

Originally Processed With FOIA(s):
S

FOIA Number:
S

FOIA MARKER

**This is not a textual record. This is used as an
administrative marker by the George Bush Presidential
Library Staff.**

Record Group/Collection:	Donated Historical Materials
Collection/Office of Origin:	Frieden, Lex, Collection
Series:	Printed Materials
Subseries:	Authored by Frieden

OA/ID Number:	52092
Folder ID Number:	52092-008

Folder Title:

"Consumer Choice and Control: Personal Attendant Services and Supports in America" [1999]

Stack:

Row:

Section:

Shelf:

Position:

CONSUMER CHOICE AND CONTROL: PERSONAL ATTENDANT SERVICES AND SUPPORTS IN AMERICA

**Report of the National Blue Ribbon Panel on
Personal Assistance Services**

produced by

**Independent Living Research Utilization (ILRU)
Program of TIRR**

August 1999

**With major support provided by the Robert Wood Johnson Foundation
through the *Building Health Systems for People with
Chronic Illness Program***

© August 1999
ILRU Program
2323 S. Shepherd, Suite 1000
Houston, TX 77019
713/520-0232 (Voice)
713/520-5785 (Fax)
713/520-5136 (TTY)
<http://www.ilru.org>

ILRU Publication Team: Sharon Finney, Laurel Richards

This report is made possible through the efforts of ILRU, the Robert Wood Johnson Foundation, members of the Blue Ribbon Panel, advisory committee members, and collaborators. The content of this report reflects the collective view of the panel members and it is not intended to represent the view of any agency or organization with which the panel members are affiliated. The views and recommendations stated herein should not be construed as representative of any agency or organization which may have contributed or been associated with this report. These contents are strictly a product of the Blue Ribbon Panel on Personal Assistance Services and ILRU.

ILRU is a program of TIRR, a nationally recognized, freestanding rehabilitation facility for persons with physical disabilities. TIRR is part of TIRR Systems, which is a not-for-profit corporation dedicated to providing a continuum of services to individuals with disabilities. Since 1959, TIRR has provided patient care, education, and research to promote the integration of people with physical and cognitive disabilities into all aspects of community living.

*. . . No American should have to live in a nursing home
or state institution if that individual can live in a
community with the right mix of affordable supports . . .*

— Donna Shalala
Secretary of Health & Human Services
July 28, 1999, National Conference of State Legislatures

CONTENTS

PAS BLUE RIBBON PANEL MEMBERS	1
INTRODUCTION	3
THE BROADER POLICY CONTEXT	5
Historical Context.....	5
The Current System.....	5
Context of Managed Care.....	7
Policies, Programs, and Limitations.....	7
Federal Policies.....	7
State Policies.....	8
Changing Epidemiology/Demographics.....	9
PAS BLUE RIBBON PANEL OBJECTIVES	11
Core Objectives.....	11
Table 1 Priority Recommendations.....	13
Table 2 Secondary Federal Recommendations.....	15
Table 3 Secondary State Recommendations.....	17
PAS BLUE RIBBON PANEL RECOMMENDATIONS	19
Priority Recommendations.....	19
Secondary Federal Recommendations	24
Consumer Direction and Participation.....	24
Service Provision.....	25
Research and Technical Assistance	25
Secondary State Recommendations.....	28
Consumer Direction and Participation	28
Service Provision.....	29
Training and Qualifications of Personal Assistants.....	30
Consumer Protection.....	31
CONCLUSION: CONSUMER CHOICE AND CONTROL	33
The Future.....	34
Next Steps.....	34
GLOSSARY	35
REFERENCES	39
ABOUT THE AUTHORS	41

PAS BLUE RIBBON PANEL MEMBERS

Mike Auberger	Executive Director, Atlantis Community, Inc., Denver, Colorado
Ian Basnett	University of California, San Francisco, California
Phillip Beatty	Research Associate, National Rehabilitation Hospital Research Center, Washington, DC
Diane Coleman	Executive Director, The Progress Center for Independent Living, Forest Park, Illinois
Gerben DeJong	Director, National Rehabilitation Hospital Research Center, Washington, DC
James Firman	President and Chief Executive Officer, The National Council on the Aging, Inc., Washington, DC
Dennis Fitzgibbons	Alpha One, South Portland, Maine
Marty Ford	Assistant Director, The Arc of the United States, Washington, DC
Judith E. Heumann	Assistant Secretary, Office of Special Education and Rehabilitative Services, Washington, DC
Andy Imparato	General Counsel and Director of Policy, National Council on Disability, Washington, DC
Dan Johnson	Director, Office for Persons with Physical Disabilities, Madison, Wisconsin
Mark Johnson	Advocacy Coordinator, Shepherd Center, Atlanta, Georgia
Bob Kafka	Director, ADAPT of Texas, Austin, Texas
Rosalie Kane	Professor of Social Work and Public Health University of Minnesota, Minneapolis, Minnesota
Simi Litvak	Director, Rehabilitation Research and Training Center on Independent Living and Disability Policy, Oakland, California
Mike Oxford	Executive Director, Topeka Independent Living Resource Center, Topeka, Kansas
Lee Page	Associate Advocacy Director, Paralyzed Veterans of America, Washington, DC
Trish Riley	Executive Director, National Academy for State Health Policy, Portland, Maine
Debra Robinson	National Council on Disability, Washington, DC
Helen Coburn Roth	OPTIONS for Independence, Logan, Utah
Marilyn Saviola	Director of Advocacy, Independence Care System, New York, New York
Bobby Silverstein	Director, The Center for the Study and Advancement of Disability Policy, Washington, DC
Robyn Stone	Executive Director, Institute for Policy Research, Washington, DC
Jane Tilly	Senior Research Associate, The Urban Institute, Washington, DC
Linda Velgouse	Director, Consumer Direction and Deputy Director of Independent Choices, National Council on the Aging, Inc., Washington, DC
Colleen Wieck	Executive Director, The Minnesota Governor's Council on Developmental Disabilities, St. Paul, Minnesota

Jody Wildy	Executive Director, DC Center for Independent Living, Washington, DC
Tony Young	Senior Policy Analyst, United Cerebral Palsy, Washington, DC
Hale Zukas	Policy Analyst, World Institute on Disability, Oakland, California

Advisory Committee Members

Mary Harahan	Deputy to the Deputy Assistant Secretary for Disability, Aging, and Long-Term Care Policy, Department of Health and Human Services, Washington, DC
Ruth Katz	Director, Division of Disability, Aging, and Long-Term Care Policy, Department of Health and Human Services, Washington, DC
John Nelson	Independent Living Branch Chief, Rehabilitation Services Administration, Washington, DC
Janet O'Keeffe	Senior Policy Analyst, American Association of Retired Persons, Washington, DC
Bob Williams	Deputy Assistant Secretary for Disability, Aging, and Long-Term Care Policy, ASPE (Assistant Secretary for Planning & Evaluation) Department of Health and Human Services, Washington, DC
Jay Wussow	Deputy Director, Building Health Systems Program Center for Health Care Strategies, Inc., Princeton, New Jersey

Collaborators

Charlene Harrington	Professor, Department of Social and Behavioral Sciences, University of California – San Francisco, San Francisco, California
Mitchell LaPlante	Director, Disability Statistics Center, Institute for Health & Aging, San Francisco, California

Staff

Pamela J. Dautel	Research Coordinator, Independent Living Research Utilization, Houston, Texas
Lex Frieden	Senior Vice President, The Institute for Rehabilitation and Research; Director, Independent Living Research Utilization, Houston, Texas

Editors

Andrea Solarz	Consultant, Washington, DC
Phillip Beatty	Research Associate, National Rehabilitation Hospital Research Center, Washington, DC

INTRODUCTION

Imagine what your life would be like if . . .

- You were dependent on someone's assistance in order to live a productive life.
- You couldn't afford to pay the entire cost for your own personal assistance, and in order to get any assistance from the state, you had to exhaust your life savings.
- You were forced to live in an institution rather than your own home, because the home and community-based waiver program in your state had a long waiting list.
- You were unable to get out of bed and get dressed when you chose.
- You had to choose between leading a productive life and receiving the support you needed.
- You had a mental disability, were institutionalized, and prohibited from participating in society.

For millions of Americans with disabilities, this is reality.

Living independently is one of the primary tasks that young people must master as they grow into self-reliant adults. For people who do not have control of this ability—owing to disability or age-related infirmity associated with old age—our current long-term care system makes it very difficult for them to acquire or resume that control over their lives.

For people with physical conditions that limit their ability to function, daily life often necessitates assistance with such routine activities as dressing, going to the bathroom, preparing meals, and other activities that are easily performed by people without disabilities. People with cognitive impairments may similarly need help with the above tasks and others such as planning, shopping and preparing healthy meals, paying bills, maintaining medication schedules, remembering to eat, dealing with personal finances, as well as tasks that require more complex decision making. For many individuals with disabilities, the lack of assistance with such non-medical, day-to-day activities can lead to health problems that are every bit as serious as health problems that result from inadequate medical care.

Lack of personal assistance services (PAS) can affect the musculoskeletal, circulatory, respiratory, and skin systems. Such problems can be extremely difficult and costly to resolve, and they can result in greater levels of disability and even greater need for health and support services. Furthermore, such problems can have a profound effect on the mental health status of persons with disabilities whose abilities to work, engage in family and social activities, and be otherwise actively involved in life are curtailed because of health problems or functional limitations.

Aside from these serious physical and mental health consequences, the absence of appropriate home and community-based PAS and supports can also lead to unnecessary nursing home placement. Such institutional placement further alienates the individual from the community and precludes her/him from engaging in age-appropriate activities.

There are a number of obstacles to increasing the provision of appropriate PAS services to people with disabilities of all ages in the United States. Many of these obstacles have deep historical and cultural roots and are embedded in the policy structure of the current long-term care system. In the following section, information is briefly provided about the long-term care system for people with disabilities, from both an historical perspective as well as challenges faced within the current health and long-term care systems.

For people with extensive functional limitations...personal assistance is a linchpin service — productivity is impossible without it. . . . personal assistance enhances employability to the extent that it enhances the individual's ability to function in society.

—Margaret A. Nosek, Ph.D.
Journal of Applied Rehabilitation Counseling, 21(4)

THE BROADER POLICY CONTEXT

Historical Context

In the past, disability was regarded as a medical condition that prevented people from participating in most activities of daily life. Many people with disabilities were segregated and isolated from society, housed in large institutions without consideration of appropriate, less restrictive, alternatives. In 1965, Medicare and Medicaid legislation was passed that included strong financial incentives to provide long-term care to both elderly and younger people with disabilities in nursing homes. At that time, policymakers assumed that these constituencies preferred to receive long term care services in nursing-home settings. The elderly population and the population of younger people with disabilities grew in number and proportion in the latter half of the twentieth century. At roughly the same time, Medicare and Medicaid legislation came to guarantee public payment for institutional services for these groups of people who often require long-term care.

As Medicare and Medicaid policy was being forged in the mid-1960s, the disability rights movement was organizing in part as an attempt to change the focus and the legislative bias away from the nursing home model of long-term care provision. The disability rights movement has fought for and created an alternative approach to long-term care that seeks to meet the specific needs of people with disabilities and their desires to live and participate actively in their communities. PAS, delivered in non-institutional settings to people with a diversity of long-term care needs, is the centerpiece of this model for a long-term care system that promotes independence and an increased quality of life among people with disabilities of all ages.

Driven by the disability and consumers' rights movements, new programs and services have emerged as alternatives to institutionalization of people with disabilities with the goal of improving their integration in society. Social integration includes such essential activities as living in the community, working in mainstream jobs, receiving education in regular classrooms along with non-disabled students, attending cultural and social events, maintaining a network of friends, and engaging in other leisure activities (Kaye, 1998). American society has moved forcefully to enable people with disabilities to participate in society. In particular, the Americans with Disabilities Act of 1990 outlawed practices of private and public entities that unreasonably restrain the participation of people with disabilities in society.

The Current System

The disability rights movement, with recent buy-in from the aging community, has been successful in pushing forward a vision of a long-term care system centered in the community. While this vision is becoming much more clear and well-articulated, there is still a strong institutional bias in federal and state policies, which provide funding for long-term care

services. This institutional bias in federal and state long-term care policy will be outlined in the paragraphs below.

The relationship between access to PAS and a number of important outcomes including maintenance of good health and functional capacity (Prince, Manley, & Whiteneck, 1995), productivity (Richmond, Beatty, Tepper & DeJong, 1997), employment (Prince, Manley, & Whiteneck, 1995; Nosek, 1990), independence in living arrangement, (HSRI, 1991), and community integration (HSRI, 1991) for persons with disabilities has been well-documented in the literature. Yet, there is still no broadly implemented strategy for assuring that such services are available to the people who require them. Despite advances that have been made in addressing the long-term care and related needs of persons with disabilities, the service delivery system continues to be fragmented, complex, and lacking a coordinated policy framework (Litvak, 1995). In particular, a coordinated national policy is needed to improve the service delivery of PAS programs. Improvement of the service delivery of PAS programs includes making them more consistent in encouraging maximum functioning and establishing and maintaining normal lives in the most integrated environment for people with disabilities.

I urge you...in recognition of the anniversary of the ADA, to strive to meet its objectives by continuing to develop home and community-based service options for persons with disabilities to live in integrated settings.

— Sally K. Richardson

Director, Center for Medicaid and State Operations, HCFA

In the absence of such a coordinated national policy, there remains in the United States a strong bias toward institutionally based long-term care and a confusing patchwork of programs that deliver long-term care services in the community. Nursing-home care in the United States is an entitlement—any person who is eligible for nursing home services cannot be denied that service if there is a nursing-home bed available. PAS delivered in the community does not have such entitlement status. Indeed, federal, state, and local public spending on nursing homes is four times greater than spending on home and community-based long-term care services. With a bias toward nursing-home services, this ratio varies widely across the states, with a high of approximately 12.0 in the District of Columbia and Rhode Island, to a low of 0.98 in Oregon (Kane, Kane, & Ladd, 1997).

Among programs that deliver community-based long-term care services across the states, there are substantial differences in the manner in which programs are administered and the degree to which program recipients can choose and control services. The level of resource commitment to people with long-term care needs vary enormously from region to region as well as from state to state. For example, a 1995 study documents that 22 states reported no commitment of funds to Medicaid personal care optional services (Winterbottom, Liska, and Obermaier, 1995).

One of the highest long-term care priorities cited by consumers and caregivers is consumer choice (Scala & Mayberry, 1997; Scala, Mayberry, & Kunkel, 1996; Benjamin et al, 1998). Consumer choice has been reported to increase the consumer's control over service

decisions, enhance flexibility and responsiveness to needs, increase independence, and improve quality of life (Scala & Mayberry, 1997). Further, people who have more choice in their long-term care and PAS decisions have been found to be more satisfied with the services they receive (Benjamin, 1998; Beatty, Richmond, Tepper, & DeJong, 1998; Prince, Manley, & Whiteneck, 1995). However, our health care system does not lend itself easily to consumer control, flexibility, and adaptability, and despite the desirability of having consumer choice, the services most readily available and most often subsidized for long-term care recipients are seldom those most favored by the consumer.

... We all have the right to interact with family and friends in our communities...to make a living...and to make a life.

— Donna Shalala

Secretary of Health & Human Service, July 28, 1999

Context of Managed Care

As state Medicaid programs move rapidly from fee-for-service to managed care, people with disabilities will more and more frequently find themselves in managed-care programs. Although a few models with effective strategies for providing high quality long-term managed care services do exist, their general emphasis on controlling costs and service utilization raises important concerns for people with disabilities. If used appropriately, managed care can be used to improve access and quality of care, as well as to contain costs. However, there is also a risk that managed care's emphasis on control over service provision will run counter to long-term care consumers' desire to control and direct their PAS and that the emphasis that managed care plans place on cost control will reduce the number of service hours to individuals beyond an acceptable level. In addition, few managed care providers have the expertise necessary to serve people with significant disability.

A critical challenge for states is to develop and manage a financially sound health and long-term care system for beneficiaries with disabilities. However, there are significant questions regarding the readiness of states to address the needs of individuals with disabilities through Medicaid services or other public health initiatives (GAO, 1996). In contrast to fee-for-service systems in which providers may be encouraged to deliver too many services, the risk under managed care is that providers will be encouraged to deliver fewer services or less costly services than are actually needed by service participants.

Policies, Programs, and Limitations

Federal Policies

In every state except Oregon, nursing home services are subsidized to a much larger degree than are home and community based long-term care services. The nursing home dominated long-term care system is a result of the collective body of long-term care policies at the federal and state levels.

The United States, by making Medicaid funds available to nursing homes on an entitlement basis, has developed a nursing-home dominated long-term care system. In order to receive federal Medicaid funding, states must have a statewide nursing home program. While states cannot deny nursing home services because of state revenue shortfalls or budget considerations, home and community based services can, and often are, denied for these reasons.

In order to receive Medicaid funded nursing home care, an individual must meet an income eligibility test. States can extend eligibility to people with countable incomes at or below 300 percent of SSI. States also can apply medically needy standards to nursing home applicants. Generally, applicants are considered medically needy when their countable incomes are lower than the cost of the nursing home care. All applicants must meet a financial asset test in addition to the income test.

Federal long-term care policy is also skewed in the direction of nursing homes by the fact that nursing homes are guaranteed inflationary payment increases by federal law, while home and community based services are not. Over time, it results in an ever-increasing proportion of revenues being spent on institutionally based long-term care.

According to federal statutes, states have no limitation on the number of nursing home beds that a state can certify for Medicaid funding. On the other hand, states are required to obtain federal approval for Medicaid waivers for home and community based services in order to expand their capacity.

... We believe that states have an obligation to provide services to people with disabilities in the most integrated setting appropriate to their needs. And we have used the law to fight for this. Many individuals with disabilities are being placed in nursing homes or other institutional settings even when they don't really need to be there.

— Janet Reno
U.S. Attorney General, May 15, 1998

State Policies

Financial eligibility requirements for Medicaid long-term care recipients at the state level are largely driven by federal standards, but states have the option of going below the 300% SSI standard, and many do. Under the Medicaid Home and Community-Based Waiver system, states have great latitude in determining what services are offered, who can provide services, and the conditions under which services are provided. State provisions are often crafted with an institutional and professional bias, precluding development and implementation of consumer-directed variants of home and community-based PAS. One of the more contested examples of such a provision includes that which requires PAS to be carried out by licensed medical professionals.

In summary: Federal and state long-term care policy is driven today by an evolving funding and administrative system that was created more than thirty years ago to address the *acute* health care needs of poor and elderly citizens. The overwhelming majority of long-term care consumers of all ages prefer to live and participate in their homes and communities. There is a growing understanding among people across varying disability and age groups that long-term care needs are most often not acute medical needs, and that a shift away from paternalistic, medically oriented policy restrictions on home and community based long-term care services is necessary to create a system that is responsive to the needs and desires of consumers. Despite the policy restrictions at the Federal and state levels discussed above, states do have substantial flexibility under current Medicaid guidelines to implement quality home and community-based long-term care systems that are under increasing demand from consumers.

Changing Epidemiology/Demographics

The need for long-term care services is associated strongly and positively with age. Approximately 2.4% of people ages 15-64 require assistance with everyday activities for example, while a full 50% of people aged 85 and over need assistance (Kane, Kane, & Ladd, 1997). While these figures seem to imply that the need for long-term care services is largely an issue among the elderly, a full 42% of those living in the community who need assistance with activities of daily living are younger than age 65 (RWJ, 1996).

... Our ultimate goal: a nation that integrates people with disabilities into the social mainstream, promotes equality of opportunity, and maximizes individual choice.

— Donna Shalala

Secretary of Health & Human Services, July 28, 1999

By the year 2000, approximately 13% of the population will be over age 65, including 2% of the population older than age 85. By the year 2040, it is projected that the percentage of Americans over the age of 65 will jump drastically to 21%, including the 4% of those over the age of 85 (RWJ, 1996). This large demographic shift associated with the aging of the "baby boom" generation will lead to a greatly increased need for appropriate long-term care services.

At the same time that these major demographic shifts are taking place, medical and rehabilitative science and practice is making it possible for people to survive a diversity of previously fatal health conditions and injuries. Another result of these medical and scientific breakthroughs is that younger people with disabilities are today much more likely to live into old age. While the mortality rates surrounding this diversity of conditions and injuries declines, the disability rate and associated need for long-term care services increases.

It is imperative that responsive systems of long-term care are in place as advances in the medical and rehabilitative fields combined with demographic changes greatly increase the demand for personal assistance and long-term care services.

PAS BLUE RIBBON PANEL

OBJECTIVES

The Blue Ribbon Panel on Personal Assistance Services was convened in March of 1997 to develop specific policy recommendations and strategies for implementing and promoting consumer-directed, community-based programs that address long-term care and other support needs of persons with physical disabilities and mental impairments. More than 30 experts from across the country, representing a wide variety of organizations of and for people with disabilities, and the elderly, were part of the Blue Ribbon Panel. Panel experts participated in teleconferences and meetings over a 24-month period. The project was in large part funded by the Robert Wood Johnson Foundation Program for Building Health Systems for People with Chronic Illnesses with a grant to ILRU, the Independent Living Research Utilization program at TIRR.

As a primary activity, Panel members collaborated with researchers at the University of California-San Francisco (Harrington, et al., 1999) to review federal statutes and regulations for PAS and home and community based services. The Panel members then further evaluated the recommendations developed through this collaboration in order to identify those of the highest priority. In addition, project staff members reviewed the literature to identify research projects focused on PAS, and either made personal visits or interviewed staff at independent living centers that operate PAS programs to identify some of the issues facing the providers and recipients of such services.

... Our mission: To build better systems of supports enabling people with disabilities to live life to the fullest.

— Donna Shalala

Secretary of Health & Human Services, July 28, 1999

Core Objectives

The members of the Blue Ribbon Panel strongly believe that meeting the PAS needs of people with disabilities is a manageable issue and that the time is long overdue for implementing the changes recommended in this report. It is already too late to help the many people with disabilities that were never provided the option of community-based PAS before their unnecessary institutionalization or ultimate death in nursing homes and other institutions. However, it is not too late for others if action is taken now. Although the focus of the Blue Ribbon Panel's work was on publicly financed services, it should be emphasized that the need to access economical and competent PAS is not limited to persons on Medicaid. Even those who are not on Medicaid can have great difficulty assembling competent services at a price they can afford and on the dates and times that they need them. Thus, the issues

addressed in this report are relevant to the broader public who may be in need of these services for themselves or for a loved one.

The Blue Ribbon Panel was guided by basic values regarding delivery of PAS to people with disabilities. **A guiding philosophy of the Panel's work was the belief that people with disabilities should have meaningful and informed choices regarding types of long-term services and supports they receive.** This choice should include choice of setting (home vs. institution) in which long-term services are received. After this choice has been made, consumers should have control over the extent to which they will manage and direct those services. This emphasis on consumer choice and control is congruent with core American values that put a priority on personal independence and responsibility. In most situations in American life, it is assumed that families are responsible for and able to take care of their own members. Outside intervention occurs only where there is clear evidence that someone needs help. However, for people who are unable to function independently, there is very little choice or control over long-term services and supports they receive.

The Panel further believes that a priority should be placed on establishing services that provide the support necessary to allow individuals to live in the community should they wish to do so. Generally, the burden of proof has thus been on PAS programs to "prove" that this approach is more effective, more economical, or in greater demand than institutional care. It is the belief of the Panel, however, that the reverse should be true. In other words, the burden of proof should be on institutional care to demonstrate that it is more effective, economical, and in greater demand than PAS. **The Panel strongly reiterates the need for a continuum or progression of long-term care services for people with disabilities so that nursing home or other institutional care is an option only when the full range of community-based care options has been exhausted or when it is the choice of the consumer.**

Thus, the objective of the Blue Ribbon Panel was to develop recommendations that:

- Emphasize the value of and demand for community-based long-term care services.
- Assure an equitable distribution of resources among available long-term care options, including consumer-directed PAS options.
- Give consumers, to the extent they desire, control in selecting, managing, and training their personal assistants.
- Assure that PAS options are available to people in full range of community settings.

Because the work of the Panel was limited to identifying key issues that must be addressed by federal and state policymakers, the Panel did not attempt to address every possible issue that might be considered, nor did it attempt to redesign the system from the ground up.

Tables 1, 2, and 3 that follow list the priority and secondary federal and state recommendations proposed by the Panel.

TABLE 1
PRIORITY RECOMMENDATIONS
(Federal and State)

Policy Number	Federal Recommendation
Federal 1	A nationwide program of technical assistance should be established to assist states in reaching the goal of <i>most integrated setting</i> and community-based placement for people with disabilities who require routine, ongoing personal assistance services. Such technical assistance should be conducted by DHHS (including ASPE), in conjunction with HCFA and other federal agencies as appropriate.
Federal 2	A series of public "Summit" discussions on the subject of <i>most integrated setting</i> should be conducted by DHHS (including ASPE), in conjunction with HCFA and other federal agencies as appropriate.
Federal 3	In order to create real choice for individuals in need of long-term services, differences should be eliminated in the basic financial eligibility and spousal impoverishment rules for home and community-based and institutional services.
Federal 4	Incentives should be established for states to make home and community-based long-term services the primary option in their long-term care service system.
Federal 5	HCFA should abandon the link between Medicare and Medicaid certification requirements for providers of home and community-based services.
Policy Number	State Recommendation
State 1	Uncertified but otherwise competent individuals should be allowed to perform certain personal assistance tasks.
State 2	The personal assistant for a particular individual should be required to have only the type of training necessary to meet the needs and preferences of the individual.

TABLE 2
SECONDARY FEDERAL RECOMMENDATIONS

Policy Number	Recommendation
Federal 6	In order to promote consumer choice and direction in Medicaid PAS programs, HCFA should develop rules and regulations for all programs to assure that consumers can be involved, to the extent they desire and are able, in selection, management, and training of their personal assistants.
Federal 7	In order to promote consumer choice and direction in Medicaid PAS programs, HCFA should require states to develop structures or processes (e.g., information sources such as provider registries) that facilitate consumers' access to and choice among qualified personal care providers, including independent providers.
Federal 8	States should be required to cover provision of PAS services in other locations outside of the home or residential care program where the person resides.
Federal 9	HCFA should fund research to study the benefits and feasibility of allowing a sliding fee scale for services for individuals who are above the minimum financial eligibility level, or of allowing some type of buy-in arrangement for those meeting financial eligibility criteria for targeted needs.
Federal 10	Current state-only programs that include PAS services should be evaluated to determine whether or not they prevent or delay non-Medicaid low-income individuals from becoming institutionalized and spending down to Medicaid.
Federal 11	To foster the adoption of objective need-based criteria, HCFA should establish an ongoing research program and convene an expert panel to develop a consensus set of criteria for the need for personal care services.
Federal 12	HCFA should fund a study of state PAS programs to determine whether or not any institutional biases are being created by limitations in the amount, duration, and scope of benefits available under home and community-based service waivers.
Federal 13	HCFA should study the long-term service needs of Medicaid recipients with mental illness and examine barriers to providing expanded services for this population.
Federal 14	HCFA should convene a task force to develop ways in which personal care and waiver programs can maximize the number of people who direct their own services and to identify methods for involving consumers in developing and evaluating delivery options and services.

TABLE 3
SECONDARY STATE RECOMMENDATIONS

Policy Number	Recommendation
State 3	Structures or procedures should be put in place that assure active involvement of consumers or their representatives (e.g., family members, when desired by the consumer, or other decision-making agents) in the needs assessment and service planning processes for personal care and waiver services.
State 4	Structures and methods should be established to assure consumer representation and participation in management and evaluation of state personal care and waiver services and in development of policies related to such programs.
State 5	For consumers of all ages, the types and amount of PAS services to be provided should be determined on the basis of an individual's need rather than on arbitrary limits on service hours or on expenditure caps.
State 6	When there is no other way of providing appropriate PAS services, parents of minor children as well as spouses of adult beneficiaries should be eligible for payment for performing these services.
State 7	Agencies or entities that perform PAS needs assessments should be prohibited from providing services recommended as a result of those assessments.
State 8	States should establish: (1) procedures for accepting and acting on complaints about services and (2) a process for appealing adverse actions (e.g., the denial, reduction, or termination of services).

PAS BLUE RIBBON PANEL

RECOMMENDATIONS

The Blue Ribbon Panel produced a broad range of recommendations directed at state and federal policymakers (See Tables 1, 2 and 3). The recommendations apply to people with disabilities of **all ages**, and with all types of disabilities. These recommendations should be used to guide **any** health care payer, whether public or private, including managed care organizations.

Priority Recommendations

The Panel gives priority to seven areas (five at the federal level and two at the state level) for immediate action and urges policymakers to take assertive action to implement them.

The following priority recommendations are directed at federal policymakers.

Federal 1	A nationwide program of technical assistance should be established to assist states in reaching the goal of <i>most integrated setting</i> and community-based placement mandate for people with disabilities who require routine, ongoing personal assistance services. Such technical assistance should be conducted by DHHS (including ASPE), in conjunction with HCFA and other federal agencies as appropriate.
------------------	---

The goal of this technical assistance program is to insure that every state develops policies and programs to achieve the goal of most integrated setting for each eligible program participant in the state. In order to accomplish this, the program will address all issues pertinent to development and operation of a state wide infrastructure designed to support provision of PAS and other related services necessary to reach this goal.

In each state, a technical assistance advisory committee that includes consumers, consumer representatives, state agency personnel, and representatives of public and private service providers should guide this program. The program should be designed and conducted with substantial input from people with disabilities, their families, and organizations representing people with disabilities. Further, the program should employ such individuals and groups as advisors, consultants, program designers, and trainers. Preference should be given to individuals with disabilities, their families, and organizations of individuals with disabilities, including centers for independent living, in the process of awarding grants and contracts that may be associated with this initiative.

The recommended technical assistance program should include multiple components, including on-site training of regional DHHS staff and state Medicaid personnel; on-going meetings with consumer groups; on-site consultation; remote consultation via telephone and Internet; one or more regional or national training programs; and support materials and information necessary to carry out the program effectively.

The technical assistance program should assist states with program design, including development of service delivery options and with maximizing their use of the existing flexibility in Medicaid to improve access to high-quality long-term services in most integrated settings as required by the ADA. It should also assist states in developing successful methods for involving consumers in program design, delivery, and continuous improvement. Further, the program should assist states in addressing liability issues--particularly with respect to health-related personal assistance service activities, and with issues pertaining to personnel development, personal assistant recruitment programming--and personal assistant training.

The technical assistance program should make demonstration grants available to states for the following purposes:

- Demonstration funds should be made available to states with minimal experience to help them develop necessary skills and infrastructure to achieve the goals of most integrated setting and,
- Demonstration funds should be made available to facilitate the transfer of best practices in relation to the goal of most integrated setting, from state to state.

Federal 2 A series of public "Summit" discussions on the subject of *most integrated setting* should be conducted by DHHS (including ASPE), in conjunction with HCFA and other federal agencies as appropriate.

The planning and implementation of state programs to achieve the goal of most integrated setting can be facilitated if these processes include input from the public. These public discussions should be designed to:

- Promote understanding of the concept of most integrated setting
- Receive recommendations related to elimination of institutional bias in HCFA-sponsored and other public programs, as appropriate;
- Receive reports and recommendations about progress toward reaching the goal of most integrated setting; and,

- Facilitate the process of planning to achieve the goals of “most integrated settings” within states by providing an appropriate forum for consumers and advocates, including representatives from the aging community, the developmental disabilities community, independent living centers, and other interested parties, to work together with state Medicaid officials and others, as appropriate, to develop implementation plans for their respective states.

The format for these public discussions should include:

- Plenary-style presentations by federal and regional officials and by consumers and their representatives related to the public goal of “most integrated setting”;
- Small group working sessions, with representatives of consumers and state agency personnel from each state within the region, that focus on facilitating planning and implementing state activities to achieve the goal of “most integrated setting” for all eligible program participants, and,
- An open forum for public discussion that includes invited input from representatives of the aging community, the developmental disabilities community, and centers for independent living.

At least one public discussion should be held in each federal region.

Federal 3 In order to create real choice for individuals in need of long-term services, differences should be eliminated in the basic financial eligibility and spousal impoverishment rules for home and community-based and institutional services.

The financial eligibility criteria for receiving personal care services in the community should not be more stringent than the financial eligibility criteria for institutional placement. Medicaid and SSI asset and income limits for persons receiving long-term services in the community should be changed to allow individuals the greatest opportunity to remain in the community and not to be forced into institutions. For example, recipients of home and community-based services could be allowed to retain the equivalent of 6 to 12 months of expenses, and the maximum income requirements for qualified disabled working individuals could be relaxed. This must apply equally to all persons who meet institutional criteria, regardless of the program type (e.g., Personal Care Option, home and community-based waiver services, etc.).

Currently, when an individual is institutionalized, the spouse who remains in the community is allowed to retain half of the couple’s resources at the time of institutionalization, or a higher minimum amount set by the state. This protects the ability of the community spouse to live in the community and preserves the couple’s home. Similar protections are needed for all state PAS programs.

Federal 4	Incentives should be established for states to make home and community-based long-term services the primary option in their long-term care service system.
------------------	---

Federal statutes must be changed so that they no longer provide incentives among the states to provide long-term care systems biased toward institutional services. Ultimately, incentives are needed that encourage states to develop systems that provide a single point of entry and coordinated screening and assessment systems for all long-term service programs.

Currently, nursing home services are provided on an entitlement basis, while PAS and other home and community-based services (HCBS) are not. The federal government should pass legislation making PAS services an entitlement on equal footing with nursing home services. Similarly, federal legislation must be enacted that requires states to have a statewide PAS program in order to receive federal funds, as is currently the case with nursing home programs.

Examples of financial incentives that could be established include negotiation of higher Federal Financial Participation (FFP) payments with states that expand home and community based long-term services. Currently, public expenditures on home and community based programs **are not** completely cost-shared with the federal government, while nursing home programs **are** fully cost-shared. This inherently provides financial incentives for states to bias their long-term care systems away from community-based options and toward institutions. The federal government could also change financial reporting and budget neutrality requirements for states to support their increased use of home based services and decreased use of institutional services.

Federal 5	HCFA should abandon the link between Medicare and Medicaid certification requirements for providers of home and community-based services.
------------------	--

Currently, federal Medicaid home health agency definitions and certification requirements are tied to Medicare. Medicare home health services are primarily short-term acute-care services, and, therefore, require professionally trained nurses to deliver them. Medicaid home and community based service programs provide primarily non-medical assistance to people with long-term needs, and, therefore, do not require the same professional standards among those who provide the services. Since the aims of the two services differ substantially, it is important for HCFA to revise the Medicaid home health regulations. The current regulations may create a medical model for PAS that is costly, inappropriate, and unnecessary.

The following priority recommendations are directed at state-level policymakers.

State 1 Uncertified but otherwise competent individuals should be allowed to perform certain personal assistance tasks.

It is not unusual for nurses to delegate a wide range of tasks to attendants and family members in the performance of their practice, and all states permit nurses to use wide discretion in teaching and delegating. Requirements for specific nurse oversight or firm requirements that the persons to whom tasks are being delegated have particular credentials, or that they be closely supervised at regular intervals drives up costs of care and reduce flexibility. Assisting consumers with medications is a particular problem, as are catheter care, ostomy care, and wound care. Several states have clarified their nurse practice acts to permit delegation to uncertified, qualified individuals with no untoward effects. Requiring long-term care providers to have professional certification in order to provide low-tech services increases the cost of long-term care programs substantially, with no discernible impact on the quality of services delivered.

State 2 The personal assistant for a particular individual should be required to have only the type of training necessary to meet the needs and preferences of the individual.

Training requirements should be flexible in order to accommodate the range of needs and resources of service recipients. Training packages required at the state level are unlikely to meet the needs of any long-term care consumer from the diverse population of individuals who need those services and are likely only to increase program costs. The consumer of long-term care services is the expert when it comes to determining her/his needs, and, so, the consumer should be allowed to direct and provide the individualized training of her/his assistant(s).

If a minimal level of training is required for personal care providers at the state level, these programs should be administered by the consumer if desired, and should include information on consumer-directed approaches and descriptions of how to maximize the independence of individual consumers.

The remainder of the Blue Ribbon Panel's recommendations follows (nine at the federal level and six at the state level). Recommendations targeted at federal policymakers are presented first, followed by state-focused recommendations.

Secondary Federal Recommendations

Consumer Direction and Participation

Federal 6 In order to promote consumer choice and direction in Medicaid PAS programs, HCFA should develop rules and regulations for all programs to assure that consumers can be involved, to the extent they desire and are able, in selection, management, and training of their personal assistants.

Under the Medicaid statute, consumers have the right to select their own qualified providers of choice. There are, however, no specific federal requirements for ensuring consumer choice with respect to personal care services and other Medicare/Medicaid programs. Thus, states have the freedom and flexibility to establish their own systems for consumer-directed services.

Because the abilities and interest of consumers vary when it comes to directing their long-term care services, varying degrees of technical assistance will need to be available in selecting, managing, and training personal assistants.

If consumers are capable of providing all of the training needed to people whom they would like to hire as personal attendants, then they should be allowed to do so. HCFA should encourage or require states to develop methods that will facilitate access to and choice among providers for the personal care and the home and community-based waiver programs.

Federal 7 In order to promote consumer choice and direction in Medicaid PAS programs, HCFA should require states to develop structures or processes (e.g., information sources such as provider registries) that facilitate consumers access to and choice among qualified personal care providers, including independent providers.

Services from home care and home health agencies dilute accountability to providers and can lead to more costly care without any greater remuneration to attendants and without greater benefits to the consumer. On the other hand, absent of an intermediary agency, some source of information is needed so consumers can identify potential attendants.

Registries of providers that consumers can use are not formally maintained in all states. If registries were made available, this would greatly facilitate consumer access to and choice of providers, especially individual providers.

Service Provision

Federal 8 States should be required to cover provision of PAS services in other locations outside of the home or residential care program where the person resides.

Currently, states have the option of covering the provision of PAS services in other locations outside of the home. There has been a tendency in home health to require a consumer to be home bound as a criterion to determine need for service. This idea is defended as a cost-control mechanism, but it is actually quite counter to a reasonable philosophy for a PAS program, the purpose of which, in large part, is to **permit the consumer to function in a wide range of social roles and places.**

Personal attendant services must also be available in other locations in order to enable the consumer to function in his or her age-appropriate social roles, such as in schools, libraries, places of employment, places for conducting commerce (e.g., banks, stores, etc.), and indoor and outdoor places of recreation, including in the homes of family and friends and, when needed, to get from his or her home to these other locations. Providing PAS services only in the home setting may actually encourage dependency, whereas the provision of services in other locations (e.g., work or school) can encourage independence and greater integration into the community. Without the provision of these services, many people with disabilities may be denied access to community or work sites, limiting both their quality of life and their potential to engage in productive employment.

Research and Technical Assistance

Federal 9 HCFA should fund research to study the benefits and feasibility of allowing a sliding fee scale for services for individuals who are above the minimum financial eligibility level, or of allowing some type of buy-in arrangement for those meeting financial eligibility criteria for targeted needs.

It may be beneficial to target services to those at risk for spend down to Medicaid. If the "near poor" who meet need requirements are allowed to buy into Medicaid personal care benefits, some of these individuals may be prevented from entering a nursing home and becoming eligible for Medicaid. States spent \$1.2 billion on these spend down clients in 1997 (Harrington, et al. 1999). Research is necessary to determine whether or not a sliding fee scale, buy-in arrangement, or a possible raising of current asset limits might prevent unnecessary institutionalization of near eligibles and the associated Medicaid expenditures.

Federal 10 **Current state-only programs that include PAS services should be evaluated to determine whether or not they prevent or delay non-Medicaid low-income individuals from becoming institutionalized and spending down to Medicaid.**

HCFA should fund research to assess the potential effects of making the personal care state plan mandatory for those who meet need criteria who would otherwise require institutional care or be at risk for needing institutional care. These at-risk individuals would otherwise need to spend down to Medicaid requirements to receive Medicaid nursing home care. Such studies could evaluate the effects of various program features and examine the relationship between personal care service utilization and utilization of nursing homes, assisted living services, and health services.

Federal 11 **To foster the adoption of objective need-based criteria, HCFA should establish an ongoing research program and convene an expert panel to develop a consensus set of criteria for the need for personal care services.**

Federal regulations for personal care services fail to specify criteria for need or level of care requirements. Thus, no uniform standards across states exist for defining eligibility criteria for a service. For example, although there is consensus among states on the use of ADLs to determine eligibility for services, states vary in the definition and measurement of ADLs (O'Keeffe, 1996). The lack of minimum standards for those who need the services may make it more difficult for individuals to access services and could ultimately result in institutionalization of individuals if access to personal care is denied or unavailable.

More study and development are needed to establish detailed, specific need criteria for personal care services. An ongoing HCFA-sponsored program of research in this area is needed in order to foster innovation and to determine effective needs determination processes, appropriate weighting of criteria used to determine need, and effective verification processes.

Objective need-based criteria should be developed that can be adopted across states. These criteria should include ADL and Instrumental Activities of Daily Living (IADL) measures, along with need for supervision due to behavior problems and cognitive and other types of mental disorders or impairments. They should also consider social isolation and safety concerns. Because the state of the art in needs assessment continues to evolve, the criteria should be periodically re-evaluated.

Federal 12 HCFA should fund a study of state PAS programs to determine whether or not any institutional biases are being created by limitations in the amount, duration, and scope of benefits available under home and community-based service waivers.

By studying state programs that differ in the amount, duration, and scope of benefits that are made available to consumers, a research program can help determine the point at which program limitations cease to be effective cost-control measures and begin to be liabilities that ultimately lead to institutionalization and higher Medicaid expenditures. Variables to be examined may include: number of service hours allowed per week, scope of settings in which services can be delivered, and limits on the duration of service provision.

Federal 13 HCFA should study the long-term service needs of Medicaid recipients with mental illness and examine barriers to providing expanded services for this population.

Individuals with mental illness may require assistance with ADLs and IADLs just as people with physical disabilities require support. HCFA should fund a research program to determine reasons why more states do not provide personal care and waiver services for people with mental illness. The current limitations of benefits for people with mental illness encourage inefficient provision of long-term care in institutions rather than in home based and community based programs. Additionally, the current statutory provisions appear to discriminate against those with mental disabilities in comparison to those with cognitive, developmental, or physical disabilities. More study is needed of the provision of personal care and waiver services to people with mental illness to better understand barriers to service.

Federal 14 HCFA should convene a task force to develop ways in which personal care and waiver programs can maximize the number of people who direct their own services and to identify methods for involving consumers in developing and evaluating delivery options and services.

When consumer input is used in programming, the quality of services is improved, and there is often an increase in health, safety, well being, and satisfaction for all consumers. Standards for self-direction should be made flexible in order to maximize the number of consumers who self-direct. Consumers who are not able to self-direct but who have surrogates or representatives who can do so on their behalf should have the right to self-direct via their surrogate or representative. In addition, self-directing individuals should be able to opt out of most required case management services and physician or health provider authorization requirements for his or her service plan. The task force should include consumers, surrogates, state and federal agency staff, providers, and advocates.

Secondary State Recommendations

Consumer Direction and Participation

State 3 Structures or procedures should be put in place that assure active involvement of consumers or their representatives (e.g., family members, when desired by the consumer, or other decision-making agents) in the needs assessment and service planning processes for personal care and waiver services.

HCBS regulations do not require states to use input from individual recipients and family members or representatives in the assessment and planning process. This is inconsistent with the philosophy of consumer-directed models of care.

Individualized service plans should be developed for each consumer based on his or her actual needs, considering consumer choice to the greatest extent possible. People with disabilities are experts on their own health conditions and long-term care needs, and their knowledge and experience should be incorporated into the assessment and care planning process.

At the level of an organized health and long-term care program, service plans include a myriad of detail that shapes a person's life. Involvement of consumers or their representatives is, thus, essential in development of these care plans. Moreover, at the policy-making level, there is a need to examine the system that serves people with disabilities to correct current problems and to prevent or identify future ones.

Medicaid regulations should clarify that individual consumer and family involvement are essential components in an assessment and planning process and should facilitate consumer choice and satisfaction with the program. It is important that HCFA articulate a clear federal philosophy of individual empowerment and independence, and states should be encouraged or required to address this in their state plan.

State 4 Structures and methods should be established to assure consumer representation and participation in management and evaluation of state personal care and waiver services and in development of policies related to such programs.

Consumer-oriented programs help promote consumer empowerment. However, there is no federal provision that requires states to have consumer-oriented personal care services. The consumer orientation of programs may be improved with consumer advisory committees or

other methods of consumer input into program development, management, and evaluation. Although establishing consumer councils does not guarantee their effectiveness, they are a step toward improving consumer direction of services. Another approach would be to establish state personal attendant services and supports councils to consumer-oriented services and programs that make it possible for individuals with disabilities to live, work, and play in communities.

Currently, there are no regulatory provisions for consumers' rights or consumer councils and the extent to which states may use advisory committees for personal care services is unknown. There may also be other mechanisms for consumer input into design, implementation, management, and evaluation of state programs for people with disabilities. The nature and extent of consumer advisory committees and other means of consumer input into personal care and waiver service programs in states should be identified and comparisons made of policy and program management in states having consumer input and those with little or no involvement. States providing best practices should be identified and the results disseminated to other states. Consideration should be given to requiring states to establish consumer advisory councils for Medicaid personal care services, HCBS waiver programs, and home care.

Service Provision

State 5	For consumers of all ages, the types and amount of PAS services to be provided should be determined on the basis of an individual's need rather than on arbitrary limits on service hours or on expenditure caps.
----------------	--

The regulatory provisions for personal care services do not specify a minimum or maximum amount, duration, or scope of services, nor do they give states guidance on what constitutes a reasonable amount of services to achieve their purposes. Rather, regulations state that services may vary based on needs of the individual. This approach has the advantage of giving states maximum flexibility in setting the amount of services provided, but it also allows states to be restrictive in the amount of services offered.

Most problematic are the ceilings on benefits for live-in services and services approaching 24 hours per day. Although the number of individuals requiring this high level of care is small, they should not be excluded from receiving appropriate personal attendant services because of arbitrary limits on hours of service. If program limitations are to be made, they should be made at the aggregate level so that those with the greatest need are not put at unnecessary risk of institutionalization.

Limitations on the maximum hours or dollars allowed below what would be needed for live-in or 24-hour care or below the nursing home costs per month penalize those individuals with the greatest levels of disability, and they may force individuals into institutional care unnecessarily. Moreover, limits on the amount of services allowed prevent allocation of services based on need.

Training and Qualifications of Personal Assistants

State 6 **When there is no other way of providing appropriate PAS services, parents of minor children as well as the children or spouses of adult beneficiaries should be eligible for payment for performing these services.**

Federal personal care services regulation state that reimbursed services may not be furnished by a "legally responsible relative," which includes spouses and parents or step-parents of the individual. The rationale is that spouses and parents are inherently responsible for meeting the personal care needs of their family members and that paying them could erode family responsibilities.

However, this definition of family prevents some individuals from receiving reimbursement for personal care services because they are unable to identify providers outside of the family (Atchley, 1996). Thus, this prohibition may limit access to personal care services, particularly in rural areas, and may encourage institutionalization. Additionally, some older persons may prefer the opportunity to choose family members or friends as workers. Presumed benefits from doing this are: less anxiety about having a stranger in the home, reduced staff turnover and non-coverage due to unscheduled absences, and increased consumer satisfaction with services (Flanagan, 1994).

Some states have elected to permit family members to be reimbursed as providers of personal care (e.g., California). However, these states must then assume the full financial liability for these consumers because federal payments are not allowable. This situation should be rectified.

State 7 **Agencies or entities that perform PAS needs assessments should be prohibited from providing services recommended as a result of those assessments.**

The obvious conflict of interest, which arises from the referenced process, must be resolved. State agencies, which provide PAS services should have at least an arms length relationship to other agencies, or private organizations, which are responsible for providing the requisite PAS needs assessment.

Consumer Protection

State 8	States should establish: (1) procedures for accepting and acting on complaints about services and (2) a process for appealing adverse actions (e.g., the denial, reduction, or termination of services).
----------------	---

Personal care service regulations do not have any specific provisions about rights and ability to file complaints about care. In contrast, there are extensive consumer protections in place in nursing home and home health agency regulations. These include, for example, the rights of people in nursing homes to be free of interference, coercion, discrimination, or reprisal; to be given notice of rights and services; to refuse treatment; to be informed of Medicaid benefits; and to have other rights such as free choice and privacy and confidentiality. Residents of nursing homes also have the right to file a report with the appropriate state agency regarding abuse or neglect and to meet with a state ombudsman upon their request.

Although due process and grievance rights of Medicaid recipients of personal care services are not specifically addressed in federal statute, a long history of court cases has established these rights, including a fairly clear record in regard to home care services. For example, recent court cases have established that current recipients of home care services not only have a right to a hearing, but that they also have the right to continue to receive services until a hearing is held. HCFA should clarify the rights of applicants for personal care and waiver services, and enforce the requirement that states assure the right to a fair hearing and an appeals process for consumers whose services are reduced or terminated.

CONCLUSION: CONSUMER CHOICE AND CONTROL

The current long-term care service delivery system in the United States originated more than 30 years ago under the medically oriented Medicare and Medicaid statutes. The current long-term care system evolved out of this medical model, which was not originally intended to meet the long-term care needs of the nation. More than three decades later, there are still strong vestiges of this medical orientation in the way non-medical, long-term care services are provided to people with disabilities—the most obvious being the fact that over 80% of Medicaid long-term care dollars is spent on services provided in institutions. This strong medical and institutional orientation of the current long-term care system runs counter to the needs and desires of an overwhelming majority of people with disabilities who require long-term services and supports.

The recommendations made in this report, if adhered to by federal and state policymakers, will help create a system that is responsive to consumers' needs and desires to receive long-term services while living in the community and to be in control of the services they receive.

Policymakers must act on these recommendations quickly. The aging of the population, coupled with the growing proportion of younger Americans with disabilities is creating an ever-expanding need for long-term services and supports. If a delay occurs in shifting the nation's long-term care emphasis toward socially-oriented, consumer-directed, community-based services, a serious risk is run of alienating and institutionalizing an ever-increasing number of Americans against their will.

The recommendations in this report directly address the desires of all people with significant or severe disabilities to participate in and direct the services they receive. These recommendations from the Blue Ribbon Panel on PAS represent a consensus of policy ideals to address the needs and desires of the following constituencies:

- People of all ages with physical disabilities.
- People of all ages with cognitive disabilities.
- People who are elderly or aging.
- People of all ages with disability due to mental illness.
- Long-term care program administrators.
- PAS researchers.
- Advocacy groups.

Recommendations for technical assistance programs at the federal level, if implemented in a timely fashion, will serve as a catalyst for implementation of recommendations in the areas of consumer-direction and participation, service provision, and training and qualifications of personal assistants.

The current long-term care system makes independence and personal responsibility contingent upon functional abilities. The Blue Ribbon Panel feels that the recommendations provided in this report are complementary, and if all are implemented in a timely manner we will be taking large steps toward a long-term care system that values independence and personal responsibility for all Americans.

The Panel recognizes the obstacles that states face in providing a full range of services for people with disabilities and calls upon Congress and the relevant federal agencies to work to remove these obstacles. There is also much progress that can and should be made at the state level regardless of actions taken at the federal level. Currently, the Medicaid waiver option allows states great flexibility in establishing and implementing creative home and community-based long-term care programs.

The Future

What we want the system to look like in ten years . . .

In the year 2010, the Blue Ribbon panel would like to have a long-term care system in place in which one setting (i.e., the nursing home) is not favored over any other under federal and state statutes. Federal and state regulations should be setting-neutral, allowing consumers to choose the setting in which services are to be delivered. Consumers should be allowed to direct and control their personal assistants if they desire to do so. The recommendations of the Blue Ribbon Panel should be addressed immediately by Congress, the Administration, and state policymakers for this system to be realized within the next ten years.

Next Steps

The Blue Ribbon Panel's recommendations should be widely distributed and considered among federal policymakers in the administration and in Congress and among every state administration and legislative body.

To facilitate a greater uniformity of action and implementation across states, these recommendations should be placed on the agenda of the next meetings of the National Governors' Association, and the National Conference of State Legislators.

A web site has been established to disseminate the findings of this research project to further encourage the networking that has been established by Panel members. The Web site (address: <http://www.ilru.org/pas>) identifies panel members, provides resource materials on PAS, and summarizes policy recommendations from the Panel.

GLOSSARY

Attendant Care Services – See Personal Assistance Services

Americans with Disabilities Act (ADA) – Civil rights legislation enacted in 1990 requiring governments and businesses to take proactive steps to offer equal opportunity to people with disabilities.

Activities of Daily Living (ADL) – Basic self-care functions. Inability to perform ADLs is a common, though limited, trigger for long-term care services and is measured through a variety of ADL scales. The most common ADLs measured are bathing, dressing, using the toilet, transferring in and out of beds and chairs, and eating.

Care Plan – Individualized program of long-term services and supports determined through a needs assessment at the state level.

Consumer – Person with a severe disability.

Consumer Choice – The ability of a consumer to choose the type of program in which long-term services and supports are delivered.

Consumer-Directed Care – Long-term care where the consumer has a strong role in planning and directing his or her own individual service. Consumer-direction means that consumers select, train, supervise, and fire their care attendants.

Disability – A limitation in ADL or IADL activities for which a person needs assistance from another person or is otherwise restricted in the conditions, manner, or duration they can perform such activities. This also includes people who can perform an activity, but require supervision, reminding, or the need to have someone nearby.

Federal Financial Participation (FFP) Payments – Federal funding.

Health Care Financing Administration (HCFA) – Federal department that administers the Medicare and Medicaid programs.

Home Care Services – Primarily refers to acute care services provided in the home with Medicare funding.

Home and Community-Based Services (HCBS) – These services include a wide range of long-term care programs that, singly or in combination, might serve as alternatives to nursing home care and ICFs/MR. The HCBS waiver permits states to use federally matched Medicaid money for a wide range of HCBS services for people who are functionally eligible for nursing homes and ICFs/MR under the Medicaid program in the state. Usual HCBS services for elderly include home care of various kinds, adult day care, case management,

home delivered meals, medical equipment, home modifications, and payment for services in assisted living, small group homes, adult foster care, or other residential settings.

Impairment – Any loss or abnormality of psychological, physiological, or anatomical structure or function. Only some impairments actually cause disability.

Independent Provider (IP) – A term often used to connote home care workers and personal assistance workers who are some equivalent of “self-employed” as opposed to being employed by home care agencies. When IP’s are covered under Medicaid, they are sometimes paid by the state (after the consumer authorizes the number of hours), sometimes by the consumer, and sometimes by agencies designated to act as fiscal intermediaries for the consumer-employers.

Institution – In the context of long-term care systems, institution refers primarily to the nursing home setting.

Instrumental Activities of Daily Living (IADLs) – Other regular tasks that require physical dexterity, strength, speech, hearing, vision, memory, and cognitive reasoning and/or the ability to exercise good judgment. Examples of IADLs include cooking, cleaning, shopping, doing laundry, driving an automobile, using a telephone, reading mail, following instructions, and paying bills.

Long-Term Care – Health, personal care, support, training, and related social services provided over a sustained period of time to people who have lost or never developed certain measurable functional abilities.

Managed Care – General term to describe the growing number of health insurance plans characterized by 1) presence of physician gatekeepers; 2) a significant degree of utilization review and case management; 3) provider assumption of financial risk; 4) channeling of patients to providers associated with the plan.

Medicaid – A state-operated and state-administered program that is financed jointly by the state government and the federal government according to a matching formula, and that provides medical benefits for low-income people in need of health and medical care. States operate their Medicaid programs with substantial policy-setting discretion but under general federal guidelines. Medicaid was authorized in 1965 under Title 19 of the Social Security Act.

Medicare – A nationwide health insurance program for people 65 and over, for people eligible for social security disability payments for two years or more, and for certain workers and their dependents who need kidney transplantations or renal dialysis. The program was enacted in 1965 as Title 18 of the Social Security Act. Under Part A, it covers hospital care and limited nursing home care. Under Part B, it includes physician services, home health care, laboratory services, and medical equipment. Consumers contribute to the costs of Medicare through premiums, deductibles, and co-payments as specified under the law.

Mental Impairment – Includes mental or psychological conditions such as mental retardation, organic brain syndrome, emotional or mental illness, and specific learning disabilities.

Most Integrated Setting – It is the setting that allows the greatest independence and personal responsibility, given the individual's needs.

Personal Care Option – Medicaid long-term care option made available to states in 1975; allows for less professional, less expensive, more flexible attendant services to be used in lieu of home health services for people needing long-term care services in their own homes.

Personal Assistance Services – Services to assist people who have ADL or IADL deficiencies with their personal care or other daily activities. PAS may be provided at a state's option as part of the state Medicaid plan. Sometimes PAS is provided through independently employed care providers and is distinguished from care in home care agencies.

Personal Assistant – Individuals who provide assistance with activities of daily living and instrumental activities of daily living to people with disabilities.

Physical Impairment – Any of the physiological disorders or medical conditions (e.g., cancer, diabetes), paralysis, disfigurement, or anatomical loss.

Representative or Surrogate – Usually a family member who assists the person with a disability in directing her/his personal assistance services.

Self-Direction – The process of directing one's own personal assistance services. Self-direction can involve the processes of locating, hiring, training, scheduling, and when necessary, firing one's personal assistants.

Social Security – The federally administered Old-Age, Survivors, and Disability Insurance (OASDI) program, which is the national pension system in the United States, established in 1935, and funded through a trust fund established by a payroll tax. The plan has been modified over the years in terms of coverage and benefit level. Over 90% of households include people over the age of 65 who received some income from Social Security, and Social Security is the sole or primary source of income for many American families.

REFERENCES

- Atchley, R.C. (1996). *Frontline Workers in Long Term Care: Recruitment, Retention, and Training in an Era of Rapid Growth*. Oxford, OH: Scripps Gerontology Center.
- Beatty, P., Richmond, G., Tepper, S., DeJong, G. (1997). Personal Assistance for People with Physical Disabilities: Consumer-Direction and Satisfaction with Services. *Archives of Physical Medicine and Rehabilitation*. 79: 674-677.
- Benjamin, A.E., et al. (1998). Comparing Client-Directed and Agency Models for Providing Disability-Related Supportive Services at Home. Briefing report provided to the Assistant Secretary for Planning and Evaluation, Office of Disability, Aging, and Long-Term Care Policy.
- Flanagan, S.A., Green, P.S. (1997). Consumer-Directed Personal Assistance Services: Key Operational Issues for State CD-PAS Programs using Intermediary Service Organizations. Washington D.C.: U.S. Department of Health and Human Services.
- GAO (1996). Medicaid Managed Care: Serving the Disabled Challenged State Programs. Washington, DC: USGAO, Report Number GAO-HEHS-96-136.
- Harrington, C., LaPlante, M., Newcomer, R., Bedney, B., Shostak, S., Summers, P., Weinberg, J., Basnett, I. (1998). A Review of Federal Statutes and Regulations for Personal Care and Home and Community Based Services: A Final Report. Department of Social and Behavioral Sciences, University of California, San Francisco.
- Human Services Research Institute (1991). New Models for the Provision of Personal Assistance Services: Final Report. Bethesda, MD: Human Services Research Institute.
- Kane, R., Kane, R., Ladd, R. (1997). *The Heart of Long-Term Care*. New York, Oxford University Press, 1998.
- Kaye, H.S. and Longmore, P.K. (1998). Disability Watch: The Status of People with Disabilities in the United States. Report. San Francisco, CA. Disabilities Rights Advocates, Inc.
- Nosek, M.A. (1990). Personal Assistance: Key to Employability of Persons with Physical Disabilities. *Journal of Applied Rehabilitation Counseling*. 21(4): 3-8.
- O'Keeffe, J. (1996) Determining the Need for Long Term Care Services: An Analysis of Health and Functional Eligibility Criteria in Medicaid Home and Community-Based Waiver Programs. AARP, Washington, D.C.

Richmond, G., Beatty, P., Tepper, S., DeJong, G. (1997). The Effect of Consumer-Directed Personal Assistance Services on the Productivity Outcomes of People with Disabilities. *Journal of Rehabilitation Outcomes Measurement*. 1(4):48-51.

Robert Wood Johnson Foundation (1996). Chronic Care in America: A 21st Century Challenge. Princeton, NJ: Robert Wood Johnson Foundation.

Sabatino, C.P., and Litvak, S. (1995). Liability Issues Affecting Consumer-Directed Personal Assistance Services. Oakland: World Institute on Disability.

Scala, M.A. and Mayberry, P.S. (1997, July). Consumer-Directed Home Services: Issues and Models. Oxford, OH: Scripps Gerontology Center, Miami University.

Scala, M.A., Mayberry, P.S., Kunkel, S.R. (1996). Consumer-Directed Home Care: Client Profiles and Service Challenges. *Journal of Case Management*, 5:91-98.

Winterbottom, C., Liska, D.W., Obermaier, K.M. (1995). State-Level Databook on Health Care Access and Financing. Washington, DC: The Urban Institute.

ABOUT THE AUTHORS

Pamela J. Dautel is the Research Coordinator for ILRU. At ILRU, her projects include: (1) collaborative relationships between Independent Living Centers and Vocational Rehabilitation Agencies; (2) funding diversity of Independent Living Centers; (3) Blue Ribbon Panel on National Policy Implications for Personal Assistance Services; (4) Research and Training Center on Managed Care and Disability; and (5) research collaboration with The Center on Emergent Disability at The University of Illinois at Chicago.

Before joining ILRU, Pamela designed and implemented health education strategies in the elementary school, emergency room, and clinical settings. She completed her Masters of Public Health, in Health Promotion, Health Education in December 1996.

Pamela's previous work experience includes 20 years in the corporate world where she was a nuclear licensing analyst and marketing analyst for the electric and natural gas industries, respectively. Her undergraduate degree is a Bachelor of Business Administration (BBA) with a major in Industrial Engineering.

Lex Frieden is Senior Vice President at The Institute for Rehabilitation and Research (TIRR) in Houston, Texas. TIRR is a comprehensive medical rehabilitation center which provides clinical, educational, and research programs pertaining to spinal cord and brain injuries and other disabling conditions. He is also Director of TIRR's Independent Living Research Utilization Program and Professor of Physical Medicine and Rehabilitation at Baylor College of Medicine.

From 1984 to 1988, Mr. Frieden served as Executive Director of the National Council on the Handicapped (now the National Council on Disability), an independent Federal agency located in Washington, D.C. In this capacity, he was instrumental in conceiving and drafting the recently enacted Americans with Disabilities Act (ADA).

A graduate of Tulsa University, Mr. Frieden has been honored as a Distinguished Alumnus. He also holds a master's degree in social psychology from the University of Houston. He has done additional graduate work in rehabilitation psychology at the University of Houston with support from an SRS doctoral fellowship, and he has been awarded a World Rehabilitation Fund Fellowship to study programs for disabled people in Europe. Currently, he is Vice President for North America of Rehabilitation International, and he serves as a member of the United Nations Panel of Experts on the Standard Rules for Disability.

Mr. Frieden, a quadriplegic due to spinal cord injury, has been involved in the organization of several groups of disabled individuals including the American Coalition of Citizens with Disabilities, the Coalition of Texans with Disabilities, and the Houston Coalition for Barrier Free Living. He is presently Chairman of the American Association of People with Disabilities (AAPD).

Working in the independent living movement by severely disabled people since the early 1970s, Mr. Frieden has published several books and papers on independent living. He served as a consultant panel member for the United States House of Representatives' Committee on Science and Technology from 1976 through 1978, and he prepared the background paper on Community and Residential Based Housing for the White House Conference on Handicapped Individuals in 1977. From 1989 to 1990, he represented the United States on a disability and employment panel at the Organization for Economic Cooperation and Development in Paris, France.

He has received two Presidential Citations for his work in the field of disability, and he was honored by the U.S. Jaycees in 1983 as one of America's Ten Outstanding Young Men. In 1998, he received the Henry B. Betts Award for "efforts that significantly improve the quality of life for people with disabilities."