



U.S. Department of Health and Human Services  
Assistant Secretary for Planning and Evaluation  
Office of Disability, Aging and Long-Term Care Policy

# **AN INTRODUCTION TO THE NATIONAL LONG-TERM CARE SURVEY**

August 1998

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This report was prepared by HHS's ASPE/DALTCP. For additional information about this subject, you can visit the DALTCP home page at [http://aspe.hhs.gov/\\_/office\\_specific/daltcp.cfm](http://aspe.hhs.gov/_/office_specific/daltcp.cfm) or contact the office at HHS/ASPE/DALTCP, Room 424E, H.H. Humphrey Building, 200 Independence Avenue, S.W., Washington, D.C. 20201. The e-mail address is: [webmaster.DALTCP@hhs.gov](mailto:webmaster.DALTCP@hhs.gov). The Project Officer was Robert Clark.

# **AN INTRODUCTION TO THE NATIONAL LONG-TERM CARE SURVEY**

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# OVERVIEW

The 1982, 1984, 1989, and 1994 National Long-Term Care Surveys (NLTCS) are nationally representative surveys of Medicare beneficiaries aged 65 or over with chronic functional disabilities (sometimes referred to as the "frail elderly"). These surveys are the major source of nationally representative information on changes in the health and functioning of the elderly population. The Survey will be administered again in 1999. The NLTCS is a unique resource for examining demographic, health and functional status changes in the disabled elderly living in the community and in nursing homes along with the trajectory of service use and costs over time.

The 1982 survey resulted from the Department of Health and Human Services (DHHS) Working Group on Long Term Care Data, which in 1980 produced a report titled DHHS Statistical Plan for Nationally Representative Data (unpublished). The original purpose of the 1982 survey was to examine the health problems and functional limitations of elderly persons living in the community, and to determine the use and cost of both formal and informal services by this population. The survey was viewed as a companion to the National Long-Term Care Channeling Demonstration.

ASPE and HCFA co-sponsored the 1982 survey. Census administered the screener and the community survey. The National Opinion Research Center (NORC) administered the informal caregiver supplement. HCFA and the National Center for Health Services Research (subsequently renamed the Agency for Health Care Policy Research) co-sponsored the 1984 survey. In 1994, Census collected and edited the data for the screener and community survey as well as a new institutional survey. Duke University prepared a public use file covering both the 1982 and 1984 surveys and including Medicare Part A bill records.

The National Institute on Aging sponsored the 1989 survey through a grant to Duke University, which in turn contracted with the Census Bureau to collect the data and create data files. ASPE supplemented funding for the basic survey to provide for the informal caregiver survey, nursing home resident follow-back (telephone interview) and addition of supply variables to the respondent record. The same pattern was repeated in 1994; support for the survey came principally from an NIA grant to Duke University, with supplemental funding from ASPE. ASPE funds were used to develop a new survey of the next-of-kin of decedents, as well as a new series of questions on nutritional status on the Community Questionnaire.

# COMPONENTS

A fundamental advantage of the NLTCS is that it is based on a list sample drawn from Medicare eligibility files. This makes it practical to draw supplementary samples of certain subgroups, e.g. extremely old persons (aged 95+) and elderly populations by race or ethnicity (e.g. African Americans, Hispanics). The NLTCS is a unique resource

for a variety of analytical purposes. For example, the very old (persons aged 85+) is the fastest growing group within the elderly population. In each of the four surveys (1982, 1984, 1989, 1994), large samples (N~2000) of the very old were obtained.

For the elderly population with disabilities the NLTCS provides both cross-sectional and longitudinal data on:

- the prevalence and patterns of functional limitations, both physical and cognitive;
- medical conditions and recent medical problems;
- use of health care services;
- kinds and amounts of formal and informal long-term care services used;
- demographic characteristics like age, race, sex, marital status and income;
- public and private expenditures for health care services; and
- housing and neighborhood characteristics.

| TABLE 1. Survey Component by Year of Administration |                 |           |                 |                                |                   |                          |                     |                    |
|---|-----------------|-----------|-----------------|--------------------------------|-------------------|--------------------------|---------------------|--------------------|
| NLTCS:<br>19--                                      | Control<br>Card | Screeener | Comm.<br>Quest. | Informal<br>Caregiver<br>Supp. | Instit.<br>Quest. | Instit.<br>Follow-<br>up | Next-<br>of-<br>Kin | Medicare<br>Claims |
| 82  | X               | X         | X               | X                              |                   |                          |                     | X                  |
| 84  | X               | X         | X               |                                | X                 |                          | X                   | X                  |
| 89  | X               | X         | X               | X                              | X                 | X                        |                     | X                  |
| 94  | X               | X         | X               |                                | X                 |                          |                     | X                  |
| 99 (plan)   | X               | X         | X               | X                              | X                 |                          | X                   | X                  |

Questions about disability and health were identical across all four surveys and were found to be reliable and replicable between surveys. The data were adjusted to ensure consistency across survey years with respect to data collection methods, nonresponse adjustment, mortality allocation and adjustment and case allocation. Any bias introduced by these adjustments was designed to be "conservative", i.e. against showing any positive health trends.

The survey data were linked to Medicare service use files for most years from 1982 through 1994. The linkage to Medicare enrollment files between 1982 and 1994 was 100%. That is, there was complete followup on all cases, including survey nonrespondents, for Medicare eligibility (including for most years Part A and Part B use), mortality and date of death. Medicare mortality records were used to estimate mortality rates for the initial two year period (1982-1984), subsequent five year period (1984-1989) and still later five year period (1989-1994).

## TYPES OF DATA COLLECTED

The survey instruments cover the following topics. (Note: There are some differences in the instruments from one survey period to another. Users of the data files

should consult the actual questionnaires and/or file documentation for the year(s) of interest.)

### **Control Card**

- Respondent control number
- Basic demographics
- Names and relationships of other persons in the household
- Names of children not living in the household

### **Screener**

- Date, time and place of interview
- Respondent's current address
- Proxy information (if appropriate)
- Questions on 9 ADLs
- Questions on 7 IADLs
- Selected demographic and residential status information

### **Community Questionnaire**

- Condition list
- ADL status (detailed questions on 6 ADLs)
- IADL status (detailed questions on 7 IADLs)
- Source, type and amount of informal help
- Source, type, amount and payor for formal help
- Questions on range of motion and impairment (Nagi items)
- Activity list
- Nutrition
- Social activities
- Alcohol consumption and smoking
- Other functioning (mental, emotional, behavioral)
- Housing and neighborhood characteristics
- Health insurance
- Medical providers and prescription medicines
- Cognitive functioning
- Military service, ethnicity, income, assets

### **Institutional Questionnaire**

- Cognitive functioning
- ADL status
- IADL status
- Admission information

- Payment source
- Health insurance
- Income and assets

### **Institutional Followup**

- Facility characteristics
- Discharge status
- Admission information
- Payment source
- Health insurance
- ADL status
- IADL status
- Income and assets

### **Informal Caregiver Survey**

- Caregiver name, address
- Basic demographics
- Relationship to sample member
- Amount and kinds of help provided
- Information on care provided by others
- Caregiver's living situation
- Caregiver's work situation
- Caregiver's health and functional status
- Caregiver's income and assets

### **Next-of-kin Survey**

- Respondent name, address
- Relationship to decedent
- Decedent's residence at death
- Source of payment for care
- Decedent's race, income and marital status at death

## **1982 NLTCS**

The sampling frame from which the 1982 survey sample was drawn is the Medicare Health Insurance Skeleton Eligibility Write-off (HISKEW) file. It included all those enrolled on or before March 31, 1982. The sample was stratified geographically into Long Term Care Primary Sampling Units (LTC PSU's) which were grouped into 173 long term care strata. Thirty-nine of the strata had a single LTC PSU, which was then designated a Long Term Care Self-Representing Primary Sampling Unity (LTC SR

PSU). The remaining 134 strata each had more than one LTC PSU. However, only one LTC PSU was selected from each stratum, converting it into a Long Term Care Non-Self Representing Primary Sampling Unit (LTC NR PSU).

The initial sampling rate within the selected PSU's, both self-representing and non-self-representing, was 10%. Those under age 65 and those who lived outside the 173 PSU's were eliminated; the remaining persons were sorted into four age strata: 65-74, 75-79, 80-84, 85+. The sample was reduced to approximately 55,000 persons.

This sample was further divided into 101 reduction groups, since it was expected to be larger than needed. To obtain the desired precision of measurement while keeping costs under control it was determined that 6,000 detailed interviews were required. Of the 101 reduction groups, 66 were retained, leaving about 36,000 candidates for a screening interview. Of these, about 2,500 persons were found to have died, entered an institution or become ineligible for some other reason by the time the sample was drawn. Almost 6,400 persons qualified for detailed interviews.

The procedures for administering the survey to the 36,000 persons in the screening sample were as follows:

1. Sending an introductory letter to each sample person to acquaint him/her with the survey.
2. Administering a short screening interview by telephone (for 70% of the cases) to delete those who had no functional limitations, who had died, or who had entered an institution.
3. Sending a second introductory letter to persons whose responses to the screen indicated that they had functional limitations.
4. Using a control card to collect demographic information and to record all contacts with the household.
5. Administering the detailed interview to persons living in the community with (according to the screen) functional limitations.
6. Interviewing in a later separate survey the informal caregivers of those with functional limitations.

On the screen, nine activity of daily living (ADL) related questions and seven instrumental activity of daily living (IADL) related questions were asked. Basically, respondents were asked whether they had any problem with individual ADL's and IADL's that has been present or was expected to be present for a period of three months or longer. This time frame was used to screen in persons with long term impairments. An impairment of this duration on any ADL or IADL fulfilled the requirement for the person's inclusion in the survey. 6,349 persons were found to be

functionally disabled based on their responses to these questions. These persons were the respondents to the Community Questionnaire.

In addition, there was conducted a separate but linked survey of the informal caregivers of these persons. A caregiver was defined as someone aged 14 and over who gave un- paid assistance with at least one ADL to a sample member. A subsample of NLTCS respondents was selected, first, by selecting a subsample of LTC PSU's and, second, by identifying a subsample of elderly persons with disabilities within the selected PSU's. All caregivers who assisted a given NLTCS sample member were interviewed where possible. A total of 2,349 individual caregivers were assigned for interview. Of these, 1,925 interviews were completed.

## 1984 NLTCS

The 1984 survey used a questionnaire for the community-based elderly with disabilities that was virtually identical to the 1982 community questionnaire. A separate questionnaire was administered to persons in institutions. There was no informal caregiver survey. Survey work was conducted between June and October 1984.

The sampling procedure for the 1984 survey differed from the 1982 survey in several respects.

- All surviving persons (a) who had reported chronic disability on the 1982 screener, or (b) who had not been not screened in due to being institutionalized on April 1, 1982 were interviewed regardless of their 1984 functional status.
- From the original 25,541 persons who had not reported functional impairments in 1982 (and who were not institutionalized), a 47% random sample (approximately 12,100 persons) was drawn and subjected to the screening procedure used in 1982.
- 4,916 persons who aged in, i.e. turned age 65 between 1982 and 1984, were screened so that, in addition to having a longitudinally followed sample in 1984, the full cross-section of persons with disabilities age 65 and over in 1984 could be assessed.
- From these four "sources"--(1) 1982 community disabled, (2) 1982 institutionalized, (3) 1982 non-disabled but screened in 1984, and (4) aged-in persons--6,264 community-based disabled elderly were identified. Detailed interviews were completed for 5,934 persons.
- Persons who were in institutions in 1984 were interviewed with a separate instrument that contained a number of questions on institutional use in the interim

period and the sources of payment for those services. Of 1,773 persons in institutions in 1984, interviews were completed for 1,690.

- A "next-of-kin" interview was conducted for persons who died between 1982 and 1984. Of 3,214 persons who had died, interviews were completed for 2,475 next-of-kin.

From a design standpoint, all persons either disabled or institutionalized in 1982 were interviewed in 1984 without screening. This had the advantage of providing data on persons who became non-disabled over the two year period. It had the disadvantage that one cannot obtain a set of persons exactly comparable to the 1982 "screen-in" sample of 6393 persons. To get a comparably defined disabled population in 1982 and 1984, one must use criteria based on questions from the detailed community survey. Medicare Part A bill data for the period from January 1978 through June 1986 has been appended to the 1982-1984 survey file.

The samples for the surveys are not simple random samples, but are drawn with a prespecified probability to increase the precision of the estimates for certain rare populations. This affects the estimate of error variance which is used in various test statistics to determine whether to accept or reject a particular hypothesis. The documentation includes a table of adjustment factors that can be used to compensate for these design effects.

## 1989 NLTCS

The 1989 survey continued to follow the initial 1982 and 1984 samples longitudinally as well as screening for additional Medicare recipients with disabilities. Persons in either 1982 or 1984 who were institutionalized or who received a detailed community interview and who survived to 1989 were reinterviewed. The latter identified some persons who, since the previous survey, became age-eligible for Medicare and were found to have a disability or persons already on Medicare who became disabled some time after the prior screens were administered. The 1989 NLTCS survey focused on the following groups.

- A subsample of 5000 persons found to be non-disabled in the 1984 survey. These persons were rescreened for disability.
- All persons age 75 and over who were found to be non-disabled in the 1984 survey and who are not the prior subsample.
- A sample of 4907 persons from Medicare files who aged in (i.e., became age 65) since the 1984 survey. These persons were screened for disability.
- All persons assigned a detailed community interview in the 1984 survey.

- All persons assigned a detailed institutional interview in the 1984 survey. A sixmonth follow-back telephone survey was also administered to this group.
- A subsample of caregivers or next-of-kin of the elderly with disabilities.

The instrumentation for the community-based elderly was very similar to the questionnaires used in the 1982 and 1984 surveys. There were some modifications, e.g. in the area of income and assets where the Survey of Income and Program Participation questions were adapted to the survey. The institutional questionnaire resembled closely the 1984 questionnaire.

The caregiver survey was similar to the 1982 ICS questionnaire, though somewhat shortened. The six month telephone follow-back for institutionalized persons was a very brief survey focusing mainly on income and asset questions. The 1989 survey was linked to Medicare Part A and Part B files and the National Death Index.

## 1994 NLTCS

As with the 1984 and 1989 surveys, the 1994 NLTCS has both a cross-sectional and a longitudinal component. The survey covered both institutionalized and community- based persons with disabilities. There was neither an informal caregiver survey or a next-of-kin survey. The survey did contain the following sample components.

- Reinterviews with all 4463 persons who were identified as chronically disabled in any prior (1982, 1984, 1989) survey, received a community interview in 1989 and are still living.
- Reinterviews of 1354 persons who received an institutional questionnaire in 1989.
- Screening for disability of a new cohort of 5000 persons who turned 65 between 1989 and 1994. This maintained the national representativeness of the cross-sectional sample for persons aged 65+.
- Interviews with a sample of approximately 1200 persons who screened "out" in 1994 to examine the health status and informal care resources of nonchronically disabled persons.
- Interviews with approximately 2200 persons aged 75+ who screened out of the 1989 NLTCS.

- Interviews with a sample of 400 persons aged 95+ in order to make inferences about the health, functional status and service use of the most extreme elderly population.

Beyond the "core" questions, the survey added questions on nutrition and physical activity, as a result of supplemental funding from ASPE.

## USES

Analyses of the NLTCS have produced important insights into the nature of health and functional status transitions for specific population groups. A few examples follow, drawn from research conducted by Ken Manton and others at Duke University.

1. Disability rates among the elderly may be declining. This finding has significant implications for the demographics of aging (e.g. rapid growth of the very old populations). It suggests the importance of research on risk factors for disability, disability delay and/or prevention, and the management of disability.
2. Informal care on a per capita basis has declined. To some extent, housing modifications and assistive devices can compensate for this decline, thereby enabling persons to cope better with disability that cannot be reversed.
3. The effect on active life expectancy from the elimination of diseases like Alzheimer's and osteo-arthritis has been modeled. The impact of eliminating these two diseases on active person years was similar. However, while eliminating dementia tended to reduce the number of years spent in an institution, elimination of arthritis affected the distribution of disability levels among community residents.
4. There are significant numbers of persons with extreme levels of impairment (i.e. 5-6 ADLs) who remain in the community. These persons tend to be male, married, homeowners and high income. Thus, persons with high levels of disability but also with adequate formal care, informal care, modified housing and assistive technology can avoid institutionalization. Education, even for persons with fewer social and economic resources, appears important in helping people use assistive devices and otherwise cope with their disabilities.

The NLTCS has also been used as a key component of the Long-Term Care Financing Model, funded by ASPE and maintained by The Lewin Group.

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**NOTE:** This is an informal orientation to the NLTCS. More information can be found at the website of the Principal Investigators, <http://cgs.duke.edu>.

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