



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

CONSUMER DIRECTION IN HOME AND COMMUNITY- BASED SERVICES:

RESEARCH PROJECT DESCRIPTIONS

October 1996

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.

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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 or contact the Project Officer, Pamela Doty, at HHS/ASPE/DALTCP, Room 424E, H.H. Humphrey Building, 200 Independence Avenue, S.W., Washington, D.C. 20201. Her e-mail address is: Pamela.Doty@hhs.gov.

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Office of the Assistant Secretary for Planning and Evaluation
U.S. Department of Health and Human Services

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TABLE OF CONTENTS

INTRODUCTION.....	1
SURVEY OF MEDICAID PERSONAL CARE.....	3
CONSUMER DIRECTION IN HOME AND COMMUNITY-BASED CARE.....	4
NATIONAL INSTITUTE ON CONSUMER-DIRECTED LONG-TERM CARE SERVICES	5
ISSUE PAPER ON PERSONAL ASSISTANCE AND RELATED SUPPORTS.....	6
ALTERNATIVE MODELS OF PERSONAL ASSISTANCE SERVICES	7
PERSONAL ASSISTANCE SERVICES "CASH AND COUNSELING" DEMONSTRATION/EVALUATION	8
FACILITATING CONSUMER-DIRECTED PERSONAL ASSISTANCE SERVICES	9
OTHER RELATED REPORTS ON CONSUMER DIRECTION.....	10

INTRODUCTION

"Personal assistance services" (PAS) is a broadly inclusive term used to refer to any and all forms of assistance, both human and technological, that enable persons with disabilities to accomplish basic and instrumental daily living activities (including but not limited to such tasks as bathing, dressing, moving around indoors and outdoors, and housekeeping).

In November, 1994, the Office of the Assistant Secretary for Planning and Evaluation's (ASPE's) Office of Disability, Aging and Long Term Care Policy (DALTCP) sponsored a planning meeting to identify high priority policy-relevant research questions related to personal assistance services and the research resources needed to address these questions. This workshop was the catalyst for DALTCP's major new initiative to study ways to expand consumer choice and empowerment in obtaining PAS.

This new initiative builds on two previous, completed projects:

- "A Survey of Medicaid Personal Care Programs" carried out by the World Institute on Disability, completed in April 1991.
- An issue paper on Personal Assistance and Related Supports, carried out intramurally by DALTCP staff, completed in November 1994.

Four currently ongoing projects make up the consumer-directed PAS initiative:

- "Alternative Models of Personal Assistance Services", being carried out by a team of researchers at the University of California, Los Angeles, and scheduled for completion in 1997.
- The "Cash and Counseling Evaluation/Demonstration", co-sponsored with the Robert Wood Johnson Foundation, being carried out by the University of Maryland Center on Aging, with Mathematica Policy Research, Inc. as the University subcontractor. The planned completion date is the year 2000.
- "Facilitating Consumer-Directed Personal Assistance Services", being conducted by the MedStat Group, with a planned completion date of December 1996.
- The "National Institute on Consumer-Directed Long Term Care Services", co-sponsored with the Administration on Aging, which is housed at the National Council on Aging in partnership with the World Institute on Disability. The Consumer Initiative grant is for three years: October 1995 through September 1998.

Brief descriptions of both ongoing and completed projects, including names and telephone numbers of individuals who may be contacted for further information, are appended.

SURVEY OF MEDICAID PERSONAL CARE PROGRAMS

PRINCIPAL INVESTIGATOR: Simi Litvak, World Institute on Disability, Oakland, CA

PURPOSE: Although the Medicaid home and community-based waiver program has been extensively studied, spending for home and community-based care is actually higher under the Medicaid personal care option. The purpose of this study was to provide detailed information on Medicaid personal care option programs by analyzing 1985 and 1989 data from a 50 state survey of home attendant programs for the elderly and younger physically disabled populations.

RESULTS: The study provides a statistical profile of all Medicaid personal care programs as compared to programs supported by other Federal and State funding sources. The comparative statistical data is supplemented by in-depth case studies of six Medicaid personal care programs.

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

COMPLETION DATE: April 1991

REPORTS AVAILABLE:

1. Kennedy, Jae and Simi Litvak: *Case Studies of Six State Personal Assistance Service Programs Funded by the Medicaid Personal Care Option* (December 1991). [<http://aspe.hhs.gov/daltcp/reports/casestud.htm>]
2. Litvak, Simi and Jae Kennedy: *Policy Issues Affecting the Medicaid Personal Care Services Optional Benefit* (December 1991). [<http://aspe.hhs.gov/daltcp/reports/optnales.htm>]
3. Litvak, Simi and Jae Kennedy: *Policy Issues Affecting the Medicaid Personal Care Services Optional Benefit: Appendices A through E* (December 1991).

CONSUMER DIRECTION IN HOME AND COMMUNITY-BASED CARE

PURPOSE: In March 1995, the Office of the Assistant Secretary for Planning and Evaluation (ASPE) and the Administration on Aging (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 HCBC service delivery systems.

RESULTS: The expert panel identified several themes and suggested strategies to promote State and local HCBC service delivery capacity. The panel recommended that Federal efforts should:

- Respond to States' needs for technical assistance to develop HCBC programs.
- Improve the knowledge and understanding of the effectiveness of various HCBC program components.
- Synthesize and disseminate information about HCBC 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 HCBC services.

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

COMPLETION DATE: 1995

REPORTS AVAILABLE:

1. Justice, Diane: National Association of State Units on Aging and National Association of Area Agencies on Aging, *Inventory of Research and Demonstration Projects on Consumer Direction in Home and Community*.

NATIONAL INSTITUTE ON CONSUMER-DIRECTED LONG-TERM SERVICES

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

PURPOSE: The Office of the Assistant Secretary for Planning and Evaluation (ASPE) and the Administration on Aging (AoA) have jointly funded a new research, technical assistance and dissemination initiative designed to educate people with disabilities, other 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; educate consumers or their representatives who want to use independent providers; and provide information to states and communities to help them evaluate the outcomes and costs of strategies involving consumer choice and consumer directed services.

The initiative will be conducted by a newly developed Institute on Consumer-Directed HCBC 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 HCBC services.

PROGRESS TO DATE: Project began in October 1995.

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

COMPLETION DATE: October 1998

REPORTS AVAILABLE: None yet available.

ISSUE PAPER ON PERSONAL ASSISTANCE AND RELATED SUPPORTS

PURPOSE: This paper provided background information on personal assistance services (on home and community-based services) and assistive devices for a working meeting of experts hosted by the Office of Disability, Aging, and Long-Term Care Policy 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.

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. 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:

1. Doty, Pamela, Nancy N. Eustis, and Brooke E. Lindsay: RESEARCH AGENDA: Personal Assistance Services and Related Supports (December 1994).
[\[http://aspe.hhs.gov/daltcp/reports/resagpas.htm\]](http://aspe.hhs.gov/daltcp/reports/resagpas.htm)

ALTERNATIVE MODELS OF PERSONAL ASSISTANCE SERVICES

PRINCIPAL INVESTIGATOR: A.E. Benjamin, University of California at Los Angeles, 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 program (IHSS). 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: Project begun in September 1994.

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

COMPLETION DATE: October 1996

REPORTS AVAILABLE: None yet available.

PERSONAL ASSISTANCE SERVICES "CASH AND COUNSELING" DEMONSTRATION/EVALUATION

PRINCIPAL INVESTIGATORS: Kevin Mahoney, University of Maryland, College Park, MD; Barbara Phillips, Mathematica Policy Research, Inc., Princeton, NJ

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 personal assistance services for the disabled. This demonstration will initially be carried out in two states: New York and Arkansas. One or two additional states may be allowed to join the demonstration in 1997. 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. 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, and other factors. The project is being co-sponsored by the Robert Wood Johnson Foundation.

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

COMPLETION DATE: 2000

REPORTS AVAILABLE: None yet available.

FACILITATING CONSUMER-DIRECTED PERSONAL ASSISTANCE SERVICES

PURPOSE: This project develops approaches and solutions for implementing consumer-directed service models for the delivery of home and community-based personal assistance services (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.

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; 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 clear, simple and accurate model contracts reflecting current federal regulatory and other requirements.

PROGRESS TO DATE: A Technical Advisory Group met in October 1995 to provide advice and guidance on the project. Several case studies have been completed and meetings with federal officials have taken place.

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

COMPLETION DATE: December 1996

REPORTS AVAILABLE: Report available December 1996.

OTHER RELATED REPORTS ON CONSUMER DIRECTION

1. Doty, Pamela, Judith Kasper, Simi Litvak, and Humphrey Taylor: *Consumer Choice and the Frontline Worker* (1994).
[<http://aspe.hhs.gov/daltcp/reports/frntlnwk.htm>]
2. Flanagan, Susan: *Consumer-Directed Attendant Services: How States Address Tax, Legal and Quality Assurance Issues* (April 28, 1994).
[<http://aspe.hhs.gov/daltcp/reports/condires.htm>]
3. 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/vahbapes.htm>]
4. 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). [<http://aspe.hhs.gov/daltcp/reports/rednhes.htm>]
5. 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>]
6. 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>]
7. Kennedy, Jae and Simi Litvak: *Case Studies of Six State Personal Assistance Service Programs Funded by the Medicaid Personal Care Option* (December 1991). [<http://aspe.hhs.gov/daltcp/reports/casestud.htm>]
8. Litvak, Simi and Jae Kennedy: *Policy Issues Affecting the Medicaid Personal Care Services Optional Benefit* (December 1991).
[<http://aspe.hhs.gov/daltcp/reports/optnales.htm>]
9. Litvak, Simi and Jae Kennedy: *Policy Issues Affecting the Medicaid Personal Care Services Optional Benefit: Appendices A through E* (December 1991).
10. Macro Systems, Inc.: *Review of State Quality Assurance Programs for Home Care* (April 1989). [<http://aspe.hhs.gov/daltcp/reports/squareves.htm>]

11. National Governors' Association: *State Long-Term Care Reform: Development of Community Care Systems in Six States* (April 1988). [<http://aspe.hhs.gov/daltcp/reports/strfrm.htm>]
12. 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>]
13. 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] [<http://aspe.hhs.gov/daltcp/reports/88cfpkes.htm>]
14. Office of Social Services Policy: *National Conference on Home Care Quality: Issues and Accountability--Volume I Proceedings* (1989). [NTIS: Accession No. PB91-122630] [<http://aspe.hhs.gov/daltcp/reports/88cfproc.htm>]
15. 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>]
16. Sabatino, Charles and Simi Litvak: *Liability Issues Affecting Consumer-Directed Personal Assistance Services* (July 1995). [World Institute on Disability and the American Bar Association Commission on Legal Problems of the Elderly].

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