



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

# **LONG-TERM CARE AND DISABILITY RESEARCH:**

## **1986-1989**

March 1989

## **Office of the Assistant Secretary for Planning and Evaluation**

The Office of the Assistant Secretary for Planning and Evaluation (ASPE) is the principal advisor to the Secretary of the Department of Health and Human Services (HHS) on policy development issues, and is responsible for major activities in the areas of legislative and budget development, strategic planning, policy research and evaluation, and economic analysis.

ASPE develops or reviews issues from the viewpoint of the Secretary, providing a perspective that is broader in scope than the specific focus of the various operating agencies. ASPE also works closely with the HHS operating divisions. It assists these agencies in developing policies, and planning policy research, evaluation and data collection within broad HHS and administration initiatives. ASPE often serves a coordinating role for crosscutting policy and administrative activities.

ASPE plans and conducts evaluations and research--both in-house and through support of projects by external researchers--of current and proposed programs and topics of particular interest to the Secretary, the Administration and the Congress.

## **Office of Disability, Aging and Long-Term Care Policy**

The Office of Disability, Aging and Long-Term Care Policy (DALTCP), within ASPE, is responsible for the development, coordination, analysis, research and evaluation of HHS policies and programs which support the independence, health and long-term care of persons with disabilities--children, working aging adults, and older persons. DALTCP is also responsible for policy coordination and research to promote the economic and social well-being of the elderly.

In particular, DALTCP addresses policies concerning: nursing home and community-based services, informal caregiving, the integration of acute and long-term care, Medicare post-acute services and home care, managed care for people with disabilities, long-term rehabilitation services, children's disability, and linkages between employment and health policies. These activities are carried out through policy planning, policy and program analysis, regulatory reviews, formulation of legislative proposals, policy research, evaluation and data planning.

This report was prepared by HHS's Division of Aging, Disability and Long-Term Care (now 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).

**LONG-TERM CARE AND DISABILITY RESEARCH:  
1986-1989**

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# TABLE OF CONTENTS

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<b>INTRODUCTION</b> .....	1
<b>ORGANIZATION</b> .....	2
<b>I. SUPPLY, DEMAND AND FINANCING ISSUES</b> .....	3
A. Overview .....	3
B. Completed or Ongoing Projects .....	4
C. Planned Projects .....	9
<b>II. POPULATION CHARACTERISTICS AND SERVICE USE</b> .....	10
A. Overview .....	10
B. Completed or Ongoing Projects .....	10
<b>III. HOME AND COMMUNITY-BASED CARE SYSTEMS</b> .....	15
A. Overview .....	15
B. Completed or Ongoing Projects .....	15
C. Planned Projects .....	2`
<b>IV. QUALITY OF CARE</b> .....	23
A. Overview .....	23
B. Completed or Ongoing Projects .....	23
<b>V. DISABILITY ISSUES</b> .....	26
A. Overview .....	26
B. Completed or Ongoing Projects .....	26
C. Planned Projects .....	30
<b>VI. LONG-TERM CARE AND DISABILITY DATA NEEDS</b> .....	31
A. Overview .....	31
B. Completed or Ongoing Projects .....	31
C. Planned Projects .....	34

# INTRODUCTION

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This compendium is published by the Division of Disability, Aging, and Long-Term Care Policy within the Office of the Assistant Secretary for Planning and Evaluation (ASPE), Office of Social Services Policy (SSP). It summarizes the results of the Division's research projects from 1986 through the present and highlights future plans.

The role of research within the Division is to produce information on the organization, financing and delivery of services to chronically impaired populations to inform the Department's policy development process. Recent work has centered on the needs of the impaired elderly and persons with mental retardation and other developmental disabilities.

# ORGANIZATION

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The compendium is divided into six subject areas:

- I. Supply, Demand and Financing Issues;
- II. Population Characteristics and Service Use;
- III. Home and Community-Based Services;
- IV. Quality of Care;
- V. Disability Issues; and
- VI. Data Needs.

Each subject area is subdivided into: (A) Overview; (B) Completed or Ongoing Projects; and (C) Planned Projects. [**NOTE: Report links were added when this compendium was made Internet-ready.**]

Project descriptions include the title of the study, principal investigator, an abstract of the subject matter and findings, a list of reports (if different from the study title), the project completion date and a division contact person. To obtain a copy of or information about the final report for completed studies, the reader should contact:

*Policy Information Center  
Office of the Assistant Secretary for Planning and Evaluation  
U.S. Department of Health and Human Services  
Room 438-F, Hubert H. Humphrey Building  
200 Independence Avenue, S.W.  
Washington, D.C. 20201  
(202) 245-6445*

SSP directly distributes a limited number of final reports from selected studies. If you would like to receive a copy of the final report from a particular study now in progress, contact:

*Brenda Thorne  
U.S. Department of Health and Human Services  
Room 410-E, HHH Building  
200 Independence Avenue, S.W.  
Washington, D.C. 20201*

Or you may call:

*(202) 245-6613*

# I. SUPPLY, DEMAND AND FINANCING ISSUES

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## A. Overview

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The Office of Social Services Policy (SSP) has undertaken a number of related projects to model the demand for and financing of long-term care. The initial work, the ICF, Inc. study, **Private Financing of Long-Term Care**, prompted the Brookings Institution to work with ICF, Inc. to develop the Brookings-ICF Long-Term Care Financing Model. This model is used to predict the effects of various financing and organizational reform options on future utilization and public and private expenditures for nursing home and home care.

The Brookings-ICF model was undergoing final testing when Secretary Bowen began his study of Catastrophic Illness Expenses which included a sub-study on private long-term care financing. SSP contracted with Brookings to use the model to estimate participation and expenditures under a series of private long-term care insurance and individual Medical Account proposals. (See below: **Modeling the Effects of Private Financing Options on Public and Private Expenditures.**)

After conducting several special studies of the model's treatment of key variables (described below, **Financing of Long-Term Care**), ASPE made a decision to bring it in house. A contract was let in September 1988 to acquire the Brookings-ICF model, update it, train HHS personnel in its use, and provide technical assistance (**Long-Term Care Microsimulation Model**). While reports have been completed for all of the above projects, readers should note that the long-term model is undergoing substantial change as more current data bases are added. The results from these original studies are now being updated.

Three additional studies of demand and financing are now underway. The first will convene an expert panel to assist in specifying public and private long-term care financing reforms, which will then become the basis for new simulations (**Analysis of Long-Term Care Financing Options**). The second is a grant to Brookings (**Premium Pricing of Prototype Private Long-Term Care Insurance Policies**) to develop prototype long-term care insurance policies, and estimate premium prices for them. The third study is an independent look at the future demand for long-term care under a series of dynamic assumptions (**The Future of Long-Term Care: Projections and Challenges**).<sup>1</sup>

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<sup>1</sup> Several projects were funded under the Long-Term Care Grants Program, announced periodically by the Division of Disability, Aging and Long-Term Care, to encourage the application of existing national data to the resolution of long-term care and disability policy issues. An asterisk next to a project title on the following pages refers to a project funded under this program.

Two related projects are being considered for 1989. The first is a seminar on long-term care supply to develop methods for projecting supply. The second will provide an economic analysis of the market for home care workers.

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## **B. Completed or Ongoing Projects**

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**TITLE: *Private Financing of Long-Term Care: Current Methods and Resources, Phase I and Phase II***

**PRINCIPAL INVESTIGATOR:** David Kennell, Lewin/ICF, Inc., Washington, DC

**SYNOPSIS:** This early work identified private long-term care financing strategies, barriers to their growth and the potential effects of reducing barriers. It also developed a long-term care financing model to estimate the impact of private long-term care insurance on government long-term care costs. The study describes various types of pooled financing arrangements including long-term care insurance, prepaid health plans and life care centers, and identifies some untested alternatives e.g., single premium annuity, combination life/LTC insurance, IRA and pension benefit options. The study also estimates how many elderly people might be able to afford long-term care insurance.

*Note:* The findings from this study are out of date. It is discussed here because it provided the initial conceptual work behind much of the later research.

**CONTACT PERSON:** Paul D. Gayer, ASPE, (202) 245-6613

**COMPLETION DATE:** January 1985

**REPORT(S) LINK:**

Private Financing of Long-Term Care: Current Methods and Resources--Phase I Final Report [<http://aspe.hhs.gov/daltcp/reports/prvfin.htm>]

Private Financing of Long-Term Care: Current Methods and Resources--Phase II Final Report [<http://aspe.hhs.gov/daltcp/reports/prvfin2.htm>]

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**TITLE: *Modeling the Effects of Private Financing Options on Public and Private Expenditures***

**PRINCIPAL INVESTIGATORS:** Joshua Wiener, The Brookings Institution, Washington, DC

David Kennell, Lewin/ICF, Inc., Washington, DC

**SYNOPSIS:** This study was undertaken in support of the Secretary's Technical Work Group on Private Financing of Long-Term Care for the Elderly. It employed the Brookings-ICF Long-Term Care Model to estimate the effects of private insurance and tax-sheltered savings for long-term care on private out-of-pocket and Medicaid



expenditures (both Federal and State). Some of the results are reported in **Report to the Secretary on Private Financing of Long-Term Care for the Elderly, Technical Work Group on Private Financing of Long-Term Care for the Elderly, November 1986** [<http://aspe.hhs.gov/daltcp/reports/pfltce.htm>]. The analyses indicated that private long-term care insurance was likely to attract far more participation than tax sheltered savings vehicles such as individual Medical Accounts. The analyses also suggested that broad market penetration of private long-term care insurance can most quickly be achieved by providing some tax incentives.

**CONTACT PERSON:** Paul D. Gayer, ASPE, (202) 245-6613

**COMPLETION DATE:** September 1986

**REPORT(S) LINK:**

Report to the Secretary on Private Financing of Long-Term Care for the Elderly  
[<http://aspe.hhs.gov/daltcp/reports/pfltce.htm>]

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**TITLE:** *Financing of Long-Term Care*

**PRINCIPAL INVESTIGATOR:** David Kennell, Lewin/ICF, Inc., Washington, DC

**SYNOPSIS:** The analyses carried out for the Secretary's study of private long-term care financing raised several questions about the validity of the long-term care model estimates and forecasts, and identified issues in need of future research. In this project, four tasks were undertaken:

- *Analysis of the Causes of Nursing Home Admission.* Using the 1982-84 National Long-Term Care Survey, eight statistically significant predictors of nursing home admission were identified: age, race, a prior nursing home stay, level of disability, use of paid home care, living situation, mental capability, and a rating of self health.
- *Analysis of the Correlation Between Nursing Home Entrance and Income.* The long-term care model did not vary the probability of nursing home admission by income. This analysis explored the relationship between income and nursing home admission. The analysis found the income of nursing home entrants is lower than all elderly but that controlling for age, sex, marital status and employment earnings eliminates most of the differences.
- *Analysis of Spend-down of Assets to Medicaid Eligibility.* This analysis explored the effect of the model's assumptions about asset transfers on Medicaid expenditures. It will be redone using the updated model.
- *Model Simulations.* Simulations were conducted to investigate the effects of current long-term care proposals and to test the sensitivity of results to various

assumptions about the rate of inflation and disability in the future. This work will be revised once the model has been updated.

*CONTACT PERSON:* Paul D. Gayer, ASPE (202) 245-6613  
*COMPLETION DATE:* 1988

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**TITLE: *Long-Term Care Microsimulation Model***

*PRINCIPAL INVESTIGATOR:* David Kennell, Lewin/ICF, Inc., Washington, DC

**SYNOPSIS:** The Brookings-ICF Long-Term Care Model has been recently acquired by SPE and will be used to simulate the utilization and financing of nursing home and home care by elderly persons for the period 1986 to 2020. It is being updated to include the results of the 1984 National Long-Term Care Survey and the 1985 National Nursing Home Survey. This project acquires the model; rewrites the code to make it useable by a variety of users in the Department; adapts it for HHS computers; and benchmarks it to permit checking on the accuracy of subsequent uses.

The long-term care model is based on the PRISM model developed by ICF, Inc. with the addition of a disability module developed by Brookings and ICF, Inc.. It begins with a nationally-representative sample of the adult population with a record for each person's age, sex, income, assets, and other characteristics. The model also simulates changes in the population each year, including changes in each individual's age, economic status, disability status, utilization of long-term care, and method of paying for care.

It generates a base case projection which assumes that current public programs and private financing remain unchanged. It also simulates changes in financing methods. These simulations are greatly affected by the choice of assumptions about the economy and individual behavior. The model can produce estimates using alternative assumptions to show how sensitive the results are to the ones chosen.

*CONTACT PERSON:* John Drabek, ASPE, (202) 245-6613  
*COMPLETION DATE:* September 1991  
*REPORT(S) LINKS:*

Brookings/ICF Long Term Care Financing Model: Model Assumptions  
[\[http://aspe.hhs.gov/daltcp/reports/modampes.htm\]](http://aspe.hhs.gov/daltcp/reports/modampes.htm)

Brookings/ICF Long Term Care Financing Model: Designing and Using Model Simulations [\[http://aspe.hhs.gov/daltcp/reports/modsimes.htm\]](http://aspe.hhs.gov/daltcp/reports/modsimes.htm)

Brookings/ICF Long Term Care Financing Model: User's Guide to Specifying Simulations [\[http://aspe.hhs.gov/daltcp/reports/usergdes.htm\]](http://aspe.hhs.gov/daltcp/reports/usergdes.htm)

Brookings/ICF Long Term Care Financing Model: Programmer's/Operator's Manual  
[\[http://aspe.hhs.gov/daltcp/reports/prgopres.htm\]](http://aspe.hhs.gov/daltcp/reports/prgopres.htm)

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**TITLE: *Analysis of Long-Term Care Financing Options***

*PRINCIPAL INVESTIGATOR:* David Kennell, Lewin/ICF, Inc., Washington, DC

**SYNOPSIS:** The purpose of this project is to provide staff assistance, research backup and design expertise for a policy research effort to develop and evaluate public and private long-term care policy options. The project will draw on the advice of Federal and State officials, researchers, insurers and service providers. Products will include: detailed analyses of problems with current financing mechanisms as well as proposed alternatives; analyses of public opinion and behavior with respect to financing choices; simulations of the effect of public and private reform proposals; and planning for additional research to fill information gaps.

*CONTACT PERSON:* Paul D. Gayer, ASPE, (202 245-6613

*COMPLETION DATE:* September 1989

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**TITLE: *Premium Pricing of Prototype Private Long-Term Care Insurance Policies\****

*PRINCIPAL INVESTIGATOR:* Joshua Wiener, The Brookings Institution, Washington, DC

**SYNOPSIS:** This project will generate estimates of benefits, costs and premiums for prototype long-term care insurance policies to provide the Federal, State and local government and private insurance companies with an independent means of estimating the potential for long-term care insurance coverage. The modeling techniques to be used in this study have been tested in other analyses.

*CONTACT PERSON:* Paul D. Gayer, ASPE, (202) 245-6613

*COMPLETION DATE:* September 1989

*REPORT(S) LINKS:*

Premium Pricing of Prototype Private Long-Term Care Insurance Policies: Final Report [<http://aspe.hhs.gov/daltcp/reports/prempric.htm>]

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**TITLE: *The Future of Long-Term Care: Projections and Challenges\****

*PRINCIPAL INVESTIGATOR:* Bob Applebaum, Miami University of Ohio, Scripps Gerontology Center, Oxford, OH

**SYNOPSIS:** This study is designed to provide comprehensive information about future long-term care needs in the United States. Using data from the U.S. Decennial Census of Population and Housing, National Long-Term Care Survey and National Nursing Home Survey, the study will develop detailed projections of the need for long-term care

among the elderly in the years 2000, 2020, and 2040. Estimates of long-term care needs have traditionally relied on static models which assume that mortality and morbidity rates will remain constant over the projection period. This study will employ a dynamic projection model. Three different sets of projections will be estimated based on varying assumptions about changes in life expectancy and rates of impairment.

*CONTACT PERSON:* Paul D. Gayer, ASPE, (202) 245-6613

*COMPLETION DATE:* February 1989

*REPORT(S) LINKS:*

Estimating the Prevalence of Long-Term Disability for an Aging Society

[\[http://aspe.hhs.gov/daltcp/reports/agsoces.htm\]](http://aspe.hhs.gov/daltcp/reports/agsoces.htm)

Long-Term Care for the Boomers: A Public Policy Challenge for the Twenty-first

Century [\[http://aspe.hhs.gov/daltcp/reports/boomers.htm\]](http://aspe.hhs.gov/daltcp/reports/boomers.htm)

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**TITLE:** *Long-Term Care in Comparative International Perspective*

*PRINCIPAL INVESTIGATOR:* Pamela Doty, ASPE, Washington, DC

**SYNOPSIS:** This ongoing research involves tracking developments in long-term care financing and delivery in other countries. The current focus is on lessons to be learned from the recent implementation of Israel's new long-term care insurance law. Past research has focused on comparative cross-national institutionalization rates, the balance of medical to non-medical comparative cross-national institutionalization rates, the balance of medical to non-medical long-term care institutional use, effectiveness of funding home and community-based care to prevent or postpone institutionalization, relative reliance on public versus private financing and differences in public financing mechanisms. A paper on comparative financing methods was presented at a Brookings Institution conference in May 1988 and a general overview of long-term care in international perspective, highlighting comparative institutionalization rates, will be forthcoming in the Health Care Financing Review 1988 Supplement.

*CONTACT PERSON:* Pamela Doty, ASPE, (202) 245-6172

*COMPLETION DATE:* Ongoing

*REPORT(S) LINKS:*

Long-Term Care in International Perspective

[\[http://aspe.hhs.gov/daltcp/reports/intpersp.htm\]](http://aspe.hhs.gov/daltcp/reports/intpersp.htm)

Dispelling Some Myths: A Comparison of Long-Term Care Financing in the U.S. and Other Nations [\[http://aspe.hhs.gov/daltcp/reports/dispmyth.htm\]](http://aspe.hhs.gov/daltcp/reports/dispmyth.htm)

U.S. Long-Term Care Financing in Comparative International Perspective: Old Myths, New Ideas [\[http://aspe.hhs.gov/daltcp/reports/mythses.htm\]](http://aspe.hhs.gov/daltcp/reports/mythses.htm)

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## C. Planned Projects

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**TITLE:** *Seminar on Long-Term Care Supply*

**SYNOPSIS:** The Division is considering initiating a new project to develop a methodology for projecting the supply of long-term care services. In the first phase of the project, it is anticipated that papers would be solicited from outside experts on supply issues and a seminar organized to propose a longer-term research strategy for addressing supply issues.

**CONTACT PERSON:** John Drabek, ASPE, (202) 245-6613

**COMPLETION DATE:** To be determined.

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**TITLE:** *Modeling the Supply of Home Care Workers*

**SYNOPSIS:** This project is intended to gain a better understanding of the market for home care workers including the potential competition for workers of this type from other industries. The study will build on projections and models which already exist, such as the Bureau of Labor Statistics Occupational Outlook Projections as well as studies which have been done for specific States. It may be conducted intramurally.

**CONTACT PERSON:** John Drabek, ASPE, (202) 245-6613

**COMPLETION DATE:** To be determined.

## II. POPULATION CHARACTERISTICS AND SERVICE USE

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### A. Overview

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Projects in this area reflect a continuing emphasis on basic and descriptive research to understand the characteristics and service use patterns of the long-term care population and to develop predictors of service use (**Long-Term Care Service Use: Longitudinal & Predictive Models; Characteristics of the Elderly Long-Term Care Population and Its Service Use; and Risk of Institutionalization Comparison 1977 to 1985.**)

The Division has also devoted considerable attention the effects of Medicare's Prospective Payment System on the service use of impaired older persons. (See **Effects of Medicare's Prospective Payment System on Medicare Beneficiaries** described below; and **A Pilot Study of the Adequacy of Post-Hospital Community Care for the Elderly** in Section III, Quality of Care.)

Also of interest are several policy issues about how the economic characteristics of people who receive long-term care affect service use and well being. For example, the effects of Medicaid eligibility requirements on spousal impoverishment and Medicaid spend-down have received attention (**The Effects of Medicaid Nursing Home Policies on Surviving Spouses in the Community; The Use, Cost, and Economic Burden of Nursing Home Care in 1985; Medicaid Spend-Down and Long-Term Care: How High the Risk? and An Analysis of Spend Down Dynamics in Nursing Homes.**) The Division sponsored a meeting of many of the people working on Medicaid spend-down studies for HHS, and further efforts are planned to coordinate related projects, and to discover the reasons for contradictory findings.

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### B. Completed or Ongoing Projects

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**TITLE:** *Long-Term Care Service Use: Longitudinal & Predictive Models\**

**PRINCIPAL INVESTIGATOR:** John Morris, Hebrew Rehabilitation Center for the Aged, Boston, MA

**SYNOPSIS:** This study will describe community and institutional service use patterns over a five year period (1982-87), based on secondary analyses of longitudinal data for over 4,000 Massachusetts elderly. Emphasis is placed on community service use of persons judged to be at high risk of institutional placement. For nursing home users, the elderly will be distinguished as long-stayers, short-stayers or terminal. The data set consists of two samples: a cross-sectional cohort of elderly living in the community

(70% of the total sample) and a cross-sectional cohort of elderly clients served in the Massachusetts Home Care Program.

**CONTACT PERSON:** Glen Harelson, ASPE (202) 245-6172

**COMPLETION DATE:** February 1989

**REPORT(S) LINKS:**

Long-Term Care Service Use: Longitudinal and Predictive Models

[\[http://aspe.hhs.gov/daltcp/reports/lcmodes.htm\]](http://aspe.hhs.gov/daltcp/reports/lcmodes.htm)

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**TITLE:** *Characteristics of the Elderly Long-Term Care Population and Its Service Use\**

**PRINCIPAL INVESTIGATOR:** Kenneth Manton, Duck University, Durham, NC

**SYNOPSIS:** The first phase of this study is a joint analysis of the 1982-1984 National Long-Term Survey and the Channeling data sets. The focus is on functional transitions at advanced ages and the impact of long-term care services on these transitions. The analytic procedures will include event history and life table models based on Grade of Membership (GOM) classifications. In the second phase, the 1984 Health Interview Survey/Supplement on Aging and the 1986 Longitudinal Survey on Aging, and the 1985 National Nursing Home Survey will be analyzed. These complementary data sources are being used to refine and expand the understanding of health and functional status changes, as well as trends in institutionalization and community service use.

**CONTACT PERSON:** Robert Clark, ASPE, (202) 245-6172

**COMPLETION DATE:** 1989

**REPORTS AVAILABLE:**

Risks of Entering Nursing Homes for Long and Short Stays

[\[http://aspe.hhs.gov/daltcp/reports/nhlsstes.htm\]](http://aspe.hhs.gov/daltcp/reports/nhlsstes.htm)

The Effect of Nursing Home Use on Medicaid Eligibility

[\[http://aspe.hhs.gov/daltcp/reports/nhumes.htm\]](http://aspe.hhs.gov/daltcp/reports/nhumes.htm)

Recent Changes in Service Use Patterns of Disabled Medicare Beneficiaries

[\[http://aspe.hhs.gov/daltcp/reports/recentes.htm\]](http://aspe.hhs.gov/daltcp/reports/recentes.htm)

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**TITLE:** *Risk of Institutionalization Comparison 1977 to 1985\**

**PRINCIPAL INVESTIGATOR:** William Weissert, University of North Carolina, Chapel Hill, NC

**SYNOPSIS:** This study will compare the determinants of institutionalization for two time periods, 1977 and 1985, and identify factors, such as supply, that are associated with any perceived differences between the periods. Data sources include the 1977 and

1985 National Nursing Home Surveys, the 1984 Health Interview Survey/Supplement on Aging, and the 1977 Health Interview Survey. The study should results in a better understanding of the determinants of institutionalization and enhance capability of home and community-based care providers to control case mix. A product of the project will be a kit that practitioners of home and community-based care can use to assess the probable risk of institutionalization of their clients and applicants.

*CONTACT PERSON:* Floyd Brown, ASPE, (202) 245-6443

*COMPLETION DATE:* January 1989

*REPORT AVAILABLE:*

Risk of Institutionalization: 1977-1985

[\[http://aspe.hhs.gov/daltcp/reports/instrkes.htm\]](http://aspe.hhs.gov/daltcp/reports/instrkes.htm)

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**TITLE: *Effects of Medicare's Hospital Prospective Payment System (PPS) on Disabled Medicare Beneficiaries***

*PRINCIPAL INVESTIGATOR:* Korbin Liu, Urban Institute, Washington, DC

**SYNOPSIS:** The purpose of this study was to determine how PPS has affected the patterns of care received by Medicare beneficiaries with chronic disabling conditions. The study used the 1982-1984 National Long-Term Care Survey to provide an empirical analysis of differences in the utilization patterns of hospital, skilled nursing facility and home health services under Medicare, before and after the implementation of PPS. Findings indicate that there were overall reductions in hospital lengths of stay after PPS, although the reductions were not uniform and appeared to be concentrated in subgroups of the disabled population. Importantly, the most disabled subgroup showed no change in length of stay. Virtually no changes were observed in post-PPS Medicare SNF use although one would have hypothesized an increase. There was an overall increase in post-PPS home health utilization. No differences were observed in overall readmission or mortality rates pre- and post-PPS.

*CONTACT PERSON:* Floyd Brown, ASPE, (202) 245-6443

*COMPLETION DATE:* 1988

*REPORT(S) LINKS:*

Effects of Medicare's Hospital Prospective Payment System (PPS) on Disabled Medicare Beneficiaries [\[http://aspe.hhs.gov/daltcp/reports/pps.htm\]](http://aspe.hhs.gov/daltcp/reports/pps.htm)

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**TITLE: *The Effects of Medicaid Nursing Home Policies on Surviving Spouses in the Community***

*PRINCIPAL INVESTIGATOR:* Korbin Liu, Urban Institute, Washington, DC



**SYNOPSIS:** The structure of the Medicaid program permits a wide variation among States in how eligibility for nursing homes is established. The consequence is that in some States relatively wealthy spouses of nursing home residents provide no financial support for nursing home costs, while in other cases, the spouse who remains in the community is literally impoverished. Although the Medicare Catastrophic Act of 1988 liberalized the amount of family income available to the non-institutionalized spouse, States have retained the flexibility to set the amount between an upper-bound (\$1,600 month) and lower-bound (pegged to a percentage of the Federal poverty level for a 2-person household).

This study used the National Long-Term Care Survey to provide estimates of persons who would be affected by the different policy options to reduce the incidence of spousal impoverishment due to nursing home use. Using the weighted estimates of disabled and non-disabled sample members who were in a married status in the 1982 survey and subsequently reflected as institutionalized in the 1984 survey, the conclusion was reached that 79,000 persons per year could be affected by spousal impoverishment policies because they were in a married status in 1982 and subsequently entered nursing homes for long-term care.

*CONTACT PERSON:* Floyd Brown, ASPE (202) 245-6443  
*COMPLETION DATE:* 1988

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**TITLE:** *Medicaid Spend-Down and Long-Term Care: How High the Risk?*

*PRINCIPAL INVESTIGATOR:* Pamela Doty, ASPE, Washington, DC  
Korbin Liu, Urban Institute, Washington, DC  
Kenneth Manton, Duke University, Durham, NC

**SYNOPSIS:** This project analyzes payment patterns, including spend-down to Medicaid eligibility among the disabled elderly both in nursing homes and the community using the 1985 National Nursing Home Discharge Survey and the 1982 and 1984 National Long-Term Care Survey. The product will be a paper analyzing the policy implications of the patterns uncovered with respect to options for long-term care financing reform.

*CONTACT PERSON:* Pamela Doty, ASPE, (202) 245-6172  
*COMPLETION DATE:* February 1989

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**TITLE:** *The Use, Cost, and Economic Burden of Nursing Home Care in 1985\**

*PRINCIPAL INVESTIGATOR:* Tom Rice, University of North Carolina, Chapel Hill, NC

**SYNOPSIS:** This study uses the 1985 National Nursing Home Survey to examine the use and cost of nursing home care among the elderly population of the United States. The following questions are addressed: How many persons aged 65 and older use nursing homes in a given year? How long do they stay and what are their annual charges? How often, and, to what extent, do residents “spend down” to Medicaid? How much of the annual charges are paid by the various payers; in particular, what are annual out-of-pocket costs?

The study found that approximately 2.1 million persons aged 65 and older (7.5% of the U.S. elderly population) spent some time in a nursing home during 1985. Over 70% were women and nearly two-thirds were single, widowed or divorced women. Mean charges per nursing home user in 1985 were \$9,600 and median charges were \$7,700. About 53% of 1985 nursing home costs were paid privately, out-of-pocket, 35% by Medicaid, 8% by Medicare, and 4.0% by other sources. About 22% of nursing home residents who initially entered nursing homes as private pay patients became eligible for Medicaid during their stay.

**CONTACT PERSON:** Pamela Doty, ASPE, (202) 245-6443

**COMPLETION DATE:** January 1989

**REPORT(S) LINKS:**

The Use, Cost, and Economic Burden of Nursing Home Care in 1985

[\[http://aspe.hhs.gov/daltcp/reports/usecstes.htm\]](http://aspe.hhs.gov/daltcp/reports/usecstes.htm)

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**TITLE:** *An Analysis of Spend Down Dynamics in Nursing Homes\**

**PRINCIPAL INVESTIGATOR:** Christine Pattee, Connecticut Department of Health Services, Hartford, CT

**SYNOPSIS:** To analyze Medicaid spend-down patterns, it is desirable to use a data set which contains source of payment information on all nursing home patients throughout their stay. It requires considerable effort to develop such data sets. This project uses the Connecticut Nursing Home Patient Registry, an eight-year longitudinal data file on all nursing home patients in the State, to analyze Medicaid spend-down. Analyses will be conducted to determine the point at which patients with various characteristics and diagnoses convert to Medicaid.

**CONTACT PERSON:** John Drabek, ASPE, (202) 245-6613

**COMPLETION DATE:** September 1989

### III. HOME AND COMMUNITY-BASED CARE SYSTEMS

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#### A. Overview

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The major research project of the Division in the area was the National Long-Term Care Channeling Demonstration co-sponsored with the Health Care Financing Administration and the Administration on Aging. This multi-year, 10 State randomized experiment was designed to test the cost-effectiveness of comprehensive case management and home care. The 25 reports from the demonstration contain a great deal of information on the provision of home and community-based services, and the data base should be a rich source for further research for years to come. The final report on Channeling and the public use tapes were published in 1986 (**National Long-Term Care Channeling Demonstration**). A recent project which uses the Channeling data is **Reducing Nursing Home Utilization Costs Through Community-Based Long-Term Care: An Optimization Analysis Using Data from the National Channeling Demonstration**. Other Division studies in this area include: a comparison of the structure of community-based care systems across States; an analysis the role of informal care giving in the long-term care system; and a synthesis of community-based care research and its implications for public policy. Future work will examine board and care issues and the delivery of personal care services under Medicaid.

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#### B. Completed or Ongoing Projects

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**TITLE:** *National Long-Term Care Channeling Demonstration*

**PROJECT DIRECTOR:** George Carcagno, Mathematica Policy Research, Princeton, NJ

**SYNOPSIS:** The National Long-Term Care Channeling Demonstration was designed as a rigorous test of comprehensive case management of community care as a way of containing long-term care costs while providing adequate care to those in need. A randomized experimental design was employed to evaluate the demonstration. Two models of Channeling were tested: (a) Basic Case Management Model (five sites) and (b) Financial Control Model (five sites). Channeling enrolled an extremely frail elderly group whose average age was 80 years. The intervention was implemented largely according to plan. Channeling increased formal community service use. It had no significant effect on nursing home use, increased client confidence in receipt of care and increased life satisfaction. Neither model had a major effect on the proportion of informal caregivers giving care; however, Channeling increased informal caregivers' satisfaction with service arrangements and satisfaction with life. Overall, the evidence

indicates that the expansion of case management and community services beyond what exists does not lead to cost savings. It does yield benefits in the form of increased home care, reduced unmet need and greater life satisfaction for clients and their informal caregivers who bear most of the care burden.

The results of the Channeling demonstration are summarized in a special issue of the **Health Services Research Journal** (HSRJ), published in April 1988 [<http://aspe.hhs.gov/daltcp/reports/hsres.htm>]

***Titles of Project Reports:***

- Planning and Implementation of Channeling: Early Experiences of the National Long-Term Care Demonstration [<http://aspe.hhs.gov/daltcp/reports/implees.htm>]
- Implementation and Early Operation of the National Long-Term Care Demonstration: An Overview
- Channeling Effects for an Early Sample at Six-Month Follow-Up [<http://aspe.hhs.gov/daltcp/reports/6monthes.htm>]
- Differential Impacts Among Subgroups of Early Channeling Enrollees Six Months After Randomization [<http://aspe.hhs.gov/daltcp/reports/difimpes.htm>]
- The Effects of Early Sample Attrition on Estimates of Channeling's Impacts for an Early Sample [<http://aspe.hhs.gov/daltcp/reports/earlyes.htm>]
- Issues in Developing the Client Assessment Instrument for the National Long-Term Care Channeling Demonstration [<http://aspe.hhs.gov/daltcp/reports/instrues.htm>]
- Initial Research Design of the National Long-Term Care Demonstration [<http://aspe.hhs.gov/daltcp/reports/designes.htm>]
- The Comparability of Treatment and Control Groups at Randomization [<http://aspe.hhs.gov/daltcp/reports/compares.htm>]
- Informal Care to the Impaired Elderly: Report to the National Long-Term Survey of Informal Caregivers [<http://aspe.hhs.gov/daltcp/reports/impaires.htm>]
- Estimation of the Equivalence of Treatment and Control Groups and the Comparability of Baseline Data [<http://aspe.hhs.gov/daltcp/reports/baslines.htm>]
- Final Report on the Effects of Sample Attrition on Estimates of Channeling's Impacts [<http://aspe.hhs.gov/daltcp/reports/atritnes.htm>]
- The Effects of Case Management and Community Services on the Impaired Elderly [<http://aspe.hhs.gov/daltcp/reports/casmanes.htm>]
- Survey Data Collection Design and Procedures [<http://aspe.hhs.gov/daltcp/reports/sydataes.htm>]
- Channeling Effects on the Quality of Clients' Lives [<http://aspe.hhs.gov/daltcp/reports/qualtyes.htm>]
- Channeling Effects on Hospital, Nursing Home and Other Medical Services [<http://aspe.hhs.gov/daltcp/reports/hospites.htm>]
- Channeling Effects on Formal Community-Based Services and Housing [<http://aspe.hhs.gov/daltcp/reports/commtyes.htm>]

- Channeling Effects on Informal Care  
[<http://aspe.hhs.gov/daltcp/reports/informes.htm>]
- The Evaluation of the National Long-Term Care Demonstration  
[<http://aspe.hhs.gov/daltcp/reports/chanes.htm>]
- Analysis of the Costs and Benefits of Channeling  
[<http://aspe.hhs.gov/daltcp/reports/1986/cost.htm>]
- The Evaluation of the National Long-Term Demonstration: An Analysis of Site-Specific Results [<http://aspe.hhs.gov/daltcp/reports/sitees.htm>]
- Analysis of Channeling Impacts Across Multiple Subgroups
- Evaluation of the National Long-Term Care Demonstration: Final Summary Report
- Methodological Issues in the Evaluation of the National Long-Term Demonstration [<http://aspe.hhs.gov/daltcp/reports/methodes.htm>]
- The Evaluation of the National Long-Term Care Demonstration: The Planning and Operational Experiences of the Channeling Projects  
[<http://aspe.hhs.gov/daltcp/reports/proceses.htm>]
- The Creation and Documentation of the National Long-Term Care Evaluation Public Use Files

*CONTACT PERSON:* Robert Clark, ASPE, (202) 245-6172

*COMPLETION DATE:* June 1986

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***TITLE: State Long-Term Care Reform: Development of Community Care Systems in Six States***

*PRINCIPAL INVESTIGATOR:* Diane Justice, National Governors Association, Washington, DC

**SYNOPSIS:** This study examined the approaches used in six States (Arkansas, Illinois, Maine, Maryland, Oregon and Wisconsin) to make their long-term care systems more responsive to the needs of older people. According to the study, each of the States was able to expand community-based care services without generating runaway costs in total long-term care spending. Experience in these States also demonstrated that some aspects of community care systems can be tightly structured and uniform State-wide, without compromising the flexibility necessary for responding to individual service needs. Nonmedical supportive services were also found to form the core of State long-term care programs.

*CONTACT PERSON:* Glen Harelson, ASPE, (202) 245-6172

*COMPLETION DATE:* April 1988

*REPORT(S) LINKS:*

State Long-Term Care Reform: Development of Community Care Systems in Six States [<http://aspe.hhs.gov/daltcp/reports/strfrm.htm>]

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**TITLE: *Policy Implications of the Past Decade's Research on Home and Community-Based Care***

**PRINCIPAL INVESTIGATOR:** Pamela Doty, ASPE, Washington, DC

**SYNOPSIS:** This project is synthesizing the major findings of ten years worth of DHHS sponsored policy research on home and community-based long-term care, encompassing major national surveys of long-term care needs and service use as well as research and demonstration projects testing the effectiveness of proposed financing and organizational reforms.

**CONTACT PERSON:** Pamela Doty, ASPE, (202) 245-6172

**COMPLETION DATE:** 1989

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**TITLE: *Reducing Nursing Home Utilization Costs Through Community-Based Long-Term Care: An Optimization Analysis Using Data from the National Channeling Demonstration\****

**PRINCIPAL INVESTIGATOR:** Vernon L. Greene, Syracuse University, Syracuse, NY

**SYNOPSIS:** A generally consistent finding of community-based long-term care demonstration, including Channeling, is that these programs do not lead to net reductions in long-term care expenditures. Even though reducing nursing home costs was a goal of these demonstrations, none involved systematic managerial and resource allocation strategies specifically designed to reach this goal. Rather, resource allocation decisions were left largely to the professional judgment of case managers. This study will address whether long-term care resources can in fact be allocated strategically among clients to reduce nursing home use and costs. It will make use of the techniques of econometrics and mathematical optimization to address this question, using data from the Channeling demonstration.

**CONTACT PERSON:** Robert Clark, ASPE, (202) 245-6172

**COMPLETION DATE:** June 1989

**REPORT(S) LINKS:**

Reducing Nursing Home Use Through Community-Based Long-Term Care: An Optimization Analysis [<http://aspe.hhs.gov/daltcp/reports/1992/rednh.htm>]

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**TITLE: *Sustaining Family Caregiving of the Elderly: Housing, Family Support, and the Demand for Institutional Care***

**PRINCIPAL INVESTIGATORS:** Sandra Newmand and Raymond Struyk, The Urban Institute, Washington, DC

**SYNOPSIS:** The study explored whether type of housing, presence or absence of relatives, and availability of informally or formally provided long-term care services reduce the risk of institutionalization among the impaired elderly, and the nature of the relationship between support and risk. The principal data source was the 1982 National Long-Term Care Survey (NLTCs), supplemented with data on whether or not the respondent had entered a nursing home between 1982 and 1984 from the 1984 NLTCs, and with data from the National American Housing Survey.

The results of the study are reported in Urban Institute Report No. 3533, "Overwhelming Odds: Caregiving and the Risk of Institutionalization," [<http://aspe.hhs.gov/daltcp/reports/ovrwhles.htm>] by Sandra Newman, Michelle Rice, and Raymond Struyk, June 1987. In general, the analyses do not find any relationship between type of housing and risk of institutionalization. They also do not find any relationship between presence of relatives and risk of institutionalization. The analyses fail to confirm the notion that informal support and formal support play important roles as predictors of institutional risk. The same investigators are continuing the research using the 1984 Long-Term Care Survey, under a grant from the National Institutes on Aging.

**CONTACT PERSON:** Paul D. Gayer, ASPE, (202) 245-6613

**COMPLETION DATE:** 1987

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**TITLE: *Caregiver Burden and Institutionalization, Hospital Use and Stability of Care\****

**PRINCIPAL INVESTIGATOR:** Baila Miller, University of Illinois, Chicago, IL

**SYNOPSIS:** This project differentiates three major dimensions of informal caregiver burden: personal burden (worsening health, costs of care), relational burden (elder forgets things, embarrasses caregiver), and time burden (limitations on work of other activities, elder's need for constant attention). Using data from the community and caregiver components of the 1982 and 1984 National Long-term Care Survey, the study will measure the association between caregiver burden on the various dimensions as reported in 1982 and outcomes such as institutionalization, hospital use, and changes in caregivers as reported in 1984.

**CONTACT PERSON:** Pamela Doty, ASPE (202) 245-6172

**COMPLETION DATE:** September 1989

*REPORT(S) LINKS:*

Caregiver Burden and Institutionalization, Hospital Use, and Stability of Care  
[<http://aspe.hhs.gov/daltcp/reports/burden.htm>]

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**TITLE:** *Factors Associated with a Breakdown in Caregiving Among Informal Caregivers to the Functionally and Cognitively Impaired Elderly Population\**

*PRINCIPAL INVESTIGATOR:* Judith Kasper, John Hopkins University, Baltimore, MD

**SYNOPSIS:** This project is examining factors associated with a breakdown in informal caregiving to the functionally impaired elderly living in the community using the 1982 and 1984 National Long-Term Care Surveys. The study will investigate whether reported caregiver burden differs among family members caring for persons who are cognitively as opposed to physically impaired. A logistic regression model will be developed to identify characteristics of caregivers or types of caregiver burden that can help predict the decision to abandon informal caregiving efforts in favor of institutional placement.

*CONTACT PERSON:* Pamela Doty, ASPE, (202) 245-6172

*COMPLETION DATE:* September 1989

*REPORT(S) LINKS:*

Factors Associated with Ending Caregiving Among Informal Caregivers to the Functionally and Cognitively Impaired Elderly Population  
[<http://aspe.hhs.gov/daltcp/reports/factores.htm>]

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**TITLE:** *Prospective Outcomes of Informal and Formal Home Care: Time to Institutionalization or Mortality\**

*PRINCIPAL INVESTIGATOR:* Burton Dunlop, Project Hope, Chevy Chase, MD

**SYNOPSIS:** The purpose of this project is to identify particular combinations of formal and informal caregiving that are more efficacious than others in preventing or delaying mortality or nursing home institutionalization. A competing risks model will be employed to predict time elapsed to death or institutionalization. Primary data sources will be the Longitudinal Study of Aging (LSOA), National Death Index and Medicare Part A records.

*CONTACT PERSON:* Pamela Doty, ASPE (202) 245-6172

*COMPLETION DATE:* September 1988

*REPORT(S) LINKS:*

Prospective Outcomes of Informal and Formal Home Care: Mortality and Institutionalization [<http://aspe.hhs.gov/daltcp/reports/prosoutc.htm>]



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**TITLE:** *Small Area Synthetic Estimation of Dependency\**

**PRINCIPAL INVESTIGATOR:** William Weissert, University of North Carolina, Chapel Hill, NC

**SYNOPSIS:** While a substantial portion of long-term care planning occurs at the State and local level, most prevalence rate estimates on functional dependency are only reliable nationally. The study will produce models to estimate the prevalence of functional dependency among the non-institutionalized elderly for small areas (States and counties) for each of three income groups: Household income less than \$3,000; \$3,000-40,000; and greater than \$40,000. Specific estimates of functional dependency for each State and selected counties will also be made. Software showing how to do these analyses will be developed and disseminated to State and local officials. The data sets employed will include the 1980 Census, the 1977, 1979 and 1980 Health Interview Surveys, and the 1977 Nursing Home Survey.

**CONTACT PERSON:** Floyd Brown, ASPE (202) 245-6443

**COMPLETION DATE:** January 1989

**REPORT(S) LINKS:**

Small Area Estimation of Dependency Final Report

[\[http://aspe.hhs.gov/daltcp/reports/1989/smareaes.htm\]](http://aspe.hhs.gov/daltcp/reports/1989/smareaes.htm)

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### **C. Planned Projects**

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**TITLE:** *Evaluation of State Models for Administering Home Care Systems*

**SYNOPSIS:** Federal and State governments are investing billions of dollars to support in-home services for a broad range of persons who experience dependency. Little information is available on how these systems can be most efficiently and effectively administered. A comparative study may be initiated to analyze the advantages and disadvantages of alternative case management models, fee for service systems, voucher and capitation approaches with respect to costs, participation rates, quality assurance, and other outcomes.

**CONTACT PERSON:** Pamela Doty, ASPE, (202) 245-6172

**COMPLETION DATE:** To be determined

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**TITLE: *Survey of Medicaid Personal Care Programs***

**SYNOPSIS:** While the Medicaid home and community-based waiver program has been extensively studied, spending for home and community-based care is actually higher under the Medicaid personal care option. The project will supplement a survey of Medicaid personal care services being conducted by the World Institute on Disability for the Department of Education's National Institute on Disability and Rehabilitation Research. Drawing on 1985 and 1989 data from a 50 State survey of home attendant programs for the elderly and younger physically disabled populations, the study will provide a statistical profile of all Medicaid personal care programs as compared to programs supported by other Federal and State funding sources. The comparative statistical data will be supplemented by in-depth case studies of Medicaid personal care programs to highlight the unique features of particular State approaches to philosophy and organization.

**CONTACT PERSON:** Pamela Doty, ASPE, (202) 245-6172

**COMPLETION DATE:** To be determined

## IV. QUALITY OF CARE

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### A. Overview

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The rapid growth of home care services, both medically-oriented home health care and social service oriented supportive care for the chronically ill and disabled, has raised questions about whether the quality of such care is being adequately monitored and safeguarded. Quality concerns with regard to Medicare financed home health care arose principally from allegations that hospital payment reform had resulted in patients being sent home from the hospital “quicker and sicker.” Critics charged that home health agencies could not adequately serve patients with heavier care needs than previous clientele and that a certain percentage of hospital discharges to home health care were inappropriate or premature. The Division initiated a joint study with HCFA to develop and test guidelines for measuring minimally adequate post-hospital care in the community (**A Pilot Study of the Adequacy of Post-Hospital Community Care**). To address broader issues of defining “quality” and developing outcome measures and structural and process indicators of quality in home care services for chronically disabled and for post-acute care populations, the Division sponsored a **National Conference on Home Care Quality: Issues and Accountability** (described below). In addition, a study of State activity in improving home care quality has recently been completed (**Review of State Quality Assurance Programs for Home Care**.)

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### B. Completed or Ongoing Projects

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**TITLE:** *A Pilot Study of the Adequacy of Post-Hospital Community Care for the Elderly*

**PRINCIPAL INVESTIGATOR:** Barbara Phillips, Mathematica Policy Research, Princeton, NJ

**SYNOPSIS:** One prominent response of hospitals to the necessity of controlling costs under the Medicare’s Prospective Payment System (PPS) has been a reduction in hospital lengths of stay. Patients appear to be sicker when they are discharged now than was the case prior to PPS. Sicker patients probably require more health and personal care services upon discharge.

The current evidence on the adequacy of post-hospital community care is largely impressionistic. A systematic assessment is required to develop objective evidence on the extent of problems and whether they lead to adverse health outcomes for patients. The methodology available up to now has not been adequate to support a systematic assessment of national scope. The primary limitations of this methodology is that it has

required physician review of individual cases, which is difficult to implement in a national study and has often been found to be unreliable.

This study, sponsored jointly with the Office of Research and Demonstrations in HCFA, has developed and tested a new methodology intended to overcome these limitations and to permit a systematic, national assessment of the adequacy of post-hospital care in the community for elderly patients and whether inadequate care leads to adverse health outcomes. The key to this methodology is a series of "guidelines" which specify standards for the amount of care that is minimally adequate to prevent adverse health outcomes for elderly patients with a wide variety of conditions commonly requiring post-hospital care in the community.

The methodology has been implemented in a pilot study in nine hospitals in two states. The conclusion of the pilot is that the methodology is generally valid, feasible, and effective although some refinements are required. The guidelines (taken as a group) provide a reasonable definition of minimally adequate care.

**CONTACT PERSON:** Robert Clark, ASPE (202) 245-6172

**COMPLETION DATE:** January, 1989.

**REPORT(S) LINKS:**

A Pilot Study of the Adequacy of Post-Hospital Community Care for the Elderly:  
Final Report [<http://aspe.hhs.gov/daltcp/reports/adeqes.htm>]

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**TITLE:** *Practitioners Conference on Quality Assurance in Home Care*

**SYNOPSIS:** To better understand the actual nature of quality problems in home care and the difficulties that home care agencies and State officials face in assuring quality of care, the Division sponsored a practitioners conference on quality assurance in home care. The June 1988 conference included researchers and Federal and State regulatory officials and emphasized the experience of practitioners in the field. Proceedings from the conference are being published in a two volume report that includes a summary of the conference presentations (Volume I) and a research agenda, identifying key research issues and ongoing or recent research on these topics (Volume II).

**CONTACT PERSON:** Pamela Doty, ASPE, (202) 245-6172

**COMPLETION DATE:** June 1988

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**TITLE:** *Review of State Quality Assurance Programs for Home Care*

**PRINCIPAL INVESTIGATOR:** Macro Systems, Inc., Silver Spring, MD

**SYNOPSIS:** The purpose of this project was to examine State activities designed to assure the quality of home care. Nineteen States were surveyed to identify activities related to the assessment and monitoring of home care quality. This included Older Americans Act Long-Term Care Ombudsman Programs in five States that have expanded to cover home care services. Study findings indicate that: a wide variety of mechanisms addressing home care quality are in place in the study sites; quality in home care programs is not perceived to be a major public or political issue in most of the States; the lack of a standardized framework for defining and measuring quality is a major barrier to understanding and ensuring the quality of home care services; and expansion of the Long-Term Care Ombudsman Program to include home care clients is an untested and unproven quality mechanism.

*CONTACT PERSON:* Floyd Brown, ASPE, (202) 245-6443

*COMPLETION DATE:* 1988

*REPORT(S) LINKS:*

Review of State Quality Assurance Programs for Home Care

[\[http://aspe.hhs.gov/daltcp/reports/squareves.htm\]](http://aspe.hhs.gov/daltcp/reports/squareves.htm)

## V. DISABILITY ISSUES

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### A. Overview

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Most of the Division's research in this area is concentrated on persons with mental retardation and other developmental disabilities likely to need long-term services and supports. Studies have been sponsored to look at where people with severe disabilities live and how needed services are financed.

In 1986, the Division prepared a report to Congress on **Medicaid Financing of Services to Mentally Retarded and Other Developmentally Disabled Persons**. As a follow-up to this report and in response to proposed legislation expanding Medicaid funding for community-based services to this population, the Division coordinated a Departmental Working Group on MR/DD Policies. The charge of the Working Group was to examine Federal policy barriers to community-based services and to develop cost-effective policy reforms. Several studies were sponsored to assist the Working Group in its analysis (e.g., **An Analysis of Federal and State Policies Affecting Services to Mentally Retarded and other Developmentally Disabled Persons: State Perspectives and Analysis of Federal MR/DD Policies**). ASPE has recently released the final report of the Departmental Working Group (**Report to the Secretary from the Working Group on Policies Affecting Mentally Retarded and Other Developmentally Disabled Persons**).

Future research will examine new approaches in financing and service delivery to those individuals with the most severe impairments. One planned project will analyze national and state level data on severely disabled children and the financial burdens their health and medical care place on family caregivers.

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### B. Completed or Ongoing Projects

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**TITLE:** *Synthesis of Cost Studies on the Long-Term Care of Disabled and Impaired Persons*

**PRINCIPAL INVESTIGATOR:** Martin Kotler, Macro Systems, Inc., Silver Spring, MD

**SYNOPSIS:** This project synthesized research on the cost of care for three vulnerable subgroups: the mentally retarded and developmentally disabled at risk of institutionalization; the frail or impaired elderly; and the physically handicapped. The analysis concluded that the current body of research cannot substantiate claims that either institutional care or community-based care is consistently less expensive for the three population subgroups identified for this study. Comparative analysis is restricted due to a number of factors including problems in defining comparison groups,

incomplete cost data and lack of cost comparability. However, findings suggest that costs for some individual clients, generally those who do not have severe impairments, may be less for home and community-based care. There is also some evidence that the movement of people from institutional settings to community settings has greater potential for costs savings than the deferral of initial institutionalization. The study further revealed that there is a paucity of data on the cost of care of physically handicapped persons.

**CONTACT PERSON:** Peg Porter, ASPE, (202) 245-6443  
**COMPLETION DATE:** 1985

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**TITLE:** *Foster Care for Children and Adults with Handicaps: Child Welfare and Adult Services*

**PRINCIPAL INVESTIGATORS:** K. Charlie Lakin, Bradley Hill, University of Minnesota, Minneapolis, MN

**SYNOPSIS:** The purpose of this project was to identify the numbers of disabled children and adults in foster homes administered by child welfare or social service agencies. All State welfare agencies were surveyed as were staff in adult services offices and State mental retardation agencies. In addition, three counties in ten States were surveyed. Study findings indicate that as of December 1985, there were approximately 54,000 handicapped children in out-of-home foster care including 14,000 with mental retardation. There were an additional 6,400 mentally retarded children and 10,700 adults in specialized foster care homes administered by State mental retardation agencies. The amount of information on disabled children and adults in "generic" foster care is limited because States collect information differently. Nevertheless, the findings indicate foster care is a significant form of community care for people with disabilities.

**CONTACT PERSON:** Peg Porter, ASPE, (202) 245-6443  
**COMPLETION DATE:** 1986  
**REPORT(S) LINK:**

Foster Care for Children and Adults with Handicaps: Child Welfare and Adult Social Services [<http://aspe.hhs.gov/daltcp/reports/fosteres.htm>]

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**TITLE:** *An Analysis of Federal and State Policies Affecting Services to Mentally Retarded and Other Developmentally Disabled Persons: State Perspectives*

**PRINCIPAL INVESTIGATOR:** Tecla Jaskulski, Macro Systems, Inc., Silver Spring, MD

**SYNOPSIS:** The purpose of this study was to analyze how Federal policies and programs influence State policy choices with respect to expanding family and community care. The study presents an in-depth review of six State MR/DD service systems (Colorado, Illinois, Michigan, Nebraska, Texas and Virginia). Data collection and analysis emphasized discussions with key policy makers and program operators in each of the six States as well as a review of relevant documents and reports supplied by those interviewed.

The study revealed that State policy decisions and overall emphasis on community-based, as opposed to institution-based services, are the result of interactions between a complex array of factors including the philosophical commitment of the State, a healthy State economy and the existence of strong, well-organized advocacy on behalf of family and community services. In general, State respondents viewed Federal policies and programs, with the exception of the Home and Community Care Waivers, as creating barriers to community-based services.

**CONTACT PERSON:** Peg Porter, ASPE, (202) 245-6443

**COMPLETION DATE:** 1987

**REPORT(S) LINKS:**

[An Analysis of Federal and State Policies Affecting Services to Mentally Retarded and Other Developmentally Disabled Persons: State Perspectives](http://aspe.hhs.gov/daltcp/reports/stapersp.htm)  
[\[http://aspe.hhs.gov/daltcp/reports/stapersp.htm\]](http://aspe.hhs.gov/daltcp/reports/stapersp.htm)

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**TITLE:** *Analysis of Federal MR/DD Policies*

**PRINCIPAL INVESTIGATOR:** Brian Burwell, SysteMetrics, Inc., Lexington, MA

**SYNOPSIS:** This study provided an overview of the various Federal programs which finance services to MR/DD people, the cost of those programs, as well as the cost implications of alternative financing and delivery systems. The analyses are incorporated in the MR/DD Working Group report described below.

**CONTACT PERSON:** Peg Porter, ASPE, (202) 245-6443

**COMPLETION DATE:** 1987

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**TITLE:** *Forecasting Trends and Costs in Residential Care Facilities for Persons with Mental Retardation*

**PRINCIPAL INVESTIGATOR:** K. Charlie Lakin, University of Minnesota, Minneapolis, MN



**SYNOPSIS:** The University of Minnesota has collected and/or analyzed extensive data on the numbers of individuals with mental retardation in residential care and in nursing homes. This information was utilized to estimate how many developmentally disabled people might participate in various policy alternatives considered by the Secretary's Working Group on Policies Affecting the Mentally Retarded and Other Developmentally Disabled Populations. Details of this analysis are included in the Working Group report.

**CONTACT PERSON:** Peg Porter, ASPE, (202) 245-6443  
**COMPLETION DATE:** 1987

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**TITLE:** *Report to the Secretary From the Working Group on Policies Affecting Mentally Retarded & Other Developmentally Disabled Persons*

**PROJECT COORDINATOR:** Peg Porter, ASPE, Washington, DC

**SYNOPSIS:** This report analyzes the impact of current Federal policies and programs on the growth of community living arrangements and supportive services for people with mental retardation and other developmental disabilities. It draws the following conclusions: 1) the principal Federal financing mechanism for MR/DD services, the ICF/MR program, is institution based and has not kept pace with the significant changes in the field of developmental disabilities particularly the movement toward community based services; 2) the lack of Federal participation in the financing of community services is widely perceived as a barrier to independence, productivity, and community integration of developmentally disabled people; and 3) the Medicaid program, with its open-ended financing and medical and welfare orientation, is not a promising vehicle for cost-effective Federal policy reform.

**CONTACT PERSON:** Peg Porter, ASPE, (202) 245-6443  
**COMPLETION DATE:** 1988  
**REPORT(S) LINKS:**

[Report from the Working Group on Improving Public Policies and Programs Affecting Persons with Mental Retardation and Other Developmental Disabilities](http://aspe.hhs.gov/daltcp/reports/mrddwges.htm)  
[\[http://aspe.hhs.gov/daltcp/reports/mrddwges.htm\]](http://aspe.hhs.gov/daltcp/reports/mrddwges.htm)

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**TITLE:** *Community Program Size and Quality\**

**PRINCIPAL INVESTIGATOR:** James Conroy, Temple University, Philadelphia, PA

**SYNOPSIS:** This study will explore the relationship between community residential setting size and quality of care for persons with developmental disabilities. The data base used to examine this issue will be the Pennhurst Longitudinal Study file. Eighteen indicators of quality are employed.

*CONTACT PERSON:* Peg Porter, ASPE, (202) 245-6443  
*COMPLETION DATE:* September 1989

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**C. Planned Projects**

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**TITLE:** *Catastrophic Costs of Caring for Disabled Children*

**SYNOPSIS:** The Congress, HHS and other Federal agencies have expressed considerable interest in the adequacy of current programs and policies affecting severely disabled children, particularly those who are technology dependent and whose health and medical care place catastrophic financial and caregiving burdens on their families. This project will analyze national and State level data to estimate the numbers of children experiencing catastrophic health care expenses, the level of expenditures and source of payment and their service utilization patterns.

*CONTACT PERSON:* John Drabek, ASPE, (202) 245-6613  
*COMPLETION DATE:* To be determined.

## VI. LONG-TERM CARE AND DISABILITY DATA NEEDS

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### A. Overview

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The Division has a long-standing commitment to improving basic data on disability and long-term care. In recent years, it has sponsored the National Long-Term Care Survey including the National Survey of Caregivers in 1982, cooperated with the National Long-Term Care Survey of 1989, and co-sponsored the National Long-Term Care Survey of 1989. Public use files have been made available from the National Long-Term Care Channeling Demonstration. In addition, a Conference on HHS Long-Term Care Data Bases was held in 1987 to enhance their accessibility to researchers and private insurers. Current efforts include support of the National Mortality Follow-back Survey of 1986, and a design study for a national survey of people with developmental disabilities and a design study for board and care homes.

### B. Completed or Ongoing Projects

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**TITLE:** *National Invitational Conference on HHS Long-Term Care Data Bases*

**SYNOPSIS:** Over the last five years the Department has fielded several major surveys which substantially enhance the breadth and quality of data available to the general public on the utilization and costs of long-term care services. The purpose of this conference which was held May 21-22, 1987, was to: 1) share technical information with respect to data base documentation issues, limitations of the surveys and alternative methods for overcoming limitations; 2) share results of on-going analytic work employing these data bases; and 3) demonstrate the potential of these data bases for assisting employers, insurance companies, CCRCs, and State agencies in projecting service needs and planning and costing out public and private financing alternatives. Approximately 300 persons attended including government policy analysts, outside researchers and insurance industry representatives. Proceedings are available.

**CONTACT PERSON:** Robert Clark, ASPE, (202) 245-6172

**COMPLETION DATE:** May 1987

**REPORT(S) LINKS:**

National Invitational Conference on Long-Term Care Data Bases: Summary of Conference Package [<http://aspe.hhs.gov/daltcp/reports/87cfpkes.htm>]

National Invitational Conference on Long-Term Care Data Bases: Summary of Conference Proceedings [<http://aspe.hhs.gov/daltcp/reports/87cfproc.htm>]

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**TITLE: *National Long-Term Care Survey***

*PRINCIPAL INVESTIGATOR:* Kenneth Manton, Duke University, Durham, NC

**SYNOPSIS:** A current grant from the National Institute on Aging (NIA) to Duke University supports the creation of a longitudinal data set that will be comprised of three waves of the National Long-Term Care Survey (NLTCS) conducted by the Bureau of the Census (1982, 1984 and 1989) and data extracted from Medicare Part A files (1980-1989). The focus is on changes in functional and health characteristics as well as long-term care service use among a nationally representative sample of elderly impaired persons.

The Division has supplemented the NIA grant to permit data collection in three areas: (a) the effects of supply on the use of long-term care services, (b) the treatment of income and assets by persons with nursing home stays, and (c) patterns of informal caregiving.

*CONTACT PERSON:* Robert Clark, ASPE, (202) 245-6172

*COMPLETION DATE:* 1990

*REPORT(S) LINKS:*

The National Long-Term Care Surveys (1982, 1984, 1989)

[\[http://aspe.hhs.gov/daltcp/reports/nltcssum.htm\]](http://aspe.hhs.gov/daltcp/reports/nltcssum.htm)

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**TITLE: *National Mortality Follow-Back Survey***

*PRINCIPAL INVESTIGATOR:* Gloria Kapantais, National Center for Health Statistics, Rockville, MD

**SYNOPSIS:** The 1986 National Follow-Back Survey is a nationally representative sample of 20,000 persons who died in 1986. The survey contains a great deal of information about health and functional status of the decedent and the use of acute and long-term care services in the year prior to death. The survey was designed and managed by the National Center for Health Statistics (NCHS); data collection was carried out by the Census Bureau. Nine agencies inside and outside the Department provided funding and technical support. ASPE provided funding and support to acquire data on impairments and use of long-term care services in the last year of life.

*CONTACT PERSON:* Robert Clark, ASPE, (202) 245-6172

*COMPLETION DATE:* 1989

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**TITLE: *Design Study for a National Survey of People With Developmental Disabilities***

*PRINCIPAL INVESTIGATOR:* Craig Thornton, Mathematica Policy Research, Princeton, NJ

**SYNOPSIS:** This study will analyze methods for collecting nationally representative data on people with mental retardation and other developmental disabilities living in the community. An operational definition of the proposed survey population will be developed and functional measures identified. The project will analyze existing surveys which include information on the target population, recommend modules for enhancing the usefulness of existing surveys and develop a prototype data collection instrument and sampling frame for a new survey. A Technical Advisory Group comprised of Federal and State officials as well as outside consultants will provide oversight.

*CONTACT PERSON:* Robert Clark, ASPE, (202) 245-6172

*COMPLETION DATE:* December 1989

*REPORT(S) LINKS:*

An Estimate of the Number of Persons with Developmental Disabilities Receiving Supplemental Security Income Benefits and Their Characteristics

[\[http://aspe.hhs.gov/daltcp/reports/ssiestes.htm\]](http://aspe.hhs.gov/daltcp/reports/ssiestes.htm)

Characteristics of Persons with Developmental Disabilities: Evidence from the Survey of Income and Program Participation

[\[http://aspe.hhs.gov/daltcp/reports/charctes.htm\]](http://aspe.hhs.gov/daltcp/reports/charctes.htm)

Design for a National Survey of Persons with Developmental Disabilities

[\[http://aspe.hhs.gov/daltcp/reports/ntlsrves.htm\]](http://aspe.hhs.gov/daltcp/reports/ntlsrves.htm)

Persons with Mental Retardation and Related Conditions in Mental Retardation

Facilities: Selected Findings from the 1987 National Medical Expenditure Survey

[\[http://aspe.hhs.gov/daltcp/reports/mrperses.htm\]](http://aspe.hhs.gov/daltcp/reports/mrperses.htm)

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**TITLE: *Data Base Technical Assistance/Channeling***

*PRINCIPAL INVESTIGATOR:* Susan Dunstan, Mathematica Policy Research, Princeton, NJ

**SYNOPSIS:** This continuation project will provide on-going technical assistance to users of the Channeling data base and make enhancements to the public use tapes and documentation based on user critiques.

*CONTACT PERSON:* Robert Clark, ASPE, (202) 245-6172

*COMPLETION DATE:* To be determined

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**TITLE: *National Long-Term Care Survey Users Forum***

**SYNOPSIS:** The National Long-Term Care Survey (NLTC) is a very rich yet complex data base involving three separate interview waves (1982, 1984 and 1989) and multiple components. The complexity of the data base had led to a number of issues related to utilization of the Survey for research purposes. As part of its objective to encourage the utilization of data bases, sponsored by HHS, ASPE held a one-day forum for users of the NLTC.

The purpose of the forum was to discuss problems experienced in using the survey, strategies for circumventing those problems and to hear suggestions regarding what the Government can do to improve the usefulness of the survey.

A number of concerns and ideas ranging from issues of weighting the population to improving the technical assistance available were generated by the participants. A summary of the proceedings, including recommendations of the participants and planned next steps by the Government will be made available.

**CONTACT PERSON:** Floyd Brown, ASPE, (202) 245-6443

**COMPLETION DATE:** February 1989

**REPORT(S) LINKS:**

Report on Problems and Suggestions for Improving the NLTC Files for 1982 and 1984 [<http://aspe.hhs.gov/daltcp/reports/probsug.htm>]

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**C. Planned Projects**

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**TITLE: *Board and Care Survey Design***

**SYNOPSIS:** Board and care living arrangements for dependent populations are an increasingly important part of the long-term care continuum. Very little national data on board and care are available. This study is intended to develop survey design options including sampling from data collection protocols and instrumentation and to offer a recommended approach for a national board and care survey.

**CONTACT PERSON:** Robert Clark, ASPE, (202) 245-6172

**COMPLETION DATE:** To be determined

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**TITLE: *Analysis of Prevalence Estimates of the Functionally Impaired Elderly***

**PRINCIPAL INVESTIGATOR:** To be determined.

**SYNOPSIS:** Because of differences among surveys on analytic samples, question working and selection of items for measurement, there is considerable variation in the

published estimates of the number of functionally impaired elderly made from existing health and long-term care surveys. This project will develop estimates from several national surveys and examine the bases for differences among them. It will also propose ways of identifying and using the most appropriate survey data on functional limitations in response to long-term care legislative proposals.

*CONTACT PERSON:* Robert Clark, ASPE, (202) 245-6172

*COMPLETION DATE:* To be determined.

## RESEARCH BOOKLETS/COMPENDIUMS

The Office of Disability, Aging and Long-Term Care Policy (and the titles the Office has previously been named) have done several booklets describing research conducted by Office funding. The Office's website was originally developed based on these research booklets. As these booklets have been scanned and readied for archival release, links to completed reports mentioned have been added.

Disability, Aging, and Long-Term Care Policy Research: 1992-1996

HTML

<http://aspe.hhs.gov/daltcp/reports/1997/ResBook97.htm>

PDF

<http://aspe.hhs.gov/daltcp/reports/1997/ResBook97.pdf>

Long-Term Care and Disability Research: 1986-1989

HTML

<http://aspe.hhs.gov/daltcp/reports/1989/ResBook89.htm>

PDF

<http://aspe.hhs.gov/daltcp/reports/1989/ResBook89.pdf>

Long-Term Care and Disability Research: 1989-1992

HTML

<http://aspe.hhs.gov/daltcp/reports/1992/ResBook92.htm>

PDF

<http://aspe.hhs.gov/daltcp/reports/1992/ResBook92.pdf>

Research on Children, Youth, and Families: 1986-1990

HTML

<http://aspe.hhs.gov/daltcp/reports/1990/ResBook90.htm>

PDF

<http://aspe.hhs.gov/daltcp/reports/1990/ResBook90.pdf>

Research and Grants on Issues Relating to Children and Youth: 1986-1991

HTML

<http://aspe.hhs.gov/daltcp/reports/1991/ResBook91.htm>

PDF

<http://aspe.hhs.gov/daltcp/reports/1991/ResBook91.pdf>



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Washington, D.C. 20201  
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