

**Statement of the Coalition for the Advancement of Health Through Behavioral and Social Science Research (CAHT-BSSR) on FY 2008 Funding for the National Institutes of Health submitted for the record to the Subcommittee on Labor, Health and Human Services, Education and Related Agencies, Committee on Appropriations, U.S. Senate
The Honorable Tom Harkin, Chair, April 30, 2007**

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) 2008 appropriations for the National Institutes of Health (NIH). CAHT-BSSR includes 16 professional organizations, 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.

The behavioral and social sciences regularly make important contributions to the well-being of this nation. Due in large part to the behavioral and social science research sponsored by the NIH, we are now aware of the enormous contribution behavior makes to our health. At a time when genetic control over diseases is tantalizingly close but not yet possible, knowledge of the behavioral influences on health is a crucial component in the nation's battles against the leading causes of morbidity and mortality: obesity, heart disease, cancer, AIDS, diabetes, age-related illnesses, accidents, substance abuse, and mental illness. As a result of the strong Congressional commitment to the NIH in years past, our knowledge of the social and behavioral factors surrounding chronic disease health outcomes is steadily increasing. The NIH's behavioral and social science portfolio has emphasized the development of effective and sustainable interventions and prevention programs targeting those very illnesses that are the greatest threats to our health, but the work is just beginning.

To ensure that progress is sustained, the Coalition joins the Ad Hoc Group for Medical Research in supporting a FY 2008 appropriation of \$30.8 billion for the NIH, a 6.7 percent increase over FY 2007. This level of funding will provide adequate resources to sustain the momentum of the recently completed campaign to double the nation's investment in the promising research supported and conducted by the NIH. Unfortunately, the President's request does not allow us to fully reap the research opportunities that the doubling campaign have made available.

Nearly 125 million Americans are living with one or more chronic conditions, like heart disease, cancer, diabetes, kidney disease, arthritis, asthma, mental illness and Alzheimer's disease. The Centers for Medicare and Medicaid Services (CMS) recently reported that health care spending in the United States rose to \$1.6 trillion in 2002, up from \$1.4 trillion in 2001 and \$1.3 trillion in 2000. Health expenditures per person averaged \$5,440 in 2002, up from \$5,021 in 2001 and \$4,670 in 2000. Today, it is even more. Significant factors driving this increase are the aging of the U.S. population, and the rapid rise in chronic diseases, many caused or exacerbated by behavioral factors: for example, obesity, caused by sedentary behavior and poor diet; addictions and resulting health problems caused by tobacco and other drug use.

Behavioral and social sciences research supported by NIH is increasing our knowledge about the factors that underlie positive and harmful behaviors, and the context in which those behaviors occur. NIH supports behavioral and social science research throughout most of its 27 institutes and centers. Numerous reports by the National Academy of Sciences (e.g. *The Aging Mind*, *New Horizons in Health: An Integrative Approach*, and *Health and Behavior*) have presented cutting edge research agendas and made eloquent cases for the applicability of the social and behavioral scientific disciplines to the myriad, complex problems of prevention, treatment and cure of diseases as well as the enhancement of quality of life.

CAHT-BSSR supports an appropriation of \$27.8 million for NIH Office of Behavioral and Social Sciences Research, an increase of 6.7 percent, commensurate with an overall increase of 6.7 percent for the NIH. OBSSR's purpose is to serve a convening and coordinating role among the institutes and centers at NIH. The Office was authorized by Congress in the NIH Revitalization Act of 1993 and established in 1995.

As highlighted by NIH Director Elias Zerhouni on the occasion of OBSSR's 10th anniversary in June 2006, "the OBSSR has been a tremendous asset to NIH throughout its first ten years . . . we are faced with an enormous and evolving national burden of disease and disability, much of which has roots in personal behavior or socioeconomic influences. The need for behavioral and social research and intervention has never been greater, and its impact has never been clearer. We need but look at recent decreases in rates of cancer, largely due to dramatic decreases in tobacco use. We can point to a remarkable demonstration of the pronounced benefits of diet and exercise - more effective than drug therapy - in preventing the onset of type 2 diabetes among high-risk individuals. These are but two among many shining examples of the widespread benefits to public health realized through our investment in basic and applied behavioral and social science research, so critical to our understanding of health and disease.

OBSSR focuses on cross-cutting behavioral and social research issues (e.g. "Long-term Maintenance of Behavior Change") using its modest budget to seed cross-institute research initiatives. OBSSR has spurred cutting edge research in areas such as measures of community health, socioeconomic status, and new methodology development. The Office has been able to leverage substantive funding initiatives with a small budget.

In FY 2008, OBSSR plans to work with the 27 NIH Institutes and Centers (ICs) to initiate two new programs. The first program is in the area of health disparities. The ***Behavioral and Social Science Contributions to Understanding and Reducing Health Disparities*** will be designed to support trans-disciplinary research involving teams of behavioral, social, and biomedical scientists, on prevention, policy, and health care. The research program will emphasize both basic research on the behavioral, social, and biomedical pathways, giving rise to disparities in health and applied research on the development, testing, and delivery of interventions to reduce disparities in the areas of policy, prevention, and health care.

The second initiative planned by OBSSR is in the area of ***Genes, Behavior and the Social Environment***. OBSSR plans to work across the institutes and centers to consider the recommendations from the Institute of Medicine's report, *Genes, Behavior, and the Social Environment, Moving Beyond the Nature/Nurture Debate*, commissioned by OBSSR, along with the National Institute of General Medical Sciences (NIGMS) and the National Human Genome Research Institute (NHGRI). The report identifies gaps in knowledge and barriers that hamper the integration of social, behavioral, and genetic research.

The IOM panel recognized "that understanding the association between health and interactions among social, behavioral, and genetic factors require research that embraces the systems view and includes an examination of the interactive pathways through which these fields operate to affect health." Such research requires the participation of scientific investigators from a variety of fields and a shift in focus from efforts that are dominated by single disciplines to research that involves collaborative participation of scientists from various expertise at all stages of the research process. Below are the IOM's 14 recommendations.

- 1. Conduct Trans-disciplinary, Collaborative Research.** The NIH should develop Requests for Applications (RFAs) to study the impact on health of interactions among social, behavioral, and genetic factors and their interactive pathways (i.e., physiological).
- 2. Measure Key Variables Over the Life Course and Within the Context of Culture.** NIH should develop RFAs for studies of interactions that incorporate measurement, over the life course and within the context of culture, of key variables in the important domains of social, behavioral, and genetic factors.
- 3. Develop and Implement New Modeling Strategies to build more comprehensive, predictive models of etiologically heterogeneous disease.** NIH should emphasize research aimed at developing and implementing such models (e.g., pattern recognition, multivariate statistics, and systems-oriented approaches) for incorporating social, behavioral, and genetic factors, and their interactive pathways in testable models within populations, clinical settings, or animal studies.

4. Investigate Biological Signatures. Researchers should use genomic, transcriptomic, proteomic, metabolomic, and other high dimensional molecular approaches to discover new constellations of genetic factors, biomarkers, and mediating systems through which interactions with social environment and behavior influence health.

5. Conduct Research in Diverse Groups and Settings. NIH should encourage research on the impact of interactions among social, behavioral, and genetic factors and their interactive pathways on health that emphasizes diversity in groups and settings. NIH should also support efforts to ensure that the findings of such research is validated by replication in independent studies, translated to patient-oriented research, conducted and applied in the context of public health, and used to design preventive and therapeutic approaches.

6. Use Animal Models to Study Gene-Social Environment Interaction. NIH should develop RFAs that use carefully selected animal models for research on the impact on the impact of interactions among social, behavioral, and genetic factors and their interactive pathways.

7. Advance the Science of Study of Interactions. Researchers should base testing for interaction on a conceptual framework rather than simply the testing of a statistical model, and they must specify the scale (e.g., additive or multiplicative) used to evaluate whether or not interactions are present. NIH should develop RFAs for research on developing study designs that are efficient at testing interactions, including variation in interactions over time and development.

8. Expand and Enhance Training for Trans-disciplinary Researchers. NIH should use existing and modified training tools both to reach the next generation of researchers and to enhance the training of current researchers. Approaches include individual fellowships and senior fellowships, trans-disciplinary institutional grants, and short courses.

9. Enhance Existing and Develop New Datasets. NIH should support datasets that can be used by investigators to address complex levels of social, behavioral, and genetic variables and their interactive pathways. This should include enhancement of existing datasets that already provide many, but not all of the needed measures and the encouragement of their use. NIH should also develop new datasets that address specific topics that have high potential for showing genetic contribution, social variability, and behavioral contributions - topics such as obesity, diabetes, and smoking.

10. Create Incentives to Foster Trans-disciplinary Research. NIH and universities should explore ways to create incentives for the kinds of team science needed to support trans-disciplinary research.

11. Communicate with Policymakers and the Public. Researchers should 1) be mindful of public and policymakers' concerns; 2) develop mechanisms to involve and inform these constituencies; 3) avoid overstating their scientific findings; and 4) give careful consideration to the appropriate level of community involvement and the level of community oversight needed for such studies.

12. Expand the Research Focus. NIH should develop RFAs for research that elucidates how best to encourage people to engage in health -promoting behaviors that are informed by a greater understanding of these interactions; how best to effectively communicate research results to the public and other stakeholders; and how best to inform research participants about the nature of the investigation (gene-environment interactions) and the uses of data following the study.

13. Establish Data-Sharing Policies that Ensure Privacy. Institutional Review Boards and investigators should establish policies regarding the collection, sharing, and use of data that include information about: 1) whether and to what extent data will be shared; 2) the level of security to be provided by all members of the research team as well as the research and administrative process; 3) the use of state-of-the-art security

for collected data; 4) the use of formal criteria for identifying the circumstances under which individual research results will be revealed; and 5) how before sharing data with others, recipients must agree to use data in ways that are consistent with those agreed to by the research participants.

14. Improve Informed Consent Process. Researchers should ensure that informed consent includes the following: 1) descriptions of the individual and social risks and benefits of the research; 2) the identification of which individual results participants will and will not receive; 3) the definition of the procedural protections that will be provided, including access policies and scientific oversight; and 4) specific security, privacy, and confidentiality protections to protect the data and samples of research participants.

Implementing the IOM's recommendations would go a long ways towards helping to realize the ultimate goal of **personalized health care**, one of Secretary Michael Leavitt's priorities. Personalization needs to reflect genes, behaviors, and environments. Assessing behavior is critical to helping individuals see how they can improve their health. It is also critical to helping health care see where it needs to put resources for behavior change. As noted by Dr. Zerhouni, "Right now, everyone is focused on finding the magic answer. But health care is different from region to region across the country." Full personalization needs to consider the environmental, community, and neighborhood circumstances that govern how individuals' genes and behavior will influence their health. For personalized health to be realized, we need a sophisticated understanding of the interplay between genetics and the environment, broadly defined.

CAHT-BSSR would be pleased to provide any additional information on these issues. We have attached a list of coalition member societies to the end of the testimony. We thank the Subcommittee for its generous support of the National Institutes of Health and for the opportunity to present our views.

CAHT-BSSR Members

American Educational Research Association
American Psychological Association
American Sociological Association
Association of Population Centers
Center for the Advancement of Health
Consortium of Social Science Associations
Gerontological Society of America
Institute for the Advancement of Social Work Research
National Association of Social Workers
National Council on Family Relations
National Mental Health Association
Population Association of America
Sex Information and Education Council of the United States
Society for Public Health Information
Society for Research in Child Development
The Alan Guttmacher Institute

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