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STATISTICAL DIVISION UNITED NATIONS

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COORDINATING DATA SOURCES FOR NATIONAL VITAL STATISTICS: THE UNITED STATES OF AMERICA

Ву

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I. Introduction

In the United States, responsibility for the registration of vital events is vested in the individual states and registration areas, rather than in the federal government. As a result the civil registration system is composed of 50 state systems, one city system (New York City), and additional separate systems for the District of Columbia (the federal district), Puerto Rico, the U.S. Virgin Islands, Guam, Northern Mariana Islands, and American Samoa, for a total of 57 separate subsystems. Each of these jurisdictions is responsible for the operation and for most of the funding for their own registration system. Each system also provides the registration data that forms the basis for U.S. national vital statistics.

While there are some advantages to a federal system such as this, there are obviously important drawbacks as well. One advantage is that the independent subsystems provide an effective internal structure, offering considerable support to the national superstructure. The major drawback is that the subsystems are under no obligation to follow national guidelines, and in many cases local or state interests may override national interests to the detriment of consistent national vital statistics. The primacy of subnational interests is a logical result of the legal basis and the source of funding for the various subsystems. Indeed, the absence of unified interests is a major reason that the national vital statistics system in the United States was not completed until 1933.

The establishment and maintenance of consistent national vital statistics has resulted from a concerted effort to promote common training, definitions, reporting forms, registration laws, and other activities within all of the subsystems. Over the past several decades, the effort to coordinate and orchestrate consistent vital statistics has been carried out by the National Center for Health Statistics (NCHS).

II. Historical Development of the National System

The registration of vital events, in particular births and deaths, began very slowly and in limited areas of the United States. The first official reports of deaths were produced in the 1790's by health boards in two cities, largely in response to outbreaks of disease. Spread of the registration systems continued at a very slow pace, so that by the 1850's only two states and a handful of other cities had well-functioning systems. From 1850 to 1910, an attempt was made to collect national information on vital events through the decennial census, but it was generally recognized that the results were seriously incomplete.

In 1900 the Census Bureau became the national office for mortality statistics, and promoted the use of standard registration forms, instructions for registrars, model laws, and the like. In the same year, the Census Bureau initiated the death registration area concept to promote the collection of uniform mortality data and to encourage its spread throughout the United States. In 1915 the national birth registration area was inaugurated. State registration systems were added to the two registration areas as they demonstrated relatively complete coverage of events. The two registration areas were completed in 1933 with the addition of the final state, Texas.

Health and sanitation issues remained the most important justifications for the production of vital statistics throughout the decades of growth of the registration systems. Professional health organizations provided important support for the growth and development of registration systems. The first national registration area was limited to deaths in part because they were felt to provide information of more interest to public health than birth registration.

The final step in the establishment of a complete and uniform system for the registration of births and deaths was ensured by changes in government policy that made vital records themselves very important to large numbers of individuals. The first such change was the introduction in the 1930's of welfare legislation, such as old age and social security programs. At the same time, pension plans were becoming increasingly common in private industry. In both the public and private sector, eligibility for these programs required a birth certificate as legal documentation of age. The rapid growth of defense-related industries during the Second World Was placed even greater demands on the state vital registration systems. Because proof of citizenship was required for employment on many defense projects, persons seeking employment in defense industries inundated state registration offices with requests for copies of their birth certificates.

The additional demands placed on the state registration systems underlined the remaining problems of standards of performance and uniformity across the state and local agencies. The result was the establishment in 1946 of a national office of vital records, located within the Public Health Service and designed to provide financial and technical assistance to improve, develop, and integrate the individual units of the national system. Although the Census Bureau had been assigned responsibility to coordinate practices in the state offices, this was in fact the first time that a federal agency had been charged with responsibility for the vital records system. Since the 1950's, this responsibility has been vested in the NCHS.

III. Organization of State Vital Statistics Systems

Before moving on to a discussion of how the vital event data collected by the various systems are coordinated, it is best at this point to provide a brief description of the organization of the various registration systems. Certain aspects of civil registration systems may vary from one state system to another. However, there are certain broad responsibilities that are largely consistent across jurisdictions.

Birth registration. The responsibility for completion of the birth certificate lies with the birth attendant, so that in the U.S. most birth certificates are completed by hospital staff. The physician or other birth attendant signs the certificate and provides the medical information requested on the form. In most states the mother has the opportunity to verify the facts, spelling of names, and the like. The hospital forwards the certificate to the local registrar, who verifies that the form is completely and accurately filled out and then transmits it to the state office. Further data verificates must be filed within 5 days of the event.

Death registration. Primary responsibility is placed on the funeral director for the completion of death certificates. The funeral director must obtain personal information from the next of kin or best qualified source, and must also obtain the medical certification of cause of death from the attending physician. The medical certificate must be completed by the physician and returned to the funeral director within 48 hours of the death, and the funeral director must file the completed death certificate with the local registrar within 5 days of the event. As with the birth certificate, the local registrar must verify the completeness and accuracy of the information recorded, and then forward the certificate to the state office.

Fetal death reporting. In about half of the states, the funeral director has primary responsibility for completion of fetal death reporting forms, exclusive of cause-of-death information. Typically the funeral director will obtain information on medical items (complications of delivery, weight gain, etc.) from the hospital, although the quality of information on medical items may suffer as a result. In the other states, the hospital is responsible for the medical items on the form. The time interval for filing of fetal death reports is the same as for live births and deaths. Marriage registration. A city or county marriage license clerk is responsible for issuing marriage licenses in most local or state systems. In most cases, the license actually combines a registration form and license form. The clerk completes the items calling for personal particulars of the individuals to be married. The civil or religious official conducting the wedding ceremony must sign the form and return it to the licensing official, who then forwards the form to the central or state office.

Divorce registration. Divorce records are the responsibility of the judicial system of each state or other jurisdiction; the Clerk of Court is usually the recording official. Personal information is recorded on the reporting forms by the couple seeking divorce or their attorneys. The clerk adds information on the divorce decree and forwards the form to the central or state office.

Transmission of Data to the National Level. At the state level, completed certificates are subjected to further editing and querying to ensure completeness and accuracy. Each state compiles the information to produce its own tabulations and annual reports. At the same time, information from the certificates is forwarded to the central government for the preparation of national vital statistics. The information is transferred either via a computer tape, or in a few cases by means of microfilm copies of certificates. NCHS compensates the states for the data provided according to a cost-sharing formula developed by a committee composed of representatives from NCHS and the association of state vital registration and statistics executives.

Preparation of Vital Rates. NCHS combines vital registration data from the states with information on the resident population from the Bureau of the Census to compute vital rates. The Census Bureau provides population data from the decennial census and from preliminary mid-year estimates of the population for other years to NCHS. Special population estimates for intercensal years are also provided to NCHS upon request. In return, NCHS provides the Census Bureau with detailed data on national vital statistics, used by the Census Bureau in population estimates and projections, quality control of census figures, and for special studies.

IV. Maintenance of a Unified National Vital Statistics System

The mission of the national office of vital statistics is to coordinate and promote uniformity in the collection of vital statistics data, and the maintenance of appropriate statistical standards. To carry out this objective, the national office prepares manuals and guidelines, develops statistical standards, and maintains a training program for employees of the state registration systems. In order to sustain operational ties between the states and the federal government, the national office supports a series of additional continuous activities including national conferences and study committees. The national office maintains continuous contact with state vital statistics offices on all aspects of their operations which have a bearing on national vital statistics.

1. Purchase of computer data tapes.

One of the important ways in which the NCHS currently maintains statistical standards is through the purchase from the states of vital statistics computer data tapes in a standard format. The Vital Statistics Cooperative Program provides for the establishment of a contract between NCHS and each participating state, in which the state is required to provide vital statistics data according to specifications and quality standards set by NCHS. Prior to award of the contract, NCHS representatives study the state office processing procedures, determine changes necessary to conform to national requirements, and provide technical assistance for the modification of the system. The result ensures uniform standards for coding and data quality from each of the state systems participating in the program. It has also served to reduce duplication of effort in coding and data entry, which in the past often took place at the local, state, and national levels.

State computer data tapes undergo a complete testing period of a year, during which they are matched against data files abstracted from the state microfilm records. If the quality requirements are met, the purchase of a complete state microfilm file is discontinued but monthly matching against a sample of records is maintained for purposes of quality control.

2. Computer software.

NCHS also makes available to the state systems computer software to assist in the processing of data from the medical certification segment of the death certificate. The first of these software systems, the "Automated Classification of Medical Entities" or ACME, provides for selection of the underlying cause of death. Under this system, all diseases or conditions on the death certificate are manually coded and entered by the user, and the software assigns the underlying cause by applying the rules of the International Classification of Diseases (ICD).

The major advantage of using ACME is to standardize the selection of underlying cause of death, a complex task that involves the application of many ICD rules. The complexity of the process is such that it is difficult to ensure consistency of selection of underlying cause across individual nosologists. The use of ACME ensures that the participating states will provide consistent cause-of-death data to NCHS. These states will also make use of this information for their own purposes, while at the same time maximizing the output of their nosologists. The use of ACME also makes possible the production of multiple cause-of-death data, an enriched source of information essential for more intensive analysis of mortality data.

While ACME succeeds in ensuring consistent selection of the underlying cause of death, manual coding of each of the causes listed on the death certificate remains a lengthy process that requires well-trained and experienced nosologists. NCHS has produced an additional software program, "Mortality Medical Indexing, Classification, and Retrieval System" (MICAR) to address these requirements. MICAR essentially allows the coder to enter the standardized nomenclature and related information for each cause mentioned on the death certificate, and the software selects the appropriate ICD code. The use of MICAR reduces the time required to process a death certificate, shortens the training period required for nosologists, and reduces the amount of on-the-job training required for the trainee to reach expected levels of productivity and accuracy. In addition, it ensures greater consistency of coding of causes of death. Work currently is underway on an enhanced version of MICAR that will allow verbatim entry of cause information from the death certificate, rather than entry of standardized nomenclature. The enhanced version should allow for a substantial reduction in formal and on-the-job training required for nosologists. The use of MICAR, and eventually of the enhanced version of MICAR, provides dividends to the states using this software and improves the quality of cause-of-death data provided to NCHS.

3. Training.

A training program is essential for the effective development and growth of a national vital statistics system. NCHS provides a regular annual program of training courses for state vital statistics personnel. Two courses offered annually focus on vital statistics records and their administration, and on measurement and production of vital statistics. In addition, training is offered on an as-needed basis on the coding of causes of death. Several levels of nosology courses are offered, depending on the level of training required for the state vital statistics staff. The nosology training courses involve training in one or both of the software packages described above. Participation in all of these training courses is offered to the state systems at no charge. The benefits to the national system include assurance that state employees receive consistent training based on appropriate statistical standards, as well as enhancing the spirit of cooperation and communication between the national and state vital statistics systems.

NCHS also provides training materials for use by state and local vital statistics offices, as well as by other groups. To improve the quality of information on cause of death, NCHS produces and distributes large quantities of plastic instruction sheets for physicians on how to complete the medical certification section of the certificate. Other training material provided for physicians includes medical conference exhibits encouraging accurate reporting of causes of death, and continuing medical education courses.

4. Model certificates.

<u>Development</u>. A major reason for the successful production of consistent national vital statistics is the preparation of model or standard certificates for the registration of vital events. Once developed, the standard certificates serve as models for the development of state forms. These model forms are revised once every ten years, through a process that itself requires about six years. The lengthy time period is required to gather suggestions for changes from a variety of constituencies, including the state systems, federal officials, members of the research community, and public health specialists. The process of developing and implementing the standard certificates involves not only the preparation of the forms, but also the promotion of standard definitions, training materials, model registration laws, and other related activities.

The periodic review of the registration forms is designed to ensure that these forms reflect changing social conditions and user demands for vital statistics information. Because the forms have multiple uses, many factors must be considered in deciding what items to include or exclude in the revision process. Among the uses to be considered are: legal and administrative purposes, statistical information for state and local government agencies, and vital statistics data for the entire nation. In particular, care must be taken to meet data needs for the decade to come without overloading the forms with too many items. The composition of the panel of consultants assisting in the evaluation, which includes state vital registration executives, representatives of those responsible for completion of certificates, and data users, serves to ensure that these competing needs are reconciled in the revision of each standard certificate.

The revision process involves the creation of a consultant group to review the existing model certificates and recommend additions, deletions, and modifications. Subgroups are established for each of the model certificates, as well as one subgroup responsible for the format of all certificates. A parent group oversees the entire evaluation process. Each subgroup is asked to determine the extent to which information collected on the forms reflects current needs and anticipated needs for the decade to come, and to recommend revisions that will enhance the effectiveness of the certificates as data collection instruments. They are also to request written statements from selected persons who they believe can provide pertinent information on data needs and uses.

In addition to their own suggestions and those of the outside experts, the subgroups are charged with the collection of recommendations from a wide range of individuals and organizations that collect or use vital statistics data and have an interest in the content and format of the certificates. A questionnaire is prepared for each of the model certificates, requesting opinions on suggested changes to the model certificates, eliciting opinions on items currently on the certificates, and asking for other comments and suggestions regarding item content and format. Copies of the questionnaires are sent to a wide range of federal and state agencies, schools of medicine and public health, and national professional organizations. Each state vital registration executive is asked to suggest a list of persons or organizations within the state who should receive the questionnaires. Special care is taken to include organizations representing individuals responsible for the completion of certificates, such as state funeral directors associations, state hospital associations, and state medical societies. This approach helps to ensure that advice on the evaluation will be received from a wide variety of individuals and organizations at both the state and federal levels.

The subgroups use the outside input and their own expertise to decide on revisions in the content and format of each of the model certificates. Because many of the items under consideration are common to more than one certificate, the subgroups communicate with each other and sometimes meet in joint session. Their recommendations are reported to the parent group, which has responsibility for coordination of all the recommended changes. Final recommendations are presented to NCHS, and are reviewed and endorsed by the Association for Vital Registration and Statistics (AVRHS), the national association for state vital registration and statistics executives.

Once the recommendations have been endorsed at the federal level and by the AVRHS, the revised model certificates are officially transmitted to each of the state vital registration executives for implementation. While the objective is for each state certificate to resemble as closely as possible the corresponding model certificate, the state executive must go through a process similar to that followed by NCHS in developing the standards. That is, each state must seek input from representatives of those responsible for completing the forms and those who utilize vital statistics data. Each state then uses this input to assist in the development of its own revised certificates. Successful and smooth implementation of the revised certificates requires extensive and close communication between the state vital statistics offices and those parties in the states that will be most affected by the changes.

The extremely close cooperation between the states and NCHS in the revision process is necessitated by the lack of central control over the state vital statistics systems. A very positive result of this collaboration, along with the active involvement of others directly affected by the revisions, is the development of standards that represent a nationwide consensus of what should be included on the forms. This consensus has contributed significantly to the acceptance of the forms by the states, those who must complete them, and those who use the data.

<u>1989 revision of model certificates</u>. Most of the changes made in the 1989 revisions concerned the birth certificate. A Hispanic identifier for both the mother and father was introduced. Three items were added to obtain information on the method of delivery, obstetric procedures, and abnormal conditions of the newborn. A section on medical risk factors for the pregnancy was added, listing 17 specific factors. A separate item on other risk factors covered tobacco and alcohol use, along with weight gain during pregnancy. In a major change in format, all of the above sections plus those on complications of labor/delivery and congenital malformations were reformatted as checkbox items. An important change in the fetal death report was the addition of parents' occupation and industry worked during the last year. Changes to the death certificate included the addition of an Hispanic identifier and the inclusion of the decedent's education. The medical certification section was redesigned to simplify completion of this section, and instructions for completion were improved.

<u>Training in use of revised certificates</u>. An important part of the revision process is the preparation of revised or new training programs for the

individuals responsible for the completion of certificates. Objectives of these training programs are not only instruction on how to complete the forms, but also information about why the changes were made and how the resulting data will be used. Achievement of all of these objectives in advance of the use of the revised certificates helps to ensure a successful implementation process in the states.

While the states are each responsible for carrying out these training programs, NCHS assists the states by preparing instructional material in a variety of formats. One of the most important of these is the set of instructional handbooks prepared for each of the model certificates and for the specific individuals responsible for completing the forms. The manuals contain item-by-item instructions for completing each item, a rationale for collecting the information, and a description of how the registration system functions. The handbooks are provided to all of the states for distribution to individuals within the state or for use as guides in developing their own manuals. For the 1989 revision, states also received computer disks containing the text of the handbooks to facilitate the preparation of their own manuals. In all, eight handbooks were prepared for the 1989 model certificates.

Videotapes on how to complete each certificate are also prepared for use as training tools. Copies of the tapes are provided to each of the states, and they are encouraged to use the tapes in their training programs or to develop their own materials. In the 1989 revision, four videotapes were developed, one concerning the birth certificate and three addressing the death certificate. The death certificate videos were aimed at three separate groups responsible for completion of the death certificate: physicians, medical examiners, and funeral directors.

A final training item prepared for the 1989 model certificates was an audio cassette on proper completion of the medical certification of cause of death. The use of the audio cassette format was designed to facilitate the use of this item by physicians: the physician can listen to it while driving or on break, similar to current usage of journals or books on tape.

<u>Model registration laws and regulations</u>. To assist the states and other registration areas in the timely adoption of the revised model certificates, new or revised model registration laws and regulations are also prepared by an expert panel. The model laws are designed to improve the quality and uniformity of state data by establishing standard reporting requirements, definitions, and procedures for registering vital events. As with the model certificates, the standard laws and regulations serve as models for states in developing their own laws and regulations. They are designed so that most states can adopt them with few modifications. The model laws also attempt to provide the basis for vital statistics laws that will allow for the development of new technologies likely to evolve during the next 10-15 years.

Similar to the expert subgroups on model certificates, the model law committee is composed of state vital registration and statistics executives and a lawyer knowledgeable of state vital statistics programs. The committee's assignment is to review the existing model laws and regulations, determine if any changes are needed, and recommend appropriate revisions, additions, and deletions. In addition, the committee seeks input from states not represented on the committee, and requests comment on various aspects of the laws and regulations from a number of federal agencies and persons and organizations outside the vital statistics programs. The final draft of the revised model laws and regulations is submitted to the association of vital registration and statistics executives for their approval. Following approval by the AVRHS, the new model laws and regulations are submitted to NCHS, and after formal approval by the federal government, are published and distributed to the states as recommended model legislation.

Changes to the model laws often include revisions in the legal definitions of vital events. In the 1992 revisions, the definitions of live birth, fetal death, and induced termination of pregnancy were changed to promote uniform collection procedures and the proper use and interpretation of reproductive health statistics. The revised definitions were prepared and approved by several medical, vital statistics, and public health professional associations. The committee also determined that the recommended definitions did not differ significantly from those recommended by the World Health Organization.

Other changes to the model laws covered a wide range of items. Some of the more important changes concerned electronic filing of event certificates and related changes. Certain revisions were required to reflect technologically advanced methods of conception. Several other changes related to the review of requests for vital statistics data or records for research purposes.

5. Conferences

Routine means for constant communication and interchange help to ensure cooperation between national and local officials of vital statistics systems. One approach to the development and maintenance of such communication is NCHS support for a biennial conference on public health records and statistics. The conference is part of a permanent organization within NCHS, with working committees assigned to specific problems during the inter-meeting period, and with an executive committee composed of registration officials, public health officials, related individuals such as census officials, and NCHS officials. While many areas of public health statistics are included in the conference, vital records and statistics continue to be a major subject area.

The conference mechanism not only provides a formal vehicle for interchange but also provides the opportunity for valuable informal and personal exchange of information among the participants. The national association of vital records and statistics executives holds meetings in conjunction with the national conference. The conference provides a forum where national viewpoints concerning the development of a vital statistics system can be discussed with state and local registration officials. It has proven to be an invaluable mechanism for the advance of vital statistics in the United States.

V. Issues Concerning the Use of Statistics from Different Sources

Because the United States has a decentralized vital statistics system, the production of consistent and complete national vital statistics is highly dependent on developing a sense of cooperation and group consensus on a variety of data issues. For the most part, this effort is successful: model certificates are the basis for reporting forms in all of the registration areas, consistent definitions are used, coding standards are the same across jurisdictions. There are exceptions, however.

Although the level of comparability between the state certificates and the 1989 revisions of the standard certificates is among the highest ever achieved, some incompatibilities still exist. For example, four states still do not collect information on educational level on the death certificate, an item we consider important for measuring the socioeconomic status of the decedent. On the birth certificate, no information is collected on congenital anomalies in three states, and APGAR scores are not reported in two states. In addition, some items that are collected are not compatible: a good example is mother's marital status on the birth certificate. In most states, the individuals responsible for the completion of certificates. Objectives of these training programs are not only instruction on how to complete the forms, but also information about why the changes were made and how the resulting data will be used. Achievement of all of these objectives in advance of the use of the revised certificates helps to ensure a successful implementation process in the states.

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A different sort of incompatibility exists between birth and death certificates. The routine production of annual linked birth-infant death files made possible an assessment of the comparability of data items common to both certificates. The results of this study showed major differences in the determination of race and ethnic status across the two certificates. The differences have caused an important underestimation of the level of infant mortality in several racial or ethnic minorities, including American Indians (17%), Hispanics (9%), Chinese (21%), Japanese (21%), Filipinos (65%), and Other Asians (25%). The incompatibility appears to arise from the fact that demographic data on the death certificate are reported by funeral directors, who determine race and ethnicity either by information from next of kin or to an unknown extent by direct observation, while on the birth certificate information on race and ethnicity is obtained directly from the mother. Methods for addressing this problem are under study at present.

Similar problems may exist in comparisons of vital statistics and census data. While the total number of events recorded by the vital statistics system and the total population enumerated in the census are reasonably accurate, problems may arise when considering certain minority groups or certain small areas within the country. One such problem concerns mortality rates for minority populations. Mortality rates make use of vital statistics data on deaths for the numerator, and census information on the resident population for the denominator. If the determination of race or ethnicity of the decedent by funeral directors differs significantly from the determination of race or ethnicity of the population by the census, there will be a direct impact on the accuracy of mortality rates for these groups. As with the discussion of infant mortality rates above, the effect on rates for the majority population will be small, but such effects may be larger for some minority populations, particularly in selected small areas.

While the factors affecting race and ethnicity reporting on the death certificate were discussed above, problems with such reporting in the population census appear to be due to the use of self-reporting forms. For example, a study of the 1980 census found that in about half of the U.S. states there was a roughly 100 percent overreporting of population of Mexican-American ethnicity, apparently because the respondents misunderstood the question on ethnic ancestry. However, because these states have a very low Mexican-American population, the effect on the national estimate of the Mexican-American population was quite small (2-3 percent overstatement).

A final issue is the problem of census underenumeration of minority populations in city centers. Despite extra efforts in this area, undercounting of the population in city centers in the 1990 census remained an important problem. To the extent to which completeness of vital event reporting for these groups differs from completeness of the census count of the population, vital rates for these subgroups will be affected. The Bureau of the Census is considering the use of statistical techniques to adjust for this underenumeration in the next census. Such an adjustment will certainly lower the vital rates computed for these subgroups.

VI. Conclusion

The operation of the vital statistics system of the United States involves the integration of data from 57 separate registration systems into the national system. Cooperation of federal and state organizations is required to ensure complete and consistent reporting of vital events, and to adapt to changing information needs. Federal support for the state systems, including some funding support, along with technical assistance in the areas of training, statistical standards, model certificates, and other activities all serve to promote cooperation between the federal and state systems. Incompatibilities in the data used to produce national vital statistics are relatively few, and are limited mainly to racial and ethnic classifications and certain small areas of the country. The national system functions well because the federal and state systems are mutually supportive and a high degree of cooperation exists between them.

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