

Availability of Nationally Representative Federal Surveys on Disability and Caregiving

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Information Infrastructure

- Policymaking is dependent on statistically representative national data. Such data are collected mainly under federal auspices.
- It essential to maintain this infrastructure in structurally sound “up-to-date” condition.
- Findings from statistically valid data may be especially useful to policymakers when they are “counter-intuitive.”
- For example, 25-30 years ago, it was widely believed that families were increasingly becoming less willing or able to provide unpaid eldercare at home.
- The first statistically valid national surveys of the chronically disabled elderly and their caregivers de-bunked what the pioneer researchers in caregiving called the “myth of family abandonment.”
- More recently, such surveys revealed that, on average, informal caregivers’ access to both supplemental paid care and secondary unpaid helpers decreased from the mid to late 1990s.

SIPP and NSFH

- The 1986 Survey of Income and Program Participation (SIPP) conducted by the Census Bureau and the 1988 National Survey of Families and Households (NSFH), conducted by the University of Wisconsin, sponsored by the NICDH and NIA.
- The SIPP and the NSFH are termed “household” surveys (as opposed to person-specific surveys) because the survey sampling frame is families (consisting of one or more individuals) residing in households from which one member who meets the sample selection criteria is recruited into the survey.
- The 1986 SIPP and 1988 NSFH provided the statistical basis for Peter Arno’s widely cited estimates of the economic value of informal caregiving.
- Although both surveys have had subsequent waves of data collection, survey content has changed. More recent waves focus on childcare and other family relationships, not informal care of the elderly and disabled
- The 1986 SIPP and 1988 NSFH data are now twenty years old and have passed their “sell by” date.

Health Interview Survey

- The Health Interview Survey (HIS) has been conducted every four or five years by the National Center for Health Statistics --- for 50 years.
- It's value lies in its consistency, so it's not easy to make changes, although the content is updated from time to time and additional "modules" may be included on a one time basis.
- For example, in 1994 the HRS included a Disability Supplement which became the main source of "recent" data on caregiving across the lifespan (that is, including caregiving for persons under age 65).
- Some questions from the Disability Supplement were subsequently incorporated in ongoing HIS, but caregiving data remain very limited.
- HIS data on caregiving are mainly useful to establish whether persons with disabilities who require human assistance rely exclusively on unpaid help or receive some paid assistance.
- Other federal surveys provide better and more recent data on informal eldercare, but HIS is virtually the only currently available federal source of nationally representative data on informal care provided to younger "working age" adults.

National Long-Term Care Survey (NLTCS)

- Nationally representative survey of elderly (65+), with special focus on obtaining a robust sample of those in need of assistance with basic and/or instrumental activities of daily living (ADLs/IADLs), including both human and technological assistance.
- NLTCS was fielded in 1982, 1984, 1989, 1994, 1999, 2004. An informal Caregiver Supplement was included in 1982, 1989, 1999, and 2004.
- Duke University has conducted the survey since its inception. The original funding came from a consortium of HHS agencies (ASPE, AoA, and CMS). However, since 1989, funding has been provided by NIA (supplemented by funding from ASPE; in particular, for the Informal Caregiver Supplement).
- The NLTCS is a person-specific survey. It consists of a sample of 35,789 people drawn from national Medicare enrollment files in 1982 augmented with subsequent samples of approximately 20,000 Medicare enrollees --- obtained by adding 5,000 people passing age 65 between successive surveys done approximately every five years.
- The NLTCS provides both a nationally representative cross-section in each survey year and a true longitudinal file. All persons entering the survey continue for life, and survivors are re-interviewed in the next round.

NLTCS, Cont'd

- Detailed data are collected on all persons with disabilities --- both those residing “at home” alone or with relatives in the community and those in nursing homes and other specialized care facilities.
- Detailed data --- except disability and caregiver information --- also are collected on a representative sample of persons without disabilities, who provide a comparison group and may also provide information on the process of becoming disabled in later survey rounds.
- A unique feature of the NLTCS when coupled with the ICS is that data are available from matched dyads: the disabled elderly respondent who receives informal care and his/her primary informal caregiver.
- In addition, in 1982 and again in 1999 a “next of kin” survey of decedents was conducted.
- Medicare claims and other administrative records are merged to the files. In 1999, appended CMS data included nursing home MDS assessments and home health OASIS assessments.
- Technical and funding issues make the continuation of the NLTCS uncertain.

Health and Retirement Survey

- The HRS is conducted by the University of Michigan, with primary funding from NIA.
- Unlike the NLTCs, it is not focused on elders in need of long-term care and their caregivers.
- In the HRS, disabled elders are a subset within a survey that is primarily concerned with “aging” and understanding how health status and retirement income/assets differ by age cohort and, over time, among Americans age 55 and older.
- The HRS is conducted in waves (data collection began in 1992) and no single wave constitutes a representative database of all older Americans. Individual respondents may participate in several waves of data collection but not necessarily “for life.”
- As of 2002, the HRS sample consisted of 16,997 adults age 55 and older. The subsets of “frail elders” age 65 and older living in the community and, especially of those with “severe” disabilities are small compared to the corresponding NLTCs sample sizes.

HRS, Continued

- The HRS sample does not include persons residing in specialized eldercare facilities (e.g. nursing homes or assisted living); however, once in the community-dwelling sample, respondents are followed into and out of nursing and related facilities.
- Caregiving data in the HRS are provided by sample members age 55+ who report providing informal care and by sample members who report receiving paid and unpaid assistance.
- Unlike the NLTCS, there are no data available in the HRS on matched “dyads” of elders receiving informal care and their identified primary caregivers (regardless of age).
- Medicare claims have been appended to the HRS survey database.
- In sum, the HRS provides some useful data on informal care, but if the NLTCS were to be discontinued, the HRS will not provide a sufficient alternative source of information on paid and unpaid eldercare.