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June O'Neill, Ph.D.

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Ruth E. K. Stein, M.D.

Professor of Pediatrics Albert Einstein College of Medicine

Virginia S. Cain, Ph.D.

Executive Secretary

August 30, 2007

Edward Sondik, Ph.D.

Director

National Center for Health Statistics

3311 Toledo Road

Hyattsville, MD 20782

Dear Ed:

On behalf of the Board of Scientific Counselors of the National Center for Health Statistics, I am pleased to forward the attached report reviewing the NCHS Natality Statistics Program that we initiated at your request. The review panel was chaired by Dr. Barbara Luke. The reviewing panel was very conscientious and thorough in their work and provided a number of important insights and recommendations. In our review of the report prepared by Dr. Luke and her colleagues, however, we found a number of areas where we disagreed with the premises and/or the conclusions, and would like to bring those to your attention as well, as you and your staff consider the next steps.

The review panel focused its attention on two key areas. First, they examined the productivity of the natality program staff in terms of data files, annual data reports, periodic analytic reports and studies, and outside presentations and publications. They commended the staff for a high level of consistent productivity of files and reports on natality, infant mortality, fetal mortality, and perinatal mortality, and for the design and publication of excellent creative studies.

The second key focus of the panel reviewers was the need for resource enhancements to the program. Many of their recommendations highlighted the need for additional resources to provide support to the states in re-engineering their electronic systems and in implementing the 2003 U.S. Standard Certificate of Live Birth and the 2003 U.S. Standard Report of Fetal Death. The lack of adequate resources to support the states was cited as the central reason for the staggered implementation of the certificate revisions, resulting in a limited data set on many critical maternal and infant health issues. This in turn impairs the usefulness of the natality files for public health research and policy. Other recommendations addressed the needs for training hospital and field staff, promoting additional collaboration with state partners and academics, and developing strategies for data release issues that take concerns for confidentiality safeguards into account. We have reviewed your program



staff's response to the recommendations and we recognize that you are already engaged in some of the recommended activities and are already making improvements in some of these areas. For example, the natality staff has launched *VitalStats*, a new Internet application for the dissemination and analysis of birth statistics data that makes it possible for users to access and examine vital statistics and population data interactively.

The BSC agrees with the general sentiment of the report, especially the positive evaluation of the natality program staff. However, I want to list several key areas where the Board members feel additional context and clarification are needed or where we disagree with some aspects of the report.

The reviewers conclude that "...there is no longer a complete national data set for births in the United States" and that "we do not have a complete, contemporary, and accurate picture of natality in the United States." It is important to clarify that for many items that have been reported over time, NCHS does have a complete, contemporary, and accurate picture for many demographic and maternal and infant health items, and is able to produce a national data set for births. Since the registration of births is at least 99% complete in the United States, data are available for virtually every one of the births occurring in this country. We would agree, however, NCHS does not have national data on the most important indicator of SES, namely mother's educational attainment, or the most widely used indicator of health care resources, namely the date prenatal care began. Further NCHS does not have national data on the essential information that would help inform understanding of the factors that further describe and explain some of the general trends observed, such as more clarity on the factors behind the cesarean delivery increase, the role of infertility treatment in levels of low birthweight and preterm births, the incidence of gestational diabetes, the impact of maternal morbidity and maternal infections on pregnancy and birth outcome, etc. Moreover a number of new items are potentially very useful in understanding maternal and infant health and outcomes. Unfortunately items that are exclusive to the 2003 revision are not available nationally, and this impairs the usefulness of the birth data files as a whole.

The reviewers assert that NCHS called for implementing the revised certificates in 2003 even though the needed resources were not forthcoming. We would clarify that NCHS called for implementation beginning in 2003 with the concurrence of the National Association for Public Health Statistics and Information Systems (NAPHSIS) (NCHS's state partner organization), with the explicit understanding that the implementation would be phased in by the states when they were able to modernize their systems.

The reviewers report that states feel there was inadequate piloting of the new data collection forms. NCHS did undertake testing of the new worksheets for the mother and the facility, and made changes to these forms as a result of the testing which was reviewed by state colleagues. NCHS also developed a test deck for states to use to evaluate whether their electronic data collection systems were working as designed. The report also states that "there were no plans for bridging inconsistencies between old and

new data items.” NCHS has done extensive work to bridge data from the old and revised items wherever possible and shared this information with state colleagues. In particular, NCHS did pioneering work to develop a “race-coding engine” and bridging techniques for single- and multiple-race birth data. Crosswalks for items determined not to be comparable between revisions would require actual information for both the old and new questions for the same births. Given that the birth certificate is a legal document, it will be necessary to develop creative strategies. One possibility to consider is that states that are about to implement the revision might be invited to collaborate with NCHS on an assessment of the viability of crosswalks for certain items.

Concerning resource shortfalls, the report states: “However, resources and funds promised to States by NCHS for implementation were not, and still have not been made available.” Here and elsewhere in the review panel’s report there are several references to “promises” of funding made by NCHS. Our understanding is that NCHS officials, including the past Director of the Division of Vital Statistics, said that NCHS would *make every effort to secure the funds to assist the states in implementing the revision*. When everyone recognized, subsequent to the revision process itself, that re-engineering the systems was a necessary pre-condition to implementing the revised certificates, the need for significant additional resources was further clarified. We recognize that Federal officials are never in the position where they can “promise” funding, only that they can promise to try to obtain funding.

Further addressing the inadequate funding for the states, the report states the Social Security Administration provides funds for states to develop and implement Electronic Death Registration Systems (EDRS), but that there is no comparable support for Electronic Birth Registration Systems (EBRS), and further that “...newborn screening, birth defects, immunizations, and child support, regularly provide more funding to the states than NCHS.” It should be recognized that the support provided by an agency such as SSA is largely driven by that agency’s direct benefits in ascertaining the facts of death as soon as possible after an individual dies. That is, the SSA gains directly and immediately by having the information needed to terminate an individual’s benefits promptly after death. Other initiatives such as child support enforcement have a similar direct “payoff” to the federal agency, in that child support enforcement helps to save the government money. At this point, there is no comparable benefit for other federal agencies for faster and more accurate reporting of birth certificate information. This may change with future regulation of birth certificate registration provided under the Intelligence Reform Terrorism Prevention Act (IRTPA).

We completely understand the resource limitations under which you are currently operating and concede that many of the panel’s recommendations would require resources well beyond that which are likely to come available in the near future. We are, in fact, concerned about the viability of the basic natality program because resources for the ongoing program have been inadequate. Nevertheless, we urge you and your staff to

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seriously consider the review panel's many useful ideas and suggestions wherever possible in your future plans for NCHS.

Please share this letter and the attached report with appropriate officials in CDC and DHHS. We would be pleased to provide additional information or respond to any questions as requested.

Sincerely,

-s-

June E. O'Neill, Ph.D.
Wollman Professor of Economics and Finance
Baruch College, City University of New York
Chair, Board of Scientific Counselors
National Center for Health Statistics
Centers for Disease Control and Prevention

Enclosure: Review of the National Center for Health Statistics Natality Statistics Program
(September 1, 2006)