

September 9, 2009

## Report of the Long-Term Care Statistics Program Review Panel to the NCHS Board of Scientific Counselors

### Overview

The Board of Scientific Counselors (BSC) of the National Center for Health Statistics (NCHS), Centers for Disease Control and Prevention (CDC) commissioned a panel to review the Long-Term Care Statistics Program (LTCSP) as part of an on-going program review process and to report its findings to the BSC. The Long-Term Care Statistics Program is administered by the Long-Term Care Statistics Branch (LTCSB) in the Division of Health Care Statistics (DHCS), NCHS. This report summarizes the review process; examines the diverse and changing long-term care (LTC) sector and resulting data implications; describes the LTCSB, its surveys, the data produced, and the users and uses of that information; outlines the issues and challenges facing the LTCSB; and presents a series of recommendations.

The panel believes that NCHS could be in a unique position to address the nation's future information needs for long-term care. Long-term care already is a significant component of health care and will become even more important as the population ages. Public programs pay for a substantial share of LTC services. Having sufficient information to guide those programs is essential. The nature of long-term care with its diverse and evolving types of services means most data sources provide only fragmentary and not fully representative information. To be fully responsive to the changing LTC environment moving forward, NCHS and the LTCSB will need to provide more regular, frequent data on a wider range of LTC provider types.

The LTCSB and the data it collects play an important role in understanding key provider sectors of the LTC system. The potential value of the LTCSB's contribution is, however, limited by the scarce resources available and by the lack of a coordinated NCHS-wide strategy for assessing future LTC information needs and deploying LTC survey resources accordingly. Although the LTCSB plans to field a new survey of licensed assisted living and other residential care facilities, the scope of the current surveys does not cover a major share of long-term care. Further, current provider surveys have been fielded on an irregular basis; data dissemination has been delayed; and pursuit of options to enhance the data's value and use are precluded.

To deliver more comprehensive information would involve a considerable expansion of existing activities and resources. The panel recommends that such an expansion be considered through a *comprehensive, strategic assessment of LTC data needs and priorities, alternative data sources, data gaps, and the most efficient means of filling them*. At the same time, the Panel recommends moving *toward a unified set of National Long-Term Care Provider Surveys to create a single conceptual framework and*

*operational platform for all of the long-term care provider surveys.* This should increase both the effectiveness and efficiency of on-going survey work. Finally, the Panel recommends a series of more specific actions that would enhance the value of both current and future surveys. The Panel’s recommendations are detailed beginning on page 14 of this report.

### **Review Process**

The LTCSP Review Panel members (attachment 1) met on February 4 and 5, 2009, at the National Center for Health Statistics, following an established agenda (attachment 2). Subsequently the panel conferred through e-mails and conference calls to reach consensus on its recommendations. Throughout the review process, the Panel reviewed and revised versions of the report prior to submitting the final Panel report to the BSC. In its deliberations, the Panel followed the “Procedures for Reviewing NCHS Programs” established by the BSC (attachment 3) which call for the reviewers to examine the current status, scientific quality, and responsiveness of each program within the context of its mission. Further, the review procedures require that the review take into account future availability of financial and staffing resources, emphasize forward thinking and future plans as well as assess current operations, and conduct an interactive review that obtains information from written materials, presentations, and discussion with program staff.

In advance, the Panel received a number of documents (attachment 4) providing background information on the LTCSB. Panel members also submitted additional questions to the LTCSB (attachment 5) to be addressed during the Panel meeting. During the two-day meeting, they heard presentations from Dr. Edward Sondik, NCHS Director; Dr. Jennifer Madans, Associate Director for Science and Acting Deputy Director, NCHS; Dr. Jane Sisk, Director, Division of Health Care Statistics; and Dr. Lauren Harris-Kojetin, Chief, Long-Term Care Statistics Branch. In addition, LTCSB members Anita Bercovitz, Christine Caffrey, Nicole Cooper, Frederic Decker, Lisa Dwyer, Adrienne Jones, Abbie Moss, Eunice Park-Lee, and Manisha Senguta attended and made brief presentations, answered technical questions or provided additional information on a number of aspects of the LTCSB.

To illustrate the use of data from the LTCSB for policy purposes and applications in the Department of Health and Human Services (DHHS) there were a number of presentations. Ruth E. Katz, Deputy to the Deputy Assistant Secretary, Office of Disability Aging and Long-Term Care Policy, Office of the Assistant Secretary for Planning and Evaluation, DHHS; William Marton, Director, Division of Disability and Aging Policy; and Gavin Kennedy, Director, Division of Long-Term Care Policy spoke of the importance of the LTSCB surveys and the data they produce.

## **Context for the Recommendations: Diverse and Changing LTC Sector**

The diverse and changing LTC sector presents multiple opportunities for NCHS to strengthen its data activities to better serve the emerging needs of LTC policy makers and providers. At the same time, the multiplicity and diversity of potential demands pose significant challenges to the cost effective allocation of scarce data resources. Here we briefly highlight several key features of the evolving LTC sector. A fuller assessment of these should be a critical component of the comprehensive strategic planning effort that is one of the Panel's key recommendations. The Panel notes that there is precedent for such a strategic assessment in the report *Toward a National Health Care Survey: A Data System for the 21<sup>st</sup> Century*, issued by the National Academy of Sciences in 1992.<sup>1</sup>

### Diverse Services, Settings and Providers

Long-term care is a variety of services that includes medical and non-medical care to people who have a chronic illness or disability. Long-term care helps meet health or personal needs. Most long-term care is to assist people with support services such as activities of daily living like dressing, bathing, and using the bathroom. Long-term care can be provided at home, in the community, in assisted living or in nursing homes.<sup>2</sup> A major portion of long-term care at home is provided by unpaid family members or others. Paid in-home care may be provided by agencies or by workers hired directly by the care recipient.

### Growing Demand

The number of people in the United States over age 65 is projected to nearly double in the next quarter century, growing to more than 71 million people by 2030. The oldest old, those 85 and over, are the fastest growing segment of this population. Many of those seniors can live healthy lives without assistance in their own homes for years, but many will require some type of long-term care and support. Thus current projections estimate that people turning age 65 will require on average three years of LTC over the rest of their lives.<sup>3</sup> The sheer numbers of this cohort will increase the need for long-term care in all its varied settings and types. In addition, at the other end of the age spectrum, the number of children and young adults with disabilities is also increasing. Life-saving and life-prolonging medical care and new technologies have increased the survival of seriously ill younger people. These children, teens and young adults will need long-term care to assist them in their homes or in nursing homes and residential facilities.

### Rapid Change

The provision of paid long-term care has changed significantly over the past 25-30 years and is certain to continue to change. Nursing homes were once the predominant source of residential based long-term care. However, the supply of nursing homes has increased

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<sup>1</sup> <http://books.nap.edu/catalog/1951.html>.

<sup>2</sup> <http://www.medicare.gov/LongTermCare/static/Home.asp>

<sup>3</sup> Kemper, Komisar and Alexcih, *Inquiry* 2005/2006.

little over the past two decades as the elderly population has grown. Currently approximately 1.6 million individuals reside in nursing homes, only modestly more than the number two decades ago. Assisted living emerged as an industry in the 1990s, and today there are about 1 million assisted living residents. The use of paid in-home care of different types has increased dramatically. Home health care involves mostly skilled nursing and therapy services. In 1980, there were 2.9 million users of Medicare-certified home health agencies; by 2006 there were more than 8 million. Reductions in hospital lengths of stay and a liberalization of Medicare coverage rules contributed significantly to this increase. Home care, another type of in-home care, generally involves more personal support (e.g., assistance with activities of daily living) from unlicensed personnel. It also increased substantially. State Medicaid programs, which used to fund almost exclusively nursing home care, have shifted resources to home and community-based services. Today the numbers of Medicaid beneficiaries receiving LTC services in nursing homes and at home or in the community are almost equal. Although Medicaid nursing home expenditures are about \$64 billion annually, Medicaid spending on home and community based services is now approximately \$42 billion, up from \$19 billion in 2000.<sup>4</sup> Monitoring these changes is complicated by the multiplicity of provider types and the lack of uniform definitions or standards across types or for a single type across states.

### Multiple Payers

Long-term care is financed by multiple sources. Personal support services are not covered by ordinary health insurance. Medicare coverage of skilled nursing facilities and home health care is primarily for skilled nursing or therapy services. Medicare coverage is often for short periods as individuals recover following a hospitalization. Longer nursing home or assisted living stays and purchased in-home care generally involve personal support services. These are paid either out-of-pocket or by state Medicaid programs or private long-term care insurance. Today, state Medicaid programs are the largest purchaser of LTC services – both nursing home care and care delivered in the home.

### Interaction with Medical Care

Concern over health care expenditures has brought increasing attention to persons with multiple chronic conditions who use the bulk of health care services. The 14 percent of the population with 3 or more chronic conditions account for almost 50 percent of health spending. Within this group, individuals with both chronic conditions and disabilities requiring long-term care are disproportionately represented. It is believed that better coordination of their services might postpone or prevent the need for additional and more intensive services. The ability to understand how differences in service utilization may contribute to or reduce expenditures is limited due to the lack of comprehensive data on individuals' health and LTC service use.

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<sup>4</sup> <http://www.hcbs.org/files/145/7239/2007LTCExpenditures.pdf>

## Description of the Long-Term Care Statistics Branch

The LTCSB is one of three branches within the DHCS and conducts all of the LTC surveys for NCHS. The mission of the NCHS is to monitor the health and health care of American, as one of the designated Federal statistical agencies. The mission of the DHCS is to collect, analyze, and disseminate data on access to and use, quality and cost of U.S. health care services and on the health-care organizations and professionals who deliver those services. DHCS conducts the National Health Care Surveys, a family of nationally representative surveys of encounters and health care providers in different settings. The mission of the LTCSB is to collect, analyze and disseminate accurate, relevant and timely data on U.S. long-term care providers, their services, their staff and the people they serve. These data are intended to provide information to inform decision making by long-term care providers, policymakers and researchers.

### LTCSB Staffing

The LTCSB currently consists of 10 staff members. There are two vacancies to fill--one the result of the retirement of a 38-year veteran who was the project officer for the upcoming National Survey of Residential Care Facilities (NSRCF). Together, the LTCSB staff has a mix of expertise in health services research, survey methods and statistical analysis. Although the LTC surveys are contracted out to vendor organizations, which conduct the surveys, implement initial data edits, and document the files for NCHS, the LTCSB staff bears overall responsibility for planning, supervising and completing this entire process. Staff members conduct extensive additional edits, assess risk disclosure, and prepare documentation for the public use files. In addition, they disseminate the survey data, provide technical assistance to users, conduct their own analyses, and disseminate survey findings through a variety of print and web-based venues.

### Long-Term Care Surveys

The long-term care surveys of the LTCSB cover nursing homes, nursing assistants, home and hospice care agencies, home health and hospice aides and residential care facilities. Detailed information on the surveys' scope and content, methodology, survey operations, and findings are available on the NHCS website at <http://www.cdc.gov/nchs/nhcs.htm>. A brief description of each survey is provided below.

LTCBS surveys include the:

- *National Nursing Home Survey (NNHS)* – The NNHS is a nationally representative sample survey of nursing homes in the United States that has been conducted 7 times beginning in 1973 and most recently in 2004-2005. Although each of these surveys emphasized different topics, they all provided basic information about nursing homes, their services, staffs, and residents. All nursing homes included in the NNHS had at least three beds and were either certified by Medicare or Medicaid or had a state license to operate as a nursing home. The NNHS provides information on nursing homes from two perspectives: the

provider of services and the recipient of care. Data about the facilities include size, ownership, certification, services provided and specialty programs offered and charges billed. For recipients of care, the data include demographic characteristics, health status, services received, and sources of payment and, in the 2004 NNHS, medications received. NNHS data have been obtained through personal interviews with facility administrators and designated staff, who used administrative records to answer question about the facilities, staff, services and programs and medical records to answer questions about the residents.

The NNHS was out of the field and redesigned between 1999 and 2004. Key features of the redesign included transition from paper and pencil data collection to a computer-assisted personal interview (CAPI) system, expanded survey content to incorporate new items on high-profile policy issues, increased sample of current residents to permit more detailed analysis by subgroups (race, for example), and inclusion of sample design variables in the public use files to aid users in accounting for the complex sample design in the calculation of accurate standard errors for the survey estimates. Another feature of the redesign was linkage to the Centers for Medicare and Medicaid Services (CMS) Minimum Data Set (MDS) data to provide additional clinical content. Perhaps the most significant change was the addition of a supplemental survey of certified nursing assistants (CNAs) employed by nursing homes. The National Nursing Assistant Supplement (described below) is the first survey of health care workers who provide the majority of hands-on care to nursing home residents.

The 2004 NNHS used a stratified two-stage probability sample design. At the first stage, a sample of 1,500 nursing homes was selected from the universe of about 16,600 nursing homes in the United States. A total of 1,174 facilities participated in the first stage for a response rate of 81 percent. The second stage sampling of current residents achieved a response rate of 96 percent for an overall response rate of 78 percent for the NNHS resident component.

- *National Nursing Assistant Survey (NNAS)* – the NNAS was first fielded in 2004-2005 as a supplement to the NNHS and is based on a randomly selected sub-sample of 790 nursing homes from the full NNHS sample. Among this sub-sample of 790 NNHS nursing homes, 76 percent were eligible for and participated in the NNAS by providing lists of their CNAs from which random samples could be drawn. NNAS was administered using a computer-assisted telephone interview (CATI). CNAs were interviewed during non-working hours and asked about recruitment; education; training and licensure; job history; family life; management and supervision; client relations, organizational commitment and job satisfaction; workplace environment; work-related injuries and socio-demographic characteristics. This second phase had a 71 percent response for an overall response rate of 53 percent for the NNAS. .
- *National Home and Hospice Care Survey (NHHCS)* – The NHHCS is a nationally representative sample survey of home and hospice care agencies in the United

States. The survey was first conducted in 1992, fielded 5 more times through 2000, and most recently conducted in 2007-2008. Information has been collected about agencies that provide home and/or hospice care and about their staff, services, current patients, and discharges. The survey covers all agencies that are licensed or certified by Medicare or Medicaid. Data for NHHCS have been collected through personal interviews with agency directors and staff, who have used administrative records to answer questions about the agencies, staff, services and programs, and used medical records to answer questions about patients. The NHHCS was redesigned during the period 2001 to 2007. The redesign is similar to that of the NNHS in many ways—transition to CAPI, expanded content, increased sample of current home health patients and of hospice discharges for subgroup analysis, better information for sample error calculation by public use file users, and planned linkage to the CMS Outcome and Assessment Information Set (OASIS) for additional clinical content. As with the NNHS, the 2007 NHHCS included a supplemental survey of the staff that provides a substantial part of the direct care, this time for those receiving care from home health and hospice agencies. The National Home Health Aide Survey (described below) is the first survey of these essential workers.

The 2007 NHHCS used a stratified two-stage probability sample design. At the first stage, a sample of 1,545 home health and hospice agencies was selected from the universe of over 15,000 home health and hospice agencies in the United States, stratified by agency type and metropolitan statistical area status. This stage of the survey had a response rate of 71 percent. The second stage sampling of current patients from home health agencies and discharges from hospice agencies was carried out by the interviewers at the time of their visits to the agencies and had a response rate of 95 percent. The overall response rate for the patient/discharge component of NHHCS was 67 percent.

- *National Home Health Aide Survey (NHHAS)* – The NHHAS was conducted as a supplement to the 2007-08 NHHCS. From the sample of 1,034 agencies that participated in some aspect of NHHCS, 961 provided a list of aides from which a sample of 4,416 aides was drawn. NHHAS was administered using CATI during the aides' nonworking hours. Agencies provided contact information on aides who could either call in or send in a post card to indicate their willingness to participate in the survey. This phase of the survey achieved a response rate of 80 percent for an overall response rate of 57 percent for the NHHAS. Like the NNAS, the NHHAS questionnaire consisted of 11 modules, the first of which screened for eligibility. The remaining modules addressed recruitment, education, training and licensure, job history, family life, management and supervision, client relations, organizational commitment and job satisfaction, workplace environment, work-related injuries, and socio-demographics characteristics.
- *National Survey of Residential Care Facilities (NSRCF)* – The NSRCF is intended to provide national estimates on the number of licensed assisted living and other residential care facilities operating in the United States, the number of

residents receiving care in these facilities, and the characteristics of both the facilities and the residents. The NSRCF was piloted and pretested in 2008; full implementation of the survey is scheduled to start in early 2010 with a goal of completing interviews with 2,250 facilities. This will be the first national survey of residential facilities. NSRCF data will be collected through in-person interviews using CAPI. Facility directors will answer questions about the facilities, staff services and programs based on their knowledge and/or the use of administrative records. Facility directors or designated staff will answer questions about residents' health, functional status and services, based on their own knowledge or by referring to resident records.

### Collaborators

LTCSB collaborators include government agencies that have provided funding to help support the surveys, LTC experts who have contributed to the development or re-design of the surveys, and provider associations that have encouraged survey participation by members of their organizations.

- Federal agency collaborators include:
  - Assistant Secretary for Planning and Evaluation, DHHS – collaborated on the design and provided the funding for the NNAS and the NHHAS. ASPE has also supported the development of the NSRCF and provided funding for the pilot and pretest in 2008. This collaboration has been critical, allowing the LTCSB to expand data collection into key areas of staffing and new and growing types of facilities.
  - The National Immunization Program (NIP), CDC – collaborated on the development of survey items on staff and resident immunization practices and funded that component in the NNHS.
  - Department of Veterans Affairs (VA) – provided funds to include veteran status of residents/patients in the NNHS, NHHCS and NSRCF as well as providing funds to include VA as a payment source in the NNHS and NHHCS.
  - Agency for Health Care Research and Quality (AHRQ) – contributed funds toward the development of a methodology for constructing a list of residential care places, a precursor developmental activity to the creation of the NSRCF sampling frame.
  - National Institute on Aging (NIA) – contributed funds for the development of a residential care typology, used to inform the development of NSRCF.
  
- A wide range of technical experts have participated in the design and redesign of the LTCSB surveys by serving on technical advisory groups on the redesign of the NNHS and the NHHCS and the supplements to those surveys, the NNAS and the NHHAS. Earlier working groups provided advice on various aspects of hospice and home health care for inclusion in the NHHCS. Most recently a Technical Expert Panel reviewed plans for the NSRCF.

- Organizations that represent the providers sampled in the LTCSB surveys have supported those surveys with letters to increase awareness of and participation in the LTCSB surveys. The major associations in the LTC field have provided letters of support for the NNHS, NHHCS, NSRCF, NNAS and the NHHAS. For the NSRCF the associations of assisted living communities also participated in a series of meetings to enhance cooperation for the survey. (See Attachment 6 for a list of supporting organizations.)

### Data Dissemination

Data from the long-term care surveys are made available to the public in various formats and through a range of mechanisms. After a thorough process of data cleanup and editing and a careful process of disclosure risk analysis, public use files are created for all of the LTCSB surveys. Each survey results in multiple files to group data by source, such as a facility file; or by client, for example, a resident file; or by service provided, such as a medications file. Downloadable public use files are available from the LTSCB web sites along with full documentation and data dictionaries. SAS data files are available as well as ASCII files with accompanying SAS, SPSS and STATA input statements for the recent surveys. The NNHS web site is at <http://www.cdc.gov/nchs/nnhs.htm> and the NHHCS is at <http://www.cdc.gov/nchs/nhhcs.htm>. For some of the surveys, detailed and extensive web tables to provide easy access to frequently requested data are also available on the web sites.

LTCSB staff produces a number of NCHS reports that present the findings from the surveys. They also author articles in peer-reviewed journals and make presentations at policy and research conferences in health care and aging. The LTCSB staff has responded to a high volume of requests for direct technical assistance and customized data products from individual and groups of data users. There is a LTC listserv, which provides a way to keep in touch with data users and inform them of new data releases, new analytical tools and services, and other opportunities to analyze and utilize the data.

### Data Users and Uses

Data from the LTCSB surveys are used for health care research, planning and public policy. NNHS and NHHCS data are resources for health reform deliberations and planning. Some of the primary users of the LTCSB survey data are the DHHS agencies, which help sponsor the surveys and other DHHS agencies with responsibilities for the planning, evaluation, funding and management of long-term care programs and services. Federal agencies use the LTCSB findings for developing the policies and regulations that govern the access, availability and quality of the LTC providers and services covered by the surveys. In particular, the data have been used by policy makers and program managers in the nursing home, home health and hospice care sectors. Research and non-profit organizations, foundations, and universities are also users of the LTCSB data.

Many users need LTSCB data to describe and profile the current status of the surveyed long-term care providers and to track trends and changes in facilities, staff and

residents/patients. Monitoring developments in the long-term care field is a basic--but essential--use of the data. For example, showing that while nursing home use has declined, the disease prevalence and comorbidity among residents has increased is an important finding from the latest NNHS. This and other findings from the 2004 NNHS appeared in the major reports on aging, health care quality, and health in America published by Federal agencies tracking the key indicators. Another tracking initiative in prevention and health promotion—Healthy People—uses the NNHS data to check the progress in the prevention of pressure ulcers among nursing home residents; this is one of the key measures by which quality of care can be assessed. Other agencies examine results from the NNHS to determine the level of oral health, the extent of conditions such as incontinence, and the prevalence of diabetes and other chronic conditions. The National Immunization Program checks the level of immunizations among staff and residents through the NNHS surveys. University researchers in collaboration with DHCS and LTCSB staff are analyzing the NNHS data to measure the frequency of inappropriate use of medications and the relationship between job tenure of nursing home administrators and directors of nursing and quality of care.

The NHHCS provides the data to describe the patterns of home health and hospice care. The Food and Drug Administration, with responsibilities in the area of medical devices, used NHHCS data to quantify the number and types of special devices used in home health care and information about the sources of those devices. Still other studies have examined home health agency characteristics, such as profit orientation, and quality of care. The NHHCS has been an important publicly available source of information on key characteristics of licensed or certified home health care and hospice agencies and their patients. Together, the surveys in the LTCBS portfolio have had much to offer in terms of monitoring the characteristics of the surveyed long-term care providers.

### **Issues and Challenges Facing the LTCSB**

The LTCSB has an impressive record of conducting long-term care provider surveys and making the data available for multiple purposes. However, the Branch has faced a number of challenges that have made it difficult or impossible to conduct the existing or planned long-term care surveys in a regular and timely fashion, let alone supply data on the broader range of services that comprise long-term care. Funding shortages have delayed the start of the NSRCF from 2009 to 2010. In addition, the long-standing shortages in funding and staff often have delayed the analysis and dissemination of data from completed surveys.

#### **Staff Shortages**

The Branch currently has 10 staff members out of its quota of 12 positions, after more than a year of being down 4 positions. The Branch has no authorization to fill the two current vacancies. Understaffing has caused the staff to make continuing survey operations (including data collection and data release functions) a top and essential priority over more long-term planning and analytical functions. While the Branch has a

multi-disciplinary staff, the Branch lacks some of the industry, practice, and clinical expertise that would be helpful in the design and conduct of the surveys and the analysis of the data in ways meaningful for clinical practitioners and practice-relevant research. Because hiring new staff with the research and statistical expertise in combination with their clinical background may be difficult, the Branch is exploring alternative ways of gaining these staff resources, such as through internships.

### Budget Shortfalls and Uncertainty

Obtaining adequate and secure funding for the LTCSB has been a continuing problem that affects every aspect of the Branch's operations and the decisions made on each of the LTCSB surveys. This is not a problem unique to the LTCSB, since all of the NCHS data systems have budget concerns. However, since the LTCSB and the DHCS overall conduct a number of relatively smaller surveys compared to the other NCHS data programs, budget problems have more frequently meant that a particular health care survey would be postponed for one or many more years rather than fielded on schedule with a reduced sample. From 1992 through 2000, the NNHS and the NHHCS were fielded in alternate years, so that an LTC survey was conducted each year. Since the NNHS and the NHHCS were removed from the field for redesign, each has been fielded only once since 2000, NNHS in 2004 and NHHCS in 2007. The lack and uncertainty of funding prohibit the LTCSB from better determining the optimum schedule for fielding the LTC surveys and implementing that schedule.

Funding from federal agency collaborators has been important in varying degrees to the LTC surveys. External funding supported 9 percent of the NNHS and 16 percent of the NHHCS, but external funding supported 100 percent of the direct health care worker survey supplements (NNAS and NHHAS). It is expected that external sources will fund about 83 percent of the NSRCF, with NCHS supplying the remaining 17 percent. However, an unavoidable delay in funding from ASPE led to a delay in fielding the NSRCF from 2009 to 2010, at which time funds will be available. Other Federal agencies that collaborate with NCHS to develop and conduct surveys experience the same uncertainty in funding and budgetary restraints that NCHS does. Thus, the problem of having reliable, adequate funding is magnified. The LTCSB is working hard to identify other possible collaborators, but that type of outreach takes staff time and effort and will not always, or even usually, result in bringing in new funds for the surveys.

### Timeliness

Both a shortage of staff to devote to data processing and data release functions as well as the periodic and irregular fielding of LTC surveys over time have resulted in data that are often viewed as not timely. The heavy demands of survey operations and time-consuming steps, such as disclosure risk avoidance, to prepare public use data files based on provider data have contributed to the problem. However, staff has taken some actions to speed up data processing and enhance the data products from the NHHCS and the 2007 public use files and documentation were released in record time.

## Scope and Coverage

While the usefulness of the data depends upon the timeliness of the data release and the policy-relevant content of the surveys (new items were added to the latest NNHS and the NHHCS to enhance their policy relevance), an even more basic factor affecting the value and relevance of the data is the scope and coverage of the surveys. Collecting data on nursing assistants and home health aides has been a significant step forward. These health care workers are greatly in demand and will be more so in the future. The occupational category of personal and home care aides is the nation's second fastest growing, according to the Bureau of Labor Statistics and has a turnover rate 40 to 50 percent a year. The newly available survey data should help answer important questions such as what motivates people to enter this field and what factors in their working conditions make it more or less likely that they will stay. The NSRCF will provide the first nationally representative data on licensed and regulated residential long-term care providers outside of nursing homes.

Even with these new data, the long-term care provider surveys do not cover all of the types of long-term care providers, including several that are growing in importance and frequency of use and which command an increasingly large share of the long-term care dollar. Assisted living and residential care facilities that are not state-regulated (i.e., that are not licensed, registered or otherwise regulated by the state) are one example. Due to state variations in licensing and regulation, many assisted living, residential care facilities and congregate care settings that provide LTC services are not necessarily state-regulated and will not fall under the purview of the NSRCF. Non-residential adult day care centers, which provide supervision and non-health related services for disabled adults both young and old, also are a provider category about which relatively little is known.

Another critical gap is the limited information on a wide range of providers that deliver care to individuals in their homes. The National Home and Hospice Care Survey samples only agencies that either are certified by Medicare and/or Medicaid or were licensed by a state to provide home health and/or hospice services. These agencies are distinguished by providing the skilled services of nurses or therapists. There is limited information on personal care and assistance with other daily tasks (e.g., homemaker or housekeeping services, or assistance with instrumental activities of daily living [IADLs]) provided through unlicensed agencies, employment exchanges, consumer-directed care programs, state or county social service programs and the like. In many cases, such assistance is publicly funded but may be provided by family members, friends or other acquaintances. In the majority of instances, however, home-based LTC services are provided by family and other informal caregivers who are not formally compensated for their work. Periodic, person-level information on sources of both paid and unpaid home and community-based care are needed to identify gaps in coverage of the provider surveys, identify emerging trends in delivery, and inform the most cost-effective deployment of future provider-level surveys.

## Role of State Policy

State policies play a central role in determining what long-term care is available and how it is financed. State Medicaid programs, as indicated, are the largest purchaser of LTC services—both nursing home care and care delivered in the home. State policies have a strong influence over the use and supply of all LTC services--whether financed by state or federal tax dollars or by personal expenditures. There is substantial variation in those policies regarding how many nursing home beds may be built, the eligibility standards for nursing home or home care assistance and the payments for these services. There is also substantial variation in the type, content and quality of policy relevant data that states are collecting. Many states have been and are continuing to modify their LTC policies seeking a more efficient and effective allocation of their resources. The variation and importance of state policy pose difficult challenges for the Division. Moving forward, strategic planning and the design of the provider surveys should recognize the importance of state policy and differences across states in policy and other dimensions. The usefulness of the LTC provider surveys might be enhanced, for example, by taking into account emerging state-level policy developments as survey content is developed, considering linking surveys to state Medicaid data at the resident or facility level, considering the importance of state as an explanatory variable in developing the sample design, enabling states to take advantage of sample frames, and ensuring researchers' access to state information through data centers to ensure confidentiality. The panel recognizes the potential difficulties of undertaking any of these design changes, but urges the Division to consider the importance of state-level differences in its strategic planning decisions.

## Response Rates and Data Quality

Many surveys are experiencing declining response rates, with the problem being more acute for some data collection efforts than others. Surveys of providers have always had to persuade those providers that the information collected will benefit them sufficiently to take time away from business operations. Participating in surveys is not an income-producing function but a time-consuming activity with no immediate payoff. LTC facilities are required to provide information in many instances--certification, inspection, licensing—by government and regulatory agencies. A voluntary health survey has to prove its worth. While the LTCSB tries to do that and succeeds in great measure, facility response rates have been declining in both the NNHS and the NHHCS. The proliferation of chain-owned facilities is credited with much of the downturn in response because chain nursing homes are more likely to refuse and it takes more time to gain approval from a corporate office than at the facility level. Sometimes the window for data collection closes before the survey can be administered in the facility. In future surveys, the LTCSB plans to engage in more outreach to corporate offices prior to implementing the surveys and to streamline the content to reduce response burden to make the surveys more acceptable to corporate officials. LTCSB is also building closer ties to provider associations to increase survey response.

### Exploiting Existing Sources of Information

Since the inception of the NNHS, a number of administrative data sources for LTC providers and users have developed. Medicare and Medicaid collect uniform information about residents of nursing homes and some users of home health care. The programs also collect information about all certified providers as part of the certification and quality assurance processes. The nationally mandated uniform nursing home Minimum Data Set (MDS) and home health care Outcomes and Assessment Information Set (OASIS) provide rich information on the clinical and functional status of the populations they include. The extent to which these administrative data can complement or substitute for information in the LTCSB surveys is an important issue. Making the best use of available administrative data could greatly enrich the surveys and free up resources to expand the scope into areas not currently covered. Linkage to these data sets is now possible as part of the recent redesign of both the NNHS and the NHHCS and should be actively pursued to the extent permitted by law.

### Outreach to Data Users/Input from Data Users

The use of the data from the LTCSB is substantial but falls far short of the potential given the range of information relevant to current policy issues collected in the LTC surveys. The LTCSB has documented the use of its data by DHHS agencies, such as ASPE, CMS, AHRQ, FDA, and CDC, and by researchers in the industry and non-profit organizations, but there is the potential for more widespread use. The LTCSB has plans to expand this use by identifying possible audiences and the best communication channels to reach them. There will be special initiatives to target students and faculty in appropriate university departments and to target a greater number of associations. DHCS has undertaken several users' surveys to describe better the current use of the data in the Division and to identify unmet data needs and potential new users. LTCSB Staff will also be collecting and making more systematic use of the information from LTCSB data requestors.

As essential as the flow of information from survey to data users is the flow of information back to survey staff for use in strategic planning efforts. The surveys have constituencies who provide feedback and the LTCSB has convened meetings of technical experts. However, it has not consistently and comprehensively incorporated that information and other knowledge of data needs and planning and policy priorities into a systematic strategic planning process focused on long-term care.

### **Recommendations**

The panel developed a series of recommendations based on its deliberations during the panel meetings, knowledge of the current and evolving nature of long-term care in the United States, an assessment of changing data requirements, an awareness of the multiple sources of data, and an understanding of the scope and capacity of the LTCSB surveys. The panel concluded that the LTCSB was doing a very good job with its current level of

resources and that the surveys conducted in the past and the more recent data expansion efforts have provided very important information about long-term care.

Moving forward, major population and policy challenges affecting long-term care are virtually upon us. Therefore, the panel believes that now is the time for NCHS to undertake a strategic review of future long-term care data needs to determine the agency's vital contribution to meeting those needs. With this as a premise, the panel makes two broad recommendations regarding future directions for NCHS's long-term care surveys. Then we make a series of more specific recommendations related to the conduct of ongoing and future surveys.

### **Overarching Recommendations**

- 1. Develop a strategic plan to define NCHS's role in the collection of long-term care data to meet future policy needs. This strategic plan should be based on a thorough and comprehensive assessment of:**
  - a. How long-term care is currently provided and financed**
  - b. The data needed to inform policy decisions regarding long-term care**
  - c. The data on long-term care provision and financing currently collected by NCHS and other public and private entities (e.g., Centers for Medicare and Medicaid Services, National Institute on Aging)**
  - d. The gaps in currently available data for policy purposes**
  - e. Currently collected data that are no longer a priority or that require modifications to increase their usefulness**
  - f. The priorities and strategies for addressing data gaps including new provider-based or person-based surveys or a combination.**

As described above, the current long-term care surveys, while providing much valuable information, do not cover the full range of long-term care services and could be more useful in providing information relevant to LTC policy makers, both state and federal. A strategy to correct the most important of these deficiencies is essential. The precise magnitude and significance of what data are not being collected is impossible to know at present. On the basis of the aggregate information available, it is apparent that there are major deficiencies. Identifying what new data would provide the greatest value requires greater knowledge of the distribution of services by provider type, financing, and the needs of the persons being served.

To support the strategic planning process, the panel recommends that NCHS seek resources for the conduct of a survey of persons living at home and needing long-term care. Similar to, but perhaps more modest than, the National Health Interview Survey on Disability conducted in 1994-95, this type of survey should provide detailed information about the distribution of LTC services and providers and should be conducted as expeditiously as possible. Consideration should be given to how existing surveys, such as the National Health Interview Survey and the National Long Term Care Survey conducted under the auspices of the National Institute on Aging and its successor the National Health and Aging Trend Study (NHATS) (which samples only older persons)

might be used and/or modified to reduce the costs and expedite the process of collecting such information. While the proposed survey may be seen as an extensive undertaking for a strategic planning effort, it would have considerable value. First, such “demand side” (i.e., individual level) information would provide a much sounder basis for allocating resources to future LTC provider surveys on the “supply side” by identifying important new classes of providers and provider types and documenting current information gaps. Second, this information would assist in the design of surveys of additional types of LTC providers, particularly in how appropriate sampling frames may be developed. Third, it would provide a baseline of information about the current population needing long-term care, their needs and service use, and service financing. Because such data were last collected almost 15 years ago, this current information would have significant value for policy purposes. Lastly, such a person-level survey could be a potential model for future periodic, person-level surveys to support ongoing assessment of the match between LTC information needs and NCHS allocation of its LTC survey resources.

A fundamental question to be answered from the recommended strategic planning effort is whether NCHS’s overall approach, primary reliance on provider based surveys, is the best or only option for collecting the long-term care data needed for policy purposes. Provider-based surveys have obvious advantages. Sampling frames for certain provider types may be readily available and there are significant efficiencies in gathering data on multiple service recipients from a single source. However, the construction of a suitable sample frame for some provider types may be extremely difficult, if not impossible. These include, for example, workers hired directly by care recipients and perhaps workers paid by Medicaid or social service programs. It may be very important for policy purposes to have adequate information about these types of providers. That would be the case if they are providing a significant share of long-term care services and/or if understanding how their supply responds to public policies is deemed important. NCHS may then need to consider periodic use of person-based surveys as part of its long-term care survey efforts.

**2. Integrate all existing and future long-term care provider surveys into a unified set of surveys– the National Long-Term Care Provider Surveys (NLTCPS) – with coordinated sampling frames across the spectrum of long-term care providers, a common set of core data elements and the capacity to add topical modules to respond to evolving policy issues.**

Each of the current surveys operates independently although there is substantial overlap in content. Uncertain and reduced funding has affected the schedule of these surveys and has created the appearance that the surveys are ad hoc and that the schedule is driven more by resources than an effective strategic plan. Creating a single conceptual framework and operational platform for all of the long-term care provider surveys would add order and continuity to the planning and conduct while securing substantial benefits from on-going data collection. These benefits could include some possible reductions in start-up costs and efficiencies by using the same data collection, follow-up, and data cleaning methodologies. Under this unified framework, the LTCSB should explore potential efficiencies of fielding various provider components on a more continuous basis

with periodic reporting when a sufficient sample has been assembled. Such a process could provide an important benefit in the form of more timely and policy relevant survey findings. Other methodological approaches under this unified framework may be beneficial and should be explored.

The NLTCPS would reflect an integrated sampling strategy with corresponding provider frames, updated regularly as required for each provider type. The overall survey approach will need to have the flexibility to include additional LTC provider types and settings, both to fill existing gaps and as new options emerge. Some categories of LTC providers, where lists are more readily available to be used for sampling, will be easier to include, while methods for sampling others, such as unlicensed home care providers, will present a challenge. Informal or directly employed care providers will likely remain outside the scope of the recommended NLTCPS, leaving an important gap in its coverage. Informal and directly employed providers are responsible for a substantial portion of long-term care, and for policy purposes it is essential to have information on them. Moreover, such information is necessary to ensure that the LTC Provider Surveys are appropriately responsive to changes in the dynamic LTC sector. Therefore, a means of obtaining periodic information on them to complete the profile of LTC must be explored, perhaps through periodic person-level surveys such as the one the Panel recommends be conducted as soon as feasible.

A central concept of a unified NLTCPS would be a common set of core data items which would be collected across the various long-term care settings and providers and allow for comparisons across settings over time. In the current LTC environment, nursing homes, residential care facilities and home and community-based providers serve many similar, as well as distinct, types of clients with common, as well as distinct needs. They also provide many similar types of services that are currently called different things and measured in somewhat different ways. The redesigned NNHS and NHHCS contain some common measures. Further standardizing key measures and “cross-walking” others (e.g., to assess patient needs for assistance with activities of daily living [ADLs] or instrumental activities of daily living [IADLs]) would facilitate comparative descriptive, if not comparative effectiveness, analysis across providers, survey waves, and types of patients. While the surveys would be designed to allow examination and analysis of health care topics across provider types they should also support examination of issues specific to individual provider types. Modules containing questions developed and designed to collect needed data about a certain type or types of providers could be incorporated in the respective surveys as needed. The NLTCPS should also have the capacity to add other one-time modules to be maximally responsive to emerging policy issues. These modules could address specific topics or aspects of long-term care. They could be incorporated in the on-going surveys or dropped when the need is gone and be replaced by other topical modules.

Consideration should be given to whether the surveys can be designed in a way to collect new information on time sensitive policy issues. While more rapid availability is heavily dependent on resources, the surveys’ design and mode of implementation can affect how quickly new information can be available.

## **Specific Recommendations**

The following recommendations were developed with the idea that creating the integrated long-term care provider surveys, the NLTCPS, would provide certain advantages and efficiencies. The recommendations also apply to the conduct of the current individual provider surveys. The panel believes it is necessary to maintain an understanding of the data needs and particularly the policy-relevant data requirements of an expanded group of data users, to develop an integrated sampling strategy and comprehensive sampling frames, establish core content throughout the surveys, develop data linkage strategies as an integral part of the overall plan, and fill an important current data gap by fielding the survey of residential health care facilities.

### **1. Engage policymakers, providers and other users to understand their needs and increase the surveys' value to them.**

To be useful for long-term care policy consideration, the NLTCPS data must be collected, analyzed and disseminated based on a working understanding of the relevance to current and potential decisions in the policy arena. The understanding of policy data needs should come through an on-going dialogue with policymakers and other users, encompassing not only a discussion of explicit data needs but also identification of emerging policy issues and programmatic options. Moreover, given that public policies and private decisions affecting one set of LTC providers or services often significantly affect others, such dialogues should be designed with attention to bridging organizational “silos” within the public and private LTC sector. It would be useful for the LTCSB to expand its outreach activities beyond traditional dissemination techniques and beyond the research community to include regular stakeholder meetings and/or panels to elicit timely and regular input from potential users with significant policy responsibility. This is especially important because it is often easier for policymakers to communicate the issues and options rather than to translate them directly into survey scope, content or specific data needs. While there is strong interest in and use of the LTC survey data for research in various aspects of long-term care, there is less direct knowledge and use by policymakers especially those outside the DHHS. It would be valuable for the LTCSB to strengthen information systems for monitoring and understanding audiences and uses. If those systems were broadly conceived, the LTCSB would have a better understanding of the intersection of the data needs of various audiences and could use that information in the transition to an integrated survey approach.

### **2. Establish a regular process for expert review of methods, content and relevance of the long-term care surveys that extends beyond the initial design and implementation of the surveys.**

It is an on-going process to design, develop and field long-term care data collection efforts that provide the information needed to guide LTC policies and programs. The information required evolves as the long-term health care environment changes and actions of the public and private sectors impact the way that care is made available and

funded. The data needs of health care providers, researchers and policymakers can best be determined by involving users beyond the initial design or implementation stages of the survey process. The LTCSB should document feedback and use this information for evaluation and redesign of the survey. It should also establish a process where surveys are part of an on-going evaluation system with appropriate experts involved. A planning and evaluation process should not be limited to efforts in advance of a survey but also as the final products are produced, reviewed, and used.

### **3. Develop a unified strategy and inclusive set of sampling frames for the NLTCPS.**

The current LTC surveys have separate and independent sampling frames built from the available listings of nursing homes, home health agencies, hospice care providers, and residential care facilities. An integrated set of NLTCPS would have a unified conceptual underpinning and comprehensive strategy for designing the individual sampling frames of all included providers. A thorough evaluation of the current sampling frames, alongside an inventory of new and evolving LTC provider types from the strategic planning effort, would identify the important gaps in scope and coverage. Plans for inclusion of other types of providers could then be based on an overall strategy that would manage the integration process.

### **4. Review and develop core content for all types of providers in the NLTCPS.**

An important characteristic of the NLTCPS would be the development of core content and comparable measures to be collected for all types of providers in the integrated survey set. LTCSB can develop consensus on core content through input from users, including policymakers, and evaluation of long-term care data needs. Topics such as individuals' service needs, services received, service adequacy, outcomes, care transitions and payment amounts and sources are examples of possible core topics. Others might be the use of health information technology, patient cost-sharing and end-of-life care. The LTCSB will need input from expert advisors for content for the core, specialized questions for specific types of providers, and topical modules to ensure that the data needs have been understood and can be addressed.

### **5. Develop a strategy for linking administrative records data to the NLTCPS to enhance the analytical potential of findings from the surveys reduce duplication and increase efficiency in survey operations.**

As previously noted, there are many data-rich administrative records systems to which the NLTCPS could be linked. The LTCSB should systematically inventory and examine the relationship of the NLTCPS to these systems and should explore the opportunities and potential barriers, such as the legal restrictions on linking data across agencies. To the extent required by law and regulation, the LTCSB should incorporate into the design of all its surveys a means of obtaining informed consent from care recipients or provider employees to permit data linkage.

**6. Fill an important gap in the existing provider surveys by fielding the NSRCF as soon as feasible and reconsider the decision not to collect resident-level data supporting data linkages.**

Residential care facilities are rapidly growing in numbers and importance as providers of long-term care. There are no other national data on these providers or residents and so the upcoming NSRCF is extremely important and fills a major data gap. As the survey is currently designed, it will not collect information to link data on residents to administrative data. The LTCSB should reconsider this important limitation. A review of the linkage possibilities and the modifications needed in the survey design and operations should begin immediately. However, modifications to support linkage should not delay the survey. Linkage capacity and other improvements to the survey should be incorporated when the survey is next conducted.

Data from the NSRCF should be distributed as rapidly and broadly as possible to get feedback so that the LTCSB can document lessons learned in methods, content and use and application of data. This survey should be considered as just the first step in collecting data on residential places of LTC. It constitutes an important transitional step to an integrated set of LTC provider surveys, and the lessons learned should prove invaluable in constructing the NLTCPS.

**7. Evaluate, consider, and test changes in data collection methodology that have the potential to increase the efficiency and the response rates of current and future surveys.**

Various methodologies for the design of surveys, conduct of survey operations, and technology for data collection exist today that may provide opportunities for improving the efficiency of the long-term care surveys. In-person interviewing, the primary mode for current data collection, is expensive and time-intensive. The LTCSB should review its experience with CATI to see if that technique can be more broadly utilized beyond the employee surveys which are conducted by CATI. The Branch should also seriously consider web-based data collection.

To fully explore alternative methodologies, LTCSB will need to conduct focused methodological research to improve survey operations. One example of a topic for this broader research agenda could be how to deal with decreasing survey response rates. A substantial portion of survey resources – staff time and survey costs—is expended to improve survey response rates. At a certain point in the process, there is a rapidly diminishing return from a nominal increase in survey response rates. These resources might be better directed to methodological research to analyze response patterns and bias and allow adjustment for non-response rather than just trying to increase response rates. Since maintaining and improving survey response rates is a widely experienced activity, interest in research on this aspect of long-term care surveys may be widespread as well.

## **8. Explore the possibility of sharing the NLTCPS sampling frames with states and researchers**

The development and maintenance of a comprehensive set of sampling frames for a National Long Term Care Provider Surveys will be a difficult and costly undertaking, particularly if additional provider types are added. These frames of LTC providers, including some categories not readily available, such as the residential care facilities, are a unique and valuable resource. Expansion of the sampling frames will be a complex process requiring thoughtful decisions on definitions, scope, quality of information, and many others. Many researchers would view the availability of the sampling frames as a substantial asset, eliminating an early and costly step in survey design and operations. The sampling frames might be particularly useful to researchers and policymakers at the state level, where the frames would be of interest in their own right as a source of information on suppliers of long-term care and as frames for conducting state-specific surveys.

There would, of course, be a number of issues to explore and questions to answer before the sampling frames could be distributed. LTCSB would have to investigate whether distributing the sampling frames could have adverse effects on the surveys such as lowering participation and response rates. There may be some types of providers where confidentiality is a concern and those frames would have to be redacted or protected in some way. The panel recommends that the frames be made available only for research and statistical purposes.

### **Conclusion**

The panel wishes to reiterate that the LTCSB and the data it collects play an important role in understanding the provision of long-term care. The two overarching recommendations and the series of more specific recommendations made in this report are made in the spirit of strengthening the contributions of the LTSCB to a critical area of national policy that will be of greater and greater importance as the population ages. A thorough strategic review and a unifying conceptual framework, bolstered by the allocation of sufficient resources, should help the LTCSB realize the potential to fulfill the future LTC needs of the nation.

**Long-Term Care Statistics Program Review  
Site Visit  
February 4-5, 2009**

**Reviewers**

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**Long-Term Care Statistics Program Review**  
**February 4-5, 2009**  
**NCHS**  
**3311 Toledo Rd. Room 7105**  
**Hyattsville, MD 20782**

**DRAFT AGENDA**

**Wednesday, February 4, 2009**

- 2:00 – 2:05      Welcome and Introductions  
*Penny Feldman, Ph.D., Review Panel Chair*
- 2:05 – 2:35      NCHS/CDC Overview  
*Edward Sondik, Director, NCHS*
- 2:35 --2:45      Division of Health Care Statistics (DHCS) Overview  
*Jane Sisk, Ph.D., Director, DHCS, NCHS*
- 2:45 – 3:15      Long-Term Care Statistics Program  
*Lauren Harris-Kojetin, Ph.D., Chief, Long-Term Care Statistics Branch (LTCSB), DHCS*
- 3:15 - 4:00      Long-Term Care Statistics in DHHS—Presentation and Discussion  
*Ruth E. Katz, Deputy to the Deputy Assistant Secretary, Office of Disability, Aging, and Long-Term Care Policy, Office of the Assistant Secretary of Planning and Evaluation, DHHS*  
*William Marton, Director, Division of Disability and Aging Policy*  
*Gavin Kennedy, Director, Division of Long-Term Care Policy*
- 4:00 - 4:15      Break
- 4:15 – 4:30      Discussion of Supplemental Questions  
*Penny Feldman, Ph.D. and LTCSB staff*
- 4:30 – 5:30      Discussion with LTCSB staff
- 7:00              Dinner at a Silver Spring restaurant

**Thursday, February 5, 2009**

8:30 – 10:00	Continued Discussion with LTCSB
10:00 - 10:15	Break
10:15-12:00	Discussion of Report and Recommendations
12:00 – 1:00	Working Lunch
1:00 – 2:00	Discussion of Report and Recommendations
2:00	Adjourn

**Procedures for Reviewing NCHS Programs:  
National Health Interview Survey (NHIS)**

Board of Scientific Counselors  
October 2007, February 2008

**A. Overview and Guiding Principles**

NCHS intends to periodically review its programs to assure the continuing vitality of the Center's efforts. The specific goals of these reviews are to examine the current status, scientific quality, and responsiveness of each program within the context of its mission.

The review should:

1. take into account future availability of financial and staffing resources focusing on the effectiveness of the program's use of current and expected resources, especially during periods in which prospects for funding increases in the near term are limited;
2. emphasize forward-thinking and future planning rather than current or past program efforts and achievements to ensure that NCHS remains a vital part of the Nation's health information infrastructure;
3. conduct an interactive review that obtains needed information through both written documentation and in person interaction with program staff.

The final report should address the program's strengths, weaknesses, and future threats and opportunities with emphasis on scientific quality and the program's responsiveness to the user community.

This document is intended to provide general guidelines for the review process. It is understood that review teams will have flexibility in how they perform their tasks. Each review team may prioritize some areas for greater emphasis given the purpose and scope of the program under review.

**B. Questions to consider in conjunction with nine review criteria**

The review criteria outlined below is intended to guide the reviewers in terms of the program's adherence to general principles of sound science and the requirements of federal statistical agencies as set out in the CNSTAT's Principles and Practices, OMB's Data Quality Guidelines, and OMB's Standards for Statistical Surveys.

<b>The Program and Its Process:</b>	<b>Scope of the evaluation</b>		
	<i>Current status/ future plans</i>	<i>Scientific quality</i>	<i>Responsiveness to users' needs</i>
<i>Capacity/Resources</i>	1	4	7
<i>Information Products</i>	2	5	8
<i>Efforts to Improve</i>	3	6	9

**The reviewers may use the questions outlined below as a guide for their deliberations. As noted above, each review needs to be tailored to the particular program and its overall mission. Thus some areas may receive greater emphasis than others. However, the review team should not limit their focus too narrowly.**

1. Capacity/Resources

- Is the program's budget being spent efficiently on current activities?
- Are personnel resources being used effectively?
- Are appropriate high quality personnel being recruited and retained?
- Are current staffing levels appropriate?
- Does the program have the right mixture of professional expertise?
- Does program staff collaborate with other federal or state agencies and if so how?
- How does the program fit within NCHS and the Federal statistical system (i.e., CDC, and other federal agencies)?

2. Information Products

- What are the program's principal products?
- Are the reports generated by the program appropriate for the content of the data collection system and mission of the program?
- Are the program's products meeting user expectations in terms of quality, timeliness, usability, etc.?
- Are there definable and measurable quality standards set for each program product?
- Is there an ongoing attempt to improve timeliness of the program's data products?
- Is there an ongoing effort within the program to review user satisfaction of its products?

### 3. Efforts to Improve

- Are there existing mechanisms to maintain and improve the scientific quality of program activities?
- Are there existing mechanisms for strategic planning of future activities?
- Are there incentives for staff to conduct long range planning?
- Are there ongoing efforts to evaluate and improve the quality of data and information products produced by the program?

#### **C. Report to the Board of Scientific Counselors (BSC)**

A preliminary report of the review should be submitted to the BSC prior to the submission of the final report. This preliminary report will be scheduled for discussion in a meeting of the full BSC. In this meeting the program staff will have an opportunity to correct any factual errors that may be present in the preliminary report. The final report, which should include a set of prioritized recommendations, will be submitted subsequent to the Board discussion and will reflect the discussion of the preliminary report by the BSC.

Attachment 4

**Background Documents Received by the LTC Panel**

1. Long-Term Care Statistics Branch, Report to the Board of Scientific Counselors and Review Panel, National Center for Health Statistics, September 5, 2008
2. Preliminary Questions for LTC Review Panel
3. Requests for use of LTCSB data by outside researchers
4. Agency eligibility criteria for the 2007 NHHCS
5. Selected Publications by Outside Researchers Using NNHS or NHHCS Data – Organized by Topic within Survey for Publications (1981 through 8/2008)
6. BSC NHHCS Graphs, 02/27/09

Attachment 5

**Questions for LTC Program to be addressed at the site visit**

- 1) What is the current underlying strategy and themes that pull together the current surveys in the Long-term Care Program?
- 2) How do you see the program moving forward with an integrated strategy for the surveys?
- 3) Are there existing reports that examine planning across agencies for long-term care data collection?
- 4) What are the legal restrictions on linking data across agencies?
- 5) How do the surveys within the NCHS Long-term Care Program fit within the existing array of efforts in long-term care?
- 6) How does the NCHS Long-term Care Program relate to other NCHS surveys and outside surveys currently and what are the plans for the future?
- 7) Who are the users of the products of the Long-term Care program and how are you meeting those needs?

Attachment 6

**Supporting Organizations for the LTC Surveys**

NNHS

American Health Care Association  
American Association of Homes and Services for the Aging  
American College of Health Care Administrators

NHHCS

National Hospice and Palliative Care Organization  
National Association for Home Care and Hospice

NNAS

National Association of Geriatric Nursing Assistants  
National Network of Career Nursing Assistants  
Paraprofessional Healthcare Institute

NHHAS

National Association of Health Care Assistants  
Visiting Nurse Associations of America  
Paraprofessional Healthcare Institute

NSRCF

American Association of Homes and Service for the Aging  
Assisted Living Federal of America  
American Seniors Housing Association  
Center for Excellence in Assisted Living  
National Center for Assisting Living