

DEPARTMENT OF HEALTH AND HUMAN SERVICES

National Institutes of Health

Behavioral and Social Sciences Research at NIH

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# Behavioral and Social Sciences Research at NIH

## Executive Summary

### Background

During the Appropriations hearing of the House Subcommittee on Labor, HHS, Education, and Related Agencies held on May 16, 2001, Congressman Patrick Kennedy asked Dr. Ruth Kirschstein, Acting Director of the National Institutes of Health (NIH), for a consolidated report of ongoing behavioral and social sciences research at the NIH. The report that follows, "Behavioral and Social Sciences Research at NIH," was prepared by the NIH Office of Behavioral and Social Sciences Research (OBSSR) in response to this request. This report updates an earlier document, "Description of Behavioral and Social Sciences Research," which was submitted in June 2000 in response to the request in Senate Report No. 106-166.

We have provided in the *Background* section the detailed definition of *Behavioral and Social Sciences Research* that was developed by OBSSR in 1996. Since behavioral and social sciences research is a large, multifaceted field, encompassing a wide array of disciplines, the definition is divided between *Core Areas of Research* and *Adjunct Areas of Research*. Core areas of research are further divided into basic/fundamental research and clinical research. OBSSR developed this definition in response to Congressional concerns that a single definition of the field was needed to enable the assessment and monitoring of NIH's overall support of the behavioral and social sciences.

### NIH Accomplishments

Since the creation of this definition, the Institutes and Centers annually report their budget for behavioral and social sciences research through the NIH Office of the Budget. This reporting permits a better assessment of the role of behavioral and social science research in accomplishing the NIH mission. Table 1, in the *NIH Accomplishments* section, presents the amount of behavioral and social science research funded by each NIH Institute and Center from fiscal year (FY) 1996 through FY 2002. Since NIH components are continuously improving their implementation of the definition, the numbers reported may not fully reflect the extent of NIH activities in the behavioral and social sciences (for example, in some cases they represent undercounts). It is estimated that NIH investments in behavioral and social sciences research totaled \$1,850,000,000 in FY 2000.

The remainder of the *NIH Accomplishments* section describes the initiatives of the Institutes and Centers that fund behavioral and social sciences research.

### Developing a Research Agenda

In 1999, OBSSR asked the National Research Council to develop a research plan to guide NIH in supporting areas of high priority in the behavioral and social sciences. The resulting committee met four times between May 1999 and February 2000 and issued its report in January

2001 (Burton H. Singer and Carol D. Ryff (eds.), [New Horizons in Health: An Integrative Approach](#). *Committee on Future Directions for Behavioral and Social Sciences Research at the National Institutes of Health*. Washington, DC: [National Academy Press](#), 2001). This report identifies a broad domain of questions at the interface of social, behavioral, and biomedical sciences whose resolution could lead to major improvements in the health of the US population. The committee also emphasized research priorities that cut across Institute boundaries at NIH, thereby underscoring the broad significance of behavioral and social science research for multiple disease outcomes as well as health promotion. The 10 recommended priority areas for research investment to integrate the behavioral, social and biomedical sciences at NIH are:

1. **Predisease Pathways:** identify early and long-term biological, behavioral, psychological, and social precursors to disease;
2. **Positive Health:** identify biological, behavioral, and psychosocial factors that contribute to resilience, disease resistance, and wellness;
3. **Gene Expression:** understand environmentally induced gene expression and its connection to positive and negative health outcomes;
4. **Personal Ties:** explicate the mechanisms by which proximal social interactions influence health and disease outcomes;
5. **Healthy Communities:** identify the collective properties of social and physical environments that influence health and disease outcomes;
6. **Inequality:** clarify the mechanisms through which socioeconomic hierarchies, racism, discrimination, and stigmatization influence health and disease outcomes;
7. **Population Health:** understand macro-level trends in health status and evaluate the performance of the health care system;
8. **Interventions:** expand the scope and effectiveness of strategies for social and behavioral interventions to improve health;
9. **Methodology:** develop new measurement techniques and study designs to link information across levels of analysis (molecular, cellular, behavioral, psychosocial, community) and across time; and
10. **Infrastructure:** establish ways to maintain long-term study populations and to train scientists to integrate health-related knowledge across multiple disciplines.

NIH, under the leadership of OBSSR, is currently considering how to implement these recommendations.

## **I. Introduction**

During the Appropriations hearing of the House Subcommittee on Labor, HHS, Education, and Related Agencies held on May 16, 2001, Congressman Patrick Kennedy asked Dr. Ruth Kirschstein, Acting Director of the National Institutes of Health (NIH), for a consolidated report of ongoing behavioral and social sciences research at the NIH. This report was prepared by the NIH Office of Behavioral and Social Sciences Research (OBSSR) in response to this request. This report updates an earlier document, "Description of Behavioral and Social Sciences Research," which was submitted in June 2000 in response to the request in Senate Report No. 106-166 for a description of NIH's ongoing work in the behavioral sciences.

## **II. Background**

The NIH mission is to fund and conduct research that will result in an improvement in health. For the past five years, the Office of Behavioral and Social Sciences Research (OBSSR), which is located in the Office of the Director, has served to stimulate the growth of the behavioral and social sciences at the NIH. Although behavioral research has a long funding history at the NIH, we have become increasingly aware of its vital importance to our overall mission. Behavioral and social factors are important contributors to health and illness and frequently interact with biological factors to influence health outcomes. They also represent critical avenues for treatment and prevention.

When Congress created OBSSR, it mandated that a standard definition of behavioral and social sciences research be established. This definition was to be used to assess and monitor funding for behavioral and social sciences research at all of the NIH Institutes and Centers. Heretofore, there had been no single definition of the field that could be used to assess and monitor NIH support of the behavioral and social sciences across all NIH Institutes and Centers.

### **Behavioral and Social Sciences Research Defined at NIH**

Behavioral and social sciences research is a large, multifaceted field, encompassing a wide array of disciplines. The field employs a variety of methodological approaches including: surveys and questionnaires, interviews, randomized clinical trials, direct observation, physiological manipulations and recording, descriptive methods, laboratory and field experiments, standardized tests, economic analyses, statistical modeling, ethnography, and evaluation. Yet, behavioral and social sciences research is not restricted to a set of disciplines or methodological approaches. Instead, the field is defined by substantive areas of research that transcend disciplinary and methodological boundaries. In addition, several key cross-cutting themes characterize social and behavioral sciences research. These include: an emphasis on theory-driven research; the search for general principles of behavioral and social functioning; the importance ascribed to a developmental, lifespan perspective; an emphasis on individual variation, and variation across sociodemographic categories such as gender, age, and sociocultural status; and a focus on both the social and biological context of behavior.

Behavioral and social science research funded at the NIH can best be understood by dividing it into two sections: Core Areas of Research, and Adjunct Areas of Research. The core areas of

research are further divided into basic or fundamental research and clinical research. (The basic and clinical research distinction serves more of an organizational function for purposes of this definition, rather than representing firm boundaries within the field.) Indeed, many studies have both basic and clinical components. Moreover, basic and clinical research is often complementary. Basic research frequently provides the foundation for subsequent clinical research, and clinical research often influences the direction of basic research. Adjunct areas of behavioral and social sciences research include many types of neurobiological research and some research on pharmacologic interventions--areas that have implications for, and are often influenced by, behavioral research.

### **(1) Definition of “behavioral” and “social”**

For purposes of this definition, the term "behavioral" refers to overt actions; to underlying psychological processes such as cognition, emotion, temperament, and motivation; and to biobehavioral interactions. The term "social" encompasses sociocultural, socioeconomic, and sociodemographic status; to biosocial interactions; and to the various levels of social context from small groups to complex cultural systems societal influences.

### **(2) Core Areas of Behavioral and Social Sciences Research**

The core areas of behavioral and social sciences research are those that have a major and explicit focus on the understanding of behavioral or social processes, or on the use of these processes to predict or influence health outcomes or health risk factors. These core areas of research are divided into basic (or fundamental) research and clinical research.

#### ***Role of Basic or Fundamental Research***

Basic research in the behavioral and social sciences is designed to further our understanding of behavioral and social functioning. As is the case for basic research in the biomedical sciences, basic behavioral and social sciences research does not address disease outcomes per se, but is designed to provide essential knowledge necessary for better prediction, prevention, and control of illnesses.

Basic behavioral and social research is divided into three categories: (A) research on behavioral and social processes; (B) biopsychosocial research; and (C) research on the development of behavioral or social procedures for measurement, analysis, and classification.

#### ***A. Research on behavioral and social processes***

Research on behavioral and social processes involves the study of human or animal functioning at the level of the individual, small group, institution, organization, or community. At the individual level, this research may involve the study of behavioral factors such as cognition, memory, language, perception, personality, emotion, motivation, and others. At higher levels of aggregation, it includes the study of social variables such as the structure and dynamics of small groups (e.g. couples, families, work groups, etc.); institutions and organizations (e.g. schools, religious organizations, etc.); communities (defined by geography or common interest); and

larger demographic, political, economic, and cultural systems. Research on behavioral and social processes also includes the study of the interactions within and between these two levels of aggregation, such as the influence of sociocultural factors on cognitive processes or emotional responses. Finally, this research also includes the study of environmental factors such as climate, noise, environmental hazards, and residential environments and their effects on behavioral and social functioning.

**Examples of research topics and their implications that are or could be funded by NIH Institutes and Centers include:**

- Sensation and perception  
(Implications: neurological and mental disorders and disorders associated with abnormalities in vision, hearing, taste and smell)
- Emotion and motivation  
(Implications: depression, anxiety, schizophrenia, conduct disorders, normal psychological development, eating disorders, obesity, addictions, sleep disturbances, behavioral and cognitive treatments)
- Vulnerability and resilience  
(Implications: psychopathology, violence, effects of child abuse and neglect)
- Attention, learning and memory  
(Implications: mental disorders involving abnormalities in cognitive processes (e.g., schizophrenia, major depression), attention deficit disorders, learning disabilities, Alzheimer's disease and other dementias, cognitive rehabilitation, education)
- Language development  
(Implications: communication disorders, autism, learning disabilities)
- Social influences and social cognition  
(Implications: all-cause mortality, psychopathology, behavioral and cognitive treatments)
- Family processes and social networks  
(Implications: domestic violence, divorce, child abuse, psychopathology, all-cause mortality, child development, aging)
- Sociocultural and environmental processes  
(Implications: better understanding of social, cultural, and environmental antecedents to mental and physical illnesses)

***B. Biopsychosocial research***

Biopsychosocial research (also known as biobehavioral or biosocial research) involves the study of the interactions of biological factors with behavioral or social variables and how they affect each other (i.e., the study of bi-directional multilevel relationships).

**Examples of research topics and their implications that are or could be funded by the institutes include:**

- Behavior genetics  
(Implications: addictions, psychopathology, heart disease, gene expression, cancer risk, diabetes, oral health)

- Behavioral and cognitive neurosciences  
(Implications: effects of brain injury, neurodegenerative diseases, learning disabilities, dementia, addictions, sleep disorders, schizophrenia, neurological development, and plasticity)
- Psychoneuroimmunology  
(Implications: stress effects on health, AIDS, dental problems, infections)
- Psychopharmacology  
(Implications: addictions, psychopathology, brain disorders, drug treatments)
- Behavioral cardiology  
(Implications: cardiovascular diseases, stroke, hypertension)

### ***C. Research on the development of procedures for measurement, analysis, and classification***

Research on the development of procedures for measurement, analysis, and classification involves the development and refinement of procedures for measuring and analyzing behavior, psychological functioning, or the social environment. This research is designed to develop research tools that could be used in other areas of behavioral and social sciences or in biomedical research.

#### **Examples of research topics in the area include:**

- Statistical modeling techniques
- Memory assessment
- Behavioral observation procedures
- Psychometric analysis self-report instruments
- Qualitative and ethnographic methods
- Neuropsychological assessment
- Psychophysiological methods
- Pain Assessment
- Instruments for determining dietary intake
- Assessment of medical adherence

#### ***Role of Clinical Research***

Clinical research in the behavioral and social sciences is designed to predict or influence health outcomes, risks or protective factors. It is also concerned with the impact of illness or risk for illness on behavioral or social functioning. Clinical research is divided into five categories: (A) research on the identification and understanding of behavioral and social risk and protective factors associated with the onset and course of illness, and with health conditions; (B) research on the effects of illness or physical condition on behavioral and social functioning; (C) treatment outcomes research; (D) research on health promotion and disease prevention; and (E) research on institutional and organizational influences on health.

***A. Research on the identification and understanding of behavioral and social risk and protective factors associated with the onset and course of illness, and with health conditions.***

Research on the identification and understanding of behavioral and social risk and protective factors associated with the onset and course of illness, and with health conditions, examines the association of specific behavioral and social factors with mental and physical health outcomes, and the mechanisms that explain these associations. It is concerned with behavioral and social factors that may be health-damaging (risk factors) or health-promoting (protective factors).

**Examples of research topics in this area include the study of such risk and protective factors as:**

- Smoking
- Dietary practices
- Physical inactivity
- Stress
- Substance abuse
- Social support
- Cultural practices
- Socioeconomic status

***B. Research on the effects of illness or physical condition on behavioral and social functioning.***

**Examples of research topics include such areas as:**

- Psychological and social consequences of genetic testing
- Behavioral correlates of head injury across developmental stages
- Emotional and social consequences of HIV infection or cancer
- Coping responses associated with chronic pain syndromes
- Effects of illness on economic status
- Coping with loss of function due to disability

***C. Treatment outcomes research***

Treatment outcomes research involves the design and evaluation of behavioral and social interventions to treat mental and physical illnesses, or interventions designed to ameliorate the effects of illness on behavioral or social functioning. This area also includes research on behavioral and social rehabilitation procedures.

**Examples of research topics in this area include:**

- Cognitive or behavioral interventions for anxiety disorders and depression
- Strategies to reduce arthritis pain
- Interventions for restoring behavioral and brain functioning following head injury
- Lifestyle (dietary change, exercise, stress reduction) approaches to reversing coronary atherosclerosis
- Procedures to enhance adherence to medical interventions

#### ***D. Research on health promotion and disease prevention***

Research on health promotion and disease prevention involves the design, implementation, and evaluation of behavioral and social interventions to prevent the occurrence, recurrence, or progression of illness, symptoms, risk factors, or health problems. Health promotion also consists of evaluating procedures that facilitate optimal health functioning.

##### **Examples of research topics in this area include:**

- The design and evaluation of programs to discourage adolescent smoking
- Approaches to increase physical activity in the elderly
- Interventions to alter dietary intake to promote health
- Family interventions to prevent injuries in children
- Teaching parenting skills to prevent sudden infant death syndrome
- Mass media interventions to promote health knowledge
- Promoting the use of condoms to prevent sexually transmitted diseases

#### ***E. Research on institutional and organizational influences on health***

Research on institutional and organizational influences on health includes studies of the organization of and access to health care, its effectiveness in real world settings (i.e., health services research), its cost efficiency, and its social and cultural acceptability. It also involves research on macro-economic phenomena (e.g. business cycles), community and neighborhood organization and the structure and functioning of families, and how these variables influence the consumption and choice of health care, and decision-making concerning health procedures. Finally, this category includes research on how successful approaches to the organization and delivery of health services can be translated into public policy.

##### **Examples of research topics in this area include:**

- The impact of providing inpatient smokers with information and brief counseling from nursing staff
- The accessibility of rural dental health care facilities for migrant workers
- The cost-effectiveness of occupational safety interventions
- The use of schools as sites for the delivery of mental health services
- The effects of capitation on health care utilization
- The effects of ethnicity and gender on referral for mental health services
- The association of health provider behavior to patient adherence to medical treatments

#### **Adjunct Areas of Behavioral and Social Sciences Research**

Adjunct behavioral and social sciences research are determined by two sets of criteria. First, these research areas do not have a major and explicit focus on the understanding of behavioral or social processes, or the use of these factors to predict or influence health outcomes or health risk factors. That is, these projects cannot be categorized as basic or clinical behavioral and social sciences research. Second, adjunct behavioral and social sciences research does include studies that have clearly articulated implications for either understanding behavioral or social processes (in the case of some basic biological research), or that utilize behavioral and social factors as

critical outcome variables (in the case of behavior-relevant pharmacologic studies).

The inclusion of adjunct research areas in this definition is an acknowledgment that there are scientific domains outside of the core areas of behavioral and social sciences where (a) the findings have clear implications for understanding behavioral and social processes, or (b) the research is an outgrowth of prior behavioral or social sciences research. Although it could be argued that these adjunct areas are really in the "biomedical" research domains, they nevertheless represent research topics that are inextricably linked to the behavioral and social sciences. Adjunct behavioral and social sciences research is divided into two categories: (A) Behavior-relevant basic biological research, and (B) Behavior-relevant pharmacologic intervention studies.

### ***A. Behavior-relevant basic biological research***

Behavior-relevant basic biological research involves studies where the understanding of behavioral and social process is a clearly articulated goal. Although these studies focus solely in the biological level of analysis (i.e., no behavioral or social measures are taken) they are designed explicitly to provide a better understanding of basic behavioral, social, or biopsychosocial processes, and typically involve independent variables known to be important to behavioral or social functioning. These types of biological studies are often designed to assist in identifying biological mechanisms that mediate associations between behavioral and social factors with health outcomes. Specifically excluded from this category is research that focuses solely on biological mechanisms underlying clinical problems that have behavioral components (e.g. depression, schizophrenia). That is, to be included in this category, the research must address basic behavioral, social, or biopsychosocial processes.

#### **Examples of research topics in this area include:**

- Studies of neural plasticity designed to improve understanding of behavioral or cognitive development
- Studies of the sympathetic nervous system designed to better understand stress/health relationships
- Studies of brain regions potentially involved in emotion
- Studies of endocrine/immune system interactions designed to enhance understanding of psychoneuroimmunological associations

### ***B. Behavior-relevant pharmacologic intervention studies***

Behavior-relevant pharmacologic intervention studies include those studies that evaluate drug treatment for mental or physical health problems, where a behavioral or social dependent variable is used (e.g. anxiety, depression, drinking behavior, smoking, etc.) These types of pharmacologic intervention studies have clearly benefited from behavioral and social sciences research, especially with respect to measurement of outcomes. This research is relevant to the behavioral and social sciences not only because behavioral and social outcomes variables are used, but because it facilitates an understanding of the biological mechanisms underlying those processes.

**Examples of research topics in this area include:**

- Effects of chemotherapeutic treatments on quality of life
- Psychopharmacologic treatments for anxiety and depression
- Side effects of drug treatments on medical compliance
- Pharmacologic approaches to nicotine addiction

### III. NIH Accomplishments to Date

#### Institute and Center Funding Levels FY1996 – FY2002

The following funding chart applies the above definition to calculate the amount of funding of behavioral and social sciences research for Fiscal Years 1996-2000, and estimates for Fiscal Years 2001-2002. Although Institutes and Centers vary in the amount of behavioral and social science research they fund, there has been a steady increase since 1996. Since NIH components are continuously improving their reporting of activities in the behavioral and social sciences, the numbers below may not fully reflect the extent of NIH activities (in some cases they represent undercounts).

TABLE 1

NATIONAL INSTITUTES OF HEALTH  
Behavioral Research and Social Science Research  
(Dollars in millions)

Participating ICs	FY 1996 Actual	FY 1997 Actual	FY 1998 Actual	FY 1999 Actual	FY 2000 Actual	FY 2001 Estimate	FY 2002 Estimate
NCI	\$169.6	\$179.8	\$153.5	\$172.7	\$205.0	\$226.0	\$248.6
NHLBI	101.4	106.4	113.9	130.3	129.2	146.7	162.1
NIDCR	10.9	12.8	13.1	14.8	18.0	20.7	23.2
NIDDK	28.0	26.4	28.3	32.2	35.0	38.0	42.0
NINDS	36.1	36.5	36.1	41.9	36.0	39.5	43.3
NIAID	7.3	8.4	9.5	11.5	12.7	14.7	16.2
NIGMS	0.0	0.0	0.0	0.0	0.0	6.0	6.5
NICHD	115.6	125.6	135.7	154.5	193.5	219.8	246.2
NEI	21.4	23.0	30.9	40.5	46.3	52.6	58.8
NIEHS	7.0	7.4	7.6	8.3	8.6	9.2	9.7
NIA	69.6	78.0	83.7	86.7	163.3	186.6	208.8
NIAMS	0.0	10.1	8.2	13.7	17.1	19.4	21.7
NIDCD	46.6	50.1	46.9	57.2	64.8	73.4	82.8
NIMH	223.2	241.9	251.6	286.0	316.6	359.8	402.7
NIDA	206.4	226.0	238.0	259.8	300.2	345.0	400.2
NIAAA	106.0	128.8	142.7	141.1	150.3	158.4	170.8
NINR	35.5	38.3	38.4	56.7	73.0	80.3	88.4
NHGRI	7.9	8.3	4.0	5.5	9.2	10.0	12.0
NCCAM	N/A	N/A	N/A	N/A	N/A	0.1	0.1
NCRR	27.8	29.6	33.8	41.0	48.3	54.4	61.8
FIC	1.5	2.2	2.2	3.0	3.2	3.4	3.6
NLM	0.4	0.6	0.1	0.0	1.1	1.3	1.6
OD	2.2	2.4	2.0	11.5	17.9	17.8	18.8
NIH*	\$1,224.6	\$1,342.6	\$1,380.2	\$1,569.0	\$1,849.6	\$2,083.0	\$2,329.1

\*May not add due to rounding.

Source: NIH Office of the Director, Office of Budget.

## **Highlights of OBSSR Activities**

OBSSR's strategic goals for the near future are to advance behavioral and social sciences research and training; integrate a biobehavioral perspective across NIH; and improve communication among scientists and with the public. (For the complete Strategic Plan, see <http://obssr.od.nih.gov/about/plan.html>).

### ***Advancing Behavioral and Social Sciences Research and Training***

OBSSR plays a leadership role in developing ideas for initiatives, and in gaining the support for them within the NIH Institutes. Since OBSSR does not have grant-making authority, OBSSR staff advise applicants on appropriate Institute contacts and encourage applicants to communicate with NIH Institute staff for feedback on proposal ideas, for suggestions regarding potential collaborating investigators, and for guidance through the NIH application process. To date, OBSSR has organized and released one Program Announcement on *Methodology and Measurement in the Behavioral and Social Sciences* and the 8 trans-NIH and trans-agency Requests for Applications (RFAs) below:

- Research on the Development of Interventions for Youth Violence
- Testing Interventions to Improve Adherence to Pharmacological Treatment Regimens
- Centers for Mind-Body Interactions in Health
- Educational Workshops in Interdisciplinary Research
- Research on Child Neglect
- Innovative Approaches to Disease Prevention Through Behavioral Change
- Research on Violence Against Women and Violence Within the Family
- Informed Consent Research Involving Human Participants

### ***Setting Priorities for Behavioral and Social Sciences Research at the NIH***

Through the sponsorship and organization of workshops, conferences, lectures, and planning groups, OBSSR works with NIH Institutes, Centers and Offices as well with outside organizations to specify priorities for behavioral and social sciences research. Some of OBSSR's current collaborative initiatives are discussed below:

- Exploring the Biological/Physiological Pathways Between Education and Health. Since the positive association between education and health is well known but poorly understood, OBSSR is developing a workshop to understand the behavioral and biological pathways through which education influences health and to discuss priority areas of research for understanding the causal pathways linking education and health.
- Ethical Issues in Behavioral and Social Sciences Research. Given recent attention to the federal system for protecting human research subjects, OBSSR is collaborating with the DHHS Office of Human Research Protections (OHRP) to consider the perspectives of the behavioral and social science research community.

- Environmentally Induced Gene Expression. OBSSR is developing an integrative research initiative aimed at understanding the role of environmentally induced gene expression in disease etiology and health promotion.
- Integrating Behavioral and Social Sciences into the Medical School Curriculum. OBSSR is collaborating with the Association of American Medical Colleges (AAMC) and the Health Resources and Services Administration (HRSA) to develop a curriculum for medical schools that integrates behavioral and social research findings.
- Community-Level Measures and Health Outcomes. In response to epidemiological and experimental studies that have shown a direct association between the social environment and health, OBSSR is developing a workshop to develop core summary measures useful for comparing social environments and health across communities. Such measures will be essential research tools for understanding the role of community-level factors in determining health patterns.
- Economic Measures in Health Surveys. In order to improve the usefulness of surveys for studying the health status of persons of different socioeconomic groups, OBSSR is developing workshops on how to apply the latest methodologies for obtaining economic data to surveys which have high quality *health* data but lack equally high quality *economic* data.
- Linking Sociocultural, Behavioral, and Biological Research on Health. OBSSR is developing a new trans-NIH Program Announcement to encourage researchers to conduct cutting-edge research on social and cultural influences on health and their integration with biomedical sciences.
- Racial Bias and Health. OBSSR is developing a workshop to review the growing evidence linking health, socioeconomic status, and macro-economics with the goal of understanding the effect of racial bias on health status.

## **Overview of Institute and Center Activities**

### **1. National Cancer Institute (NCI)**

#### ***History***

The Division of Cancer Control and Population Sciences (DCCPS) was created in 1997. The Behavioral Research Program was formed at that time as one of the three (now four) fundamental components of the new Division. One of our core principles is the integration of epidemiology, behavioral, surveillance and survivorship research. The continued expansion of this program over the last four years exemplifies the importance of behavioral science research as one of the foundations of effective cancer control. NCI's strengthened commitment to behavioral science research is evident by the designation of *Cancer Communications, Tobacco and Tobacco-Related Cancers*, and *Reducing Cancer-Related Health Disparities* as opportunities for investment, which are among the highest scientific priorities of the Institute.

#### ***Mission***

The Behavioral Research Program (BRP) initiates, supports and evaluates a comprehensive program of behavioral research ranging from basic behavioral research to research on the development, testing and dissemination of disease prevention and health promotion interventions in areas such as tobacco use, cancer screening, dietary behavior, and sun protection. The goal is to increase the breadth, depth and quality of cancer prevention and control behavioral science. To realize this goal, the NCI has expanded collaborations with other NIH Institutes and agencies that support behavioral science research.

#### ***Institute-wide Leadership***

The Behavioral Research Program plays a central role in both establishing and implementing the Institute's research agenda for several critical areas, including cancer communications, tobacco control, and health disparities and underserved populations.

NCI's scientific priority in Cancer Communications is grounded in behavioral research. The goal of this broad set of initiatives is to increase our knowledge about, tools for, access to, and use of cancer communications by the public, consumers, patients, survivors, and health professionals - with a special focus on diverse populations - to accelerate reductions in the U.S. cancer burden. Several of the objectives are being led by the Behavioral Research Program's Health Communication and Informatics Branch, including the establishment of Centers of Excellence in Cancer Communications Research, and the development of a national biennial survey to assess information needs and trends related to cancer communications.

NCI's scientific priority in Tobacco and Tobacco-Related Cancers also involves behavioral research, ranging from basic biobehavioral research to community-level interventions. The goal of this scientific priority is to understand the causes of tobacco use, addiction, and related cancers and apply this knowledge to their prevention and treatment. The Behavioral Research Program's Tobacco Control Research Branch is leading this initiative, with broad participation and support from the entire Institute.

The goal of NCI's scientific challenge to Reduce Cancer-Related Health Disparities is to understand the causes of cancer health disparities and develop effective interventions to reduce them. To do this, we must increase fundamental research into the social causes of health disparities, the psychosocial factors that mediate them, and the biologic pathways that can explain their impact. NCI is committed to a research program to address cancer health disparities across the cancer control continuum from prevention to end of life care.

### ***Program Accomplishments***

The NCI has committed substantial resources, both personnel and fiscal, to the Behavioral Research Program (BRP). Through successful recruitments, the NCI has increased, strengthened and broadened behavioral science expertise on its staff, and will continue to do so. In the short time since the creation of the BRP, NCI has launched numerous initiatives targeted to both new and established behavioral science investigators (Requests for Applications, Program Announcements, Supplements, and Career Development Awards). Many of these are listed below. In addition, the NCI has strengthened its outreach to professional organizations in behavioral science as well as increasing its involvement in trans-NIH behavioral science activities.

### ***Behavioral Research***

- *Innovative Cancer Control Initiatives in Cancer Centers (Supplement)*: Eleven centers are currently funded to establish a cadre of junior cancer control investigators who have not previously received research funding. The intent is to train these investigators to conduct cancer control research and to enable them to successfully compete for NCI grant funding.
- *Centers for Mind/Body Interactions and Health (Request for Applications - RFA)*: NCI is funding one P50 Center grant as part of a multi-center initiative and partnership with OBSSR.
- *Basic Biobehavioral Research on Cancer Related Behaviors (RFA)*: Through the first issuance in 1998, eight applications were funded. Recently, this initiative was revised and reissued to target a broader applicant pool and to encourage proposals in diverse areas of cancer-related behavior. Six more applications were funded, several in the area of biological factors related to smoking cessation, and several related to stress/psychological functioning and the impact of these factors on the immune system. These grants should provide new knowledge about how people become addicted and the mechanisms by which stress might affect the immune system.
- *Small Grants Program for Behavioral Research in Cancer Control (Program Announcement)*: This initiative is designed to facilitate the growth of a nationwide cohort of new scientific investigators with a high level of research expertise in behavioral cancer control research. Ten applications were approved for funding in FY 2000 that focus on behavioral science issues. We are planning to reissue this program announcement in 2001.
- *Exploratory Grants for Behavioral Research in Cancer Control (Program Announcement)*: This is a new initiative to encourage pilot projects or feasibility studies to support creative, novel, high risk/high payoff research to accelerate advances in behavioral science. Six grants focusing on behavioral science have been funded since the R21 mechanism was initiated. We are planning to reissue this program announcement in 2001.

### ***Communications Research***

- *Centers of Excellence in Cancer Communications Research (RFA)*: The Centers will facilitate rapid advances in knowledge about cancer communications and develop, implement, and evaluate strategies to improve access to and the efficacy, effectiveness, and dissemination of cancer communications. By assembling interdisciplinary teams of researchers committed to answering important health communications questions, and by ensuring adequate infrastructures, we can speed the process of discovery and its application. Funding for 4-5 Centers is anticipated for March 2002.
- *Identify Patients' Communication Needs (Administrative Supplement to the CCOPS)*: We recently provided funds to Dr. Gary Morrow, at the University of Rochester, to conduct surveys of patients in community practices to identify their information and communication needs. These data will be critical in developing programs to meet patients' needs.
- *Health Information National Trends Survey (Contract)*: This is the first nationally representative survey of the American public - with emphasis on underserved populations - about their access to and use of cancer-related health information. The survey will be in the field in September 2001, pending OMB approval.
- *Making Quality Count for Consumers and Patients (RFA)*: NCI is partnering with the Agency for Healthcare Research and Quality to fund a research grant that facilitates consumer and patient use of information about quality health care decisions with a focus on vulnerable populations. The investigator team at Dartmouth is developing and evaluating a booklet to improve the way people think about and make use of numbers in health decision making.
- *Health Communication in Cancer Control (RFA)*: Five grants were funded from this RFA. These grants focused on communicating genetic test results to families, tailoring communications for colorectal cancer screening, developing innovative strategies for adherence to nutrition recommendations, enhancing effective cancer communications for Latina women, conducting culturally tailored cancer prevention in African American women, and creating computerized symptom reporting systems for cancer patients. These grants should lead to new programs for communicating with diverse groups.
- *NCI's Media Technology/Health Communication Small Business Innovative Research Grant/Small Business Technology Transfer Research Program*: The goal of this program is to develop, implement, and test the effectiveness of new or existing models of behavior modification or informational/ educational applications to reduce the risk of cancer or promote the health of cancer survivors. NCI promotes innovative ways of translating cancer research into interventions, programs, and products to reduce cancer risks, increase use of screening, improve decision making about treatment options, and address the needs of cancer survivors.

### ***Tobacco Control Research***

- *Transdisciplinary Tobacco Use Research Centers (RFA)*: Beginning FY 2000, seven new research centers are focusing on a range of issues from biological and behavioral factors in tobacco use and nicotine addiction to the prevention of tobacco use among youth of diverse cultures. The Centers are jointly managed with the National Institute on Drug Abuse, with an additional large investment by the Robert Wood Johnson Foundation to assure that research findings are communicated quickly not only to relevant health professionals and organizations but to the public as well. Scientists from the seven centers have already met

three times with staff from the NCI, NIDA, and RWJF to identify cross-cutting issues, form working groups, examine barriers to research proposals, and enhance cross-site collaboration.

- *Research in State and Community Tobacco Control Interventions (RFA)*: Twelve grants to conduct community-based research on policy and media interventions were announced in FY 2000. This RFA was reissued, with plans to fund up to ten additional projects in FY 2002 to test the most effective ways to reduce tobacco use at the state and community level.
- *Review and Analysis of Tobacco Industry Documents (Program Announcement)*: Four grants were awarded in FY 2000 to facilitate a systematic, comprehensive analysis of scientific and marketing documents released by the tobacco industry during the 1990s that will help researchers develop strategies to reduce tobacco use.

### ***Health Disparities Research***

- *Digital Divide Pilot Projects (Contract)*: This FY 2000 award supports research and development projects to narrow the digital divide in the access to and use of online cancer information. Four institutions in different parts of the country -- the Memorial Sloan-Kettering Cancer Center in New York; the University of Wisconsin, Madison in partnership with the Karmanos Cancer Center; the Yale Cancer Center; and Kentucky's Markey Cancer Center in collaboration with the Louisiana State University Health Sciences Center -- are working with the regional Cancer Information Service centers to test the efficacy of new communication technologies in cancer prevention and education.
- *Special Populations Networks for Cancer Awareness Research and Training (RFA)*: This large initiative by the NCI Center to Reduce Cancer Health Disparities addresses the unequal burden of cancer with funding over a 5 year period. The program supports collaborations between large research institutions and community-based programs. Eighteen grants at seventeen institutions have created cancer control, prevention, research and training programs in minority and underserved populations. These grants include a wide, quite exhaustive list of ethnic minority/underserved groups.

### ***Cancer Survivorship Research***

- *Support of Family Research (Administrative Supplements to Cancer Centers)*: NCI funded ten grants to identify the problems cancer causes for families and develop pilot interventions to help families cope with the burden caused by cancer. This is the first time the NCI has committed funds specifically to focus on the family impact of cancer. Nine of the ten projects focused on families of adult cancer survivors or those at high risk for cancer and one grant focused on the families of pediatric cancer survivors. Cancer sites were widely represented among the projects including prostate, breast, colon, pediatric, brain, and head and neck.

### ***Research Dissemination***

- *Disseminate Promising Cancer Control Interventions Tested in Effective Research Projects (Competitive Supplements)*: We have created a new competitive grant mechanism to provide support for dissemination efforts by NCI-funded investigators with evidence of effective cancer control interventions. This will strengthen NCI's partnerships with voluntary health organizations, HMOs, community organizations, and others. Moreover, since effective dissemination rarely occurs, NCI's support will increase the likelihood that citizens will benefit from the NCI's investment in research. The announcement is currently being advertised, with funding anticipated for FY 2002.

In addition to the initiatives noted above, the NCI has been actively involved in a number of other research endeavors and has expanded training opportunities as noted below:

### ***Training***

The NCI has substantially expanded opportunities for training for behavioral scientists with cancer-related interests, to provide behavioral scientists with funding opportunities throughout their careers. NCI's new R25 Cancer Education and Career Development Program supports the development of interdisciplinary training programs that provide behavioral scientists with the necessary knowledge and skills to conduct cancer-related research. NCI supports the newly revised K23 Mentored Research Career Development award, which is open to clinical psychologists and other clinically oriented behavioral scientists. This mechanism is complemented by the NCI's K07 Career Development Award in Cancer Prevention, Control, and Population Sciences, that is now being marketed directly to behavioral scientists through advertisements in relevant publications. Behavioral scientists who have completed their doctoral training and mentored experience are eligible for the new NCI K22 Transition Award, which provides support to investigators who are moving from a mentored to an independent research position. This award is expected to increase opportunities for behavioral scientists who are seeking faculty positions at our nation's leading cancer research institutions. The KO5 mechanism is also available for more mid-level to senior behavioral scientists. Thus, funding for the most productive and recognized behavioral scientists to devote substantial time to cancer-related research is now available.

### ***New Directions***

In the next year, we will issue announcements and establish programs in several new areas. Two are described briefly.

- *Centers for Population Studies in Cancer (RFA)*: Understanding cancer-related health disparities requires a broad perspective that integrates many disciplines and includes a focus on social determinants. We are planning to issue an RFA for Centers in this area in order to have a major population level impact on cancer. The Centers will expand understanding of the social and environmental causes of cancer-related health disparities and the psychosocial, behavioral, and biological factors that mediate them. We are exploring co-sponsorship with other NIH institutes and a major foundation.
- *Tobacco Intervention Research and Smoking Cessation Clinic*: NCI is establishing a clinic that will serve as a state-of-the-science center for multidisciplinary tobacco intervention research by NCI scientists and collaborators. The clinic will be a resource for scientists conducting a range of genetic, epidemiological, and basic science and behavioral research studies. It also will provide research-based tobacco cessation services to the NIH community. This establishment of a clinic is an unprecedented opportunity to fund studies to develop and test new behavioral, pharmacological, and combination therapies to treat nicotine dependence, evaluate current tobacco cessation programs for adolescents and young adults, disseminate proven interventions, target research that focuses on the tailoring of interventions for high-risk populations, provide a rich training environment for new and established investigators, and expand collaborations with federal and private partners.

## 2. National Eye Institute (NEI)

In 1968, the Congress established the National Eye Institute (NEI) to conduct and support research, training, health information dissemination, and other programs with respect to blinding eye diseases, visual disorders, mechanisms of visual function, preservation of sight, and the special health problems and requirements of the blind. Although seldom fatal, eye diseases cause suffering, disability, and loss of productivity for millions of people in this country and throughout the world. The most pronounced effects of diseases of the eye and disorders of vision are on an individual's quality of life. They affect the ability to act independently, recognize family and friends, read, drive a car, and perform a host of other activities that we consider routine daily tasks.

Our ability to perform these tasks under neurosensory control is one of the most fundamental and critical of our human abilities and one that has been an important area of NEI-sponsored research. Much of this work has concentrated on the visual/oculomotor system that controls sensory-motor coordination. By understanding how visual system neurons convey complex messages, scientists can explore how physical and behavioral components of the message contribute to higher visual cognitive functions like perception, attention, and memory. This information is vital to our understanding of visual system deficits and in developing visual prosthetic devices to compensate for other visual system defects or blindness. A number of advances have occurred in this area of research over the past year.

- Researchers supported by the NEI recently studied how the decision to focus the eyes on one of two targets begins with the sighting of both targets (sensory input) and ends with the coordinated movement of the eyes to focus on one target (motor outcome). The milliseconds between sensory input and motor output are more than a simple “knee jerk” reflex response as once thought. Primates trained to respond to visual cues demonstrate that anticipation of a reward, based on past experience, or the relative size of the reward associated with the target greatly influences target selection. The decision-making process is correlated with the increased firing of neurons in the sensory-motor processing area of the central nervous system. This provides an important framework to model and understand the neurophysiological basis of visual-guided behaviors.
- Other scientists have shown that as we move through the environment, we experience highly stereotyped patterns of visual motion, called optic flow. Their studies of eye movements indicate that our brains are able to process optic flow information very rapidly, permitting automatic adjustments of gaze without the subject having to think about it. These behaviors use sensory-motor linkages that are known to involve particular regions of the cerebral cortex and are helping us to understand how the cortex processes visual information.
- NEI intramural investigators have also determined that the human visual system distinguishes between the motion of objects in the world about us and the motion that results because we ourselves move about in that world. An area of the cerebral cortex of the monkey, whose motion perception is very similar to that of humans, has been identified, which is particularly appropriate for seeing the motion of objects because neurons in this area both differentiate the object from its surround and they separate objects moving at different

distances from the observer. Because previous experiments had identified areas related to motion generated by observer motion, researchers now believe that both types of motion (object and observer) might be represented in different areas of cerebral cortex.

The NEI is also supporting the Age-related Eye Diseases Study (AREDS), which is designed to assess the clinical course, prognosis, and risk factors of age-related macular degeneration (AMD) and cataract. Among the risk factors being studied are lifestyle and behavioral factors associated with dietary deficiencies, smoking, drugs, and sunlight exposure. The AREDS also has a clinical trial component that will evaluate, in randomized clinical trials, the effects of pharmacologic doses of (1) antioxidants and zinc on the progression of AMD and (2) antioxidants on the development and progression of lens opacities.

The NEI recently launched a Low Vision Education Program to provide communities nationwide with materials and technical support to increase awareness of local low vision services and resources. Low vision is broadly defined as a visual impairment, not corrected by standard glasses, contact lenses, medicine, or surgery, which interferes with the ability to perform everyday activities. While lost vision usually cannot be restored, this program will help people learn to make the most of the vision that remains. The Low Vision Education Program will include a multimedia public service campaign and a traveling exhibit that will be displayed in shopping malls around the country.

### **3. National Heart, Lung, and Blood Institute (NHLBI)**

In recognition of the important influence of behavior on health and illness, and the high potential for improving health through the application of behavioral principles to the treatment and prevention of disease, the National Heart, Lung, and Blood Institute has supported a vigorous program of research and development in the behavioral sciences related to its mission. The Institute's first behavioral research grant was awarded in 1955, just a few years after the formation in 1948 of what was then the National Heart Institute. The project, by Dr. Caroline Bedell Thomas at Johns Hopkins University, was the first known attempt to ascertain the psychological characteristics of individuals with hypertension and coronary heart disease, and it continued to be supported for more than a decade. In 1977 the NHLBI became the first Institute at the National Institutes of Health to form a separate component - the Behavioral Medicine Branch - dedicated to developing behavioral research. At the present time, the Institute's support of behavioral and social sciences research includes training programs for new and advanced investigators, review and assessment of the field through workshops, conferences, and task forces, support of Institute- and investigator-initiated basic and applied research, multicenter clinical trials of behavioral interventions for prevention and treatment of disease, and dissemination of information through public education programs designed to translate research findings into public health benefits. The full compendium of the Institute's training programs is available to behavioral scientists, many of whom are recipients of research support and participants in the Institute's efforts to identify training needs for the successful implementation of its mission. The NHLBI supported numerous institutional behavioral training grants in FY 2000, as well as career development awards and fellowships. The following highlights provide an overview of selected behavioral and social sciences research efforts under way.

## *Observational Epidemiologic Studies*

Observational epidemiologic studies have been the source of much of the progress in understanding the influence of psychosocial factors in cardiovascular diseases. Psychosocial factors and their interactions with biological risk factors are being studied in several major epidemiological studies. For example, the Framingham and Jackson Heart Studies are important sources of information about changing patterns of smoking, eating, and physical activity habits and how these influence health. The CARDIA study, which includes minorities and individuals from a range of socioeconomic strata, is designed to help understand how cardiovascular disease risk factors change during the critical years of transition from adolescence through young adulthood and middle age, while The Family Heart Study provides data on the extent to which risk factors and their combination explain familial aggregation of heart disease. Finally, the Multiethnic Study of Atherosclerosis (MESA) employs the most sophisticated technology available to study relationships between newly identified and established risk factors and diagnosis of heart disease at its earliest stages. Together, these studies are a rich source of information about the role of lifestyle, stress, social support, and other behavioral factors and how they interact with biological systems in health and illness.

Anger as a Risk Factor for Cardiovascular Disease. Recently published data from the Atherosclerosis Risk in Communities (ARIC) study showed that individuals with normal blood pressure who exhibit high propensity for anger had 75 percent more “hard” cardiovascular disease (CVD) events than those with low trait anger scores. This relationship was not seen for individuals with high blood pressure, suggesting that the effects of anger are independent of other biological pathways, and that proneness to anger imparts a significantly higher risk of death from coronary heart disease. A relationship between anger and heart disease also has been described outside of the United States. Data from an NHLBI-supported study in Kuopio, Finland, conducted in collaboration with American epidemiologists at the University of Michigan, showed that men who reported a high incidence of expressed anger were at twice the risk of stroke during more than 8 years of follow-up. The relationship persisted even when use of antihypertensive medication, age, blood pressure, smoking, body mass, and socioeconomic status were taken into account, again suggesting that anger influences heart disease independent of well-established risk factors. The findings were amplified in men with a history of ischemic heart disease, in whom the risk of stroke was 6-fold after adjustments for other biological risk factors. An important observation is that controlling anger rather than expressing it did not impart additional risk, as had been theorized by others.

These data are consistent with previous data based on the NHLBI Framingham Heart Study, which showed that the trait of anger in young men confers a higher risk than anger in older individuals. The strength of the Framingham data is that it includes a large number of men and women on whom data have been collected over many years, enabling a longitudinal analysis of risk factors. It is also broad based - it is possible to control for the influence of numerous other factors that influence CVD risk. To pursue further the relationships between negative emotions and CVD, the NHLBI this year funded a study specifically to examine more extensively the Framingham data in relation to anger and other behavioral factors. Also under way are studies to evaluate the role of anger in cardiovascular reactivity in men in their early teens to determine if it is linked with development of high blood pressure in adulthood, and research in animal models

to understand the intricacies of neural pathways and neurochemical signaling processes involved in regulating the hormonal systems that influence cardiovascular function under emotional states.

Socioeconomic Status (SES) has been shown to be one of the most important influences on health status and the basis for many of the well-documented disparities in health in various segments of the population. The Institute is actively evaluating data from nationally representative databases such as the National Longitudinal Mortality Study to document the magnitude and changes over time of health disparities and behavioral risk factors. In addition, data collection is being conducted for international comparisons of the complex factors driving such disparities, and many of the prevention and treatment research studies described below target minority groups. The Institute recently convened a Working Group on Early Life Influences on Health to evaluate psychosocial factors acting on mothers and children that may contribute to health disparities, and it is participating in an interagency effort to design a longitudinal birth cohort study to evaluate the influence of early exposures on future health.

### ***Behavioral Interventions for Prevention and Treatment***

Design of Effective Behavioral Interventions for Prevention and Treatment of Disease is a major goal of the Institute's behavioral research efforts. The NHLBI supports numerous studies on health behavior interventions to improve cardiovascular and lung health, including studies on diet, physical activity, smoking, and health-care-seeking behavior, and psychosocial factors such as depression, social isolation, and anger. In some instances the primary objective is to foster adherence to preventive interventions or medical regimens, rather than to treat a specific disorder. Results from various studies are incorporated into national public and professional educational programs such as the National High Blood Pressure Educational Program, the National Cholesterol Education Program, the National Heart Attack Alert Program, and the NHLBI Obesity Education Initiative.

Prevention Research. In the obesity/overweight area, the NHLBI has just completed PATHWAYS, a multicenter study of obesity prevention in American Indian schoolchildren that tested a school-based intervention for diet and physical activity. The intervention achieved healthful changes in dietary components, but progression toward obesity was not reduced. The Girls Health Enrichment Multisite Studies (GEMS) is a four-study program to develop and evaluate approaches for preventing obesity in black adolescent girls. Four field centers are developing and testing interventions to prevent excessive weight gain as the girls proceed through puberty (beginning at age 8-10 years), which is a high-risk period for this high-risk population group. The field centers test unique interventions while obtaining common key measurements according to a standardized protocol. The results of PATHWAYS and GEMS will be relevant to national obesity prevention efforts.

The physical activity research portfolio includes studies examining the effects of various physical activity regimens as well as testing interventions to promote physical activity in a number of settings. Several studies are testing the effects of different patterns of physical activity on cardiovascular risk factors and cardiorespiratory fitness, including various durations, intensities, frequencies, and types of activity. Other studies are testing intervention approaches to improve physical activity levels in various population groups, such as obese or overweight

women, low-income or Hispanic women, children and adolescents, college students, and blacks. The Activity Counseling Trial (ACT), which was just completed, tested two patient education and counseling interventions designed to be feasible for delivery in primary care settings to increase physical activity and fitness levels of sedentary patients. Both of the interventions significantly increased cardiorespiratory fitness over two years compared with usual care in women, and the interventions were equally successful. There was no effect on fitness in men. A new multicenter study, the Trial of Activity in Adolescent Girls (TAAG), is under way to test the effectiveness of a coordinated school- and community-based intervention in preventing the decline in physical activity in girls that typically occurs during adolescence.

In the nutrition area, the NHLBI is funding numerous studies to examine the effects of various nutritional strategies on cardiovascular risk factors and test intervention approaches to improve dietary behaviors in various population groups. Results from the DASH-Sodium multicenter study revealed that either following the DASH diet (which is rich in fruits, vegetables, and low-fat dairy products) or lowering dietary sodium to a level well below the currently recommended maximal intake improved blood pressure levels, and the greatest improvement resulted from the combination of the DASH diet and the lower sodium level. Results from the DASH studies are being incorporated into recommendations of the National High Blood Pressure Education Program. NHLBI is also supporting a multicenter study, PREMIER, that is testing behavioral interventions for multiple lifestyle behaviors to control blood pressure, including weight loss and weight control, reduced dietary sodium, increased physical activity, and following the DASH dietary pattern.

The NHLBI also supports Nutrition Academic Awards in U.S. medical schools to improve nutrition training during medical and health professional education. Their purpose is to develop or enhance curricula to improve practice skills in nutrition, so that health professionals can better apply nutrition in their clinical practice, and to disseminate training materials and guidelines nationally.

The Rapid Early Action for Coronary Treatment (REACT) study tested a community-based educational program to encourage prompt seeking of emergency medical treatment for heart attack symptoms. The intervention resulted in significant increases in appropriate use of the emergency medical system (911, ambulance use), though it did not significantly decrease time from symptom onset to arrival at the hospital. Many REACT results related to symptom attribution, reasons for delay, and educational needs are being used by the National Heart Attack Alert Program to design a national education program on this topic.

Long-term maintenance of behavior change and adoption of healthy lifestyles continues to be a challenge. The NHLBI convened a special Conference on Maintenance of Behavior Change to tackle this issue and, in 1999, was the largest contributor to a trans-NIH effort, Innovative Approaches to Behavior Change, to fund a series of grants devoted to developing behavior-theory-based interventions for clusters of risk factors. The Institute is also completing interventions for the last of the more than 2,000 patients enrolled in a clinical trial for depressed heart attack victims. This study (Enhancing Recovery in Coronary Heart Disease) will teach us much about managing depression and social isolation, two very common conditions in CVD patients.

Development of interventions for anger and hostility. Depression and social isolation are not the only psychosocial factors that contribute to or affect survival after heart attack. As described above, evidence has been accumulating on the important role of negative emotions, particularly anger and hostility, in cardiovascular health. Therefore, it is prudent to begin testing interventions that might reduce the associated elevated CVD risk. Under way is a new study to test the effectiveness of cognitive behavior therapy (CBT) in reducing anger and hostility and its effect on nervous system regulation of heart rate variability, an indicator of cardiovascular health. In this study, healthy subjects with high levels of hostility, as measured by standardized clinical diagnostic instruments, will be assigned randomly to a CBT intervention or a control condition. If the intervention is effective through the hypothesized autonomic nervous system pathways, hostility will be reduced and autonomic control of the heart will be improved, as reflected in improved heart rate variability. If this proves true, the next step will be to test whether this intervention will translate into a lower number of cardiac events in patients at high risk of developing CVD or in patients who have already have it.

Heart failure is one of the few cardiovascular conditions that is increasing in prevalence. It is a chronic illness that progresses to increasing functional decline, repeated hospitalizations, and placement in long-term care, all of which result in considerable health care expenditures. Progression can be slowed by drug therapy and lifestyle modifications, but non-adherence to these treatment recommendations has been high, approaching 90 percent in some populations. Self-management interventions are becoming increasingly popular as a treatment for chronic illness but they have not yet been directed specifically to the problem of heart failure. These interventions are distinguished by their focus on stimulating the patient to take responsibility for the behavioral side of the illness and developing self-efficacy in this role by teaching SM skills that are basic to making needed lifestyle changes. In 2001, the NHLBI funded the Heart Failure Adherence and Retention Trial (HART), a randomized clinical trial of 900 patients recruited from 7 hospitals, to evaluate the effects of a self-management intervention designed for heart failure patients on hospitalization, death, progression of heart failure, quality of life, and health care costs. Potential mediators of effectiveness, such as improved adherence to medical regimens and improved psychosocial function, will also be monitored.

Research on Adherence to Medical Regimens. Although effective strategies are available for treating cardiovascular, lung, and blood diseases, many preventive and therapeutic measures are not consistently adopted by patients and physicians and many are not maintained over time. To address this issue, the Institute recently sponsored several RFAs, a Workshop, and a Working Group, and is funding a number of research grants to study adherence. In 1998, the NHLBI-sponsored Workshop on Maintenance of Behavior Change in Cardiorespiratory Risk Reduction examined the status of research on maintenance of health-promoting changes in the areas of diet, smoking cessation, obesity, and physical activity and identified related research needs. In 1999, a Working Group on Adherence to Medical and Lifestyle Interventions developed clinical practice and research recommendations for improving adherence to medical and lifestyle interventions for the treatment and prevention of heart, lung, and blood diseases. As a direct result of that Working Group, several initiatives were developed or are in process. The RFA Overcoming Barriers to Treatment Adherence in Minorities and Persons Living in Poverty was organized under NHLBI leadership and is co-sponsored by several other Institutes.

Findings from past adherence research initiatives have demonstrated the difficulty of developing interventions to promote adherence. An additional finding from these trials was that self-reported adherence was not consistent with more objective measures of adherence (e.g., electronic monitoring), suggesting that objective methods are preferred. A second RFA program, entitled Improving Hypertensive Care for Inner-City Minorities, sought to develop and evaluate methods for maintaining therapy and control of hypertension for newly and previously diagnosed individuals in the inner city, primarily minorities. The studies found beneficial results on blood pressure outcomes, particularly with more intensive interventions, and reported that enhanced tracking and outreach increased the proportion of persons with elevated blood pressure who continued in medical care. Data from a number of investigator-initiated grants supported by the NHLBI are currently being collected and will be available in the future.

Community-Responsive Interventions in American Indian and Alaska Natives. The NHLBI Strong Heart Study began in 1988 to estimate CVD disease mortality and morbidity rates among American Indians living in central Arizona, southwestern Oklahoma, and North and South Dakota. Its results indicated that the prevalence of coronary heart disease was significantly and independently related to percentage of body fat, age, diabetes, hypertension, smoking, insulin concentrations, and low HDL-cholesterol levels. Diabetes was found to be the strongest risk factor associated with coronary heart disease. Although rates varied considerably across tribes and regions, diabetes and obesity were found to be at epidemic proportions. For example, the prevalence of diabetes ranged from one-third of Dakotan men to almost three-fourths of Arizona women. The incidence rates of coronary heart disease found in American Indians was almost twice as high as in a comparison study of other U.S. populations. In addition, coronary heart disease may more often be fatal in American Indians. In light of the health disparities in native populations identified by the Strong Heart Study, the NHLBI is planning to develop an initiative to solicit research proposals in an open competition from partnerships of American Indian and Alaska Native Tribes/Communities and/or research organizations. The research will focus on an intervention to reduce the risk of an important heart, lung, blood, or sleep disorder in native communities.

Development of Interventions for Youth and Young Adults. Efforts to develop interventions are not limited to the adult population. Several ongoing studies focus on school-aged children and adolescents. The Child and Adolescent Trial of Cardiovascular Health (CATCH) targeted school food service modifications, enhanced physical education, classroom health curricula, and family education to test methods for preventing CVD at the earliest possible ages. The NHLBI now funds a number of school-based prevention studies that address cardiovascular health behaviors and risk factors in pre-schoolers to college-age young adults. The Institute maintains an active and vigorous research program for developing smoking cessation, weight loss, and exercise programs for all segments of the population and in all age groups, including those in whom exercise capacity is impaired. Finally, in recognition of the urgent need to improve sleep habits of our children and youth, the National Center on Sleep Disorders Research has initiated two major educational interventions this year: a program targeting 7-11 year old children and their teachers as well as parents and pediatricians, utilizing Garfield as the "spokescat" for healthy sleep, and programs directed at high school students to disseminate information about the effects of chronic sleep loss on school performance, behavior, and driving safety.

Smoking and Cardiovascular Disease. Although smoking rates have declined, nearly one-fourth of all American adults smoke. Tobacco use is the leading preventable cause of death and disability in the United States, and remains the most important modifiable risk factor for diseases of the heart, blood vessels, and lungs. Tobacco use is responsible for 400,000 deaths each year. Furthermore, maternal smoking is the leading cause of infant respiratory disease. Reducing tobacco use can reduce cardiovascular and respiratory disease substantially. For example, smoking cessation after a heart attack can reduce subsequent cardiovascular mortality by 25-50 percent. NHLBI is committed to a continuing research effort to develop effective smoking cessation interventions in order to reduce cardiovascular and respiratory morbidity and mortality. Recent evidence suggests that a combination of behavioral counseling and pharmacotherapy produces higher success rates, and three randomized, placebo-controlled trials are investigating the potential benefits of combining an antidepressant with behavioral treatment. Other studies are evaluating the effectiveness of behavioral smoking cessation interventions for pregnant smokers and hospitalized patients in order to capitalize on the opportunities afforded by health-related life events.

### ***Biological Pathways***

Research on Biological Pathways through which behavioral and social factors influence health forms the foundation for potential interventions or improved medical care. The Institute supports five major interdisciplinary program project and research center grants devoted to behavioral research, as well as numerous individual grants on topics such as gene-behavior interactions, mental stress, and study of brain structures involved in coordinating behavioral demands and cardiovascular function.

Influences on Neuroendocrine Factors. As is the case with physical stress, persisting psychosocial factors such as depression, anxiety, or psychological stress alter the body's metabolic processes and activate a cascade of neuroendocrine responses designed to cope with ongoing demands. These changes involve increases in sympathetic tone, decreases in vagal influences, down-regulation of certain immune parameters, and changes in glucose metabolism. However, just as stressors can have negative neuroendocrine effects on the body, psychosocial buffers can have positive effects through their influence on the nervous and endocrine systems. Examples of research under way to understand these systems include studies of the psychosocial effects of ethnicity and work environment on blood pressure; the effects of hostility on lipid metabolism, serotonin function, sympathetic activation, and autonomic control of the heart; psychosocial influences on cellular adhesion molecules involved in the atherosclerotic process; the effects of social support on the hormone oxytocin and its effects on the cardiovascular system; the effects of mental stress on heart failure; and the effects of anxiety on nervous system control of the heart.

Interactions between Genes and Behavior. Behavioral and psychosocial influences can affect cardiovascular health through interactions with genetic predispositions for heart and vascular diseases. These interactions can either promote health or increase risk for disease. An obvious example of this would be the effect that healthful behaviors can have on people with a familial predisposition for high blood pressure. Genetic predisposition for hypertension involving salt sensitivity can serve as an example. If an individual has a salt-sensitive genotype, then a low

sodium diet will help to reduce phenotypic expression. Often the specific genotype is not known and only a phenotypic risk (e.g., for hypertension) can be established. In such a case, it is especially important to adhere to multiple behaviors that decrease risk for hypertension, including proper diet and exercise. However, behavioral influences on phenotypic expression are only one aspect of behavior–gene interactions in CVD risk. Psychosocial factors can also interact with genetic predisposition to increase risk or promote health. Examples of this can be seen in the NHLBI Family Heart Study, which indicates that men and women who have high risk of coronary artery disease based on their familial history have significantly increased likelihood of coronary heart disease and carotid artery atherosclerosis if they also have high hostility, even after relevant health behaviors are taken into account. Analyses examining the physiological mediators of these associations are continuing. Many important questions remain to be answered, including the relative roles of genes and environment in insulin response to behavioral stress, alterations in the regulation of psychophysiological responsiveness to mental stress by environmental exposure, the characteristics of individuals who are at greatest risk for acute, behaviorally triggered events, and the modulation of genetic susceptibility to atherosclerosis by psychosocial and behavioral processes.

The Institute plans to conduct a workshop to review the state of current knowledge involving human and animal studies of gene–behavior interactions in heart, lung, and blood diseases, to evaluate statistical and methodological approaches used in investigating these complex interactions, and to obtain advice and recommendations concerning the most fruitful directions for behavioral genetic research at NHLBI.

### ***Demonstration and Education Research***

NHLBI demonstration and education (D&E) research evaluates educational and behavioral approaches and environmental and organization strategies that may improve the prevention or management of widely prevalent conditions such as asthma. D&E studies have shown the effectiveness of teaching self-management strategies to patients of all ages. Current research focuses on identifying the educational elements that are essential and the methods or combination of methods that promote the most efficient use of patient and clinician efforts (i.e., group vs. individual education, use of interactive multi-media, separate asthma education vs. education that is integrated into routine primary medical care, and adjunctive education in the community setting). Research is also under way to determine more effective ways to promote a partnership between health care professionals and patients, especially in the managed care environment. A related issue is research on training health care professionals, to improve clinician communication skills with patients, use computer tools for patient visits, and use quality improvement programs to integrate quality asthma care into all aspects of medical care. This will lead to wider dissemination and adoption of new advances in disease or risk factor management throughout the medical community and the population at large. An agency-wide research program announcement in 2001 encourages research to improve the quality of emergency medical services for children, and includes asthma as a high priority area.

Education and outreach in asthma. A major thrust of recent D&E research has been on identifying appropriate strategies for extending the benefits of asthma management to diverse populations and reduce the disparities in asthma care experienced by minorities and economically disadvantaged individuals—the populations that are at greatest risk for serious

asthma-related disability death. Educational outreach programs using non-medical approaches such as school- or neighborhood-based interventions or home visitors for peer education are testing culturally sensitive behavior change strategies for children with asthma and their families. Other studies are evaluating such specific asthma management interventions as programs to reduce smoking among parents of children with asthma and programs to promote continuous, comprehensive management of asthma rather than episodic emergency care.

Two new NHLBI-wide initiatives in 2000 and 2001 will encourage research to develop and evaluate innovative strategies for improving patient adherence in chronic illness. One specifically focuses on overcoming socio-cultural and economic barriers to adherence among minority populations and people living in poverty.

Because children under 18 years of age have experienced a dramatic increase in asthma prevalence and children with asthma miss twice as much school as the national average, the NHLBI launched a research program in schools in three different cities to evaluate ways to optimize management of asthma in schools. The study is investigating approaches to ensure that children with asthma have access to medications, an environment as free of allergens and irritants as possible, and resources in the school to support the child's and the family's efforts to manage asthma. Findings, expected in 2001, will provide three different models for helping schools be "asthma friendly."

### ***Research Translation***

The NHLBI effort in translation research includes studies of the application of basic science findings to problems of clinical care, as well as of the dissemination of effective treatments, interventions, and prevention methods to broaden their utilization. The Institute also maintains vigorous efforts to disseminate research findings through the National High Blood Pressure Education Program, the National Cholesterol Education Program, the National Asthma Education and Prevention Program (NAEPP), and the NHLBI Obesity Education. All seek to translate the results of behavioral research into practice. Two translation research efforts are highlighted below.

1. The NAEPP is responsible for translating research on asthma into practical health education materials and tools for use by health professionals, patients, and the public. It NAEPP was initiated in March 1989 with the goal of reducing asthma-related morbidity and mortality and enhancing the quality of life of asthma patients.

The NAEPP works with a wide range of organizations to conduct asthma educational interventions. A group of 35 professional, voluntary health, lay, and governmental organizations involved with asthma form the NAEPP Coordinating Committee. The coordinating committee advises the program and the members assist in activities to achieve the goal of the program. These coordinating committee organizations help communicate to their members the key messages the NAEPP is trying to convey.

*Management Guidelines.* The first major activity of the NAEPP was the development of guidelines for the diagnosis and management of asthma, culminating in updated guidelines

produced in 1997 and known as the *Expert Panel Report 2: Guidelines for the Diagnosis and Management of Asthma*. Major attention is now devoted to promoting use of the guidelines, including adoption by managed care organizations.

*Clinician Education.* The NAEPP Coordinating Committee has organized a series of partnership activities to facilitate the implementation of the new guideline recommendations in various clinical settings. For example, the NAEPP is working with the American Academy of Allergy, Asthma, and Immunology (AAAAI) to develop a multi-faceted program to help all clinicians who care for children with asthma to learn about and adopt the recommendations. A summary guide, based on the 1997 Expert Panel Report but tailored to the needs of primary care physicians, is being sent to pediatricians, family physicians, and nurses practitioners around the country and will be the centerpiece for numerous continuing education programs.

Further examples of partnership activities to promote dissemination and adoption of clinical practice guidelines include projects with the National Medical Association to develop pocket guides for resident trainees, efforts to develop a nurse's guide for managing asthma, and an effort to delineate the role of pharmacists in asthma care.

Future plans in clinician education include replicating successful strategies in additional managed care organizations as well public health organizations and other communities. Activities at the local, state, and national levels will facilitate adoption and use by health care providers of the most effective therapies available for asthma management and thereby help to improve the quality of life of asthma patients and their families.

*Family/Patient Education.* The NAEPP has produced an extensive array of patient and public education materials in both English and Spanish to help patients and their families increase asthma self-management skills.

*Public Education.* The NHLBI continues to implement a strong public education campaign to increase awareness of warning signs and symptoms of undiagnosed asthma for schools, communities, and numerous professional organizations involved in child care or delivery of health care.

*Quality of Delivery System.* The NAEPP, in partnership with the National Commission on Quality Assurance and the American College of Chest Physicians, provides conferences and training programs concerned with development of quality improvement disease management programs. Based on the work of the NAEPP Cost Effectiveness Task Force, the partnership efforts are developing performance measures for health care purchasers to use in evaluating asthma care services.

2. Translational Research in the Behavioral Sciences. Life-style and behavior change remain among the greatest challenges in prevention and treatment of heart, lung, blood diseases and sleep disorders. Although a great deal of progress has been made in understanding why people adopt healthy or unhealthy lifestyles, changing behavioral risk factors and maintaining those change over time have proven difficult. A majority of individuals relapse soon after completing intervention programs. Clearly, innovative approaches are needed.

Theories and models from the behavioral sciences have been used successfully to understand and change health-related behavior, but more can be done. Review of the psychological literature shows a large research effort devoted to uncovering the principles that govern how human beings perceive the environment, process information, make decisions, form and change their attitudes, and become and remain motivated to change behavior. However, diffusion of new concepts and discoveries from the basic behavioral and social sciences is not as rapid as it might be, and many innovative findings are not being applied to the prevention and treatment of heart, lung, and blood diseases and sleep disorders.

Translating findings from basic behavioral science research to clinical investigation is vital for ensuring progress in designing and implementing innovative disease prevention programs in clinical care settings. To facilitate such translation, an initiative is planned to promote interaction between basic and applied social scientists and to stimulate application of behavioral research to develop new approaches to change behavioral risk factors for heart, lung, blood, and sleep disorders. The mechanism to be used is Coordinated Behavioral Science Translational Research Project grants, a series of linked R01 research projects to promote collaboration between basic behavioral scientists and clinical researchers. Using this approach, research teams will conduct studies that use basic social science theories, methods, and findings to design and test strategies for encouraging adoption and maintenance of healthy behaviors and adherence to medical regimens. Principles from these studies will be adapted for use in population-based studies and clinical trials to test their applicability to disease prevention. Examples of relevant topic areas include the application of findings on attitude change, on how people perceive and process information, and on how to develop innovative methods to better frame public messages to encourage people to engage in health-promoting behaviors, and investigations of cognitive biases that lead to sub-optimal decisions concerning behavioral and medical risks.

### ***Other Research***

Health-related Quality of Life. Interest in assessing and improving the quality of life of individuals with chronic disease has increased dramatically among researchers and clinicians over the past two decades, reflecting changes in health care and in society as a whole. Given the increased interest in assessing a broad array of health outcomes, the NHLBI now includes measures of health-related quality of life (HQL) in virtually all of its Institute-initiated clinical trials, and in many Institute-sponsored epidemiologic studies as well. Trials that assess HQL and psychosocial components include studies of treatments for myocardial infarction, arrhythmias, hypertension, coronary artery disease, heart failure, sickle cell disease, and pulmonary diseases. Current examples include the Action to Control Cardiovascular Risk in Diabetes (ACCORD) study of cardiovascular complications in diabetics, and the MESA study. Inclusion of HQL and psychosocial measures in NHLBI-sponsored studies has shown that HQL can be reliably measured and that these assessments can provide important complements to clinical end points in studies of treatment efficacy. However, more work remains to be done in refining measures; in further identifying the HQL effects of various treatments; and in integrating data from HQL assessments into clinical decision-making, selection of therapies, and the structure of rehabilitation.

Qualitative Methods in Adherence Research. Data from qualitative studies that use ethnographic methods to uncover participants' attitudes and beliefs about disease risk and treatment have revealed some striking cultural and environmental influences on adherence to antihypertensive treatment that may provide new avenues for understanding and affecting adherence to treatment and healthy lifestyles. These studies suggest that addressing the problem of adherence requires an understanding of the context in which a patient lives and consideration of the meaning of an illness or the actions required to manage it.

A Working Group is being planned to discuss the use of qualitative research in the development of qualitative and socioculturally informed interventions to improve adherence to lifestyle changes and pharmacological treatment to control heart disease risk factors. It will address the use of intervention models that incorporate a mixed-methods (qualitative and quantitative) approach, with an emphasis on understanding the conditions occurring in everyday life and a patient's attempts to adapt to them. Studies using this approach would involve an initial phase involving gathering of qualitative data (e.g., through use of in-depth interviews, ethnographies, focus groups) to understand the social, cultural, and environmental influences on lack of adherence to antihypertensive treatments in defined subgroups of the populations (e.g., specific ethnic groups, lower SES groups), followed by an intervention study based on knowledge gained during the qualitative phase.

#### **4. National Human Genome Research Institute (NHGRI)**

The NHGRI Division of Extramural Research's Ethical, Legal and Social Implications (ELSI) Program funded a number of research grants in FY 2000 that are behavioral and social sciences research. The NHGRI is co-funding (with NHLBI) a large, five-year, multi-center clinical trial designed to examine issues surrounding phenotypic and genotypic screening for iron overload and hereditary hemochromatosis. The study will examine attitudes about, acceptance of, and impact of screening in a very diverse population (about 50% of the participants will come from minority communities). NHGRI continues to support grants that have been part of the Cancer Genetics Studies Consortium, a group of grants funded initially in FY 1994 to examine the psychosocial and clinical impact of using gene-based diagnostic tests in families with heritable forms of breast, ovarian, and colon cancer; assess public knowledge and attitudes about genetic testing for cancer risks; and gather information needed to establish clinical protocols for the optimum use of these risk assessment technologies in the future. The ELSI Research Program also has three projects that are examining issues surrounding genetic testing in Alzheimer disease. All of these grants are multifaceted and include assessments of knowledge and attitudes toward genetic testing, interest in and demand for testing, the impact of testing on individuals and their families, and the development of effective strategies for educating people and health care providers about the benefits, risks, and limitations of genetic testing. Also funded were a number of projects designed to examine how individuals from diverse racial, ethnic and socio-economic groups view and are affected by genetic information and technologies, such as those utilized in newborn screening and prenatal screening and diagnosis.

The Medical Genetics Branch of NHGRI's Division of Intramural Research is also funding behavioral and social sciences research, focusing on issues in counseling psychology, ethical considerations in counseling, and genetic counseling methodology. The increasing availability

of genetic technologies capable of identifying the presence of gene mutations that predispose individuals to increased risk for genetic conditions has heightened the need for original research in genetic counseling. The issues presented to individuals and families by the application of these technologies present enormous challenges to their psychological well being, integrity, self-perception, relationships, thoughts regarding child bearing, education, employability, and insurability. There also remains an important need to understand the impact of living with a genetic condition and effects on quality of life, coping, and adaptation. The ultimate goal is to provide research-based methods and tools for comprehensive, client centered, ethically responsible genetic counseling to individuals and families considering the use of genetic technology.

Research efforts have focused on:

- Outcomes of education and counseling for BRCA 1 & 2 testing
- Randomized trial of breast cancer genetics education using an interactive computer program
- Outcomes of education and counseling for HNPCC testing
- Illness perception, medical adherence, quality of life and reproductive decisions in adults with Marfan syndrome
- Attitudes of people with achondroplasia toward prenatal testing
- Quality of life for people with achondroplasia
- Understanding the perceived stigma that may be associated with the genetics of schizophrenia
- Needs of couples carrying pregnancies to term affected with holoprosencephaly
- Beliefs about genetic susceptibility to alcoholism and their effect on drinking behavior
- Increasing client participation in prenatal genetic counseling
- Exploring personal meaning in prenatal genetic counseling
- Decisions to use preimplantation diagnostics amongst fertile couples

Further research efforts include: process studies of genetic counseling for adults with Turner syndrome; understanding how study coordinators in clinical research deal with recruitment, informed consent, and retention of subjects; the attitudes of patients and the public towards research involving human biological specimens; and understanding how the “benefits” of gene transfer research are described in consent forms and understood by principal investigators, study coordinators, subjects, and Institutional Review Board chairs.

## **5. National Institute on Aging (NIA)**

NIA supports basic and clinical behavioral and social research to improve the health and quality of life of older Americans, to understand principles of and strategies for healthy aging processes, and to reduce health disparities among older persons and populations. Behavioral and social research is supported across several NIA extramural Programs, most prominently in the Behavioral and Social Research Program and the Neuroscience and Neuropsychology of Aging Program. NIA's Intramural Research Program conducts active investigations in this arena, primarily through the Laboratory of Epidemiology, Demography and Biometry, and the Laboratory of Personality and Cognition. NIA behavioral and social science research and training activities include support of regular research grants, career development awards, training

grants, meeting support, interagency agreements, and contracts. The NIA also is an organizing and active member of the Federal Forum on Aging-Related Statistics, established to improve statistical data on the older population that are produced and used by federal agencies.

Research to Improve Health and Quality of Life of Older People. NIA-sponsored research focuses on developing strategies for maintaining health and function, on understanding observed disability declines in the older population, and on preventing or reducing the incidence of age-related diseases, including Alzheimer's disease and selected geriatric conditions.

Recent findings from the National Long-Term Care Survey demonstrated a dramatic and unexpected reduction in disability rates among older persons, countering widely held views that old-age disability would become a pandemic. This finding has led to increased efforts to investigate the causes of the disability decline (including internationally), to improve measurement of the burden of illness, and to estimate the economic impact of improved health.

Several major studies are supported on cognitive, physical, sensory, and behavioral functioning. For example, the ROYBAL Centers are translating basic behavioral and social research into practical interventions to promote independence, activity, and productivity in later life. Foci include computer skills, driving, exercise, caregiving, and nursing home care. The ACTIVE clinical trial is investigating whether interventions to improve memory, reasoning, or speed of processing can improve instrumental activities of daily living and promote independence in older adults. NIA has an initiative on higher order cognitive functioning, including financial and medical decision making.

The Women's Health and Aging Study is providing a detailed understanding of the causes and course of physical disability. The REACH study investigates the effects of stress on the health and functioning of family caregivers with the goal of finding ways to better cope with the burdens of caring for patients with Alzheimer's disease. Basic research addresses the role of other factors such as diet, smoking, and exercise as well as the role of neurotrophic factors and steroid hormones in maintaining neuronal integrity and neural circuitry. Recent exercise research has, for example, found that even light to moderate physical activity, such as walking, can attenuate age-related decline in some cognitive skills, especially for those functions associated with frontal regions of the brain, and that strength training exercises combined with motivational sessions can improve physical functioning in frail elders. The related Health ABC study is trying to determine how body weight, muscle mass, fat, and bone affect muscle strength, endurance, and physical function. Promising research with biofeedback techniques has shown that elderly women with urinary incontinence fare as well, if not better, from engaging in a behavioral program of pelvic muscle exercises as from standard pharmacological therapy.

Research to Understand Healthy Aging Processes. Ongoing NIA-sponsored research is working toward unlocking the secrets of aging, health and longevity, including biological, genetic, environmental, psychological, and lifestyle factors. NIA supports basic research on population issues, including forecasting the size of the elderly population, life expectancy, and active life expectancy, monitoring the impact of global population aging on the burden of chronic disease and disability, and understanding the retirement process and its relationship to old age health and economic well-being. For example, the 11 Centers on Demography of Aging focus on these

issues and are in the forefront of developing the needed data infrastructure for studying these topics. An example of data infrastructure is the longitudinal Health and Retirement Study which is collecting data on the antecedents and consequences of retirement and on the combined economic and health circumstances of people as they age. In addition to being widely used by NIA grantees, the data from this longitudinal study are used by many other departments, agencies and units, including Treasury, Labor, the Social Security Administration, CBO and several other countries have decided to initiative comparable studies.

NIA supports basic research on understanding behavioral and biological changes that occur with normal cognitive and brain aging and with neurodegenerative disorders such as Alzheimer's disease. New findings this year have increased our understanding of the nature and quality of cognitive function in elders and the mechanisms that underlie this, using new methods such as brain imaging and molecular strategies. NIA supports research on understanding the types of behavioral symptoms associated with the progression of Alzheimer's disease. Researchers are investigating how personality traits change with age, their relationship to health and mortality, and the contributions of genes, heritability and environment on cognition and personality in old age. A number of projects address the behavioral consequences of age-related changes in movement and perception, including taste, smell, vision and hearing; studies have found that the decline in speech understanding in older individuals under conditions of background noise is related to both changes in the periphery and in the central nervous system auditory pathway. Other projects seek to identify what factors are responsible for successful hearing aid use in the elderly. Sleep complaints are prevalent in elderly individuals, more particularly in AD patients, and can have severe behavioral consequences. NIA addresses sleep physiology and circadian rhythms in the elderly and in AD patients, particularly the biological mechanisms underlying changes in sleep patterns with age and disease. Interventions employing a high technology behavioral training program and a multifaceted behavioral intervention are being evaluated in different elderly populations. NIA also stimulates research on stress, immune function, and behavior in the elderly. Research stemming from a multi-disciplinary project supported by the Institute is investigating immune system dysfunction in elders, how it may be mediated by stress, and how it may be ameliorated by stress reduction. Psychological stress was shown to slow wound healing in elders.

Research to Reduce Health Disparities among Older Persons and Populations. Ongoing NIA research aims to improve active life expectancy and health status for older minority individuals; understand health differences associated with race, ethnicity, gender, environment, socioeconomic status, geography, and culture; and monitor health, economic status, and life quality of elders in order to inform policy debates. The RCMAR Center Program is dedicated to increasing the number of researchers (especially minority), studying older minority populations and increasing minority participation in clinical and behavioral research. NIA also supports basic and clinical studies of special populations, such as the Honolulu-Asia Aging Study, a longitudinal epidemiologic investigation of older Japanese-American men in Hawaii focusing on the development and progression of dementia, Parkinson's disease, and on patterns of stability or decline in cognitive, physical, and sensory functioning. The Mexican Health and Aging Study will allow an assessment of the durability of the purported health advantage of migrants. The WHICAP study, the Indiana-Ibadan project, and the Chicago Health and Aging Project are helping us understand the differences in dementia rates and severity in African, African-

American, Hispanic, and White populations, from both environmental and genetic perspectives. NIA has funded the National Academy of Sciences to update an earlier report *Race and Ethnic Differences in the Health of Older Americans* and make recommendations on a research agenda on race and ethnic minorities and aging

Other NIA research aims to understand the causes of the striking and well-documented relationship between socioeconomic status, health, and longevity. While health behaviors and access to medical care explain some individual health outcomes, research has suggested that long-term impacts of early childhood, the cumulative effects of prolonged exposures to individual stressful events, or reactions to macro-societal factors such as rising levels of income inequality play a role. For example, NIA sponsors research on the causal direction of this relationship and recent findings show that economic resources appear to impact health outcomes most strongly prior to middle age, with relationship changing direction in old age, with illness events resulting in reductions in wealth. NIA research also focuses on the significant impact of job conditions on health and survival. NIA has also contracted with the National Academy of Sciences to initiate advisory panels on topics such as elder abuse, the frontiers of social psychology, and technology transfer and application.

## **6. National Institute on Alcohol Abuse and Alcoholism (NIAAA)**

NIAAA's large portfolio of behavioral and social science research (BSSR) and training grants is supported in each of its extramural Divisions; BSSR studies also are part of its Intramural program. The importance of behavioral and social science research follows from the fact that alcohol consumption is a socially defined behavior that has major health-related consequences, including alcoholism, and that many interventions to treat and prevent the psychological, social, legal, and economic consequences of alcohol-related problems also are behavioral or social.

Alcohol epidemiology seeks to identify and explain factors that shape the distribution of alcohol use, abuse, and dependence and their consequences in various populations. Current research includes: a) studies of methodological improvements in measurement of alcohol consumption and related problems, including studies of long-term changes in drinking norms, contexts, and cultural influences on alcohol consumption and development of classification systems and diagnostic instruments; b) studies of the adverse consequences (e.g., morbidity and mortality) of alcohol consumption, including unintentional and intentional injuries, cirrhosis, sexually transmitted diseases, and comorbid psychiatric disorders, as well as potential benefits of moderate drinking; and c) consumption patterns and problems of special populations, including women, racial/ethnic minorities, the elderly, and youth and their families.

Basic behavioral research includes studies of addiction and other neuroadaptive behaviors in both animal models and humans. The former studies focus largely on neural mechanisms of sensitization, tolerance, dependence, withdrawal, relapse, and the reinforcing and hedonic effects of alcohol that can lead to alcohol-seeking behavior and excessive drinking. Animal models also have been constructed to study innate neural and behavioral traits as well as the acute and chronic effects of alcohol on behaviors, such as learning, memory, and aggression. For example, four studies investigate environmental factors in an operant reinforcement paradigm to evaluate the reinforcing efficacy of ethanol alone versus multiple reinforcers that differ in taste. A new

area of animal studies focuses on studies of adolescents, since early alcohol exposure correlates with the development of alcoholism in adulthood. Human studies include grants that examine a) the consequences of acute and chronic alcohol use on cognitive and other behavior, including structural changes associated with behavioral deficits, using imaging technologies; b) the neural mechanisms of alcohol-motivated behaviors, such as craving; and c) the consequences of brain damage and cognitive and motor dysfunction in chronic alcoholics and Korsakoff patients, using neurocognitive and/or MRI techniques. Also, studies on the social, behavioral, and genetic factors that predispose to liver cirrhosis are supported.

Health services research on alcohol addresses the utilization, effectiveness, outcomes, and costs of care, and the impact of managed care and other developments in the organization and financing of services for alcohol treatment and prevention. Two recent program announcements have stimulated research on the cost and cost-benefits of alcoholism treatment and on secondary analyses of existing health services data sets. Health services research also focuses on facilitating the adoption of the most current scientific findings by the alcohol treatment community. A new program announcement encourages examination of the process of adopting evidence-based research in treatment practice, which will guide efforts to improve the delivery of effective alcohol treatment services.

Treatment-related research includes evaluation of various behavioral interventions alone and in combination with pharmacotherapies. An example is COMBINE, a cooperative agreement involving 11 clinical research units and a coordinating center. It is currently the largest treatment initiative of the Institute. COMBINE builds on the results of Project MATCH, a multi-site study that tested three behavioral interventions, and on previous research with pharmacological agents that act directly on brain centers known to be involved in the addictive process. The objective is to determine which of nine treatment combinations is the most effective in reducing drinking among alcohol dependent patients seeking treatment. In addition, behavioral studies (eight clinical and six human laboratory studies) have also been initiated in the treatment of patients suffering from both alcohol and nicotine dependence. Recent evidence indicates that alcohol and tobacco addictions are closely linked. An RFA issued jointly in FY 1998 by NIAAA and CSAT/SAMHSA for research on Treatment for Adolescent Alcohol Abuse and Alcoholism resulted in funding of 14 new grants. These 10 clinical studies and four questionnaire development projects together provide opportunities to identify effective interventions for adolescent alcohol problems (family therapy, cognitive behavioral therapy, brief motivational enhancement therapy, and self-guided change) among diverse groups of adolescents (high school students, juvenile delinquents and street youth, as well as minority youth). Finally, eight treatment-related behavioral studies are being supported to identify or modify factors that influence changes in drinking behavior over time. Four of these projects examine mechanisms underlying long-term changes in drinking behavior in different populations. These include natural history studies in both community and treatment samples. Another four projects are exploring the augmentation of treatment with aftercare or behavioral family therapy interventions designed to reduce or prevent post-treatment drinking and to minimize its negative consequences such as domestic violence.

Prevention research involves both pre-intervention and intervention studies. Areas of emphasis include: a) fetal alcohol syndrome where 10 intervention studies are underway including a

community trial of comprehensive prevention strategies among the Plains Indians; b) alcohol abuse among college students, where numerous studies are testing interventions to change college norms, environments, and personal risk behaviors; c) DWI recidivism, where five randomized trials are testing combinations of sanctions, therapies, and monitoring devices; d) alcohol advertising, where three studies of youth are measuring possible effects on drinking expectancies, intentions, and behavior, and another study examines effects of the new spirits advertisements on TV; e) alcohol-related violence, where pre-intervention studies focus on violence in families (including child abuse and neglect), gangs, and bar environments, and intervention studies test the preventive potential of server strategies and a program to reduce sexual assault among teens; f) community-based interventions, where studies focus on reducing alcohol-related trauma, border-crossings to binge-drink, youth access to alcohol, early drinking-initiation by youth, and evaluating natural experiments that include changes in the price of alcohol; g) family interventions, where prevention strategies include advice and training for parents to increase communication with children and to set clear, consistently enforced limits regarding alcohol; h) worksite problems, where pre-intervention studies assess effects of stressors (such as downsizing, racism, and retirement) on drinking behavior, and the effectiveness of existing alcohol policies; i) alcohol-related HIV/AIDS exposure/transmission, where studies test preventive interventions and explore risk trajectories; j) behavioral research on adolescent development, cognition, and behavioral genetics; and k) race/ethnic disparities in intervention effects.

BSSR figures prominently in the NIAAA Centers program, with 10 of the 15 Centers having at least 20 percent of funds devoted to behavioral and social science research and in the training program, where more than half of the 30 training grants focus on BSSR studies. In the Division of Intramural Research, both the clinical studies and the genetics research program address behavioral issues.

Under a developmental program initiated last year in collaboration with the Fetzer Institute, NIAAA researchers are assessing spirituality as it may relate to treatment, recovery or to the prevention of alcohol abuse. The NIAAA also is developing *A Social Work Education Model for the Prevention and Treatment of Alcohol Use Disorder* to be used in graduate and continuing social work education programs. Another developmental program has been initiated to assess the role of fortified alcoholic beverages in youth drinking behavior.

## **7. National Institute of Allergy and Infectious Diseases (NIAID)**

NIAID supports an extensive portfolio of behavioral and social sciences research within its three extramural research divisions, which encompasses adherence to therapeutic regimens or preventive interventions, behavioral factors that influence the risk and/or transmission of asthma, allergic diseases, sexually transmitted diseases, HIV/AIDS, and other infectious diseases, as well as the behavioral factors that increase organ donation. Specific research programs are highlighted below.

### ***Division of AIDS (DAIDS):***

The Division of AIDS supports domestic and international studies that evaluate behavioral interventions to prevent the sexual, parenteral, and perinatal transmission of HIV. To date, the

majority of the behavioral studies have been conducted through the HIV Network for Prevention Trials (HIVNET). In early 2000, a new initiative, the HIV Prevention Trials Network, will be funded to support large-scale randomized, controlled trials of promising biomedical and behavioral strategies for the prevention of HIV transmission among at-risk adult and pediatric populations. In addition to other prevention strategies, the network will support community outreach and educational efforts in preparation for HIV prevention trials, studies of factors affecting acceptability of and adherence to prevention modalities, and socio-cultural factors related to implementation of successful prevention strategies.

In addition, studies within the Adult AIDS Clinical Trials Group, Pediatric AIDS Clinical Trials Group and the Community Program for Clinical Research on AIDS are examining adherence/compliance to therapeutic regimens and other behavioral issues that impact quality of life and the clinical management of HIV-infected people.

***Division of Microbiology and Infectious Diseases (DMID):***

Prevention and control strategies for infectious diseases focus on blocking transmission, identifying and treating cases, and interrupting progression of disease. Behavioral research can help prevent and control disease by: changing behaviors to prevent exposure; increasing acceptance of vaccines in both child and adult populations; promoting health behaviors leading to diagnosis of infection; and improving adherence to treatment regimens.

The most active area of behavioral research is within the Sexually Transmitted Diseases (STD) Branch and is supported through seven multi-disciplinary STD Cooperative Research Centers (STD CRCs) as well as individual (R01 and U01) behavioral research projects. This intervention-oriented research is directed at prevention of STDs in a variety of populations. Studies are ongoing in high-risk adolescent populations, STD clinic populations, minority women, and patients in HMOs and in rural populations. Some of the objectives include characterization of the differences in rural versus urban social networks; identification of sexual partner networks that contribute to the spread of STDs; improvement of STD education programs for clinicians; and development of effective screening instruments to identify high-risk patients in clinical settings. In the recently awarded STD CRCs, behavioral research projects focus on adolescents and social networks as communities in which STDs are transmitted.

***Division of Allergy, Immunology and Transplantation (DAIT)***

The objective of DAIT's behavioral research is to translate information from biomedical research on immune-mediated diseases into behavioral changes that will lead to the early diagnosis, effective treatment, and eventual prevention of these diseases, particularly among minority populations. DAIT supports behavioral research in asthma, transplantation and organ donation.

*1. Asthma*

The NIAID National Cooperative Inner City Asthma Study (NCICAS) identified behavioral risk factors for asthma morbidity among inner-city minority children, and evaluated the effectiveness of an educational and behavioral intervention in reducing asthma morbidity in this population. The 5-year study demonstrated the effectiveness of the intervention in reducing asthma severity as well as direct and indirect costs associated with hospitalizations, emergency room visits, lost school days and lost workdays on the part of caregivers.

Over the next 4 years, the NIAID, in collaboration with the Centers for Disease Control and Prevention (CDC), will disseminate and implement the successful NCICAS intervention in 23 inner-city health care delivery sites through the U.S., benefiting approximately 6,000 children with moderate to severe asthma.

NIAID's current support of the Inner City Asthma Study (ICAS) involves two interventions with a major behavioral component: an environmental intervention to teach families how to reduce levels of allergens and tobacco smoke, and a physician education intervention to improve physician management of patients. In addition, NIAID supports Demonstration and Education research projects, which attempt to understand and to reduce, through behavioral change, the high asthma morbidity found in under-served, predominantly minority, inner-city communities.

## 2. *Transplantation and Organ Donation*

NIAID also supports three demonstration and education research projects aimed at increasing organ donation through a number of educational and behavioral interventions. These projects are evaluating the effect of a variety of interventions on potential donors, hospital staff, and the community at large. Interventions include: (i) assessments of knowledge of and attitudes toward donation and changes in attitude due to specific interventions; (ii) a variety of printed educational materials designed to raise awareness about the need for and value of transplantation and organ donation; (iii) the development and evaluation of behavior models focused on stages of readiness for decision-making around health care issues; and (iv) the implementation of a statewide donor registry.

Adherence to immunosuppressive drug regimens, including investigation of racial and ethnic influences on adherence, also is being examined and research is underway to assess factors that prevent or promote adherence in asthma management and in the treatment regimens for tuberculosis.

## ***Training in Behavioral and Social Sciences Research***

NIAID provides training and career development for researchers in behavioral and social sciences through the NRSA and Career Development Award mechanisms:

### 1. National Research Service Awards

*Institutional Research Training Grants (T32s)*: to develop or enhance research training opportunities for individuals, selected by the institution, who are training for careers in specified areas of biomedical and behavioral research. The purpose of the NRSA program is to help ensure that a diverse and highly trained workforce is available to assume leadership roles related to the Nation's biomedical and behavioral research agenda.

*Postdoctoral Fellowships (F32s)*: to help ensure that highly trained scientists will be available in adequate numbers and in appropriate research areas to carry out the Nation's biomedical and behavioral research agenda.

*Individual Predoctoral Fellowships for Minority Students or Students with Disabilities (F31)*: to support research training leading to the Ph.D. or equivalent research

degree; the combined M.D./Ph.D. degree; or other combined professional doctorate/research Ph.D. degrees in the biomedical or behavioral sciences.

2. Career Development Awards (K series): supports basic and/or clinical biomedical and behavioral research at several stages (mentored, independent, and senior)

NIAID also supports the development of young minority scientists interested in behavioral and social sciences, through the Research Supplements for Underrepresented Minorities. These supplements support high school, undergraduate, medical and graduate students, as well as postdoctoral scientists, by providing additional funding on existing NIAID grants

## **8. National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS)**

The diseases within the mandate of the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) are among the most chronic and costly affecting our Nation, and the Institute is committed to bettering the quality of life for people suffering from these disorders. NIAMS researchers have developed a number of ways to assess health status quantitatively, such as the Arthritis Impact Measurement Scales and the Health Assessment Questionnaire, and have used these quality-of-life instruments to demonstrate, for instance, that a sustained program of telephone contacts with trained non-medical interviewers can improve physical health and reduce pain in patients with osteoarthritis, and that a dance-based aerobic exercise program for people with rheumatoid arthritis can reduce joint pain, swelling, and depression. NIAMS grantees are now working on developing a health status measure for patients with skin disease.

One of the Institute's priorities is the study of how people adapt to and cope with chronic disease. Repeatedly, NIAMS research has shown that the concept of self-efficacy is key to managing chronic conditions. Enhancing a patient's belief that he or she can achieve a specific behavior or state of knowledge will improve that person's quality of life. Originally, this finding was verified with arthritis patients. Since then, it has been applied to patients with other diseases including, most recently, to patients with lupus. The Institute is also funding research aimed at developing education programs for physicians and other health professionals who treat patients with chronic diseases in which self-management plays a major role.

NIAMS is currently supporting research on innovative approaches to disease prevention through behavior change. One such project compares two health promotion models to provide an understanding of how, and under what conditions, behavior change can occur and be maintained. An area in which change in behavior has been shown to bear significantly on health outcomes is osteoporosis. Institute scientists are exploring the effects of diet and exercise on bone density in both women and men. It is now recognized that men develop osteoporosis and osteoporotic fractures about a decade later than women do. With the decline in premature cardiovascular mortality in men, fractures later in life are becoming an increasingly important cause of morbidity and mortality in older men. NIAMS has recently launched a large epidemiologic study involving men over age 65 to determine risk factors for the development of osteoporotic fractures. In other work, NIAMS-funded scientists are pursuing a longitudinal study that tests two approaches for promoting exercise and healthy dietary practices in groups of fire fighters. The nature of the population will allow for both individualized and group interventions.

NIAMS is also supporting a novel behavioral and educational intervention designed to decrease modifiable risk factors for osteoporosis in at-risk preadolescent girls. Girl Scout troops are receiving either a behavioral and educational intervention, or education only. The intervention group receives interactive sessions using various media to present instructional material on osteoporosis and its prevention; incentives (e.g., jump ropes and a booklet of jump rope games) are provided; and self-monitoring of calcium intake and weight-bearing activity is used to reinforce healthy behaviors. The group of girls targeted is ideal for this intervention, since they are at a stage of rapid accrual of bone mass. It is hoped that the intervention will maximize their opportunity for attaining peak bone mass, thus serving to further the ultimate goal of osteoporosis prevention.

Furthermore, the Institute is supporting work to enhance our understanding of the effects of ethnicity on health outcomes in patients with scleroderma – an autoimmune disorder of the body's connective tissue that is characterized by widespread thickening of the skin and internal organs. The NIAMS is funding research on a cohort of Caucasians, Hispanics, and African Americans to investigate genetic, socioeconomic, demographic, and behavioral factors related to a form of scleroderma known as systemic sclerosis, a condition that can result in outcomes such as pulmonary fibrosis, renal disease, heart disease, gastrointestinal disorders, disability, and death. This study should help identify factors to target for modification to improve disease course, and will result in our ability to identify high-risk patients who would benefit from earlier and more aggressive therapy, which may ultimately improve the prognosis of this disease.

Another major public health problem is work-related illnesses and injuries to the skin and musculoskeletal system. The Institute has a long history of supporting research in this area. NIAMS and other NIH components joined forces in a collaborative request for applications (RFA) with the National Institute of Occupational Safety and Health (a component of CDC) to increase knowledge of the pathophysiology, diagnosis, treatment, and prevention of work-related musculoskeletal and skin disorders, such as low-back injury and occupational irritant dermatitis. The awards made by the participating Institutes represent the largest single infusion of funding ever by the Federal Government to support extramural occupational safety and health research.

Fibromyalgia, a chronic disorder characterized by widespread musculoskeletal pain, fatigue, and tenderness in localized areas of the neck, spine, shoulders, and hips, is also of major concern to the Institute. Scientists are currently studying the effects of two of the most promising non-pharmacologic interventions for fibromyalgia: cognitive behavior therapy and physical exercise training. If these interventions prove beneficial, the researchers plan to evaluate the combination of therapies in patients with other rheumatic diseases in which pain is a key factor. Most recently, NIAMS has funded a number of grants with a focus on behavioral and social sciences research in response to a special solicitation on basic and clinical research on fibromyalgia. Among these are behavioral insomnia therapy for fibromyalgia patients, and employment and health status in women with fibromyalgia.

Several studies confirm that lower extremity weakness is associated with osteoarthritis (OA) - or degenerative joint disease - of the knee, but it has not been clear whether the weakness precedes the development of OA, or is a result of the disease. Currently, NIAMS is supporting a study that suggests that strength training may improve the prognosis in patients with mild OA,

decreasing both long-term pain and disability. In addition, NIAMS, together with other components of the NIH, is currently sponsoring a new funding opportunity for the prevention of onset, progression, and disability of OA.

Recognizing that in chronic disease, the patient is often the principal care giver, the Institute will continue to pursue its goal of improving health by conducting and supporting not only high-quality basic and clinical investigations, but also promising research in the area of behavioral and social sciences, including professional and patient education, epidemiology, and health services. For example, the Institute recently announced a new program to support Multidisciplinary Clinical Research Centers in arthritis, musculoskeletal disorders, and skin diseases; behavioral and social sciences research is one of the areas of emphasis for this initiative.

## **9. National Institute of Child Health and Human Development (NICHD)**

The National Institute of Child Health and Human Development seeks to ensure that every individual is born healthy and has the opportunity to fulfill his or her potential for a productive life unhampered by disease or disability. Healthy sexuality, conception, growth and development from a single fertilized cell to a fully functioning adult involves a complex interplay of biological, behavioral, and social processes. Since its inception in 1962, the NICHD has dedicated a large percent of its research to understanding the dynamics between these processes. In FY 2000, the NICHD supported over 1000 projects and subprojects in the behavioral and social sciences. Listed below are highlights of the Institute's diverse portfolio, which includes new and continuing research and research training activities.

In *maternal and infant health research*, the NICHD supports a broad range of studies to ensure that mothers have safe pregnancies and that babies are born wanted, at a time and in a manner that best ensures their future physical and mental health, and that they are able to reach their full potential. The NICHD supports a broad range of behavioral studies that can be applied to the important issues of infertility treatment, to the development of improved methods of family planning, and to the identification of behavioral factors that influence both fertility and infertility. Examples of studies in this area include:

- research on how various maternal behaviors (e.g., exercise and nutrition) influence pregnancy outcomes
- research and interventions to prevent Sudden Infant Death Syndrome through modification of maternal behaviors in placing their infants to sleep on their backs
- interventions to improve parenting skills among high risk mothers
- interventions to prevent adolescent pregnancy
- studies of fatal and nonfatal injuries among infants and young children
- research on the determinants of lack of age appropriate immunizations
- studies of racial and neighborhood disparities in infant health
- interventions to prevent smoking in pregnant women

In *child development and behavior and social processes research*, the Institute supports studies to better understand the complex interplay among external, biological, and behavioral factors that affect, and are affected by, developmental processes over time and that lead to typical and

atypical developmental outcomes. Projects in this area include a broad range of developmental issues from brain maturation, to personality, to the ability to learn, and to social traits and behaviors. Examples of projects include:

- studies concerning the early development of math, language, and visual perception skills
- several projects to study factors and conditions that affect literacy development in Spanish-speaking children, as well as the interactions among cognitive, sociocultural and instructional factors that promote or impede the early acquisition of English and Spanish reading and writing abilities.
- comparative studies of normal behavioral, cognitive, social-emotional, and physiological development in humans and in non-human primates
- research on early assessment and intervention for individuals with developmental disabilities
- studies of the role of family structure on the optimal development of disabled family members
- research on variations in cognitive, language, and motor development in Down Syndrome and other types of mental retardation
- effects of day care on child development from infancy to middle childhood
- research on how neglect affects the social, behavioral, and psychological development of children
- studies of racial discrimination's effect on adolescent development
- research on the effect of marital conflict and divorce on child development
- research on the psychosocial antecedents of aggression in childhood
- multiple studies on conflict resolution and violence prevention
- research to prevent and remediate learning and reading disabilities such as attention deficit/hyperactivity disorder and dyslexia
- neuroimaging studies to link regions in the brain with specific behaviors and cognitive functions over the course of development
- behavioral interventions in children to prevent chronic disease such as osteoporosis, obesity, atherosclerosis, and diabetes later in life
- studies to increase safety of teen driving and prevent underage drinking and driving
- interventions to prevent alcohol use, drug abuse, and other problem behaviors in youth
- institutional training grants in mental retardation and developmental disabilities, psycholinguistics, and developmental psychology
- multidisciplinary research centers and networks addressing autism and mind/body interactions

In **population research**, the NICHD supports a variety of studies to understand the biological, physical, social, behavioral, and demographic factors affecting population dynamics, the functioning and well being, and health related behaviors of individuals, families, and communities. Many of these factors contribute to the earliest beginnings of health disparities, another focus area of the Institute. Examples of projects include:

- Add Health, a national, longitudinal study that has collected an unprecedented range of information on the social context of adolescents' health promoting and risk behaviors

- a broad range of data collection activities to study behavioral, health, and social trends, including the National Longitudinal Survey of Youth and the Federal Interagency Forum on Child and Family Statistics
- analyses of single motherhood and the societal effects of teenage childbearing
- analyses of the impact of welfare reform, child support reform, and adoption on child well-being
- studies of fathers' roles in family formation and parenting
- research on the effect of family socioeconomic status on child well-being
- studies of how acculturation affects health care outcomes in various immigrant populations
- institutional training programs in demography and population research

In *HIV/AIDS research*, the Institute supports behavioral studies to prevent the transmission of HIV in infants, mothers, couples, and adolescents and to understand the risk taking behaviors that lead to HIV infection. Examples of studies include:

- research to design and test strategies to prevent the early initiation of sexual intercourse in children ages 6-12
- studies to 1) prevent early sexual initiation and its precursor behaviors among urban minority pre-teen boys and girls before they enter middle school, and 2) design and test interventions that support pre-teens and their parents through the important transition into early adolescence
- multiple studies to validate newly designed interventions aimed at reducing or eliminating risky sexual behaviors in young minority teens in a variety of settings and multicultural communities, with the intent of preventing pregnancy and transmission of HIV and other STDs during adolescence
- studies of the acceptability of using various barrier methods for disease prevention
- studies of the acceptability of using new HIV and/or other STD prevention methods, including microbicides
- interventions to prevent HIV transmission in culturally diverse adult couples
- abstinence interventions to prevent HIV/STD transmission in youth

In *medical rehabilitation research*, the Institute supports studies to develop the scientific knowledge needed to promote the health, productivity, independence, and quality of life of people with disabilities. Examples of projects in this area include:

- studies of psychosocial support and education for family caregivers of individuals with brain injury
- projects specifically targeted to improving health promotion of women with disabilities
- research on occupational therapy for children with sensory disorders
- studies of memory retention in children with spina bifida

## **10. National Institute on Deafness and Other Communication Disorders (NIDCD)**

The mission of the National Institute on Deafness and Other Communication Disorders (NIDCD) is to conduct and support research and research training in the normal and disordered processes

of hearing, balance, smell, taste, voice, speech and language. Accordingly, the NIDCD devotes considerable resources to research relevant to the behavioral and social sciences as defined by OBSSR. In particular, the NIDCD conducts and supports research that is related to disease prevention and health promotion and that addresses the special biomedical and behavioral needs of individuals who have communication impairments or disorders.

Behavioral and social sciences research supported by the NIDCD includes basic and clinical studies in each of the mission areas of the Institute. Studies evaluate normal and disordered communication processes across the lifespan, clinical and applied behavioral medicine, language development and speech acquisition, cognition and perception, and normal and disordered motor function. Examples of research are included below.

- The effects of education and habilitation on speech and language skills of deaf children who have a cochlear implant are being examined. The benefits obtained from the cochlear implant are related to the child's dependence on spoken language for communication and the amount of auditory, speech and language training the child receives after implantation. Establishing the amount of training needed in relation to the amount of benefit achieved with an implant is an important outcome of the study.
- Scientists are determining if repeated bouts of otitis media (middle ear infection) in children and the associated hearing loss from the disease causes delays in language, auditory processing and later learning problems. How the relationship of the child's environment (parent-child and classroom interactions) impacts the child's development is also being investigated. The study will examine the extent to which otitis media, with accompanying hearing loss during early childhood, and subsequent auditory processing is related to language and academic performance during elementary school.
- The vestibular system is responsible for maintaining the body's orientation, posture and stability during movement. Scientists supported by the NIDCD are studying how the vestibular system perceives motion while undergoing functional changes to adapt during development, aging and disease.
- The role of phonation in enhancing oral communication in individuals with motor speech disorders, such as Parkinson's disease, multiple sclerosis and closed head injury, is being studied. Research is also underway to examine the speech-sound production ability of young children with severe traumatic brain injury. Information from these projects will help clinicians develop treatment models for speech production.
- There is great need for methods to identify and confirm language impairment in children. Some African American children, who are also speakers of African American English, are at risk for being diagnosed incorrectly as language impaired. Likewise, children with language impairment may go undetected and fail to reach their academic potentials in the absence of needed interventions. Scientists are collecting data to establish the prevalence and nature of Specific Language Impairment in African American English-speaking children.

- Researchers are evaluating the possible impact of age-related constraints in adult immigrants acquiring a second language. The study will help investigators determine if a critical age period exists that is independent of the influence of a person's native language structure in acquiring a second language.
- The acquisition of American Sign Language (ASL) by deaf children with deaf parents and deaf children with hearing parents will be compared with the acquisition by hearing children of three spoken languages - English, Japanese and Spanish (languages which each displays certain grammatical characteristics common with ASL). This cross-linguistic study of early syntax will provide information on the acquisition of ASL and other languages.

## **11. National Institute of Dental and Craniofacial Research (NIDCR)**

In addition to NIDCR's own investments in behavioral and social science research and research training, two NIH organizations provided substantial support for NIDCR-initiated behavioral and social science research projects. Specifically, OBSSR provided funds for the continuation of the Center for Stress and Wound Healing at Ohio State University, for the continuation of a research training program in dental disease prevention, and for two research workshops. In addition, the National Center for Complementary and Alternative Medicine (NCCAM) provided funds for the continuation of a NCCAM-funded Craniofacial Complementary and Alternative Medicine Center programmed by NIDCR staff to take full advantage of opportunities to use sensitive, reliable behavioral and clinical outcome measures to test the impacts of CAM interventions on temporomandibular pain/dysfunction and other oral/craniofacial disorders.

NIDCR's comprehensive research centers include support for ten behavioral/social science research projects, including community outreach projects that are tied to the central themes of the various centers. For example, a center at the University of Pittsburgh focusing primarily on the pathogenesis of oral cancer and improving oral cancer treatments includes a behavioral intervention study to reduce tobacco use and increase treatment compliance in cancer patients.

These NIDCR and NIH investments indicate the recognition that many dental and craniofacial diseases (e.g., dental caries, periodontal diseases, oral cancers) are significantly influenced by personal behaviors, such as hygiene practices, dietary choices, or tobacco and alcohol use. Also, the relatively accessible oral cavity provides excellent opportunities for non-invasive biobehavioral studies of tissue response to psychosocial stressors or environmental changes.

NIDCR supports both basic behavioral and social science research and applied health promotion/behavioral intervention research. Significant areas of research supported in FY 2000 are summarized below:

***Assessing behavioral and social effects of dental and craniofacial diseases and oral treatments:*** Researchers are evaluating the impacts of poor oral health on overall health and quality of life, particularly in older populations, children, and socioeconomically disadvantaged populations. Improved measurement of the effects oral health or its absence has on functioning can provide useful tools for evaluating the benefits of new treatments, as experienced by patients. Participants in these studies include children with cleft lip and palate and patients with other acquired or inherited craniofacial anomalies. Ongoing studies are also evaluating the

psychosocial benefits of orthognathic surgery and personal characteristics that influence satisfaction with surgical outcomes. NIDCR has recently funded research projects to develop more sensitive measures of oral health-related quality of life in children.

***Stress and tissue response:*** Studies of oral mucosal wound healing are determining the effects of transient, predicable stressors, such as academic examinations, and other more sustained stressful conditions on the body's capability for tissue repair. Neuroimmunological processes mediating the body's response to stressors are also being studied, as are psychosocial and environmental factors that influence the speed and quality of wound healing.

***Tobacco prevention/cessation interventions:*** Ongoing intervention studies are testing dental office-based strategies for informing adolescents about health risks of tobacco use, preventing high-risk youth from initiating tobacco use, and providing cessation programs to youth who use tobacco. In addition, NIDCR has recently funded a large study of dental practice-based tobacco cessation interventions that will be conducted by scientists from Sloan-Kettering Memorial Hospital and dental clinicians and faculty from the NYU School of Dentistry. Both smoked and spit tobacco have harmful oral and systemic health effects. The oral effects of tobacco use and results from tobacco prevention/cessation intervention studies were reviewed in depth at an NIDCR/OBSSR supported workshop held in 2000. Results from the workshop are being widely disseminated through a special issue of the Journal of Dental Education "Tobacco and Oral Disease: Strategies for Dental Professional Interventions" (April, 2001, vol 65/No.04). Dentistry is poised to make important contributions to tobacco prevention/cessation efforts once effective office-based interventions are developed that can be readily incorporated into regular dental care.

***Behavioral risk factors for chronic pain disability:*** Research has demonstrated that costs of treatment and risks of long-term disability can be reduced by including behavioral approaches in the treatment provided to patients whose social or personal characteristics place them at higher risk of falling within the 10–20 percent of patients who develop long term pain disability. Tailoring treatments based on both physical/clinical variables and psychosocial characteristics has been shown to improve long-term outcomes and reduce disability.

***Behavioral therapies in pain treatment:*** NIDCR supported researchers are evaluating the effects of various behavioral interventions (educational, biofeedback, cognitive-behavioral) in reducing persisting pain in the jaw and face (temporomandibular joint pain). Other studies are evaluating synergistic effects of combining clinical and educational-behavioral approaches to accelerate recovery and reduce health care costs.

***Disparities in oral health and perceived need for care:*** Community-based studies are evaluating how recent immigrants, socioeconomically disadvantaged individuals, and other groups with poorer than typical oral health status differ in their self-care practices, attitudes regarding the need for dental care, and expectations regarding the likelihood and value of maintaining their teeth over a lifetime. In addition, studies of relationships between health attitudes and knowledge and access to oral health care and patterns of use are providing important insights to develop strategies for improving oral health across all segments of our population. Intervention research to improve health in health-disadvantaged groups must rest on

accurate knowledge regarding health values and needs, as perceived within different communities, as well as knowledge about processes through which individual, community, and health care system changes can lead to improved prevention of oral diseases and improved oral health status.

***Clinical decision-making:*** NIDCR supports studies focused on understanding how delivery approach for provision of new scientific information influences clinicians' treatment practices and clinical decisions. These studies aim to develop effective interventions to improve the quality of clinical decision-making and to accelerate integration of new scientific findings into practice.

NIDCR has been an active collaborator in trans-NIH behavioral and social science research initiatives. NIDCR co-sponsored six Requests for Applications (RFAs) and Program Announcements (PA) during 2000 that addressed behavioral and social research topics in partnership with OBSSR, NINR, NIDDK, NCI, and other NIH Institutes. NIDCR staff has also contributed to planning trans-NIH research meetings on topics including stigma, improving end of life care, treatment adherence, and tobacco prevention/cessation in adolescents and children. Each of the behavioral and social topics selected for co-sponsored research solicitations or workshops are directly relevant to specific craniofacial disorders and diseases or their prevention and treatment.

## **12. The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK)**

The NIDDK has lead responsibility for a number of chronic diseases with behavioral and social aspects to their etiology, pathogenesis, treatment, and prevention. The following reviews the areas covered by the NIDDK.

### ***Diabetes: Behavioral and translation research***

*Diabetes Research and Training Centers, Demonstration and Education Components.* The NIDDK has provided long-term support to six Diabetes Research and Training Centers. In addition to serving as a focus for diabetes research and training, these centers include a mandatory demonstration and education (D&E) component. This component conducts behavioral research that spans the range from risk-taking behavior in adolescence to health provider behavior as influenced by physician patient communications skills. There is also a focus on translation research in moving scientific advances in prevention and treatment to the public.

As an example, the NIDDK-sponsored Diabetes Control and Complications Trial, completed in June 1994, demonstrated that intensive glycemic control prevents or delays the development and progression of diabetes-related complications in persons with insulin-dependent diabetes. This study was designed as an efficacy trial and barrier translatability was inherent in the trial design. The D&E investigators worked to develop a translation blue print for addressing these issues. The document the investigators produced reviewed behavioral issues and needed research and barriers to implementation, and recommended the creation of a National Diabetes Education

Program (NDEP). The NIDDK has since implemented the NDEP. Behavioral researchers from the diabetes centers program were instrumental in its development.

*Diabetes Prevention Program.* Behavioral research is a main focus of the Diabetes Prevention Program (DPP). The DPP is a national multicenter clinical trial attempting to prevent or delay the onset of type 2 diabetes in populations at risk for this condition. The trial is comparing an intensive behavioral lifestyle intervention (exercise and diet changes) with drug intervention, compared with a control group of participants. Approximately 3,000 patients have been recruited into the trial. Minority populations are disproportionately affected by type 2 diabetes, and comprise nearly one-half of those participating in the DPP. Four of the Institute's Diabetes Research and Training Centers are participating in the trial. These centers, together with other behavioral investigators within the study, were instrumental in designing the lifestyle intervention, follow-up protocol, recruitment and now retention and adherence approaches.

In recognition of the importance of understanding why some people succeed and some fail in adhering to treatment protocols, a substantive plan was developed for the DPP to monitor the characteristics of individuals in the trial, and was implemented with support from OBSSR. This plan includes monitoring of mood, general adjustment, stress, family functioning, social resources, and key aspects of intervention support throughout the trial. The study will continue through the end of the DPP in the year 2002 and should provide major insights into personality and behavioral factors that contribute to successful adherence to various treatment regimens, and will likely have value to areas beyond diabetes.

### ***Diabetes: Psychosocial and behavioral aspects of diabetes***

The NIDDK research portfolio also includes a number of R01 grants that focus primarily on psychosocial aspects of diabetes. These include:

- behavioral weight loss as a treatment for type 2 diabetes
- investigations of depression in newly-diagnosed type 1 diabetics
- behavior therapy for families of diabetics
- family contexts of outcomes in diabetic adolescents
- examination of psychiatric disorder in adults with diabetes
- cognitive strategy processes in diabetic children

To extend the breadth of the behavioral research program in diabetes a conference entitled "Behavioral Science Research in Diabetes" was held on November 18-19, 1999, on the NIH campus. The objectives of this meeting were to determine the current status of behavioral science research for both diabetes as well as for other chronic diseases, and to develop an agenda for future research based on expert opinion. The meeting attendees and speakers represented both the diabetes research community as well as behavioral researchers from other chronic disease areas. The meeting overview and outcomes have appeared as a series of reports in the journal Diabetes Care Volume 24, Number 1, 2001.

The NIDDK partnered with the National Institute of Mental Health and OBSSR to hold a conference January 29-30, 2001 entitled "Depression and Mental disorders in Patients with Diabetes, Renal disease, and Obesity/Eating Disorders." The conference was interdisciplinary

involving endocrinologists, nephrologists, internists having a focus on obesity and eating disorders, psychiatrists, psychologists and clinical trial experts. The major aims of the conference included 1) recognition of the increased prevalence of major depression and mental disorders in patients with chronic diseases (specifically diabetes, renal disease, and obesity/eating disorders), 2) review of the cultural and ethnic differences in manifestation of the co-morbid conditions that were the focus of the conference, 3) recognition of depression as a risk factor for diabetes onset and complications and present its role in the pathogenesis of obesity, and 4) assessment of the physiologic pathways linking depression and mental disorders with mechanisms of chronic disease. The meeting participants developed a set of recommendations for future research which has led to an RFA that will appear in the NIH Guide to Grants and Contracts in the fall of 2001.

### ***Obesity***

The NIDDK obesity and eating disorders research portfolio recognizes obesity as a complex disorder that includes genetic, environmental as well as behavioral components. Behavioral research grants supported by the institute include studies of appetite behavior, eating patterns, determinants of energy intake and physical activity, and lifestyle modification for weight loss and weight maintenance. Recent new grants awarded in the result of an NIDDK initiative entitled “Innovative Approaches to the Prevention of Obesity” involve a mentor-based approach to long-term weight loss, and the effect of active play on obese at-risk toddlers. The NIDDK recently launched a long-term, multicenter clinical trial, ‘Look AHEAD: Action For Health in Diabetes’ (formally the SHOW trial) in obese patients with type 2 diabetes. This large, multicenter trial is designed to study if interventions to produce sustained weight loss in obese individuals with type 2 diabetes will improve health. The NIDDK expects that the Look AHEAD trial will include participants from a range of minority populations--those with the greatest risk for developing type 2 diabetes. The Institute also is planning ancillary studies in conjunction with the Look AHEAD trial, which may include the participation of other NIH and federal components.

### ***Women's Urological Disorders***

The NIDDK sponsors two studies on urological disorders in women. The first study examines the psychosocial risk factors for urinary tract infections (UTIs) among college women, including behaviors before and after the initial UTI infection in those with and without recurrences. The second study examines how menopause and the associated use of supplemental estrogen modifies the relationships between health behavior, bacterial virulence factors, and the risk of UTI among white and non-white women, ages 40 to 65.

### ***Kidney Disease***

The NIDDK supports a small portfolio of behavioral and psychosocial research related to the problems faced by patients with renal failure. An RFA issued in FY2001 solicits additional applications for clinical research on the impact and treatment of depression in this patient population.

In FY 2000, the NIDDK launched a major new preventive medicine program, the National Kidney Disease Education Program, designed to implement national strategies for slowing the progression of kidney disease and improving health outcomes for patients. The program will implement a variety of outreach activities directed at improving patient and physician awareness of optimum care. Evaluation strategies, using the methods of behavioral and social sciences, will be critical to this effort.

The NIDDK supports the National Minority Organ and Tissue Transplant Education Program (MOTTEP), was established in 1995. MOTTEP's goal is to expand the organ donor rate among minority populations through a national campaign that has:

- Created a network of informed speakers who promote organ donation in churches, religious organizations, and other community groups
- Generated publicity in the media to advance the concept of organ donation and to increase public awareness about the issues involved
- Sponsored and organized national and local forums on organ donation. These forums targeted opinion leaders, heads of organizations, and other influential persons within minority communities
- Established a lending library of film, videotapes, and publications about organ donation; this material is available to organizations within the minority community

The NIDDK is also supporting a study that examines psychosocial risk factors for urinary tract infections (UTIs) among college women, including behaviors prior and subsequent to initial UTI infection in those with and without recurrences. Another study is examining how menopause and associated use of supplemental estrogen modifies the relationships between health behavior, bacterial virulence factors, and risk of UTI among white and non-white women aged 40-65.

### **13. National Institute on Drug Abuse (NIDA)**

Behavioral and social sciences research plays an important role in the National Institute on Drug Abuse's (NIDA's) search for solutions to the complex social and public health problems posed by drug abuse and addiction. These scientific disciplines provide NIDA with the knowledge necessary to better predict, prevent, and treat drug abuse and addiction problems. Listed below are some highlights and accomplishments of the Institute's diverse portfolio, which includes both research and research training endeavors.

Combating Nicotine Addiction. Establishment of Transdisciplinary Tobacco Use Research Centers. Over the past decade, NIDA's nicotine-related research has provided crucial insights into the neurobiological and behavioral aspects of nicotine addiction, and this research has led the way to important advances in treating nicotine addiction. NIDA's behavioral science research has contributed to the development, testing, and validation of new behavioral therapies to help smokers resist the craving that often defeats the most determined efforts to stop smoking. NIDA has also taken its behavioral research agenda to new heights by merging it with other disciplines through a unique collaborative effort. NIDA joined with the National Cancer Institute and the Robert Wood Johnson Foundation to co-fund seven Transdisciplinary Tobacco Use and Research Centers across the country. The Centers draw scientists from diverse disciplines to work collaboratively on tobacco use problems. The researchers have the freedom to investigate

broad aspects of nicotine addiction, from social, biological and environmental factors that influence smoking initiation to the role of brain substrates and chemicals in patterns of dependence and abuse. The focus of these programs is to optimize the potential trans-disciplinary interactions (from cellular/genetic to social and community level analysis) to contribute to a greater understanding of the processes regulating teen and adult smoking behaviors.

Basic Behavioral and Cognitive Science Research. NIDA supports both human and animal basic research to determine how behavioral and cognitive factors underlies, or can lead to, drug addictions. NIDA researchers look at variables such as individual differences (e.g. “sensation-seeking,” drug history, prior learning experiences, or prenatal drug exposure); environmental factors (e.g. learning and conditioning, parenting), genetic predispositions, as well as motivational factors that may contribute to drug craving or relapse. NIDA also supports studies that look at the effects of drugs on memory and learning, perceptions, as well as supporting studies that determine the potential abusability of drugs. NIDA supports research that will lead to a better understanding of risky behavior, generally, such as research on self-control or impulsivity. Studies on social factors, such as peers, schools and family as they influence the development of drug abuse are also supported.

Treatment Outcomes Research. Research has shown that the most effective approaches for the treatment of drug addiction will include, biological (when available), behavioral, and social components. Integrating these components in ways specific to an individual’s need is likely the best way to treat addictive disorders. The development of new and improved behavioral treatments will continue to be an important area of research for NIDA. NIDA will bring new behavioral treatments to fruition through its Behavioral Therapies Development Program (BTDP). Once the therapies are tested and shown to be effective in laboratory settings, they will be tested in clinical trials in communities throughout the country through NIDA’s newly established National Drug Abuse Treatment Clinical Trials Network.

Adherence to Treatments. The efficacy of combination therapy with antiretroviral drugs (ART) has dramatically altered the landscape of HIV treatment. However, benefits of combination medication regimens require careful adherence to precise dosing schedules and other dosing requirements. NIDA has teamed with NIAAA and NIMH to address the role of adherence through all phases of treatment and illness. Researchers will address the need to broaden the scope of interventions to enhance treatment adherence, and the importance of tailoring methodological and intervention advances to the special needs and context of affected populations. Researchers are being encouraged to develop innovative approaches to adherence and behavior change, especially models of interventions to improve adherence. Approaches based on basic behavioral principles such as cognition, emotion, decision-making, motivation, social interaction, and cultural context are particularly encouraged.

Behavioral, Social, Mental Health, And Substance Abuse Research With Diverse Populations. NIDA teamed with the National Institute of Mental Health, the National Institute of Child Health and Human Development, Office of Research on Women's Health, and OBSSR to increase scientific understanding of the health status of various population groups (lesbian, gay, bisexual, transgendered, (LGBT) and related populations) that will lead to more effective health

interventions and services for individuals within those groups. Behavioral, social, mental health, and substance abuse research will be encouraged. Current scientific evidence clearly indicates that the majority of LGBT people do not suffer from clinical disorders. However, recent data from both national health surveys and targeted studies suggest that prevalence rates of affective disorders, tobacco addiction, alcohol abuse, certain forms of drug abuse, and possibly other dysfunctions are higher for LGBT populations (or particular segments of those populations) than for the general population. Further research is required to clarify the nature, extent, and determinants of mental disorders and substance abuse among LGBTs.

Identifying and Understanding Vulnerability to Drug Abuse. NIDA uses a multidisciplinary research approach to determine the interaction of factors that make individual's more or less vulnerable to addiction. Researchers are not just focusing on what initially puts an individual at risk for addiction, but are beginning to look at all phases of addiction. They are looking at other stages, such as escalation, continuation, discontinuation, relapse, and recovery from drug abuse and addiction to account for individual differences in vulnerability to drug abuse. Determining the factors that predispose and protect an individual from drug abuse, from initial use through different stages of drug involvement, is essential to successfully preventing and treating drug abuse.

Research on the Effects of Illness on Physical Condition, Behavioral and Social Functioning. NIDA has a comprehensive program on the medical health and developmental consequences of drug abuse, the effects of drug use on other diseases, and the multidisciplinary aspects of HIV/AIDS. Some of the basic studies that NIDA supports in this portfolio focus on how drugs affect an individual's ability to sense and perceive things, while others focus on how drugs affect higher cognitive abilities such as planning and organizing. Recognizing that injection drug users and their sex partners now account for more than half of all new HIV infections annually, NIDA supported researchers are working to better understand the dynamic patterns in the transmission of HIV and other infectious diseases in drug using populations, to develop effective behavioral risk reduction interventions and to reduce the morbidity and mortality associated with HIV/AIDS.

Research on Health Promotion and Disease Prevention. NIDA's health promotion and disease prevention portfolio supports studies that examine what works, for whom, and under what conditions. Programs are developed and tested for a variety of populations and contexts. These studies try to gain a thorough understanding of how to enact programs in settings with low access or other difficult factors. Prevention services research projects use a variety of methods to describe the organization, management, and financing of health care systems. It is important that such studies focus on program elements that produce successful outcomes.

Improving Measurement, Analysis and Classification. NIDA supports research directed toward improving the precision and efficiency of epidemiological (survey) studies; developing assessment protocols for use in general populations; developing new sampling, surveillance, culturally appropriate data collection methods; and refining statistical tools to analyze survey data.

Research on Institutional and Organizational Influences on Health. NIDA's portfolio in this area consists of health services research on drug abuse treatment, with a focus on the quality, cost, access, outcomes, and cost-effectiveness of care for drug abuse and addiction disorders, and how these are influenced by the organization, financing, and management of drug abuse treatment.

Training in the Behavioral and Social Sciences. Given the critical role that behavioral and social scientists can play in curtailing drug abuse and addiction, as well as reducing the spread of infectious diseases such as HIV/AIDS, NIDA is taking extra steps to ensure this important scientific pipeline does not run dry. NIDA supports the training of behavioral and social sciences researchers at various stages of their careers through a variety of funding mechanisms. These include the National Research Service Awards for pre- and postdoctoral fellows, career development awards that support a period of mentored training for young scientists, and a recently developed program, B/START (Behavioral Science Track Awards for Rapid Transition) program to help prospective behavioral researchers more rapidly enter the drug abuse and addiction research environment.

The B/START program offers fast-track small grants to newly independent behavioral scientists through rapid review and funding decisions of applications. Research applications are encouraged across a wide variety of behavioral factors in drug abuse, including neurocognitive, cognitive and perceptual processes, psychosocial, and more broadly motivational, social and community factors in drug abuse.

In 1999 a series of workshops were organized and held at seven national scientific conferences ("Early Career Pathways") to aid new investigators in applying for research grants, learning about topics in drug addiction research, and getting information about training opportunities. NIDA's Behavioral Science Working Group also hosted a successful career development workshop at APA in 2000.

#### **14. The National Institute of Environmental Health Sciences (NIEHS)**

NIEHS strives to reduce the burden of human illness and dysfunction from environmental causes through a multidisciplinary biomedical research program, prevention and intervention efforts, and a communication strategy that encompasses training, education, technology transfer, and community outreach. Because of the desire of the public for research about health risks of exposure to physical and chemical agents, NIEHS is playing an increasingly important role in numerous public health issues.

Over the last five years, the NIEHS has developed translational research programs to help address environmental public health issues. The Institute's activities share the following objectives: 1) To improve understanding of how environmental factors affect human health; 2) To develop better means of preventing environmentally related health problems; and 3) To promote partnerships among scientists, health care providers, and community members. NIEHS' Division of Extramural Research and Training supports several translational research activities, which include environmental health science education, NIEHS Center Community Outreach and Education Program (COEP). Environmental Justice, Community-Based Prevention/Intervention Research and the Children's Environmental Health and Disease Prevention Research Centers.

NIEHS has partnered with EPA and CDC to create eight Children's Environmental Health and Disease Prevention Research Centers. The Centers will encourage multidisciplinary interactions among basic, clinical, and behavioral scientists to facilitate research programs that address the environmental contributions of children's health and disease. Each of the centers will maintain an intervention component and will focus on asthma and other respiratory diseases, as well as intellectual development, and growth development.

NIEHS supports a number of studies with biobehavioral/neurocognitive endpoints. These studies are designed to assess the effects of environmental agents such as tobacco smoke, lead exposure, polychlorinated biphenyls, and mercury on such outcomes as IQ and cognitive development, ADHD, and delinquency.

NIEHS supports twenty-six center grants, including Developmental Centers, Environmental Health Sciences Centers, and Marine and Freshwater Biology Centers. The Centers grant is a program of core facility support for institutions having a group of investigators conducting multidisciplinary research in environmental health science. Each Center is required to develop community outreach and education programs. The objective of the COEP is translation of research of results into knowledge applied to public health. Appropriate activities include continuing professional education, disease prevention programs, education (primary, secondary, and/or college), information dissemination, and community issue programs, and public awareness seminars, etc. As part of this effort, each NIEHS Center defines the community and/or region that it serves and develops productive outreach efforts that are specifically designed to address the environmental health concerns of that particular community.

Additionally, NIEHS currently supports nine community-based prevention/intervention research (CBP/IR) grants and twelve environmental justice grants. Both of these grant programs link members of the community (directly affected by adverse environmental health conditions) with researchers and health care providers. The Environmental Justice program was recently re-announced and new awards are expected in FY 2000. The CBP/IR program is co-sponsored by OBSSR and the National Institute for Nursing Research (NINR). OBSSR supports annual meetings financially, and NINR provides support for one CBPIR grant. A conference report entitled "Advancing the Community-Driven Research Agenda" is available.

Prospective partnerships with NINR, NIDCR, and NICHD are underway on a program announcement addressing low birth weight babies in minority populations. NIEHS, NCI and NIA are partners on a program announcement on Age, Ethnicity, and Prostate Cancer. Additionally, NIEHS is partnering with NHLBI, NIA, NIMH and NICHD on a PA on Socioeconomic Status and Health Across Life Course. NIEHS also is collaborating with NIAID on a Cooperative Inner-City Study to Reduce Asthma Severity in Children.

NIEHS has been the primary force in developing awareness about the importance of disease susceptibility, including childhood susceptibility and susceptibilities arising from socioeconomic status, in defining the effects of environmental agents. Within the Healthy People 2010 framework and the Department's efforts to reduce/eliminate health disparities in racial and ethnic groups, NIEHS has initiated research on the relationship of poverty and environmental pollution to natural health disparities. NIEHS also convened a series of regional workshops on Health Disparities, held in Oakland, CA, Chicago, IL and Baltimore, MD. NIEHS held a concept forum on Health Disparities and Socioeconomic Status (SES) to explore ways in which NIEHS, in

partnership with other NIH OD Offices, Institutes and Centers, can effectively address this important health issue. The purpose of the meeting was to set the stage and to generate interest in a larger trans-NIH multidisciplinary conference that was held in September 1999.

#### **15. National Institute of General Medical Sciences (NIGMS)**

The mission of the National Institute of General Medical Sciences (NIGMS) is to support research and research training in the basic biomedical sciences. Almost 90 percent of the budget of these programs goes toward the support of investigator-initiated research. The projects supported by the NIGMS are in the most basic and fundamental areas of biomedical science and provide the foundation for subsequent disease-targeted studies supported by the other components of the NIH. Through its Minority Opportunities in Research Division, NIGMS also administers several programs to increase the research capacities at minority-serving institutions and increase the representation of minorities in biomedical and behavioral science careers.

Included among NIGMS's basic research portfolio are studies of biobehavioral mechanisms. Pharmacological studies are supported to determine behavioral sensitivity to neurotransmitters, central nervous system receptors, and neurotoxins, and to identify the basis of individual differences in these responses. Other supported studies use broad multidisciplinary approaches involving molecular biology, biochemistry, biophysics, morphology, physiology, and psychology to study mechanisms such as: the genetic determinants of neural and hormonal control of circadian behavior; the release of neuropeptides and their influence on behavioral states; genetic factors that affect behavior plasticity (development, learning, and motivation); and studies to elucidate the cellular mechanisms associated with long-term sensitization and learning. In addition to research project grants in these areas, behavioral and social science research on a wide variety of topics is conducted in subprojects supported through the NIGMS Minority Biomedical Research Support (MBRS) Program.

Some research training in the behavioral and social sciences is supported through NIGMS's Medical Scientist Training Program (a training program leading to the combined M.D.-Ph.D. degree) and the Institute's MBRS and Minority Access to Research Careers programs. All of these programs solicit applications for research training support in a broad range of disciplines, including the behavioral and social sciences.

#### **16. National Institute of Mental Health (NIMH)**

The mission of the National Institute of Mental Health (NIMH) is to diminish the burden of mental illness and AIDS through research and research training in basic neuroscience, behavioral science, and genetics. The institute is comprised of three extramural research divisions: Division of Mental Disorders, Behavioral Research, and AIDS (DMDBA); Division of Neuroscience and Basic Behavioral Science (DNBBS); and the Division of Services and Intervention Research (DSIR). Behavioral science research and research training is supported by each of the Divisions. In addition the Office for Special Populations (OSP) coordinates, develops, and administers research and research training in basic and applied social and behavioral science concerning the mental health needs of women and minority populations.

DMDBA supports research and research training related to behavioral, developmental, epidemiologic and intervention development studies on the causes, prevention, and treatment of mental and behavioral disorders and HIV/AIDS. The Division is comprised of three research branches with each supporting behavioral research.

- **Developmental Psychopathology and Prevention Research Branch** focuses on: risk/protective factor identification; early social, emotional, and cognitive developmental processes leading to psychopathology or resilience; early manifestations and course of psychopathology in childhood and adolescence; and the translation of risk and developmental research into new prevention, early intervention, and treatment strategies.
- **Adult Psychopathology and Prevention Branch** focuses on: identifying the prevalences and risk factors for mental disorders across the adult lifespan; developing new approaches to the etiology and assessment of adult psychopathology and related functional impairment; clarifying the relations among psychological, biological, social, cultural, and environmental factors involved in adult mental health, illness, disability, and recovery; and translating the findings and methods of basic research into studies of the biobehavioral mechanisms of disorders and the development of new preventive, treatment, and rehabilitative interventions.
- **Health and Behavioral Science Research Branch** focuses on general medical illnesses and behavior and their relationship to mental disorders. Emphasis is on the mechanisms and processes linking medical and mental illnesses (i.e., comorbidity) and the development and the testing of early interventions; factors that influence adherence to treatment, therapeutic alliance, research ethics, and help-seeking behavior; and cognitive and decision-making factors that influence the choice of treatment or mental health services, acceptance or denial of illness, services utilization for mental illness, and stigma.

Also within DMDBA is the **Center for Mental Health Research on AIDS**. The Center supports behavioral science research and training aimed at developing and testing behavior-change and prevention strategies to reduce the further spread of HIV and other sexually transmitted diseases (STDs); conducting interventions to prevent the consequences of HIV infection; identifying and addressing the behavioral issues in vaccine trials; identifying the role of couples, families, and communities in preventing and adapting to HIV/STDs; defining the clinical phenomena of HIV-related neuropsychological and neuropsychiatric disorders; and improving mental health services relevant to HIV infection and people with severe mental illness.

DNBBS supports research and research training in the areas of basic and clinical neuroscience, genetics, therapeutics development, and basic behavioral science. The Division is comprised of five research branches, with two branches supporting behavioral research and training.

- **Behavioral Science Research Branch** focuses on the basic behavioral mechanisms that underlie behavioral functioning and development across the lifespan. This includes research on: behavioral regulation and homeostasis, including sleep, reproduction, ingestion, and thermoregulation; cognition, including perception, action, attention, memory, learning, knowledge, reasoning, and language; emotional processes in emotion, mood, and motivation; personality processes (e.g., individual differences, traits, self and self-processes) and social

cognition (e.g., social decision making, attitudes, persuasion, impression formation, stereotypes, and group processes).

- **Behavioral and Integrative Neuroscience Research Branch** supports research on the brain mechanisms underlying cognition and behavior. This includes research on the functional organization of brain systems and how behavior maps onto the brain and how systems responsible for coordinating internal states (e.g., neural circuitry, circadian rhythms, Neuroendocrine systems) are changed by external environmental events and situations. Also, supported are studies investigating the brain mechanisms underlying cognitive processes, such as learning, perception, and reasoning.

DSIR supports research and research training in prevention, treatment interventions, services research and clinical epidemiology. Behavioral science research is supported in each of the three research branches.

- **Adult and Geriatric Treatment and Preventive Intervention Research Branch** focuses on treatment, prevention, and rehabilitation of mental disorders in adults, including older persons. Preventive and treatment interventions may include pharmacologic approaches, psychotherapeutic, behavioral, and psychosocial treatments.
- **Child and Adolescent Treatment and Preventive Intervention Research Branch** focuses on treatment, prevention, and rehabilitation of mental disorders in children and adolescents. Preventive and treatment interventions may include pharmacologic approaches, psychotherapeutic, behavioral, and psychosocial treatments.
- **Services Research and Clinical Epidemiology Branch** supports research on the organization, delivery and financing of mental health services; interventions to improve the quality and outcomes of treatment and rehabilitative services; clinical epidemiology of brain disorders; and, dissemination research that includes examination of psychological and social factors influencing decision-making by consumers, practitioners, and health-care delivery systems, and identification of psychosocial factors that influence the delivery of and adherence to mental health treatments by consumers and providers.

## 17. **National Institute of Neurological Disorders and Stroke (NINDS)**

The mission of the National Institute of Neurological Disorders and Stroke (NINDS) is to reduce the burden of neurological disorders by conducting and supporting research on the normal and diseased nervous system. To this end, NINDS supports a broad portfolio of both basic and clinical behavioral and social science research and training. This includes basic studies of the neural bases of cognition and behavior, and clinical studies of the adverse effects of neurological disease on cognitive and behavioral functioning, along with the development of behavioral interventions designed to ameliorate the symptoms of some neurological disorders.

A major portion of the NINDS behavioral and social science research portfolio consists of cognitive and behavioral neuroscience research aimed at understanding the neural bases of a variety of cognitive and behavioral processes. These include studies of sensation and perception

(e.g., visual, auditory, somatosensory), attention, motor behavior and movement, learning and memory, language abilities (both reading and writing), and higher cognitive processes (i.e., decision-making ability). These studies are being done on a variety of levels, from the molecular and cellular to the physiological and systems level. For example, the molecular and cellular bases of learning and memory are being studied in several animal model systems. At the physiological and systems level, the neural bases of perception and attention are being studied in animal models by measuring changes in brain electrical activity as the animal performs behavioral tasks that require it to shift its attention from one task to another.

The development of powerful new imaging technologies such as positron emission tomography (PET) and functional magnetic resonance imaging (fMRI) is giving researchers the extraordinary ability to study the neural bases of a variety of cognitive processes in humans in real time. For example, researchers are using these techniques to study normal language development and how this development is altered in children with reading disabilities such as dyslexia. Other researchers are using these techniques to study differences in brain activity between normal individuals and brain lesion patients in order to gain a better understanding of the neural bases of language, face recognition, and decision-making ability, among other processes.

In addition to basic behavioral research, NINDS also supports a number of clinical behavioral studies on the adverse effects of neurological disorders on behavioral and cognitive functioning. For example, a number of studies are investigating the adverse effects of childhood neurological disorders such as epilepsy, autism, neurofibromatosis, and spina bifida on cognitive and behavioral development. Other studies are looking at the adverse effects of stroke, traumatic brain injury, chronic pain and headache on cognition, attention, mood, and other behaviors. These studies should aid researchers in developing effective interventions to ameliorate, and ultimately reverse the adverse cognitive and behavioral effects of these disorders.

NINDS also supports research aimed at the development and evaluation of behavioral and social interventions designed to ameliorate the symptoms of some neurological disorders. Examples of these interventions include a psychosocial intervention to increase functional recovery from stroke and stress management techniques to treat chronic tension headaches.

In terms of training activities, NINDS supports a number of training and career awards in the area of cognitive/behavioral neuroscience. These include individual pre- and post-doctoral National Research Service Awards (NRSAs), Independent Scientist Awards, and Mentored Clinical Scientist Development awards. In addition, behavioral neuroscience projects are among those being supported as part of the Specialized Neuroscience Research Program (SNRP) at the Morehouse School of Medicine in Atlanta. The NINDS SNRP program is designed to assist minority medical and graduate schools to develop state-of-the-art basic and clinical neuroscience programs.

## **18. National Institute of Nursing Research (NINR)**

The National Institute of Nursing Research (NINR) supports clinical and basic research to establish a scientific basis for the care of individuals across the lifespan. According to its broad mandate, the Institute seeks to understand and ease the symptoms of acute and chronic illness, to

prevent or delay the onset of disease or disability or slow its progression, and to find effective approaches to achieving and sustaining good health. NINR's research extends to problems encountered by patients, families, and caregivers, emphasizes the special needs of at-risk and underserved populations, and addresses problems throughout the lifespan. Consistent with its broad mandate, NINR supports numerous research studies and research training projects relating to behavioral and social sciences research. Highlights of projects that specifically address the influence of behavior on health and disease include the following:

Heart Disease. NINR researchers are studying ways of preventing heart disease through risk assessment and interventions in children. An NINR investigator has shown that an intervention with knowledge/attitude information and a physical activity program reduced cholesterol and body fat in elementary school children at high risk for the development of cardiovascular (CV) disease. She is continuing this work to determine the dose of activity needed to prevent obesity and other CV risk factors. Another investigator is studying CV risk factors in preschool children in order to describe specific risk factors associated with cardiovascular disease and to identify appropriate outcome measures. NINR also supports research to explain and reduce patients' delay in seeking treatment for acute myocardial infarction (AMI), specifically testing an educational intervention to facilitate identification of an AMI in a culturally diverse, at-risk population.

AIDS. NINR supports a variety of behavioral research projects aimed at prevention of AIDS, particularly in vulnerable populations such as infants, adolescents, minorities, and women. One investigator is testing the effectiveness of two behavioral interventions designed to decrease perinatal transmission of HIV in African-American women. Another project is testing an education program aimed at preventing HIV in Latino and African-American adolescent mothers (a particularly at-risk group). Additional studies on prevention in adolescent populations include: an evaluation of the effectiveness of a culturally-specific intervention in increasing HIV prevention behaviors for inner city Hispanic women; and testing an intervention designed to promote safer sex practices among African American and Hispanic parenting adolescent couples. Other investigators are testing interventions to improve adherence to AIDS treatment regimens.

Suicide Prevention. NINR investigators are exploring several aspects of suicide prevention, including validating a comprehensive measure of suicide potential for adolescents, testing the longitudinal effects of a preventive intervention program for suicide-vulnerable youth and their parents, and testing a suicide prevention program specifically designed for rural Native American adolescents (a particularly vulnerable group). Suicide is a leading cause of death among youth aged 15 to 19 years, and these studies will increase our understanding of behavioral and social risk factors, as well as appropriate interventions.

Childhood Conduct Disorders. To address the increasing problem of children's behavioral and conduct problems, NINR-supported researchers are testing comprehensive community or school-based intervention programs for a variety of populations. The studies include testing an intervention program for families with school-aged children with oppositional defiance and conduct disorders, investigating the effectiveness of a comprehensive, community-based video intervention for low-income minority parents and daycare teachers of toddlers (2-3 years old) who are at increased risk for behavior problems, and determining the effectiveness of a

temperament-based, preventive intervention for inner city minority school-age children in the first and second grade.

Health Promotion and Disease Prevention. A number of NINR investigators are exploring the behavioral antecedents of effective health promotion and disease prevention. Examples include: identifying determinants of health promoting behaviors among adolescents; testing a smoking prevention/cessation program for employed adolescents; testing a nurse-managed, lay-led tobacco cessation intervention in rural Appalachia; and testing the effectiveness of a home-based, moderate intensity walking program in improving physical fitness and exercise behavior for midlife women. In addition, NINR supports two Core Centers grants focused on expanding interdisciplinary research in the area of health promotion and risk reduction in special populations, such as racial and minority groups, women and children, people living in poverty, and those with disabilities.

Behavioral Interventions to Manage Symptoms. NINR supports many investigators seeking to determine effective behavioral interventions to manage symptoms of chronic illness, for patients and their families/caregivers. One investigator has found an Arthritis Self-Management Program for Spanish-speaking populations is effective in improving exercise and general health, and decreasing pain and disability. The PI is currently expanding this intervention to three other chronic disease populations. Another study found that an intensive intervention plus coping skills training improved quality of life and metabolic control for diabetic youth aged 13-20. The PI is continuing this work to determine sustainability of the outcomes over a longer period of time, and the effectiveness of this intervention in pre-adolescents. Several studies focus on the assessment and management of pain in a variety of populations, including determining how sex hormones mediate gender differences in pain relief and developing tools to objectively assess pain in infants and nonverbal children. Other studies include testing a home-based nursing intervention targeting inner-city children with asthma, and exploring the symptoms of fatigue, pain, and sleep disturbances during radiation therapy for oncology outpatients; and testing behavioral interventions to reduce urinary incontinence.

## **19. National Library of Medicine (NLM)**

NLM believes that access to health-related information can have important health benefits, and that research into ways of improving information access for health care providers, patients, and families can have a positive impact on health behaviors.

NLM has historically focused its services and products on an audience of health professionals and biomedical scientists. With widespread deployment of computers and telecommunications, NLM is providing access to health information that is useful both to the general public and to practitioners who need information outside their particular field of expertise. The managed care environment is pushing members of the public to take responsibility for their health by becoming well-informed patients. Increasingly members of the public and health professionals turn to the Internet for information, where there are already thousands of health-related Web sites, including many with inaccurate, out-of-date, or misleading information. As the world's largest medical library, NLM has a responsibility to develop technologies and information systems that meet the public's interest in accurate, current, and understandable health information. NLM is partnering

with federal agencies, voluntary health organizations, and others to identify gaps, arrange for development of understandable content, and help the public make effective use of electronic health information. NLM will also promote research on ways that information services can improve personal health care decisions and outcomes.

To serve these new users more effectively, in 1998, NLM launched the MEDLINEplus web site (<http://medlineplus.gov/>), which provides access to a rich array of full-text consumer health information on major diseases and conditions in addition to pre-formulated MEDLINE searches. MEDLINEplus is for anyone with a medical question. Both health professionals and consumers can depend on it for accurate, current, medical information. This service provides access to extensive information about specific diseases and conditions and also has links to consumer health information from the National Institutes of Health, clearinghouses, dictionaries, lists of hospitals and physicians, health information in Spanish and other languages, and clinical trials. MEDLINEplus is being improved based on user feedback, advice from expert advisory panels, and usability testing. NLM has also created an easy-to-use database containing information about clinical trials (both Federal and non-Federal) for experimental treatments for serious diseases and conditions (<http://clinicaltrials.gov/>).

## **20. Warren Grant Magnuson Clinical Center (CC)**

The mission of the Warren Grant Magnuson Clinical Center at the National Institutes of Health (Clinical Center) is to provide the patient care, services, environment, and training to support the clinical research conducted by the NIH intramural program. Clinical Center investigators contribute to the intramural research portfolio through the conduct of independent research and as collaborators on Institute clinical research protocols.

The Clinical Center supports a wide breadth of behavioral health and social science research projects. The Pharmacy Department, in collaboration with the National Institute of Diabetes, Digestive and Kidney Disorders, supports several studies assessing patients' appraisals and perceptions of post-transplant functioning and satisfaction using a variety of quality of life measures. Clinical Center Nursing Department investigators are evaluating the quality of life of patients with HIV/AIDS, melanoma, and in patients undergoing non-myeloablative allogeneic peripheral blood stem cell transplants. The Nursing Department also supports a study assessing behavioral responses of demented patients to invasive diagnostic testing. The impact of educational and support groups on the quality of life of thyroid cancer patients is the focus of a study conducted by the Social Work Department in the CC. The Rehabilitation Medicine Department supports research protocols designed to correlate the physiological and psychological components of fatigue, the individual's perception of fatigue with performance and to validate a battery of self-administered assessment tools. Another study initiated by the Rehabilitation Medicine Department evaluates the coping responses of patients with chronic disease and disability.

The Clinical Center Clinical Bioethics Program has several research protocols that assess a broad range of behavioral health and social science issues. These research initiatives include: a) a study that queries Medicare beneficiaries and patients at risk for Alzheimer's disease about their willingness to participate in clinical research, their attitudes about research with stored tissue,

and their attitudes about the use of research advance directives; b) a survey of Organ Procurement Organizations regarding policies about harvesting organs of patients with living wills or other advance directives, or when there is conflict between the dead patient's family and the patient's previously expressed wishes; and c) a study of international research professionals to determine views on various ethical issues associated with international research and the impact of U.S. regulations on human subjects research.

## **21. National Center for Complementary and Alternative Medicine (NCCAM)**

NCCAM is dedicated to exploring complementary and alternative (CAM) healing practices in the context of rigorous science; educating and training CAM researchers; and disseminating authoritative information to the public and professionals. Consistent with this mission, NCCAM supports studies in five primary areas that have a varying degree of overlap with conventional medical research. These five CAM domains are: alternative medical systems; biologically based therapies; manipulative and body-based methods; mind-body medicine; and energy therapies. Because the behavioral and social sciences are widely studied within the context of conventional medical research, they are represented to only a limited extent within the NCCAM research portfolio. As such, NCCAM supports behavioral and social science studies when a CAM modality is under evaluation, or when an otherwise conventional modality is employed for an unorthodox purpose. These studies fall primarily within the domains of mind-body medicine, energy therapies, and biologically based therapies. NCCAM-supported research in behavioral and social science research includes those in which the disease (e.g., depression) or outcome (e.g., stress reduction, quality of life) is associated with some health behavior regardless of the type of intervention, as well as those studies in which the intervention itself is considered behavioral (e.g., meditation, imagery, etc.), regardless of the disease or outcome.

## **22. National Center for Research Resources (NCRR)**

The National Center for Research Resources (NCRR) supports health and behavior research through its funding of multidisciplinary resources for PHS-supported researchers. These resources include sophisticated instrumentation and technology, appropriate animal and non-animal models, flexible support mechanisms to handle emerging scientific opportunities, highly trained staff, and cost-effective clinical settings for translating research findings to the patient. This broad range of NCRR-supported resources permits the integration of behavioral and biological approaches into basic and clinical investigations.

The NCRR contributes a significant portion of its budget to health and behavior research. Shifts in the Center's resources and funding are driven by the demands of PHS-sponsored investigators. Thus, the NCRR's future directions will be influenced by forthcoming activities undertaken by other NIH and PHS components to meet the goals of *Healthy People 2010*, and other NIH initiatives such as, health disparities research.

Described below are the four NCRR areas highlighting key Biomedical Technology, Clinical Research, Comparative Medicine and Research Infrastructure areas of research resource support related to health and behavior. To continue the current level of support for these initiatives and

for the rest of the NCRR's broad-based support for resources for health and behavior research, the Center's budget levels are projected to grow.

A number of NCRR activities aim to reduce health disparities among women, minorities, and people of low socioeconomic status. These efforts are supported through the Research Infrastructure and Clinical Research areas and include the recruitment of these populations into clinical trials and supporting surveillance and intervention programs to promote behavior changes that improve health. Better representation of underserved populations in clinical trials, especially AIDS, clinical trials, is being sought through collaborative efforts of two NCRR programs: the Research Centers in Minority Institutions Program and the General Clinical Research Centers Program. In addition, primarily through these two networks of centers, the NCRR supports research on lifestyle choices and risk factor interactions for a range of diseases, including AIDS, studies on ways to improve adherence to treatment regimens, and programs to prevent unintended pregnancies and the transmission of sexually transmitted diseases.

Through support of Comparative Medicine research, which involves nonhuman primates, a wealth of knowledge has been gained about the acquisition of language and the cognitive abilities underlying learning and memory. The NCRR's Regional Primate Research Centers Program will continue comparative biobehavioral studies on a range of topics, many of which correlate directly to improvements in the teaching of language and cognitive skills to severely and profoundly mentally retarded children and young adults. Examples of research topics include defining the requisites to language, counting, and complex learning, new methods of assessing speech comprehension, imitation learning models, and the neurobehavioral and cognitive factors associated with the development of symbol-based communication skills.

Behavioral factors play a critical role in health and effective functioning. The Biomedical Technology area provides opportunities to explore the individual differences in brain structure, particularly in the elderly, through research using noninvasive techniques for brain imaging. Imaging and spectroscopy for mapping brain function, blood flow, and metabolism are included in research using magnetic resonance and multimodality imaging. Further development of these techniques will allow refined analysis of brain structure and activity to permit correlation with behavioral, cognitive, sensory, or other measures of brain function. Future opportunities could include uses for monitoring various disease states as well as the effects of drugs and other interventions on outcome.

An example of how the NCRR supports behavioral research is the influence of behavior on depression and hypertension. Studies are designed to determine the relationship of serotonergic dysfunction, cognitive dysfunction, the role of estrogen and stress, exercise training, corticosteroid dysregulation, and glucocorticoid feedback effects on ATCH secretion in depressed patients. Additional studies examine the effect of depression on coronary heart disease, and the effect of early adverse life events, and exaggerated platelet reactivity in major depression. Researchers are studying the effect of behavior and exercise on hypertension, and the biomechanics of blood pressure regulation. All four NCRR areas contribute to this research.

### **23. John E. Fogarty International Center (FIC)**

Since 1968, the Fogarty International Center (FIC) for Advanced Study in the Health Sciences has supported international cooperation, extramural research, and research training in the behavioral and biomedical sciences to reduce disparities in global health. FIC programs promote the identification of causal agents for health disparities in the U.S. and abroad through the establishment of international collaborative partnerships, infrastructure development, and research capacity building. Behavior, genetic and environmental factors, nutrition, access to health education and services, and other factors are all key contributors to disparities in health among groups, and are therefore of primary concern to FIC.

Behavioral and social science research is supported by FIC through a range of funding mechanisms, including institutional training grants; cooperative agreements, small research grants, fellowships, and increasing participation and leadership in inter-institute activities dedicated to these areas.

FIC has broadened its staff with behavioral and social science expertise so that it might successfully marshal the new programs that include significant efforts in these areas. These new programs address the following principal areas of concern globally:

- HIV/AIDS prevention and behavioral components of HIV transmission;
- Substance abuse patterns;
- Mental health;
- Behavioral intervention design and evaluation;
- Maternal, reproductive, and child health;
- Risk factors leading to comorbidity;
- Health consequences of demographic change; and
- Economic and social ramifications of poor health status.

Plans are also underway to expand the FIC portfolio to include three new programs that will include support for behavioral and social science, one to examine the impact of health status and health behaviors on economic productivity; another to support clinical, operational and health services research in the area of mental health; and one to examine the links between health behavior and social and health ramifications of tobacco use. These efforts are discussed in greater detail below.

#### ***Training and Research Capacity Building Programs***

FIC programs universally demonstrate a commitment to research capacity building in developing countries. FIC training programs, which operate primarily through U.S. institutions, encourage infrastructure development in the trainee's home country, and to this end provide re-entry grants to trainees upon their return home. FIC provides short-, medium-, and long-term training, career development, and scientific capacity building opportunities for researchers in behavioral and social sciences through the following programs:

Since its inception in 1988, the *AIDS International Training and Research Program (AITRP)* has provided opportunities for behavioral and biomedical researchers from developing countries to obtain training for the express purpose of combating the global HIV/AIDS epidemic. Research training supported through the AITRP program includes risk factor identification for HIV/AIDS, intervention development directed at prevention of STDs in a variety of age cohorts and ethnic populations, vaccine preparedness, design of blood safety strategies, research on care-seeking behaviors, epidemiology and prevention of maternal-to-child transmission, and co-morbidity studies (including identification of those risk behaviors underlying co-morbidity). The focus of the AITRP program is multidisciplinary intervention-oriented research, integrating biomedical and behavioral approaches.

The *International Training and Research in Population and Health (ITRPH) Program* provides an opportunity for developing country scientists to explore the demographic processes of aging, longevity, biodemography, mortality, morbidity, fertility, migration, linkages between health and economic development, and other social, behavioral, and economic factors that influence population dynamics. Current programs are involved in census analysis throughout the African continent, determination of the social and cultural factors involved in fertility, health in populations under stress, assessment of well-being among the elderly, and the demographic and health consequences of migration.

The *International Maternal and Child Health Research Training (IMCHRT) Program* was initiated by FIC in 1999 as a collaborative effort with NICHD to increase research capacity in maternal, perinatal, and early childhood health, especially in developing countries. Current behavioral and social science research training areas being addressed by participants in this program include social consequences of HIV/AIDS, and nutritional interventions to improve maternal and child health. Trainees also engage in research to assess cultural, socioeconomic, and infrastructural barriers to appropriate medical attention and maternal/child care, as well as to identify the social and cultural determinants of health-related behaviors affecting fertility, pregnancy, and maternal/child health outcomes, such as breastfeeding and sexual practices.

In an effort to increase research capacity for maternal and child health research in developing countries, FIC is supporting an NICHD initiative to develop a Global Network for Women's and Children's Health Research through an expansion of the IMCHRT program, described in more detail in the section on program growth below.

### ***Research Grant Programs***

FIC provides training, career development, and scientific capacity building opportunities for researchers in behavioral and social sciences through the following grant programs:

Small grants offered through the *Fogarty International Research Collaboration Awards (FIRCA) Program* provide an opportunity for U.S. behavioral and social scientists to undertake collaborative research with foreign collaborators seeking to improve their research capacity. Research projects in this program include studies examining the effects of alcohol and drug abuse on neurotransmission and brain chemistry, mental health and basic neuroscience research to elucidate the causality of and inform treatment of developmental disorders like dyslexia,

studies examining the effects of substance abuse on neurological response, and research on behaviors that affect transmission of vector-borne diseases.

A substantial proportion of the investigators receiving small grants through the *AIDS-FIRCA Program* focus on elucidating behavioral factors in the transmission, prevention, and management of HIV/AIDS. Their research addresses topics including, but not limited to, the links between HIV risk behaviors and drug use, the impact of behavior on HHV-8 transmission in communities, and risk factors for and comorbidity patterns of HIV with other infectious diseases. The program also supports behavioral interventions to reduce the risk of contracting HIV/AIDS, especially among adolescent cohorts in Africa and Latin America.

### ***FIC Program Growth and Development in Behavioral and Social Sciences***

Scheduled for funding in FY 2001, a new *International Studies in Health and Economic Development (ISHED) Program* will support research to further examine the complex relationship between health and economic growth in low- and middle-income nations. Although it is widely accepted that better education can lead to improved economic performance, the relationship between better health and the alleviation of poverty has not been fully explored in low- and middle-income countries. The program's long-term objectives will utilize psychosocial assessments, socioeconomic surveys, demographic datasets, behavioral interventions, and social science methodologies to determine the extent to which population health status and mental health status serve as predictive indicators of economic performance and productivity at the macro- and microeconomic level. Focal areas of research may include the relationship of early child development to adult productivity, behavior changes and social policy shifts to accommodate the needs of a growing elderly population worldwide, the impact of nutrition on later work performance, and research investigating the impact and optimal mix of private and public health funding on health outcomes and productivity.

Scheduled for funding in FY 2001, the *International Clinical, Operational and Health Services Research and Training Award (ICOHRTA)* is another new FIC program to support collaborative, multidisciplinary, international clinical, operational, health services and prevention science research training between U.S. institutions and those in both developing countries and emerging democracies of Eastern Europe, Russia, and the Newly Independent States (NIS). Eligible topics include all clinical, operational, health services and prevention science research areas supported by or relevant to the participating NIH institutes (including mental health/neuropsychiatric disorders, drug abuse/addiction, aging-related and dental/craniofacial-related diseases and disorders and complementary and alternative medicine).

FIC is in the process of initiating an *International Tobacco and Health Research and Capacity Building Program* to address the urgent need for a public health response to the alarming increase in global tobacco consumption, and in recognition of the anticipated catastrophic physical, economic, political, and social burden of disease stemming from tobacco use, especially in low- and middle-income countries. This program will foster transdisciplinary behavioral and epidemiological research, training, and interventions to increase the body of available data on tobacco use. Anticipated categories of research include, but are not limited to, behavioral surveys on incentives and disincentives for tobacco use and cessation, gender and age

differences in such use patterns, identification of high-risk individuals and groups, intervention effectiveness evaluations, comorbidity associated with tobacco use, studies investigating the links between mental illness and smoking behaviors, and approaches to link smoking with abuse of other substances and engagement in risk-taking behavior. FIC plans to initiate this new program in early FY 2002.

### ***Inter-Institute Collaborative Efforts in Behavioral and Social Sciences***

In an effort to stimulate international research and training capacity building in maternal and child health research, FIC is supporting a collaborative NICHD effort to develop a *Global Network for Women's and Children's Health Research*. This Global Network has as its core a maternal and child health research program funded by NICHD and features a Data Center component for sharing of research findings among network participants. The FIC International Maternal and Child Health Research Training (IMCHRT) Program mentioned above serves as the training arm of this global network to complement research projects funded by NICHD. The FIC IMCHRT Program was simultaneously competed with the NICHD program in FY 2000 for funding in FY 2001.

Having historically occupied a position at the forefront of HIV/AIDS research and prevention, FIC is a partner with NIDA in its efforts to establish a *Global Research Network on HIV Prevention in Drug-Using Populations*. This international research forum to facilitate rapid international exchange of information on HIV patterns and trends in drug-using populations was established in 1998 with the support of UNAIDS and WHO.

FIC is part of a trans-NIH consortium, led by NIAID, that in 1998 established the *HIV Prevention Trials Network (HPTN)*, as a collaborative effort to create a clinical trials network for the prevention of HIV/AIDS. The HPTN invites behavioral scientists involved in HIV/AIDS research to participate in multidisciplinary study teams with clinical, epidemiological, laboratory, operations, and statistical researchers, to evaluate a broad range of HIV prevention strategies and behavioral interventions, and to conduct cross-cultural comparisons among different host and viral populations. FIC has also participated in the development of the *Vaccine Trials Network (VTN)*, an initiative also headed by NIAID to complement the HPTN. The VTN is intended to be a coordinated, global framework encouraging clinical vaccine research and the dissemination of research findings.

FIC also worked with NIMH to develop a global community-level HIV/STD prevention program—the *Popular Opinion Leader Program*—to explore the diffusion of innovations and information about health interventions utilizing community Popular Opinion Leaders (C-POLS). This program engages C-POLS to serve as behavior change agents to friends and neighbors in their community. The intervention is expected to strengthen norms about safer sexual behavior and encourage risk reduction among at-risk populations.

FIC, in partnership with other NIH ICs and U.S. agencies, is planning a conference on Stigma and Global Health to be held in the fall of 2001. It is anticipated that the conference will examine gaps in research and knowledge on stigma as it relates to health status. The behavioral underpinnings of stigma and how these are expressed for different diseases and in different

cultural and geographic settings will be explored, among other issues. It is expected that the results of the conference would inform an RFA in FY 2002 to address the research needs in this field.

#### IV. Conclusion

The creation by OBSSR of a working definition of behavioral and social sciences research, the consistent (although still improving) application of this definition by the Institutes and Centers, and the annual budget reporting by the NIH Office of Budget are all factors that contribute to a better assessment of the role of behavioral and social sciences research in accomplishing the NIH mission. Although the amount of funding of behavioral and social sciences has varied across the Institutes and Centers, most show a steady increase since FY 1996. NIH funding of behavioral and social sciences research totaled \$1,850,000,000 in FY 2000.

To ensure that behavioral and social sciences research continues to play a critical role in fulfilling the NIH mission, OBSSR asked the National Research Council to develop a research plan to guide NIH in supporting areas of high priority in the behavioral and social sciences. The resulting committee met four times between May 1999 and February 2000 and issued its report in January 2001 (Burton H. Singer and Carol D. Ryff (eds.), *New Horizons in Health: An Integrative Approach. Committee on Future Directions for Behavioral and Social Sciences Research at the National Institutes of Health.* Washington, DC: [National Academy Press](#), 2001). This report identifies a broad domain of questions at the interface of social, behavioral, and biomedical sciences whose resolution could lead to major improvements in the health of the US population. The committee also emphasized research priorities that cut across Institute boundaries at NIH, thereby underscoring the broad significance of behavioral and social science research for multiple disease outcomes as well as health promotion. The 10 recommended priority areas for research investment to integrate the behavioral, social and biomedical sciences at NIH are:

1. **Predisease Pathways:** identify early and long-term biological, behavioral, psychological, and social precursors to disease;
2. **Positive Health:** identify biological, behavioral, and psychosocial factors that contribute to resilience, disease resistance, and wellness;
3. **Gene Expression:** understand environmentally induced gene expression and its connection to positive and negative health outcomes;
4. **Personal Ties:** explicate the mechanisms by which proximal social interactions influence health and disease outcomes;
5. **Healthy Communities:** identify the collective properties of social and physical environments that influence health and disease outcomes;
6. **Inequality:** clarify the mechanisms through which socioeconomic hierarchies, racism, discrimination, and stigmatization influence health and disease outcomes;
7. **Population Health:** understand macro-level trends in health status and evaluate the performance of the health care system;
8. **Interventions:** expand the scope and effectiveness of strategies for social and behavioral interventions to improve health;

9. **Methodology:** develop new measurement techniques and study designs to link information across levels of analysis (molecular, cellular, behavioral, psychosocial, community) and across time; and

10. **Infrastructure:** establish ways to maintain long-term study populations and to train scientists to integrate health-related knowledge across multiple disciplines.

NIH, under the leadership of OBSSR, is currently considering how to implement these recommendations.