

Testimony on behalf of the
Population Association of America/Association of Population Centers
Regarding the Fiscal Year 2014 Appropriation for the
National Institutes of Health and National Center for Health Statistics
Submitted to the
Senate Committee on Appropriations
Subcommittee on Labor, Health and Human Services and Education
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Introduction

Thank you, Chairman Harkin, Ranking Member Moran, and other distinguished members of the Subcommittee, for this opportunity to express support for the National Institutes of Health (NIH) and the National Center for Health Statistics (NCHS). The Population Association of America (PAA) and Association of Population Centers (APC) are pleased to endorse funding recommendations made by the Ad Hoc Group for Medical Research Funding and Friends of National Center for Health Statistics for NIH and NCHS, respectively. Specifically, we urge the Committee to provide the NIH with \$32 billion in fiscal year 2014 and to provide the NCHS with the Administration's request, \$181.5 million. Further, we encourage the Subcommittee to stop the pernicious cuts to research funding and statistical agencies that squander invaluable scientific opportunities and threaten the ability of our members to continue making important contributions towards improving the health and well being of the American people, to train the next generation of population scientists, and to prevent the permanent loss of key longitudinal survey data.

Background on the PAA/APC and Demographic Research

The Population Association of America (PAA) (www.populationassociation.org) is a scientific organization comprised of over 3,000 population research professionals, including demographers, sociologists, statisticians, and economists. The Association of Population Centers (APC) (www.popcenters.org) is a similar organization comprised of over 40 universities and research groups nationwide that foster collaborative demographic research and data sharing, translate basic population research for policy makers, and provide educational and training opportunities in population studies.

Demography is the study of populations and how or why they change. Demographers, as well as other population researchers, collect and analyze data on trends in births, deaths, and disabilities as well as racial, ethnic, and socioeconomic changes in populations. A key component of the NIH mission is to support biomedical, social, and behavioral research that will improve the health of our population. The health of our population is fundamentally intertwined with the demography of our population. Recognizing the connection between health and demography, NIH supports extramural population research programs primarily through the National Institute on Aging (NIA) and the National Institute of Child Health and Human Development (NICHD). Below are examples of the important population research activities that these Institutes support.

National Institute on Aging

According to the U.S. Census Bureau, the number of people age 65 and older will more than double between 2010 and 2050 to 88.5 million or 20 percent of the population; and those 85 and older will increase three-fold, to 19 million. To inform the implications of our rapidly aging population, policymakers need objective, reliable data about the antecedents and impact of changing social, demographic, economic, health and well being characteristics of the older population. The NIA Division of Behavioral and Social Research (BSR) is the primary source of federal support for basic research on these topics.

In addition to supporting an impressive research portfolio, that includes the prestigious Centers of Demography of Aging, the NIA BSR Division also supports several large, accessible data surveys. These surveys include a new nationally representative study, the National Health and Aging Trends Study (NHATS), which has enrolled 8,000 Medicare beneficiaries with the goal of studying trends in late-life disability trends and dynamics. The study also includes a supplement to examine informal caregivers and their impact on the long-term care utilization of people with chronic disabilities. NHATS is enabling researchers to continue important research on late-life disability trends and those factors (socio-economic, demographic, health) that may influence changes in disability across different populations.

Another NIA survey, the Health and Retirement Study (HRS), has become one of the seminal sources of information to assess the health and socioeconomic status of older people in the U.S. Since 1992, the HRS has tracked 27,000 people, providing data on a number of issues, including the role families play in the provision of resources to needy elderly and the economic and health consequences of a spouse's death. HRS is so respected that the study is being replicated currently in 30 other countries, providing important data on how the U.S. compares with other countries whose populations are aging more rapidly. In March 2012, HRS posted genetic data collected voluntarily from over half of the HRS participants to dbGAP, the NIH's online genetics database. These data are now available for analysis by qualified researchers to track the onset and progression of diseases and disabilities affecting the elderly. In the last year, HRS data were used to report a number of findings, including a significant study published in *The New England Journal of Medicine* in April 2013, which identified the costs of dementia. The study found that caring for people with dementia in the United States in 2010 costs between \$159 billion to \$215 billion, and these costs could rise dramatically with the increase in the numbers of older people in coming decades. The researchers found these costs of care comparable to, if not greater than, those for heart disease and cancer.

As members of the Friends of the NIA, PAA and APC endorse the coalition's recommendation that NIA receive \$1.4 billion in fiscal year 2014.

Eunice Kennedy Shriver National Institute on Child Health and Human Development

Since its establishment in 1968, the Eunice Kennedy Shriver NICHD Center for Population Research has supported research on population processes and change. As a result of the Institute's recent reorganization, this research is now housed in the Population Dynamics Branch. This branch supports research in three broad areas: demography, HIV/AIDs, other sexually transmitted diseases, and other reproductive health; and population health, with focus on early life influences and policy.

NICHD is the major supporter of the national studies that track the health and well being of children and their families from childhood through adulthood. These studies include Fragile Families and Child Well Being, the first scientific study to track the health and development of children born to unmarried parents; the National Longitudinal Study of Youth, a multigenerational study of health and development; and the National Longitudinal Study of Adolescent Health (Add Health), tracing the effects of childhood and adolescent exposures on later health. NICHD supports the prompt and widespread release of demographic data collected with NIH and other Federal government funding through the Demographic Data Sharing and Archiving project.

One of the most important population research programs the NICHD supports is the Research Infrastructure for Demographic and Behavioral Population Science (DBPop). This program promotes innovation, supports interdisciplinary research, translates scientific findings into practice, and develops the next generation of population scientists, while at the same time providing incentives to reduce the costs and increase the efficiency of research by streamlining and consolidating research infrastructure within and across research institutions. DBPop supports research at 24 private and public research institutions nationwide, the focal points for the demographic research field for innovative research and training and the development and dissemination of widely used large-scale databases.

NIH-funded demographic research provides critical scientific knowledge on issues of greatest consequence for American families: marriage and childbearing, childcare, work-family conflicts, and family and household behavior. Demographic research is having a large impact in public health, particularly on issues such as infant and child health and development, and adolescent and young adult health, and health disparities. Research supported by the Population Dynamics branch has revealed the critical role of marriage and stable families in ensuring that children grow up healthy, achieving developmental and educational milestones. Branch-supported researchers have published a number of recent findings, including a study, based on Add Health data, which concluded that women who are overweight or obese years during the transition from adolescence to adulthood are more likely to later deliver babies with a higher birth weight, putting the next generation at a higher risk of obesity-related health outcomes. In another published study, researchers using genetic and survey data from the Fragile Families and Child Well Being Study, found that post-partum depression was most likely among women with both at-risk genetic profiles and low educational levels.

As members of the Friends of the NICHD, PAA and APC endorse the coalition's recommendation that the Institute receive \$1.2 billion in FY 2014.

National Center for Health Statistics

Located within the Centers for Disease Control (CDC), the National Center for Health Statistics (NCHS) is the nation's principal health statistics agency, providing data on the health of the U.S. population and backing essential data collection activities. Most notably, NCHS funds and manages the National Vital Statistics System, which contracts with the states to collect birth and death certificate information. NCHS also funds a number of complex large surveys to help policy makers, public health officials, and researchers understand the population's health, influences on health, and health outcomes. These surveys include the National Health and

Nutrition Examination Survey (NHANES), National Health Interview Survey (HIS), and National Survey of Family Growth. Together, NCHS programs provide credible data necessary to answer basic questions about the state of our nation's health. The wealth of data NCHS collects makes the agency an invaluable resource for population scientists.

Despite recent steady funding increases, NCHS continues to feel the effects of long-term funding shortfalls, compelling the agency to undermine, eliminate, or further postpone the collection of vital health data. For example, in 2009, sample sizes in HIS and NHANES were cut, while other surveys, most notably the National Hospital Discharge Survey, were not fielded. In 2009, NCHS proposed purchasing only "core items" of vital birth and death statistics from the states (starting in 2010), effectively eliminating three-fourths of data routinely used to monitor maternal and infant health and contributing causes of death. Fortunately, Congress and the new Administration worked together to give NCHS adequate resources and avert implementation of these draconian measures. Also, funding from the Prevention and Public Health Fund has been an invaluable source of support for the agency since FY 2011, providing much needed funding to, for example, add components to NHANES, purchase updated vital statistics data from the states, and facilitate the implementation of electronic birth records in the all states. With funding from the NIH, the agency is also working to expedite the release of mortality data from the National Death Index. However, the progress NCHS has made is threatened if the agencies that it relies on for support (through funding from the HHS evaluation tap and via interagency agreements) continue to be cut.

Thank you for considering the importance of these agencies under your jurisdiction that benefit the population sciences. Despite challenges facing the Subcommittee, we urge you to support \$32 billion for NIH and \$181.5 million for NCHS in fiscal year 2014. Further, we urge you to work to reverse the impact sequestration and years of funding levels below inflation have had on the entire public health continuum, which includes NIH and NCHS.