The vital statistics system represents a core function of government and constitutes a unique and extremely valuable national resource that merits consistent support. The Review Panel is gravely concerned about the recent degradation of the U.S. Natality Statistics Program. Due to inadequate funding, there is no longer a complete national natality dataset, nor will there be within the foreseeable future.

**Purpose and Organization of This Report**

This report has been prepared by an eight-member interdisciplinary panel invited to evaluate the operations and activities of the NCHS Natality Statistics Program. The Panel reviewed a detailed description of the Natality Statistics Program and numerous other relevant materials, convened at the NCHS on two occasions, and communicated through conference calls and emails. The Panel met with staff and leadership at NCHS and conducted a conference call with State Registrars from Hawaii, Utah, Kansas, Alabama, Tennessee, and New York City, as well as the Executive Director of the National Association for Public Health Statistics and Information Systems (NAPHSIS). This organization represents State vital records and public health statistics offices in the 57 jurisdictions that provide birth data to NCHS. The first section of this report describes the use and value of natality statistics data, accomplishments of NCHS staff, and what we view as a crisis involving the 2003 revision of the U.S. Standard Certificate of Live Birth. The remainder of the report discusses major challenges facing the Natality Statistics Program. Recommendations of the Review Panel are offered throughout the report.

**NCHS Staff**

The staff of the Reproductive Statistics Branch should be commended for their high level of consistent productivity despite substantial budgetary and staffing limitations. Annually they produce the Natality files, Linked Birth/Infant Death files (including numerator and denominator files), and Fetal Death files. The Matched Multiple Birth/Death file, which reconstructs sibling sets in multiple births, is prepared periodically. The size and complexity of these data sets has grown immensely in recent years. These data files are used extensively by researchers, and represent one of the critical functions of the Reproductive Statistics Branch. They also regularly produce comprehensive annual reports on national maternal and infant health, including the Final Natality Report and the Linked Birth-Infant Death Report, as well as periodic special reports evaluating trends in areas of interest, such as teenage and nonmarital childbearing, cesarean births, smoking during pregnancy, and multiple births. In addition,

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The Use and Value of Natality Statistics

Natality statistics have historically been used for civil registration, public health, and commercial purposes. Among the varied uses of the data have been: (1) Legal documentation, linked to citizenship and identification; (2) Monitoring of population growth; (3) Surveillance of vital events and sentinel health events; (4) Public health assessment, including trend recognition, (5) Development and monitoring of the Healthy People 2010 objectives, which rely on natality data for 24 different objectives; (6) Monitoring of key health indicators (low birthweight, preterm birth, teen pregnancy rates, infant mortality, prenatal care); (7) Identification and tracking of racial and ethnic health disparities and other subgroup analyses; (8) Identification of population-based risk factors for adverse outcomes; (9) Assessments of regional and local health status and services; (9) Media reports on the health of the nation; and (10) International comparisons of health status.

At both the Federal and State levels, the environment in which vital statistics data are collected, analyzed, and distributed has changed dramatically—and will continue to change—in response to: (1) Heightened concerns regarding national security and confidentiality, and (2) Mandated transitions to electronic systems that require ongoing development and maintenance.

Crisis in the Implementation of the 2003 Revised Birth Certificate

The collection of vital records data and the registration of vital events is a State function. The 50 States, New York City, the District of Columbia, and five territories provide data to NCHS for the compilation of national data sets through a cooperative, contractual arrangement. Given the nature of the Federal-State vital statistics cooperative effort, the central leadership role inescapably falls on NCHS. With regard to natality statistics, NCHS has a strong past record of capably discharging that responsibility. However, NCHS’s current leadership role in this capacity is in jeopardy, as reflected by the delayed implementation of the 2003 revision of the birth certificate by nearly all jurisdictions. A system that was intended to be fully implemented in 2003 will not be available until 2010 or later. As a result, there is no longer a complete national data set for births in the United States. The Natality Program staff has gone to great lengths to assist the States in planning the transition process, but most states have not been able to implement those procedures due to inadequate funding.

Statement of the Problem

The compilation of National natality data requires State vital statistics offices to send to NCHS selected items collected on their State birth certificates. The items are identified in the US Standard Certificate of Live Birth, which is periodically revised (roughly every 10-15 years) by adding new data items, modifying select current items, and eliminating unnecessary items to reflect changing data needs. The

most recent revision occurred in 2003. While prior revisions required only a short adjustment period for implementation, at this time the 2003 revision has been implemented in fewer than 20 States (see map below). Primarily due to lack of funding, many jurisdictions lack even preliminary plans for implementation of the revision.

The revision process took place in 1998-99, with the revision evaluation committees funded, staffed and coordinated by NCHS, chaired by State registrars, and composed of members of the professional and research communities most involved with vital statistics. These committees deliberated item content and made recommendations to the parent committee, comprised entirely of State registrars. At that time no one—neither the NCHS leadership nor the State registration executives—anticipated the need to fundamentally re-engineer their systems for registering vital events and collecting vital statistics. By 2000, it became evident to both NCHS and the States that implementing the revision would entail much more than simply updating data items and that very significant resource were needed for the States to accomplish this. Even though such resources were not forthcoming, NCHS called for implementing the revision in 2003. With its limited available resources, NCHS supported the efforts to develop national models of electronic vital registration systems by developing specifications for the new systems, working with the States to establish system requirements and developing materials such as worksheets and guidebooks that States could use when revising their certificates. However, as indicated earlier, few States have been able to utilize these tools because are unable to afford to implement the revision.

States that have implemented the revision have not authorized NCHS to utilize new data items in reports or presentations, nor can NCHS make the data available to other federal agencies (including the Surgeon General), analysts, policy makers, researchers, businesses, or the media, thereby undermining the purpose of the revision. See Appendix I for a list of the new data items. States are concerned that there was inadequate piloting of the new certificate, and that a failure to provide for formal training for hospital staff on the completion of the new certificate may result in poor data quality. In addition, there were no plans for bridging inconsistencies between old and new data items. See Appendix II for examples.

Source of the Problem
No plan was in place for the implementation of the 2003 revised certificate. NCHS asked States to begin using the revised certificate on January 1, 2003, or as soon as possible after that date. However, resources and funds promised to States by NCHS for implementation were not, and still have not been made available. Implementation of the 2003 revision was more difficult than earlier revisions because of the electronic data systems required, and the larger number of new data items involved.
Implications of the Current Situation
As a result of the problems cited above, we do not have a contemporary, complete, and accurate picture of natality in the United States. The purpose of the 2003 revision was to provide the data needed to develop a better understanding of important public health issues including the widening health disparities among racial and ethnic groups, the rise in preterm and early preterm births, the increasing rate of cesarean births, possible adverse outcomes after infertility treatment, and the impact of perinatal infections. Since NCHS does not have the authorization by the States to distribute these new data, they are not publicly available. The failure to implement the 2003 revisions is a manifestation of broader challenges facing the Natality Statistics Program, particularly in three areas: (1) Organizational structure within NCHS/CDC, (2) Relationships with State partners, and (3) Data quality issues. These are discussed below.

I. Organizational Structure within NCHS/CDC
Vital statistics are different than any other function of the CDC. Vital statistics provide the basic ongoing demographic measures of the nation’s population, serving as the cornerstone for public health assessment, assurance, and policy development. It is therefore essential that the Natality Branch have sufficient resources “…to be a credible source of relevant, accurate, and timely statistics.” [Committee on National Statistics, National Research Council, 2005]16

The Natality Statistics Program, with its critical national role in collecting vital statistics, is currently within the Reproductive Statistics Branch, within the Division of Vital Statistics (DVS), within the National Center for Health Statistics, within the Coordinating Center for Health Information and Service, within the Centers for Disease Control and Prevention, within the Department of Health and Human Services. See Appendix III for the organizational chart. This current organizational structure results in: 1) Lack of visibility; 2) Delayed dissemination; and 3) Lack of protected funding for ongoing operations that are vital to the nation’s public health infrastructure.

Major Recommendations
1. The CDC must accept its responsibility to provide adequate support to DVS to allow DVS to carry out its mandated mission of producing timely and accurate vital statistics.
2. DVS should be a line item in the Secretary of DHHS budget in recognition of its critical and unique role as an ongoing provider of data that are essential for monitoring national events and the nation’s health.

Additional Recommendations
3. Strategies should be developed to improve communication and coordination between the Natality Program and the Data Acquisition and Evaluation Branch (DAEB) of NCHS, which is located at Research Triangle Park, North Carolina. NCHS acknowledges that distance is an obstacle to developing and maintaining as close a partnership with DAEB as they would prefer to ensure that high quality data are collected from the states. In describing their relationship with DAEB, staff of the Natality Program reported that: (1) At least twice a year, DAEB provides detailed written reviews of the nature and quality of the reporting for every data item and every state, as well as comparisons of on "not stated" responses over several years. (2) When individual reporting problems are identified, branch staffs work together to develop solutions. (3) Subject-specific workgroups are being developed across the two branches to address particular quality issues, such as the reporting of infant deaths.

4. Relationships with related Federal agencies (e.g. Maternal and Child Health Bureau, NIH) should be enhanced, and efforts should be made to obtain support for vital statistics activities from Federal agencies that are heavy users of the data.

5. Strategies for promoting the visibility of natality data should be identified.

II. Relationship of NCHS to the States
The inability of NCHS to adequately fund State efforts has severely strained the essential Federal-State cooperative program that is at the core of the vital statistics system.

- At the Federal level, NCHS has been insufficiently funded to contract for even a single year of data from the States, and has habitually relied on future funding to obtain complete data in a given year.
- While NCHS promised to provide States with funding to implement the 2003 revision, this funding was never delivered.
- States are concerned that their participation in a program to electronically verify the authenticity of vital records for federal agencies, Electronic Verification of Vital Events (EVVE), as mandated by Intelligence Reform Act legislation, could result in loss of revenue to vital records offices since federal agencies want to pay only a small fee for this service. NCHS is preparing the Intel Reform regulations that will govern EVVE, and States are concerned that NCHS will support their federal partners rather than the States in setting EVVE fees, even though money received through EVVE could be used by States to improve systems.

**Major Recommendations**
1. NCHS should be provided a budget that will allow it to meet its contractual obligations to States for data collection and the maintenance of their systems.
2. Funding should be secured to fully implement the 2003 revision of the birth certificate as a top priority. NAPHSIS estimates that a one-time allotment of $65 million is necessary to: 1) Reengineer electronic systems in States that have not yet implemented the 2003 revision, and 2) Reimburse States that have already implemented the revision. See Appendix IV for details. NCHS and NAPHSIS should work together to develop a plan to prioritize steps for implementation. This plan should be the basis for the formal request for this crucial funding. The plan must be acceptable and equitable for States that have and those that have not already implemented the 2003 revision.
3. Since NCHS will play a pivotal role in coordinating EVVE activities, NCHS should support the States in setting EVVE funding at a level that will provide revenue to States to improve systems and data quality.
4. NCHS should collaborate with NAPHSIS to fund and implement programs for training of both vital records staff and hospital staff, particularly birth registration clerks.

**Additional Recommendations**
5. NCHS should establish a Data User’s Group to advice and advocate for improvements in vital statistics at the Federal and State levels.
6. NCHS should enhance its understanding of State operations by arranging to include staff with registration experience who can more fully understand the data collection and quality issues at the State level. For example, staff may be temporarily assigned to State health offices, as is common with other CDC programs.

III. Data Quality Issues
The national natality statistics system begins with data collection at the birth hospital, continues through the State vital records office, and finally reaches the Natality Branch, where national data sets are created. Data quality is essential to the vital statistics system, and it depends critically upon the training of the hospital staff completing the birth certificate. From NCHS’ perspective, the most important gain
anticipated from the 2003 revision was the potential for improvement in data quality. To this end, NCHS implemented a number of initiatives with the goal of improving data quality (see Appendix V). We have identified quality-related problems in several areas: overall, validation, and training.

**Overall**
- In times of lean budgets, quality and timeliness suffer. Since the late 1990s, NCHS has not had sufficient funding to fully support the Vital Statistics Cooperative Program (VSCP), and as a result have formally lowered standards for data timeliness and data quality (i.e., allowances for unknown responses have increased) and has had to reduce the amount of data purchased from the States.
- Lack of funding undermines the quality of current data. Some data are no longer collected; fewer field staff results in poorer quality data; and less time can be spent on labor-intensive linkage of birth and infant death records.
- NCHS cannot expect revisions to be a priority for States when NCHS is having difficulty meeting its contractual obligations to fund States to provide even routine data.
- More than half of the States have not adopted the new revision of the birth certificate. This provides an opportunity for studies of comparability of old and new items to be developed and implemented.
- Among national data sets, only vital records still collect single race data; all other surveys and the census are now using multiple race coding. For instance, the presently used Asian/Pacific Islander category is biologically and socially meaningless since it includes relatively high socioeconomic status groups—Japanese, Chinese, East Indians, Koreans, as well as lower socioeconomic status groups such as Filipinos, Samoans, and Hawaiians. It also encompasses both the physically large Hawaiians and Samoans, and the physically small Hmong.
- Fetal death data are also an essential component of the vital statistics system. The quality of these data is likely to be poor since few resources are available to ensure that high quality data are collected and reported.

**Validation**
- Quality of new and modified data items on the revised certificate is not known.
- There has never been a national validation study of the items on the birth certificate.

**Training**
- Training, particularly the training of hospital staff responsible for completing birth certificates, is left largely to the States and results in inconsistent quality assurance.
- Birth registration software systems are developed by States or vendors. NCHS provides materials for guidance, but there is no national standard with follow-up or oversight to ensure consistency.

**Recommendations**
1. Each State should have a Health Statistician/Perinatal Epidemiologist with a specific responsibility to monitor data quality.
2. The CDC should provide funding for masters and doctoral degree grants to support studies of data quality.
3. There should be thorough testing and piloting of future revised certificates.
4. Use the Pregnancy Risk Assessment Monitoring System (PRAMS) to validate new data items.
5. Fund a national validation study, based on a cooperative effort between the natality branch, NAPHSIS, and academic partners.
6. More work needs to be done to ensure that the necessary records, particularly prenatal records, are available to personnel completing certificates in hospitals and that better paternal information, including age, education, race/ethnicity be collected to the greatest extent possible.
7. The registrar support position at NCHS should be revived. Among the responsibilities of this position should be the development of procedures for ensuring data confidentiality and ensuring that States have adequate disaster preparedness plans.

IV. Future Programmatic Enhancements
In addition to the recommendations made above, the Review Panel concluded that there were several other important areas to consider.

1. There should be support for research on data security, confidentiality issues as impediments to research, and inconsistencies in standards from State to State. Attention should also be given to strategies to allow Natality data users to access data by sub-national geographic region that are acceptable to the States.

2. There is a need to develop the role of external users from organizations such as the March of Dimes, Annie E. Casey Foundation, Robert Wood Johnson Foundation, Packard Foundation, and Gates Foundation in supporting vital statistics.

3. Incentives, primarily in the form of protected time, should be provided to NCHS staff to encourage vigorous research collaborations with State and academic partners.

4. An external grants program should be developed to provide funding for validation studies; development of methods to improve data collection; attaching census tract characteristics to birth certificate data; studies on perinatal health based on vital statistics data, and linkage studies. Linking large existing data sets offers a relatively inexpensive approach to many important public health issues. These might include linkage of births and fetal deaths to the same mother, with the same and different fathers; linkage of mother’s death certificate to birth and fetal death certificates; and linkage of child’s birth certificate to mother’s birth certificate, to facilitate intergenerational studies.

5. Assuming that adequate funding is appropriated, the Intelligence Reform Act offers a unique opportunity for States to improve their birth systems. The Social Security Administration provides funds for States to develop and implement Electronic Death Registration Systems (EDRS). However, no such support exists for Electronic Birth Registration Systems (EBRS). States reported that other initiatives, including newborn hearing screening, birth defects, immunizations, and child support, regularly provide more funding to the States than NCHS. This results in a system that is increasingly lacking in coordination.

6. We urge that efforts to build a crosswalk between the old and modified items in the 2003 revised U.S. Standard Certificate of Live Birth be given a very high priority. The non-comparability of data items across revisions, and even between States for a single year, weakens our understanding of natality in the United States.

Respectfully submitted,

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APPENDIX I.

2003 U.S. STANDARD CERTIFICATE OF LIVE BIRTH
NEW DATA ITEMS TO BE TRANSMITTED FROM STATES TO NCHS

- Time of birth
- Facility – State hospital code
- Mother ever married
- Mother not married --
  - Paternity acknowledgement signed
- Father’s education
- Date of last live birth
- Date of last other outcome
- Mother transferred for maternal medical or fetal indications for delivery
- Date of last prenatal care visit
- Plurality – Set order
  - Number live born
  - Matching certificate number
- Apgar score at 10 minutes
- Cigarette smoking 3 months prior to pregnancy
- Principle source of payment for delivery
- Mother’s height
- Participation in WIC program during pregnancy
- Infections present and/or treated during pregnancy
- Maternal morbidity (complications associated with labor and delivery)
- Transfer of infant within 24 hours of delivery
- Infant living at time of report
- Infant being breastfed at discharge
- Pregnancy resulted from infertility treatment
APPENDIX II.

COMPARABILITY OF REVISED AND UNREVISED DATA—U.S. CERTIFICATE OF LIVE BIRTH

Prenatal care in the 1st trimester of pregnancy according to unrevised and revised data: Reporting areas, 2003 and 2004

Late or no prenatal care according to unrevised and revised data: Reporting areas, 2003 and 2004

High school completion according to unrevised and revised data: Reporting areas, 2003 and 2004

College education according to unrevised and revised data: Reporting areas, 2003 and 2004

Maternal smoking rates according to unrevised and revised data: Reporting areas, 2003 and 2004

Source: NCHS/CDC/National Vital Statistics System

Source: NCHS/CDC/National Vital Statistics System

Source: NCHS/CDC/National Vital Statistics System

Source: NCHS/CDC/National Vital Statistics System

NOTE: Unrev = 12+ years of schooling completed; Rev = HS diploma or GED+

NOTE: Unrev = 16+ yrs of schooling completed; Rev = BA, BS, equivalent or more

Source: NCHS/CDC/National Vital Statistics System
APPENDIX III.
ORGANIZATIONAL STRUCTURE OF CDC AND NCHS

DEPARTMENT OF HEALTH AND HUMAN SERVICES
CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)

OFFICE OF THE DIRECTOR

Office of Chief Science Officer
Office of Chief of Public Health Practice
Office of Chief Operating Officer
CDC Washington Office

Office of Strategy and Innovation
Office of Workforce and Career Development
Office of Enterprise Communication
Office of Chief of Staff
Office of Equal Employment Opportunity

Coordinating Office for Global Health
Coordinating Office for Terrorism Preparedness & Emergency Response
Coordinating Center for Environmental Health and Injury Prevention
Coordinating Center for Health Information and Service
Coordinating Center for Health Promotion
Coordinating Center for Infectious Diseases
National Institute for Occupational Safety and Health

National Center for Environmental Health/Agency for Toxic Substances & Disease Registry
National Center for Health Marketing
National Center for Health Statistics
National Center for Injury Prevention and Control
National Center for Chronic Disease Prevention and Health Promotion
National Office of Public Health Informatics
National Office of Public Health Genomics
National Immunization Program
National Center for HIV, STD, & TE Prevention
National Center for Birth Defects and Developmental Disabilities

*ATSDR is an OPDIV within DHHS but is managed by a common ODC of the Director with NOSEH

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APPENDIX IV.

Costs of Implementing Electronic Birth Registration Systems in all Jurisdictions
(Information obtained from a larger NAPHSIS survey)

Twelve jurisdictions have implemented an Electronic Birth Registration System (EBRS) and eight could provide comparable costs. The costs for implementing an EBRS included software purchase or development, software licenses, hardware purchase, hardware licenses, data storage and personnel costs. The costs vary due to size of the jurisdiction, project scope and method used to develop the EBRS. The costs are as follows:

- Median---$958,000
- Mean-----$1,330,000
- The cost to implement an EBRS in the remaining 45 jurisdictions could range from $43.1M to $59.8M. For the purposes of this report we are estimating $50.0M

The annual ongoing cost to maintain an EBRS according to the States that implemented one is:

- Median----$112,000
- Mean------$146,000
- The total annual cost to maintain an EBRS in the 57 jurisdictions could range from $6.4M to $8.3M. For the purposes of this report we are estimating $7.3M.

The jurisdictions need technical support to ensure EBRSs are developed according to the national standards and to assist jurisdictions in transferring best practices. NAPHSIS will provide the startup and ongoing support at a cost of $.4M

**The startup cost to implement EBRS in all jurisdictions is $50.4M**
Appendix V. Major Initiatives Implemented by NCHS to Improve Data Quality with the 2003 Revision*

- Engaged a contractor (former state registrar) to work with RSB staff to design and develop detailed specifications for the new electronic systems which included guidelines for automatic edits at time of entry for the revised birth and death certificates and the fetal death report
- Developed worksheets for the mother (in English and Spanish) and tested them in our cognitive research lab (every item was tested)
- Developed worksheets for birth facilities to collect the medical and health data, and tested the worksheets in a variety of hospitals in three states with real birth clerks (every item was tested)
- Separately tested the proposed response categories for the revised congenital anomaly item, to ascertain whether the information was available on the medical records in time to be reported in the birth registration process.
- All of the above materials were developed in collaboration with state colleagues
  - A workgroup of state registration executives (the implementation workgroup) reviewed these materials and the results of the testing all along the way
  - A number of changes were made to the recommended certificates as a result of the testing
- Designed and developed a detailed guidebook for completing the facility worksheets for the certificate of live birth and fetal death
  - Engaged a contractor with medical and obstetric expertise to develop and design the guidebook and the guidebook was reviewed by hospital personnel and by state colleagues
  - Many thousands of copies of the guide were printed and distributed to the states; the guidebook is also available on our website
- Developed a test deck for the new electronic systems, so that states could test the output of their re-engineered systems against the reported data
  - A test deck made available to all states and software vendors
  - NCHS offered to run the test deck for states that didn’t have staff to do this
  - Some states took advantage of this, but others declined to do so
- Analyzed the limited data for several items where the data are comparable across revisions, and found potentially improved data quality
  - Tobacco use reporting and reporting for several checkbox items have increased to levels more consistent with other data sources
- Analyzed data for items that states have not authorized NCHS to distribute, and prepared special analyses of these items, focusing on data quality, that NCHS distributed to state colleagues; more analyses are forthcoming.
  - Infant living at time of report; WIC food receipt; Breastfeeding

*List provided to the Review Committee by the NCHS staff*