AMERICAN ANTHROPOLOGICAL ASSOCIATION

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AMERICAN ASSOCIATION FOR PUBLIC OPINION RESEARCH

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SOCIETY FOR RESEARCH IN CHILD DEVELOPMENT

WENDY A. NAUS EXECUTIVE DIRECTOR

JAMES S. JACKSON, PH.D.

PRESIDENT

Dear Drs. Altman and Pizzo:

Bethesda, Maryland 20892

I am writing to you on behalf of the organizations comprising the Consortium of Social Science Associations (COSSA) regarding the ongoing review of the National Children's Study (NCS). We applaud your willingness to spearhead this effort, which we trust will delineate a feasible future course for this important study.

COSSA is nonprofit organization serving as a united voice for more than 115 professional associations, scientific societies, research centers and institutes, and colleges and universities who care about a robust social and behavioral scientific research enterprise. A list of our members is enclosed. COSSA works to promote federal funding for and federal policies that positively impact the social and behavioral sciences. Given the breadth of our member organizations, representing a wide range of behavioral and social scientists (e.g. psychologists, demographers, sociologists, geographers, and linguists), COSSA has had a long-standing interest in the development of the NCS.

COSSA believes the NCS has the potential to become an invaluable resource, yielding new insights into the complex linkages between social, genetic, and environmental factors and how these factors interact to influence health, growth and development across the life course. To ensure the study produces meaningful data, the NCS study design is paramount. COSSA member organizations have closely followed the development of the study since its inception and have offered their expertise to help inform its development though formal and informal comments and advice to numerous stakeholders, including Congress, the National Institutes of Health (NIH), National Research Council (NRC), Institute of Medicine (IOM), and the NCS Federal Advisory Committee.

COSSA appreciates the urgency of the working group's task and the magnitude of the challenge you and your colleagues face, synthesizing years of studies, comments, and other reports to develop recommendations before the end of this year. Accordingly, I am writing to reiterate some of our member organizations' primary concerns regarding the NCS and request that these important issues and positions receive thoughtful consideration as your work progresses.

National Probability Sample

A central aspect of the study is how its 100,000 participants will be selected. Given the study's mandate and ambitious objectives, sampling experts recognized early in the study's development that a national probability sample of participants was necessary to reach scientifically valid conclusions applicable to the general population. In 2004, the scientific research community, including demographers, epidemiologists, pediatricians, psychologists, and sociologists, were pleased that the study committed to employing a national probability sample to select locations and participants. In 2008 and 2014, independent panels convened by the National Academy of Sciences endorsed probability sampling as a key element of the survey's design.

We believe that the benefits associated with drawing a representative sample in the NCS far outweigh its incremental costs. A representative sample is particularly important for investigating health disparities mandated by the 2000 *Children's Health Act*, for example by showing how race, ethnicity, and other socioeconomic and demographic factors are related to exposures and long-term health and development in children and young adults. Probability samples are also essential for ensuring that difficult-to-reach populations are represented in the study, which is particularly important in health disparities research. Even though the study design has shifted from household-based to provider-based recruitment, the methods of probability sampling can continue to be used in a scientifically valid and fiscally responsible manner. Given the ongoing deliberations within NIH regarding the cost and flexibility of probability sampling, we urge that the working group base its recommendations on a solid understanding of the comparative costs and benefits of a national probability sampling approach.

Inclusion of mental health measures and outcomes

We continue to support the integration of mental health research into the NCS, including mental, behavioral, and emotional disorders, and continue to emphasize the need for inclusion of positive factors and outcomes such as resiliency. We appreciate the efforts of NCS to assess health disparities, and encourage efforts to assure appropriate sampling of underserved and disadvantaged populations in order to achieve this goal; this includes using culturally appropriate assessments and outcome measures where they are needed. We also believe that it is important that the NCS retain a robust range of behavioral measurements to depict a comprehensive view of health and development. Furthermore, in order to assure that the role of social, behavioral, and environmental factors are adequately monitored and assessed, they should be viewed both as outcomes as well as *drivers* of other health outcomes.

Review of study protocols and instruments

We concur with the 2014 NRC/IOM report that there is a need for a clearly articulated and transparent process of review of study protocols and instruments. As the report concluded, this will require sufficient expertise in the program office and advisory groups in the content areas of the study as well as in assessing the reliability and validity of proposed study instruments. Of particular concern is that the program office reflect expertise in the range of social and behavioral sciences needed to provide input into study protocols related to children's health behaviors and social environments. Further, we urge that developmental science be well represented in the program office and in expert review groups for the study content and instruments in order to assure input into the most rigorous approaches for measuring children's development across the age span covered by the NCS.

With respect to measurement, we feel that there is an urgent need to assure that the measures used in the NCS are appropriate for the full range of demographic subgroups to be included in the sample, including low-income children and families who may be facing multiple stressors, as well as families with a home language other than English. Some existing measures, even those that have been extensively tested for reliability and validity (such as the NIH Toolkit measures) may nevertheless not capture reliable and valid data on low income or otherwise vulnerable populations. We are appreciative of efforts to develop appropriate measures for capturing such key constructs as executive function in low income and homeless populations. We urge careful consideration of the reliability and validity of selected instruments and measures for the full range of demographic subgroups.

Again, thank you for your service on the NCS Working Group. COSSA appreciates your attention to the issues outlined above. Please do not hesitate to contact me if any of our member organizations can be a resource to you and your colleagues as you chart the study's future course.

Sincerely,

Wendy A. Naus Executive Director

Consortium of Social Science Associations

Wendy G. Rans

Cc: Kathy Hudson

Lyric Jorgenson





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