



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

# **DISABILITY, AGING, AND LONG-TERM CARE POLICY RESEARCH:**

## **1992-1996**

January 1997

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

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POLICY RESEARCH:  
1992-1996**

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# INTRODUCTION

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This inventory of long-term care, aging and disability research has been prepared by the Office of Disability, Aging and Long-Term Care Policy (DALTCP), in the Office of the Assistant Secretary for Planning and Evaluation (ASPE), within the U.S. Department of Health and Human Services (HHS). It summarizes the status of current research, the results of research projects sponsored from 1992 through 1996, and highlights future research plans. Previous editions of this inventory were issued in 1988 and 1992. DALTCP research products can now also be found through our Internet home page ([http://aspe.hhs.gov/\\_office\\_specific/daltcp.cfm](http://aspe.hhs.gov/_office_specific/daltcp.cfm)). This inventory will be incorporated into our home page and will be updated there as needed.

DALTCP is responsible for the development, coordination, research, and evaluation of HHS policies and programs which support the independence, productivity, health, long-term care, and economic security of children, working age adults, and older persons with disabilities. The Office is also responsible for policy coordination and research to promote the economic and social well-being of the elderly.

In particular, the Office is responsible for policies concerning: long-term care and personal assistance services, including informal caregiving; linkages among the acute, post-acute and long-term care systems; long-term rehabilitation services; children's disability; and the encouragement of mechanisms for coordinating the housing, health, income supports, and education, training and employment needs of people with disabilities. These responsibilities are carried out through policy planning, policy and budget analysis, regulatory reviews, formulation of legislative proposals, evaluation, and policy research.

In these matters, DALTCP works closely with the Health Care Financing Administration (HCFA), Administration on Aging (AoA), Administration on Developmental Disabilities (ADD), National Institute on Aging (NIA), National Institute on Child Health and Human Development (NICHD), National Center for Health Statistics (NCHS), Agency for Health Care Policy and Research (AHCPR), and the Social Security Administration (SSA).

DALTCP pursues a rigorous research agenda, aimed at providing comprehensive information to address policy questions for Federal, State, and local policy makers and program managers. In turn, entities offer help in formulating the questions, data systems, and sites for study.

# ORGANIZATION

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The inventory is divided into eight subject areas:

- I. Managed Care/Other Developing Health Care Systems and People with Disabilities
- II. Home and Community-Based Services and Personal Assistance Services
- III. Children and Working Age Adults with Disabilities
- IV. Residential Care Settings
- V. Financing/Modeling
- VI. Data Development
- VII. International Comparisons
- VIII. *ASPE Research Notes*

Each report listed is coded--[DALTCP] or [NTIS]--so that the reader will know where it can be requested from. To obtain a copy of a report, the reader should send their name, address, telephone and FAX numbers, and the complete report title to the organization below that corresponds to the report's code. Specific questions about the project or questions about a report's content should be directed to the project's contact person. [**NOTE: Report links were added when this compendium was made Internet-ready.**]

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[NTIS] National Technical Information Service  
Department of Commerce  
5285 Port Royal Road  
Springfield, Virginia 22161

If available at the time of this printing, an Accession Number is included with each NTIS report listed. Be sure to include the Accession Number when ordering a report from the National Technical Information Service.

# I. MANAGED CARE/OTHER DEVELOPING HEALTH CARE SYSTEMS AND PEOPLE WITH DISABILITIES

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## A. Overview

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In an era marked by rapidly growing health care expenditures, the public and private sectors are increasingly looking toward **managed health care systems** to control health care costs and improve access to a coordinated continuum of services. People with disabilities account for a disproportionate share of overall health care expenditures, and until payers can contain the costs and more effectively manage the care of people with disabilities, savings in overall health care expenditures will be difficult to realize. Yet designing managed care systems for the disabled has proven to be extremely difficult to achieve. The development of cost-effective, outcomes-oriented, and consumer-sensitive managed care systems for people with disabilities continues to be extremely challenging for both the private and public health care sectors.

Unfortunately, neither the public nor private sectors have much information on: (a) the experience of disabled populations in the traditional health care system, and (b) what happens to these populations when they are enrolled in managed care plans. In an effort to better understand the impact of managed care on disabled populations, DALTCP has developed a series of research and evaluation projects focused on managed care and people with disabilities (sometimes in collaboration with HCFA and other parts of HHS). Specific projects investigate the experiences of disabled populations in managed care in public health care systems such as Medicaid and Medicare, as well as in employer-based and self-insured plans.

In addition to managed care arrangements, projects supported by DALTCP are also monitoring other developments in the health care system. Among them are the emergence of **subacute care** and the growth of **Medicare nursing facility and home health care**.

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## B. Completed Projects

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**TITLE:** *ISSUE PAPER AND EXPERT MEETING ON MANAGED CARE FOR PERSONS WITH DISABILITIES*

**PURPOSE:** The purpose of this paper, written by DALTCP staff, was to provide background information for a meeting of experts brought together to discuss managed care for people with disabilities and to assist in the development of a research agenda



on managed care for DALTCP to pursue. At the meeting, which was held on December 5, 1994, experts were asked to: (1) discuss the benefits and risks that managed care may pose for people with disabilities; (2) identify key policy concerns that the Federal Government and States must consider in designing managed care initiatives for people with disabilities; (3) highlight relevant completed research or research that was underway; and (4) suggest policy relevant projects and studies which ASPE might pursue.

**FINDINGS/RESULTS:** The policy and research areas identified in the paper include: functional and demographic characteristics of people with disabilities in managed care; the impact of managed care on access, quality, affordability, costs, satisfaction, health status, and functioning; targeting of managed care to people with disabilities; financing and reimbursement; service coverage and organization of the delivery system; and quality assurance. Under each of these areas, policy issues, research completed and underway, and directions for future research are discussed.

**CONTACT PERSON:** Andreas Frank, ASPE (202-690-6443)

**COMPLETION DATE:** January 1995

**REPORTS AVAILABLE:**

Frank, Andreas: *RESEARCH AGENDA: Managed Care*. (January 1995). [DALTCP]  
[\[http://aspe.hhs.gov/daltcp/reports/resagmc.htm\]](http://aspe.hhs.gov/daltcp/reports/resagmc.htm)

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**TITLE: *RESEARCH INVENTORY ON MANAGED CARE AND PEOPLE WITH DISABILITIES***

**PRINCIPAL INVESTIGATOR:** Mimi Bernardin, MEDSTAT Group, Lexington, MA

**PURPOSE:** The purpose of the research inventory was to bring together all empirical research on managed care and people with disabilities of all ages including children, working age adults, and the impaired elderly.

**FINDINGS/RESULTS:** The completed inventory identifies completed and ongoing research studies in the following areas: utilization and costs, outcomes data, quality assurance activities, implementation analyses, risk selection/risk adjustment, case management practices, and others. Each research project's methodology is explained, and the date of expected completion, the sponsoring organization, and principal investigator are listed.

**CONTACT PERSON:** Andreas Frank, ASPE (202-690-6443)

**COMPLETION DATE:** February 1996

**REPORTS AVAILABLE:**

Bernardin, Mimi: *Inventory of Research on Persons with Disabilities in Managed Care Programs* (February 1996). [DALTCP]  
[\[http://aspe.hhs.gov/daltcp/reports/inventry.htm\]](http://aspe.hhs.gov/daltcp/reports/inventry.htm)

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**TITLE: *INNOVATIVE MANAGED CARE PLANS SERVING PEOPLE WITH DISABILITIES***

**PRINCIPAL INVESTIGATOR:** Sally Bachman, MEDSTAT Group, Lexington, MA

**PURPOSE:** In spite of the rising level of interest by public and private payers in expanding managed care enrollment to include people with disabilities, there are few systematic data available about plans that successfully serve individuals with complex health care needs. The purpose of this project was to gather qualitative data about public and private managed care plans that provide efficient yet clinically appropriate care to working age adults with disabilities. Data was gathered through site visits to approximately six plans and telephone interviews with another ten plans. Research questions focused on consumer participation, provider training and recruitment, quality of care, risk adjustment and risk sharing arrangements, service delivery models, disease specific practice guidelines, and outcome measurement.

**FINDINGS/RESULTS:** Site visits were completed in February 1996. Plans visited included: Health Alliance, Intermountain Health Care, Group Health of Puget Sound, Community Medical Alliance, Arizona's Physician IPA, and others. Sites on which information has been collected on include: Fallon Community Health Plan, FHP, Harvard Community Health Plan, Kaiser Permanente--Colorado, MCARE, Pacificare, United HealthCare Corporation, and others. A written report will be available in February 1997 and was presented at DALTCP's national managed care conference held in November 1996.

**CONTACT PERSON:** Andreas Frank, ASPE (202-690-6443)

**COMPLETION DATE:** April 1996

**REPORTS AVAILABLE:** None yet available.

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**TITLE: *DEVELOPING INTEGRATED MANAGED CARE SYSTEMS FOR CHILDREN WITH DISABILITIES***

**PRINCIPAL INVESTIGATOR:** Sally Bachman, MEDSTAT Group, Lexington, MA

**PURPOSE:** The purposes of this study included:

- documenting the state-of-the-art in developing managed care systems for children with disabilities;
- learning how States are using the Medicaid and Title V sponsored managed care plans to serve low income children with disabilities; and
- identifying lessons/best practices and managed care models from State experience.

**FINDINGS/RESULTS:** Site visits were conducted in four States (California, Florida, Massachusetts, and Michigan). Medicaid 1992 tape-to-tape data were analyzed to document enrollment and disenrollment patterns of children with disabilities in Medicaid managed care. The study concludes that there is little information available to States about service use patterns of children with disabilities and virtually no operational financing mechanisms. Barriers to moving ahead are described and pockets of innovation are identified.

**CONTACT PERSON:** Ruth Katz, ASPE (202-690-6443)

**COMPLETION DATE:** December 1996

**REPORTS AVAILABLE:**

Bachman, Sara S., Mimi Bernardin, and Brian Burwell: *Developing Managed Care Systems for Children with Disabilities: The State of the Art* (December 1996). [DALTCP] [<http://aspe.hhs.gov/daltcp/reports/startes.htm>]

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**TITLE: COSTS AND QUALITY OF SUBACUTE CARE**

**PRINCIPAL INVESTIGATOR:** Barbara Manard, Lewin-VHI, Inc., Fairfax, VA

**PURPOSE:** Medicare expenditures for post-acute and acute care are expected to rise substantially as both the number and proportion of persons over age 65 grows. As an effort to reduce costs, "subacute care" is being promoted by many providers as a cost-effective alternative to inpatient hospital care with potential savings of 40%-60%. While there is no specific definition of subacute care, there is general agreement that subacute care encompasses a wide range of medically complex and/or technologically advanced services at the lower end of acute care but at a higher level of care than traditionally provided in non-acute care settings. Services previously provided in acute care hospitals are more frequently delivered in non-acute care hospital settings (i.e., long-term care and rehabilitation hospitals, nursing homes, and home health agencies). This project was designed to provide an understanding of subacute care in select market areas. In addition to examining a variety of subacute care providers, patients, and payers (both public and private), the project identifies incentives and barriers to the provision of subacute care and reports the impact of subacute care as perceived by key stakeholders in targeted markets. The project also develops methodologies that can be used to assess the costs, savings, and quality of subacute care.

**FINDINGS/RESULTS:** Site visits were conducted in four targeted market areas (selected in consultation with experts from the subacute care industry) to 19 institutional state-of-the-art, self-declared subacute care providers including hospital-based and freestanding skilled nursing facilities, rehabilitation hospitals and units, and long-term care hospitals. Telephone interviews were conducted with several home care agencies, and discussions were held with key stakeholders in the targeted markets.

Findings from the study indicate that subacute care has emerged as a result of Medicare payment policies (including hospital DRG payments and cost-based post-

acute care payments that permit exceptions for other providers such as SNFs) and the pursuit of low cost, appropriate alternatives to hospital care by managed care payers. Much of what is labeled as subacute care appears to refer to patients previously identified as “high-end Medicare patients.” Most subacute care providers in the study were implementing some but not all of the “ideal” characteristics of a subacute acute care program. Additional information is needed about the costs of and outcomes associated with subacute care before conclusions about its cost-effectiveness can be reached.

**CONTACT PERSON:** Jennie Harvell, ASPE (202-690-6443)

**COMPLETION DATE:** November 1995

**REPORTS AVAILABLE:**

Lewin-VHI, Inc.: *Subacute Care: Policy Synthesis and Market Area Analysis*, (November 1, 1995). [DALTCP] [<http://aspe.hhs.gov/daltcp/reports/absacute.htm>]

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**TITLE: TRAINING FOR PROFESSIONALS CARING FOR PEOPLE WITH DISABILITIES**

**PRINCIPAL INVESTIGATOR:** Christopher DeGraw, George Washington University Center for Health Policy Research, Washington, DC

**PURPOSE:** Because people with disabilities generally use more health care services than those without disabilities and more often require the use of a continuum of care which includes long-term care and supportive community services, effective health care for persons with disabilities requires the services of both health care and human service professionals. At a time when increasing numbers of disabled persons may be served by managed care programs, the ability of professionals to work in an interdisciplinary manner is important. The purpose of this project was to identify and describe particular programs where professionals and students in the health care and human service professions receive interdisciplinary instruction and practicum experience in the provision of care to people with disabilities. The project included a literature review, site visit reports, and a final report on interdisciplinary training in relation to care for people with disabilities.

**FINDINGS/RESULTS:** There is a growing consensus that meeting clients' needs cannot be accomplished effectively and efficiently by one discipline alone. While not every client with a disability may require assessment and service delivery by a team, professionals from a variety of disciplines will be increasingly called upon to work interactively. If training is one of the bases for quality managed care, managed care may be building on a precarious base as far as clients with disabilities are concerned. Interdisciplinary training programs are addressing managed care only peripherally, and managed care organizations (MCOs) have little appreciation for the specific knowledge, attitudes and skills needed by providers to appropriately serve people with disabilities. The final report recommends (1) promotion of opportunities for dialogue between MCOs and persons with disabilities, the professionals who serve them, and educators and

trainers; (2) development of incentives to encourage pre-service and in-service interdisciplinary training; (3) support of research to investigate connections between interdisciplinary education and care and access, quality, and positive outcomes for people with disabilities; and (4) dissemination of information regarding interdisciplinary curricula and approaches, innovative use of community sites for training, how managed care can be infused in curricula, and sources of funding and support for interdisciplinary training.

**CONTACT PERSON:** Kathleen Bond, ASPE (202-690-6443)

**COMPLETION DATE:** December 1996

**REPORTS AVAILABLE:**

DeGraw, Christopher, Michael Fagan, Marion Parrott, and Susan Miller:

*Interdisciplinary Education and Training of Professionals Caring for Persons with Disabilities: Current Approaches and Implications for a Changing Health Care System*, (December 1996). [DALTCP]

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

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**TITLE: NATIONAL CONFERENCE ON MANAGED CARE FOR PEOPLE WITH DISABILITIES**

**PRINCIPAL INVESTIGATOR:** Mimi Bernardin, MEDSTAT Group, Lexington, MA

**PURPOSE:** The goal of the national conference (entitled *Beyond the Water's Edge: Charting the Course of Managed Care for People with Disabilities*) was to bring together researchers, policy makers, providers, and consumer representatives to examine the available empirical evidence regarding the impact on people with disabilities of Medicare and Medicaid managed care plans as well as managed care in the private sector. The conference was organized along four broad topic areas:

- the impact of managed care on children with disabilities;
- managing acute care for people with significant disabilities;
- consumer satisfaction with managed care among people with disabilities; and
- managed care system design and people with disabilities.

**FINDINGS/RESULTS:** A steering committee comprised of DALTCP staff, selected outside groups, and representatives from over a dozen agencies planned the conference and identified presenters and research to be covered. The conference took place on November 20-22, 1996. Anticipated products include meeting materials and a series of commissioned papers.

**CONTACT PERSON:** Andreas Frank, ASPE (202-690-6443)

**COMPLETION DATE:** November 1996

REPORTS AVAILABLE:

Conference Resource Book [DALTCP]

[\[http://aspe.hhs.gov/daltcp/reports/96cfpkes.htm\]](http://aspe.hhs.gov/daltcp/reports/96cfpkes.htm)

Commissioned Papers [forthcoming, DALTCP]

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**TITLE: *IMPACT OF MANAGED CARE ON CHILDREN WITH DISABILITIES IN FLORIDA***

**PRINCIPAL INVESTIGATOR:** Elizabeth Shenkman, University of Florida Institute for Child Health Policy, Gainesville, FL

**PURPOSE:** The purpose of this grant is to assess how different organizational and financial characteristics of managed care organizations (as measured by physician and other provider payment methods, financial incentives, risk sharing, benefit package design, and management of referrals) affect health care use, functional status, families out-of-pocket expenses, and per capita expenditures for children with special health care needs. A total sample of 750 children will be included.

**FINDINGS/RESULTS:** Preliminary data analysis compares families' out-of-pocket expenses for commercially insured special needs children enrolled in HMOs and Medicaid insured special needs children in fee-for-service arrangements. Children in the commercially insured program were in families with higher incomes and had higher functional status scores than the children covered by Medicaid. The commercially insured families incurred smaller out-of-pocket expenses in terms of both absolute amounts and percentage of family income than families of Medicaid fee-for-service enrollees. A detailed report is available.

**CONTACT PERSON:** Andreas Frank, ASPE (202-690-6443)

**COMPLETION DATE:** Fall 1996

REPORTS AVAILABLE:

Shenkman, Elizabeth A.: *Families' Out-of-Pocket Expenses When Caring for Children with Special Needs: A Preliminary Report Comparing Children in Medicaid and a Commercial Product Line* (November 1996). [DALTCP]

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**C. Ongoing/Planned Projects**

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**TITLE: *IMPACT OF MANAGED CARE ON MEDICARE DISABLED BENEFICIARIES UNDER THE AGE OF 65***

**PRINCIPAL INVESTIGATOR:** Leonard Gruenberg, DataChron, Inc., Cambridge, MA

**PURPOSE:** The overall purpose of this project is to learn more about utilization patterns, health status, access to care and patient satisfaction for disabled Medicare beneficiaries under age 65 in both the fee-for-service and managed care systems. The project is a collaborative effort of DataChron Health Systems, Inc., the Center for Health

Research at Kaiser Permanente, and the Fallon Clinic. Data regarding utilization patterns of 2,300 under 65 disabled Medicare members of two TEFRA (risk) HMOs will be analyzed and compared with similar data regarding 2,000 disabled fee-for-service Medicare recipients who participated in the Medicare Current Beneficiary Survey (MCBS). This project will provide descriptive and comparative information about utilization, costs, patient characteristics, satisfaction and access in both TEFRA plans and fee-for-service arrangements for this population. In addition, this project will include an examination of the HMO casemix issues and of HMO costs for these populations.

**PROGRESS TO DATE:** Data are being analyzed.

*CONTACT PERSON:* Andreas Frank, ASPE (202-690-6443)

*COMPLETION DATE:* Spring 1997

*REPORTS AVAILABLE:* None yet available.

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**TITLE: *DISABILITY SUPPLEMENT TO HCFA EVALUATION OF THE OREGON HEALTH PLAN***

*PRINCIPAL INVESTIGATOR:* Margo Rosenbach, Health Economics Research, Inc.,  
Waltham, MA

**PURPOSE:** HCFA's existing evaluation examines the impact of changes in the financing and delivery of health care services to AFDC recipients and low income persons not eligible for Medicaid in the State of Oregon, through the 1115 waiver demonstration authority. This supplement to the Oregon evaluation will add a disability focus. The supplement will focus on the experiences of SSI disabled children and adults (physically disabled, mentally ill, mentally retarded, developmentally disabled) enrolled in the Oregon Health Plan. The disability supplement will examine cost and utilization data, and link these data to functional data collected by State agencies. In addition, the supplement will conduct a survey of consumers and providers to examine issues of satisfaction, access, quality, health status, and functioning.

**PROGRESS TO DATE:** Work is underway on the project and survey design.

*CONTACT PERSON:* Andreas Frank, ASPE (202-690-6443)

John Drabek, ASPE (202-690-6443)

*COMPLETION DATE:* Fall 2000

*REPORTS AVAILABLE:* None yet available.

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**TITLE: *DISABILITY SUPPLEMENT TO HCFA EVALUATION OF MEDICAID MANAGED CARE IN TENNESSEE***

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

**PURPOSE:** This project adds a disability component to the existing HCFA evaluation of Medicaid 1115 waiver demonstrations in five States, with a focus on the Tennessee evaluation. The study will follow the experiences of SSI disabled children and adults (physically disabled, mentally ill, mentally retarded, or developmentally disabled) enrolled in the TennCare and TennPartners Programs. The project will conduct in-depth qualitative analyses of the State's experience in enrolling individuals with disabilities into managed care systems, and will conduct quantitative analysis to examine cost and utilization data for these populations. The supplement will also include a survey of disabled consumers to examine issues of satisfaction, quality, health status, and functioning.

**PROGRESS TO DATE:** Work is underway on the project and survey design.

**CONTACT PERSON:** Andreas Frank, ASPE (202-690-6443)  
John Drabek, ASPE (202-690-6443)

**COMPLETION DATE:** Fall 2000

**REPORTS AVAILABLE:** None yet available.

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**TITLE: *COMPARATIVE OUTCOMES AND PROCESSES OF PREPAID MANAGED CARE FOR HIGH-RISK POPULATIONS***

**PRINCIPAL INVESTIGATOR:** Richard Kronick, University of California, San Diego, CA

**PURPOSE:** The purpose of this study is to learn more about the effects of managed care on persons with disabilities. Specifically, this study will address questions in five areas: (1) In what ways, if any, do providers reorganize the delivery of care to persons with disabilities under managed care? (2) When given a choice between capitated HMOs and fee-for-service reimbursement, what subsets of people with disabilities are attracted to HMOs? (3) What are the effects of managed care on health care utilization and on health expenditures for persons with disabilities? (4) What are the effects of managed care on health outcomes and patient satisfaction? (5) What conditions, health care consumption patterns, or other indicators are particularly good markers of severe disability in working age adults and children? How can this information be used to construct reimbursement systems that encourage health plans to serve severely impaired subsets of persons with disabilities?

The research will be conducted in four widely different settings: (1) The Community Medical Alliance, a health plan in Massachusetts that was created to develop specialized delivery systems for a small number of Medicaid eligibles with end-stage AIDS and with severe physical disabilities; (2) Detroit and surrounding areas in Michigan, where over 30,000 SSI recipients are receiving care in full at-risk HMOs and another 90,000 SSI recipients are receiving care in a primary care case management model; (3) Health plans in Columbus and Cleveland, Ohio, that are centered around



academic health centers; and (4) a health plan in central Missouri that is attempting to develop delivery systems that serve the needs of persons with disabilities in a rural setting.

**PROGRESS TO DATE:** Investigators have completed a major refinement of a disability diagnostic classification system and applied the system to claims from multiple plans. Service utilization and diagnostic profile data from Michigan and Colorado have been analyzed.

**CONTACT PERSON:** Andreas Frank, ASPE (202-690-6443)

**COMPLETION DATE:** Fall 1996

**REPORTS AVAILABLE:**

Kronick, Richard, Tony Dreyfus, Lora Lee and Zhiyuan Zhou: "Diagnostic Risk Adjustment for Medicaid: The Disability Payment System," *Health Care Financing Review* (Fall 1996). [DALTCP] [<http://aspe.hhs.gov/daltcp/reports/diarskad.htm>]

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**TITLE: PRIVATE PAYERS SERVING DISABLED INDIVIDUALS AND RESEARCH SYNTHESIS ON MANAGED CARE FOR PERSONS WITH DISABILITIES**

**PRINCIPAL INVESTIGATOR:** Brian Burwell, MEDSTAT Group, Lexington, MA

**PURPOSE:** This research project is focusing on: (1) the inclusion of people with disabilities in employer-based managed care, and (2) an ongoing synthesis of policy relevant research results on the impact of managed care on people with disabilities.

The employer-based study includes the following components: (1) methodology development to identify people with disabilities in databases constructed from private insurance claims; (2) cost and utilization analyses to determine the health care utilization patterns and care coordination of people with disabilities in private health care plans; (3) data on the impact of managed care on total health care costs; (4) risk adjustment methodologies used by employers to set rates with managed care plans; and (5) the employer-based study will examine issues related to the functional status of people with disabilities served in managed care plans (i.e., what functional data do employers collect? how do employers use this data to set rates? what types of outcome data do employers collect about persons with disabilities?, etc.)

In addition to the employer-based study, this project will attempt to synthesize ASPE-wide research related to managed care and people with disabilities with other similarly privately and publicly sponsored research. This synthesis will address some of the following questions: How does participation in managed care plans for people with disabilities vary by payment source, disability group, or geographic area? Are the health care needs of people with disabilities being met through managed care arrangements? What are financing arrangements that are most likely to lead to both consumer satisfaction and appropriate care management in managed care plans?

**PROGRESS TO DATE:** The investigators have developed a methodology to identify persons with disabilities through claims data in employer-based plans and have begun to identify potential employers willing to participate in the study.

**CONTACT PERSON:** Andreas Frank, ASPE (202-690-6443)

**COMPLETION DATE:** 1998 (Employer-Based Study)  
2000 (Research Synthesis)

**REPORTS AVAILABLE:** None yet available.

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**TITLE: *EVALUATION OF PRACTICE IN CARE (EPIC)***

**PRINCIPAL INVESTIGATOR:** Peter Shaughnessy, University of Colorado Health Sciences Center, Denver, CO

**PURPOSE:** From 1989 to 1992, there was a 210% increase in Medicare expenditures for home health services. This increase in utilization has generated widespread policy interest in appropriate measures to control expenditures without compromising quality. Medicare home health has been the subject of considerable research, but the actual practice of home health care has not been extensively examined. This study will analyze “episodes” of care under the Medicare home health benefit, assess the actual practice of care, the extent to which there is variation in practice between acute and long-term patients, and the factors that account for that variation. This study will also examine decision-making processes between patients, providers and physicians. What takes place during a visit and between visits as “actual practice” has never been measured. Furthermore, the function of decision-making by various parties has not been observed in “actual practice.” This effort to understand issues surrounding regional and practice variations of home health care delivery will aid the Department and the industry in combating fraud and abuse, as well as contribute valuable data to a future prospective payment system.

**PROGRESS TO DATE:** The final research design is being developed. Actual recruitment of sites to the project will begin in January 1997.

**CONTACT PERSON:** Robert Clark, ASPE (202-690-6443)

**COMPLETION DATE:** 1998

**REPORTS AVAILABLE:** None yet available.

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**TITLE: *MANAGED DELIVERY SYSTEMS FOR MEDICARE BENEFICIARIES WITH DISABILITIES AND CHRONIC ILLNESS***

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

**PURPOSE:** The last decade has brought tremendous changes in the health care system as payers and providers struggle to bring health care expenditures under control. The momentum to achieve a reformed, more managed U.S. health care system, one which seeks to bring costs under control while improving access to, continuity and coordination of care, appears unstoppable. However, it remains unknown how this transforming health care system will affect the health and well-being of people with significant disability and chronic illness. For now, the Medicare program has lagged behind the private insurance market and even the Medicaid program in the proportion of its beneficiaries participating in managed care plans. In 1995, about 2.3 million older persons out of a total Medicare beneficiary population of 25 million were enrolled in the Medicare Risk Program implemented under TEFRA. There is little information on the experience of older persons with disabilities in these and other managed care plans. The purpose of this study is to address the characteristics of elderly persons with chronic illnesses and disability that need to be accommodated in designing and operating managed delivery systems (MDS), the issues that health care policy makers, plan administrators and providers need to consider in designing, operating, and monitoring MDS for the elderly with disabilities and chronic illness, how MDS actually perform in meeting the needs of the elderly disabled, and the factors that influence the success of MDS in meeting the needs of this population.

**PROGRESS TO DATE:** This project began in Fall 1996. A Technical Advisory Group (TAG) was created and has met to provide advise and guidance on this project. TAG membership includes representatives from health plans, medical and nursing professions, experts in the needs of persons with chronic illnesses and disabilities, government officials with expertise in Medicare fee-for-service and managed care, and researchers with expertise in the disabled elderly and managed care.

**CONTACT PERSON:** Jennie Harvell, ASPE (202-690-6443)  
Floyd Brown, ASPE (202-690-6443)

**COMPLETION DATE:** 1998

**REPORTS AVAILABLE:** None yet available.

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**TITLE: *EVALUATION OF THE DISTRICT OF COLUMBIA'S 1115 WAIVER FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS***

**PRINCIPAL INVESTIGATOR:** Carol Irvin, Abt Associates, Cambridge, MA

**PURPOSE:** This project, co-sponsored by ASPE and HCFA's Office of Research and Demonstrations (ORD), is an evaluation of the District of Columbia's 1115 waiver demonstration. The District's waiver is the first approved demonstration to integrate acute and long-term care services for SSI eligible children with disabilities in a single capitated payment system. The study will analyze enrollment data and document the experiences of the District, plan, providers, and children and their families. The study will be used to inform both State and Federal policy makers who increasingly regard managed care as a means of containing growing health care expenditures.

**PROGRESS TO DATE:** The demonstration began enrolling children in January 1996. The first enrollment report will be available in March 1997, with subsequent reports following every 6 months.

*CONTACT PERSON:* Andreas Frank, ASPE (202-690-6443)

*COMPLETION DATE:* 1998

*REPORTS AVAILABLE:* None yet available.

## II. HOME AND COMMUNITY-BASED SERVICES AND PERSONAL ASSISTANCE SERVICES

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### A. Overview

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There is increasing recognition that people of all ages who have disabilities prefer to receive long-term care services in home and community-based settings. The projects listed in this section describe efforts to address estimates of the number of people potentially eligible for programs, issues regarding State and local administration of home and community-based services, the role of case management in home and community-based services, and consumer direction in acquiring and managing services.

To estimate the number of persons with disabilities conceivably eligible for home and community-based long-term care services, a project on the **Analysis of Eligibility Issues** examined national data to assess alternative measures of severity of impairment for use as eligibility criteria for services for various target populations. A follow-up project has taken a close look at the long-term care needs of individuals with mental illness. **People with Serious Mental Illness: How Do They Fit Into Long-Term Care** focused on how this population would use long-term care services and how eligibility criteria would be structured and operationalized.

“Personal assistance services” (PAS) is a broadly inclusive term used to refer to any and all forms of assistance that enable persons with disabilities to accomplish tasks that an individual would normally do himself or herself if he or she did not have a disability. In November 1994, DALTCP sponsored a planning meeting to identify high priority policy-relevant research questions related to PAS. The results of this workshop are available in the paper entitled **RESEARCH AGENDA: Personal Assistance Services and Related Supports** (described in this Section).

DALTCP is pursuing a major new initiative to study ways to expand consumer choice and empowerment in PAS. One major new study is evaluating **cash versus in-kind benefits** in the provision of Medicaid-funded PAS to the disabled. With co-sponsorship from the Robert Wood Johnson Foundation, the demonstration and evaluation will involve the “cashing out” of Medicaid PAS services in two States. “Cashing out” of services is expected to save Medicaid monies, mainly by reducing State administrative costs.

Several other projects in the section concern consumer direction in home and consumer-based services including a **National Institute on Consumer Direction in Home and Community-Based Services**, a study of client-directed in-home care

programs in California, and a project documenting approaches to implementing consumer-directed PAS.

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## **B. Completed Projects**

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**TITLE: KEY ASPECTS OF STATE/LOCAL ADMINISTRATION OF HOME AND COMMUNITY-BASED CARE SERVICES PROGRAMS**

**PRINCIPAL INVESTIGATOR:** Brina Melemed, National Association of Area Agencies on Aging, Washington, DC

**PURPOSE:** This study examined some of the implications for States of block granting Medicaid home and community-based services (HCBS). Five States (Arkansas, Illinois, Indiana, Maine, and North Dakota) were selected for in-depth case studies of how they managed home and community-based service programs using uniform eligibility criteria and fixed funding.

**FINDINGS/RESULTS:** The study highlighted the substantial variation in size, scope, and organizational features across States in home and community-based care. At the same time, most HCBS administrators indicated that they had considerable experience working within the constraints of capped funding levels because most of the funding sources they relied on involved fixed annual budgets. Indeed, they pointed out that, from a State perspective (that is, in regard to State matching fund requirements) the so-called “open-ended” entitlements such as Medicaid personal care tended to be treated as if they were fixed appropriations. Thus, most State and local officials interviewed felt that they would be able to meet the needs of beneficiaries under a capped HCBS benefit such as the one proposed in President Clinton’s health care reform plan.

**CONTACT PERSON:** Pamela Doty, ASPE (202-690-6172)

**COMPLETION DATE:** December 1994

**REPORTS AVAILABLE:**

Melemed, Brina B.: *An Examination of Issues Related to How Home and Community-Based Services Programs Operate Within Fixed Budgets and to the Administrative Linkages Between Eligibility Determination, Needs Assessment and Care Planning Functions* (December 1994). [DALTCP]  
[\[http://aspe.hhs.gov/daltcp/reports/examines.htm\]](http://aspe.hhs.gov/daltcp/reports/examines.htm)

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**TITLE: THE ROLE OF CASE MANAGEMENT IN HOME AND COMMUNITY-BASED SERVICES: IMPLICATIONS FOR HEALTH CARE REFORM**

**PRINCIPAL INVESTIGATOR:** Beth Jackson, MEDSTAT Group, Cambridge, MA

**PURPOSE:** This project investigated targeting case management services on a subset of the long-term care population with the highest level of need.

**FINDINGS/RESULTS:** The researcher visited six States that do not universally prescribe case management services to all long-term care recipients. She studied the organization and role of case management; the types of clients served; how clients are "triaged;" and approaches and challenges to quality assurance when case management is rationed.

**CONTACT PERSON:** Ruth Katz, ASPE (202-690-6443)

**COMPLETION DATE:** September 1994

**REPORTS AVAILABLE:**

Jackson, Mary E.: *Rationing Case Management: Six Case Studies* (1995).

[DALTCP] [<http://aspe.hhs.gov/daltcp/reports/rationes.htm>]

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**TITLE: *ISSUE PAPER AND EXPERT MEETING ON PERSONAL ASSISTANCE SERVICES AND RELATED SUPPORTS***

**PURPOSE:** This paper provides background information on personal assistance services (on home and community-based services) and assistive devices for a working meeting of experts hosted by DALTCP to assist in shaping the Office's expanding agenda in disability research. Goals of the meeting, convened on November 10, 1994, were: to select high priority policy-relevant research topics; to define research strategies in the context of existing research, resources, and data; and to specify projects appropriate to ASPE. Our emphasis was on strategies that move toward a consumer-directed and generic (age and diagnosis neutral) system of personal assistance (PAS). The paper addresses the following topics: (1) need, use, and costs of PAS; (2) quality assurance and related issues of liability and risk; (3) paid and unpaid assistance; (4) cash payments to consumers in lieu of reimbursing providers directly; (5) assistive technology; and (6) service delivery system infrastructure.

**FINDINGS/RESULTS:** At the meeting and in written comments, participants placed highest priority on research to measure service needs, use and costs; quality assurance; and infrastructure/implementation issues. For example, participants placed high priority on understanding patterns of expressed need and use of PAS and on need for a better understanding of agency costs. Participants also placed high priority on approaches to assuring quality using an independent provider or consumer-directed approach to PAS. The summary of the meeting also includes specific research projects for each of the topics discussed.

**CONTACT PERSON:** Pamela Doty, ASPE (202 690-6172)

**COMPLETION DATE:** December 1994

**REPORTS AVAILABLE:**

Doty, Pamela, Nancy N. Eustis, and Brooke E. Lindsay: *RESEARCH AGENDA: Personal Assistance Services and Related Supports* (December 1994).

[DALTCP] [<http://aspe.hhs.gov/daltcp/reports/resagpas.htm>]

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**TITLE: CONSUMER DIRECTION IN HOME AND COMMUNITY-BASED CARE**

**PURPOSE:** In March 1995, ASPE and AoA convened a meeting of researchers and State and local administrators to advise the government on future directions for research and technical assistance that would promote the development of HCBS delivery systems.

**FINDINGS/RESULTS:** The expert panel identified several themes that characterized the need for research and technical assistance and suggested strategies to promote State and local HCBS delivery capacity. The panel recommended that Federal efforts should:

- Respond to States' needs for technical assistance to develop HCBS programs.
- Improve the knowledge and understanding of the effectiveness of various HCBS program components (assessment, care planning, service management, provider selection, etc.).
- Synthesize and disseminate information about HCBS program and policy strategies to States and communities.
- Enhance the ability of States and communities to respond to the changing needs of the consumers of HCBS.

Two products were developed as a follow-up to the Expert Panel meeting. One is a summary of the meeting, along with a refined set of recommended strategies that could be undertaken in developing infrastructure capacity building. The second is the *Inventory of Research and Demonstration Projects on Consumer Direction in Home and Community-Based Care* funded by several Federal agencies and private foundations.

**CONTACT PERSON:** Floyd Brown, ASPE (202 690-6613)

**COMPLETION DATE:** 1995

**REPORTS AVAILABLE:**

Justice, Diane: *Inventory of Research and Demonstration Projects on Consumer Direction in Home and Community*. [Diane Justice, National Association of State Units on Aging, 1225 Eye Street, NW, Suite 725, Washington, D.C. 20005]

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**TITLE: ANALYSIS OF ELIGIBILITY ISSUES**

**PRINCIPAL INVESTIGATOR:** Mary E. Jackson, MEDSTAT Group, Inc., Cambridge, MA



**PURPOSE:** The purpose of this project was to analyze the 1989 National Long-Term Care Survey and the 1987 National Medical Expenditures Survey for purposes of assessing alternative measures of severity of impairment for use as eligibility criteria for home and community-based long-term care services.

**FINDINGS/RESULTS:** The paper "Use of the 1989 National Long-Term Care Survey for Examining Cognitive Impairment Eligibility Criteria" (listed below), was presented at the 25th Public Health Conference on Records and Statistics and the National Committee on Vital and Health Statistics, Washington, D.C., July 1995. It was published in *Data Needs in an Era of Health Reform, Proceedings of the Public Health Conference on Records and Statistics*, U.S. Department of Health and Human Services, Public Health Service, Centers for Disease Control and Prevention, National Center for Health Statistics, Rockville, MD, 1995.

**CONTACT PERSON:** Pamela Doty, ASPE (202-690-6172)

**COMPLETION DATE:** May 1995

**REPORTS AVAILABLE:**

Jackson, Mary Elizabeth and Pamela Doty: *Use of the 1989 National Long-Term Care Survey for Examining Cognitive Impairment Eligibility Criteria* (July 1995). [DALTCP] [<http://aspe.hhs.gov/daltcp/reports/89nltces.htm>]

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**TITLE: *PEOPLE WITH SERIOUS MENTAL ILLNESS: HOW DO THEY FIT INTO LONG-TERM CARE?***

**PURPOSE:** Long-term services, which are needed by chronically disabled people to carry out activities of daily life, have traditionally been viewed as services for the elderly. However, increased attention has been given to other disabled populations who also need long-term services, such as individuals with mental retardation, developmental disabilities, and severe mental illness. In designing a program to provide long-term assistance, specifically in the home or the community. Issues arise in accurately defining the population needing services and identifying the benefits that different populations need.

The focus of this report was on how people with serious mental illness (SMI) would fit in the long-term service system, specifically in relation to eligibility criteria and benefits. Perhaps the most challenging aspect of establishing a long-term services program that provides benefits to individuals with SMI is dealing with the cyclical nature of mental illness, which can result in service needs that can change quickly and dramatically. Ensuring that a basic level of service is available to individuals with SMI when necessary, but that unnecessary services are not utilized, is a difficult balance to achieve and raises many policy questions regarding appropriate eligibility criteria and level of benefits.

**FINDINGS/RESULTS:** The study highlights the inadequacy of currently available data and measures for estimating the size of the population of persons with serious mental illness in need of home and community-based long-term care. The study also underscores the differences between traditional "home care" programs for the elderly and disabled, which tend to focus on providing assistance with personal care and homemaking activities and home and community-based services for the seriously mentally ill, which tend to focus on psycho-social rehabilitation, including programs designed to increase the likelihood of clients' employability at some future point.

**CONTACT PERSON:** Pamela Doty, ASPE (202-690-6172)

**COMPLETION DATE:** April 1995

**REPORTS AVAILABLE:**

Kuntz, Crystal: *Persons with Severe Mental Illness: How Do They Fit Into Long-Term Care?* (May 1995). [DALTCP] [<http://aspe.hhs.gov/daltcp/reports/mentalil.htm>]

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**TITLE: *EVALUATION OF THE ELDERLY NUTRITION PROGRAM***

**PRINCIPAL INVESTIGATOR:** Michael Ponza, Mathematica Policy Research, Inc.,  
Washington, DC

**PURPOSE:** As part of DALTCP's interest in home and community-based care, ASPE supported a two-year evaluation of the *Elderly Nutrition Program* (ENP). The program provides grants to State Agencies on Aging to support the provision of daily meals in either group or home settings to persons age 60 and older, specifically targeting elders who have the greatest economic and social need. The evaluation: (1) described the demographic, functional, health, and service-use characteristics of participants; (2) compared the characteristics of congregate meal and home-delivered meal program participants, and assessed how well the program is reaching special elderly populations, such as low income and minority elderly; (3) provided estimates of the impact of the program's nutritional components on the nutrition and social well-being of participants; (4) included a thorough "process" analysis of how the program is administered and operated, and the quality and effectiveness of those components; and (5) examines funding amounts, sources, and uses, and assesses the adequacy of funding. Data collection from nationally representative samples included: (a) telephone surveys of the 57 State Units on Aging, 350 Area Agencies on Aging, 100 Indian Tribal Organizations, and 200 Nutrition Projects; (b) in-person surveys of 200 meal sites, 1,200 congregate meal participants and 800 home-delivered meal participants; and (c) in-person surveys of 600 nonparticipants eligible for the congregate meals program, and 400 nonparticipants eligible for the home-delivered meal program in areas served by nutrition projects.

**FINDINGS/RESULTS:** Key findings of the evaluation include the following:

- People who receive ENP meals have higher daily intakes of key nutrients than similar nonparticipants.

- ENP meals provide approximately 40%-50% of participants' daily intakes of most nutrients.
- Participants have more social contacts per month than similar nonparticipants.
- Most participants are satisfied with the services the ENP provides.

**CONTACT PERSON:** Floyd Brown, ASPE (202-690-6443)

**COMPLETION DATE:** July 1996

**REPORTS AVAILABLE:**

Ponza, Michael, James C. Ohls, Barbara E. Mullen, Audrey M. McCool, Karen E. Needels, Linda Rosenberg, Dexter Chu, Catherine Daly, and Paula A.

Quatromoni: *Serving Elders at Risk, The Older Americans Act Nutrition Programs: National Evaluation of the Elderly Nutrition Program 1993-1995 (Volume 1: Title III Evaluation Findings)* (July 1996). [DALTCP]

[<http://www.aoa.dhhs.gov/aoa/nutreval/execsum.html>]

### **C. Ongoing/Planned Projects**

**TITLE:** ***CLIENT-DIRECTED IN-HOME CARE/PERSONAL ASSISTANCE SERVICES***

**PRINCIPAL INVESTIGATOR:** A.E. Benjamin, University of California, Los Angeles, CA

**PURPOSE:** This survey of personal assistance services clients, workers, and case managers will compare measures of quality of care, quality of life, client satisfaction and worker satisfaction across modes of service provision: client-directed modes (independent provider and supported independent provider) and professionally managed (agency-employed providers). The study is being carried out in the context of California's In-home Supportive Services (IHSS) program. Telephone or in-person interviews will be conducted with approximately 1250 IHSS consumers, 500 providers, and 50 social work case managers. The study will also compare the outcomes associated with use of family, friends, and neighbors as independent providers as compared to services provided by aides previously unknown to the client.

**PROGRESS TO DATE:** As of December 1996, client interview had been completed, and provider and case manager interviews were underway.

**CONTACT PERSON:** Pamela Doty, ASPE (202-690-6172)

**COMPLETION DATE:** August 1997

**REPORTS AVAILABLE:** None yet available.

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**TITLE: ASSESSMENT INFORMATION FOR HOME CARE**

*PRINCIPAL INVESTIGATOR:* Catherine Hawes, Research Triangle Institute,  
Research Triangle, NC

**PURPOSE:** This project was designed to provide for supplemental field testing of the Uniform National Assessment Instrument (UNAI) in area agencies on aging and other locations affiliated with home and community-based long-term care programs and to develop improved measures of cognitive impairment. A main purpose of this supplemental field testing is to determine the feasibility and appropriateness of using the UNAI as an instrument for determining eligibility for home and community-based long-term care benefits.

*CONTACT PERSON:* Pamela Doty, ASPE (202-690-6172)  
Sue Nonemaker, HCFA (410-966-6825)

*COMPLETION DATE:* September 1998

*REPORTS AVAILABLE:* None yet available.

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**TITLE: NATIONAL INSTITUTE ON CONSUMER-DIRECTED HOME AND  
COMMUNITY-BASED CARE SERVICES**

*PRINCIPAL INVESTIGATOR:* Donna Wagner, National Council on Aging,  
Washington, DC

**PURPOSE:** DALTCP and AoA have jointly funded a new research, technical assistance and dissemination initiative designed to:

- Increase the awareness of people with disabilities (both the over 65 and under 65 populations) to exercise choice and control with regard to home and community-based services, including the option to use independent providers (rather than agency-employed workers) to furnish PAS.
- Educate consumers or their representatives who want to use independent providers about effective strategies for recruiting, training and managing independent PAS providers.
- Educate consumers, their representatives and program personnel regarding consumer participation in care planning, on-site supervision of agency-employed workers and ways to work with case managers and agency personnel to modify care plans.
- Provide information to States and communities to help them evaluate the outcomes and costs of strategies involving consumer choice and consumer-directed services, and to develop and implement cost effective policies and programs.

The initiative will be conducted by a newly developed National Institute on Consumer-Directed HCBS with special emphasis on adult disabled populations (over and under the age of 65). The Institute will serve as a clearinghouse and research organization for a broad range of issues related to consumer choice and consumer decision making for PAS and HCBS.

**PROGRESS TO DATE:** A Technical Advisory Group met to assist staff in defining issues and directions. The following activities have also been completed via this project:

- Inventory of Consumer-Directed State Programs Serving Persons with Disabilities and Older Adults. An inventory of consumer-directed State programs serving persons with disabilities and older adults.
- Nurse Delegation Symposium and Proceedings Document. A meeting of consumer advocates, nursing professionals, and State policy makers to explore the current status of nurse delegation in HCBS.
- Case Study of the Massachusetts Personal Care Attendant Program. An analysis of the experience in the State's personal care program through interviews with State officials, representatives of the Independent Living Centers (15 statewide) and research into the policy guidelines and administrative procedures put in place to manage this program.

**CONTACT PERSON:** Floyd Brown, ASPE (202-690-6443)  
Al Duncker, AoA (202-619-1269)

**COMPLETION DATE:** October 1998

**REPORTS AVAILABLE:**

National Institute on Consumer-Directed Home and Community-Based Care Services. Consumer Choice News, a monthly newsletter. [National Council on the Aging, 409 Third Street, SW, Washington, DC 20024; fax (202)479-0735.]  
Wagner, Donna: Autonomy or Abandonment: Changing Perspectives on Delegation, (forthcoming). [DALTCP] [<http://aspe.hhs.gov/daltcp/reports/autoabes.htm>]

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**TITLE: PERSONAL ASSISTANCE SERVICES "CASH AND COUNSELING"  
DEMONSTRATION/EVALUATION**

**PRINCIPAL INVESTIGATOR:** Kevin Mahoney, University of Maryland, College Park, MD

**PURPOSE:** This project will employ a classical experimental research design (i.e., random assignment of participants to treatment and control groups) to test the effects of "cashing out" Medicaid-funded PAS for the disabled. The demonstration will include elderly as well as younger disabled consumers. Two States are expected to participate in the demonstration. In these States, control group members will receive "traditional"

benefits--i.e., case managed home and community-based services, where payments for services are made to vendors--while treatment group members receive a monthly cash payment in an amount roughly equal to the cash value of the services they would have received under the traditional program. It is hypothesized that cash payments will foster greater client autonomy and that, as a result, consumer satisfaction will be greater. Consumers are expected to purchase a somewhat different mix of disability-related services and/or assistive technologies when they make the decisions and payments themselves than when case managers contract with vendors on their behalf. It is also hypothesized that States will save Medicaid monies (mostly in administrative expenses) from cashing out benefits. The analysis will consider the effects of the demonstration according to the varying characteristics of the consumers including age, disability, gender, family support, and other factors. The evaluation is being co-sponsored by the Robert Wood Johnson Foundation. The evaluation subcontract has been awarded to Mathematica Policy Research, Inc., in Washington, DC; Barbara Phillips is the Principal Investigator.

**PROGRESS TO DATE:** Arkansas and New York were selected from a pool of 17 States seeking to implement similar programs. These two States have received funds from the Robert Wood Johnson Foundation to carry out the demonstrations.

**CONTACT PERSON:** Pamela Doty (202-690-6172)

**COMPLETION DATE:** 2000

**REPORTS AVAILABLE:** None yet available.

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**TITLE: *FACILITATING CONSUMER-DIRECTED PERSONAL ASSISTANCE SERVICES***

**PRINCIPAL INVESTIGATOR:** Susan Flanagan, MEDSTAT Group, Lexington, MA

**PURPOSE:** This project develops approaches and solutions for implementing consumer-directed service models for the delivery of home and community-based PAS for persons with disabilities. It addresses issues arising from regulatory compliance requirements as well as issues concerning potential tort liability faced by payers, consumers, and providers of these services. Many of these issues were identified in previous research sponsored by this Office (Flanagan, 1994) and by the Retirement Research Foundation (Sabatino and Litvak, 1995). Some of the tentative solutions proposed in that research will be explored in this project. Work on the current project is divided into three main activities: (1) case studies of up to twenty programs that use a variety of "intermediaries" (and the services these intermediaries provide) will be conducted to determine how the intermediary assists consumers and their providers to comply with tax, labor law, and other regulatory requirements, as well as supplying other supportive services (e.g., training, supervision) that serve the interests of consumer-employers, public and private payers and the providers themselves; (2) meetings with Federal officials (e.g., IRS, DoL/FLSA and OSHA) to identify pertinent Federal tax and labor law and other legal requirements and to discuss clarification and

streamlining of requirements arising from tax and labor regulations affecting PAS providers and consumers; and (3) development of up to three model contracts reflecting current Federal regulatory and other requirements in clear, simple and accurate terms for the benefit of all parties to these arrangements.

**PROGRESS TO DATE:** All site visits have been completed, and a draft final report has been received and is currently being edited. The report identifies key administrative, organizational labor and tax issues that must be addressed by State program administrators as they develop consumer-directed PAS programs. The report also identifies and discusses strategies related to resolving those key issues.

**CONTACT PERSON:** Floyd Brown (202-690-6443)

**COMPLETION DATE:** March 1997

**REPORTS AVAILABLE:** None yet available.

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#### D. Other Related Reports

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1. Clark, Robert F.: *Physical and Cognitive Impairment: Do They Require Different Kinds of Help?* (1991). [NTIS] [<http://aspe.hhs.gov/daltcp/reports/physical.htm>]
2. Elliot, Robert: *Assistive Technology for the Frail Elderly: An Introduction and Overview* (December 2, 1991). [NTIS] [<http://aspe.hhs.gov/daltcp/reports/asttech.htm>]
3. Flanagan, Susan: *Consumer-Directed Attendant Services: How States Address Tax, Legal and Quality Assurance Issues* (April 28, 1994). [DALTCP]
4. Grana, John M. and Sandra M. Yamashiro: *An Evaluation of the Veterans Administration Housebound and Aid and Attendance Allowance Program* (April 15, 1987). [NTIS: Accession No. PB87-187654/AS] [<http://aspe.hhs.gov/daltcp/reports/vahbap.htm>]
5. Greene, Vernon L., Mary E. Lovely, Mark D. Miller, and Jan I. Ondrich: *Reducing Nursing Home Use Through Community Long-Term Care: An Optimization Analysis Using Data from the National Channeling Demonstration* (October 1992). [DALTCP] [<http://aspe.hhs.gov/daltcp/reports/1992/rednh.htm>]
6. Jackson, Mary E. and Brian O. Burwell: *Publicly-Financed Home Care for the Disabled Elderly: Who Would be Eligible?* (December 1990). [NTIS] [<http://aspe.hhs.gov/daltcp/reports/pubfines.htm>]
7. Jackson, Mary E. and Brian O. Burwell: *Use of Functional Criteria in Allocating Long-Term Care Benefits: What Are the Policy Implications?* (November 1989). [NTIS: Accession No. PB93-146751] [<http://aspe.hhs.gov/daltcp/reports/functnes.htm>]
8. Jackson, Mary E., Brian O. Burwell, Robert F. Clark, and Mary Harahan: "Eligibility for Publicly Financed Home Care," *American Journal of Public Health* (June 1992).
9. Kemper, Peter, Robert Applebaum, and Margaret Harrigan: *A Systematic Comparison of Community Care Demonstrations* (June 1987). [NTIS: Accession No. PB91-106948] [<http://aspe.hhs.gov/daltcp/reports/sytmates.htm>]

10. Kunkel, Suzanne R. and Robert A. Applebaum: *Estimating the Prevalence of Long-Term Disability for an Aging Society* (April 1991). [DALTCP] [<http://aspe.hhs.gov/daltcp/reports/agsoces.htm>]
11. Macro Systems, Inc.: *Review of State Quality Assurance Programs for Home Care* (April 1989). [NTIS] [<http://aspe.hhs.gov/daltcp/reports/squareves.htm>]
12. National Governors' Association: *State Long-Term Care Reform: Development of Community Care Systems in Six States* (April 1988). [NTIS] [<http://aspe.hhs.gov/daltcp/reports/strfrm.htm>]
13. Newman, Sandra, Michelle Rice, and Raymond Struyk: *Overwhelming Odds: Caregiving and the Risk of Institutionalization* (June 1987). [NTIS: Accession No. PB91-106930] [<http://aspe.hhs.gov/daltcp/reports/ovrwhles.htm>]
14. Office of Social Services Policy: *National Conference on Home Care Quality: Issues and Accountability--Conference Package* (June 1, 1988). [NTIS: Accession No. PB91-106369/AS]
15. Office of Social Services Policy: *National Conference on Home Care Quality: Issues and Accountability--Volume I Proceedings* (1989). [NTIS: Accession No. PB91-122630]
16. Phillips, Barbara R.: *A Pilot Study of the Adequacy of Post-Hospital Community Care for the Elderly* (September 13, 1989). [NTIS: Accession No. PB91-181693/AS] [<http://aspe.hhs.gov/daltcp/reports/adeqes.htm>]



## III. CHILDREN AND WORKING AGE ADULTS WITH DISABILITIES

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### A. Overview

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In 1994, DALTCP expanded its research efforts in the area of health and long-term supports for children and working age adults with disabilities. As a result of a grant announcement placed in the *Federal Register* in the spring, DALTCP funded seven grants to analyze existing data bases on various aspects of childhood disability. These projects range from an analysis of the Survey of Income and Program Participation on **Child Care and Children with Disabilities: Utilization, Costs and Family Labor Supply to Disabled Children and the AFDC and SSI Programs** to research into long-term care services, the Part H program, the use of medical services by children with disabilities, and functional disability definitions for children.

Some of DALTCP's work in other areas (e.g., health care and home and community-based services) related to children will be found in other sections of this inventory. For example, as reported in Section I on Managed Care, DALTCP is supporting an initial inquiry into managed care arrangements that provide acute care (and, if possible, long-term care, too) for children with disabilities. DALTCP is also implementing or supporting a series of projects related to non-elderly adults with disabilities. As reported in Section II on Home and Community-Based Services, for the past several years we have supported research into personal assistance services (PAS). Projects are concerned with PAS clients, workers, and case managers as well as quality concerns and client and provider satisfaction.

Another project on adults, **An Exploratory Study of Barriers and Incentives to Labor Force Participation Among Persons with Significant Disabilities**, focused on barriers faced by people with disabilities who want to work, and how incentives and long-term supports can be structured to encourage people to work. A new project, co-sponsored with the Social Security Administration, will examine **Health Care Coverage and Employment of People with Disabilities**.

### B. Completed Projects

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**TITLE:** *COMMUNITY PROGRAM SIZE AND QUALITY*

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

**PURPOSE:** Researchers and program administrators and managers debate the importance of the relationship between community residential size and quality of care for persons with developmental disabilities. This project examined this relationship;

differences in cost and among small facilities (less than ten residents) were of special interest.

**FINDINGS/RESULTS:** Results are based on data from the National Consumer Survey of Persons with mental retardation or other developmental disabilities (MR/DD) conducted by each State with a standard protocol as well as detailed analysis of two States--Connecticut and Pennsylvania. Overall, information from the National Consumer Survey indicate that generally people are more satisfied and better integrated in group homes with fewer than ten residents than in larger places. Data from the two States show that there appears to be more satisfaction in group homes with fewer than five residents. Cost data are mixed and more investigations need to be done. Larger group homes in Pennsylvania appear to cost less, while the opposite appears to be true in Connecticut.

**CONTACT PERSON:** Michele Adler, ASPE (202-690-6172)

**COMPLETION DATE:** March 1992

**REPORTS AVAILABLE:**

Conroy, James W.: *Size and Quality in Residential Programs for People with Developmental Disabilities* (February 1992). [DALTCP]

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**TITLE: *COMMUNITY SUPPORT LIVING ARRANGEMENTS***

**PRINCIPAL INVESTIGATOR:** Brian Burwell, MEDSTAT Group, Lexington, MA

**PURPOSE:** Community supported living programs are a significant departure from traditional, continuum-based, developmental models of residential services for people with developmental disabilities. Several State mental retardation service systems, as well as national policy leaders have embraced supported living approaches, recognizing them as a vehicle to translate into reality the goals of independence, integration, and productivity. The Department encouraged the growth of these models in its home and community-based waiver program and in the "community supported living arrangements" (CSLA) Medicaid State plan option.

**FINDINGS/RESULTS:** This project took a closer look at how supported living programs work, identifying strengths and weaknesses of the approach. The project provided descriptions of five established community supported living programs for people with developmental disabilities. The project identified the elements of these programs that contribute to their success. In addition, national data on the strengths and weaknesses, cost-effectiveness and extent of the use of this model were collected and analyzed. The project staff worked with experts to develop a short and long range research agenda on community supported living services. The draft policy paper describes the programs that were visited, and outlines the policy issues in this new service modality.

CONTACT PERSON: Ruth Katz, ASPE (202-690-6443)

COMPLETION DATE: August 1992

REPORTS AVAILABLE:

Burwell, Brian, Ruth Katz and Mary Ann Allard: Community Supported Living Arrangements (draft report). [DALTCP]

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**TITLE: *STUDY OF THE MEDICALLY UNINSURED, MENTAL ILLNESS AND MENTAL RETARDATION***

**PRINCIPAL INVESTIGATOR:** Mitchell LaPlante, University of California, San Francisco, CA

**PURPOSE:** The purpose of this project was to provide special studies of health and long-term care financing issues affecting nonelderly persons with disabilities, derived from nearly a decade of data from the National Health Interview Survey (NHIS).

**FINDINGS/RESULTS:** The Medically Uninsurable Study examined the number and characteristics of persons unable to obtain health insurance, because of a limitation of activity (disability) or chronic medical condition. Comparisons were also made to disabled persons with health insurance, nondisabled persons without health insurance, and the general population.

An estimated 35.3 million people under age 65 were uninsured in 1989. This included 4.1 million people with activity limitations; 547,000 children and 3.5 million adults.

CONTACT PERSON: Michele Adler, ASPE (202-690-6172)

COMPLETION DATE: March 1993

REPORTS AVAILABLE:

LaPlante, Mitchell P.: Disability, Health Insurance Coverage, and Utilization of Acute Health Services in the United States (October 1993). [Sean Sweeney, Department of Education/NIDRR/OSERS, MES 3425, 600 Independence Avenue, SW, Washington, DC 20202-2705]  
[\[http://aspe.hhs.gov/daltcp/reports/dhicies.htm\]](http://aspe.hhs.gov/daltcp/reports/dhicies.htm)

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**TITLE: *FAMILIES WITH DISABILITIES IN THE UNITED STATES***

**PRINCIPAL INVESTIGATOR:** Mitchell LaPlante, University of California, San Francisco, CA

**PURPOSE:** The purpose of the project was to determine how disability is clustered in families, the extent of clustering, and the characteristics of such families. Data came from the 1990 National Health Interview Survey.

**FINDINGS/RESULTS:** Although much research has been done on individuals with disabilities, almost none had addressed disability in families. Using a broad definition of disability (any limitation in activity), 20.3 million (29.2%) of all families have at least one disabled member. However, 13.7% of all individuals have a disability. The high family rate suggests that fewer people overall may be affected by disability (their own or a family member's) than previously expected. In general, since both disability and marriage are so highly associated with age, when one partner has a disability, the chance that the other partner also has a disability, is twice as high as expected. There are 3.4 million such families. For families with children, having a child with a disability is highly associated with poverty. Over half of single female-headed households with two or more children with disabilities are poor. The types of families which were analyzed (with and without children) included partnered families, male-headed families, and female-headed families. Characteristics included income, poverty, receipt of SSI and SSDI, race/ethnicity, education, and use of medical services.

**CONTACT PERSON:** Michele Adler, ASPE (202-690-6172)

**COMPLETION DATE:** August 1995

**REPORTS AVAILABLE:**

LaPlante, Mitchell P.: *Families with Disabilities in the United States* (September 1996). [Sean Sweeney, Department of Education/NIDRR/OSERS, MES 3425, 600 Independence Avenue, SW, Washington, DC 20202-2705]  
[\[http://aspe.hhs.gov/daltcp/reports/famdises.htm\]](http://aspe.hhs.gov/daltcp/reports/famdises.htm)

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**TITLE: *EXPLORATORY STUDY OF THE BARRIERS AND INCENTIVES TO BE ADDRESSED IN IMPROVING THE LABOR FORCE PARTICIPATION OF PEOPLE WITH DISABILITIES***

**PRINCIPAL INVESTIGATOR:** David Stapleton, Lewin-VHI, Fairfax, VA

**PURPOSE:** A growing consensus is emerging in the disability community that virtually all working age adults regardless of the severity of their disability should be assumed to be capable of work and have the opportunity to do so. The purpose of this project was to provide background information on barriers and incentives to improving the labor force participation of people with significant disabilities, particularly as related to HHS programs and policies. This exploratory study includes a concise review and synthesis of existing research on factors related to labor force participation by persons with disabilities and four analytical studies on special issues related to employment by persons with significant disabilities including: (1) the impact of disability on welfare reform strategies; (2) the role of PAS in the employability of persons with significant disabilities; (3) the use of assistive devices in increasing employment opportunities; and (4) comprehensive approaches and program models designed to coordinate or integrate the economic, health, vocational, and continuing support needs of working persons with significant disabilities.

**FINDINGS/RESULTS:** The chapters of the report delineate the conceptual framework within which the research literature on labor force participation by people with disabilities is reviewed; review, in detail, the literature on the labor market for people with disabilities spelling out the strengths and limitations of each study; provide what information there is about the use of PAS and assistive technology by workers with disabilities; consider how welfare reform strategies affect people with disabilities by reviewing research literature and reporting on interviews with administrators of welfare programs; and describes four comprehensive employment-oriented services for people with disabilities. The report ends with numerous recommendations for further research on each of these topics. The results of the study are available in a summary as well as a full-length (300 page) report.

**CONTACT PERSON:** Kathleen Bond, ASPE (202-690-6443)

**COMPLETION DATE:** June 1995

**REPORTS AVAILABLE:**

Stapleton, David, Lisa Alecxih, Burt Barnow, Kevin Coleman, Gina Livermore, Gilbert L, Steve Lutsky, and Andrea Zeuschner: *An Exploratory Study of Barriers and Incentives to Improving Labor Force Participation Among Persons with Significant Disabilities* (June 30, 1995). [DALTCP]  
[\[http://aspe.hhs.gov/daltcp/reports/explores.htm\]](http://aspe.hhs.gov/daltcp/reports/explores.htm)

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**TITLE: CHILDREN'S DISABILITY RESEARCH ISSUES**

**PRINCIPAL INVESTIGATOR:** Charles Johnson, Texas Engineering Experiment Station, College Station, TX

**PURPOSE:** This project examined the costs, incentives, and outcomes for families, communities, and government for institutional care versus community care for children with disabilities. This study is based on data from a 1995 telephone survey of parents of medically fragile children in Texas. The study compared 197 medically fragile children under 21 in Texas nursing facilities, 576 medically fragile children receiving services at home through the Medically Dependent Children Program (MDCP), and 529 children on the MDCP waiting list (approximately 85% of children on the waiting list are eventually found to qualify for the MDCP program). Children in the MDCP program require at least four hours of skilled nursing care per week.

**FINDINGS/RESULTS:** Study findings include the following: Families of medically fragile children with health insurance, either public or private, enjoy relatively comprehensive coverage while the uninsured have greater difficulty getting treatment. The majority of uninsured children have problems finding a pediatrician or other doctor to treat their special needs. Half of Medicaid recipients have a difficult time finding doctors to accept Medicaid payments. Children with private insurance are least likely to have trouble finding providers. Compared to the other two insurance groups, Medicaid recipients were more likely to report that services were well coordinated. However, parents providing in-home care were significantly more likely to view the service system as

complex compared to those with children in nursing facilities. Families of uninsured children are more likely to delay care until high-cost emergency services are required. The majority of parents surveyed were pleased with their child's care, however, those with medically fragile children at home were significantly less likely to be "extremely" satisfied compared to those with children in institutions. Private insurance companies are much more likely to finance some of the costs of care if children remain in the community. Parents expressed a need for more information when faced with decisions about where to provide care: more information about available programs and services; how to meet qualifying criteria; how to get needed equipment; where to go for support groups or training. Parents also reported the need for various services including respite, home modification, and equipment.

**CONTACT PERSON:** Kathleen Bond, ASPE (202-690-6443)

**COMPLETION DATE:** March 1996

**REPORTS AVAILABLE:**

Carmichael, Dottie J., Dena Stoner, and Cheryl B. Silver: *Health Policy for Medically Fragile Children: An Analysis of Factors Impacting Care in Texas* (March 1996). [DALTCP] [<http://aspe.hhs.gov/daltcp/reports/txfrages.htm>]

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**TITLE: *DISABLED CHILDREN AND THE AFDC AND SSI PROGRAMS***

**PRINCIPAL INVESTIGATOR:** Marcia Meyers, Syracuse University, Syracuse, NY

**PURPOSE:** This project examined the interaction of children with disabilities and public assistance programs, specifically: (1) factors responsible for the rapid growth in the SSI rolls especially transitions from AFDC to SSI; (2) impact of care for a disabled child on the labor force participation, welfare receipt and earnings in AFDC families; and (3) additional costs for low income families with disabled children. The data base for this study was Wave II of the California AFDC Household Survey, a stratified random sample of 15,000 recipient households selected from four counties in November 1992. The project analyzed information from the first 1,320 households randomly selected from the larger survey.

**FINDINGS/RESULTS:** Among the study's findings are the following: Over 40% of households had either a disabled mother or at least one child with special needs--30% of the mothers indicated that they had a physical or mental disability which limited their ability to work; 21% report the presence of at least one child with a chronic health problem or disability. Respiratory diseases, especially asthma, were the most common chronic condition for children in AFDC, affecting 5.7% of children. Behavior and learning problems together formed the next most common category (2%); 0.7% were affected by other chronic diseases or physical impairments. In terms of severity, most conditions were mild to moderate; however, 44% of children's conditions were severe because the child required substantial help with daily activities, the condition interfered with the child's attendance at school, or the child received SSI. Eleven percent of all families cared for at least one child with a severe disability or illness; 7% of families

received SSI for their children. Five percent of families were caring for more than one child with chronic conditions. Half of the families with one or more special needs children had average out-of-pocket expenses related to the child(ren)'s needs in the previous month. Expenses averaged approximately \$131 with a range from \$6.00 to \$665. Expenditures were for medical care and medications that were not covered by insurance, special child care arrangements, and special food and diets. Mothers of special needs children were less likely to be working. Three-quarters of the families who received SSI still had incomes at or below 125% of poverty.

**CONTACT PERSON:** Michele Adler, ASPE (202-690-6172)

**COMPLETION DATE:** April 1996

**REPORTS AVAILABLE:**

Meyers, Marcia K., Anna Lukemeyer, and Timothy M. Smeeding: *Work, Welfare, and the Burden of Disability: Caring for Special Needs of Children in Poor Families* (April 1996). [DALTCP] [<http://aspe.hhs.gov/daltcp/reports/wrkwlfes.htm>]

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**TITLE: IDENTIFYING THE SERVICES, COSTS, AND REIMBURSEMENTS FOR YOUNG CHILDREN WITH DISABILITIES THROUGH DATA COLLECTED BY THE TENNESSEE PART H IDEA PROGRAM**

**PRINCIPAL INVESTIGATOR:** Mark Wolraich, Vanderbilt University School of Medicine, Nashville, TN

**PURPOSE:** The goal of this project was to better identify what services are provided children under age 3 with severe disabilities, how the services are financed, and how diagnosis, socio-economic status, place of residence and other factors determine receipt of services. Data come from a statewide data system of The Early Intervention System (TEIS) and data of its nine regional offices. Data were available for two fiscal years 1992-93 and 1993-94. The fact that Tennessee has enacted a statewide health reform using managed care is an important context for the study. Data analyses will address the following questions: (1) service utilization of children with disabilities; (2) service mix; (3) costs for services; (4) service combinations and related outcomes; (5) reimbursement patterns; and (6) the influence of managed care on reimbursement patterns.

**FINDINGS/RESULTS:** Findings from the study include the following: Tennessee administers the Part H program through nine district offices staffed by professionals from among early childhood education, clinical psychology, occupational therapy, speech/language therapy, pediatrics, and early childhood development. Each office has service coordinators who make family visits, help obtain evaluations, help families determine eligibility for various programs, help identify appropriate services, organize IFSP meetings, develop IFSPs, and help monitor services. The project reviewed 550 case files. Of the sample chosen, 20% were diagnosed with congenital defects such as Down's Syndrome, cerebral palsy, spina bifida, and other congenital conditions. Forty-one percent were diagnosed with developmental delays including delays in speech,

language, or feeding; autism; and other delays. Twenty percent were diagnosed with prematurity. Boys were more prevalent than girls in all categories. The majority of children with congenital defects and prematurity were taken into the program before age 18 months while the majority of those with developmental delays were taken in at age 2 years and older.

**CONTACT PERSON:** Kathleen Bond, ASPE (202-690-6443)

**COMPLETION DATE:** April 1996

**REPORTS AVAILABLE:**

Wolraich, Mark L., E. Michael Foster, Sara C. Willis, and Lynne M. Cushing:  
*Identifying the Services, Costs, and Reimbursement for Young Children with Disabilities Through Data Collected by Tennessee Part H IDEA Program* (April 1996). [DALTCP] [<http://aspe.hhs.gov/daltcp/reports/tnprthes.htm>]

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**TITLE: SERVICE UTILIZATION AND THE INDIVIDUAL, FAMILY AND NEIGHBORHOOD CHARACTERISTICS OF CHILDREN WITH DISABILITIES IN ILLINOIS**

**PRINCIPAL INVESTIGATOR:** Robert Goerge, University of Chicago, Chicago, IL

**PURPOSE:** The objective of this project was to describe demographic and socio-economic characteristics and services for all children and adolescents who are identified as having a disability in Illinois, as well as to understand the stability of the care that they receive through childhood and adolescence. Specifically, their goals were to: (1) describe the trends in demographic characteristics of the disabled child population in Illinois; (2) examine the extent to which socioeconomic characteristics are related to children's disabilities; (3) describe the pattern of multi-service use of disabled children; (4) describe the pattern of movement and stability of care of disabled children across different service settings; (5) demonstrate the utility of administrative data for advancing the state of knowledge of children with disabilities; and (6) determine the policy implications of these findings. The project follows both birth cohorts and cohorts of children with newly identified handicaps from the late 1980s through the present. This project also studies the population of disabled children and youth for each year from 1987 to 1994. The children will be tracked using the Integrated Database on Children's Services in Illinois.

**FINDINGS/RESULTS:** The study is based on an integrated database on all children in Illinois identified as having a disability by the Department of Public Aid, the State Board of Education, the Department of Mental Health and Developmental Disabilities, and Medicaid reimbursement files between 1989 and 1994. Some of the major findings include the following: the overall number of children identified as being disabled increased by 7% between FY 1990 and FY 1994. In FY 1994, 8% of all children in Illinois were identified as disabled from the combination of data sources. The number of children receiving SSI increased from 12,184 in FY 1990 to 43,941 in FY 1994. The percentage of SSI children in special education decreased from 51% to 42% between



FY 1990 and FY 1994. In each fiscal year, the majority of the children participating in both special education and SSI were mentally retarded. Over time, learning disabled and severely emotionally disturbed children were increasingly likely to participate in SSI and special education at the same time. In FY 1994, the majority of children participating in Medicaid reimbursed services and either special education or SSI were being treated for mental disorders. In each of the fiscal years, boys were more likely than girls to have been identified as disabled.

**CONTACT PERSON:** Kathleen Bond, ASPE (202-690-6613)

**COMPLETION DATE:** April 1996

**REPORTS AVAILABLE:**

Goerge, Robert, Lucy Mackey-Bilaver, Bong Joo Lee, David Koepke, and Allison Harris: *Service Utilization and the Individual, Family, and Neighborhood Characteristics of Children with Disabilities in Illinois* (September 30, 1996). [DALTCP] [<http://aspe.hhs.gov/daltcp/reports/ilseruti.htm>]

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**TITLE: *USE OF MEDICAL SERVICES BY CHRONICALLY ILL CHILDREN IN THE MEDICAID PROGRAM***

**PRINCIPAL INVESTIGATOR:** Gerard Anderson, Johns Hopkins University, Baltimore, MD

**PURPOSE:** The goal of the project was to know more about rates of services use (especially the use of case management services), costs, or patterns of services received over time for children receiving SSI benefits compared to children with similar conditions who are not receiving SSI payments. The project seeks to examine the use and cost of medical services for approximately 30,000 children with serious ongoing physical health conditions under age 18 enrolled in the Washington State Medicaid program who had a medical encounter in 1992 or 1993. The project intended to describe: (1) number and type of encounters and services received over a two year period; (2) actual costs of these services; and (3) longitudinal patterns of services received. Data are presented for children with and without chronic conditions and by age, gender, racial and eligibility categories (e.g., SSI, AFDC).

**FINDINGS/RESULTS:** This study is based on 1993 Medicaid claims data from the Washington State Medical Assistance program for all children 18 and under. The study focused on children with at least one of ten chronic conditions--asthma, chronic respiratory disease, cerebral palsy, epilepsy, cancer, diabetes, mental retardation, muscular dystrophy, spina bifida, and cystic fibrosis. Data from the study can be used to plan health care services. Findings from the study include the following: 8% of the total sample of children were identified as having at least one of the conditions. They represent 34% of the total expenditures. Average costs per child with the selected conditions ranged from approximately \$3,000 to \$37,000, depending on the condition. Asthma had the second lowest mean cost among the conditions, but accounted for the highest total expenditure because of its significantly higher prevalence (46/1000

compared to 4.2/1000 for diabetes, for instance). The average cost per child who had at least one of these conditions is over six times greater than the average cost per children without one of the conditions. Payments for home health care ranged from 4.4 to 116 times higher for chronically ill children than payments for the average child.

**CONTACT PERSON:** Kathleen Bond, ASPE (202-690-6613)

**COMPLETION DATE:** April 1990

**REPORTS AVAILABLE:**

Ireys, Henry T., et al.: *Cost of Care for Medicaid-Enrolled Children with Selected Disabilities* (draft paper, May 1996). [DALTCP]  
[\[http://aspe.hhs.gov/daltcp/reports/carcstes.htm\]](http://aspe.hhs.gov/daltcp/reports/carcstes.htm)

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**TITLE: ASSESSMENT OF THE POLICY IMPLICATIONS OF ALTERNATIVE FUNCTIONAL DEFINITIONS OF DISABILITY FOR CHILDREN**

**PRINCIPAL INVESTIGATOR:** Ruth Stein, Albert Einstein College of Medicine, Brooklyn, NY

**PURPOSE:** There is no simple way to define and identify children with disabilities. Different ways of identification for program purposes can lead to vast differences in how many and which children are identified. Three different ways of measuring functional disability were used in three data sets. The three different measures were: (1) functional measures based on the children's section of the 1994/96 National Health Interview Survey on Disability; (2) compensatory dependency or accommodations (i.e., dependency on medications, special diet, technology, assistive devices, and personal assistance); and (3) service use beyond routine care (medical, educational, psychological, related services above the usual given the child's age, need). The three data sets included: (1) a telephone survey of 1,200 children in the Bronx; (2) a telephone survey of a national sample of 1,350 children; and (3) a sample of 1,200 children in Arizona.

**FINDINGS/RESULTS:** Report is forthcoming.

**CONTACT PERSON:** Michele Adler, ASPE (202-690-6172)

**COMPLETION DATE:** June 1996

**REPORTS AVAILABLE:** None yet available.

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**TITLE: CHILD CARE AND CHILDREN WITH DISABILITIES: UTILIZATION, COSTS, AND FAMILY LABOR SUPPLY**

**PRINCIPAL INVESTIGATOR:** Peter Brandon, University of Wisconsin, Madison, WI

**PURPOSE:** This project involved analysis of the Survey of Income and Program Participation (SIPP) data to examine the child care needs of families with children with

disabilities. There is little research to substantiate claims that child care costs prohibit some parents from working and that child care alternatives are not available for children with disabilities. The objectives of this study were to: provide the first national estimates on the incidence of nonparental child care arrangements for children with disabilities; investigate whether children with disabilities receive the same type of child care as children without disabilities; analyze how the costs of specialized child care for children with disabilities affect the labor force participation of parents; and, estimate the differences in child care costs for children with and without disabilities.

**FINDINGS/RESULTS:** Report is forthcoming.

*CONTACT PERSON:* Michele Adler, ASPE (202-690-6172)

*COMPLETION DATE:* June 1996

*REPORTS AVAILABLE:* None yet available.

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### **C. Ongoing/Planned Projects**

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**TITLE:** ***EXPLORATORY STUDY OF HEALTH CARE COVERAGE AND THE EMPLOYMENT OF PEOPLE WITH DISABILITIES***

*PRINCIPAL INVESTIGATOR:* David Stapleton, The Lewin Group, Fairfax, VA

**PURPOSE:** The purpose of this project is to review and analyze available information on how health insurance coverage and the particular provisions of health care policies are related to employment by people with disabilities. The review will consist of an examination of the available research literature on the relationship of health care coverage and employment among people with disabilities; the analysis of any additional information from States which extend health care coverage to people with disabilities through employer mandates or other provisions; an examination of employment rates and patterns among recipients of Veterans Administration disability benefits, and any other relevant available data such as national survey data

**PROGRESS TO DATE:** Various information is being located and analyzed, and a meeting of a Technical Advisory Group is planned for January 1997.

*CONTACT PERSON:* Kathleen Bond, ASPE (202-690-6443)

*COMPLETION DATE:* June 1997

*REPORTS AVAILABLE:* None yet available.

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**TITLE:** ***THE ROLE OF HOME AND COMMUNITY-BASED SERVICES IN MEETING THE HEALTH CARE NEEDS OF PEOPLE WITH HIV/AIDS***

*PRINCIPAL INVESTIGATOR:* Jennifer Schore, Mathematica Policy Research, Inc., Princeton, NJ

**PURPOSE:** The purpose of this project is to consider the long-term care needs of people with HIV/AIDS (PWAs) and efficient and effective approaches for financing, organizing, and delivering long-term care services to this population. Specifically, the project will consider the appropriate role of home and community-based services (HCBS) in meeting the health care needs of PWAs in an effective and efficient manner, the estimated demand for HCBS and factors likely to influence demand, and the strengths and limitations of various approaches to organizing, paying for, and delivering HCBS services to PWAs. The project includes two major components: (1) 5-7 case studies of community-based HIV/AIDS programs providing HCBS and (2) analysis of data on health care service use and expenditures of PWAs enrolled in Medicaid in Maryland and New Jersey, which maintain statewide Medicaid data bases that are linked to HIV/AIDS registries.

**PROGRESS TO DATE:** A literature review has been received and is presently being reviewed.

**CONTACT PERSON:** Gavin Kennedy, ASPE (202-690-6443)

**COMPLETION DATE:** September 1997

**REPORTS AVAILABLE:**

Schoff, Jennifer, and Jennifer Schore: *The Role of Home and Community-Based Services in Meeting the Health Care Needs of People with AIDS: Literature Review* (January 17, 1997). [DALTCP]  
[\[http://aspe.hhs.gov/daltcp/reports/aidslit.htm\]](http://aspe.hhs.gov/daltcp/reports/aidslit.htm)

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#### **D. Other Related Reports**

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1. Adler, Michele: "Federal Disability Programs," *Encyclopedia of Financial Gerontology*, (1996). [ ] [\[http://aspe.hhs.gov/daltcp/reports/encyclo.htm\]](http://aspe.hhs.gov/daltcp/reports/encyclo.htm)
2. Adler, Michele: *Health and Disability Status of AFDC Families* (1988). [NTIS] [\[http://aspe.hhs.gov/daltcp/reports/afdc.htm\]](http://aspe.hhs.gov/daltcp/reports/afdc.htm)
3. Alder, Michele: *Programmatic Definitions of Disability: Policy Implications* (1991). [NTIS] [\[http://aspe.hhs.gov/daltcp/reports/prodefes.htm\]](http://aspe.hhs.gov/daltcp/reports/prodefes.htm)
4. Adler, Michele: *The Disabled: Their Health Care and Health Insurance* (August 1990). [NTIS] [\[http://aspe.hhs.gov/daltcp/reports/disabled.htm\]](http://aspe.hhs.gov/daltcp/reports/disabled.htm)
5. Burwell, Brian O.: *Federal Programs for Persons with Disabilities (Task II)* (January 1990). [DALTCP] [\[http://aspe.hhs.gov/daltcp/reports/task2es.htm\]](http://aspe.hhs.gov/daltcp/reports/task2es.htm)
6. Burwell, Brian, Elicia Herz, and John Drabek: *Variations in the Medicaid Safety Net for Children and Youth with High Medical Costs: A Comparison of Four States* (November 1990). [NTIS] [\[http://aspe.hhs.gov/daltcp/reports/4stvares.htm\]](http://aspe.hhs.gov/daltcp/reports/4stvares.htm)
7. Doyle, Pat: *Population Profile of Disability (Task I)* (October 1989). [DALTCP] [\[http://aspe.hhs.gov/daltcp/reports/task1es.htm\]](http://aspe.hhs.gov/daltcp/reports/task1es.htm)
8. Ku, Leighton: *Who is Paying the Big Bills? Very High Cost Pediatric Hospitalizations in California, 1987* (August 1990). [NTIS] [\[http://aspe.hhs.gov/daltcp/reports/bigblles.htm\]](http://aspe.hhs.gov/daltcp/reports/bigblles.htm)

9. Martini, Alberto: *A Labor Force Profile of Persons with Disabilities (Task IV)* (March 19, 1990). [DALTCP] [<http://aspe.hhs.gov/daltcp/reports/task4es.htm>]
10. Miller, Esther and Jim Sears: *Program Participation Patterns Among Persons with Disabilities (Task III)* (May 10, 1990). [DALTCP] [<http://aspe.hhs.gov/daltcp/reports/1990/task3.htm>]
11. Rymer Ellwood, Marilyn and Elicia Herz: *Longitudinal Analysis of High Cost Medicaid Children in California* (October 1990). [NTIS] [<http://aspe.hhs.gov/daltcp/reports/cahcmces.htm>]
12. Rymer Ellwood, Marilyn: *SSI-Related Disabled Children and Medicaid* (June 1990). [NTIS] [<http://aspe.hhs.gov/daltcp/reports/ssireles.htm>]
13. Rymer Ellwood, Marilyn: *Summary and Policy Implications: Analyses of Medicaid Financing for Disabled or High Cost Children* (December 1990). [NTIS] [<http://aspe.hhs.gov/daltcp/reports/hghcstes.htm>]
14. Weissert, William G., Jennifer M. Elston, and Gary G. Koch: *Risk of Institutionalization: 1977-1985* (July 24, 1990). [NTIS] [<http://aspe.hhs.gov/daltcp/reports/instrkes.htm>]

## IV. RESIDENTIAL CARE SETTINGS

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### A. Overview

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Overwhelmingly, the frail elderly prefer to remain in their own homes rather than moving to a nursing home. However, in many cases, they are unable to receive the needed support in their own homes yet do not require skilled nursing in an institutional setting. As a consequence, community-based residential care models have emerged as a significant long-term care option. Residential care models are designed to enable the frail elderly and other persons with disabilities to receive personal care and other supportive services in a homelike environment. Over the past decade, DALTCP has been examining systematically various residential care models from a variety of perspectives. This body of research provides insight into the role of residential care models in the long-term care system; the appropriateness of such care arrangements for subgroups of the frail elderly population; and the quality, costs, and financing of care in residential care facilities.

One prominent residential care model is board and care. In 1991, ASPE funding was used to augment the **National Health Provider Inventory (NHPI)**, sponsored by the National Center for Health Statistics. The 1991 NHPI was used to develop a national inventory of nursing homes, home health agencies, and hospices. ASPE funds made possible for the first time the inclusion of licensed board and care homes in the inventory. As a result, there are now basic national data on the number and characteristics of licensed board and care homes as well as the characteristics of their resident populations.

ASPE also sponsored a landmark **Analysis and Comparison of State Board and Care Regulations and the Effect of Regulation on the Quality of Care in Board and Care Homes**. The project described the characteristics of the board and care industry in ten States and examined the quality of care in board and care homes, how it varies across States and between licensed and unlicensed homes, and the role of regulation in affecting quality of care outcomes.

Assisted living has grown in popularity as a residential care model. In 1991, ASPE sponsored a **Policy Synthesis on Assisted Living for the Frail Elderly**, a review of the literature on a range of policy-relevant topics in assisted living (e.g., size and growth of the industry, public and private financing, role of regulation). More recently ASPE commissioned a **National Study of Assisted Living**, which will analyze the role of assisted living from the perspective of consumers, owners and operators, workers, regulators, investors, and other stakeholders.

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## B. Completed Projects

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**TITLE: *POLICY SYNTHESIS ON ASSISTED LIVING***

**PRINCIPAL INVESTIGATOR:** Barbara B. Manard, Lewin-VHI, Inc., Fairfax, VA

**PURPOSE:** The purpose of the project was to: (1) examine the range of housing and service options available to the frail elderly; (2) identify critical public policy issues in the financing, delivery, and appropriateness of supportive housing alternatives; and (3) assist ASPE in developing a policy-relevant research agenda in supportive housing. The report identifies a series of policy-relevant questions on public and private financing of assisted living, regulatory concerns, quality of care and appropriateness for special populations; e.g., persons with Alzheimer's Disease or related dementias.

**FINDINGS/RESULTS:** Eligibility for assisted living is based on three factors: age, income and functional capacity. Important outcomes for assisted living include life satisfaction, nursing home placement, functional capacity and caregiver satisfaction. Public programs have played a limited role in financing the development of assisted living but this has begun to change in a number of States. The report lays out an agenda for further data collection and research in assisted living.

**CONTACT PERSON:** Robert Clark, ASPE (202-690-6443)

**COMPLETION DATE:** September 1992

**REPORTS AVAILABLE:**

Manard, Barbara, William Altman, Nancy Bray, Lisa Kane, and Andrea Zeuschner:  
*Policy Synthesis on Assisted Living for the Frail Elderly* (December 16, 1992).  
[DALTCP] [<http://aspe.hhs.gov/daltcp/reports/polsynes.htm>]

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**TITLE: *ANALYSIS AND COMPARISON OF STATE BOARD AND CARE REGULATIONS AND THEIR EFFECT ON THE QUALITY OF CARE IN BOARD AND CARE HOMES***

**PRINCIPAL INVESTIGATOR:** Catherine Hawes, Research Triangle Institute,  
Research Triangle, NC

**PURPOSE:** The primary objectives of this project were: (1) to determine the quality of care in board and care homes, and how it varies across States and programs and between licensed and unlicensed homes, and (2) to examine the effect of State regulations on the quality of care in board and care homes. To accomplish these objectives the project: (1) identified and examined the factors associated with differences in quality, with particular emphasis on the effect of regulation; (2) described generally the regulatory systems in 50 States and described in detail the systems in the ten study States; (3) described the key characteristics of the board and care industry in the study sample--the homes, the owners/operators, the staff, the residents, and the care and services that residents receive; and (4) compared the performance of licensed

and unlicensed board and care homes. Data were collected from 600 board and care homes, including 600 operators and 900 staff, and from 3,780 residents.

**FINDINGS/RESULTS:** The study found that board and care residents are significantly older and more frail than was true a decade ago. The mix of physically frail and cognitively impaired elderly, and residents with mental illness and developmental disabilities presents a complex caregiving challenge. The study found several factors that suggest that appropriate regulations and licensure requirements result in homes that are better prepared to cope with this challenge. These include: (1) greater availability of supportive services in licensed homes; (2) greater operator training in the care of the elderly and disabled; and (3) lower use of psychotropic drugs and medications contraindicated for use in the elderly in homes in extensively regulated States. The study also found that licensed homes were more likely to have in place a wider array of the safety features and supportive devices considered important to the well-being of residents.

The project also describes the utilization of Medicare services by this population, and models Medicare use and costs as a function of resident, facility, and regional characteristics. The research also compared the use of specific Medicare services by the board and care population with the use of these services among a nursing home population. This portion of the research will use data on approximately 1,300 board and care residents in ten States and 2,000 nursing home residents in ten States.

**CONTACT PERSON:** Floyd Brown, ASPE (202-690-6443)

**COMPLETION DATE:** October 1995

**REPORTS AVAILABLE:**

Hawes, Catherine, Vincent Mor, Judith Wildfire, Vince Iannacchione, Linda Lux, Rebecca Green, Angela Greene, Victoria Wilcox, Diana Spore, and Charles D. Phillips: *Executive Summary: Analysis of the Effect of Regulation on the Quality of Care in Board and Care Homes* (July 10, 1995). [DALTCP] [<http://aspe.hhs.gov/daltcp/reports/care.htm>]

Hawes, Catherine, Judith Wildfire, Vince Iannacchione, Linda Lux, Angela Greene, Vincent Mor, and Linda Laliberte: *Report on Study Methods: Analysis of the Effect of Regulation on the Quality of Care in Board and Care Homes* (January 19, 1996). [DALTCP] [<http://aspe.hhs.gov/daltcp/reports/stumthes.htm>]

Hawes, Catherine, Judith Wildfire, Vincent Mor, Victoria Wilcox, Diana Spore, Vince Iannacchione, Linda Lux, Rebecca Green, Angela Greene, and Charles D. Phillips: *A Description of Board and Care Facilities, Operators, and Residents* (December 1995). [DALTCP] [<http://aspe.hhs.gov/daltcp/reports/bcdescs.htm>]

Phillips, Charles, Judith Wildfire, Catherine Hawes, Vince Iannacchione, Rebecca Green, Linda Lux, Angela Green, George Dunteman, Vincent Mor, and Diana Spore: *Report on the Effects of Regulation on Quality of Care: Analysis of the Effect of Regulation on the Quality of Care in Board and Care Homes* (December 1995). [DALTCP] [<http://aspe.hhs.gov/daltcp/reports/b&crpt.htm>]



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### C. Ongoing/Planned Projects

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**TITLE: ASSISTED LIVING: DESCRIPTION, QUALITY AND STANDARDS**

**PROJECT DIRECTOR:** Catherine Hawes, Research Triangle Institute, Research Triangle, NC

**PRINCIPAL INVESTIGATORS:** Rosalie A. Kane, University of Minnesota, Minneapolis, MN  
Barbara B. Manard, Lewin-VHI, Inc., Fairfax, VA

**PURPOSE:** “Assisted living” refers to residential settings for people with disabilities which combine both housing and personal assistance services within a homelike or noninstitutional environment. The number of assisted facilities nationally is not known; estimates range from 8,000 to 30,000. Similarly, estimates for the number of frail elderly and other persons residing in such facilities range from 350,000 to 1,000,000. This study will, among other things, generate a more reliable estimate of the number of these facilities and their residents. As assisted living options multiply, a challenge facing the Federal and State Governments is how to regulate such arrangements, balancing consumer protection concerns (especially if public funds reimburse costs) with resident rights for self-direction, taking risks and maintaining accustomed lifestyles.

The major purpose of this project is to analyze the role of assisted living within the current long-term care system from the perspective of consumers, owners/operators, workers, regulators, investors and other stakeholders, and to issue a report on its current status and future directions. The study will address several broad policy-relevant issues, including supply and demand trends; barriers; how closely practice parallels philosophy; the impact of key features on outcomes; and quality and accountability. The contractor will assist HHS and other Federal agencies in the formulation of regulatory and financing policy options for assisted living. A Technical Advisory Group has been established to provide guidance to the contractor.

**CONTACT PERSON:** Robert Clark, ASPE (202-690-6443)

**COMPLETION DATE:** 1997

**REPORTS AVAILABLE:**

Lewin-VHI, Inc.: *National Study of Assisted Living for the Frail Elderly: Literature Review Update* (February 1996). [ ] [<http://aspe.hhs.gov/daltcp/reports/litrev.htm>]

Mollica, Robert L., and Kimberly Irwin Snow: *State Assisted Living Policy: 1996* (November 1996). [ ] [<http://aspe.hhs.gov/daltcp/reports/96states.htm>]

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### D. Other Related Reports

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1. Mollica, Robert L.: *Assisted Living Policy and Regulation: State Survey* (April 1995). [DALTCP] [<http://aspe.hhs.gov/daltcp/reports/stasvyes.htm>]

## V. FINANCING/MODELING

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### A. Overview

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Long-term care financing issues and the modeling of long-term care expenditures remain a key component of ASPE's long-term care research agenda. A major contribution to our cost estimating capacity is the **Long-Term Care Financing Model** which uses national survey data to simulate the utilization and financing of long-term care services by the elderly--both nursing home and home care--through the year 2020. The model is being updated to incorporate the results of recent surveys of disability, nursing home and home care utilization. Economic assumptions are being updated and the projection will extend to 2030.

Other projects have considered how Medicaid pays for long-term care services including the extent to which **Medicaid asset spend-down** occurs and the effects of **catastrophic acute and long-term care costs**. One analyzes data on use of nursing homes in Florida. Although many people enter nursing homes, eventually spend-down their assets, and become eligible for Medicaid, it is difficult to accurately estimate how often this occurs using existing data sets. Because some elderly people enter nursing homes more than once, it is essential to have longitudinal data over many years to study their lifetime financing pattern. The Florida Nursing Home Reporting System has such data available for analysis. These data will be merged with Medicare and Medicaid data which will permit studies of the combined burden of acute and long-term care financing.

New efforts are underway to estimate the impact of various reforms on children with disabilities and the working age disabled population. Another new project, **Health and Long-Term Care Expenditure Patterns of Children with Disabilities**, is examining two large claims data sets to gather information on the number of children with disabilities and their service use and expenditures.

How private long-term care insurance plays a part in the financing of long-term care is the focus of other projects. As of 1995, over 3.5 million private long-term care insurance policies have been sold and sales have increased, on average, about 20% each year for the past ten years. Most experts agree that long-term care insurance products must include both nursing home and home care if they are to be commercially acceptable. One new study, **Assessment of Home Care Benefits Used by Holders of Private Long-Term Care Insurance**, will collect detailed information on the experience of long-term care policy holders who have filed insurance claims to receive home care benefits and how their formal and informal service use compares to a comparable population of elderly persons without private insurance. A related project will organize a small seminar involving the Federal Office of Personnel Management and other Federal officials and selected State personnel who have implemented a

public long-term care benefit for State employees. To encourage the formation of a Federal planning process to explore adding long-term care benefits to the Federal employees insurance plan or the Federal retirement program.

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## **B. Completed Projects**

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**TITLE: CONSUMER PROTECTION AND PRIVATE LONG-TERM CARE INSURANCE**

**PRINCIPAL INVESTIGATOR:** David Kennell, Lewin-VHI, Inc., Fairfax, VA

**PURPOSE:** This paper reviews the current status of consumer protection issues associated with private long-term care insurance. It examines possible roles that the Federal Government might play in this area. The views of a panel of experts drawn from government, industry, academia, and consumer organizations are reported.

**FINDINGS/RESULTS:** The panel concluded that the Federal Government could make an important contribution by educating consumers about long-term care insurance and related issues. Clarifying the tax status of these products, collecting better data on the risk of long-term care, and expanding the capabilities of State insurance departments would also help. The panel did not reach consensus on whether certain specific features should be required on all policies; e.g., inflation protection and nonforfeiture benefits. These issues have been under review by the National Association of Insurance Commissioners Long-Term Care Task Force.

**CONTACT PERSON:** John Drabek, ASPE (202-690-6173)

**COMPLETION DATE:** February 1992

**REPORTS AVAILABLE:**

Alecxi, Lisa and David Kennell: *The Federal Role in Consumer Protection and Regulation of Long-Term Care Insurance* (June 1991). [NTIS]  
[\[http://aspe.hhs.gov/daltcp/reports/fedrole.htm\]](http://aspe.hhs.gov/daltcp/reports/fedrole.htm)

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**TITLE: LONG-TERM CARE FINANCING POLICY REVIEW**

**PRINCIPAL INVESTIGATOR:** Brian Burwell, MEDSTAT Group, Lexington, MA

**PURPOSE:** In cooperation with the MEDSTAT Group, the Office produced five monographs which review what we have learned about key long-term care problems and issues.

**FINDINGS/RESULTS:** A summary report, *An Analysis of Long-Term Care Reform Proposals*, assesses the strengths and weaknesses of the current system, and critically analyzes various reforms which have been proposed. Data on the numbers of disabled elderly and their use of nursing and home care services are presented in *The Disabled Elderly and Their Use of Long-Term Care*. The current status of the public long-term

care system is discussed in Federal and State Roles in the Financing of Long-Term Care Services. Recent developments in private long-term care insurance are presented in The Emergence of Private Long-Term Care Insurance. Finally, the affordability of long-term care services and of private long-term care insurance policies are analyzed in The Economic Impact of Long-Term Care on Individuals. This report also contains projections of future expenditures for long-term care services.

CONTACT PERSON: John Drabek, ASPE (202-690-6172)

COMPLETION DATE: 1992

REPORTS AVAILABLE:

Burwell, Brian, Mary Harahan, David Kennell, John Drabek, and Lisa Alecxih: An Analysis of Long-Term Care Reform Proposals (February 1993). [DALTCP]

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

The Disabled Elderly and Their Use of Long-Term Care

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

Federal and State Roles in the Financing of Long-Term Care Services

The Emergence of Private Long-Term Care Insurance

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

The Economic Impact of Long-Term Care on Individuals

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

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**TITLE: LONG-TERM CARE MICROSIMULATIONS MODEL**

**PRINCIPAL INVESTIGATOR:** David Kennell, Lewin-VHI, Inc., Fairfax, VA

**PURPOSE:** ASPE uses the Brookings/ICF Long-Term Care Financing Model to simulate the utilization and costs of nursing home and home care by impaired elderly persons for the period 1986-2020. The model has been updated to include the results of the 1984 National Long-Term Care Survey and the 1985 National Nursing Home Survey. The long-term care model begins with a nationally-representative sample of the adult population generated from the pension and retirement income model (PRISM) developed by ICF, Inc. These data include age, sex, marital status, labor force participation, income, assets, and other characteristics. The model then simulates changes in the population each year, including changes in each individual's economic status, disability status, utilization of long-term care, and methods of paying for care.

**FINDINGS/RESULTS:** Two reports developed from this project describe the model and the simulations which have been performed with it. Model Assumptions provides pertinent details about the variables, data, and equations on which the model is based. Designing and Using Model Simulations presents a base case projection which assumes that current public programs and private financing remain unchanged. In addition, the report contains simulations of various measures to promote the growth of private long-term care insurance and to expand/create public programs.

The Brookings/ICF Long-Term Care Financing Model is available to interested researchers. However, access to a mainframe computer and significant amounts of computer time are required. The computer tape containing the code of the model and associated input data can be purchased through NTIS. Two volumes of documentation have been prepared for those who have a serious interest in learning how to use the model. The *User's Guide to Specifying Simulations* discusses the parameters of the model and provides examples of how these parameters can be changed to simulate alternative scenarios of the utilization and financing of nursing home and home care by elderly persons for the period 1986-2020. The *Programmer's/Operator's Manual* provides additional information on the structure of the computer program.

**CONTACT PERSON:** John Drabek, ASPE (202-690-6172)

**COMPLETION DATE:** February 1992

**REPORTS AVAILABLE:**

Alecxih, Lisa and Peter Robertshaw: *Brookings/ICF Long-Term Care Financing Model: Programmer's/Operator's Manual* (February 1992). [DALTCP] [<http://aspe.hhs.gov/daltcp/reports/prgopres.htm>]

Alecxih, Lisa and Peter Robertshaw: *Brookings/ICF Long-Term Care Financing Model: User's Guide to Specifying Simulations* (February 1992). [DALTCP] [<http://aspe.hhs.gov/daltcp/reports/usergdes.htm>]

Kennell, David L., Lisa Maria B. Alecxih, Joshua M. Wiener, and Raymond J. Hanley: *Brookings/ICF Long-Term Care Financing Model: Designing and Using Model Simulations* (February 1992). [DALTCP] [<http://aspe.hhs.gov/daltcp/reports/modsimes.htm>]

Kennell, David L., Lisa Maria B. Alecxih, Joshua M. Wiener, and Raymond J. Hanley: *Brookings/ICF Long-Term Care Financing Model: Model Assumptions* (February 1992). [DALTCP] [<http://aspe.hhs.gov/daltcp/reports/modampes.htm>]

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**TITLE: SYNTHESIS OF MEDICAID SPEND-DOWN STUDIES**

**PRINCIPAL INVESTIGATOR:** Brian Burwell, MEDSTAT Group, Lexington, MA

**PURPOSE:** Medicaid spend-down is a topic of considerable interest in long-term care policy because it is an indication of the catastrophic impact of long-term care expenses on the economic status of disabled elderly persons. This paper provides an overview of research on Medicaid spend-down in nursing homes. It addresses major conceptual, methodological, and measurement issues, and provides a synthesis of findings. Implications for long-term care policy and directions for future research are discussed.

**FINDINGS/RESULTS:** The report concludes that between one-in-four and one-in-five persons enter nursing homes as private pays and spend-down to Medicaid eligibility. The report also concludes that more longitudinal data bases are needed to determine whether the research results apply to other States. More information is also needed on the process of spend-down; e.g., do the elderly liquidate their home equity to pay for care, do they transfer assets to children?

CONTACT PERSON: John Drabek, ASPE (202-690-6172)

COMPLETION DATE: February 1992

REPORTS AVAILABLE:

Adams, E. Kathleen, Mark R. Meiners, and Brian O. Burwell: *A Synthesis and Critique of Studies on Medicaid Asset Spenddown* (January 1992). [DALTCP]  
[\[http://aspe.hhs.gov/daltcp/reports/syncri.htm\]](http://aspe.hhs.gov/daltcp/reports/syncri.htm)

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### C. Ongoing/Planned Projects

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**TITLE: HEALTH AND LONG-TERM CARE EXPENDITURE PATTERNS OF CHILDREN WITH DISABILITIES**

PRINCIPAL INVESTIGATOR: Bill Crown, MEDSTAT Group, Lexington, MA

**PURPOSE:** Because childhood disability is relatively rare, most surveys and data sets have relatively little information on the number of children with disabilities, their service use and expenditures. This project examines two very large claims data sets which are likely to contain a significant number of children with disabilities. The first of these comes from the Medicaid Tape-to-Tape Project, and contains claims and enrollment data for every child covered by Medicaid in 1992 in selected States. The second comes from the MEDSTAT Market Scan data, and contains claims information from numerous employer-based private health insurance plans throughout the U.S.

Using diagnosis codes and other criteria, an attempt will be made to identify all children in the data set with severe disabilities. Data on the amounts and types of services that they use will be tabulated. Every child who receives Medicaid services will be included in the study, not just those who receive Medicaid coverage through SSI.

**PROGRESS TO DATE:** The Medicaid tape-to-tape data have been merged with information on principal disabling conditions, for those who receive Medicaid due to SSI enrollment. Initial analyses are nearly completed.

CONTACT PERSON: John Drabek, ASPE (202-690-6172)

COMPLETION DATE: Summer 1997

REPORTS AVAILABLE: None yet available.

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**TITLE: ANALYSIS OF DATA ON USE OF NURSING HOMES IN FLORIDA**

PRINCIPAL INVESTIGATOR: Brian Burwell, MEDSTAT Group, Lexington, MA

**PURPOSE:** Many people who enter nursing homes eventually spend-down their assets and become eligible for Medicaid. However, it has been difficult to estimate how often this occurs. Because some elderly people enter nursing homes more than once before they die, it is essential to have longitudinal data over many years to study their financing

pattern. Only a few such data sets are available. Previous ASPE projects have utilized longitudinal data from the State of Connecticut on nursing home use. This project utilizes the Florida Nursing Home Reporting System, which contains data on all nursing home residents since 1986. Medicare and Medicaid data have been merged with the nursing home data. In addition to Medicaid spend-down issues, this project will study the use of hospital and home health services by persons who at some point also use nursing homes. This merged data base will permit studies of the combined burden of acute and long-term care financing, as well as studies of specific subgroups of persons; e.g., those who have hip fractures.

**PROGRESS TO DATE:** The Florida Nursing Home Registry data, Medicaid data, and Medicare data have been merged, and the initial analyses have begun.

*CONTACT PERSON:* John Drabek, ASPE (202-690-6172)

*COMPLETION DATE:* Fall 1997

*REPORTS AVAILABLE:* None yet available.

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**TITLE: *UPDATE OF LONG-TERM CARE MICROSIMULATION MODEL***

*PRINCIPAL INVESTIGATOR:* David Kennell, Lewin-VHI, Inc., Fairfax, VA

**PURPOSE:** This five-year project will update and expand the capability of the Brookings/ICF Long-Term Care Financing Model, which takes a national sample of persons, ages them over time, and estimates their long-term care use and financing when they become elderly. It will incorporate results from recent surveys of nursing homes and home care utilization; e.g., the 1989 and 1994 National Long-Term Care Surveys. The model will be expanded to include acute care expenditures, and the period of simulation will be extended to 2030. The economic assumptions will be updated.

The model will continue to be used to project future trends and to perform policy simulations, including expanded coverage for nursing home and home care, changes in Medicaid eligibility and services, and private long-term care insurance.

**PROGRESS TO DATE:** Work to date has concentrated on the conversion of the model's computer program from the mainframe computer to the personal computer. In addition, the 1994 National Long-Term Care Survey, the Medicare Current Beneficiary Surveys, and other data are being analyzed in order to revise the disability and home care use portions of the model.

*CONTACT PERSON:* John Drabek, ASPE (202-690-6172)

*COMPLETION DATE:* October 1999

*REPORTS AVAILABLE:* None yet available.

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**TITLE: ASSESSMENT OF HOME CARE BENEFITS USED BY HOLDERS OF PRIVATE LONG-TERM CARE INSURANCE**

**PRINCIPAL INVESTIGATOR:** Marc Cohen, LifePlans, Inc., Boston, MA

**PURPOSE:** Most experts agree that long-term care insurance products must include both nursing home and home care benefits if they are to be commercially acceptable. Yet private insurers as well as public payers are concerned about their ability to control home care claims, particularly given the potential substitution of formal home care services for care provided by families. The purpose of this study is to collect detailed information on the experience of long-term care policy holders who have filed insurance claims to receive home care benefits and how their formal and informal service use compares to a comparable population of elderly persons without private insurance. Primary data collection will involve face-to-face interviews with approximately 1,000 persons (500 disabled insurance claimants and 500 next-of-kin of those claimants) to collect information on functional and medical characteristics of claimants as well as formal and informal services use. The sample of claimants will be drawn from the files of insurance companies that account for the majority of private long-term care policies now in force.

**PROGRESS TO DATE:** Project just began in Fall 1996.

**CONTACT PERSON:** Pamela Doty, ASPE (202-690-6443)

**COMPLETION DATE:** 1999

**REPORTS AVAILABLE:** None yet available.

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**TITLE: SEMINAR ON PRIVATE LONG-TERM CARE INSURANCE**

**PURPOSE:** This project will organize a small seminar involving the Office of Personnel Management (OPM) and other Federal officials as well as selected State personnel who have implemented a public long-term care benefit for State employees. The purpose of the seminar is to inform OPM and relevant HHS and Office of Management and Budget officials about the experience of these States, and to encourage the formation of a Federal planning process to explore adding long-term care benefits to the FEHBP or the Federal retirement program.

**PROGRESS TO DATE:** Two meetings were held in September 1996 and October 1996.

**CONTACT PERSON:** Pamela Doty, ASPE (202-690-6443)

**COMPLETION DATE:** Ongoing

**REPORTS AVAILABLE:** None planned at this time.



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## D. Other Related Reports

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1. Kennell, David: Private Financing of Long-Term Care: Current Methods and Resources (January 1985). [NTIS: Accession No. PB85-128568]  
<http://aspe.hhs.gov/daltcp/reports/prvfin2.htm>;  
<http://aspe.hhs.gov/daltcp/reports/prvfin2.htm>
2. Kennell, David L., Lisa Alecxih, Polly Ericksen, Joshua M. Wiener, and Raymond Hanley: Financing of Long-Term Care (September 30, 1988). [NTIS]
3. Kotler, Martin, George Wright, Tecla Jaskulski, and Ilene Kreisberg: Synthesis of Cost Studies on the Long-Term Care of Health-Impaired Elderly and Other Disabled Persons (June 1985). [NTIS: Accession No. Volume 1--PB86-116381/AS, Volume 2--PB86-116399/AS]
4. Liu, Korbin, Carol DeVita, Kenneth G. Manton, and Terri Coughlin: Risks of Entering Nursing Homes for Long and Short Stays (1988). [NTIS: Accession No. PB92-119577] [<http://aspe.hhs.gov/daltcp/reports/nhlsstes.htm>]
5. Liu, Korbin and Kenneth G. Manton: Effects of Medicare's Hospital Prospective Payment System (PPS) on Disabled Medicare Beneficiaries (February 1988). [NTIS: Accession No. PB91-106336] [<http://aspe.hhs.gov/daltcp/reports/pps.htm>]
6. Liu, Korbin and Kenneth G. Manton: The Effect of Nursing Home Use on Medicaid Eligibility (1989). [NTIS: Accession No. PB91-106351]  
<http://aspe.hhs.gov/daltcp/reports/nhumes.htm>
7. Manton, Kenneth G. and Korbin Liu: Recent Changes in Service Use Patterns of Disabled Medicare Beneficiaries (1990). [NTIS]  
<http://aspe.hhs.gov/daltcp/reports/recentes.htm>
8. Technical Work Group on Private Financing of Long-Term Care: Report to the Secretary on Private Financing of Long-Term Care for the Elderly (November 1986). [NTIS: Accession No. PB89-193031/AS]  
<http://aspe.hhs.gov/daltcp/reports/pfltce.htm>
9. Wiener, Joshua M., Raymond J. Hanley, Denise A. Spence, Sheila Murray, David Kennell, and John Sheils: Estimating the Demand for and Impact of Private Sector Financing Options for Long-Term Care (February 9, 1987). [NTIS: Accession No. PB91-169243]
10. Wiener, Joshua M., Katherine M. Harris, and Raymond J. Hanley: Premium Pricing of Prototype Private Long-Term Care Insurance Policies (December 1990). [NTIS] [<http://aspe.hhs.gov/daltcp/reports/prempric.htm>]

## VI. DATA DEVELOPMENT

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### A. Overview

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DALTCP has a longstanding commitment to improving basic data on disability, aging, and long-term care. Typically, ASPE works with other HHS agencies to augment planned or existing surveys. In particular, ASPE's staff expertise and funding are used to: (a) fill gaps in planned data collection activities; (b) make sure that surveys contain policy relevant questions; (c) make sure that samples are of sufficient size to represent small but policy-significant populations (e.g., mentally retarded and developmentally disabled persons); and (d) help set priorities for data analysis.

One of the most significant activities currently underway is the **1994/1996 National Health Interview Survey on Disability**. DALTCP staff were responsible for coordinating, planning, developing, and identifying sources of support for this Survey. For the first time ever, the resulting analyses will provide detailed information on the prevalence and characteristics of children, working age adults, and elderly Americans with disabilities; how they live, work, and go to school; health care utilization, income, assets, participation in Federal programs, and health insurance; and nonmedical services, including frequency of use, sources of payment, and out-of-pocket costs.

Another project, **Americans with Disabilities**, provided funds to the Census Bureau to analyze the 1990 Census questions on disability. This project served as a much needed national baseline on people with disabilities and will be the only source of State and county level data on disability.

DALTCP provided support to the University of Michigan's Institute for Social Research, for the **Asset and Health Dynamics of the Oldest Old Survey (AHEAD)**. This survey provides important information on the health, wealth, functional capacity, and service use of the population over age 70.

DALTCP has continued its support of the **National Long-Term Care Survey (NLTCS)**, the major source of information on the frail elderly. For the 1994 NLTCS, support from DALTCP enabled the survey to include information on nutritional status of the elderly and plans for a next-of-kin survey. ASPE serves as cosponsor for the **1993 National Mortality Followback Survey**, sponsored by the National Center for Health Statistics, and adds support to the **National Survey of Special Care Units in Nursing Homes**.

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## B. Completed Projects

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### **TITLE: *ISSUE PAPER AND EXPERT MEETING ON DISABILITY DATA***

**PURPOSE:** In early 1995, several major policy initiatives on persons with disabilities of all ages facing the Department included: (1) the comprehensive Review of Disability Policy initiated by the White House; (2) scrutiny of public benefits for children with disabilities and the newly-established Commission on Childhood Disability; (3) the national health reform debate and the aftermath of that debate; (4) State or private health and long-term care reform initiatives; and (5) welfare reform. To address the data needs on disability, DALTCP organized an invitational meeting of experts in March 1995 to advise DALTCP on its disability research agenda. The meeting focused on: (1) assessment of available data sets pertaining to persons with disabilities; (2) identifying usable State, area, and private data bases including data from large-scale demonstrations; (3) specifying next steps in accessing and analyzing available disability data; and (4) discussing a minimum set of disability-related variables for inclusion in surveys.

A background paper on disability data was prepared to inform discussion at the meeting. The paper discusses policy issues and available data related to several populations of persons with disabilities: working age adults, children, persons age 65 and older, and special populations (e.g., persons with developmental disabilities, persons with mental illness). An appendix contains one-page summaries of national data sets including household and person-based surveys, provider-based data sets, and administrative data for Federal benefit programs.

**CONTACT PERSONS:** Robert Clark, ASPE (202-690-6443)  
Michele Adler, ASPE (202-690-6172)

**COMPLETION DATE:** May 1995

**REPORTS AVAILABLE:**

Eustis, Nancy N., Robert F. Clark and Michele C. Adler: *RESEARCH AGENDA: Disability Data* (August 1995). [DALTCP]  
[\[http://aspe.hhs.gov/daltcp/reports/resagdd.htm\]](http://aspe.hhs.gov/daltcp/reports/resagdd.htm)

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### **TITLE: *INFORMAL CARE OF THE DISABLED ELDERLY: A RESEARCH AND POLICY INITIATIVE***

**PRINCIPAL INVESTIGATORS:** Brian Burwell, MEDSTAT Group, Lexington, MA  
Mary E. Jackson, MEDSTAT Group, Lexington, MA

**PURPOSE:** The purpose of this project was to provide necessary background information for policy relevant research and a national conference on informal caregiving of the disabled elderly.

**FINDINGS/RESULTS:** This project encompassed: (1) analysis of family caregiving patterns in the 1989 National Long-Term Care (NLTCS) and companion Informal Caregivers Survey (ICS) as well as analysis of trends in family caregiving based on comparison with previous (1982 and 1984) NLTCS/ICS data; and (2) organization of a national conference on informal caregiving to assess the state-of-the-art in policy research with respect to such issues as work/caregiving conflicts, stress and satisfaction among family caregivers, integration of formal and informal services, and the role of volunteers and community organizations.

**CONTACT PERSON:** Pamela Doty, ASPE (202-690-6172)

**COMPLETION DATE:** December 1992

**REPORTS AVAILABLE:**

*The Changing Face of Informal Caregiving--A National Conference on Policy Directions for the 1990s: Conference Package* (October 1992). [DALTCP]

Doty, Pamela, *Eldercare: The Impact of Family Caregivers' Employment on Formal and Informal Helper Hours*, ASPE Research Note, August 1995. [DALTCP]  
[\[http://aspe.hhs.gov/daltcp/reports/rn14.htm\]](http://aspe.hhs.gov/daltcp/reports/rn14.htm)

Doty, Pamela, Mary E. Jackson, and William Crown, "The Impact of Female Caregivers' Employment Status on Patterns of Formal and Informal Eldercare," paper presented at the annual meeting of the Gerontological Society of America, November 1995 and forthcoming in *The Gerontologist*.  
[\[http://aspe.hhs.gov/daltcp/reports/femcares.htm\]](http://aspe.hhs.gov/daltcp/reports/femcares.htm)

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**TITLE: NATIONAL SURVEY DEVELOPMENT: ASSET AND HEALTH DYNAMICS OF THE OLDEST OLD**

**PRINCIPAL INVESTIGATORS:** Beth J. Soldo, Georgetown University, Washington, DC  
Regula A. Herzog, University of Michigan, Ann Arbor, MI

**PURPOSE:** For health and long-term care reform initiatives, it is important to have current estimates of the health, wealth, functional capacity and service use of the elderly. In 1993, the National Institute on Aging awarded a two year cooperative agreement to the University of Michigan's Institute for Social Research to carry out the Asset and Health Dynamics of the Oldest Old Survey (AHEAD). This award was a supplement to a five year cooperative agreement to conduct the Health and Retirement Survey (HRS). AHEAD yielded current nationally representative information on the elderly aged 70+. It is particularly strong in the areas of income and assets, health status, physical and cognitive functioning, and service use.

There are plans to link the AHEAD data to Medicare files, National Death Index and, possibly, State Medicaid files. Among other things, the survey sheds light on estimates of the number of cognitively impaired elderly, Medicaid spend-down patterns, and intergenerational transfers.

ASPE funds were used for three purposes: (1) Maintain the necessary sample size for the survey. (2) Support of an early results workshop using preliminary AHEAD data. Over 20 papers on a variety of issues were presented at the Institute for Social Research, University of Michigan, September 21-22, 1994. (3) Preparation of AHEAD data runs on issues pertaining to health care reform and other policy-relevant issues.

**FINDINGS/RESULTS:** An Early Results Workshop was held on September 21-22, 1994.

**CONTACT PERSON:** Robert Clark, ASPE (202-690-6443)  
Richard Suzman, NIA (301-496-3136)

**COMPLETION DATE:** March 1995

**REPORTS AVAILABLE:**

- Agree, Emily M.: *The Role of Technology in Long-Term Care Portfolios.* [DALTCP]
- Chand, Harish and Li Gan: *Untitled.* [DALTCP]
- Couper, Mick P., Robert M. Groves, and Willard L. Rodgers: *Cost Implications and Predictors of Unit Nonresponse in AHEAD.* [DALTCP]
- Dunn, Thomas A.: *The Importance of Intergenerational Income Transfers on the Economic Well-Being of Older Persons.* [DALTCP]
- Fogel, Barry S.: *Depressed Mood, Future Expectations, and Self-Assessed Needs for Help: A Proposal for an AHEAD Early Results Paper.* [DALTCP]
- Herzog, A. Regula and Robert Wallace: *The Measures of Cognitive Functioning in the AHEAD Study.* [DALTCP]
- Jay, Gina M. and A. Regula Herzog: *Relationship Between Health Conditions and Functioning Outcomes: The Role of Coping Strategies and Resources.* [DALTCP]
- Knauper, Barbel and Robert Belli: *Respondent Performance as Affected by Question Difficulty, Time of Day, and Mode of Presentation.* [DALTCP]
- McGarry, Kathleen and Robert F. Schoeni: *Health and Familial Support of the Elderly in the AHEAD Survey.* [DALTCP]
- Miller, Baila, Richard T. Campbell and Max Woodbury: *Comparative Analysis on Access to Services.* [DALTCP]
- Norgard, Theresa M. and Willard L. Rodgers: *The Use of Informal and Formal Sources of Home Care by Older Whites and African Americans.* [DALTCP]
- Parnell, Allan M., George C. Myers, and Carol Patterson: *Patterns of Functional Ability Among Elderly Couples.* [DALTCP]
- Sloan, Frank A.: *Effects of Medicaid Policies on Families' Savings Decisions.* [DALTCP]
- Smith, James P.: *Racial and Ethnic Differences in Wealth Among Older Americans.* [DALTCP]
- Soldo, Beth J., Martha S. Hill, John C. Henretta, Douglas A. Wolf: *Intergenerational Flows of Assistance: How Parent-to-Child Transfers Later Influence Child-to-Parent Transfers.* [DALTCP]
- Stoller, Eleanor Palo and Stephen J. Cutler: *The Impact of Health and Financial Resources on the Configuration of Support Networks.* [DALTCP]

- Sung, Hai-Yen: *Health, Welfare, and Access of Health Care Among the Oldest Old.* [DALTCP]
- Verbrugge, Lois M. and Susan S. Merrill: *Evaluating the Many Facets of Disability.* [DALTCP]
- Waidmann, Timothy and Michael Schoenbaum: *Race, Socioeconomic Status and Health: Accounting for Race Differences in Health in the U.S. Elderly.* [DALTCP]
- Wallace, Robert B., Frank Kohout; Janice Alexander, and A. Regula Herzog: *The Health and Economic Status of America's Oldest Old: Contrasting Findings Among Ethnic Groups.* [DALTCP]
- Wolf, Douglas A., Beth J. Soldo and Vicki Freedman: *Family Care for Elderly Parents: Findings from the AHEAD Survey.* [DALTCP]
- Wolinsky, Fredric D.: *The Structure of Health Status in the AHEAD.* [DALTCP]

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**TITLE: AMERICANS WITH DISABILITIES**

**PRINCIPAL INVESTIGATORS:** Jack McNeil, Bureau of the Census, Washington, DC  
 Michele Adler, US Department of Health and Human Services, Washington, DC

**PURPOSE:** This project provided funds to the Census Bureau to analyze the 1990 Decennial Census questions on disability, in which data were collected for the population 16 and over on several types of disability--limitations in work, ability to work, mobility limitations, and self-care limitations. The tabulations are the only source of disability data for States, counties and metropolitan statistical areas, and the only source which includes persons with disabilities residing both in the community and in all types of institutions. The information serves as a national baseline. As such, the data will be useful for virtually every aspect of disability policy and for portions of health care reform and welfare reform which pertain to people with disabilities.

**FINDINGS/RESULTS:** Results from this joint ASPE/Census Bureau project are now available on the Internet. Results are presented in tables, graphs, and maps. Tables for States, counties, and metropolitan statistical areas contain information by disability status and type of disability on a variety of characteristics including employment and labor force status, education, income, poverty, marital status, race and ethnicity. Separate tables are available for the elderly and nonelderly. In addition, national disability estimates from two other Census surveys: the Survey of Income and Program Participation and the Current Population Survey are presented. The Internet address is: <http://www.census.gov/hhes/www/disable/census.html>.

**CONTACT PERSON:** Michele Adler, ASPE (202-690-6172)

**COMPLETION DATE:** June 1996

**REPORTS AVAILABLE:** On the Internet at <http://www.census.gov/hhes/www/disable/census.html>.

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**TITLE: CHARACTERISTICS OF AMERICAN CHILDREN WITH DISABILITIES**

**PURPOSE:** This report presents information on the size, characteristics, and prevalence of disability among American children. Data primarily come from the 1990 Survey of Income and Program Participation, supplemented by the 1990 Decennial Census.

The report contains basic counts of children with disabilities who live in the community and who reside in institutions. Comparisons are made between children in the community with and without disabilities in terms of age, gender, race/ethnicity, family characteristics, income, poverty, health insurance, and participation in AFDC, Food Stamps, and Medicaid. Information on the leading causes of childhood disability is also presented.

**CONTACT PERSON:** Michele Adler, ASPE (202-690-6172)

**COMPLETION DATE:** August 1996

**REPORTS AVAILABLE:** A summary of this report appears in the ASPE Research Notes article, "Disability Among Children."

[\[http://aspe.hhs.gov/daltcp/reports/rn10.htm\]](http://aspe.hhs.gov/daltcp/reports/rn10.htm)

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**TITLE: CONDITIONS AND IMPAIRMENTS AMONG THE WORKING AGE POPULATION WITH DISABILITIES**

**PURPOSE:** This report presents descriptive information on a wide range of characteristics of the civilian noninstitutionalized working age (18-64) population with disabilities. Basic demographic and socio-economic characteristics were related to ten major health conditions and functional impairments including mental illness, mental retardation and other developmental disabilities, visual impairments, hearing impairments, spinal cord injury, heart disease, arthritis, bad back, cancer, and respiratory problems. Comparisons were made between people with and without disabilities as well as among the ten condition and impairment groups. These comparisons were based on demographic factors (income, poverty, employment), health status and health care utilization (health insurance coverage, general health status, hospital stays, physician visits), and program participation (participation in Food Stamps, Medicare, Medicaid, SSDI, SSI). Data came from Wave 3 of the 1990 Survey of Income and Program Participation.

**FINDINGS/RESULTS:** Within the disabled population, several condition/impairment groups were strikingly different. Persons with mental illness or MR/DD were significantly less likely to be employed, married, and need long-term care. They were also significantly more likely to live in poverty and rely on Federal programs. Health status and the utilization of health care was not significantly different for those with MR/DD than for all those with disabilities. However, health care utilization was

significantly higher for persons with mental illness than for the entire disabled population.

Persons with chronic diseases typically did not significantly differ from the overall disabled population in educational attainment, poverty, or reliance on Federal programs (although a higher proportion of those with SSI received SSDI). However, persons with chronic diseases were much more likely to need long-term care, to be in fair or poor health, and to use health care.

People with visual impairments were more likely to be poor, to be African-American, to have not graduated from high school, to rely on food stamps (but not SSI or SSDI), and to be in fair or poor health.

**CONTACT PERSON:** Michele Adler, ASPE (202-690-6172)

**COMPLETION DATE:** October 1995

**REPORTS AVAILABLE:**

Adler, Michele: "Conditions and Impairments Among the Working Age Population with Disabilities," *Proceedings of the Annual Meeting of the American Statistical Association*, 1995. [<http://aspe.hhs.gov/daltcp/reports/conimpwa.htm>]

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**TITLE: NATIONAL MORTALITY FOLLOWBACK SURVEY**

**PURPOSE:** The National Mortality Followback Survey (NMFS), conducted by the National Center for Health Statistics, is a nationally representative sample of adults age 15 and over who died in 1993. Unlike other surveys, the NMFS data will provide a lifetime picture of lifestyle, health and socio-economic status and service use, as well as the use of health and long-term care services prior to death. The NMFS is a collaborative effort involving twelve co-sponsors, including ASPE. Since the frail elderly and other persons with disabilities are major users of health and long-term care services, it is important to have lifetime and prior-to-death estimates of their health, functional capacity, service use and expenditures and to be able to compare these data with data on the population as a whole. Information has been gathered on about 20,000 deaths. The NMFS supplements information from death certificates with information on important characteristics of the decedent.

**FINDINGS/RESULTS:** The data are collected through telephone and/or personal interviews with the next-of-kin of the decedent. Corroborative information is being collected from hospitals, hospices, and nursing homes. The survey is administered through a telephone screen and an in-person detailed interview. ASPE has helped in the development of questions included in the 1993 NMFS, so that they address issues like income, lifestyle, functional limitations and nursing home use. ASPE will receive a data tape. ASPE will also participate in an NMFS users group and help identify priorities for data analysis.



*CONTACT PERSON:* Robert Clark, ASPE (202-690-6443)  
*COMPLETION DATE:* 1996  
*REPORTS AVAILABLE:* None yet available.

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**TITLE: NATIONAL SURVEY OF SPECIAL CARE UNITS**

*PRINCIPAL INVESTIGATOR:* Joel Leon, Project Hope, Bethesda, MD

**PURPOSE:** Under an ASPE-NIA Interagency Agreement, ASPE helps support a census of special care units (SCUs) in licensed nursing homes in the United States. Special care units include: (a) SCUs targeted to persons with dementia, (b) subacute care specialty units, (c) special units for persons with AIDS, and (d) special rehabilitation units. It is important for health and long-term care policy development to have data on the growth and major trends in institutional long-term care. Nursing homes, in particular, have branched out to provide different types of services and to target specific subgroups of persons with disabilities. Many have established SCUs for persons with dementia or persons with AIDS, where some mix of subacute care, rehabilitative care and personal care are provided.

**PROGRESS TO DATE:** Using data from the National Nursing Home Survey, approximately 17,000 nursing homes were identified. A screening instrument was developed to identify the characteristics of nursing homes that have developed SCUs and the nature of and populations served by those units. This instrument was mailed to all identified nursing homes. Approximately, 40% of nursing homes responded to the screener.

A follow-up to survey of a sample of nursing homes with subacute care programs will be conducted. The follow-up will identify the organizational, programmatic, staffing, and financing characteristics of nursing homes providing subacute care. The questionnaire for this follow-up survey has been developed is undergoing review by a technical advisory group.

Upcoming reports include: (1) a report on the characteristics of nursing homes that have developed SCUs and nature of and populations served by those units (March 1997); and, (2) a report on the organizational, programmatic, staffing, and financing characteristics of nursing homes providing subacute care (December 1997).

*CONTACT PERSON:* Robert Clark, ASPE (202-690-6443)--initial screening instrument  
Jennie Harvell, ASPE (202-690-6443)--follow-up survey

*COMPLETION DATE:* December 1997

*REPORTS AVAILABLE:* None yet available.

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### C. Ongoing/Planned Projects

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**TITLE: NATIONAL HEALTH INTERVIEW SURVEY ON DISABILITY**

**PRINCIPAL INVESTIGATOR:** National Center for Health Statistics, Hyattsville, MD

**PURPOSE:** The 1994/96 National Health Interview Survey on Disability, which was conducted along with the 1994 and 1995 National Health Interview Surveys (NHIS), has two parts. The Phase I interview will screen in the relevant populations and collect basic descriptive information about people with disabilities, including their disabling conditions and the nature, severity, and duration of their disabilities. Phase I interviews were conducted from January 1994 through December 1995. The Phase II interview (conducted about eight months after Phase I) will collect detailed information on how people with disabilities live (i.e., their housing, transportation, employment accommodations) and their service use and expenditure patterns--key information for policy analysis. Phase II interviews began in the Fall 1994 and will end in Fall 1997. Nationwide, about 225,000 people in 100,000 households participated in Phase I and approximately 45,000 in Phase II. The Survey will provide policy-relevant information on the extent and nature of disability among the American people. No such survey has been conducted or attempted since 1978 and no other survey will realistically occur before the end of the decade. The Survey will also be the only source of national comprehensive data on the developmentally disabled and children with disabilities.

A consortium of Federal agencies, along with a private foundation, are contributing funds to the survey. This is primarily a data collection effort, although a number of reports will be published. Preliminary data tapes have been released for the 1994 portion of Phase I.

**PROGRESS TO DATE:** A data tape for the 1994 portion of Phase I is now available. Phase II data collection for the 1995 portion will end in the Fall 1997. Data tapes for the 1994 portion of Phase II and the 1995 portion of Phase I will be released in the Spring 1997.

**CONTACT PERSON:** Michele Adler, ASPE (202-690-6172)

**COMPLETION DATE:** Spring 1997

**REPORTS AVAILABLE:** Data tapes can be ordered from Bob Krasowski, NCHS (301-436-7087).

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**TITLE: NATIONAL LONG-TERM CARE SURVEY**

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

**PURPOSE:** The National Long-Term Care Survey (NLTC) is the major source of information on the frail elderly. The survey has been administered in 1982, 1984, 1989 and 1994. The survey provides nationally representative data on the characteristics, service use and long-term care expenditures of the frail elderly.

ASPE originated the NLTCS in 1982 and co-funded it with HCFA as part of an overall long-term care data collection strategy. ASPE has continued to provide supplemental funding since. Among other things, this involvement has given ASPE influence on the survey's data elements, production of public use tapes and analytical priorities. ASPE - funds have provided Duke University with the resources to: add new questions dealing with the nutritional status of the frail elderly; and generate early analyses of 1994 data.

Three issues in particular were highlighted: (1) whether trends in disability rates among the elderly have continued to decline (as observed between 1982 and 1989); (2) whether assistive technology continues to substitute for hands-on care; and, (3) the role of private insurance in long-term care financing.

**PROGRESS TO DATE:** Public use files of the NLTCS (1982, 1984, 1989 and 1994) are available from Duke University. On the Internet, go to URL <http://cde.duke.edu> and click on the National Long-Term Care Survey Files.

**CONTACT PERSON:** Robert Clark, ASPE (202-690-6443)  
Richard Suzman, NIA (301-496-3136)

**COMPLETION DATE:** N/A

**REPORTS AVAILABLE:** None yet available.

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**TITLE: NATIONAL LONG-TERM CARE SURVEY: NEXT-OF-KIN SUPPLEMENT**

**PRINCIPAL INVESTIGATORS:** Kenneth Manton, Duke University, Durham, NC  
Larry Corder, Duke University, Durham, NC

**PURPOSE:** Under an ASPE-NIA Interagency Agreement, ASPE funds will be used to support a Next-of-Kin Supplemental Survey as part of the 1994 NLTCS. Approximately 4,800 persons who are selected for interviews under the 1994 NLTCS will have died between 1989 and 1994. The next-of-kin or other knowledgeable persons will be interviewed about the deceased person's use of medical and long-term care services. These data will become part of the 1994 NLTCS data set. ASPE funding will permit the survey to obtain information on an estimated 80% of decedents. The information on decedents is needed in order to make a number of important estimates, such as total long-term care costs and the extent to which nursing home residents spend-down to qualify for Medicaid benefits. Because the 1989 NLTCS did not contain a survey on decedents, it was not possible to generate an estimate of total nursing home and other long-term care service use for the survey population. A Next-of-Kin Survey on decedents will help remedy this problem.

**PROGRESS TO DATE:** Funds for this project were awarded in 1996. The supplement is in the design stage.

CONTACT PERSON: Robert Clark, ASPE (202-690-6443)

COMPLETION DATE: 1998

REPORTS AVAILABLE: None yet available.

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**TITLE: ASSESSING THE FEASIBILITY OF MAKING STATE LEVEL ESTIMATES FROM NATIONAL SURVEYS**

PRINCIPAL INVESTIGATOR: Lisa Alecxih, Lewin Group, Alexandria, VA

**PURPOSE:** This project is a component of the Data Initiative--a broader HHS strategy to improve the Department's capacity to generate valid and reliable State level estimates, to measure the impact of social policy interventions, as HHS health and human services programs rapidly change their focus from the national to the State level.

This project focuses on three well known Federal surveys widely used for policy analysis: the Survey of Income Program Participation, the Current Population Survey, and the National Health Interview Survey. In relation to these surveys, this project will: (1) closely evaluate statistical concerns to determine suitability and potential of using these surveys for State level estimates and to identify differences between states; (2) assess the current capabilities of these surveys to provide State level data; and, (3) present options for obtaining valid reliable State level data from relatively minimal enhancements and changes to the design of the surveys.

**PROGRESS TO DATE:** Project just began.

CONTACT PERSON: Michele Adler, ASPE (202-690-6172)

Sarah Jane Holcombe, ASPE (202-690-7804)

COMPLETION DATE: May 1997

REPORTS AVAILABLE: None yet available.

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**D. Other Related Reports**

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1. Adler, Michele: *Federal Disability Data: Creating A Structure in the 1990s to Further the Goals of the ADA* (December 8, 1992). [DALTCP] [<http://aspe.hhs.gov/daltcp/reports/feddd.htm>]
2. Adler, Michele: *The Future of SIPP for Analyzing Disability and Health* (April 1991). [DALTCP] [<http://aspe.hhs.gov/daltcp/reports/sipp.htm>]
3. Adler, Michele, Suzanne Kitchen, and Albert Irion: *Databook on the Elderly: A Statistical Portrait* (June 1987). [NTIS] [<http://aspe.hhs.gov/daltcp/reports/databkes.htm>]
4. Applebaum, Robert A., Randall S. Brown, and Peter Kemper: *An Analysis of Site-Specific Results* (May 1986). [NTIS: Accession No. PB90-244930] [<http://aspe.hhs.gov/daltcp/reports/sites.htm>]

5. Applebaum, Robert A. and Margaret Harrigan: *Channeling Effects on the Quality of Clients' Lives* (April 1986). [NTIS: Accession No. PB86-218690/AS] [\[http://aspe.hhs.gov/daltcp/reports/qualtyes.htm\]](http://aspe.hhs.gov/daltcp/reports/qualtyes.htm)
6. Applebaum, Robert A., Margaret N. Harrigan, and Peter Kemper: *Tables Comparing Channeling to Other Community Care Demonstrations* (May 1986). [NTIS: Accession No. PB86-246931/AS] [\[http://aspe.hhs.gov/daltcp/reports/tablees.htm\]](http://aspe.hhs.gov/daltcp/reports/tablees.htm)
7. Baxter, Raymond J., et al.: *Implementation and Early Operation of the Channeling Demonstration: Overview* (December 1983). [NTIS]
8. Baxter, Raymond J., Robert Applebaum, James J. Callahan, Jr., Jon B. Christianson, and Stephen L. Day: *The Planning and Implementation of Channeling: Early Experiences of the National Long-Term Care Demonstration* (April 15, 1983). [NTIS: Accession No. SHR-0010870] [\[http://aspe.hhs.gov/daltcp/reports/implees.htm\]](http://aspe.hhs.gov/daltcp/reports/implees.htm)
9. Brown, Randall S. and Margaret Harrigan: *The Comparability of Treatment and Control Groups at Randomization* (October 27, 1983). [NTIS: Accession No. PB86-242690/AS] [\[http://aspe.hhs.gov/daltcp/reports/compares.htm\]](http://aspe.hhs.gov/daltcp/reports/compares.htm)
10. Brown, Randall S. and Peter A. Mossel: *Examination of the Equivalence of Treatment and Control Groups and the Comparability of Baseline Data* (October 1984). [NTIS: Accession No. PB86-236775/AS] [\[http://aspe.hhs.gov/daltcp/reports/examines.htm\]](http://aspe.hhs.gov/daltcp/reports/examines.htm)
11. Brown, Randall S., Peter A. Mossel, Jennifer Schore, Nancy Holden, and Judy Roberts: *Final Report on the Effects of Sample Attrition on Estimates of Channeling's Impacts* (January 13, 1986). [NTIS: Accession No. PB86-234325/AS] [\[http://aspe.hhs.gov/daltcp/reports/atritnes.htm\]](http://aspe.hhs.gov/daltcp/reports/atritnes.htm)
12. Brown, Randall and Barbara Phillips: *The Effects of Case Management and Community Services on the Impaired Elderly* (February 1986). [NTIS: Accession No. PB87-102786/AS] [\[http://aspe.hhs.gov/daltcp/reports/casmanes.htm\]](http://aspe.hhs.gov/daltcp/reports/casmanes.htm)
13. Brown, Randall S.: *Methodological Issues in the Evaluation of the National Long-Term Care Demonstration* (July 1986). [NTIS: Accession No. PB86-239977/AS] [\[http://aspe.hhs.gov/daltcp/reports/methodes.htm\]](http://aspe.hhs.gov/daltcp/reports/methodes.htm)
14. Burwell, Brian O.: *An Estimate of the Number of Persons with Developmental Disabilities Receiving Supplemental Security Income Benefits and Their Characteristics* (December 1990). [NTIS] [\[http://aspe.hhs.gov/daltcp/reports/ssiestes.htm\]](http://aspe.hhs.gov/daltcp/reports/ssiestes.htm)
15. Carcagno, George, Robert Applebaum, Jon Christianson, Barbara Phillips, Craig Thornton, and Joanna Will: *The Planning and Operational Experiences of the Channeling Projects* (July 18, 1986). [NTIS: Accession No. Volume 1--PB87-120606/AS; Volume 2--PB87-120598/AS] [\[http://aspe.hhs.gov/daltcp/reports/proceses.htm\]](http://aspe.hhs.gov/daltcp/reports/proceses.htm)
16. Christianson, Jon B.: *Channeling Effects on Informal Care* (May 1986). [NTIS: Accession No. PB86-240033/AS] [\[http://aspe.hhs.gov/daltcp/reports/informes.htm\]](http://aspe.hhs.gov/daltcp/reports/informes.htm)

17. Christianson, Jon B. and Susan A. Stephens: *Informal Care to the Impaired Elderly: Report to the National Long-Term Care Demonstration Survey of Informal Caregivers* (June 6, 1984). [NTIS: Accession No. PB86-240058/AS] [<http://aspe.hhs.gov/daltcp/reports/impaires.htm>]
18. Cohen, E. and L. Sterthous: *Community Services and Long-Term Care: Issues of Negligence and Liability* (1982). [NTIS: Accession No. PB86-244753/AS] [<http://aspe.hhs.gov/daltcp/reports/negliab.htm>]
19. Corson, Walter, Thomas Grannemann, Nancy Holden, and Craig Thornton: *Channeling Effects on Formal Community Based Services and Housing* (May 1986). [NTIS: Accession No. PB86-236593/AS] [<http://aspe.hhs.gov/daltcp/reports/commtyes.htm>]
20. Dunlop, Burton D. and James A. Wells: *Prospective Outcomes of Informal and Formal Home Care: Mortality and Institutionalization* (December 19, 1990). [DALTCP] [<http://aspe.hhs.gov/daltcp/reports/prosoutc.htm>]
21. Grannemann, Marilyn: *The Channeling Financial Control System* (1985). [NTIS: Accession No. PB86-240041/AS]
22. Grannemann, Thomas W., Jean Baldwin Grossman, and Shari Miller Dunstan: *Differential Impacts Among Subgroups of Channeling Enrollees* (May 1986). [NTIS: Accession No. PB86-243532/AS] [<http://aspe.hhs.gov/daltcp/reports/enrolles.htm>]
23. Grannemann, Thomas W., Randall S. Brown and Shari Miller Dunstan: *Differential Impacts Among Subgroups of Channeling Enrollees Six Months After Randomization* (July 1984). [NTIS: Accession No. PB86-235348/AS] [<http://aspe.hhs.gov/daltcp/reports/difimpes.htm>]
24. Jackson, Mary E.: *Prevalence and Correlates of Unmet Need Among the Elderly with ADL Disabilities* (February 1991). [NTIS] [<http://aspe.hhs.gov/daltcp/reports/prvcores.htm>]
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## VII. INTERNATIONAL COMPARISONS

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### A. Overview

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The aging of the population worldwide has led to a number of international comparisons and collaborations by several countries to share information. Aging and health policy experts in other countries are interested in the U.S. long-term care experience; similarly, the U.S. can learn from other countries.

DALTCP is involved in two international aging efforts. The **International Collaborative Effort on Aging (ICE): Outcomes of Nursing Home Care in Five Countries** is part of an international study supported by the National Center on Health Statistics. The goal of this component of the analysis is to compare the number of people in nursing homes, their outcomes, and characteristics, across five countries.

The **U.S. and Japan Long-Term Care Data Comparability** project examined the comparability of the U.S. and Japan's long-term care data systems and surveys. Some preliminary analyses of comparable survey data from both countries were undertaken. Overall, the goal is to improve data coverage, collection, analysis and dissemination in both countries.

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### B. Completed Projects

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**TITLE:** *LONG-TERM CARE IN COMPARATIVE INTERNATIONAL PERSPECTIVE*

**PURPOSE:** 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 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 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.

**FINDINGS/RESULTS:** Early results appeared in a paper by Pamela Doty on comparative financing methods, presented at a Brookings Institution conference in May 1988. A general overview of long-term care in international perspective, highlighting comparative institutionalization rates, was published in the *Health Care Financing Review 1988 Annual Supplement* in an article by Pamela Doty. Additional results appear in the articles listed below.

**CONTACT PERSON:** Pamela Doty, ASPE (202-690-6172)

**COMPLETION DATE:** Ongoing

REPORTS AVAILABLE:

Doty, Pamela: *Dispelling Some Myths: A Comparison of Long-Term Care Financing in the U.S. and Other Nations* (1990). [NTIS]

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

Doty, Pamela: *International Long-Term Care Reform: A Demographic, Economic, and Policy Overview* (1993). [DALTCP]

Doty, Pamela: *Long-Term Care in International Perspective* (1988). [NTIS: Accession No. PB91-106344/AS]

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

Doty, Pamela: *U.S. Long-Term Care Financing in Comparative International Perspective: Old Myths, New Ideas* (April 1990). [NTIS]

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

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**TITLE: U.S. AND JAPAN LONG-TERM CARE DATA COMPARABILITY**

**PRINCIPAL INVESTIGATOR:** Robert N. Butler, Mount Sinai Medical Center, New York, NY

**PURPOSE:** Japan is a rapidly aging society. By 2020, 25% of all Japanese are expected to be age 65 or over. The Japanese have become very aware of the impact of their aging population, particularly with respect to long-term care. They are eager to learn from the United States experience. Conversely, the United States can learn much from Japan, since they are approaching the problem with a fresh perspective based on their analyses of other countries' experience in long-term care.

In order for U.S.-Japan comparative analyses to be valid and reliable, it was necessary to examine the two nations' data collection activities related to long-term care, identify areas of comparability, and recommend improvements. A report was issued that: (a) describes the long-term care data collection activities in the United States and Japan; (b) summarizes what is known from available data sets; and, (c) recommends improvements in measures and data collection strategies to improve comparability.

**CONTACT PERSON:** Robert Clark, ASPE (202-690-6443)  
Bernice Parlak, HRSA (301-443-6887)

**COMPLETION DATE:** October 1995

REPORTS AVAILABLE:

Muller, Charlotte, Mariann Fahs, Haruko Noguchi, and Jianjin Ling: *U.S.-Japan Collaborative Effort: Study of Long-Term Care Data Comparability* (October 27, 1995). [DALTCP] [\[http://aspe.hhs.gov/daltcp/reports/usjapnes.htm\]](http://aspe.hhs.gov/daltcp/reports/usjapnes.htm)

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## C. Ongoing/Planned Projects

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**TITLE: *CARING FOR FRAIL ELDERLY PEOPLE***

**PRINCIPAL INVESTIGATOR:** Patrick Hennessy, Organization for Economic Cooperation and Development, Paris, France

**PURPOSE:** The Organization for Economic Cooperation and Development (OECD) is an international organization based in Paris, France, whose membership is comprised of advanced industrial nations--including the United States, Canada, Australia, New Zealand, Japan, and most of the countries of Western Europe. Since 1991, the OECD has been conducting comparative research on long-term care for the frail (i.e., functionally disabled) elderly across member countries. The study is under the overall direction of Patrick Hennessy, a consultant to the Directorate for Education, Employment, Labour, and Social Affairs. Three "expert" meetings have been held--in 1991, 1992, and 1994--which were attended by ASPE staff. The 1994 meeting was attended by Robyn Stone, former Deputy Assistant Secretary for DALTCP. In addition, DALTCP has contributed a "country report" (written by Pamela Doty) describing long-term care policy in the United States. OECD's cross-national study of care of the frail elderly is now nearing completion. A follow-up study examining the broader effects of population aging on OECD countries is planned.

**PROGRESS TO DATE:** *Caring for Frail Elderly People: Policies in Evolution* was published by OECD, which compiles similar reports from each of the OECD member countries. Chapter 14 covers the United States.

**CONTACT PERSON:** Pamela Doty, ASPE (202-690-6172)

**COMPLETION DATE:** July 1995 (Care of the Frail Elderly)  
July 1997 (Impact of Aging Populations)

**REPORTS AVAILABLE:**

Organization for Economic Cooperation and Development: *Caring for Frail Elderly People: Policies in Evolution* (1996). [Chapter 14; DALTCP]  
[\[http://aspe.hhs.gov/daltcp/reports/chap14.htm\]](http://aspe.hhs.gov/daltcp/reports/chap14.htm)

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**TITLE: *INTERNATIONAL COLLABORATIVE EFFORT (ICE) ON AGING: OUTCOMES OF NURSING HOME CARE IN FIVE COUNTRIES***

**PRINCIPAL INVESTIGATOR:** Joan Van Nostrand, Chair, U.S. Representative  
Robert Clark, U.S. Representative  
Betty Havens, Canada Representative  
Anna Howe, Australia Representative  
Tor Inge Romoren, Norway Representative  
Wim van den Heuvel, Netherlands Representative

**PURPOSE:** The Outcomes of Nursing Home Care in Five Countries is one of a number of initiatives being conducted under the NCHS-sponsored International Collaborative Effort on Aging.

The aging of the population worldwide reveals the urgency of the issue of long-term care. The establishment of nursing homes is one way in which several societies have tried to meet the needs of a proportion of the dependent elderly. An international study including Australia, Canada, the Netherlands, Norway and the United States, supported by NCHS, makes available comparable data on the number of persons in nursing homes and the characteristics of nursing home care in these countries.

These data show how the different health care systems deal with the very dependent elderly receiving institutional care, including differences in nursing home outcomes using indicators like live versus dead discharges and place discharged to. Outcome indicators are related to characteristics of the patients prior to admission and to diagnosis on admission. Recommendations for strengthening comparable data across countries are discussed.

**PROGRESS TO DATE:** Several articles done by NCHS staff; proceedings of 1988 International Symposium on Data on Aging. Meetings and presentations, including: a roundtable presentation at the World Congress of Gerontology, Budapest, Hungary, July 1993; a symposium at the 47th Annual Scientific meeting, Gerontological Society of America, Atlanta, Georgia, November 1994.

**CONTACT PERSON:** Robert Clark, ASPE (202-690-6172)  
Joan Van Nostrand, NCHS (301-436-7104)

**COMPLETION DATE:** Ongoing

**REPORTS AVAILABLE:**

Clark, Robert F.: Home and Community-Based Care in the USA (October 1991).

[NTIS] [<http://aspe.hhs.gov/daltcp/reports/hcbcusa.htm>]

Clark, Robert F.: International Comparisons in Long-Term Care: Service Use (1993). [DALTCP]

Clark, Robert F.: Long-Term Care Demographic and Residential Patterns in Five Countries (draft). [DALTCP]

Van Nostrand, Joan, Robert F. Clark, and Tor Inge Romoren: Nursing Home Care in Five Nations (June 1993). [DALTCP]

[<http://aspe.hhs.gov/daltcp/reports/nh5nates.htm>]

Havens, Betty and Francois Beland, "Long-Term Care in Five Countries," Canadian Journal on Aging Special Issue (Fall 1996). [ ]

## VIII. *ASPE RESEARCH NOTES*

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### A. Overview

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ASPE RESEARCH NOTES are two-page reports designed primarily to provide research information in a form which is useful for policy officials within the Department. They are not a substitute for research articles published in peer-reviewed professional journals, nor for the executive summaries prepared for research and evaluation grants and contracts. Instead, they are internal staff memoranda which highlight significant findings for policy, primarily from in-house research and ASPE-sponsored grant and contract studies (although syntheses of other research are sometimes used). Fourteen ASPE RESEARCH NOTES have been published and there are several more in preparation.

The ASPE RESEARCH NOTES articles published so far have been well received within the Department, and have now been cleared for distribution outside of HHS. Although initiated through the Office of Disability, Aging and Long-Term Care Policy, they are written by policy analysts throughout ASPE.

ASPE RESEARCH NOTES have now also entered the cyberspace age, through their availability on the Internet. Articles are listed and can be downloaded soon after originals are disseminated. Full copies of the articles listed below can be viewed at the ASPE RESEARCH NOTES Internet address [<http://aspe.hhs.gov/daltcp/ASPErns.htm>] or requested from DALTCP at our address on Page 2.

### B. Completed Articles

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**TITLE: *ELDERCARE: THE IMPACT OF FAMILY CAREGIVERS' EMPLOYMENT ON FORMAL AND INFORMAL HELPER HOURS***

**SUMMARY:** The 1989 National Long-Term Care Survey is the first nationally representative survey to collect data on weekly hours of assistance received by ADL and/or IADL disabled elders living in the community by individual caregivers, both formal and informal. Thus, it is now possible to investigate the effects of primary caregivers' employment status on the amount of help that disabled elders receive, while simultaneously controlling for disability status and other potentially confounding variables. Under an ASPE task order contract, Mary Elizabeth Jackson of the MEDSTAT Group carried out a series of regression analyses, using, as the dependent variables, four different measures of hours of care: hours provided by the primary informal caregiver, hours from all unpaid sources other than the primary caregiver, hours from paid caregivers, and total hours of care received by care recipients from both paid and unpaid caregivers. Primary caregivers who are employed were found to provide significantly fewer hours of help personally (7.6) than primary caregivers not in

the labor force. However, there were no significant differences in the total hours of help received by care recipients associated with the employment status of their primary caregivers--except for part-time employees. That is, care recipients of part-time employed caregivers received significantly fewer total hours of care (8.4) than other caregivers (including both full-time employees and those not in the labor force). For care recipients of full-time workers, the lower number of hours that the employed caregivers personally provided was made up by comparatively greater use of a combination of other informal and paid help. The same was not true for part-time employed caregivers.

**CONTACT PERSON:** Pamela Doty, ASPE (202-690-6172)  
**RELEASE DATE:** August 1995  
**REPORT URL:** <http://aspe.hhs.gov/daltcp/reports/rn14.htm>

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**TITLE: POPULATION ESTIMATES OF DISABILITY AND LONG-TERM CARE**

**SUMMARY:** A large minority of Americans (42.7 million or 17.2%) have disabilities, 12.7 million of whom need long-term care. About 29.7% of all people with disabilities and 5% of the entire population need long-term care. Estimates of the number of people with disabilities or with long-term care needs are derived for both the community and institutionalized population for children, working age adults, and the elderly. Community estimates are based on the 1990 Survey of Income and Program Participation and estimates from institutions come from the 1990 Decennial Census, work from the University of Minnesota, and a Federal census of mental facilities.

**CONTACT PERSON:** Michele Adler, ASPE (202-690-6172)  
**RELEASE DATE:** February 1995  
**REPORT URL:** <http://aspe.hhs.gov/daltcp/reports/rn11.htm>

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**TITLE: DISABILITY AMONG CHILDREN**

**SUMMARY:** According to the 1990 Survey of Income and Program Participation and data from institutions, 4,536,000 children under 18 were reported as having a disability, with 4,444,500 living in the community and 91,800 residing in institutions. The leading causes of disability among children were (in order) learning disabilities, speech disorders, mental retardation and other developmental disabilities, mental illness, and respiratory conditions. Compared to children with no disabilities, those with disabilities were more likely to be boys, over age 6, White, and to have Medicaid; less likely to have private health insurance; and, almost equally as likely to be poor.

CONTACT PERSON: Michele Adler, ASPE (202-690-6172)  
RELEASE DATE: January 1995  
REPORT URL: <http://aspe.hhs.gov/daltcp/reports/rn10.htm>

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**TITLE: THE MEDICAID PERSONAL CARE SERVICES OPTION PART II:  
CONSUMER-DIRECTED MODELS OF CARE**

**SUMMARY:** This ASPE RESEARCH NOTES article is a follow-up to the earlier article--The Medicaid Personal Care Option, Part I: Cross-State Variations and Trends Over Time--that provided a descriptive overview of Medicaid personal care services (PCS) programs. Part II compares models of care that promote greater or lesser degrees of consumer control or choice and discusses research findings associating greater consumer satisfaction with increased choice. It concludes by discussing the relationship of these variables to indicators of worker satisfaction and worker pay and benefits, and by signaling some unanswered questions.

CONTACT PERSON: Pamela Doty, ASPE (202-690-6172)  
RELEASE DATE: December 1994  
REPORT URL: <http://aspe.hhs.gov/daltcp/reports/rn09.htm>

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**TITLE: THE ELDERLY WITH DISABILITIES: AT RISK FOR HIGH HEALTH CARE  
COSTS**

**SUMMARY:** According to the 1987 National Medical Expenditure Survey, elderly persons with severe disabilities (defined as needing assistance with one or more activities of daily living) had out-of-pocket health care expenses nearly four times greater than persons without disabilities. Approximately 9% of the elderly population was categorized as having a severe disability. Much of the difference in out-of-pocket expenditures is due to greater home health spending among those without disabilities, who also have far greater hospital and physician expenses. Older people with disabilities also spend a greater proportion of family income on health care than do older people with disabilities--12% versus 3%. However, there is substantial variation in expenditures among persons with substantial disability. For instance, over 70% of the severely disabled elderly do not have any out-of-pocket expenditures for home health care. Elderly persons with severe disabilities who were enrolled in Medicaid for only part of the year had highest out-of-pocket expenditures (nearly 20% of family income).

CONTACT PERSON: John Drabek, ASPE (202-690-6172)  
M. Eugene Moyer, ASPE (202-690-7861)  
RELEASE DATE: February 1994  
REPORT URL: <http://aspe.hhs.gov/daltcp/reports/rn08.htm>



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**TITLE: THE MEDICAID PERSONAL CARE SERVICES OPTION PART I: CROSS-STATE VARIATIONS AND TRENDS OVER TIME**

**SUMMARY:** The past decade or so has seen considerable growth in the number of Medicaid programs electing to cover personal care services--from only ten in FY 1979 to 29 in FY 1992. Substantial inter-State variation exists in Medicaid personal care services coverage. In 1988, participation rates per 1,000 aged/disabled Medicaid recipients ranged from a low of four (New Hampshire) to a high of 215 (South Dakota). Federal law and regulations place few limitations on States' discretionary authority. States that interpret Federal requirements more liberally are ones that have consciously sought to develop "consumer-directed" models of service delivery.

**CONTACT PERSON:** Pamela Doty, ASPE (202-690-6172)  
**RELEASE DATE:** November 1993  
**REPORT URL:** <http://aspe.hhs.gov/daltcp/reports/rn07.htm>

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**TITLE: LICENSED BOARD AND CARE HOMES: PRELIMINARY FINDINGS FROM THE 1991 NATIONAL HEALTH PROVIDER INVENTORY**

**SUMMARY:** Board and care homes are non-medical community-based facilities that provide at least two meals a day and routine protective oversight to one or more residents with functional limitations. Unweighted data from the 1991 National Health Provider Inventory (NHPI) indicate that there were about 30,000 licensed board and care homes in the United States serving over half a million persons. These data confirm that the board and care industry plays a significant role in the housing and care of the frail elderly and other functionally disabled populations.

**CONTACT PERSON:** Robert Clark, ASPE (202-690-6172)  
Joan Turek-Brezina, ASPE (202-690-6141)  
**RELEASE DATE:** May 1993  
**REPORT URL:** <http://aspe.hhs.gov/daltcp/reports/rn06.htm>

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**TITLE: INFORMAL CAREGIVER "BURNOUT": PREDICTORS AND PREVENTION**

**SUMMARY:** Three studies sponsored by HHS confirm previous research linking health impairment levels, advanced age, and various indicators of caregivers' physical burden and emotional stress with individual caregivers' decisions to stop giving care and increased likelihood of nursing home placement. In contrast, the lack of association between caregivers' employment status and withdrawal from caregiving or decisions to institutionalize fails to support some widely held theories about the effects of female

labor force participation on informal eldercare. Finally, informal care networks add paid helpers to cope with more intensive demands for assistance and/or losses in membership. Over time, however, formal services become less effective in preventing nursing home use.

**CONTACT PERSON:** Pamela Doty, ASPE (202-690-6172)  
**RELEASE DATE:** April 1993  
**REPORT URL:** <http://aspe.hhs.gov/daltcp/reports/rn05.htm>

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**TITLE: *ESTIMATING ELIGIBILITY FOR PUBLICLY-FINANCED HOME CARE: NOT A SIMPLE TASK...***

**SUMMARY:** A number of proposals have been advanced to establish a uniform home care benefit for the frail elderly. Measures of disability using the Activities of Daily Living (ADL) have been used to estimate the numbers of persons potentially eligible under such proposals. This article shows that, even with a common approach to eligibility based on ADLs, the estimates from national surveys vary widely--from 0.5 million to 3.8 million persons. Such differences are affected by program targeting criteria but also by each survey's sampling frame, sample size, wording of questions on ADL status and the selection of variables for analysis.

**CONTACT PERSON:** Robert Clark, ASPE (202-690-6172)  
**RELEASE DATE:** April 1992  
**REPORT URL:** <http://aspe.hhs.gov/daltcp/reports/rn01.htm>

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**C. Future Articles**

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**TITLE: *MEDICARE HOME HEALTH AGENCY SERVICES USE AMONG THE DISABLED AND NON-DISABLED ELDERLY***

**SUMMARY:** Between 1988 and 1994, Medicare home health agency expenditures grew by 550%. Many argue that most of this growth is not associated with post-hospital convalescence or rehabilitation but represents "long-term care" for chronically disabled elderly who primarily require long-term assistance with activities of daily living. This project is examining data from the 1989 and 1994 National Long-Term Care Surveys to compare Medicare home health service use of elderly Medicare beneficiaries with and without functional assistance needs. 1989-90 data indicate that disabled home health benefit users accounted for approximately two-thirds of all home health visits and two-thirds of total home health expenditures. Seventy-three percent of home health episodes experienced by Medicare beneficiaries were associated with a prior (or interim) hospital stay. Regression analyses show that severity of disability was a significant predictor of both home health use and more visits per episode, but indicators of medical need were also significant predictors. The study concludes that there is little

evidence in 1989-90 that the Medicare home health benefit was a major source of long-term care for disabled elderly. Although nearly one in five disabled Medicare beneficiaries used Medicare home health services over the one-year period, only 3% had "long-term" episodes (defined as more than 120 visits).

*CONTACT PERSON:* Pamela Doty, ASPE (202-690-6172)  
*RELEASE DATE:* 1997

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**TITLE: *ESTIMATES OF DISABILITY AND LONG-TERM CARE USING  
ALTERNATIVE DISABILITY DEFINITIONS***

**SUMMARY:** This will be a special 5-10 page edition of ASPE RESEARCH NOTES. It will be the first publication from newly released data in the 1994/96 National Health Interview Survey on Disability.

*CONTACT PERSON:* Michele Adler, ASPE (202-690-6172)  
Robert Clark, ASPE (202-690-6443)  
*RELEASE DATE:* January 1997

## **IX. ALPHABETICAL INDEX OF PROJECTS**

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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

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

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Long-Term Care and Disability Research: 1986-1989

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

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