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

RESEARCH AGENDA:

PERSONAL ASSISTANCE SERVICES AND RELATED SUPPORTS

December 1994

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.

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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, in conjunction with a contract between DALTCP and Lisboa Associates. 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 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. The Project Officer was Nancy Eustis.

RESEARCH AGENDA:
Personal Assistance Services and Related Supports

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This package includes the Background Paper which was distributed at the Office of Disability, Aging and Long-Term Care Policy's first "Expert" meeting and the Summary Paper of the meeting's discussion. The opinions and views expressed in this package are those of the authors. They do not necessarily reflect the views of the Department of Health and Human Services, the contractor or any other funding organization.

TABLE OF CONTENTS

BACKGROUND PAPER ON PERSONAL ASSISTANCE SERVICES AND RELATED SERVICES

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I. INTRODUCTION

The purpose of this paper is to provide background information for the Working Group Meeting on Personal Assistance to be hosted by the Office of the Assistant Secretary for Planning and Evaluation (ASPE) of the U.S. Department of Health and Human Services in Washington, D.C. on November 10, 1994. The purposes of the meeting are to: (1) select high priority policy-relevant research questions; (2) define research strategies in the context of existing research, resources, and data; and (3) to identify cost-effective studies appropriate to ASPE.

II. CONCEPTUAL FRAME WORK

A. “Personal Assistance Services”: An Emerging Paradigm

“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 the individual would normally do himself if he or she did not have a disability.” (Litvak et al. 1991). Such tasks include--but are not limited to--personal care (i.e., basic Activities of Daily Living (ADLs) as bathing, dressing, transferring, eating, toileting) or to other maintenance ADLs (i.e., those generally included in Instrumental Activities of Daily Living (IADLs) scales--such as shopping, housecleaning, meal preparation, doing laundry, etc.). PAS is not limited to services provided in specific settings (e.g., the home). Nor is PAS limited to human assistance. PAS can also include assistive technologies, environmental adaptations (including transportation services), animal assistance (e.g., guide dogs), and the appropriate training for utilizing both human and other forms of assistance.

The growing popularity of the term PAS as a replacement or synonym for “home and community-based long-term care”--reflects a reconceptualization of long-term care policies, programs, and services to take into account the needs of persons of all ages (not just those aged 65 and over) for functional assistance. Specifically, “PAS” reflects the philosophy of the Independent Living Movement for persons with disabilities. As such, the PAS concept encompasses modalities of assistance intended to enable persons with disabilities to engage in any and all life activities that nondisabled persons normally pursue: going to school, going to work, socializing with friends, participating in sports, hobbies, and other recreational activities, and attending community functions.

Until recently, the presumed purposes of long-term care, including home and community-based services, have been rather narrower in focus. “Long-term care” policy and research initiatives have been defined almost exclusively around the perceived service needs of “frail elders”--persons aged at least 65 but more often 75 or 80 and older whose chronic health problems and related disabilities necessitate or put them at risk of receiving care in a nursing home or related facility. The probability that disability will lead to nursing home use increases dramatically with age. Hence the traditional focus on “frail elders” has meant that the design of financing mechanisms and service delivery systems for “home and community-based long-term care services” has been typically conceptualized in terms of “alternatives to institutionalization.”

Even when home and community-based services targeted at frail elders have envisioned more than just preventing or postponing nursing home entry, the scope of services has been limited by implicit assumptions about retirement lifestyles. Persons of advanced aged are believed to lead comparatively inactive and “home-centered” lives in which maintenance rather than goal-oriented or productive activities take up most of the day. Relationships with other people are assumed to be largely limited to a small--and very likely shrinking--circle of close family, old friends, and long-time neighbors.

Over the past ten years or so, there has been a growing societal recognition of the barriers that often prevent persons with disabilities--especially those below the normal retirement age of 65--from active participation in the kinds of life activities (i.e., school, work) engaged in by their nondisabled peers. The most recent major embodiment of this rising awareness is the Americans with Disabilities Act (ADA). This landmark piece of legislation has created a civil rights framework according to which government and the private sector are increasingly being held accountable for promoting and facilitating access by persons with disabilities. The initial emphasis was on physical access to public places and via public transportation. The focus then moved to expansion of educational and employment opportunities. Most recently, the focus has begun to shift again toward greater attention to the financing and delivery of health care and related services such as PAS. Viewed against the backdrop of the ADA, policy makers are beginning to realize that the traditional aims of “home care” programs and policies are very limited and, as such, may be limiting--albeit unintentionally--of the potential of persons with disabilities.

B. The Policy Context: Health Reform 1993 and Beyond

ASPE--most specifically the Office of Disability, Aging, and Long-Term Care Policy (DALTCP)--played a central role in developing the long-term care provisions of President Clinton’s Health Care Reform plan. The centerpiece of the plan’s long-term care proposals was a greatly expanded home and community-based long-term care services program for people with significant disabilities of all ages. It was estimated that 3.1 million Americans would qualify for benefits and that nearly one-third of these individuals would be younger than age 65. Eligibility criteria for the benefit explicitly sought to bring in persons with certain disabling conditions that have often been overlooked in the past as bases for inclusion in the long-term care population. These target populations included persons with serious mental illness, persons with severe and profound mental retardation, and children with severe medical conditions or developmental disabilities under age six.

In response to input from consumers with disabilities and their advocates, the President’s long-term care reform proposals deliberately emphasized consumer empowerment in a variety of ways. In particular, consumers were afforded more choice and control through the inclusion of a requirement that States make personal assistance services available through both consumer-directed and professionally managed modes of provision. In addition, States were given the option to offer cash allowance and vouchers rather than paying directly for services. States were also given the option of capitating long-term care benefits for inclusion in managed health care arrangements. Finally, rather than listing defined benefits that could be covered, States were given the flexibility to tailor services specifically to the needs to individual beneficiaries.

The Clinton plan also included tax incentives for the purchase of PAS by individuals. These provisions were intended to facilitate the employment of persons with disabilities.

Although the 103rd Congress did not enact the President's health reform initiative, the proposed legislation is likely to serve as the starting point for future discussions about long-term care reform. Although the focus of future health reform initiatives may have shifted to the individual States in the immediate future, this does not in any way diminish the policy relevance of the issues raised in the design of the Clinton plan's long-term care reform proposals.

First and foremost, the concept of a "generic" long-term care system that encompasses the needs of persons with disabilities across all ages, diagnoses, and conditions is now firmly established. The Clinton long-term care reform proposal also attempted to reframe some of the key issues in policy and program design by acknowledging the desires of many persons with disabilities for more choice among service modalities and more possibilities for consumer-direction. However, the changes in direction introduced in the Clinton plan were not without controversy. Most notably:

- Some key supporters of long-term care reform in the Congress felt that Federal policy should provide much more direction to the States in terms of defining and mandating quality assurance safeguards.

- Some advocacy organizations expressed concern about the lack of definition of services that would and would not be covered in the new Federal/State program. Some advocates for persons with particular types of disabling conditions were skeptical that the types of PAS appropriate to their constituencies would be included in State plans. Some advocates also worried that many younger persons would be ineligible for coverage, despite the severity of their needs due to the proposed new program's emphasis on ADLs as eligibility criteria.

- State officials questioned the accuracy of underlying assumptions used to arrive at budget estimates for the proposed "capped" Federal funding--especially given that the proposed new program would be required to serve persons of all ages. Although the program did not, legally speaking, create an individual, disability-based "entitlement" to services, States were explicitly prohibited from using age, type of condition, or severity of disability criteria to prioritize applicants if funding proved inadequate to serve all who met the Federally-defined eligibility criteria.

These and other concerns raised about the Clinton long-term care proposals seem to ASPE staff to flag issues in need of further research.

III. INVENTORY OF POLICY ISSUES, KNOWLEDGE GAPS, AND FUTURE RESEARCH DIRECTIONS

A. Measuring PAS Needs, Service Use, and Costs in Relation to Persons with Disabilities Under Age 65

1. Policy Issues

Population-based estimates of need for services as well as information about likely service use cost patterns are required to project public program funding requirements. It is important to develop a capacity to project the amount, type, and likely cost of services among individuals with particular kinds of disabilities, at different ages. It is also important to understand the impact of defining certain kinds of services as ones that may or may not be covered--e.g., psychosocial habilitation and rehabilitation services for the mentally retarded and mentally ill. It is equally vital to understand the service use and cost consequences of providing services via particular service delivery models or modes (e.g., independent provider as compared to agency-employer personal assistants).

2. Research Completed or Underway

There is a wealth of nationally representative survey data available on the functional assistance needs of community-dwelling persons aged 65 and older and their patterns of formal and informal services use. In contrast, the 1990 Survey of Income and Program Participation (SIPP) has been the only source of nationally representative survey data on younger adults with disabilities. Nationally representative survey data on children under age 15 has been all but nonexistent.

To address the dearth of nationally representative data on the under-65 disabled population, ASPE has led a consortium of Federal agencies in supporting the design, development, and funding of the Disability Survey, a supplement to the 1994 and 1995 National Health Interview Surveys (NHIS). Phase I interviews screen in 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 began in January 1994 and will continue through December 1995. The Phase II interviews (conducted several months after Phase I) will collect detailed information on how people with disabilities live (i.e., their housing, transportation, and employment arrangements) and their service use and expenditure patterns. Phase II interviews begin in late 1994 and will continue until the fall of 1996. Nationwide, about 250,000 people in one million households will participate in Phase I and approximately 40,000 people will be included in Phase II.

ASPE has also funded, via an Interagency Agreement with the Census Bureau, special analyses of 1990 Census questions on disability. Due to the stringent confidentiality restrictions governing the 1990 Census, these analyses can only be performed by the Census Bureau.

In addition, ASPE has awarded a number of grants focusing on the service needs and services use of children with disabilities. In the area of measurement development, ASPE has funded an assessment of the policy implications of alternative functional definitions of disability among children. The Principal Investigator of this study is Ruth Stein at the Albert Einstein College of Medicine, Brooklyn, New York. Another grant, to Peter Brandon at the University of Wisconsin, attempts to measure the use of formal child care and the need for specialized child care services for families of children with disabilities. Projects at Johns Hopkins University and the University of Chicago will analyze data bases from Washington State and Illinois (respectively) concerning patterns of service use by disabled children.

3. Directions for Future Research

Are there particular age groups and types of disabilities--in addition to disabled children under age six--who are likely to be seriously under represented in national surveys? Are there any untapped data sources (i.e., available but un or under analyzed data bases) pertaining to these groups? What new data collection strategies are appropriate for obtaining information about these groups?

Are minority group persons with disabilities likely to be under represented in national data bases? Are there particular groups with special needs or potential problems in accessing services that merit special research efforts?

Is there a need to develop measures beyond the traditional ADL/IADLs for measuring service needs that may be appropriate for persons with particular types of disabilities? Do ADL and IADL impairment measures adequately capture the range of service needs among younger disabled persons who are expected to attend school or who may be able to work? Are there measures that have been developed that should be tested?

What is the potential to use State Medicaid claims or other program data bases for analyzing cost patterns?

How can we address the problems posed by existing patterns of service use being so heavily influenced by the rules and regulations of existing payment sources?

B. Quality Assurance

1. *Policy Issues*

A substantial percentage (almost half) of public programs that currently finance PAS services permit personal attendant services to be provided only through licensed home health or home care agencies. Such requirements contradict the strongly expressed preferences of many persons with disabilities, especially those under age 65 who are involved in the Independent Living Movement, to hire, fire, and manage their own providers. On the other hand, many other States limit consumer choice by requiring the use of independent providers because this mode is believed to be more cost efficient. Whereas some PAS users may wish to hire and manage their own assistants, others may find this responsibility a burden or may feel ill prepared to undertake it. Still other consumers may be mentally incapable of hiring and managing their own assistants.

Programs requiring the use of independent providers also raise questions about the adequacy of public accountability vis a vis quality and safety issues, including client vulnerability to provider abuse or neglect. Can clients adequately judge the quality of care they are receiving? Are they able and willing to take appropriate actions even when they know that they realize that they are receiving substandard services or even when they know that they are being abused and exploited? Is it possible to assure timely access to back-up and replacement sources of help and to arrange for liability insurance protection when consumers are responsible for hiring their own independent providers?

Many of the same issues come up with respect to case management by State-employed case managers or provide agencies that specialize in providing case management services. For example, to what extent should receipt of case management services or the nature and frequency of case management be a matter of consumer choice?

How much risk of untoward consequences are PAS consumers willing to assume in connection with consumer direction and what level of risk is politically acceptable? If future policy directions promote greater choice among modalities of care provision, what criteria--if any--should be used to override consumer preferences and assign individuals to consumer-directed versus professionally managed service modes? Advocates argue that the abilities and willingness of consumers to assume management responsibilities should be determined through an objective assessment process (Nosek 1991). However, formal assessment is not standard practice.

Advocates also argue that consumers who want to manage their own providers should be afforded opportunities for training in PAS management skills and some consumers may only become capable of managing their own providers if they receive such training. Independent Living Centers routinely offer training in PAS management for persons with disabilities and the Administration on Developmental Disabilities has funded training programs in self-advocacy for individuals with developmental disabilities.

2. Research Completed or Underway

We have identified only a handful of studies--mostly very small-scale--that have attempted to measure preferences for or compare outcomes of consumer-directed versus professionally managed services. In 1991, the Commonwealth Fund sponsored a survey in three States of low-income individuals age 65 and older receiving Medicaid funded personal care services in which clients who reported more consumer choice also reported higher levels of satisfaction. Mattson-Prince (1994) has reported favorable health and psychosocial outcomes associated with provision of services through an independent living model of consumer-directed PAS as compared to agency-provided services, based on data collected from a small sample of persons with spinal cord injuries. Similarly, positive outcomes were also found to be associated with consumer direction in a National Institute for Disability and Rehabilitation Research (NIDRR) study carried out by the Human Service Research Institute and the United Cerebral Palsy Association that involved a small sample of consumers with mobility, sensory, and cognitive impairments (Kimmich 1991).

Additional NIDRR-sponsored projects focusing on outcomes of consumer-directed as compared to professionally managed services are currently underway at Baylor University’s Center for Research on Women with Disabilities, the National Rehabilitation Hospital, and the World Institute on Disability (WID).

ASPE has just awarded a contract to the University of California at Los Angeles (A.E. Benjamin, Principal Investigator) to design and carry out a survey of PAS consumers in California’s In-Home Supportive Services Program (IHSS). The study will compare outcomes associated with client-directed modes of service provision (independent provider and supported independent provider) and professionally managed (agency) services. Outcomes measures include consumer satisfaction, health status, consumer safety, and consumer empowerment. This study builds on related research, now nearly completed, that was sponsored by the State of California and conducted by Carol Barnes at Sacramento State University.

In 1993, ASPE has funded a Task Order contract (with SysteMetrics, Inc., Cambridge, MA) to examine the criteria that State home and community-based services programs use to determine whether or not clients do or do not need case management and at what levels of intensity. Case studies focused on State-administered, statewide programs in Maine, Connecticut, Washington, and

Oregon as well as localized programs in Ohio (two county-funded programs) and California (a hospital-affiliated program). This study is nearing completion.

The WID and a few other programs have done some adaptation of independent living skills training programs to make them appropriate to elderly users of PAS.

With respect to liability concerns, the Commonwealth Fund sponsored some preliminary research several years ago by Marshall Kapp at Wayne State University and Charles Sabatino at the American Bar Association (Committee on Legal Problems of the Elderly). Through a Task Order contract with SysteMetrics, Inc., ASPE examined existing concerns about and methods of addressing liability in eight States (Flanagan 1994). Nearing completion is a study of liability issues affecting consumer-directed PAS. It is directed by Simi Litvak of WID and Charles Sabatino and funded by the Retirement Research Foundation. The study addresses tax law, personal injury, and licensure/certification liability.

3. Directions for Future Research

How can we gauge consumer preferences for consumer-direction or for professional case management or quality monitoring, given that existing programs tend to offer little choice?

Are there other ways of conceptualizing “consumer-directed” PAS besides the “independent provider” mode? Do other models already exist that could be evaluated? Or would it be preferable to develop models that could be demonstrated and find sites where they might be implemented?

What priority should be given to evaluating the effectiveness of PAS management training? If such research seems worthwhile, what existing training programs might be good candidates for evaluation?

Can ASPE facilitate clarification of Federal tax and labor laws that pertain to employers of independent providers? Should guidelines for States and employers be developed?

C. Assistants: Paid and Unpaid

1. Policy Issues

Most persons with disabilities of all ages receive PAS predominantly from informal helpers--i.e., unpaid family, friends, and neighbors. According to the 1990 SIPP, which is the only source of comparative data available, younger persons with disabilities rely even more heavily on informal supports than do older persons. Informal caregiving accounts for 92 percent of caregiving to the nonelderly and 83 percent for the elderly. (Adler 1994).

It is not clear, however, to what extent such heavy reliance on informal support is due to lack of access to--including inability to afford--paid assistance versus a genuine preference for relying on family members. Advocates point out that persons with disabilities who have no choice but to depend on family for unpaid assistance may be hampered in their efforts to develop or to maintain levels of independence and self-direction that might otherwise be achievable. This can be so at any age, but is particularly true of individuals who are born with disabilities or who develop disabilities prior to adulthood and rely on their parents for PAS. Dependence on parental assistance poses additional problems in cases where children with disabilities can expect to outlive their parents-- which is becoming more and more the norm.

The appropriate public role in helping persons with disabilities gain access to paid assistance--at least in regard to long-term care for the elderly--has traditionally been seen as largely limited to assisting and providing respite to family caregivers. Substitution of formal for informal services is seen as legitimate only in those situations in which disabled elders lack close family or their family caregivers have died or become incapacitated or where there appears to be serious potential for abuse.

However, for a child to continue being dependent on parental support into adulthood runs counter to cultural expectations in our society. Thus, accessing help from nonfamily members--which for persons who need extensive assistance must include substantial paid assistance--is increasingly being seen by many advocates for younger persons with disabilities as an important developmental step and “rite of passage”. That is, obtaining paid assistance is viewed as part of the normal maturation process for a person with disabilities seeking to negotiate the transition from child to adult.

Moreover, concerns are increasingly being raised about the feasibility and the fairness of maintaining traditional expectations for family members to provide informal assistance, especially now that most women are in the paid workforce as much out of economic necessity as by desire. Many advocates believe that if persons with disabilities prefer to have family members provide the assistance they require, they should be able to pay them. Whereas some public programs permit family members to be employed as paid caregivers; others do not.

At the same time, many persons with disabilities and their advocates are troubled by a prevailing market for PAS in which persons with disabilities cannot readily obtain the assistance they need without becoming involved in what seems to many to be the “exploitation” of service workers who are poorly paid and often lack access to pension, health insurance, unemployment compensation, and other employee benefits. In addition, the current structure of the job market for PAS workers leaves many assistants unemployed or only able to find part-time employment for significant periods of time in any given year. Opportunities for promotion and advancement are rare. These and other unattractive features of PAS work create problems for recruitment and retention of individuals with the appropriate skills and attitudes to provide high quality PAS services.

2. Research Completed or Underway

There is an extensive literature on informal elder care that, from a polity perspective, has focused especially on aspects of stress and burden among family caregivers and on the usefulness of respite services. Much less work seems to have been done around family caregiving in relation to younger persons with disabilities.

Nathan Linsk, et al. (1988) have done seminal work in regard to public policies toward payment of family caregivers and some recent studies are examining such policies in international comparative perspective.

Bill Crown at Brandeis University and SysteMetrics, Inc. and his colleagues (Crown, et al. 1991, 1992; Crown 1992) have used data collected by U.S. Labor Department surveys to profile the existing labor market for PAS workers.

ASPE recently sponsored a small-scale study looking at the mechanisms that State programs use to ensure that the employment of consumer-directed PAS workers complies with Federal and State requirements regarding tax withholding for Social Security and coverage for unemployment and workers compensation insurance. (Flanagan 1994)

ASPE’s contract with A.E. Benjamin of UCLA (described earlier) has a subsidiary purpose of examining the use of family caregivers as paid assistants in California’s IHSS program. This study also will include a telephone survey of some 500 PAS workers (whose employers will also have been interviewed) to obtain information on worker characteristics associated with higher consumer satisfaction as well as workers’ own levels of job satisfaction.

A number of well-regarded studies on enhancing the availability and performance of paraprofessional providers of personal assistance services have been carried out. These include Bayer, Stone and Friedland 1993; Feldman 1994; Feldman, Sapienza and Kane 1990; Cantor and Chichin 1990. Additional work along these lines is being carried out by Robert and Rosalie Kane at the University of Minnesota, and Bill Crown and colleagues at SysteMetrics, Inc.

Some interesting work has also been done in the areas of job training (e.g., training welfare recipients to become PAS workers) and alternative recruitment strategies. For example, ACTION (recently renamed the National Corporation for Community Service) has sponsored demonstrations and evaluations of its senior companion program. Approximately 12,000 low-income volunteers are paid stipends of $2.50 per hour to provide at least 20 hours per week of escort and other PAS that do not involve “hands-on” assistance. Recipients of these volunteer services may be older persons or younger adults with disabilities. The Corporation is interested in greatly expanding the number of senior companion volunteers. Currently, PAS has also included as a service option for younger people under the newly created National Service Corp. The Administration on Developmental Disabilities’ Americorp projects are training and placing 70 PAS volunteers for service in three States (Alabama, Georgia and Pennsylvania).

3. Directions for Future Research

What kinds of research needs to be done specifically around family caregiving relationships involving younger--as distinct from elderly--persons with disabilities? What data sources might be used?

What kinds of cooperative research might be pursued with the Department of Labor around paid PAS workforce issues?

Are there States that are undertaking or considering innovative programs involving the recruitment, training, and retention of PAS workers that merit evaluation?

Are there alternative models of organizing PAS employment (that is, alternatives to the “independent provider” and “certified agency” modes of employment) that merit demonstration and evaluation?

Should we consider evaluating programs that recruit, train, and place volunteers as well as paid workers?

D. Cash Versus In-Kind Benefits Versus Tax Subsidies

1. Policy Issues

Many persons with disabilities express a preference for cash payments or vouchers which enhance consumer control over spending of their personal assistance dollars.

In the United States there is a bias toward providing services and “in-kind” benefits, rather than cash (Keigher and Stone 1993), and few cash programs exist. Exceptions include the Department of Veterans Affairs (VA) Housebound Aide and Attendance Allowance program, voucher programs offered by some counties in some States, and a few State programs which provide cash supplements. Colorado’s Home Care Allowance Program, Wisconsin’s Community Options Program, Pennsylvania’s Family Support Services (for families of people with mental retardation) are examples of States offering cash payments (Cameron 1993). A primary obstacle to public acceptance of cash benefits is the issue of accountability. Policy makers are concerned about misuse of cash payments (e.g., to buy liquor, drugs, etc.) and doubt consumers' ability to make appropriate choices among providers and services in a fragmented and confusing system.

Cash or disability allowances, however, are prevalent in European countries. In Germany, the German Federal Ministry of Labor and Social Affairs estimates 80 percent of eligible participants in a government program chose cash payments over in-kind benefits (Cameron 1993). Forty-five percent of clients given a choice opted for cash instead of services in a demonstration program in the Netherlands (Miltenburg 1994).

President Clinton's long-term care reform proposals included the creation of special tax credits to help defray the costs of PAS for employed persons with disabilities. Critics of this approach argue, however, that tax credits favor high earners. Some advocates--such as Drew Batavia, a PAS user who has also done research on PAS and currently works on the staff of a conservative Republican Senator--believe that the traditional distributional biases of tax credits can be overcome by making PAS tax credits refundable.

2. Research Completed or Underway

An ASPE-sponsored evaluation of the VA Housebound Aide and Attendance Allowance program compared 139 recipients of cash to 610 persons receiving in-kind services using data from the National Long-Term Care Survey. The results indicated that recipients of cash were no worse off in terms of acute care utilization, and that cash benefits may be more cost effective than in-kind services for many beneficiaries (Grana and Yamashiro 1987).

The Robert Wood Johnson Foundation has sponsored an 18 month investigation of cash and counseling programs that is being carried out by James Firman and Kathy Cameron at United Seniors Health Cooperative. This research will produce primarily qualitative descriptions on existing cash and counseling programs in Europe (Austria and Germany) and the United States.

3. Directions for Future Research

What would be a useful strategy for combining demonstration and evaluation components in order to study a program of cash grants to consumers?

What possibilities exist for designing and evaluation demonstration programs that would permit public program beneficiaries to choose between cash payments and in-kind services?

How can we address similarities and differences between cash payments to persons with disabilities and family allowances--concepts that are analytically distinct but often overlap in practice?

Would it be useful to conduct preference surveys to gauge the potential popularity of cash versus in-kind services, that characteristics of those who would prefer each type of benefit, and the extent to which persons with disabilities would plan to use cash benefits to purchase PAS or would tend to rely on unpaid help within the household and to use cash benefits to supplement household income?

How might we attempt to gauge the potential impact of tax credits or other tax subsidies on the employment of persons with disabilities or the affordability of PAS to persons with disabilities? What methods could be used: simulations? surveys? demonstrations?

E. Assistive Technology

1. Policy Issues

Assistive technologies--especially those that could substitute for human assistance--appear to have significant potential to reduce the costs of PAS. They also hold out the promise of making persons with disabilities more truly independent by reducing their reliance on other persons whose possibly conflicting needs and wishes have always to be taken into account.

There has been significant growth in use of assistive technology in the last decade (LaPlante, Hendershot, and Moss 1992). However, some unmet needs for technology were reported in the 1990 NHIS Supplement on Assistive Devices (Adler 1994; LaPlante 1992).

Promoting access to assistive technology involves more than the simple purchase of a piece of equipment. Persons with disabilities may also require assistance in selecting appropriate devices, help with installation, training in the proper use of equipment, as well as access to maintenance and repair work and replacements when equipment becomes nonfunctional or obsolete (Enders 1988). Environmental adaptations/modifications to homes as well as public places may also include under a broad definition of assistive technology.

One major set of policy issues concerns mechanisms for financing assistive technologies. Both Medicare and Medicaid can provide funding for some forms of assistive technology but the implications for access posed by coverage rules related to “medical necessity” are not entirely clear. Differences across States in interpretation of medical need limitations raise equity concerns (Seelman 1993). The Tech Act provides Federal funding for technical assistance, information, training and public awareness programs with regard to the provision of assistive devices and services. This is done through Federal grants to States (Title I) and Programs of National Significance (Title II).

Third party payers must impose some forms of “gatekeeping” to prevent fraudulent and abusive marketing of ineffective technologies to persons with disabilities as well as to control costs more generally. But what criteria are appropriate?

2. Research Completed or Underway

Research in the area of assistive technology has been largely clinically oriented, pertaining to specific devices and assessments of their ability to meet physiological long-term care needs (Agree 1994; Batavia and DeJong 1990).

The National Council on Disability conducted a study, involving significant consumer input, whose purpose was to identify problems with the current system of financing assistive devices. Respondents reported on the complexity of the system, poor information on how to access devices, lack of coordination between funding agencies, lack of training and maintenance resources, lack of individual choice over assistive technology services, and the significant numbers of people who remained unserved or under served (National Council on Disability 1993). Seelman (1993) notes the following additional access barriers: the deficiency of consumer information on technology, lack of ties to the technology culture, language differences, and institutional living situations.

NIDRR has funded a number of projects focusing primarily on access issues in connection with the Tech Act. These include grants for several new rehabilitation and research training centers (RRTCs). An RRTC on Aging with a Disability has been established at Los Amigos Research and an RRTC on Aging with a Spinal Cord Injury has been established at the Education Institute. An RRTC on Families of Adults with Disabilities has been set up at Through the Looking Glass in Berkeley, which has a study underway to identify, develop, and evaluate assistive technology for parents with disabilities. The RRTC on Independent Living at the Institute for Rehabilitation and Research has been awarded a five year grant to develop and evaluate an independent living center- based model program that will offer assistive technology repair and maintenance. The program also offers counseling on sources of purchase of equipment and seeks to improve the delivery of rehabilitation engineering services.

In addition, NIDRR has funded a research and demonstration project at RESNA to develop quality assurance guidelines for assistive technology delivery. This includes the development of content for criteria, outcome measures, and provider qualifications. A NIDDR grant to the State University of New York/Buffalo focuses on dissemination and utilization programs for assistive technologies and environmental intervention for older people with disabilities.

ASPE's role in sponsoring research on assistive technology has been quite limited to date. Several years ago, ASPE conducted a small intramural research project on assistive technologies that was primarily a literature review and "think piece" (Elliott 1991). In connection with ASPE's sponsorship of analyses of 1982, 1984 and 1989 National Long-Term Care Survey data, Ken Manton and his colleagues at Duke University have explored the question of substitutability of technology for human help. Their findings indicated that use of assistive technology is growing and that some substitution of technology for human assistance is taking place (Manton, et al. 1993). However, work by Agree (1994) suggests that use of assistive technology by older persons tends more often to supplement than substitute for human assistance. Most of the research on patterns of use of assistive technology to date has focused on the over 65 population of persons with disabilities.

3. Research Questions

How can we move forward in determining the potential substitutability of assistive technologies for human assistance?

What kinds of research partnerships might be possible between ASPE and other HHS agencies such as the Agency for Health Policy Research (AHCPR, FDA) with responsibilities for evaluating the safety and effectiveness of medical devices (a mandate which presumably also includes some assistive technologies)?

What are alternatives to "medical necessity" as a criterion for needing assistive devices and for constraining costs? To what extent do sources of funding for PAS allow for purchase of assistive devices, and more generally, can funds for PAS and assistive devices be pooled to facilitate substitution as appropriate?

F. PAS Financing and Service Delivery System Infrastructure

1. Policy Issues

PAS or home and community-based long-term care services programs are typically administered at the State and local level by organizations associated with "welfare" programs (e.g., county social services departments) or by State agencies and non-profit organizations (e.g., State units on aging, area agencies on aging) that were established to address the needs of disabled elders or other narrowly defined groups (e.g., the mentally ill or mentally retarded). As a result, persons with disabilities under age 65 who are not mentally retarded or mentally ill are typically referred for purposes of assessment, case management and service provision to programs and organizations designed for and used to dealing with persons age 65 and older. In recent years, for example, Area

Agencies on Aging (AAAs) have been increasingly called up to serve disabled children and their parents, young adults with AIDS, adults under age 65 with disabilities resulting from spinal cord and head injuries (including victims of violence who may previously have been involved in the criminal drug culture) and other individuals whose backgrounds and perspectives on life are undoubtedly quite different from that of the prototypical “frail elders” who were the original target population for AAAs and other elements of the “aging network.” The question arises whether AAAs and other such programs and organizations are capable of attending to the distinctive, age-appropriate PAS service needs of younger persons with disabilities. Or, in effect, do they simply deal with younger clients as if they were “prematurely aged” and develop the same kinds of service plans and recommend the same kinds of service modalities that they would for elderly clients?

Some models of service delivery have been developed for specific target populations. For example, “supported living services” is an approach that was designed by MR/DD professionals for this particular target population. The questions arises whether the development of “generic” financing and service delivery systems designed to accommodate persons with disabilities of all ages, all types of conditions and diagnoses will promote more rapid diffusion and “cross-fertilization” of new models? Or will generic systems tend to dampen innovation and promote “one-size-fits-all” approaches?

Case managers and counselors who work with younger persons who are mentally retarded or mentally ill tend to see their jobs rather differently than those who work with elderly clients. Those who work with younger clients see their role as maximizing the client’s participation in the community and training him or her to assume greater independence and self-direction. Case managers for frail elders focus on needs assessment, care planning, and the authorization of payment for specific services to be made to specific providers.

Case managers for frail elders tend to develop a service plan based on one or two home visits, then make periodic visits to see whether the plan is working or needs to be revised. In contrast, case managers for younger disabled persons with cognitive impairments seem to provide more direct personal support to their clients.

Case managers for mentally disabled clients also tend to work more intensively with clients in helping them plan their futures--via exercises in developing short and long-term care goals and laying out the steps to achieve those goals. They often help arrange housing (including housing outside of specialized disability settings). They help arrange volunteer work for clients and to place them in paying jobs when possible. They go with clients to help them learn how to use public transportation to get to their volunteer or paid jobs. It is not clear, however, whether or to what extent the funding mechanisms, rules and regulations, and existing organizational structures in existing “home and community-based care” programs designed principally for frail elders can accommodate the broader conceptions of case management that are used in programs designed for the MR/DD and mentally ill populations.

2. Research Conducted or Underway

ASPE's recently funded contract with A.E. Benjamin of UCLA to survey clients in the California IHSS program (described in greater detail earlier) will permit comparison of the attitudes and experiences of older as compared to younger clients. California's IHSS program, more than many State programs, appears to have been designed to meet the needs of clients across the age spectrum (although some critics believe that it is not well designed to meet the needs of persons with cognitive as opposed to physical disabilities).

ASPE funded research on community supported living arrangements (CSLA) under a Task Order contract with Brian Burwell at SysteMetrics, Inc. This work is now being followed up with a project to develop a strategy for information dissemination about CSLAs.

ASPE also has a collaborative project on "infrastructure" underway with the Administration on Aging. The purpose of this project is to look at the organizational capacity at State and local levels, particularly in State units on aging and AAAs, to administer home and community-based services programs along the lines of the new benefit proposed in the President's health care reform initiative.

3. Directions for Future Research

Should we undertake research that compares consumer preferences and outcomes for particular types of clients in "generic" versus "specialized" (i.e., target population specific) programs? If yes, what programs might make good candidates for study?

Should we be developing "benchmarks" for evaluating State and local program infrastructure from the perspectives of several different target populations? If so, how should we go about developing such measures?

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SUGGESTED RESEARCH PRIORITIES AND PROJECTS PERTAINING TO PERSONAL AND RELATED SUPPORTS FOR PERSONS WITH DISABILITIES:

Summary of Discussion and Written Comments From Expert Meeting

December 1994

Goals of the Expert Meeting on Personal Assistance and Related Supports included: 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 services (PAS).

Participants placed highest priority on research to measure service needs, use and costs; quality assurance; and infrastructure/implementation issues in discussion and written comments (see Table). This document is a summary of suggested studies in areas discussed.

We welcome feedback on this summary, particularly on the relative importance of the studies listed and on data sources for conducting the research.

The substance of the meeting will help us elaborate research projects contained in the draft 1995 research plan of the Office of Disability, Aging, and Long-Term Care Policy (DALTCP) as well as identify additional research strategies. The following summary of the meeting reflects the discussion on each section of the Background Paper as well as written comments provided at the end of the meeting or subsequently.

Priority Rankings on Questionnaire
(14 of 25 Participants)

Topic Area	Total "High" Scores
Service needs, use and costs	10
Quality Assurance	8
Cash versus In-Kind Assistance	3
Assistive Technology	2
Infrastructure	8
Workforce (left off survey by mistake)	2 (out of a total of 4 written in scores)

I. MEASURING NEED FOR, USE, AND COSTS OF PAS

Participants placed high priority on understanding patterns of expressed need and use of personal assistance services. For example, we need simple descriptive information about how people with varying levels of disability or different ages currently use PAS and what additional services they also use.

The group also emphasized a need for better understanding of agency costs in providing services. What are the relative costs of various components of agency services, and of different types of agencies? How might policy changes affect these costs?

In addition, it was noted that data collection should measure variation by ethnicity, rate, and gender as well as take into account differences in rural and urban PAS service settings. It was noted that the homeless are undercounted in surveys.

A. Service Needs and Use

- Document how personal assistance or similar services are used with or without other services by the elderly and younger people with disabilities. Document what services consumers buy for themselves (i.e., what they pay for out-of-pocket).
- Compare use of services by persons with similar disabilities. For example, PAS needs are similiar for persons with similar types of spinal cord injury.
- Identify PAS tasks by function and measure average length of time to accomplish each task.
- Study the degree to which reimbursement policies and existing service settings rather than consumer need determine the types of services delivered.
- Study needs for PAS by disabled parents to perform parenting tasks; conduct a follow-up of disabled parents in Disability Supplement to the National Health Interview Survey.

B. Cost Studies

- Develop a methodology for disaggregating the costs of providing agency directed services; e.g., for supervision, RNs, scheduling, overhead, and indirect costs.

Include specification of “home office” costs. Any study should be consistent with how agencies account for costs and should identify ways to engage organizations in the inquiry.

- Compare costs and outcomes between: different modes of agency-administrated services; certified home care agencies and noncertified agencies that provide PAS.

- Study cost-effectiveness of supervisory requirements associated with Medicare home health benefits. Compare costs of different types of supervisory visits. Compare outcomes of supervisory visits conducted with or without worker present.

- Provide Medicare waivers so home health agencies could deliver care differently and study consequences for costs and outcomes. For example, we know little about what models of nurse instruction and supervision on an “as-needed” basis would cost.

- Study PAS costs for persons who need 24-hour-per-day services; use New York experience.

II. QUALITY ASSURANCE

Participants placed high priority on approaches to assuring quality using an independent provider or consumer-directed approach to PAS. There was considerable emphasis on further specification of a fiscal or supportive intermediary, such as a third party (public or private) that may perform such tasks as paying taxes, screening or training workers. Protections for both consumers and workers were covered in this discussion.

Participants also proposed costs effectiveness comparisons of various modes of providing PAS as well as research regarding measuring outcomes.

A. Facilitating Quality for Client-Directed PAS

- Examine “supportive brokerage” and supportive intermediary models as flexible ways to ensure that people of all ages and disabilities get support and as much control as they choose and can handle. Analyze the cost effectiveness of the supportive intermediary model verses the traditional agency model. Also compare this approach with other approaches; e.g., Independent Living Center referral and training services or those identified below.

- Evaluate the effectiveness of various types of care management to facilitate client-directed services such as background checks, occasional monitoring, and arrangements for backup. Assess effect on consumer satisfaction.

- Analyze the impact of government subsidized emergency back-up systems in terms of need, projected costs, and effectiveness.

- Develop model contracts for use between PAS providers and consumers, and between consumers and payer agencies to reduce risk and enhance quality.

- Assess the feasibility of developing models for consumer and employee training around PAS. Use the training process to assess clients’ ability to direct their workers. Look at Massachusetts and Maine for examples. Research how assistive technology can be used in training consumers of PAS. For example, MedCom Video, Inc., in California has videos for training consumers of PAS.

- Identify regulations that are minimally necessary to ensure health and safety of consumers and workers (OSHA, tax, labor). Develop a model for use by States that clarifies IRS and Department of Labor requirements pertaining to the PAS independent provider.

B. Cost-Effectiveness Studies

- Compare costs and outcomes between agency and independent provider modes in States other than California. Possible sites include Wisconsin and Virginia.

- Evaluate service use, cost and consumer satisfaction for PAS under managed care, and fee-for-service programs under Medicaid, Medicare, and other State funded programs (for both SSI population under 65 and for frail elderly population).

- Evaluate consequences for costs and consumer satisfaction before and after changes in nurse practice acts to allow less skilled personnel to perform tasks formerly done by nurses.

- Perform randomized testing of different models of quality assurance; e.g., case management, an ombudsman-type complaint mechanism, and regulations enforced through survey mechanisms. For each, document problems and how well they were solved.

C. Quality Indicators

- Study quality indicators and relevant outcomes from the consumer perspective, and develop a process to measure quality. Possibly pursue a quality study in selected Medicaid personal attendant programs that would focus on consumer measures of quality.

- Develop alternative frameworks for conceptualizing needs and outcomes for PAS. Do this across disability subpopulations. Consumer satisfaction measures should ask how do you want to live? how are you living? For policy purposes, it is necessary to consider the extent to which consumer preferences and satisfaction should drive a program. What is good enough?

III. WORKFORCE ISSUES

The group discussed research to evaluate new sources of personal assistance workers, including use of volunteers, alternative sources of paid providers, and issues regarding immigration policies.

This discussion also covered research on supports to agency employed and independent providers to improve working conditions. Note that much of the above discussion on quality assurance is also relevant; e.g., fiscal and supportive intermediary mechanisms.

Several studies on family caregiving were also proposed, particularly to examine its use in comparison with, or in addition to, paid PAS.

A. Worker Supply

- Study longitudinal trends in worker supply, including number of workers and hours worked. Data sources, including the Home Health and Hospice Survey and Bureau of Labor Statistics (for paraprofessional statistics). Also consider doing more work with the Current Population Survey.

- Study use of volunteers, from the Senior Companion program for example, to supplement/complement paid workers. Conduct a study to test the cost effectiveness of Senior Companions in the PAS context.

- Study use of alternative sources of PAS workers such as immigrants, “deadbeat parents” who pay back with long-term care services, AFDC mothers who want to care for families, or former hospital employees who have been laid off. With regard to employing immigrants, investigate immigration policy and practice regarding making exceptions or a special category for PAS workers. Evaluate impact of Prop 187 in California on supply of workers.

B. Improving Working Conditions (see also Section IIA above)

- Conduct a comparison of turnover, wages, benefits, and job satisfaction of workers employed by agencies and of workers directly hired by consumers.

- With regard to independent providers, identify approaches to and best practices in training, providing compensation and benefits, and other support systems in the field now. Study impacts on availability and quality of providers, as well as worker satisfaction. What is the best model to improve employment of workers? Study Wisconsin’s experience. Explore possibilities of a national group health insurance plan that could be purchased by persons with disabilities for their personal assistance workers.

- With regard to agency employed workers, survey innovative agency practices or projects to enhance productivity, including use of technology or scheduling according to location.

- Survey States regarding requirements for and approaches to training workers.

C. Family Caregiving

- Study the use of paid family members in unique settings/situations (e.g., geographic isolation, language), or for relief.

- Research the quality and costs of PAS given by compensated family members compared to nonfamily members, possibly in the State of Oregon. Study the frequency of choosing a family member when real choice is given, and reasons for choosing family to provide personal assistance.

- Develop a valid methodology for examining informal service arrangements and the interrelationship of informal with formal arrangements.

IV. PROVIDING CASH OR VOUCHERS TO PURCHASE PAS SERVICES

Several participants called for clarification of terms, including: voucher, cash out, family allowance, tax credit, and so forth. Recommendations focused on studies to compare costs and benefits of cash or vouchers and other modes of financing PAS.

- Fund a comparison study (preferably with random assignment) of various modes of financing PAS: cash out, vouchers, fiscal agent, case management, and agency. Such a study might include a tax credit option as well. Use Medicaid waiver or State funds to finance benefits. Issues to address include: consumer preferences and satisfaction, incentives to work, accountability, the “woodwork effect”, elasticity of demand, and appropriate amounts of money for benefits. With regard to accountability, there is need to study how cash benefits are used and the extent to which consumer needs are neglected by responsible family members.

- Study costs and outcomes of cash support programs in Colorado, Pennsylvania, Wisconsin or other States.

- Study costs and benefits of cash support provided by the Department of Veterans Affairs (VA) system. The large number of cases should allow for subgroup analysis among types of disabilities as well.

V. ASSISTIVE TECHNOLOGY

Several participants asserted that use of assistive technology is not a substitute for PAS. While there can be some substitution, it was argued that PAS and assistive technology are complementary and that both are needed. Consumers need access to assistive technology and flexibility in combining it with PAS.

A. Use of Assistive Technology

- Evaluate how restrictions of "medical necessity" in public funding of assistive technology impact the independence of consumers.

- Screen Medicare home health claims for occupational, physical and speech therapies where "supplies" are charged in addition to services, and then analyze how the assistive supplies may have reduced numbers of providers needed.

- Research what assistive technology and home modification is purchased by Medicare, Medicaid, and Medicaid/State funded home and community-based services programs.

B. Combined Funding of PAS and Assistive Technology

- Conduct a demonstration that combines assistive technology, PAS and housing modifications into a single funding stream so trade-offs can be realized.

- Conduct studies of currently combined funding streams in Medicaid waiver programs (that include both assistive technology and PAS), in the VA Housebound Aide and Attendant Allowance program, and in other countries.

VI. SERVICE SYSTEM INFRASTRUCTURE

Participants placed high priority on research concerning infrastructure or implementation of PAS programs. Suggestions related to research on care planning; the extent to which one “generic” system can serve several client groups of different ages or having different disabilities (e.g., cognitive versus physical); and on accomplishing greater flexibility for administrators by consolidating various funding streams.

Note that many of the suggestions in previous sections relate to infrastructure and implementation issues.

A. Service Planning

- Describe, demonstrate and evaluate how to develop a person-centered plan of care; research alternative ways to create a person-centered package of services for people with disabilities.

- Develop models of “person-driven support” for persons with cognitive limitations. Look at the competencies, financing, etc., that would be required and the policy implications of such models.

B. Generic Systems

- Research consolidation of funding streams for various support system components. Research the impact of allowing States more flexibility in blending funds and programs.

- Research impacts on administrative costs and client satisfaction of a system that serves all age groups and types of disabilities and of using a uniform eligibility assessment protocol versus impacts of age or disability specific systems. Study how well such a system deals with differences; e.g., cultural, rural residence, and so forth. For example, examine how well aging network works with younger disability populations, and the extent of redundancy.

- For a selected group of States, survey various publicly funded PAS programs to obtain information about how needs, eligibility, service authorization levels, and outcomes are conceptualized and measured. Analyze the data to determine the extent of consistency. Seek to explain the variation on the basis of such factors as disability specific considerations, Federal program definitions, and State specific factors.

- Implement a uniform eligibility assessment tool that combines data items from different agencies, then implement the tool in various agencies to examine differences between agencies in service eligibility and amount of services allocated. Current efforts for developing uniform assessment tools are underway at the Health Care Financing Administration, the Trace Center at the University of Wisconsin, and the Long-Term Care Resource Center at the University of Minnesota.