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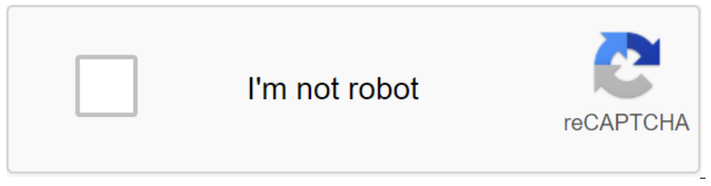

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U.S. Department of Health and Human Services Introduction to the National Long-Term Care Survey by Robert F. Clark August 21, 1998 PDF Version: (15 PDF pages) This document was prepared by the Office of Disability, Aging and Long-Term Care Policy with the U.S. Department of Health and Human Services. For more information, please visit the DALTCP homepage at or contact the Office at HHS/ASPE/DALTCP, 424E, H.H. Humphrey Building, 200 Independence Avenue, SW, Washington, DC 20201. Email: DALTCP2@osaspe.dhhs.gov. TABLE OF CONTENTS OVERVIEW COMPONENTS TYPES OF DATA COLLECTED 1982 NLTCS 1984 NLTCS 1989 NLTCS 1994 NLTCS OVERVIEW THE 1982, USES THE 1982, 1984, 1989 and 1994 National Long-Term Care Survey (NLTCS) are nationally representative surveys of Medicare beneficiaries age 65 and older with chronic functional disabilities (sometimes referred to as infirm elderly). These surveys are the main source of nationally representative information on changes in the health and functioning of the elderly population. The survey will be re-examined in 1999. NLTCS is a unique resource for studying demographic, medical and functional changes in the condition of older people with disabilities living in the community and nursing homes, as well as the trajectory of services and costs over time. The 1982 survey was conducted by the Department of Health and Human Services Working Group (DHHS) on long-term care data, which in 1980 produced a report entitled the DHHS Statistical Plan for National Representative Data (unpublished). The initial purpose of the 1982 survey was to examine the health problems and functional limitations of older persons living in the community, as well as to determine the use and cost of both formal and informal services for this group. The survey was seen as a companion to the National Long-Term Care Demonstration. ASPE and HCFA co-authored the 1982 survey. The census was conducted by a screening and community survey. The National Centre for Public Opinion Research (NORC) has introduced an unofficial care supplement. HCFA and the National Centre for Health Research (later renamed the Health Policy Research Agency) co-authored the 1984 survey. In 1994, the Census collected and edited data for a survey of screeners and communities, as well as a new institutional survey. Duke University has produced a public-use file covering both the 1982 and 1984 surveys and The National Institute on Aging sponsored a 1989 survey based on a Duke University grant, which in turn contracted with the Census Bureau to collect data and create data files. ASPE supplemented the funding of the basic survey to conduct an informal survey of caregivers, nursing home residents (telephone interview) and variables of supplies in the respondent's report. The same pattern was repeated in 1994; support for the survey was provided mainly by NIA grant to Duke University with additional funding from ASPE. ASPE funds have been used to develop a new survey of the next of kin of children, falling out of the dilapidated capital, as well as to conduct a new series of questions on the state of nutrition in the questionnaire of the community. THE MAIN advantage of NLTCS is that it is based on an example of a list taken from files that are eligible for Medicare. This makes it practical to sample additional samples from some subgroups, such as the extremely elderly (aged 95) and the elderly based on race or ethnicity (e.g. African-Americans, Latinos). NLTCS is a unique resource for a variety of analytical purposes. For example, very elderly people (aged 85) are the fastest growing group in the elderly population. Each of the four surveys (1982, 1984, 1989, 1994) produced large samples (N-2000) of the oldest. For older people with disabilities, NLTCS provides both cross-sectional and longitudinal data on: prevalence and patterns of functional limitations, both physical and cognitive; Health status and recent medical problems; Use of health services The types and volumes of formal and informal long-term care services used; demographic characteristics such as age, race, gender, marital status and income; Public and private spending on medical services; and housing and neighbourhood characteristics. TABLE 1. Compenent review by NLTCS Administration Year: 19-- Control card by Screener Comm. Quest. Unofficial educator Supp. It's exhausting. Quest. Instit. Follow-up Next-of-Kin Medicare 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. These figures have been adjusted to ensure consistency over the years of the survey regarding data collection, non-response adjustments, mortality distribution and adjustment and distribution of cases. Any bias imposed by these adjustments has been designed to be conservative, i.e. not to show any positive health trends. The survey data were related to the use of Medicare files for most years from 1982 to 1994. The connection to Medicare enrollment files between 1982 and 1994 was 100%. That is, there was a complete follow-up on all cases, including the survey misresponsum, for Medicare eligibility (including for most years Part A and Part B mortality and the date of death. Medicare mortality records were used to estimate mortality rates for the initial two-year period (1982-1984), the subsequent five-year period (1984-1989) and the even later five-year period (1989-1994). TYPES OF DATA COLLECTED COLLECTED The tools cover the following topics. (Note: There are some differences in tools from one survey period to another. The Checkpoint Card Respondent Control Number Basic Demographic Names and Relationships of Other Persons in the Home Names of Children Not Living in a Home Screener Date, Time and Place Interview Respondent Current Address Proxy Information (If Necessary) Issues by 9 ADLs Issues about 7 IADLs Selected Demographic and Residential Status Community Questionnaire Status ADL Status ADL (Detailed Questions about 6 ADL) IADL Status (Detailed Questions on 7 IDL) Type, Amount and Payment for Formal Assistance Issues on Range of Movement and Disruption (Nagi Items) List of Activity Nutrition Social Activities Alcohol Consumption and Smoking Other Functioning (Mental, Emotional, Behavioral) Housing and Neighborhood Characteristics Health Insurance Medical Providers and Prescription Drugs Cognitive Functioning Military Service, Ethnicity, Income , Assets Institutional Cognitive Insurance Questionnaire Functioning ADL Status IADL Status Acceptance Information Source Health Insurance Income and Assets Institutional Followup Fund Characteristics Discharged Status Admission Information Source Health Insurance ADL Status IADL Status Income and Assets Unofficial Caregiver Survey Caregiver Name, Address Basic Demographic Attitudes to The Sample Member Amount and the Types of Assistance Provided by Care Information provided by other Caregiver's Living Address Attitude to Residence decedent Decedent on Death Source Payment for Care Decedent Race, Income and Marital Status at Death 1982 NLTCS Sampling Frame, from which 1982 survey sample was compiled is The Medicare Health Insurance Skeleton Write-off (HISKEW) file. It included all persons enrolled on or before 31 March 1982. The sample was stratified geographically into long-term care primary sample units (LTC PSU's), which were grouped into 173 long-term care layers. Thirty-nine layers had a single LTC PSU, which was then assigned a long-term care self-representation primary unity sample (LTC SR PSU). The remaining 134 layers had more than one LTC PSU. However, only one LTC PSU was selected from each layer, turning it into a long-term care that does not represent the primary sample group (LTC NR PSU). The initial sample rate for the selected PSU, both self-evident and non-self-test, was 10%. Persons under the age of 65 and those living outside 173 PPPs were eliminated; the rest of the faces have been sorted four age layers: 65-74, 75-79, 80-84, 85 years. The sample was reduced to about 55,000. This sample was further divided into 101 group reductions, as it was expected to be larger than was necessary. In order to obtain the desired accuracy of measurements, while maintaining control over costs, it was found that 6,000 detailed interviews were required. Of the 101 reduction groups, 66 were retained, leaving about 36,000 candidates for interviews. Of these, it was established that by the time the sample was taken, some 2,500 people had died, had been admitted to the institution or were otherwise ineligiblicy ineligiblican. Nearly 6,400 people were interviewed in detail. The survey procedures for 36,000 samplers were as follows: sending an entry letter to each sample person to review it. Administer a short telephone interview (in 70% of cases) to remove those who had no functional limitations, who died or who entered the institution. Sending a second introductory letter to people whose responses to the screen indicate that they have functional limitations. Use a control card to collect demographic information and record all contacts with the household. Administer detailed interviews with individuals living in the community with (according to the screen) functional limitations. Interviewed in a later separate survey of informal caregivers with functional disabilities. Nine questions related to everyday life (ADL) and seven instrumental questions of everyday life (IADL) were asked on the screen. The main respondents were asked whether they had any problems with individual ADL and IADL who attended or were expected to be present for three months or longer. This period has been used to check in persons with long-term violations. Violation of this duration on any ADL or IADL complied with the requirement to include a person in the survey. 6,349 people were recognized as functionally disabled based on their answers to these questions. These individuals were the defendants in the Community questionnaire. In addition, a separate but related survey of informal caregivers was conducted. The caregiver was identified as someone aged 14 and over who gave unpaid care to at least one ADL for a sample member. The NLTCS subsection of respondents was chosen first by selecting the LTC PSU subsection and, secondly, by identifying sub-families of elderly people with disabilities within the chosen PSU. All caregivers who assisted this member of the NLTCS sample were interviewed where possible. A total of 2,349 caregivers were assigned to the interview. Of these, 1,925 interviews were completed. 1984 The 1984 survey used a questionnaire for disabled people who are almost identical to the 1982 Community questionnaire. A separate questionnaire was prepared for those who entered the institutions. There was no informal examination of caregivers. Surveys were carried out between June and October 1984. The sampling procedure for the 1984 survey was in some cases different from the 1982 survey. All (a) survivors who reported chronic disability on the 1982 screener, or (b) who were not screened because they were placed in special institutions on 1 April 1982, were interviewed regardless of their functional status in 1984. Of the original 25,541 persons who did not report functional impairments in 1982 (and who were not placed in special institutions), 47 per cent of random samples (approximately 12,100) were taken and subjected to the selection procedure used in 1982. 4,916 persons under the age of 65 between 1982 and 1984 were tested to ensure that, in addition to the longitudinal sample in 1984, a full section of persons aged 65 and over could be assessed in 1984. Of these four sources---1) 1982 community disabilities, (2) 1982, 3) 1982, not disabled but screening in 1984, and (4) elderly persons - 6,264 disabled persons in the field were identified. Detailed interviews were conducted for 5,934 people. Persons who were in the institutions in 1984 were interviewed through a separate document containing a number of questions about the institutional use in the interim period and the sources of payment for these services. Of the 1,773 persons in the institutions in 1984, 1,690 were interviewed. Interviews were conducted on the deaths between 1982 and 1984. Of the 3,214 victims, 2,475 were interviewed. In terms of design, all persons, either disabled or placed in special institutions in 1982, were interviewed in 1984 without verification. The advantage of this is to provide data on persons who have not been disabled for two years. The downside was that it was impossible to obtain a set of faces exactly comparable to the sample of 6,393 people in 1982 screen-in. Criteria based on questions set out in a detailed community survey should be used to obtain a relatively definite definition of the number of persons with disabilities in 1982 and 1984. Data from the Medicare Part A bill between January 1978 and June 1986 were encoded to the 1982-1984 survey file. Survey samples are not simple random samples, but are taken with a predetermined probability to improve the accuracy of estimates for some rare populations. This affects the error variance assessment that is used in various test statistics to determine whether or reject a specific hypothesis. The documentation includes a table of adjustment factors that can be used to offset these design effects. The 1989 NLTCS Survey of 1989 continued initial samples from 1982 and 1984 are longitudinal, as well as screening for additional Medicare recipients with disabilities. Persons in 1982 or 1984 who had been placed in special institutions or had been interviewed in detail in the community and who had lived to see 1989 had been re-interrogated. In the latter case, some individuals who were given age eligibility for Medicare after the previous survey were identified as disabled or those who already had Medicare who had become disabled some time after previous surveys. The 1989 NLTS survey focused on the following groups. A 1984 survey found that 5,000 people were not disabled. These individuals were re-regulated for disability. All persons aged 75 and over who were found not to be disabled in the 1984 survey and who are not previous persons. A sample of 4,907 people from Medicare files who are aged (i.e. age 65) since the 1984 survey. These individuals have been tested for disability. In the 1984 survey, all persons received a detailed interview with the community. In the 1984 survey, all individuals received detailed institutional interviews. The group was also given a six-month follow-up telephone survey. Subsection of caregivers or immediate family of elderly with disabilities. Community-based older persons are very similar to the questionnaires used in the 1982 and 1984 surveys. Some changes have been made, for example in the area of income and assets, in which income survey and participation in programmes have been adapted to the survey. The institutional questionnaire was very similar to the 1984 questionnaire. The survey of caregivers was similar to the ICS 1982 questionnaire, although it was slightly reduced. The six-month telephone response to those placed in special institutions was a very brief survey, focusing mainly on income and assets. The 1989 survey was linked to the Medicare Part A and Part B files and the National Mortality Index. 1994 NLTS As in the 1984 and 1989 surveys, the 1994 NLTS has both a transverse and a longitudinal component. The survey covered both persons with disabilities, both in institutions and on a community-based basis. There was no informal examination of caregivers or surveys of next of kin. The survey contained the following sample components. Re-views of all 4,463 people who were identified as chronically disabled in any previous (1982, 1984, 1989) survey, received community interviews in 1989 and still live. Re-inses of 1,354 people who received questionnaire in 1989. Disability screening for a new cohort of 5,000 people who turned 65 between 1989 and 1994. This has maintained the national representation of the cross-sectional sample for 65-year-olds. Interview with a sample of approximately 1,200 people who came out in 1994 to study health and informal resources for caring for disabled people Interviews with approximately 2,200 individuals aged 75 who were shown in 1989 by THE NLTCS. Interviewed with a sample of 400 people aged 95 to draw conclusions about the health, functional status and use of the services of the most extreme elderly population. In addition to key issues, the survey added questions about nutrition and physical activity as a result of additional funding from ASPE. The NLTCS ETS analysis provides an important insight into the nature of health transitions and functional status for specific populations. Several examples follow from studies conducted by Ken Manton and others at Duke University. Disability rates among the elderly may decline. This finding has significant implications for the demographics of ageing (e.g., the rapid growth of very old populations). It points to the importance of research on disability risk factors, disability delay and/or prevention, and disability management. Informal per capita care has declined. To some extent, changes in housing and support can offset this decline, which will enable people to cope better with disabilities that cannot be reversed. The effect on active life expectancy from the elimination of diseases such as Alzheimer's disease and osteo-arthritis has been modeled. The impact of the elimination of these two diseases on an active person for years was similar. However, while the elimination of dementia tends to reduce the number of years spent in the institution, the elimination of arthritis affects the distribution of disability rates among community residents. A significant number of people with extreme impairment rates (i.e. 5-6 ADL) remain in the community. These individuals are usually men, married, homeowners and high income earners. Thus, persons with a high level of disability, but also with adequate formal care, informal care, modified housing and assistive technologies, can avoid institutionalization. Education, even for people with fewer social and economic resources, seems to be essential for helping people to use assistive devices and otherwise cope with their disability. NLTCS is also used as a key component of the ASPE-funded long-term care financing model and served by the Levin Group. Prepared by Robert F. Clark, DPA., USDHHS/ASPE/DALTCP, 200 Independence Avenue, SW, Room 424E, H.H. Humphrey Building, Washington, D.C. 20201. Phone: 202-690-6443 Email: bclark@osaspe.dhhs.gov NOTE: This is an unofficial focus on NLTCS. More information can be found on the main website. To get a printed copy of this report, send a full Report and Your Email Information: U.S. Department of Health and Human Services From Disability, Aging and Long-Term Care PolicyRoom 424E, H.H. Humphrey Building200 Independence Avenue, S.W.Washington, D.C. D.C. RETURN TO: Office of Disability, Aging and Long-Term Care Policy (DALTCP) Home (Assistant Secretary for Planning and Evaluation (ASPE) Home 'U.U. Department of Health and Human Services Home ( ) mary kay skin care survey pdf. mary kay skin care survey cards

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