

How the National Long-Term Care Survey Can Address Policymakers' Disability and Long-Term Care Questions^{*}

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Abstract

For over two decades the National Long-Term Care Survey (NLTC) has provided valuable information to policymakers for addressing a wide range of issues related to the health and long-term care of the nation's elderly. This paper discusses six high priority areas—long-term care financing and service delivery, the provision of home and community-based services, family caregiving, improving the quality of long-term care, coordination/integration of acute health and long-term care services, and emerging issues such as the implementation of Medicare Part D—and ways in which the NLTC can be used to further our understanding and evaluate important policy options. We conclude with a short list of issues to be considered to improve the NLTC.

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Introduction

The National Long-Term Care Survey (NLTC) has been an invaluable resource for policymakers over the last two decades. Unlike many general purpose surveys of the elderly, the NLTC was developed as a collaborative effort between policymakers and academic researchers. As a result, it has proven to be extremely useful for addressing acute health and long-term care policy research questions. For example, the survey has been used extensively by the Office of the Assistant Secretary for Planning and Evaluation (OASPE) in the U.S. Department of Health and Human Services (HHS) to: monitor trends in disability in the elderly and explore the impact of recent declines on health and long-term care utilization and spending; understand the factors associated with the use of federal health and long-term care programs and their interaction with informal family caregiving; model the impact of proposed changes in policy such as tax deductions for caregiving and the implementation of a tax credit for the purchase of private long-term care insurance; and project the number of elderly persons with chronic disabilities to estimate future demand for long-term care services. The following is a discussion of issues related to the long-term care of the elderly that can be addressed with the NLTC:

Long-Term Care Financing and Service Delivery

A key policy priority is to assure that long-term care financing and service delivery systems (nationally and at the state and local level) are capable of meeting current and future demand. This issue is of particular interest to OASPE and directly affects a number of HHS agencies. OASPE and the Administration on Aging (AoA) have a broad mandate to address the needs of older Americans who are unlikely to be financially eligible for Medicaid. Addressing the needs of non-Medicaid eligible elders requires analysis of their available resources to pay out-of-pocket for formal services, private long-term care insurance coverage, availability of home equity that could be tapped via reverse mortgages, etc. The following are examples of analyses of interest to policy makers:

- estimating the aggregate demand for long-term care services by monitoring the health and disability of older Americans over time;
- evaluating trends and interactions between the use of formal (paid) long-term care services (such as nursing home care, other residential care, and home and community-based services) and informal (unpaid) care from family, friends, and neighbors;
- monitoring and understanding the use of paid/unpaid human assistance as compared to the utilization of assistive technologies and environmental modifications; and
- modeling future public program eligibility/participation, use of public benefits, private insurance coverage/use, per capita public/private spending on services, etc.

In many respects, the NLTC is the only survey that can address the full range of issues mentioned above. Its uniqueness stems from the fact that it was explicitly designed to study

changes in the health and functional status of older Americans, and that the sample is drawn from Medicare administrative records and is thus representative of virtually the entire elderly population. The large sample size is also a major advantage when conducting analyses of subgroups of the population (e.g., by severity or type of disability, or cognitive impairment). In retrospect, it is not surprising that the NLTCs was the first survey to document the decline in the prevalence of disability in the elderly population.

For policymakers, a key task is to understand the reasons for the recent declines, the likelihood of declines continuing into the future, and the policy implications of these changes. Current hypotheses for the decline include long-term improvements in the health of the elderly population stemming from improvements in nutrition, better public health infrastructure and wide-spread use of effective medical treatments such as antibiotics. More recent changes in life-styles (higher levels of physical activity and less smoking), better treatment of chronic diseases through medical procedures and pharmaceuticals, and use of assistive devices and technology may also have contributed to the decline. Future improvements in disability and changes in health care utilization and spending will be heavily dependent on which of these hypotheses is correct. For example, if current declines in disability are primarily due to changes in the environment and health care that occurred long ago, the likelihood of further reductions in disability will be low. The impact on future health care utilization and spending is also likely to be negligible. However, if the reasons for the current decline are the result of more recent changes in life-style or better treatment of chronic diseases that are amenable to (further) public health interventions, then the possibility of continued declines in disability will be much higher. And to the extent that there is a concrete link between changes in disability and acute and long-term health care utilization and spending, the direct impact on Medicare, Medicaid, and private long-term care could be substantial.

Home and Community-Based Services

Another key policy objective is to ensure that older Americans with chronic disabilities who are financially eligible for Medicaid have access to appropriate home and community-based services in lieu of institutional care. This is a CMS priority in particular, but it is also of interest to OASPE, AoA, and the Agency for Healthcare Research and Quality (AHRQ). Policymakers are particularly interested in:

- determining whether or not older Americans with a high likelihood of nursing home admission, or who are judged to “need” a nursing home equivalent level of care, have adequate access to home and community-based alternatives;
- determining whether or not the amount and type of home and community-based services (HCBS) is sufficient to meet individual need; and
- assuring that informal care remains available in order to keep the cost of formal, paid home care below that of nursing home care.

A major advantage of the NLTCs compared to other surveys is that it allows policy researchers

to estimate how many older Americans reside in nursing homes or other forms of “community-based” residential elder care. Specifically, the NLTCS data permits policy researchers to count the absolute number and percentage of chronically disabled elderly living in the community who use paid and unpaid home care (e.g., paid care only, informal care only, or a combination of paid and unpaid care). Comparison of these patterns across survey waves provides useful trend data and allows policymakers to determine if increases and decreases in public funding correlate with discernable changes in rates of nursing home use and utilization of formal home care services.

Until recently, the NLTCS was very limited in its usefulness for measuring individual sample members’ transitions from the community to nursing homes. Nursing home use between surveys was only picked up if the nursing home stay was Medicare-covered, or if the respondent was still alive and could be questioned about his or her nursing facility use at the next survey. No information was available about the nursing home use of respondents who died during the period between surveys, except in a “next-of-kin” follow-up survey that—for budget reasons—was not carried out between 1984 and 1999. This limitation can be overcome, at comparatively lower expense, however, by taking better advantage of CMS administrative data that can be merged to the NLTCS files. In the past, Medicare claims data were routinely merged to the NLTCS (main survey); however, it is now possible to merge nursing home Minimum Data Set (MDS) assessments that are carried out on all nursing home residents (including private pay residents as well as those whose nursing home care is being funded by Medicare, Medicaid or other public funding sources). For the first time, it will be possible to take full advantage of the NLTCS longitudinal data on survey respondents to measure the likelihood that any NLTCS respondent residing in the community in a given baseline survey year (e.g., in 1999 or 2004/2005) subsequently entered a nursing home, estimate the number of episodes and duration, and determine what funding source(s) paid for the nursing home stay(s). The likelihood of post-baseline nursing home use can then be analyzed with respect to other characteristics, such as disability and other demographic, socioeconomic, and program participation variables.

Similarly, by merging Medicaid claims from the Medical Statistical Information System (MSIS) to the NLTCS, it will now be possible to measure respondents’ use of Medicaid funded acute and long-term care services, including non-institutional long-term care (e.g., home and community-based services, personal care, home health) as well as nursing home care. This will enable CMS, for example, to estimate the number of Medicaid eligible persons at risk for nursing home use (e.g., those having three or more ADLs and/or severe cognitive impairment) who actually receive Medicaid funded home care, including what kind of services are utilized, how much, and at what cost. Policymakers could also determine the extent to which Medicaid eligible persons residing in the community rely exclusively on Medicaid and other publicly-funded formal services (e.g., Medicare home health), rely exclusively on informal help from family caregivers, or on some combination of informal and publicly-funded services. Additionally, indicators of use/non-use and extent/type of Medicaid-funded home care contained in MSIS data could be analyzed (with appropriate controls for disability level at baseline, etc.) to determine whether access to Medicaid funded home care postpones or prevents nursing home use. This would involve analyses of the relationship between Medicaid HCBS use and the likelihood of nursing home admission and length of stay for Medicaid eligible or potentially eligible persons.

Family Caregiving

A key policy goal is to ensure that family caregivers who provide informal care to elderly persons with disabilities are not over-burdened by these responsibilities and likely to suffer adverse consequences, such as negative physical and mental health consequences, conflict between their informal elder care responsibilities and paid employment, and conflicts between informal elder care and other family responsibilities, such as child care. Congress has shown considerable interest over the years in assisting caregivers. To date, Congressional interest in relieving caregiver stress and burden has resulted in the Family and Medical Leave Act and in grant funding from AoA for a program to fund states to assist family caregivers of the elderly. Congress has also considered and, at various times, the Administration has recommended, legislation that would provide tax credits to family caregivers and/or broad-based respite programs. A number of HHS agencies (the Centers for Disease Control, the National Institutes of Health, the Substance Abuse and Mental Health Services Administration, the Administration for Children and Families) have initiatives related to improving/maintaining caregiver health in response to Congressional interest.

The NLTCs in combination with the Caregiver Supplement to the NLTCs, which was done in 1982, 1989, 1999, and 2004-2005, can be used to analyze how many hours of ADL/IADL help chronically disabled elders receive weekly, and what number and percentage of those hours are provided by informal caregivers (further broken down by primary and secondary caregivers and by relationship, e.g., spouse, son, daughter, friend, etc) as compared to paid workers. This enables policy researchers to measure the time burden of providing informal care on caregivers (especially primary caregivers) in relation to the severity of disability and other care recipient characteristics. The relationship between weekly time burden of informal care and self-reported indicators of caregiver stress can then be analyzed. Further analyses could be carried out with respect to relationships among time burden of informal care, self-reported caregiver stress, use/non use of formal services, and funding source for formal services (public/private). Finally, the NLTCs/ICS contains numerous questions regarding the primary informal caregiver's perception of the need or lack thereof for formal services and the reason why these services are not being used if they are perceived as needed (e.g., lack of affordability, lack of local availability, etc.). This enables policymakers to estimate (using various different criteria) the potential size and characteristics of the target population for public policy interventions to assist caregivers that are currently under discussion—respite programs, paid family leave, tax credits, income tax deductions, etc.

It is important to note that the data needed to address the above issues do not come from the Caregiver Supplement by itself, but from the Caregiver Supplement in combination with the main NLTCs. Other surveys focus exclusively on either care recipients or caregivers. Among national surveys that collect data about informal caregiving, the NLTCs/ICS is unique in being able to link data from the main survey of disabled elders with data collected by interviewing their primary informal caregivers. Changes made to the Caregiver Supplement questionnaire in 1999 made the survey even more policy relevant.

Improving the Quality of Long-Term Care

Improving the quality of long-term care programs managed by HHS, especially home and community-based services, is a long-standing policy priority. This priority is of particular importance to AHRQ and CMS, and requires monitoring and understanding the implications of trends in the quality of long-term care services (as judged by service users, government regulators, and the general public who are or whose family members are potential service users).

The NLTCS can be used to measure the quality of long-term care insofar as NLTCS' respondents' self-reports of unmet and under-met need for help with ADL tasks and some IADL tasks. However, there are no measures of consumer satisfaction with formal services (publicly or privately funded) in the NLTCS. One intriguing possibility would be to merge nursing home information contained in the Online Survey, Certification and Reporting (OSCAR) system to the institutional NLTCS sample. Thus, it would be possible to analyze the characteristics of NLTCS sample members residing in nursing homes with “excellent” as compared to “satisfactory” and “poor” survey and certification track records with respect to deficiencies and other quality measures.

Cost-Effective Coordination/Integration of Acute Health and Long-Term Care Services

Another long-standing policy priority of HHS has been to improve the coordination (and, in some cases, integration) of acute, post-acute, and long-term care to assure appropriate access to necessary care while also seeking to minimize total Medicare/Medicaid costs among the “dual eligible” population—persons covered under both Medicare and Medicaid. This is primarily a CMS priority. Most dual eligibles have higher than average long-term care costs and a majority of elderly dual eligibles only become Medicaid eligible because of their long-term care needs. Advancing this objective requires understanding how acute health and long-term care service utilization of chronically disabled elders differs from those of non-chronically disabled elders, and how these patterns are affected by dual eligibility for Medicare and Medicaid.

The ability to merge Medicare claims, other administrative data (MDS), and MSIS (Medicaid) claims to the NLTCS enables much more detailed and sophisticated analysis of the combined use of both Medicare and Medicaid funded services. The main reason that the NLTCS is more useful than other surveys is because it has a large sample of chronically disabled elders and has more detailed measures of disability (especially if there is interest in analyses of subgroups of chronically disabled elders with mild, moderate, and severe ADL/IADL disabilities and no, mild, moderate, severe cognitive impairment).

Other Emerging Policy Issues

A major advantage of the NLTCS compared to other data sets is that it has been collecting extensive information on the elderly with chronic disabilities for over two decades. This has allowed policymakers to explore the implications of large-scale policy interventions by examining outcomes pre- and post-policy implementation. For example, there was very significant and rapid growth of home health service use from 1989 through the 1990s. The rapid increase in spending was addressed by Congress through provisions of the Balanced Budget Act of 1997 (BBA). The Congressional intent of BBA was to reduce perceived overuse of Medicare home health services, especially long-term use of home health aide services paid for by Medicare. Under BBA, an Interim Payment System was adopted from 1998 to 2000, which was then superseded by the Prospective Payment System. The NLTCS was used by OASPE to track how the BBA legislation and related administrative policy changes affected patterns of home health service use. It was determined that the high point of Medicare home health use was in 1994, when approximately one-half of all chronically disabled elders with three or more ADL impairments used some home health care during the year; approximately one-quarter were using the benefit at any point in time. Since then, use of Medicare home health services, particularly aide services, has decreased considerably. Follow up analyses will examine beneficiaries use and access to Medicare home care, and patterns of reported met and unmet need for ADL/IADL help, particularly for those elderly with severe disabilities who are not receiving or eligible to receive Medicaid-funded home care.

Assuming that a seventh wave of the NLTCS is funded, the NLTCS could be used to explore issues related to the new Medicare Part D drug benefit, which became effective January 1, 2006. Prior to the drug benefit's implementation, many seniors could not afford prescription drug coverage. Evidence showed that some beneficiaries, particularly those without drug coverage, did not fill some needed prescriptions and skipped doses to make their drugs last longer due to cost concerns. Low-income, non-Medicaid eligible beneficiaries, in particular, were sometimes forced to choose between purchasing medications and other essentials. CMS is very interested in evaluating the impact of the Part D program for the foreseeable future. A few important questions include: Has the new benefit increased access to prescription medication, particularly for the low-income population? Has better access to medications contributed to improving health (and decreasing disability) in the elderly population? The NLTCS may be able to assist in addressing these questions, especially if it is linked to CMS administrative data from prescription drug plans.

Summary

The NLTCS has been used extensively by policymakers to address a wide range of policy issues and questions. As we approach a possible seventh wave of the survey, the following is a short list of issues to be considered to improve the NLTCS:

- **Continue linkages to administrative data:** As discussed above, linking CMS administrative data and vital statistics data to the NLTCS increases its usefulness and

analytic power tremendously. Data linkages are also very efficient and cost-effective, thereby freeing resources to be applied to other important data collection/processing activities. New sources of information (e.g., MSIS and prescription drug data) can add to the analytic power of the NLTCS; however, appropriate safeguards need to be in place to ensure respondents' confidentiality and that summary information from administrative records is both useful and well-documented.

- **Review and revise residential care measures:** The NLTCS began to collect information on alternative residential care places such as assisted living and continuing care retirement communities in the 1990s. In fact, the NLTCS was one of the first national surveys to collect information on the full range of residential care places. As other surveys (e.g., the Medicare Current Beneficiary Survey) begin to collect this type of information, it would be extremely useful to review the types of questions being asked and try to measure similar concepts as closely as possible. Estimates of the number of residential care facilities and the characteristics of residents have varied widely because of differences in question wording and data collection methodology. Developing more consistent questions would enable researchers to better estimate a baseline and measure changes in the use of alternative residential care over time.
- **Revise disability measures:** The NLTCS contains the broadest measures of disability found on any current survey of the elderly. However, many of the measures were developed many years ago and have not been updated. While it is imperative to consistently measure trends in disability over time, aspects of the NLTCS disability questions could be improved. For example, OASPE and NCHS have provided resources to develop and test a new series of questions to better measure disabled elderly persons' use of assistive technology and home modifications. The entire module or a subset of questions could be included in a future wave of the NLTCS, and responses to the two sets of questions could be compared. Similarly, updated versions of the ADL/IADL questions could be (carefully) introduced to both allow continued evaluation of the trend in disability and updating to reflect changes in today's environment.
- **Reduce the five-year period between data collection:** Because the five-year period between surveys is quite long and many important health and demographic transitions may be missed, it is critical to collect information more frequently. Obviously, the best approach would be to collect data over a shorter time period, either from the entire sample or possibly a subsample (e.g., from those respondents most likely to make a health/residential care transition). Unfortunately, this option is likely to be quite costly and thus not feasible. However, it may be cost-effective to continue to collect information on decedents through a next-of-kin survey. This would allow policymakers to follow residential transitions beyond movements into and out of hospitals and skilled nursing facilities. How older Americans are using alternatives to nursing home care, such as assisted living and board and care, is a major policy question.