CAHT-BSSR

Coalition for the Advancement of Health Through Behavioral and Social Science Research

Testimony

submitted for the record

regarding the

FY 2002 Appropriations

for the

National Institutes of Health

Labor, Health and Human Services, Education and Related Agencies Subcommittee

Committee on Appropriations

U.S. House of Representatives

The Honorable Ralph Regula, Chair

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Angela L. Sharpe, MG
Consortium of Social Science Associations
1522 K Street, NW, Suite 836
Washington, DC, 20005
Tel: 202/842-3525 Fax: 202/842-2788

Pat Kobor
American Psychological Association
750 First Street, NE
Washington, DC 20002
Tel: 202/336-5933 Fax: 202/336-6063

Mr. Chairman and Members of the Subcommittee, the Coalition for the Advancement of Health Through Behavioral and Social Science Research (CAHT-BSSR) appreciates and welcomes the opportunity to comment on the Fiscal Year (FY) 2002 appropriations for the National Institutes of Health. CAHT-BSSR includes 19 professional associations, scientific societies, coalitions, and research institutions concerned with the promotion of and funding for research in the social and behavioral sciences. Collectively, we represent more than 120 professional associations, scientific societies, universities, and research institutions.

We would like to welcome you, Mr. Chairman, to the Subcommittee. We look forward to working with you and to your leadership. It is important that Congress, with the guidance of this Subcommittee, continue to invest in the promise of health-related research that transcends political and regional boundaries.

The National Institutes of Health (NIH)

On behalf of the social and behavioral science community, CAHT-BSSR thanks the Subcommittee for its increasing support of social and behavioral science research at the NIH, especially that which falls under the rubric of "health and behavior" research. Mr. Chairman, we are standing at the threshold of an exciting new era of health-related progress, particularly in the social and behavioral sciences. Opportunities for creating sustainable interventions and prevention programs targeting the leading causes of death and disability in our society have never been greater. Despite the significant funding increases provided to the NIH, biomedical and behavioral research opportunities still outpace available funding. **Accordingly, CAHT-BSSR strongly recommends an appropriation of $23.7 billion for the NIH in FY 2002. This will maintain progress toward the goal of doubling NIH's budget.**

Mr. Chairman, six of the ten leading causes of death in the United States are behaviorally based, including HIV/AIDS, smoking, violence, accidents, diet, and substance abuse. Other behavioral factors are now known to increase individuals' risk for disease, disability and early death: obesity, physical inactivity, inadequate social support, environmental contaminates, anxiety, and traits of anger, hostility or depression. Individual behavior is important to health, though, it must not be the only focus to solving our complex problems. Social and economic factors — racial/ethnic status, gender, age, income, education, cultural orientation, and community — also have important effects on health.

CAHT-BSSR strongly believes that social and behavioral science research is critical to America's quest to promote health, prevent disease, and provide quality treatment. This research provides knowledge about the social, cultural, and economic environments that influence human health and behavior and the means by which these environments exert their influence. As you are undoubtedly aware, over the past decade significant advances have been made in uncovering the biological and genetic basis for specific diseases and condition. Yet, despite the impressive scientific gains, it is becoming increasingly apparent that knowledge about biological and genetic markers are important but limited in predicting who gets sick, who seeks treatment for their health problems, and who recovers from illness. Social and behavioral science contributes to filling these gaps in our understanding of health.

As noted in a draft report based primarily on the recommendations formulated by scientists participating in a conference sponsored by the NIH Office of Behavioral and Social Sciences Research, *Towards Higher Levels of Analysis: Progress and Research on the Social and Cultural Dimensions of Health* — "An understanding of current and changing population rates of morbidity, survival, mortality, and use of health services requires that we consider the demographic, social, economic, and cultural structure dynamics of the population as well as its genetic composition and exposure to infectious agents."

NIH Office of Behavioral and Social Sciences Research. NIH's Office of Behavioral and Social Sciences Research (OBSSR), under the auspices of its former Director Norman B. Anderson and its current Director Raynard Kington, has made significant progress in increasing the visibility and stature of social and behavioral science research at NIH. Created by Congress in recognition of the substantial influence of social and behavioral factors on health, OBSSR is congressionally mandated to foster the development of cross disciplinary communication and research collaboration among social and behavioral sciences and between social and behavioral sciences and biomedical sciences.

Unfortunately, since its inception in 1995, the OBSSR has been operating with a very small staff and budget. Despite its small budget, however, the OBSSR has very effectively served as a point of coordination for crosscutting NIH initiatives. CAHT-BSSR believes that the Office has the potential to accomplish much more with the continued support of the Congress and the necessary resources.

At NIH, the OBSSR plays a leadership role in developing ideas for initiatives, and in gaining support for them within the NIH Institutes. While the Office does not have grantmaking authority, it has been active in organizing trans-NIH and trans-agency Requests for Applications (RFAs) and Program Announcements (PAs). Through the sponsorship and organization of conferences, workshops, lectures and planning groups, OBSSR works with NIH Institutes and Offices, as well as with outside organizations, to determine priorities for behavioral and social sciences research. In FY 2001, OBSSR's contributions to the NIH mission include the organization of two RFAs and the convening of a major NIH conference:

- Interpersonal violence has become endemic and constitutes a major public health problem for all Americans, with consequences that include severe psychological and social dysfunction as well as injury and death. Moreover, children and adolescents appear to be disproportionately at greater risk than others for violence perpetration and/or victimization. There continues to be a need for a richer understanding of the social, environmental, psychological, developmental, and biological factors involved in risk as well as a deeper understanding of how these factors interact. The OBSSR, along with NIAAA, NICHD, NIDA, and NIMH, collaborated to develop an RFA ("Research on the Development of Interventions for Youth Violence") to solicit research proposals that explore the translation of ideas from basic behavioral and social science research into novel interventions for children and youth demonstrating or at risk for violent behavior.

- Understanding and improving adherence to treatment is critical to all of NIH, and involves multiple levels of analysis — from patient, to the provider, to the context in which the adherence to a treatment must occur. Joining 12 NIH Institutes — NCI, NHGRI, NHLBI, NIA, NIAAA, NIAMS, NICHD, NIDCR, NIDDK, NIDA, NIMH and NINR — OBSSR initiated, coordinated, and released a call for research on "Testing Interventions to Improve Adherence to Pharmacological Treatment Regimens."

- Advancing our understanding of the role of the social environment in health requires a new commitment. Factors related to the social environment including socioeconomic status, race, gender and place have an impact on the distribution of disease and death. In June 2000, the OBSSR, in collaboration with ten Institutes, sponsored the first NIH-wide conference — ***Toward Higher Levels of Analysis: Progress and Promise in Research on Social and Cultural Dimensions of Health*** — on the role that social and cultural factors play in health and disease. The conference drew more than 800 scientists representing multiple disciplines. OBSSR is working to implement the research agenda that came out of the conference.

Future Directions for OBSSR. The OBSSR's current budget is $20.65 million. ***CAHT-BSSR supports an appropriation of $23.75 million for OBSSR in FY 2002, an increase of 15 percent***. A 15 percent increase would enhance the OBSSR's ability to continue coordinating social and behavioral research across the NIH. Such an increase would allow the Office to implement the recommendations in the National Research Council's (NRC) report, ***New Horizons in Health: An Integrative Approach,*** a research plan designed to guide OBSSR and the NIH in supporting areas of high priority in the social and behavioral sciences. The 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 U.S. population." It identifies research priorities that cut across Institute domains, underscoring the broad significance of social and behavioral science research for multiple disease outcomes as well as health promotion. Ten priority areas for research investment are recommended: predisease pathways, positive health, gene expression, personal ties, health communities, inequality, population health, interventions, methodology, and infrastructure.

One of several new initiatives that OBSSR hopes to pursue with increased funds is coordinating a program of research that will help determine what aspects of education lead to increased health. We know from research that education has an almost direct relationship to health: the more educated a person is, the better his or her health status. What exactly is it about education that leads to better health? Is it that educated people are better able to assess risk, or that they more often read food and medicine labels? Knowing in a more precise way how education leads to better health would have huge economic and human benefits for our nation. OBSSR plans to bring together experts in various fields to learn how best to study this issue, and to provide seed money for a comprehensive research program.

Another new initiative that the Office hopes to pursue is organizing a research program that will examine how the workplace influences employee health. It is well known that the costs associated with employee illness is a significant expense for employers. These costs come in the form of increased absenteeism, turnover, and health benefit claims. Likewise, the costs due to illness affect employees and their families. To help drive down these costs, a number of employers have instituted workplace health promotion programs (e.g., physical exercise, diet and smoking cessation). Because these behaviors represent only one set of factors affecting health, the approach is limited in its ability to improve the health of the overall workforce. While factors such as work and family conflict and job control are receiving attention in some workplaces, there are many other factors that need to be considered. OBSSR proposes consideration of the full range of determinants of health (e.g., participation and control over jobs, flexible/non flexible terms of employment, employee ownership, and social support, and others) that have enormous potential and consequences, both economic and human.

Aging. The U.S. is in the midst of a longevity revolution. Increased life span and the aging of the baby boom generation present unique challenges to health over the next several decades. As more of the U.S. population ages — the number of Americans ages 65 and older is expected to double by 2030 to nearly 68 million — it becomes increasingly vital to the health of our entire society that we age well. Many of the problems that can accompany aging, especially chronic diseases, stem from behaviors and environments that place individuals at risk of negative health outcomes. **National Institute on Aging (NIA)**- supported research has shown that lifestyle and other environmental influences can profoundly impact outcomes of aging, and that remaining healthy and emotionally vital until advance ages is a realistic expectation. CAHT-BSSR strongly believes that there continues to be a need for social and behavioral science research to develop, maintain, and/or enhance the health and well-being, both physical and cognitive functions, of older individuals throughout the life span.

Health Disparities. Among minority populations in the U.S., health disparities have remained persistent and have, in some cases, increased. Expected demographic changes magnify the importance of addressing disparities in health status. Beyond the need to monitor changes in the health status of different racial and ethnic groups, there is a need to understand the causal factors underlying these differences which include: genetic factors, socioeconomic position, health risk behaviors, and psychosocial factors (e.g., stress, access to health care, and environmental and occupational risk factors). Research has revealed a well-documented relationship between socioeconomic status, health, and longevity. People with higher incomes and greater wealth tend to be healthier and live longer. The causes of this relationship, however, are unknown. To aid in understanding causal links between health and wealth, additional social and behavioral research is needed, including the support of more economics measures in future clinical trials to allow scientists to assess the impact of economic status on health, and vice versa.

AIDS. The HIV/AIDS epidemic in the U.S. continues to evolve. While the incidence of new AIDS cases has declined, HIV infection rates are continuing to climb in a number of population groups (e.g., women, racial and ethnic minorities, young homosexual men, people older than 50 years of age, and individuals with additive disorders). African Americans and Hispanics accounted for 45 percent and 20 percent, respectively, of newly diagnosed AIDS cases in 1998. Research has shown that behavioral change can successfully prevent or reduce the spread of HIV/AIDS. A better

understanding, however, is needed of how to actually change behavior prior to HIV transmission, including how to maintain protective behaviors once they are adopted. We are far from realizing the full potential of prevention research on a global scale. A more refined understanding of social and cultural factors that contribute to HIV risk or protection is needed.

Drug Abuse. The latest estimate of the economic burden for illegal drug use exceeds $110 billion. These costs are incurred through virtually every sector of American society. The **National Institute on Drug Abuse (NIDA)** supports a comprehensive portfolio of research into all aspects of drug abuse and addition. Despite NIDA's efforts, additional funding for new research is needed to ensure that our current drug prevention efforts are responsive to all populations and to differences in the needs and responses of audiences that often vary in gender, ethnicity, and age. Mr. Chairman, prevention research is vitally important, given that the greatest risk for initiating drug use occurs during adolescence.

Alcohol Use and Abuse. It now estimated that alcohol use and abuse costs the nation $185 billion annually. According to the **National Institute on Alcohol Abuse and Alcoholism (NIAAA**), about 14 million adult Americans have an alcohol-use disorder. Unfortunately, children also suffer from these disorders — 23 percent of 14- to 18-year-olds interviewed in a state survey reported having had at least one clinically diagnosable symptom of alcohol abuse or dependence during their lifetime. Even worse, among college-age youth, alcohol abuse is epidemic. How to reduce drinking among young people is a complex and urgent issue, one that needs to be addressed by social and behavioral science research. The problem spans a range of issues, from policymaking to mental and physical health. NIAAA-supported research has identified gaps in the available data on college drinking. The Institute is planning to expand its research in this area. Such an expansion would better inform the design of interventions. Additionally, the Institute should be commended for its assemblage of college and university presidents with scientists to assess the problem of college drinking and to develop and disseminate strategies for preventing it.

Diabetes. Sixteen million Americans have diabetes, and another five million are undiagnosed. Both type 1 and type 2 diabetes requires careful self-management and both can lead to acute and chronic complications compromising health and quality of life. Type 2 diabetes, which is more prevalent, occurs predominantly in adults age 40 and older. Over the last 10 years, however, children and adolescents are increasingly susceptible to type 2 diabetes. This trend is particularly evident in racial and ethnic minority groups, especially African Americans and American Indians. Diabetes and its impact on metabolic control, personal lifestyles, work productivity, the society as a whole, and health care costs underscore the need to develop more efficacious and effective diabetes self management interventions. All age, socioeconomic, and ethnic groups are affected.

Translational and patient-oriented research on self-management and adherence in diabetes are needed. Further, research is required that addresses the factors related to the degree of success with sustained intensive self-management (e.g., coping styles, social support strategies/systems, personality dispositions, the burden of care, stress, impact on quality of life, economic considerations, and health outcomes). Research is also needed on intervention strategies that examines the cultural, ethnic, lifestyle, and age-related factors and on strategies that promote quality of life and eases the psychosocial burden of diabetes on individuals and their families.

Mental Health and Depression. According to the World Health Organization's "Global Burden of Disease" study, mental disorders represent four of the ten leading causes of disability for individuals age five and older. In the U.S., as well as other "developed" nations, major depression is the leading cause of disability. As noted by the **National Institute of Mental Health (NIMH)**, mental disorders are "tragic contributors to mortality, with suicide perennially representing one of the leading preventable causes of death in the U.S. and worldwide." Mental disorders, which often strike early in life, during childhood, adolescence or early adulthood, are profoundly destructive to individuals and the well being of families. These diseases cause immeasurable human suffering. The current social and economic burden of mental illness in America is estimated at more than $148 billion in direct and indirect costs each year.

According to the report ***Translating Behavioral Science into Action*** by the National Advisory Mental Health Council's Behavioral Science Workgroup, behavioral science offers critical insights into the nature of mental illness and mental health, and the processes and interventions that can prevent or lead from disorder to remission, recovery, and rehabilitation. Progress in translating behavioral science advances in knowledge into meaningful advances in clinical care requires building a research environment in which collaborations across disciplines is the norm. Three specific areas of study are highlighted: 1) understanding basic behavioral processes in mental illness, 2) understanding how mental illness and their treatments affect the abilities of individuals to function in diverse settings and roles, and 3)

understanding how social or other environmental contexts influence the etiology and prevention of mental illness and the treatment and care of those suffering from mental disorders.

Cancer. The pivotal role of lifestyle and other environmental exposures as causes of cancer is reflected in the considerable variation of cancer incidences around the world and in the changes in risk observed among groups that migrate and settle in a new country. Unfortunately, substantial barriers prevent major segments of the population from seeking and/or using cancer information. New information technologies must complement, not replace, older but effective strategies, such as the mass media, one-to-one counseling, and targeted print communications. Accordingly for cancer communication to be effective it must be integrated in the cancer continuum from prevention through treatment to survivorship and to end-of-life issues. For example, effective health communications have influenced adults to increase their daily consumption of fruits and vegetables, to get screened for breast and cervical cancers, and to stop or limit their use of tobacco products.

The National Cancer Institute (NCI) has long been a leader in health communications. Yet, despite the progress that has been made, major gaps remain in our understanding of how consumers use health information. There is a need to understand how individuals distinguish important from insignificant health risks, as well as deal with contradictory or inaccurate health messages so that they can make informed choices. There is additional need to narrow the gap between what is known about cancer communication and what is practiced. Research is needed to examine the best ways to inform physicians, nurses, and other health care providers of emerging best practices in patient care.

Adolescents. The transition from childhood to adolescence is typically a volatile period characterized by dramatic changes and rapid growth. Adolescence appears to be a time of increased vulnerability to emotional disturbance or stress. CAHT-BSSR believes that is important to understand how children adjust behaviorally, socially, emotionally, and academically during this period and how this adjustment affects the health behaviors, traits, and competencies with which they enter adolescence and adulthood. Unfortunately, there has been too little comprehensive research on adolescence, especially about the transitions into and out of adolescence. While there is information about health behaviors in adulthood (e.g., smoking, diet, exercise), there is a tremendous need to learn much more about health-related behaviors during childhood and how they influence developmental as well as lifelong health outcomes. The **National Institute of Child Health and Human Development (NICHD**) strives to better understand these factors. NICHD recognizes that "if we truly wish to understand human health and behavior and devise effective, practical ways to apply basic science advances to improving human health and behavior, we must first understand the complex interplay among external, biological, and behavioral factors that results in a human being."

Conclusion. In closing, Mr. Chairman, CAHT-BSSR would like to emphasize that we are in an era when Americans' health is increasingly damaged by preventable chronic diseases. Fortunately, we are also in a period of exceptional promise in the social and behavioral sciences. Modifying behaviors and our social environments hold the key to major health benefits. Social and psychological factors — how we think, feel and behave, as well as the environment in which we live — have profound influences on health. Increasingly, our knowledge of the significance of social and behavioral factors is critical to improving the health of all Americans, as well as maintaining our economic growth. Your continued support for the social and behavioral science research programs at the NIH is vital to maintaining America's status as the world premier biomedical, social, and behavioral research leader.

We thank the Subcommittee for the opportunity to present our views.

American Anthropological Association
American Psychological Association
American Sociological Association
Consortium of Social Science Associations
Federation of Behavioral, Psychological and Cognitive Sciences
Gerontological Society of America
Institute for the Advancement of Social Work Research
National Council on Family Relations
National Mental Health Association
Society for Research in Child Development