HEALTH DISPARITIES STRATEGIC PLAN

Director's Message

In 1974, Congress granted authority to form the National Institute on Aging (NIA) to provide leadership in aging research, training, health information dissemination, and other programs relevant to aging and older people. Today, millions of Americans are leading healthier lives based, in part, on discoveries from aging research. But more must be done to redress disparities in health among U.S. minority groups. Since the beginning of the 20th century, life expectancy at birth in the U.S. has increased from less than 50 years to more than 76 years. Life expectancy at birth has more than doubled for African Americans (and "other races" combined) since 1900, from 33 years to 69 years in 1991. For Caucasians, the increase was from 48 years to 76 years. The gap is narrowing, however, causes of this gap between minorities and non-Hispanic Caucasians are unclear. The NIA is supporting many research grants to help us better understand the problem. We know that the problem can be associated with wealth, income, at-risk behaviors, social and environmental factors, and race and ethnicity. The challenge for the 21st century will be to narrow and ultimately, eliminate this gap in life expectancy and to make the added years of life as healthy and productive as possible while maintaining or improving the current trend of decline in disability across all segments of the population, minority and non-minority alike.

For the past several months, NIH has been developing a comprehensive NIH *Strategic Plan to Reduce and Ultimately Eliminate Health Disparities.* The goal is for the Strategic Plan to be ready for submission as part of the NIH Fiscal Year 2002 budget request, as an outline of the NIH's priorities and commitment to research on health disparities. The Plan sets forth the NIH objectives for reducing and, ultimately, eliminating health disparities. While this goal appropriately highlights the critical importance of this endeavor, it is not clear to what extent its objectives can be achieved over the next decade, even with the most optimistic assumptions for improving health among minorities.

What science will be able to do in the next decade is to address and answer questions about causes of health disparities among older adults. The immediate goal will be to identify research needs, such as the need to understand the racial gap in life expectancy, and promote appropriate research and training activities in response to these needs. A longer-term goal will be to apply the outcomes of research to measures that will reduce and ultimately eliminate racial disparities in health.

Development of the ***NIA Strategic Plan to Address Health Disparities*** was started with the goal of addressing health disparities in older Americans. The NIA plan, like the NIH plan, focuses on three major areas: 1) research; 2) research infrastructure; and 3) public information, outreach and education, and includes ongoing and future initiatives. The plan is composed of over sixty activities to help the NIA advance research and better understand health disparities among ethnic and racial older adults.

We are committed to fulfilling our own role in the battle against health disparities in older adults. We have the responsibility to place special emphasis on those diseases and conditions that are major contributors to health disparities among older individuals, with the goal of making measurable progress against these and other problems. The ***NIA Strategic Plan to Address Health Disparities***, in union with the NIA Strategic Plan for Aging Research and the recently completed Review of Minority Aging Research by the National Advisory Council on Aging, presents a vision and approach to redress health disparities in older adults.

HEALTH DISPARITIES STRATEGIC PLAN
This NIA plan is not meant to address all health disparities but rather a plan to address health disparities within the context of the congressionally mandated mission of the NIA. The NIA is working with other NIH Institutes and Centers to develop an overall strategy that in total will address the diseases and conditions that challenge older men and women. I am pleased to present this first public presentation of the NIA plan and welcome your comments on its content. The plans of other Institutes and Centers can be found on the NIH Home Page at: http://www.nih.gov. The NIH Strategic Plan can be found at: www.nih.gov/about/hd/strategicplan.pdf.

National Institute on Aging
Strategic Plan to Address Health Disparities in Aging: Fiscal Years 2000-2005
Overview

The health status of all U.S. racial and ethnic groups has improved steadily over the last century. However, disparities in major health indicators among segments of the U.S. population, white and non-white groups, are growing. In general, African American, American Indian, and Hispanic ethnic and racial groups are disadvantaged relative to whites on most health indices, whereas Asian Americans appear to be as healthy, if not healthier, than whites on most indicators. A key component of the Institute's mission is to better understand age-related diseases and problems of older persons – this mission involves a special focus on elders of U.S. minority population groups. The term "health disparity" covers a broad range of diseases and includes virtually all population groups, however, the focus of this plan is on research initiatives that will advance aging research closer to the ultimate objectives of reducing and eliminating health disparities among older racial and ethnic minorities.

The National Institute on Aging (NIA), one of the 25 institutes and centers of the National Institutes of Health, leads a broad scientific effort to understand the nature of aging and to extend the healthy, active years of life for all citizens. Millions of Americans are leading healthier lives based, in part, on discoveries from aging research. But more must be done to redress disparities in health among U.S. minority groups. Since the beginning of the 20th century, life expectancy at birth in the U.S. has increased from less than 50 years to more than 76 years. Life expectancy at birth has more than doubled for African Americans (and "other races" combined) since 1900, from 33 years to 69 years in 1991. For Caucasians, the increase was from 48 years to 76 years. The challenge for the 21st century will be to make these added years as healthy and productive as possible and to maintain the current trend of decline in disability across all segments of the population.

NIA Mission. In 1974, Congress granted authority to form the National Institute on Aging to provide leadership in aging research, training, health information dissemination, and other programs relevant to aging and older people. Subsequent amendments to this legislation designated the NIA as the primary federal agency on Alzheimer's disease research. The NIA's mission is to improve the health and well-being of older Americans through research, and specifically to:

MISSION STATEMENT

- Support and conduct high quality research on:
  - aging processes
  - age-related diseases
  - special problems and needs of the aged.
- Train and develop highly skilled research scientists from all population groups.
- Develop and maintain state-of-the-art resources to accelerate research progress.
- Disseminate information and communicate with the public and interested groups on health and research advances and on new directions for research.

NIA Research Planning. The NIA maintains a year-round scientific planning process that draws upon interactions with scientists throughout the world, members of Congress, the Institute's National Advisory Council on Aging (NACA) and other advisory committees, constituency groups, and the public. These interactions stimulate internal consideration of potential new research strategies and provide a broad perspective for refining plans. Emphasis is given to novel proposals and collaborative projects that promise to stimulate activities with other research organizations.

The NIA's health disparities strategic planning effort covers a 6-year period from fiscal years 2000 to 2005 and addresses goals for research, research training, research resources, and dissemination of health information that will ultimately reduce or eliminate domestic health disparities. Members of NIA's Minority Aging Research Review Committee, the scientific community and the general public have been active in the plan's development. The health disparities strategic plan is one component of NIA's institute level strategic planning process.

As a part of the NIA's continuing effort to improve the health of minority groups as well as to encourage research careers for underrepresented population groups, the National Advisory Council on Aging was asked, in September 1998, to form a special committee to conduct a year long review of the NIA minority research and training efforts. The committee, comprised of selected members of Council, extramural researchers and ad hoc federal representatives, held several meetings, reviewed several hundred pages of material, and heard presentations by program staff and NIA leadership. The committee's 8 primary recommendations are summarized below and have been considered in the development of this strategic plan. The final report of the NACA Minority Aging Review Committee will be published, and the detailed recommendations will be entered into the ongoing NIA scientific planning process. Briefly, their recommendations are to:

1. Eliminate health disparities among ethnic and racial populations
2. Improve definitions of race, culture, ethnicity and socioeconomic status
3. Implement longitudinal and life course studies
4. Integrate biology, genomics and genetics of aging with studies in special populations

5. Refine methods and strategies for minority aging research
6. Improve recruitment and retention of minority subjects in research
7. Strengthen and clarify the policy on inclusion of minorities in clinical research
8. Build capacity and enhance training and information dissemination for minority populations

The NIA Strategic Plan to Address Health Disparities addresses three major areas of focus:

- ♦ Area of Focus #1: Research to advance understanding of the development and progression of disease and disability that contribute to health disparities in older persons and populations as well as research to develop new or improved approaches for disease and disability detection, diagnosis, prevention, delay and treatment.
- ♦ Area of Focus #2: Research Infrastructure to train a skilled and diverse research workforce and provide support for institutional resources that facilitates health disparities research.
- ♦ Area of Focus #3: Public Information, Outreach and Education to sustain a diverse workforce and a professional environment that supports and encourages excellence in aging research by developing research-based information resources, communicating information to increase public awareness, and transferring knowledge to health professionals.

Areas of Focus 1, 2, and 3 represent broad areas of research, training, public information, outreach and education that NIA will pursue in the years to come and that will help ensure that aging as well as health disparities research benefit from a strong infrastructure to support future research, program management, and information dissemination. The areas are not meant to be mutually exclusive, and there are many areas of overlap and interdependence among the NIA initiatives. For example, knowledge gained from basic research can lead to clinical interventions that improve health and quality of life and in turn reduce health disparities among population groups.

The initiatives discussed below complement ongoing and anticipated investigator-initiated research that will contribute to the overall pool of health disparities research. The initiatives are categorized as ongoing or future and are not meant to reflect research priority or timeframe for implementation.

To reiterate, the Strategic Plan to Address Health Disparities (www.nih.gov/nia/strat-planhd/2000-2005/), the NIA Strategic Plan for Aging Research (www.nih.gov/nia/strat-plan/) and the year-long review of minority aging research (1998-1999) are integral parts of the overall NIA research planning process to support research initiatives that hold the greatest promise for advancing knowledge and redressing health disparities. Throughout this document reference will be made to relevant sections of the NIA Strategic Plan for Aging Research. Goal C of the Strategic Plan for Aging Research has a direct and overlapping relationship with the NIA Strategic Plan to Address Health Disparities. Members of the scientific community and the National Advisory Council on Aging have been involved in the development of the health disparities plan.

The NIA Strategic Plan to Address Health Disparities includes over sixty initiatives describing research that the NIA will continue over the next five years as well as future initiatives to eliminate or reduce health disparities among older minority individuals and population groups. To reiterate, the plan is divided into three major goals: research, research infrastructure and public information, outreach and education. Following each goal are initiatives labeled as “ongoing initiatives” and ”future initiatives.” Ongoing initiatives are NIA research projects and activities currently funded and anticipated to continue. Future initiatives are planned activities expected to begin during the period covered by the plan, and may require additional vetting through conferences, workshops, special panels or other expert advice, as well as through the usual process for developing and approving program announcements or request for applications. Future initiatives are an indication of probable actions and are contingent upon adequate levels of appropriations. This tactical document is dynamic and subject to additions, modifications and yearly revisions.

A. RESEARCH GOALS TO REDUCE OR ELIMINATE HEALTH DISPARITIES

Health disparities are associated with a broad, complex, and interrelated array of factors. Risk factors, diagnosis, progression, response to treatment, caregiving, and overall quality of life may each be affected by aspects such as race, ethnicity, gender, socioeconomic status, age, education, occupation, and as yet unknown lifetime and lifestyle differences. The underlying causes of such relationships require in-depth research. Understanding differences and interactions is critical for developing behavioral and public health interventions to reduce burdens of illness and increase quality of life for older persons and older populations.

This research area of focus has four primary goals. The primary goals for older minority persons and population groups are to: (1) advance understanding of the development and progression of disease and disability that contributes to health disparities in association with genetics, environmental/socioeconomic status, mechanisms of disease, epidemiology and other risk factors, (2) develop new or improved approaches for detecting or diagnosing the onset or progression of disease and disability, (3) develop new or improved approaches for preventing or delaying the onset or progression of disease and disability, and (4) develop new or improved approaches for treating disease and disability.

A1. Advance understanding of the development and progression of diseases and disability that contribute to health disparities in older racial and ethnic minority groups

Chronic diseases and disabilities were once thought to be inseparable from aging. This view is changing rapidly as the means are developed to prevent, treat, or control diseases. If chronic disease is not intrinsic to aging, then what is “normal” aging? Normal or usual changes with aging, like diseases, are influenced by genetics, environment, and lifestyle. The link between genes and life span is no longer questioned. Recent studies of human centenarians have found that extreme longevity runs in families, suggesting a strong genetic influence on aging.

Complementing the genetic influences on aging are the strong effects of environmental factors, such as toxins, radiation, and oxygen radicals—highly reactive molecules produced as cells turn food and oxygen into energy. Progress is being made in understanding and counteracting these environmental effects in minority and majority groups. Lifestyle choices, including diets, physical activity, and other health habits, as well as behavioral and social factors, also have a potent effect on aging processes.

For over a hundred years, medical and social scientists have studied differences in health status among racial groups in the U.S. However, in the last twenty years, scientific inquiry has moved from simple descriptions of health differences between racial groups to attempts to explain the underlying factors that account for the differences. According to Kington and Smith (1997) understanding these underlying causes requires disentangling a complex mesh of factors labeled as age, race, socioeconomic status and health.

Additionally, aging research targets diseases and conditions that contribute significantly to mortality or disability in old age. A major focus of NIA research is Alzheimer's disease, a devastating neurodegenerative disease that robs people of memory and other intellectual abilities, leading to loss of social and occupational function and ultimately to complete dependence on others. A number of research groups have examined differences in AD prevalence among racial and ethnic groups, and it appears from some studies that the risk is higher for African Americans and Hispanic Americans than it is for Caucasians, though not all studies provide similar results. These differences are important to study, not only because of the growing percentage of non-Caucasians in the older U.S. population (by the year 2050, the percentage of the population over the age of 85 that is non-Caucasian will have increased from 16 percent to 34 percent), but because the variations in prevalence may reflect different roles of particular genetic and environmental factors in the development of AD.

Other important causes of disease and disability among racial and ethnic minorities may include cardiovascular disease and cancer, the two leading causes of death in older people; bone, muscle, and joint disorders such as osteoporosis and osteoarthritis that contribute to pain and loss of mobility; vision, hearing, and other sensory disorders that can isolate older people; and numerous other age-related conditions that deprive individuals of their independence. Ongoing and future initiatives designed to advance understanding of the development and progression of disease and disability in older racial and ethnic minority population groups follow. There are thirty-one initiatives in this section.

- **Ongoing Initiative: Epidemiology of Alzheimer's Disease.**

Minority research in the epidemiology of age-related dementia, including Alzheimer's disease (AD), is focused on whether there is a different risk for dementia and AD in particular ethnic groups and whether the course of disease is different in different groups.

Action Plan: From the public health perspective, these questions assume great importance as the demographics of the U.S. population change. Not only will there be over four- fold more persons over the age of 85 in the year 2050 but the percentage of the population over the age of 65 that is non-Caucasian will increase from 16% to 34%. Methodological effects on assessment of cognition in aging and dementia prevalence such as cultural and educational bias in assessment are being addressed. A number of grants are directed toward comparing the prevalence and incidence of AD in African-American, Hispanic, Japanese-American and Caucasian populations, including genetic epidemiology studies to assess the importance of different genetic risk factors such as APOE4 in these populations. Non-genetic risk and preventative factors such as socioeconomic status, early life environment, nutrition, education and health are being studied, as are effects of concurrent illnesses such as cardiovascular disease and stroke.

- **Ongoing Initiative: Alzheimer's Disease and Caregiving.**

Action Plan: Family caregivers of persons with Alzheimer's disease are at risk for negative psychosocial and health consequences of chronic stress. The extent of this risk will vary from one individual to another and also may vary from one group to another, depending on the special strengths and problems experienced by members of a particular group. The long term effects of caregiving, nursing home placement and patient death are being compared in white caregivers and in African American caregivers, each compared to appropriate non-caregiving controls. The results will show the longitudinal effects of the stress of continued caregiving, the long-term effects of caregiver adjustment to nursing home placement or death of the patient, and will identify variables that predict individual differences in caregiver adjustment, with special emphasis on strengths and problems of African American families and the long term course of caregiving stress that they experience.

- **<u>Ongoing Initiative:</u> Normal Cognitive Aging.**

Action Plan: In order to understand the course of normal aging among racial and ethnic populations, it is necessary to develop neuropsychological performance norms for different groups and factors affecting these norms. Two studies in progress should help establish age- and culture-appropriate test norms for neuropsychological assessment of African-American elders. One will investigate the potential influence of several factors on the variance in performance including: age; gender; years of education; educational experience; quality of education; degree of literacy; degree of acculturation. The other study, in addition to the primary goal of developing norms for diverse neurocognitive abilities, will examine the relationship between performance and illness in a senior African American cohort. Additionally, as research on AD focuses on mild cognitive impairment and earlier stages of the disease process, the distinction between AD-related research and that on normal aging is becoming more and more blurred. Examples are the cognitive tests being developed for different ethnic groups within the AD Centers and their satellites, including measures to be used in clinical trials of normal individuals. These instruments will help assess normal cognitive aging as well as development of mild cognitive impairment and AD in minority populations.

- **<u>Ongoing Initiative:</u> Menopause.**

Most studies of menopause are limited in generalizability, for they are based on clinic-derived samples or restricted to Caucasian (non-Hispanic) populations.

Action Plan: Funded initially in 1994 by National Institute on Aging, National Institute of Nursing Research and the Office of Research on Women's Health, the *Study of Women's Health Across the Nation* (SWAN) is a ten-year, multiethnic, community-based study of the natural history of menopause and the change in ovarian function. SWAN is collecting longitudinal biological, psychological, cultural and lifestyle data on 3150 women of five ethnic/racial groups, initially aged 42-52 years of age and premenopausal at baseline. SWAN is comprised of seven clinical field sites, a central reproductive hormone laboratory, a coordinating center and a repository of biological specimens for use by SWAN and the extramural community. The targeted enrollment of 1450 Caucasian, 900 African-American, 300 Hispanic American, 250 Chinese and 250 Japanese women (n=3150) was completed in 1997.

SWAN will contribute substantive new knowledge on the menopause transition through its prospective design, multi-ethnic/racial composition, representativeness of defined populations, and comprehensive measurement and power. No other recent or ongoing study is in a position to respond to the breadth of identified gaps in scientific knowledge on the menopause transition, either because sample sizes or follow-up data are insufficient, the multidisciplinary data are lacking or are restrictive, or because the sample populations are homogeneous. The SWAN study will determine age of menopause in five ethnic groups: Hispanic, Chinese, Japanese, African Americans and Caucasians. An essential feature of SWAN is inclusion of sufficient numbers of ethnic group members to provide comparative risk/association estimates with those in Caucasian groups. Swan's four major aims are to: 1) collect and analyze data on demographics, health and social characteristics, race/ethnicity, reproductive history, pre-existing illness, physical activity, health practices as potential predictor variables, 2) elucidate factors that differentiate symptomatic from asymptomatic women during the menopausal transition, 3) identify and utilize appropriate markers of the ovarian-hypothalamus-pituitary axis and relate these markers to menopause-related changes, and, 4) elucidate factors that differentiate women most susceptible to long-term pathophysiological consequences of ovarian hormone deficiency from those who are protected.

More specifically, in characterizing the psychosocial aspects, the biological processes and the sequelae of the pre- to peri- to postmenopausal transition, SWAN is collecting data on changing menstrual cycle characteristics, markers of hypothalamic-pituitary-ovarian function, symptoms, health and social characteristics, race/ethnicity, reproductive history, current sexuality, risk factors for diabetes, osteoporosis, hypertension and cardiovascular disease and medications (including estrogen use). Additional research objectives include monitoring changes in bone mass, body composition and psychiatric and psychosocial aspects.

- **Ongoing Initiative: Physical Function and Disability.**

The NIA supports epidemiological research on the onset and progression of physical disabilities in older minority populations.

Action Plan: At the present time there are limited data on the underlying factors leading to impairments, functional limitations and disability in different minorities. For instance, Mexican Americans represent the most rapidly growing segment of the US elderly population and strategies for prolonging active life expectancy of Mexican Americans have not been fully explored. NIA is supporting an epidemiological study of community-dwelling elderly Mexican Americans and European Americans of low, middle and high SES status from the San Antonio Longitudinal Study of Aging (SALSA). Objectives of the study are to identify potential ethnic differences in the underlying factors leading to impairments, functional limitations and disability due to diabetes and osteoarthritis. Results of this study will provide important information on the optimal timing of interventions to effectively alter the course of disability due to diabetes and osteoarthritis. Another project is examining prevalence rates and incidence rates of physical disability in urban, African Americans and its etiological factors, including the influence of SES. It is anticipated that results from these studies will lead to novel strategies for improving the active life expectancy of older minority individuals.

- **Ongoing Initiative: NIA Intramural Research Program Mobile Medical Research Vehicle.**

Action Plan: The National Institute on Aging (NIA) Intramural Research Program (IRP), with financial support from the National Institutes of Health (NIH) Office of Research on Minority Health and the NIH Office of the Director, has designed and procured a mobile Medical Research Vehicle (MRV). We will use this vehicle to conduct age-related community based longitudinal and cross-sectional clinical research studies. One of the most vexing problems in clinical research is the unique challenge of recruiting and retaining minority, medically underserved, and socioeconomically diverse populations. The NIA IRP Medical Research Vehicle (MRV) was conceived, designed, and developed as a tool for creating an effective methodology for the recruitment and retention of non-traditional research participants into age-related clinical research. The vehicle is a 53-foot customized semi-trailer with three working areas: an examination room with blood donor station; a cardiovascular fitness and muscle strength testing area; and a bone density/body composition and vascular studies testing area.

Studies conducted by the intramural program staff as well as extramural collaborators will focus on understanding the possible basis for health disparities among minority and lower SES population subgroups. Specific emphasis will be placed on cardiovascular disease, cerebrovascular disease, age-associated changes in cognition, strength and physical functioning, body composition, and psychophysiologic assessments. Among the questions to be addressed are: what is the influence of socioeconomic status on the normal age-related declines in function, what is the influence of socioeconomic status on the incidence of age-related diseases, what is the influence of socioeconomic status on the natural history of common age-related diseases? The vehicle will also provide an important direct recruitment path for minority and lower SES minority and non-minority subjects into the Baltimore Longitudinal Study of Aging (BLSA) with three goals in mind: 1) increase the overall participant accrual to the BLSA, 2) enhance the longitudinal collection of data on normative aging in minority populations, and 3) enhance the retention of elderly, frail participants in the study.

- **Ongoing Initiative: Sleep Disorders in Aging.**

Action Plan**:** The natural history of sleep apnea is being studied in older African-Americans and Caucasians. The focus is on differences between daily fluctuations in blood pressure, sleep disordered breathing (SDB), and possible effects on cognition. African Americans with high blood pressure that does not lower at night may be more prone to oxygen deprivation, possibly related to cognitive impairment for some groups of elderly. Another ongoing study is on the Hmong people. This ethnic group is at high risk for Sudden Unexpected Nocturnal Death Syndrome. Analysis of the interview data on sleep problems in Hmong men and women has indicated potentially important differences between Hmong and Caucasians in the correlates of self-reported breathing disturbances during sleep. Studies of heart rate abnormalities in conjunction with apnea and hypopnea are underway.

- **Ongoing Initiative: Cancer, Aging, Race, and Ethnicity.**

Action Plan: NIA has strongly emphasized attention to minority-related issues in its Program Announcements (PAs) on cancer and aging, especially in two PAs: Aging, Race, and Ethnicity in Prostate Cancer, and Aging Women and Breast Cancer.

In October 1999, the initiative, PA-00-001, Aging Women and Breast Cancer, was re-issued by the NIA, National Cancer Institute, and National Institute on Nursing Research to express our continuing interest and encourage grant applications. The PA has generated many queries from investigators and several new applications are anticipated for the coming summer and fall receipt dates. The NIA intends to re-issue the expiring PA-97-01, Aging, Race, and Ethnicity, once again either as a PA or Request for Applications (RFA) expressing our ongoing interest. Three research foci will be emphasized in the prostate cancer initiative: (1) Clinical determinants of age- and ethnicity-associated differences in prostate cancer treatment efficacy and effectiveness for such outcomes as survival, treatment complications, side effects of treatment, and functional status; (2) epidemiologic studies of age-related familial, genetic, and environmental factors that may affect the age of onset, rate of progression, and duration of survival for prostate cancer; and (3) testing of improved methods to identify high risk older white and black men and low risk men of different race and ethnic origin through development of new techniques to distinguish premalignant changes from nonmalignant age-associated changes in prostate tissue.

Currently, the NIA's most active cancer research focus on minorities is on prostate cancer. One study is examining quality of life among prostate cancer survivors and their partners. The cancer survivors were selected from men in the ethnically diverse Hawaii Tumor Registry who had a diagnosis of localized prostate cancer during 1987-1994. The study will provide some of the first findings on long-term impact of prostate cancer diagnosis and treatment on quality of life, depression, and satisfaction with treatment. It will explore possible differences associated with ethnicity (Chinese, Filipino, Hawaiian, Japanese, and white) and type of cancer therapy. It will provide data about Asian and Pacific Islander populations for whom no information is currently available. Another project is exploring how prostate cancer risk is affected by genetic factors affecting levels and metabolism of sex hormones in African American men, who are at elevated risk for prostate cancer compared to whites.

- **Ongoing Initiative: Honolulu-Asia Aging Study (HAAS).**

Action Plan: The NIA joined the National Heart, Lung and Blood Institute in supporting the Honolulu Heart Program (HHP), an ongoing, prospective study of coronary heart disease and stroke among men of Japanese ancestry born between the years 1900 and 1919 and living on the island of Oahu, Hawaii, in 1965. The Honolulu-Asia Aging Study (HAAS), a study of dementia and aging, was added to the HHP in 1991. Approximately 80 percent of the surviving cohort (3,734), then aged 71 to 93 years, was examined and interviewed. The HAAS and the contract with Kuakini Medical Center has been extended through the year 2000 to ascertain episodes of sleep apnea using NHLBI methods and procedures. Autopsy acquisition protocol for neuropathology will continue, pending approval of a research grant to continue specimen collection, analysis and reporting. A study of age, gene/environment susceptibility in etiology based on a family study of diabetes is being implemented.

- **Ongoing Initiative: Racial Differences in the Vascular Biology of Hypertension.**

Recent studies have shown that the carotid artery intimal-medial wall thickness (IMT) and stiffness are increased in hypertensives and are associated with increased rates of future cardiovascular events. Whether racial differences in carotid artery IMT and stiffness exist and potentially contribute to the higher rates of hypertensive complications in African Americans than Whites is unknown.

Action Plan: The purposes of this initiative will be to: 1) compare the prevalence of unrecognized, untreated and undertreated hypertension in African Americans versus Caucasians and identify demographic and lifestyle factors predictive of these racial differences, 2) compare carotid artery IMT and stiffness, using ultrasonography and applanation tonometry, in African American versus Caucasian hypertensives, 3) use the NIA Medical Research Vehicle as a research platform, and complete medical histories and physical examinations on 2,500 African Americans community-dwelling volunteers (500/yr). From these examinations, the prevalence of hypertension (BP equal to or greater than 140/90 mmHg), and of its recognition and treatment with drugs or lifestyle measures will be determined. These data will be compared with those of the Caucasian and socioeconomically advantaged African Americans volunteers in the Baltimore Longitudinal Study of Aging. Carotid artery B-mode ultrasonography and applanation tonometry will be performed in hypertensive African American subjects identified here. These data will be compared with those of similarly aged volunteers from the Baltimore Longitudinal Study of Aging. Comparison of carotid artery IMT, stiffness moduli, augmentation index and carotid-femoral pulse wave velocity will be compared between African American and Caucasian subjects. 4) Longitudinal follow-up of both groups will determine the predictive power of these measurements for future cardiovascular events.

- **Ongoing Initiative: I. Cognition in the Context of Culture and Environment**.

Understand cognition in the context of culture and environment in order to understand how individuals adapt in various ways to maintain cognitive functioning as they age.

Action Plan: Cognitive function reflects contexts and environments within which people engage, so research will examine important sources of variation in cognition in the meanings, artifacts, practices, and institutions that structure context and environment in minority populations. Conduct research to determine the conditions under which cognitive instrumental activities of daily living, especially complex cognitive activities are maintained despite declines in underlying basic cognitive abilities.

- **Ongoing Initiative: Paradox of Hispanic Health.**

Study immigration and health disparities of racial/ethnic minorities in the US with the aim to understand why foreign-born Hispanics are seemingly healthier and experience lower mortality risks than US-born Hispanics or non-Hispanic whites (termed the "Paradox Of Hispanic Health").

Action Plan: Enhance ongoing collaboration with NICHD on the New Immigrant Survey that will provide important longitudinal data on the health of ethnic and racial minorities who are immigrants to the US, and their children. Enhance ongoing studies in Mexico and Puerto Rico to understand the origins of health disparities in US Hispanic populations. Consider developing comparable studies in the Caribbean.

- **Ongoing Initiative: Projections of Burdens and Costs of Illness.**

Produce projections of burdens and costs of illness, healthy life expectancy, longevity, and mortality trajectories by race and ethnic status.

Action Plan: Through the NIA Demography Centers and interagency agreement contracts to other US agencies and multilateral organizations, produce projections of burdens and costs of illness, healthy life expectancy, longevity, and mortality trajectories by race and ethnic status. This model would project changes in health differentials that would occur through expected changes in education and economic distributions in the population, net of any public health interventions. Develop more complex behavioral models to specify a health production function for different race and ethnic groups -- in effect develop an input-output model that would show which interventions are likely to have the highest cost/benefit ratios. The model would incorporate known effects based upon completed intervention studies and could also be used to decide which intervention or epidemiologic studies are most needed. The model could also serve a heuristic function in providing suggestions for data needs and in determining the adequacy of sample sizes in terms of needed precision.

- **Ongoing Initiative: Financial Impacts on Families from the Onset of Acute Health Events and Chronic Disease.**

Action Plan**:** Encourage research using NIA supported longitudinal studies with significant minority over-samples, such as the Health and Retirement Study and the Panel Study of Income Dynamics, to monitor the evolving financial status of the older population and to understand how to buffer the economic effect on families of health events and onset of chronic disease.

- **Ongoing Initiative: Women's Health and Aging Study (WHAS).**

Action Plan: The Women's Health and Aging Study (WHAS) is a prospective cohort study of community-resident, cognitively intact, women age 65 years and older with moderate to severe physical disability. The overall goal of the study is to understand the causes and course of physical disability, particularly related to the presence and severity of disease. Prior to the WHAS, such a comprehensive, research-focused medical evaluation of functionally limited older adults had not been attempted in a home setting. The comprehensive information on the presence and severity of disease, obtained using physiologic and clinical measures, and the rich data characterizing the dimensions of functioning as well as psychosocial and socio-cultural factors including race (28 percent black), will contribute to increased understanding of the complexities of functional decline in older women. The prospective component of the study will characterize change in function and relate it to underlying changes in disease status, taking into account the impact of medical care, psychosocial factors, and important life events. In addition, the racial and SES composition of the WHAS population enables examination of the joint and independent effects of socio-cultural and economic factors on the severity and progression of disability.

- **Ongoing Initiative: Sensory Changes in Aging**.

Action Plan: The Salisbury Eye Evaluation (SEE) study, which began in 1992, had an original enrollment of more than 2,500, of which approximately one-fourth are African American. Rates of visual impairment in the areas of acuity, contrast sensitivity, stereoacuity and visual fields were found to be greater in African American than Caucasian participants. These studies will move into tests of dynamic measures of visual function and motion sensitivity. In addition, an extensive battery of cognitive tests will measure learning, memory, verbal fluency and attention in order to better understand the relationship between visual and cognitive changes during aging. In another study, body composition and the chemical senses (smell and taste) will be studied in two groups (20-35 and 65-80 years old) of healthy African American women. It is hypothesized that body composition is related to olfactory dysfunction, which increases as a function of aging. Body composition will be assessed by anthropometric measurements. Usual dietary intakes will be determined through the food frequency questionnaire. Olfactory perception, taster status, dental/oral health, and salivation will be measured by screening tests and interviews. The study specifically over-sampled the African American population of Salisbury, MD, in order to have sufficient statistical power to make direct comparisons between African American and Caucasian subjects.

- **Ongoing Initiative: Health and Body Changes (HEALTH ABC)**.

Action Plan: The Health ABC Study is a longitudinal cohort study with a population of 3,075 people aged 70-79; 46 percent of the women in the study and 33 percent of the men are black. The major objective of this 7-year study is to examine whether loss in muscle, with concomitant increases in fat and decreases in bone, represents a common pathway by which multiple diseases contribute to disability. The study involves characterization of the cohort in terms of the major weight-related health conditions, which contribute to disability: cardiovascular disease, pulmonary disease, osteoporosis, osteoarthritis, diabetes, and depression. By linking these data to detailed functional health measures, the HEALTH ABC Study should contribute to understanding similarities and differences in the progression of disability among older blacks and whites.

- **Ongoing Initiative: Disability Decline among Racial and Ethnic Minority Populations.**

Action Plan: Support research using NIA supported longitudinal studies, such as the National Long-Term Care Survey, Longitudinal Study of Aging, and the Health and Retirement Study, to track changing disability rates by race and ethnicity and to better understand ways to maintain and accelerate declining disability.

- **Ongoing Initiative: Understanding Elder Abuse, Neglect and Fraud**.

Action Plan: Support research on the consequences of elder abuse and neglect on all-cause mortality, on the development of clinical practice guidelines to aid health practitioners in recognizing abuse in the elderly population, and on neglect in nursing homes as a consequence of poor nutrition. Commit to a focus on diverse populations and to the conduct of the first nation-wide probability survey of the prevalence of elder abuse and neglect and its associated risk factors.

- **Future Initiative: II. Cognition in the Context of Culture and Environment.**

Study cognition in the context of culture and environment in order to understand how individuals adapt in various ways to maintain cognitive functioning as they age.

Action Plan: The NIA asked the National Academy of Sciences to identify areas of research opportunity that would improve our understanding of cognitive functioning and aging, specifically at the intersection of behavioral science, cognitive science and neuroscience. The NAS report has recommended that NIA undertake a research initiative to understand the effects of behavioral, social, cultural, and technological context on the cognitive functioning and life performance of aging persons. This initiative will have a specific focus on older ethnic and racial minority populations.

- **Future Initiative: Whitehall in Washington (WIW) Conference.**

Action Plan: The Whitehall Study in the United Kingdom found that occupational grade level, even holding many risk factors constant, is associated with a significant fraction of the variation in health by socioeconomic status. A question is whether supervisory status compensates for the negative effects of race. A workshop would help inform the decision about the advisability of a "Whitehall in Washington" study that would be developed by NIA extramural and intramural units along with NCHS, possibly NIOSH, and other ICs.

- **Future Initiative**: **End-of-Life Care.**

The NIA will develop an integrative research agenda that will provide a basis for providing end-of-life care in culturally sensitive ways to diverse populations.

Action Plan: Following a joint NIA/Fetzer Institute Working Conference, NIA will create a series of research initiatives soliciting research on integrative topics that deal with how and where older Americans die. The initiatives will be sensitive to and specifically solicit research on race/ethnic disparities in the social process of death, the location of death, the involvement of the family in end-of-life, and decision-making process for older diverse populations. Additionally, attention will be paid to how various organizational forms relate to and care for a diverse population at the end of life.

- **Future Initiative: Multi-level Investigation of Black-White Differences in Cardiovascular Function.**

Studies suggest that elevated blood pressure seen in African Americans may be related to both psychosocial and cellular factors. One common link between the psychosocial and the cellular levels may be the parasympathetic nervous system. However, to date, studies have not been conducted that would link these diverse systems in a comprehensive multi-level model. The goals of the proposed research are to examine the blood pressure regulation system in the context of such an integrated model.

Action Plan: The purposes of this initiative are to explore differing cardiovascular responses to psychosocial challenge; describe differing autonomic responses to psychosocial challenge; and define the interaction of cardiovascular polymorphisms, ethnicity, and cardiovascular and autonomous responses to psychosocial challenge.

Invasive and non-invasive techniques will be used to assess autonomic control of the cardiovascular system during resting conditions and psychosocial challenge. Independent variables will include ethnicity, gender, and genotype. Dependent measures will include heart rate variability, blood pressure variability, impedance cardiography, vascular resistance, nitric oxide and catecholamine levels.

- **Future Initiative: National Alzheimer's Coordinating Center (NACC)**.

Use the data handling capabilities of the NACC to plan and conduct studies that will characterize minority and ethnic differences in normal aging subjects and Alzheimer's disease patients.

Action Plan: At present there are virtually no data on clinical and pathological ethnic heterogeneity due to the limited numbers of minority patients seen at any one Center. Using larger data sets developed by the NACC and autopsies at individual Centers will allow characterization of the rarer and mixed phenotypes, and genetic and ethnic differences that would not be possible with the smaller numbers of subjects in individual centers. It will allow research on normal aging using control subjects and also the transition from normal aging to mild cognitive impairment to AD. By pooling ethnic and minority patient information and autopsies from many centers, it will also be possible to begin to identify potential biomarkers which will help to diagnose AD, permit characterization of disease course, monitor response to treatment in diverse groups and perform clinicopathological correlations.

- **Future Initiative: Evolution of Cardiovascular Risk with Normal Aging.**

Action Plan: This study will characterize traits (intrinsic aging changes versus cardiovascular disease risk factor burden) in a biracial (black-white) population that may influence progression of sub-clinical cardiovascular disease in an aging population. It will expand support of a well-characterized biracial (black-white) population that has been followed for cardiovascular disease risk factors and lifestyles in the Bogalusa Heart Study over the past 25 years into middle age and beyond. New research will provide insight into the interaction between normal aging, including the growth and maturation process in childhood, and predisposing risk factors that may influence development of sub-clinical cardiovascular disease in a black-white population reaching middle age. This initiative will provide a greater understanding of the evolution of cardiovascular disease risk in normal aging and may also lead to improved lifestyle programs for successful aging and longevity, including cardiovascular disease prevention.

- **Future Initiative: Effect of Early Life Factors on Adult Health.**

Action Plan: There is an unresolved tension between the proximal and distal causes of poor health. Many studies have identified significant risk factors for the development of chronic diseases that pre-date onset of symptoms by at least a decade. Population-based studies in which individuals are tracked from birth to their adult death help researchers observe the continuities and discontinuities in health over time, and have the potential to provide the necessary data to foster understanding of the large variations in health across racial and ethnic populations. Such combined studies would provide us with full life-course data on health and risk factors. This initiative would continue collaborative efforts with NICHD and other countries to understand the impact of early-life factors, including prenatal nutrition in the first trimester, on adult health.

- **Future Initiative: Racial and Ethnic Differences in Health in Late Life in the United States.**

Fund a new NAS Panel on "Racial and Ethnic Differences in Health in Late Life in the United States" and promote research on the impact of new OMB definitions of race and ethnicity on health disparities.

Action Plan: The NIA will contract with the NAS Committee on Population (CPOP) to hold a two-day workshop on racial and ethnic differences in health in late life as a follow-on activity to a workshop organized by the Committee on the same topic in December 1994, which resulted in the volume Racial and Ethnic Differences in the Health of Older Americans (NAP, 1997). The workshop will consider the extent of racial and ethnic disparities in life-expectancy, health, and disability and the extent to which these disparities can be attributed to differences in lifestyle risk factors, access to health care, and other social and economic factors. The workshop will also consider the impact of new OMB definitions of race and ethnicity on health disparities and will chart the scientific progress in this area since the NIA-sponsored 1994 workshop. As a related activity, NIA will encourage research on the impact of changing self-definitions of race and ethnicity, and of the new OMB definitions, on health disparities.

- **Future Initiative: Health Disparities in Normal Cognitive Aging and Alzheimer's Disease.**

Action Plan: Coordinate demographic and epidemiological studies to identify ethnic, racial, geographical, SES, educational and health factors affecting maintenance of cognitive, sensory and motor health and development of mild cognitive impairment, AD and other age-related neurodegenerative diseases. This program initiative will be undertaken in conjunction with other NIH Institutes as part of the Healthy Brain Initiative, an NIH Area of Emphasis. The initiative should start with analysis of ongoing studies, what they are projected to accomplish and where the gaps in knowledge are in this field. One essential early part of the initiative would be a conference and follow up research to determine and develop standardized measures of cognitive change. The kinds of additional studies to be supported would depend on the outcome of the analysis and conferences. Note: The breadth of this initiative crosscuts each of the research subgoals to include activities associated with: (1) new or improved approaches for detecting and diagnosing, (2) preventing and delaying, and (3) treating disease and disability.

- **<u>Future Initiative</u>: Subjective and Physiological Well-Being in Special Populations**.

Develop culturally appropriate indices of subjective and physiological well-being in special populations for use in longitudinal studies.

Action Plan: Reports by elderly persons in social science surveys of declining health but high levels of life satisfaction, point to the need to improve our understanding of how well-being, health, and preferences are measured or mis-measured in surveys. The measurement of well-being and satisfaction, individual decision-making to improve well-being, and adaptation are also interrelated with the psychological foundations of economic evaluation. The NIA will consider an initiative on the measurement of well-being which would emphasize interdisciplinary work between economists, psychologists and epidemiologists. This initiative would have broad implications for the array of population surveys that are currently supported by NIA and fits into a broader NIH and Departmental concern with improving the measurement of the burden of illness. This initiative would have a specific focus on racial and ethnic minority populations and on capturing some of the variation in well being between and among populations.

- **<u>Future Initiative:</u> Disability Decline among Racial and Ethnic Minority Populations.**

Increased focus on research into the disability decline among racial and ethnic minority populations.

Action Plan: Through analyses of the 1999 wave of the National Long-Term Care Survey, and other surveys such as the Longitudinal Study of Aging and the Health and Retirement Study, improve tracking of changing disability rates by race and ethnicity, understand causal determinants of changing disability rates, and search for ways to accelerate the disability decline among racial and ethnic minority populations.

- **<u>Future Initiative:</u> Understanding Elder Abuse, Neglect and Fraud.**

Develop a research program to determine prevalence of abuse, neglect, and fraud, associated risk factors, and mechanisms for prevention in diverse populations.

Action Plan: Both the IOM report of a “paucity of research” on elder abuse and neglect (Violence in Families, 1998) and significant NIA supported research recently published in JAMA (Lachs MS, et al. 1998;280:428-432) demonstrate the devastating long-term consequences of elder mistreatment. Research is needed on the prevalence of elder abuse, interventions to reduce the incidence of elder abuse, and reliable measurement tools for assessing elder abuse by health care professionals. NIA will consider an NRC/IoM Panel to assess these issues, and if successful, will create a series of research initiatives to address abuse, neglect, and fraud with special emphasis on diverse populations. For example, do diverse ethnic/racial populations define abuse/neglect differently? Variability of definition in diverse groups will be emphasized in future efforts to resolve confusion about the variables of interest. Research on the impact of abuse, neglect, and fraud in diverse ethnic/race groups and the creation and testing of race/ethnicity sensitive interventions to prevent or ameliorate the impact of these events will be solicited.

A2. Develop new or improved approaches for detecting or diagnosing the onset or progression of disease and disability among older ethnic and racial minorities

Racial and ethnic disparities in incidence, mortality and survival rates, and trends exist for many diseases. For example, disproportionate increases in dementia morbidity in ethnic minorities challenge established screening methodologies because of language and cultural barriers, varying access to health services, and a relative paucity of cross-cultural data validating their use.

The NIA is meeting the challenge of developing new or improved approaches for detecting and diagnosing the onset and progression of disease and disability among older racial and ethnic adults. Genes associated with aging processes, longevity, and age-related diseases are providing insight into disease pathologies and individuals' vulnerability to disease. Defining the underlying changes in biologic functions controlled by the genes can lead to possible targets for treatment, and may help in early detection and diagnosis of disease. These findings are derived in part from studies of populations or families known to be at high risk for a disease. Population studies also uncover other potential risk factors, including the influence of coexisting conditions on the progression of a disease. In addition, remarkable progress is being made through advances in imaging technology, a non-invasive means of observing the body's biological activity. For example, these techniques can provide images of nerve cells as they communicate, can accurately measure cerebral blood flow, and can gauge the production of particular gene products. Plans are being developed to improve the resolution of this technology to assist in early detection and diagnosis. Additional goals and objectives relative to this section are included in the NIA Strategic Plan for Aging Research, Goal A. (http://www.nih.gov/nia/strat-plan/)

- **Ongoing Initiative: Alzheimer's Disease Clinical trials.**

Action Plan: The Alzheimer's Disease Cooperative Study (ADCS) is a consortium of over 30 sites across the U.S. set up to do clinical trials on Alzheimer's disease. From its inception in 1991, the ADCS has had a focus on recruitment of minority individuals, especially African-Americans and Hispanics. There is a minority recruitment core, the purpose of which is to improve minority participation in clinical trials by a variety of mechanisms and thus ensure that safety and efficacy of potential treatments are adequately evaluated for these groups. Meta-analysis of placebo groups will yield data on both normal and abnormal cognitive changes with age in different ethnic and racial groups. The ADCS has a mandate to develop new test instruments for evaluating the effects of drug interventions on the symptoms and course of AD. Most of the neuropsychological and clinical evaluation instruments used in ADCS clinical trials are translated into Spanish and are being used in ADCS trials for Spanish-speaking individuals.

- **Ongoing Initiative: Early Criteria to Identify African-American Men at Increased Risk for Prostatic Cancer and Benign Prostatic Hyperplasia.**

Action Plan: The Baltimore Longitudinal Study of Aging has defined the time course for prostate specific antigen (PSA) in prostate cancer and hyperplasia in Caucasian men, and has demonstrated the usefulness of PSA for early diagnosis and as a risk factor for these diseases. These findings improve the ability to screen men for this disease and can identify men who are at higher risk of developing an aggressive cancer. By knowing early that a cancer is present, and by knowing its aggressiveness, men and their physicians can better plan appropriate strategies to deal with this potentially devastating disease. For men who are likely to have a less aggressive cancer, watchful waiting may be appropriate with intermittent evaluations to follow the progression of disease. We do not know how to best use longitudinal measures of PSA and prostate volume in assessing prostate cancer risk in African American men who have the highest rate of prostate cancer in the world and who have higher baseline PSA levels. Longitudinal collection of this data will better equip physicians to determine which strategies of screening and diagnosis are most appropriate.

Using the Medical Research Vehicle as a community-based research platform we hope to establish a collaboration with Howard University to longitudinally evaluate African American men in Washington D.C with PSA assessment, MRI, and urological evaluations.

- **<u>Ongoing Initiative:</u> Meeting the Health Care Needs of an Aging and Increasingly Diverse Population.**

Develop research to assess the most effective mechanisms for meeting the health care needs of the elderly, with special emphasis on differences in service and setting use by minority populations.

Action Plan: Following an agenda setting conference, initiatives will be issued to suggest research on ethnic/race differences in the use of, processes associated with, and outcomes of various health care delivery systems and settings. Interventions for facilitating system access and use by a variety of minority groups will be emphasized. Additionally, these initiatives will include research on disparities in the use of various settings ancillary to the formal health care delivery system. These include research on minority and non-minority variability in the use of independent but age segregated housing, continuum of care retirement communities, assisted living facilities, PACE, and nursing homes.

- **<u>Future Initiative:</u> Development of Standardized Measures of Cognitive Change in Normal Aging in Different Ethnic Groups.**

Action Plan: This future initiative is titled “Health disparities in normal cognitive aging and Alzheimer’s disease.” It is the first step in a multi-ethnic initiative. In an attempt to capitalize upon and expand current funded research efforts to establish neuropsychological test norms for African-American elders, we plan to first hold a conference to bring together investigators to discuss development of standardized measures of cognitive change in normal aging in <u>multiple</u> ethnic groups. Goals of the conference would include: establishment and appraisal of an inventory of currently available instruments; discussion of gaps that need to be filled and improvements that need to be made in order to achieve more valid and reliable norms for diverse groups; the multiplicity of factors to be considered when establishing culture-fair tests, including educational attainment, quality of education, gender, and degree of acculturation; barriers to overcome for implementation of both research and practice. Building upon the results of the conference, a standard set of measures for testing in diverse communities would be developed, tested and implemented.

- **<u>Future Initiative</u>: Effectiveness of Interventions to Improve the Diagnosis and Treatment of Chronic Illnesses in Older Minority/Ethnic Populations.**

Provider/Patient Communication in Diverse Populations. Develop and evaluate the effectiveness of interventions to improve the diagnosis and treatment of chronic illnesses in older minority/ethnic populations

Action Plan: NIA supports an ongoing portfolio of research on the impact of medical encounters on the health outcomes of older patients. A portion of this ongoing program will be focused on the impact of doctor-patient interactions on minority/ethnic populations. Minorities are often disadvantaged in terms of not having their chronic illnesses recognized as soon or treated as aggressively as the majority population. This is particularly critical in later life when illnesses are often more severe and health consequences catastrophic. Targeted studies are needed on the role of doctor-patient interactions as a key factor in explaining health disparities in diagnosis, treatment and management of chronic illnesses. This initiative will examine minority, SES, gender, and age differentials in the context, processes, and outcomes of health care encounters, in the development and testing of strategies for enhancing communications in older minority populations, and in the creation of new measures and methodologies for examining provider-older patient interactions in diverse populations.

A3. Develop new or improved approaches for preventing or delaying the onset or progression of disease and disability among older racial and ethnic minorities

To develop ways of preventing, delaying, and halting disease requires the contributions of many disciplines. Epidemiology can identify the magnitude, and possibly the variability, of a disease in different populations and may identify those at greatest risk. An understanding of disease mechanisms can produce means of preventing or delaying the onset of disease by determining the cause of a disease, how it affects cells or organs, or whether there is a genetic predisposition for the disease. Behavioral studies are important since intervention may require new medication or change in behavior. Clinical research and trials are the only means of evaluating new therapies or behavioral approaches. Remarkable progress is being made through basic, clinical, and epidemiologic research toward developing innovative, safe, and effective approaches to prevention and therapy for the population over age 65. The NIA has five continuing initiatives in this area. For additional initiatives relevant to this goal, please see Goals A1 and A2 under the research section.

- **Ongoing Initiative: Adult Psychological Development.**

Action Plan: Continue program activities at the NIA addressing cognitive function and aging, and personality and social psychological aging. Program initiatives and activities include interventions designed to improve cognitive or related perceptual abilities and skills that can reduce the need for formal care and hospitalization, and maintain independence for older people. Everyday tasks that use inductive reasoning can be taught by demonstrating strategies to identify rules or patterns or by practicing problem solving. Regular challenges of the brain can help retain cognitive abilities and mental acuity. Research with such practical applications for improving everyday functioning is encouraged.

- **Ongoing Initiative: The Role of Education in Health Status.**

Understand the role of education in health status and its association to other socio-cultural and economic variables.

Action Plan: Encourage the analysis of NIA supported longitudinal surveys, such as the Health and Retirement Study, National Long Term Care Survey, and Panel Study of Income Dynamics, to study how education affects health and cognitive functioning. Specifically encourage research using the minority over-samples of these surveys to study health disparities, including the application of analytic results to older adults with varying educational levels.

- **<u>Ongoing Initiative</u>: Culturally Appropriate Family Caregiving Interventions for Dementia Care**.

Evaluate the effectiveness and dissemination of culturally appropriate family caregiving interventions for dementia care, and other conditions of an aged population.

Action Plan: Relatively little is known about minority caregiving and most caregiving interventions have not included sufficient numbers of minorities to know how to best tailor interventions in order to help caregivers maintain their loved ones at home for as long as possible. As part of our AD preventive initiative, we are currently funding the Resources for Alzheimer's Caregiver Health (REACH) program, initial set of coordinated studies to examine the effects of psychoeducational support groups, behavioral skills training programs, family-based systems interventions, environmental modifications, and technological computer-based information services in over 1000 Caucasian, Hispanic, and African-American families in Alabama, California, Florida, Massachusetts, Pennsylvania, and Tennessee. A major outcome of this initiative will be the availability of a pooled database that will enable investigators to answer key questions about optimal intervention strategies for maintaining and improving the health and quality of life of caregivers of dementia patients.

- **<u>Ongoing Initiative</u>: Cognitive Interventions to Reduce Risk of Loss of Independence and Hospitalization in Older Minority Populations**.

Develop and test culturally appropriate cognitive interventions to reduce risk of loss of independence and hospitalization in older minority populations.

Action Plan: Outreach will be made to community organizations to recruit older minority populations for cognitive intervention research and deliver the interventions in the community. Proposed research would target those cognitive abilities and personality dispositions that affect and are affected by health behaviors, provider-patient interactions, adherence, and associated health outcomes in older, minority populations.

A4. Develop new or improved approaches for treating disease and disability

New information on the underlying causes of and risk factors for diseases and disabilities are helping researchers develop interventions to delay onset, slow progression, and reduce the severity of disease and disability. Behavioral and social science findings are also being applied to develop strategies that promote health and prevent disease.

In order to prevent or lessen the effects of disease, interventions must be designed that are culturally appropriate. For example, minority elderly individuals are more likely to use their medication appropriately if the labels and instructions are printed in their native language. Interactions with health care professionals can be difficult if there are language and cultural barriers. In order to diagnose Alzheimer’s disease in minority elderly, assessments of cognitive impairment must be designed for individuals with low levels of education or lack of fluency in English.

Future research will focus on strategies for self-management of chronic diseases such as arthritis, heart disease, lung disease, and diabetes. Research will also investigate the factors affecting medication misuse and strategies for enhancing proper use and compliance with medication regimens. For additional initiatives relevant to this goal, please see Goals A1-A3.

- **Ongoing Initiative: Behavioral Medicine and Medical Sociology**.

Action Plan: The research in this initiative includes a focus on burdens of care associated with Alzheimer's disease caregiving as well as research focused on older adults and health care organizations and social institutions. Studies targeted to enhancing healthy behavior in older racial and ethnic populations are a high priority. Efforts to reduce disparities through this research will include development of culturally appropriate screening tools and health care services, as well as means to enhance the likelihood of elders initiating and maintaining health promotion interventions.

- **Future Initiative**: **Interventions to Improve Medication Use and Enhance Self-Management Skill.**

Develop cognitive, behavioral, social and technological interventions to improve medication use and enhance self-management skills appropriate to older ethnically diverse populations.

Action Plan: The current NIA initiative on diversity in medication use and outcomes has focused on identifying minority differentials in medication use and prescription. Based on promising studies showing the potential of behavioral, environmental and technological interventions for improving medication use in younger, non-minority populations, we propose a set of targeted studies to investigate strategies for reducing medication errors and mismanagement in older, diverse populations. Randomized clinical trials testing viable medication "prompts" in diverse populations and new technologies for enhancing self-management in various settings (e.g., nursing homes and assisted living facilities) will be included. These research activities will be set within a broader initiative that includes the development and testing of culturally sensitive interventions to enhance self-management skills for common age-related chronic conditions such as diabetes, arthritis, or heart disease (e.g., strategies for increasing adherence to recommended pharmaceutical and behavioral regimens). As a related activity, consider enhancing existing longitudinal surveys, such as the National Long Term Care Survey, to collect data on medication use among the minority older population.

B. Research Infrastructure Goals

In addition to pursuing specific research opportunities, the NIA is developing the infrastructure to support future research, program management, and information dissemination to racial and ethnic minority groups. These include resources to train a skilled and diverse research workforce, providing necessary equipment and resources, and disseminating information to scientists and the public.

B1. Support research training and career development

Despite the existence of several NIA- and NIH-supported programs to increase the participation of minority students in research, minority researchers continue to be underrepresented in most fields of biomedical and behavioral research on aging. This underrepresentation limits the cultural and ethnic diversity of the research workforce as well as the important perspective that comes with such diversity.

The NIA is redressing this imbalance through developing and enriching existing efforts by organizations to recruit minority students to research. The NIA is supporting collaborations that link faculty and staff in different institutions who have the common interest of furthering minority participation in research careers. The goal of such initiatives is to increase the cultural and ethnic diversity of the research study and the workforce conducting the research on aging.

- **Ongoing Initiative: Alzheimer's Disease Research Centers (ADRC) Satellite Diagnosis and Treatment Clinics.**

Action Plan: The NIA will continue its funding of 28 Alzheimer's Disease Centers (ADCs), included among which are 26 Satellite Diagnosis and Treatment Clinics (SDTC), designed to increase the diversity of the research patient pool and enhance the research capabilities of the Alzheimer's Disease Centers. Since initial funding of the satellites, minority recruitment into the ADC Clinical Cores has increased from 4% to 16%. The satellite clinics extend the diagnostic and management services as well as educational activities offered by the Alzheimer's Disease Centers to under-served areas. The satellite clinics also enhance the clinical research capabilities of the Alzheimer's Disease Centers through the diversification of the research patient pool by offering the opportunity to special population groups to enter clinical drug trials and to participate in other clinical research efforts. Many have hired minority staff to be the liaison with the communities. Most of the satellites focus on outreach, recruitment and retention of specific minority populations, often working closely with local and state agencies, health care organizations, churches, community clinics and housing projects. Many are developing culturally and language sensitive cognitive and dementia screening instruments, as well as neuropsychological and neurological examinations. Along with the parent ADCs, several are conducting studies on the onset and course of AD in specific minority populations. All ADCs have an Education and Information Transfer Core. This core supports both the development of professional staff to improve clinical and research skills related to Alzheimer's disease and outreach programs for the lay public that will publicize the ADRC and educate families and other caregivers about the disease. Cultural sensitivity is emphasized and, where appropriate, they outreach programs to minority groups and provide information structured so that it can effectively reach minority populations, including non-English-speaking people.

Two of the Centers have special relationships with African American Medical Schools, the University of Kentucky with Meharry Medical School in Nashville, TN and University of California at Los Angeles with the Martin Luther King/Charles Drew Medical Center in South Central Los Angeles. These relationships afford opportunities for minority patients and families to participate in clinical studies. Another NIA-sponsored program, the Research Centers for Minority Aging Research (RCMARs), has two centers that coexist and interact with ADRCs at Columbia University and the University of Michigan. This proximity includes opportunities for joint staffing and sharing of some programmatic initiatives such as recruitment and education of minority subjects and families.

As noted in the previous section, with the establishment of the NACC data about enrollments in all of the ADCs are collected in a central database. The NACC is also set up to fund cooperative studies involving a number of Centers, including studies involving minority issues. Examples of funded activities are disease progression in minority cohorts. Another is autopsy enrollment that provides the opportunity to do clinico-pathological correlations, an important tool in understanding differences between normal aging and disease pathologies. This is especially important in minority communities where a constellation of different diseases may together affect cognitive status.

- **<u>Ongoing Initiative</u>**: **Resource Centers for Minority Aging Research**.

Continue and build upon the successes of the existing Resource Centers for Minority Aging Research (RCMARs) to create scientific infrastructure for conducting research on disparities between and within various race/ethnic groups of minority and non-minority elders. Continue the mentoring of minority investigators for these objectives. Note: because of the breath of this initiative, RCMAR's goals crosscut several of the Strategic Plan's subgoals. Across sites, approximately 20% of the Centers' efforts are devoted to support for institutional resources including the management and administrative infrastructure of the Center, fixed equipment and facilities. Target year: reissue RFA FY 2001.

Action Plan: NIA will revise and reissue the RFA leading to the creation of the initial six RCMARs for the second iteration of this Center concept. The new RCMARs will include: (1) focused research on recruiting and retaining minority group members in research; (2) links between ongoing research for the purpose of recruiting and retaining minority members; (3) research links between other appropriate NIA supported Centers (e.g., AD Centers) and other funded initiatives; (4) development of race/ethnic sensitive, yet comparable measurement; (5) expanded opportunities of mentoring minority and non-minority investigators for research and sustained careers in the health of older minority populations; (6) opportunities to develop research and mentoring links between research institutions and Traditionally Minority Based Institutions; and (7) improve communication between researchers and minority end-result research users.

- **<u>Ongoing Initiative:</u> The Claude D. Pepper Older Americans Independence Centers (OAICs) Program.**

The OAIC program has contributed substantively to the growth of the geriatrics field through the success of the Centers' emphasis on career development of promising clinical investigators.

Action Plan: In recent years the OAICs have supported 1-3 minority supplements per year for the purpose of providing several years of career development support in aging research to minority candidates with an interest in aging research. It is expected that over the next five years this program will continue to provide career development opportunities to 1-3 minority candidates in aging research. The OAICs are an especially good site for learning a variety of methods and analytic approaches useful in aging research because of the concentration of aging researchers present, and the large amount of aging research carried out at the institutions which have successfully competed for these "centers of excellence in aging research."

- **<u>Ongoing Initiative</u>: Special Populations Initiatives.**

Action Plan: The Office of Special Populations, Office of the Director, coordinates initiatives aimed at increasing the quantity and quality of research on minority health as well as increasing the number of racial and ethnic group investigators involved in research on aging. This office in concert with the NIA Minority Work Group is the lead contact for numerous minority activities including Minority Youth Initiatives, Minority Organizations Internship Programs, NIA Regional Meetings and outreach to minority and community organizations. For example, this Office plans, organizes and directs NIA's exemplary "**Summer Institute on Aging Research.**" This one-week training initiative done in partnership with the Brookdale Foundation and the Office of Research on Minority Health is highly competitive and supports training experiences for scientists at the beginning stages of a research career in aging. Minority applicants are highly recruited to participate in this initiative.

- **<u>Ongoing Initiative</u>: Trans-NIA Training Initiatives for Underrepresented Minorities in Aging Research.**

Action Plan: This ongoing trans-NIA training initiative addresses five major activities by the NIA to enhance research training and career development for underrepresented minorities in aging research: (1) Research Supplements For Underrepresented Minorities, (2) Minority Pre-doctoral Fellowship Awards, (3) Minority Dissertation Awards, (4) Training Grant (T32) Add-On Slots, and (5) MERIT Minority Supplements. Reducing health disparities will require multiple approaches including increased inclusion of minorities in the health and medical research professions. The NIA will continue and expand its efforts to attract and train a diverse, highly skilled, workforce in aging research.

- **<u>Ongoing Initiative</u>: Intramural Research Training Awards (IRTA).**

Action Plan: The Intramural Research Program (IRP) of the NIA has three options for reaching out and engaging underrepresented minorities in training opportunities at the Gerontology Research Center(GRC): Visiting Scientists, IRTA, and IRP Summer Students. Each of these programs is designed to enrich the diversity of the IRP staff and to provide cutting-edge training in NIA's laboratories.

The NIA Intramural Research Program is comprised of the GRC in Baltimore, Maryland, the Laboratory of Neurosciences (LNS) located in the NIH Clinical Center, and the Epidemiology, Demography, and Biometry Program (EDBP) located in the Gateway Building in Bethesda. Exclusive of EDBP, the IRP is organized into 10 Laboratories and Branches. The Research Resources Branch provides specialized resources to IRP investigators; and the Laboratory of Clinical Investigation, Longitudinal Studies Section (LSS) is responsible for administration and management.

The NIA Intramural Research Program has hired minority Preventive Medicine Residents from The Johns Hopkins University Medical Center for short-term appointments. One of these candidates is a co-author of the publication that addresses nursing home use in a biracial population (*Am J Public Health* 1993;83:1765-1767).

- **<u>Ongoing Initiative</u>: Minority Access to Research Careers (MARC).**

Action Plan: In 1975, the Minority Access to Research Careers (MARC) program was formally established. The impetus to develop the MARC program came at the end of the 1960s, in response to an increasing demand for minority scientists by academic institutions, industry, and government and a historically low proportion of minority group members among the nation's biomedical scientists. The MARC program supports biomedical research training for students and faculty members at 4-year colleges and universities with substantial minority enrollments (Rene and Fakunding, 1992).

The NIA was successful in recruiting a minority candidate through the Minority Access to Research Careers Program. Following her assignment in the Intramural program, this student continued toward the pursuit of her M.A. degree in counseling psychology at Howard University. We continue to advertise for research fellows to the predoctoral and postdoctoral training programs.

- **<u>Ongoing Initiative</u>: Minority Biomedical Research Support (MBRS).**

Action Plan: The Minority Biomedical Research Support (MBRS) program began in 1972 as an effort to strengthen institutional research capabilities and provide for faculty and student participation in research at 2- and 4-year colleges, universities, and health professional schools with substantial minority enrollments. This program primarily supports biomedical research projects, with an emphasis on promoting the involvement of undergraduate and graduate students and enhancing the overall research capabilities of the grantee institutions. The MBRS program awards include funds for students, who are selected by the grantee institutions, to participate in the faculty members' research. This continues to be a broad-based NIA program supporting a number of students and investigators at minority institutions across the United States.

- **Ongoing Initiative: Equal Employment Opportunities (EEO) and Diversity in the NIA Workforce.**

Action Plan: The NIA EEO Manager and the Affirmative Action/Diversity Workgroup developed several goals from the Underrepresented Index (URI) analysis as a frame work for: (a) identifying problem areas in hiring minorities and women, (b) assessing the effectiveness of programs and activities, and (c) anticipating future directions and actions. The comprehensive evaluation serves as a systematic function to assess policies and guidelines relative to diversity. The EEO evaluation provides data to various internal organizations; measure to what extent the NIA strategies and objectives are met: and provides information to management to assess to what degree employees are aware and satisfied with training and career development programs. During FY 1999/2000, the EEO Manager and the EEO Specialist attended several professional and national conferences of minority group associations. These included (among others):

Society for Advancement of Chicanos and Native Americans in Science (SACNAS)
National Minority Research Symposium (NMRS)
Association of Minority Health Professions Schools (MHPF)
Visits to local universities and colleges.

- **Future Initiative: Identify minority investigators interested in research in relevant topics in biology of aging.**

Action Plan: The NIA has taken several steps to increase the opportunity to identify minority investigators interested in biology of aging research. These are: a) co-funding a training grant that supports the travel of minority students and young minority investigators to present their research at the annual American Society for Cell Biology meetings, and/or to participate in the summer course on Molecular Biology of Aging at the Marine Biological Laboratories, Woods Hole, MA., b) invite Principal Investigators of research grants funded by NIA to apply for travel funds for minority students and investigators not already supported on their grants to attend scientific workshops, conferences and annual meetings relevant to topics in biology of aging, and c) provide a mechanism for minority students and investigators to self-identify their interest in participating in these same meetings and apply for travel funds allowing them to participate.

B2. Provide support for institutional resources

- **Ongoing Initiative: Resource Centers for Minority Aging Research.**

Continue and build upon the successes of the existing "Resource Centers for Minority Aging Research" (RCMARs) to create scientific infrastructure for conducting research on disparities between and within various race/ethnic groups of minority and non-minority elders. Across sites, approximately 20% of the Centers' efforts are devoted to support for institutional resources including the management and administrative infrastructure of the Center, fixed equipment and facilities. Target year: reissue RFA FY 2001.

Action Plan: RCMARs will continue to include and emphasize: (1) research links between other appropriate NIA supported Centers (e.g., AD Centers) and other funded initiatives; (2) expanded opportunities of mentoring minority and non-minority investigators for research and sustained careers in the health of older minority populations; (3) opportunities to develop research and mentoring links between research institutions and traditionally minority based institutions; and (4) improve communication between researchers and minority end-result research users. The RCMARS will forge relationships with Research Centers in Minority Institutions (RCMI) and states with limited research support. This plan of action should help to expand the Nation's capacity for the conduct of biomedical and behavioral research and is a component of the overall RCMAR mission described in the section under Goal B1 "Support research training and career development."

C. Public Information/Outreach/Education Goals

C1. Develop research-based information resources

- **<u>Ongoing Initiative:</u> Dissemination of Public Information.**

Action Plan: Over the past 3 years the NIA Office of Communications and Public Liaison (OCPL) has carried out a number of activities related to reducing health disparities among older people and populations. Activities have included newsletters, press releases, and other health communication projects.

Newsletters: The OCPL provides creative, editorial, and logistical support for the NIA Work Group on Minority Aging newsletter *Links*, which is produced twice a year. Each issue includes: profiles of successful minority scientists with an interest in aging research; highlights from research focusing on aging issues within minority communities; and research support available from NIA for minority researchers. Press activities: Alzheimer's disease briefing (10/98), which included a discussion of the growing minority population at risk for AD (Dr. Morrison-Bogorad) and a presentation on behavioral and social aspects of AD focused on African-American families (Lisa Gwyther, MSW) Press release: "Older disabled women have trouble managing pain" from an article (Marco Pahor and Jack Guralnik) in <u>AJPH</u>, (6/99) with data from the Women's Health and Aging Study in Baltimore. Press release on REACH, "Innovative programs to be tested for Alzheimer's disease caregivers" (11/95) announcing the study, and an article, "Reaching Out to Dementia Caregivers" by Richard Schulz and Marcia Ory in <u>Innovations</u> (1999).

Article on RCMARs: "Centers work to enhance minority research" in <u>Innovations</u> (1999)

Health Communication Activities: Developed Spanish-language radio broadcast on forgetfulness for Dr. Elmer Huerta. Produced and distributed a Spanish-language version of *Age Page: Forgetfulness*. Updated packaged literature search, *Ethnicity and AD: Assessment, Research, and Education*, for distribution to health professionals. Sent promotional mailings for the ADEAR Center's Spanish-language, cost-recovery materials to organizations concerned with ethnic and minority issues. Developed exercise exhibit featuring minority. Promoted and distributed five Spanish-language bulletins, produced by the Suncoast Gerontology Center, about AD and related care issues. Developed proposal to the Office of Research on Minority Health to develop Spanish-language exercise video.

- **<u>Ongoing Initiative:</u> The Chartbook and Health Disparities.**

Work through the Interagency Forum on Aging-Related Statistics to gather data from statistical agencies to identify health disparities and relevant issues.

Action Plan: Participate in an interagency effort to develop a "Chartbook on the Well-Being of the Older Population" which will highlight important indicators of the health and well-being of America's aging population. The Chartbook will identify disparities by race and ethnic status. Consider reissuing this chartbook at 2 to 4 year intervals.

- **<u>Future Initiative</u>: Databases on Health Disparities.**

Action Plan: Enhance the capacity of various centers such as the National Archive on Computerized Data on Aging (NACDA) and the demography and RCMAR centers to 1) collect and archive databases suitable for secondary data analyses on health disparities, 2) distribute the data through CD-ROMS, FTP, and where necessary the creation of special enclaves that permit analyses of linked administrative or sensitive (e.g. geographic specific) data, and 3) provide workshops and summer institutes to assist potential users especially at non-research universities, and 5) provide post workshop assistance through 800 numbers and online help.

- **<u>Future Initiative:</u> Minority Subjects in Longitudinal Studies.**

Ensure that older minority subjects are retained in longitudinal studies.

Action Plan: The differential loss of older minority subjects in longitudinal studies, especially those below the median in income and education, presents a major threat to the generalized validity of the findings. Relatively small differentials in retention can, when accumulated over many years, result in substantial losses to longitudinal studies. Most minority tracking data focuses on just the numbers in the studies and not the retention rate. Improved tracking is needed especially for Mexican Americans who move back to Mexico, and for minority subjects who move into medical and long-term care institutions. Encourage research, workshops and pilot studies (for example through the RCMAR program) on retention research, and encourage the development of new approaches (such as more frequent contacts, higher payments to respondents, and post interview satisfaction studies) to counteract this problem.

C2. Communicate research-based information to increase public awareness

The Office of Communication and Public Liaison of the National Institute on Aging (NIA) has developed an exercise guide to inform older people about the benefits of exercise in improving and maintaining good health in later life. This guide is based on NIA-supported research results and the recommendations of the U.S. Surgeon General and the Centers for Disease Control and Prevention.

According to the 1990 Census, as many as 40 percent of elderly Hispanics either do not speak English or do not speak it well. To meet the information needs of this growing target audience, health education materials must take into account not only cultural sensitivities, but also language preferences. According to a recent survey conducted by the Health Care Financing Administration

(HCFA), older Hispanics would like to have all information, regardless of the way it is communicated, available to them in Spanish. HCFA also found that many of the Spanish-speaking participants in their survey could not read in English or Spanish and therefore would require health and beneficiary information in non-printed form.

- **Future Initiative: NIA Exercise Guide – Spanish Version.**

Action Plan: Translate and print the NIA Exercise Guide in Spanish.

- **Future Initiative: Outreach to Minority Communities.**

Action Plan: Target magazines serving special populations to promote health materials' such as Spanish Age Pages and Age Pages particularly relevant to African Americans and promote the NIA Exercise Guide for Older People to community groups such as churches, local health care clinics, and community centers serving special populations.

? Future Initiative: Age Pages.

Action Plan: Translate and print three additional **Age Pages** into Spanish; explore the advisability of developing a special version of the NIA Video Exercise Guide for the African American Community. Test the effectiveness of 4 Age Pages – cancer, stroke, high blood pressure, diabetes in an African American community in Baltimore.

C3. Transfer knowledge to health care providers

- **Future Initiative: Outreach to Minority Health Professionals.**

Action Plan: Attend (with exhibit) National Medical Association meeting to inform health providers of free health education materials from the NIA. Identify and media train one or several minority grantees to serve as spokesperson for the NIA to special populations.

- **Future Initiative: Dissemination of NIA Publications.**

Action Plan: Attend and exhibit at selected specialty meetings around health problems such as High Blood Pressure, Cancer, Diabetes, Stroke to make NIA publications available to minority health professionals and the association of clinicians for the underserved. Translate into Spanish and print two Age Pages.