disparities populations studied by the NIH; in other words add additional populations, such as: lesbian, gay, bisexual, and transgender communities; Haitians;

individuals suffering from orphan diseases; underrepresented Asian subpopulations; the mentally ill; men; prisoners; and the disabled.

- Use racially and culturally sensitive and appropriate communication and ensure that all
  communications with health disparities populations and their subgroups address their needs and
  perspectives.
- Expand the scope of scientific inquiry to include cultural, psychological, behavioral, social, racial, and gender-based influences on health, and study access to health care. Produce accurate "health disparities" definitions and data.
- Improve research infrastructure at minority academic institutions.
- Strengthen the capacity of minority communities by broadening partnerships and leveraging resources available from professional associations, health care organizations, academic institutions, and other community entities that serve minority communities.
- Distribute NIH resources equitably across all population groups by increasing research regarding men, American Indians and Alaska Natives, Hispanics, and groups from Southeast Asia.

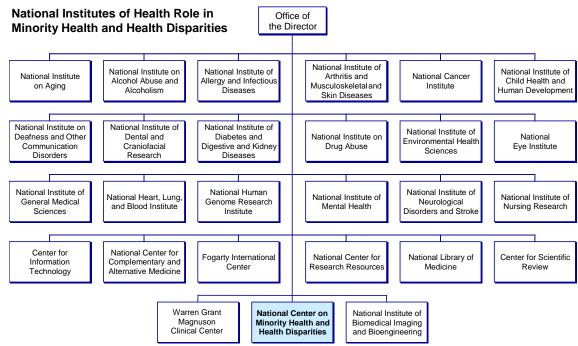
The public comments received were provided by the NCMHD to each of the NIH Institutes and Centers (ICs) and involved offices of the NIH Office of the Director (OD) for their consideration in developing their updated submissions contained within Volume II of the NIH Health Disparities Strategic Plan, Fiscal Years 2004-2008. Each IC and OD Office was asked specifically to address how they applied the public comments in developing their revised submission.

As indicated above, the NCMHD received a number of public comments recommending that additional groups be designated as health disparity populations. The NCMHD is sensitive to these comments and will follow the process described above to determine whether additional groups should be so designated. The thorough consideration of public comment will continue to be a fundamental component of the development of the *NIH Health Disparities Strategic Plan*.

## 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, composed of 27 ICs and other program offices in the OD, has long been committed to addressing and eliminating health disparities. The 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 ICs 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 NIH 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 capacitybuilding activities in 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

# 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

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 OD. Furthermore, the Center functions as the central repository for minority health and health disparity research information and fosters knowledge sharing among the ICs. 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 5-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. This plan allows for the evaluation of the NIH's progress and the extent to which the NIH meets its projected goals. The plan is not merely a compilation of all the activities of the relevant NIH entities, but rather aggregates the primary areas of emphasis and describes activities conducted across the agency, thereby providing 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 based on public comments received, public health need, scientific opportunity, changes in available funds, and other factors.

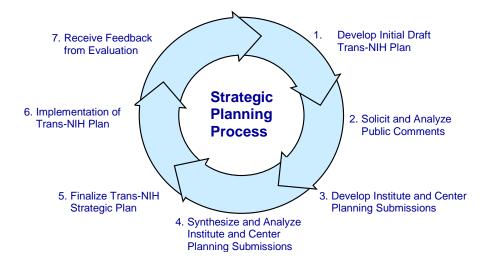
## ORGANIZATION OF THE STRATEGIC PLAN

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 ICs, as well as from NIH's Office of Research on Women's Health (ORWH), Office of Rare Diseases Research (ORD), Office of Intramural Research (OIR), 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 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  IV. Strategic Planning Model	Describes HHS and NIH efforts to address minority health and other health disparities and the coordination of the interdisciplinary approach  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	, p
Individual IC, ORWH, ORD, OIR, OAR, and OBSSR Strategic Plan Submissions	Provides IC, ORWH, ORD, OIR, 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 5-year Trans-NIH Strategic Plan incorporated the efforts of a Trans-NIH working group, which consisted of each NIH IC 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 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.



The first iteration of the *NIH Strategic Research Plan and Budget to Reduce and Ultimately Eliminate Health Disparities, Fiscal Years* 2002-2006, was submitted to the Congress in March 2003. The Plan was posted on the NCMHD web site for a 60-day public comment period from October 30, 2003 to January 5, 2004.

Accordingly, this revised and updated version of the 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.

After this initial draft in 2004, NIH policies continued to evolve further to reflect the Agency's mission and dedication to health disparities research. Consequently, each IC, the OBSSR, and the OAR reviewed and updated its strategic plan in concordance with these policies. This current plan reflects these modifications as of March 2007.

During the implementation of the Strategic Plan, the NCMHD will continue to seek additional public comment to aid in revising the plan. The Center also will continue to 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.

In addition, the NCMHD has asked the National Academy of Sciences/IOM to conduct a study that will review the NIH Strategic Research Plan. This review will assess the adequacy of the plan in achieving the NIH's goals and objectives regarding research, research infrastructure, and public information and community outreach. The study also will assess the adequacy of coordination across NIH ICs in helping to develop and carry out the elements of the strategic plan.

The primary product of this study will be a technical report, reviewed in accordance with National Research Council procedures. The report, will be widely disseminated to stakeholders, including the NCMHD, NIH ICs, scientific leaders, health policymakers (including the Congress and relevant

federal agencies), advocacy groups, major health care provider professional organizations, foundations, and relevant individuals and organizations. Copies of the report summary will be produced for broader distribution, and made available on the Internet through the National Academy Press (<a href="https://www.nap.edu">www.nap.edu</a>).

## Section II: Background on Minority Health and Health Disparities

The health disparities that afflict racial and ethnic 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 IC and certain offices within the NIH OD. A brief sample of relevant diseases follows:

- Infant Mortality During the last decade, the infant mortality rate has remained twice as high among African Americans as compared to Whites, even when controlling for socioeconomic factors. Native American and Alaska Native infants also have a death rate almost double that of Whites.
- Heart Disease and Stroke Cardiovascular disease takes a heavy toll on certain populations. Heart disease rates consistently have been higher in the African American population than in Whites. Data on stroke risk factors are sparse for most racial and ethnic populations, except for African Americans, whose stroke death rates, when adjusted for age, are almost 80 percent higher than those of Whites. Stroke death rates from 1991 to 1998 for people older than 35 years of age show that African American men (182 per 100,000 population) and women (153 per 100,000 population) have higher stroke death rates than any other race or ethnic group.
- Cancer Cancer deaths vary by gender, race, and ethnicity. Certain racial and ethnic groups have lower survival rates than Whites for most cancers. Colorectal cancer rates among Alaska Natives are higher than the national average, and Asian Americans suffer disproportionately from stomach and liver cancers. African American men have the highest rates of prostate, lung, colon/rectum, and oropharyngeal cancers.
  - Specifically, colorectal cancer incidence and death rates were higher among men than among women and were higher among African American men and women than among White men and women. Five-year trends in death rates in all states were stable or declined for both men and women, with the exception of African American men in Louisiana and Oklahoma.
- Mental Health The disease burden associated with mental disorders falls disproportionately on ethnic minority populations. Native Americans and Alaska Natives not only suffer disproportionately from depression, but this population also experiences a higher rate of suicide.
- **Type 2 Diabetes** The prevalence of diabetes in African Americans is nearly 70 percent higher than in Whites. American Indians, Hispanics, African Americans, and some Asian Americans, Native Hawaiians, and Pacific Islanders, including Japanese Americans and Samoans, are at particularly high risk for development of type 2 diabetes.
- **HIV and AIDS** The disproportionate impact of HIV/AIDS on certain populations underscores the importance of sustained research and prevention efforts. In 2002, the AIDS diagnosis rate among African Americans was almost 11 times the rate among Whites. African American

women had a 23 times greater diagnosis rate than White women. African American men had almost a nine times greater rate of AIDS diagnosis than White men. In addition, the AIDS incidence per 100,000 population among Hispanics in 2000 was 22.5, more than three times the rate for Whites.

The table that follows further describes, in quantitative terms, health disparities for 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. These data were 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 ISLAND ER	AMERICAN INDIAN or ALASKA NATIVE
Infant mortality rate per 1,000 live births <sup>1</sup>	5.9	13.9	5.8	5.1	9.1
Cancer mortality rate per 100,000 <sup>2</sup>	199.3	255.1	123.7	124.2	129.3
Lung cancer – age- adjusted death rate <sup>3</sup>	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 <sup>2</sup>	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 <sup>2</sup>	218	873	DNA	344	589
AIDS – diagnosed rate per 100,000 <sup>4</sup>					
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.
- <sup>2</sup> Healthy People 2010. Understanding and Improving Health (Second Edition). Department of Health and Human Services. November 2000.
- <sup>3</sup> 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, pp. 1-16.
- <sup>4</sup> HIV/AIDS Surveillance Report. *U.S. HIV and AIDS Cases Reported Through December 2001 Year-End Edition*. Slides 13 & 14. (Available at: http://www.cdc.gov/hiv/graphics/surveill.htm).
- <sup>5</sup> National Vital Statistics Reports. 2002 Deaths: Leading Causes for 2000. Vol. 50:16:1-41.

#### MULTIFACTORIAL BASIS OF HEALTH DISPARITIES

The causes of health disparities are posited to be multifactorial and hence 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 other underserved populations as well. The common denominator in the latter case is related to low SES and the protean effects of poverty on health.

A Framework for Understanding the Relationship Between Race and Health HEALTH PRACTICES Smoking BIOLOGICAL PSYCHOLOGICAL STRESS Family Stress CULTURAL FACTORS ENVIRONMENTAL SOCIO-ECONOMIC STRESS RACE BIOLOGICAL HEALTH Residential Stress **FACTORS** PROCESSES Occupational Stress PSYCHOSOCIAL RACISM RESOURCES Social Ties Perceptions of Contro POLITICAL FACTORS MEDICAL CARE Access

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

SES/Education Level. An extensive body of literature has demonstrated a strong association between health and SES. (The highest educational level achieved is often considered one of the best indicators of SES.) For instance, Marmot and colleagues have shown that illness and mortality decreased in British civil servants as measures of SES rose. Low SES and poor health were most closely correlated with a perception of reward imbalance and lack of control in the workplace. This also correlated with an increase in fibrinogen, a biological marker of inflammation and certain chronic disease states. The negative health effects of depressed SES are relevant to many racial and ethnic minorities, as well as to underserved White populations.

**Biology.** Even after controlling for SES 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 SES 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 to 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

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<sup>&</sup>lt;sup>1</sup> 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.

minorities and other health disparity groups suffer from barriers to medical care for multiple reasons, (i.e., lack of insurance; unemployment; 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, although disadvantaged Whites who are unemployed or uninsured face many of the same issues. Equalizing access, however, 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 SES.

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.** 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.

## COORDINATION OF A TRANS-NIH 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 trans-NIH 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 interagency 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 conditions that afflict health disparity groups cut across boundaries of several ICs. Examples include coronary artery disease, diabetes, obesity, depression, and behavioral factors that contribute to all of these diseases and conditions. This suggests a need for enhanced collaboration among the ICs in conducting health disparity research. In addition, ICs that are traditionally biological must develop an increased awareness of, and an integration with, the non-biological factors contributing to disease, for example by 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 essential that the ICs 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 ICs and Offices is important in this effort. Once again, establishing and sharing best practices in this regard would be highly beneficial.

- To facilitate research toward reducing health disparities, it is important to strengthen the research infrastructure at diverse academic institutions interested in pursuing health disparities research. It is anticipated that support of academic institutions engaged in health disparities research will be accompanied by a concurrent increase in the number of researchers examining health disparities, and in the scope and depth of health disparities research.
- Finally, 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 ICs can learn from each other in establishing best practices in measuring outcomes related to the reduction of health disparities.

Support for the aforementioned endeavors is emphasized in the White House Executive Orders, the Higher Education Act of 1965, as amended, the NIH Reform Act of 1993, as amended, the NIH Reform Act of 2006, as amended, and the NIH Research Supplements to Promote Diversity in Health-Related Research (PA 05-015), as highlighted below:

Executive Order 13256: President's Board of Advisors on Historically Black Colleges and Universities. The President's Board of Advisors on Historically Black Colleges and Universities was established to provide advice to the President and to Historically Black Colleges and Universities (HBCUs) toward the promotion of the long-term viability and enhancement of these institutions. Participating executive departments and agencies emphasize programs and activities that develop the capacity of HBCUs in the areas of: (1) infrastructure development and acquisitions for instruction and research; (2) student and faculty doctoral fellowships and faculty development; (3) domestic and international faculty and student exchanges and study abroad opportunities; (4) undergraduate and student internships; and (5) summer, part-time, and permanent employment opportunities.

Executive Order 13230: President's Advisory Commission on Educational Excellence for Hispanic Americans. The White House Initiative on Educational Excellence for Hispanic Americans was established to aid in the elimination of the educational achievement gap of Hispanic Americans by promoting efforts to increase participation of Hispanic Americans in federal education programs and services. In addition, there is an emphasis on including Hispanic-serving school districts, Hispanic-serving institutions, and other educational institutions for Hispanic Americans in federal education programs and services.

Executive Order 13270: Tribal Colleges and Universities. The President's Board of Advisors on Tribal Colleges and Universities was established to advise the President through the Secretary of Education on ways the federal government can help tribal colleges strengthen the viability of educational institutions; promote federal education initiatives; enhance physical infrastructure to facilitate more efficient operation and effective recruitment and retention of students and faculty; and help implement the No Child Left Behind Act of 2001.

Executive Order 13125: Increasing Participation of Asian Americans and Pacific Islanders in Federal Programs. The President's Advisory Commission on Asian Americans and Pacific Islanders was established to provide advice to the President through the Secretary of Health and Human Services on the facilitation of federal efforts to improve the quality of life of Asian Americans and Pacific Islanders through increased participation in federal programs where such

persons may be underserved. This Commission also promotes the collection of public health data related to Asian American and Pacific Islander populations and sub-populations through increasing community involvement in improving health and well being, and through conducting research and collecting data on public health in this community.

NIH Revitalization Act of 1993 (PL 103-43). The NIH Revitalization Act of 1993 required the NIH to conduct and support research, research training, and other activities that provide for an increase in the number of women and individuals from disadvantaged backgrounds, such as racial and ethnic minorities, in research activities (U.S. Congress, 1993). This Act echoed the intent of the 1980 Science and Engineering Equal Opportunities Act, which not only authorized the National Science Foundation (NSF), but also pronounced it to be in the national interest to promote and encourage the full use of human resources in science and engineering, and called for substantial support to increase participation by women, minorities, and disabled persons (U.S. Congress, 1980).

**NIH Reform Act of 2006 (P.L. 109-482).** Specific sections within the NIH Reform Act of 2006 relevant to health disparities research focused primarily on the authorities of the NIH Director and on the writing of the Biennial Report. Within this Act, Section 402 (b) (4) states that the Secretary of Health and Human Services, acting through the NIH Director, "shall assemble accurate data to be used to assess research priorities, including information to better evaluate scientific opportunity, public health burdens, and progress in reducing health disparities."

Several sections of the NIH Reform Act of 2006 describe important components to be included in the Biennial Report: (1) in the case of clinical research, the Act requires that study populations be identified by demographic and other variables that contribute to research on minority health and health disparities (Section 403 (a) (4) (B)) to ensure compliance with Section 492B regarding the inclusion of women and minorities in clinical research (Section 403 (a) (4) (C) (v)); (2) that research activities listed in the report include training activities, including National Research Service Awards, and a breakdown by demographic variables and other appropriate categories (Section 403 (a) (4) (C) (iv) (IV)); and (3) that the summary of the research activities include a category for minority health and health disparities (Section 403 (a) (5) (K)).

## NIH Research Supplements to Promote Diversity in Health-Related Research (PA 05-015).

These research supplements were formerly known as *Research Supplements for Underrepresented Minorities* and *Research Supplements for Individuals With Disabilities* and have broad eligibility criteria that include consideration of a larger number of backgrounds that could disadvantage individuals. The primary aim of these supplements is to promote diversity in the biomedical, behavioral, and clinical and social sciences research workforce through the recruitment and retention of (1) individuals from racial and ethnic groups shown to be underrepresented in the health-related sciences by the NSF; (2) individuals with disabilities; and (3) individuals from disadvantaged backgrounds.

Congress established the NCMHD to play the central role in leading, coordinating, and monitoring health research and training efforts toward reducing and ultimately eliminating health disparities. Initial steps toward this goal were to develop and continue to update the NIH Health Disparities Strategic Plan and to expand on the NIH's collaboration with other agencies that promote research and training in health disparities.

Although the NIH currently provides multiple opportunities to develop research careers and improve participation for individuals from groups with low representation in the biomedical and behavioral sciences, reports from the National Science Foundation (NSF)

(<u>http://www.nsf.gov/sbe/srs/women/start.htm</u>) and others provide strong evidence that insufficient diversity remains an important problem that the entire research enterprise must actively address.

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

#### **HHS EFFORTS**

In developing the NIH Strategic Plan, a review of existing HHS activities to address minority health and other health disparities was undertaken to ensure that the 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 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 because 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 HHS to eliminate the disparities in six areas of health status experienced by racial and ethnic minority populations.
- Complementing the *Initiative to Eliminate Racial 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 (USDA) 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.

The 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 U.S. population, especially racial and ethnic minority and other health disparity populations.

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

In response to several White House Executive Orders (13256, 13230, 13270, 13125), the HHS Office of Minority

# 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

Health has provided support to several National Youth Initiatives. These programs are designed to increase the pool of minority and underrepresented students entering health-related fields that have not traditionally produced significant numbers of minority and underrepresented health professionals in the academic pipeline. Various agencies of HHS, including ICs within the NIH, support the

Initiatives. The primary goal is to contribute to the reduction of racial and ethnic health disparities through increased availability of minority health care providers and researchers.

Scholars selected to participate in the Initiatives are economically disadvantaged students who reside in urban areas across the United States. The Initiatives are specifically tailored to provide them with perspectives on (1) health care delivery in the United States; (2) the importance of biomedical research and the health sciences in improving the health of the Nation; (3) other opportunities for health careers in government and the private sector; and (4) health disparities facing racial and ethnic minority populations. The Initiatives emphasize health promotion and disease prevention through attitudinal and behavioral change and include an emphasis on issues of violence and crime, HIV/AIDS, substance abuse, teen pregnancy prevention, nutrition, tobacco use prevention, and children's health initiatives. Student activities include: site visits to agencies within HHS to explore health-related professions, exposure to a national network of health professionals and scientists who serve as role models and mentors, and participation in lectures and workshops.

Some projects are co-funded with other organizations such as the Interamerican College of Physicians and Surgeons (ICPS), the National Medical Association (NMA), the Association of American Indian Physicians (AAIP), and the Asian and Pacific Islander American Health Forum (APIAHF).

#### NCMHD EFFORTS

Among its many activities, the NCMHD addresses the national need to develop a diverse, strong, and culturally competent scientific workforce by eliminating barriers that prevent racial and ethnic minority students and students from disadvantaged backgrounds from pursuing research careers.

The NCMHD has accomplished much since its creation. Today, the NCMHD has 71 Health Disparities Centers of Excellence spread across the nation. These Centers of Excellence, now located in 26 states, the District of Columbia, and Puerto Rico, support health disparities research and research training and community involvement to identify factors that contribute to health disparities and to develop and implement new diagnostic, treatment, and prevention strategies.

Currently, the NCMHD supports more than 450 young scientists in all but eight states across the country through its two Loan Repayment Programs, which help to level the playing field and make it possible for underrepresented individuals to enter the scientific, technological, and engineering workforce. These Health Disparities Ambassadors are key to creating the culturally competent scientific and clinical research workforce of the future.

The NCMHD also has created a one-of-a-kind Research Endowment Program (PHS Act, Section 485E(h), as amended). Unique at the NIH, this program addresses the national need to build research and training capacity in institutions that make significant investments in the education and training of minority and disadvantaged individuals. This program is making it possible for 14 institutions to establish health disparities endowed chairs and programs; enhance student recruitment efforts; provide merit-based scholarships; recruit and retain faculty; develop innovative instruction delivery systems in minority and health disparities research areas; and access emerging technologies.

The NCMHD has supported the development of the research infrastructure and capacity at resource-limited institutions through a number of its programs. One such program is the Research Infrastructure in Minority Institutions (RIMI) Program, which was born out of a partnership between the NIH National Center for Research Resources and the former NIH Office of Research on Minority Health (the predecessor to the NCMHD). The RIMI is making it possible for institutions to target research efforts on health disparities that exist in the Southwest Border States; in rural communities, such as the Appalachia Region, the Mississippi Delta, and the Frontier States; and in urban centers of the nation. Since assuming responsibility for the RIMI program, the NCMHD has tripled the number of participating institutions.

In addition to using its core programs, the NCMHD strategy to eliminate health disparities also includes leveraging NIH dollars and expertise by creating partnerships with the NIH ICs and other agencies within HHS to fund health disparities research, training, and outreach programs. The NCMHD has provided support to more than 400 collaborative research projects.

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)*, the Agency for Healthcare Research and Quality's *Excellence Centers to Eliminate Racial and Ethnic Health Disparities (EXCEED)* programs, and the Indian Health Service's *Tribal Epidemiology Centers* program.

## **Summary**

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.

NIH supports the position that there are compelling reasons to promote a diverse workforce and increase participation and representation among underrepresented groups. Advancing diversity through NIH training support programs is expected to produce a number of tangible and overlapping benefits, including:

- Enhancing the overall capacity to address and eliminate health disparities;
- Improving the overall quality of the training and educational environment;
- Creating and preparing a culturally competent workforce; and
- Increasing the recruitment of the most talented researchers from all groups.

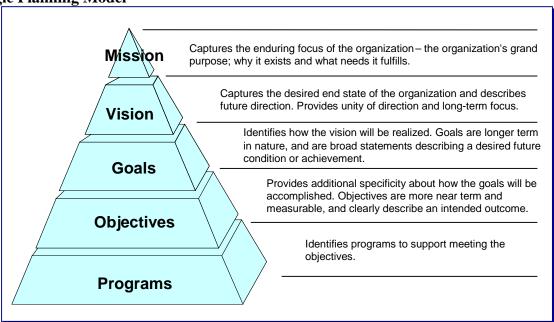
Although NIH-funded research yields information important to addressing the complex problems among racial and ethnic minorities and other underserved populations, it is only a part of a

multifaceted 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.

**Strategic Planning Model** 



#### MISSION TO REDUCE AND ULTIMATELY ELIMINATE HEALTH DISPARITIES

The NCMHD leads, coordinates, supports, and assesses the NIH effort to reduce and ultimately eliminate health disparities. In this effort the NCMHD conducts and supports basic, clinical, social, and behavioral research; promotes research infrastructure and training; fosters emerging programs; disseminates information; and reaches out to minority and other health disparity communities.



# VISION TO REDUCE AND ULTIMATELY ELIMINATE HEALTH DISPARITIES

The vision to support minority health and the elimination of 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 focuses on three major goals:

- Research
- Research Capacity; and
- Community Outreach, Information Dissemination, and Public Health Education



Each goal area has multiple objectives relating to how each goal will be accomplished.

**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 developing new and improved approaches for detecting, diagnosing, preventing, treating, or delaying onset or progression of diseases and disabilities that contribute to health disparities. It also includes advancing understanding of the multifactorial causes of health disparities.

GOAL	OBJECTIVES		
Research	<ul> <li>Advance understanding of the development and progression of diseases and disabilities that contribute to health disparities.</li> </ul>		
	<ul> <li>Develop new or improved approaches for detecting or diagnosing the onset or progression of diseases and disabilities that contribute to health disparities.</li> </ul>		
	<ul> <li>Develop new or improved approaches for preventing or delaying the onset or progression of diseases and disabilities that contribute to health disparities.</li> </ul>		
	<ul> <li>Develop new or improved approaches for treating diseases and disabilities that contribute to health disparities.</li> </ul>		
	<ul> <li>In partnership with other agencies of HHS, advance understanding of the multifactorial causes of health disparities, including non-biological bases of disease incidence and progression.</li> </ul>		

Research Capacity. 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 capacity 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 depend upon recruitment, training, support, and retention of biomedical and behavioral investigators from diverse population groups. To ensure this, the NIH has identified nine research capacity objectives:

GOAL	OBJECTIVES		
Research	■ Increase the number of participants in clinical trials from racial and ethnic		
Capacity	minority populations and other health disparity populations and groups.		
	Expand opportunities in research training and career development. Increase		
	the number of researchers conducting health disparities research.		
	■ 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.		
	<ul> <li>Increase representation in peer review from racial and ethnic minority</li> </ul>		
	populations and other health disparity populations and groups.		
	■ Promote the development of inter-institutional partnerships in order to develop		
	a more diverse, culturally competent workforce.		
	■ Improve research data collection systems, enhance data quality regarding		
	health disparities, and develop uniform data systems that facilitate strategies		
	for the elimination of health disparities.		
	■ In collaboration with schools and programs of public health, state and local		
	health departments, and academic health departments, support and promote		
	community-based participatory research.		

## Community Outreach, Information Dissemination, and Public Health Education.

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 racial and ethnic minorities and other health disparity populations 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 community outreach, information dissemination, and public health education our objectives include the following:

GOAL	OBJECTIVES
Outreach	<ul> <li>Provide the latest research-based information to health care providers to enhance the care provided to individuals within racial and ethnic minority populations and other health disparity populations.</li> <li>Facilitate the incorporation of science-based information into the curricula of medical and allied health professions schools, theological education institutions, and public health schools, and into continuing education activities of health professionals.</li> <li>Maintain ongoing communication linkages and partnerships with community-based and faith-based organizations, health care associations, foundations, and academic institutions, and foster dialogue with racial and ethnic minority populations and other health disparity populations, including the underserved.</li> <li>Develop computer databases and Internet resources to disseminate current information about scientific research and discoveries and other activities regarding health disparities.</li> <li>Develop targeted public health education programs focused on particular disease areas to reach those individuals within racial and ethnic minority populations and other health disparity populations who experience health disparities within these disease areas.</li> <li>Facilitate, document, and disseminate practical strategies responsive to the health care needs, and appropriate to the cultural and linguistic needs, of communities throughout the United States.</li> <li>Collaborate with public health and other health-oriented policy centers to translate research findings into policy documents that can be used by policy groups and other stakeholders to explain new discoveries from a policy perspective to decision makers.</li> </ul>

# 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 capacity, 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 description 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 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 representative examples of the variety of 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 research programs and provides selected examples of program performance measures:

**Selected Examples of Programs: Research** 

Selected Examples of Programs: Research				
IC AND RESEARCH OBJECTIVES	IC PROGRAMS			
National Heart, Lung, and Blood Institute (NHLBI) Support research to increase understanding of the development and progression of heart, lung, and blood diseases and sleep disorders that contribute to health disparities.	<ul> <li>Multi-Ethnic Study of Atherosclerosis,</li> <li>Specialized Centers of Research (SCOR) on Ischemic Heart Disease in Blacks</li> <li>Glucose Tolerance and Risk for Cardiovascular Disease in the Elderly</li> </ul>			
National Human Genome Research Institute (NHGRI) Study genetic factors that contribute to diseases disproportionately affecting minority populations.	<ul> <li>African American Diabetes         Mellitus Study (AADM)</li> <li>African American Hereditary         Prostate Cancer Study Network         (AAHPC)</li> <li>Barbados Prostate and Breast         Cancer Study</li> <li>Study of Hereditary         Hemochromatosis and Iron         Overload Disease in Diverse         Populations</li> </ul>			
National Institute of Allergy and Infectious Diseases (NIAID) Reduce disparities in the incidence and prevalence of asthma.	■ Inner-City Asthma Study			
National Institute on Drug Abuse (NIDA) Address racial/ethnic disparities in basic neuroscience, epidemiology, prevention, treatment, and service delivery of drug abuse and its related health consequences, including infectious diseases.	<ul> <li>Monitoring the Future</li> <li>Community Epidemiology Work Group</li> <li>Behavioral Therapy Development Program</li> <li>National Drug Abuse Treatment Clinical Trials Network (CTN)</li> </ul>			

National Institute of Diabetes and Digestive and	<ul> <li>Diabetes Prevention Program</li> </ul>
Kidney Diseases (NIDDK)	(DPP)
Combine genetic linkage data from collaborating	
research groups and identify regions of the human	
genome that show evidence for linkage in type 2	
diabetes.	
National Institute of Mental Health (NIMH)	<ul> <li>National Institute of Mental</li> </ul>
National Institute of Mental Health (NIMH) Identify factors that overcome health disparities	<ul> <li>National Institute of Mental Health's Child and Adolescent</li> </ul>
Identify factors that overcome health disparities	Health's Child and Adolescent
Identify factors that overcome health disparities related to health service delivery and use by ethnic	Health's Child and Adolescent Research Consortium, the

# National Institute of Nursing Research (NINR) Demonstrate community partnerships to reduce health disparities in racial and ethnically diverse minority populations.

Identify and address the disparities in health and health outcomes among racial and ethnic minority males.

 Interventions to Reduce Health Disparities

Education

University's Center for Ethics

Health Promotion Among Racial & Ethnic Minority Males

# **Selected Examples of Measuring Program Performance**

- Tracking of the number of articles published in scientific journals
- Percentage increase mechanisms for health care providers to better diagnose, prevent, and treat conditions related to minority health and health disparities
- Percentage of studies that are "targeted studies"
- Percentage of studies that are "inclusion studies"
- Percentage of total research budget spent on addressing minority health and health disparities
- Percentage of research that influences policy
- Tracking of rates of health disparity indicators and projection of a percent reduction of the those rates over a set period of time

**Sample Programs – Research Capacity.** Research capacity programs provide selected examples of the variety of activities that the NIH supports 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 research capacity programs in this area and provides selected examples of program performance measures:

**Selected Examples of Programs: Research Capacity** 

Selected Examples of Programs: Research Capacity			
IC AND RESEARCH CAPACITY OBJECTIVES	IC PROGRAMS		
National Institute of Allergy and Infectious Diseases (NIAID) Provide training opportunities for scientists from underrepresented and disadvantaged backgrounds.	<ul> <li>Introduction to Biomedical Research Program</li> <li>Bridging the Gap Symposia</li> <li>Training Grants Program</li> </ul>		
National Heart, Lung, and Blood Institute (NHLBI)  Expand the opportunities in research training and career development for students and faculty from underrepresented and disadvantaged backgrounds.	<ul> <li>Historically Black Colleges and Universities (HBCU)</li> <li>Research Scientist Award</li> <li>NHLBI Mentored Career Development Award to Promote Faculty Diversity in Biomedical Research (K01)</li> <li>Biomedical Research Training Program for Individuals from Underrepresented Groups (BRTPUG)</li> <li>NHLBI Minority Institution Research Scientist Development</li> </ul>		
National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK)  Expand the genetic/familial studies of diabetic nephropathy to include more minority patients.	Award  FIND Study – Family Investigation in Nephropathy of Diabetes		
National Institute of Nursing Research (NINR) Enhance research infrastructure, allowing for an increased emphasis on projects relating to health disparities. Enhance mentorship, training, and research opportunities for students and researchers from underrepresented and disadvantaged backgrounds	<ul> <li>NINR Mentored Research Scientist Development Award for Underrepresented or Disadvantaged Investigators (K01)</li> <li>Research Supplements to Promote Diversity in Health- Related Research</li> </ul>		
National Cancer Institute (NCI) Increase the number of scientists from underrepresented and disadvantaged backgrounds in biomedical research and enhance the careers of those already in the field.	<ul> <li>Center to Reduce Cancer</li> <li>Health Disparities (CRCHD)</li> <li>Comprehensive Minority</li> <li>Biomedical Program (CMBP)</li> <li>Continuing Umbrella of</li> <li>Research Experiences (CURE)</li> </ul>		

# National Center for Research Resources (NCRR)

Increase research competitiveness through Institutional Development (Section 481A(c)(2)(D)i of PHS Act, as amended).

- Institutional Development Award (IDeA)
- Biomedical Research Infrastructure Networks (BRIN)
- Centers of Biomedical Research Excellence (COBRE)

# The Eunice Kennedy Shriver Institute for Child Health and Human Development (NICHD)

Promote the entry and participation of institutions with a traditionally high (more than 50 percent) minority student enrollment in biomedical and behavioral research and research training. Improve the research capacity and infrastructure at institutions with traditionally high (more than 50 percent) minority student enrollment. Increase the number of competitive grants issued to institutions with traditionally high (more than 50 percent) minority student enrollment. Monitor number and progress of scientists entering training programs, including but not limited to Black Americans, Hispanic Americans, Asians/Pacific Islanders, and American Indians/Native Alaskans (Native Americans). Increase and track the number of scientists engaged in research, including but not limited to Black Americans, Hispanic Americans, Asians/Pacific Islanders, and American Indians/Native Alaskans (Native Americans). Increase and track subjects enrolled in research and clinical trials, including but not limited to Black Americans, Hispanic Americans, Asians/Pacific Islanders, and American Indians/Native Alaskans (Native Americans). Increase research partnerships with institutions that

have traditionally high (more than 50 percent) minority student enrollment in biomedical and behavioral research and research training. Increase the number of research projects addressing minority health and health disparities. Track the number of articles published in scientific journals by investigators who include but are not limited to Black Americans, Hispanic Americans, Asians/Pacific Islanders, and American Indians/Native Alaskans (Native Americans). Increase the number of faculty, postdoctoral fellows, and graduate students trained in biomedical and behavioral research, including but not limited to Black Americans, Hispanic Americans, Asians/Pacific Islanders, and American Indians/Native Alaskans (Native Americans).

- Extramural Associates (EA)Program
- Extramural Associates
   Research Development Award
   (EARDA) Program

## **Selected Examples of Measuring Program Performance**

- Monitor the number and progress of students from underrepresented and disadvantaged backgrounds entering training programs (e.g., percent increase in minorities entering training programs over previous years and number completing training programs).
- Increase and track the number of scientists from underrepresented and disadvantaged backgrounds engaged in research (establish targets).
- Increase and track subjects from underrepresented and disadvantaged backgrounds enrolled in research and clinical trials.
- Determine the percentage increase in partnerships with institutions serving primarily underrepresented and disadvantaged populations.
- Increase the number of research projects addressing minority health and health disparities.
- Track the number of articles published in scientific journals by investigators from underrepresented and disadvantaged backgrounds.
- Determine the number of faculty, postdoctoral fellows, and graduate students of underrepresented and disadvantaged backgrounds trained while conducting research.
- Determine the number of competitive grants issued to researchers from underrepresented and disadvantaged backgrounds.

Sample Programs – Community Outreach, Information Dissemination, and Public Health Education. The 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 Programs: Outreach

Science Examples of Frograms. Outreach			
IC AND OUTREACH OBJECTIVES	IC PROGRAMS		
National Institute of Dental and Craniofacial	<ul> <li>Health Communication and</li> </ul>		
Research (NIDCR)	Information Dissemination		
Ensure the development, collection, and distribution of	Research: Opportunities in		
proven oral health communication and education	Oral Health		
methods/materials for populations associated with	<ul><li>Health Information National</li></ul>		
health disparities to oral health education program	Trends Survey (HINTS)		
planners.	• , , ,		
Ensure the integration of science-based oral health	<ul> <li>Administration for Children</li> </ul>		
messages and materials into existing federal health	and Families' Head Start		
communication and education programs for	program		
racial/ethnic minorities and the underserved.	■ USDA's Women, Infants, and		
	Children program (WIC)		

National Heart, Lung, and Blood Institute (NHLBI) Expand and strengthen our programs of outreach and education for minority populations.  National Institute on Drug Abuse (NIDA)	<ul> <li>Asian American and Pacific Islander (AAPI) ASPIRE Project</li> <li>Strengthening the Heartbeat of American Indian/Alaska Native Communities</li> <li>NIDA Toolkit Program</li> </ul>
Put research into practice in minority communities by providing science-based prevention and treatment information to service providers serving these populations.	
National Library of Medicine (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.	<ul> <li>Naomi Berrie Diabetes Center at Columbia/Presbyterian Hospital in New York City to study type 1 diabetes</li> <li>Children's Hospital in Los Angeles Project</li> </ul>

## **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

**Sample Programs – Cross-Cutting.** In conjunction to the individual IC programs geared towards research, research capacity and outreach, there are a variety of cross-cutting programs that all of the ICs participate in. The table below outlines several programs and their objectives:

**Selected Examples of Programs: Cross-Cutting** 

CROSS-CUTTING PROGRAMS	PROGRAM OBJECTIVES	
Undergraduate Scholarship Program	<ul> <li>Provide scholarships to students from</li> </ul>	
(UGSP)	disadvantaged backgrounds to pursue	
-Section 487D of PHS Act, as amended	careers in professions needed by the NIH	
Clinical Research Loan Repayment	■ Provide, for each year of clinical research	
Program for Individuals from	service, not more than \$35,000 of	
Disadvantaged Backgrounds (CRLRPDB)	principal and interest of the educational	
-Section 487E of PHS Act, as amended	loans of qualified health professionals	
	who are from disadvantaged backgrounds	

Visiting Scientist Awards -Section 488 of PHS Act, as amended	<ul> <li>Provide Visiting Scientist Awards to individuals who agree to serve as visiting scientists at institutions of post-secondary education that have significant enrollments of disadvantaged students</li> </ul>
Research Supplements to Promote Diversity in Health-Related Research (Diversity Supplements) -PA-05-015	<ul> <li>Promote diversity in the biomedical, behavioral, clinical and social sciences workforce</li> </ul>
Ruth L. Kirschstein National Research Service Award (NRSA) -Section 487(a)(4) of PHS Act, as amended	<ul> <li>Provide biomedical and behavioral research and research training programs that will result in the recruitment of women and individuals from disadvantaged backgrounds (including racial and ethnic minorities)</li> </ul>
MARC Undergraduate Student Training in Academic Research, Institutional NRSA Research Training Grant (T34) -PAR-07-337	<ul> <li>Support undergraduate research training to help ensure that a diverse and highly trained workforce is available to assume leadership roles related to the Nation's biomedical and behavioral research agenda</li> </ul>
MBRS Support of Competitive Research (SCORE) Institutional Development Award -Section 301(a)(3) of the PHS Act, as amended (42 U.S.C. 241 (a)(3))	<ul> <li>Support research projects that foster diverse faculty and student participation in biomedical research, thereby helping to create a growing and diverse cadre of scientists who are making important contributions in the health sciences</li> </ul>

# NIH Minority Health and Health Disparities Budget

The tables below, based upon the new NIH Guidelines, provide total minority health and health disparities research budget figures for each NIH IC. 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. 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.

# NATIONAL INSTITUTES OF HEALTH **Health Disparities**

(Dollars in Millions)

Participating	FY 2003*	FY 2003**	FY 2004**	FY 2005**
ICs	Actual - Old Def.	Actual - New Def.	Actual	Actual
NCI	\$414.0	\$256.6	\$264.8	\$272.9
NHLBI	279.0	276.9	295.3	295.6
NIDCR	27.1	36.9	42.3	36.5
NIDDK	237.9	196.4	197.7	205.0
NINDS	57.2	77.9	73.8	111.3
NIAID	734.7	282.9	338.1	343.9
NIGMS	162.0	174.6	202.4	207.1
NICHD	307.0	180.1	184.5	189.1
NEI	40.7	16.6	18.4	26.5
NIEHS	33.7	29.1	31.2	29.9
NIA	91.5	142.3	158.8	164.0
NIAMS	54.3	36.1	32.3	33.8
NIDCD	8.5	19.9	22.8	23.4
NIMH	202.9	202.9	213.2	212.6
NIDA	120.4	119.0	127.3	131.9
NIAAA	34.6	39.8	39.3	40.7
NINR	32.2	34.8	36.9	40.0
NHGRI	13.7	12.2	19.1	34.1
NIBIB	1.7	12.3	11.5	10.9
NCRR	100.5	74.5	66.6	67.2
NCCAM	11.5	11.5	12.8	15.5
NCMHD	181.7	181.7	186.4	190.0
FIC	2.3	0.6	1.4	1.0
NLM	6.1	3.6	5.6	5.4
OD	9.2	10.9	6.2	7.0
Roadmap			0.9	3.0
NIH	3,164.4	2,429.9	2,589.6	2,698.7

Columns may not add exactly due to rounding.

<sup>\*</sup> Funding is based on the prior health disparities research definition.

<sup>\*\*</sup> Funding is based on the new health disparities research definition methodology developed by the NIH Committee for Minority and Health Disparities Reporting.

# NATIONAL INSTITUTES OF HEALTH

# **Minority Health**

(Dollars in millions)

Participating ICs	*FY 2003 Minority Health Direct (Actual)	**FY 2003 Minority Health Total (Actual)	**FY 2004 Minority Health Total (Actual)	**FY 2005 Minority Health Total (Actual)
NCI	\$131.7	\$140.4	\$218.3	\$250.8
NHLBI	266.5	272.7	289.7	287.6
NIDCR	24.1	32.7	38.5	32.3
NIDDK	190.5	190.5	185.2	198.0
NINDS	57.2	75.1	72.2	104.7
NIAID	282.9	281.0	334.3	338.5
NIGMS	152.2	152.2	162.5	167.0
NICHD	304.1	160.8	166.3	172.8
NEI	23.0	15.6	17.0	23.3
NIEHS	7.1	15.2	18.9	17.1
NIA	86.6	105.1	116.9	119.2
NIAMS	53.2	34.6	30.8	32.3
NIDCD	8.5	18.6	21.7	22.3
NIMH	176.3	176.3	184.2	183.7
NIDA	86.3	97.5	95.2	96.1
NIAAA	3.5	36.4	35.6	36.7
NINR	27.5	27.5	30.1	33.5
NHGRI	12.1	10.6	17.3	24.7
NIBIB	1.0	10.6	9.1	7.4
NCRR	62.1	59.0	59.7	62.7
NCCAM	11.3	11.3	12.6	14.6
NCMHD	154.8	154.8	159.6	164.0
FIC	0.5	0.5	1.4	1.0
NLM	3.2	3.2	4.0	3.6
OD	8.2	8.4	6.1	7.0
Roadmap			0.9	3.0
NIH	2,134.3	2,090.5	2,288.4	2,403.9

Columns may not add exactly due to rounding.

<sup>\*</sup>Funding is based on the methodology used for the Moyer Material.

<sup>\*\*</sup> Funding is based on the new definition methodology provided by the NIH Committee for Minority and Health Disparities Reporting.

#### **Conclusion**

This document describes an ambitious and evolving plan being undertaken by the NIH for reducing and ultimately eliminating the increased burden of disease and premature mortality suffered by racial and ethnic minority and other health disparity populations. This effort cuts across disease areas and organizational boundaries and involves a trans-Agency commitment. It augments the efforts of each IC and relevant program offices in the NIH OD 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 2003, 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.