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Report to Congressional Requesters

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ADULTS WITH SEVERE DISABILITIES

Federal and State Approaches for Personal Care and Other Services

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The Honorable Pete V. Domenici
Chairman
Committee on the Budget
United States Senate

The Honorable John R. Kasich
Chairman
Committee on the Budget
House of Representatives

Millions of adults of all ages have severe disabilities; are unable to perform basic daily activities such as bathing and dressing; and often require substantial financial, medical, or other supportive services. Financing for these and other long-term care services comes from both public and private sources. For example, the federal government provides cash assistance, health insurance, and other supportive services, many of which are targeted at individuals with disabilities. Historically, public funding for such individuals has consisted primarily of cash benefits or services delivered in nursing homes or similar institutions. However, the provision of long-term care has changed, as an increasing number of adults with disabilities receive services in the community.

Medicaid, a joint federal/state program that provides medical care for certain categories of low-income Americans, has played a significant role in the movement toward community-based personal care and support services. Medicaid gives states flexibility in how they provide personal care services—for example, through such innovations as allowing individuals with disabilities to select and direct their own caregivers. States most frequently approach community-based services under Medicaid using one of two optional benefits, both of which give states flexibility in deciding which beneficiaries will be served and allow a wide range of services to be covered. Recently, some advocacy groups and consumers with disabilities have challenged the optional nature of community-based long-term care with its flexibility to limit both the number and categories of individuals served.

The cost and policy implications of changing the current provision of community-based care are considerable and require a broad understanding of the current framework under which adults with disabilities receive services. With the goal of obtaining basic information

to enhance understanding of these issues, you asked us to (1) estimate the number and characteristics of adults with severe disabilities; (2) quantify the federal assistance available to such individuals; (3) describe Medicaid coverage of personal care and related services; and (4) discuss how a sample of selected states have implemented Medicaid policies that allow consumers to select their own caregivers, an approach called consumer direction. We used the National Health Interview Survey (NHIS) to derive estimates of the number of individuals with severe disabilities who live in the community, rather than in institutions. We also conducted interviews with research and advocacy groups on disability, identified public programs that addressed the needs of adults with severe disabilities, and visited a sample of states identified as innovators in the provision of personal care: California, Kansas, Maine, and Oregon. We conducted our review from June 1998 through April 1999, in accordance with generally accepted government auditing standards. Appendix I contains a more detailed discussion of our scope and methodology.

Results in Brief

Our analysis of 1994-95 NHIS data showed that, nationwide, 2.3 million adults of all ages lived in home- or community-based settings and required considerable help from another person to perform two or more activities of self-care. For such individuals with severe disabilities, obtaining personal care on what is often a daily basis is critical to avoiding institutionalization. However, without help from family, friends, or public programs, affording such assistance may be problematic, because individuals with severe disabilities were usually less well off economically than the general population. Adults with disabilities were more likely than the general population to live in a family with an income of less than $20,000 and were almost twice as likely to live below the U.S. poverty threshold. Eighty-four percent of adults aged 18 to 64 with severe disabilities were either out of work or did not participate in the workforce. In addition, adults of all ages with severe disabilities were more likely to have less than a high school education. Over 80 percent of the adults with severe disabilities in our sample reported having public health insurance, primarily Medicare, Medicaid, or both.

At least 70 different federal programs provide assistance to individuals with disabilities. Having a disability is a central eligibility criterion for 30 programs that have estimated fiscal year 1999 expenditures totaling $110 billion. The majority of these funds ($79 billion) are used to pay cash benefits, primarily through the Social Security Disability Insurance and Supplemental Security Income programs. Other programs provide a

mixture of cash and services to veterans with disabilities ($28 billion) or offer other individuals educational, training, employment, social, and other services ($3 billion). For a second, larger group of 40 programs, disability is one of many potential eligibility criteria. Within these 40 programs, Medicare and Medicaid are the most significant sources of federal funds that cover nonskilled personal care services for individuals with disabilities. Medicare's home health benefit, which cost over $17.7 billion in 1997, has become a significant source of personal care funding and over time has changed in focus from solely a short-term, acute care benefit to a longer-term, chronic care benefit.

Most Medicaid personal care and related services are optional benefits that are provided at the discretion of each state. The fastest growing expenditures are for Medicaid home- and community-based services (HCBS) waivers, which grew at an average annual rate of 31 percent between 1987 and 1998—twice as much as Medicaid home health (a required benefit) and three times as much as the personal care services (PCS) optional benefit. States apply to the federal government for HCBS waivers, which, if approved, allow states to limit the availability of services geographically, target specific populations or conditions, control the number of individuals served, and cap overall expenditures. Nearly all states have HCBS waivers, and 40 states use them as the primary funding source for Medicaid community-based care. However, recent court challenges to the service and expenditure limits imposed by HCBS waivers have raised questions regarding whether states will be allowed to continue these practices. These pending cases have raised concerns in a few states that waiver costs will increase; if so, there may be additional costs for the federal government as well.

The consumer direction policies of the Medicaid programs in California, Kansas, Maine, and Oregon reflected the advantages and complexities of self-direction as well as the competing concerns among states, caregivers, and consumers. While most states offered consumers choice regarding the selection and hiring of a caregiver, consumer direction varied most often in the extent to which consumers had authority to train their own caregivers and manage the payroll. Despite differences in models of consumer direction, all four states confronted similar issues regarding the quality and availability of consumer-directed services. In general, states and consumers identified two challenges: (1) ensuring a qualified pool of personal caregivers for what are usually low-wage positions that typically attract individuals with little or no training and (2) balancing states'

concerns regarding consumer safety with consumers' right to direct their own care.

Background

The term "disability" can be broadly applied to mean limitations that are physical, mental, or both and that hinder performance of everyday activities. Within this broad characterization, there are considerable differences in severity and in the need for assistance.[1] For some individuals with disabilities, assistance from another person is necessary—either direct "hands-on" assistance or supervision to ensure that everyday activities are performed in a safe, consistent, and appropriate manner. For others, special equipment or training can enable continued independent functioning. Disability can be present from an early age, such as in the case of individuals with mental retardation/developmental disabilities; occur as the result of a disease or traumatic injury; or manifest itself as a part of the natural aging process. Moreover, different forms of disability can pose different challenges. For example, individuals with physical disabilities often require significant help with daily activities of self-care. In contrast, individuals with Alzheimer's disease or chronic mental illness may be able to perform everyday tasks and may need supervision more than hands-on assistance.

Personal care, a key component of community-based long-term care services, is one term used to describe "hands-on" or one-on-one assistance provided to individuals needing help with basic activities of daily life in a noninstitutional setting.[2] Personal care is nonmedical and involves aiding individuals with limitations in the ability to perform activities of daily living (ADL) and instrumental activities of daily living (IADL). ADLs include bathing, dressing, eating, transferring from a bed to a chair, using the toilet, and moving around the house, while IADLs cover preparing meals, shopping, managing money, using the telephone, and performing heavy or light housework. The number of self-care tasks for which an individual requires assistance is a good indicator of severity of need, and the amount and intensity of long-term care assistance a person needs increase appreciably with the number of his or her impairments. The increase in need for assistance is especially dramatic for individuals with limitations in three or more ADLs. While there are other definitions of

[1]In fact, estimates of the number of individuals with disabilities ranged from 1 million to well over 10 million, depending upon the definitions used.

[2]Some people with disabilities prefer to use the terms "supports" or "services" rather than "care" and think of themselves as "consumers" rather than "clients" or "care recipients." We use the term "personal care" because of its use by and common association with the Medicaid program. However, it is intended as a broad descriptive term for hands-on assistance to or supervision of an individual.

disability, ADL and IADL limitations can be directly linked to the need for personal care.[3]

Medicaid and, to some extent, Medicare are the two primary sources of public funding for personal care. Medicaid, a joint federal/state health financing program for low-income Americans who are aged, blind, or disabled, is the principal source of public funding for long-term care, with 1998 expenditures of $59.1 billion. In 1996, Medicaid accounted for 38 percent of total long-term care spending. Historically, Medicaid long-term care expenditures financed services delivered in nursing homes or other institutions, whereas home- or community-based care was predominantly provided informally by family, friends, or both, or paid for with private funds. While most community-based care continues to be provided on an informal basis, Medicaid has increased its funding of community-based services. Between 1987 and 1998, community-based long-term care expenditures increased from 10 percent to 25 percent of Medicaid long-term care spending.

Medicaid offers three benefits that provide personal care: the home health benefit; the PCS benefit; and HCBS waivers, which operate under section 1915(c) of the Social Security Act. Within broad federal guidelines, states determine the amount and duration of services offered under their Medicaid programs. States may, for example, place reasonable limits on services or require authorization to be obtained prior to service delivery.

Home Health Benefit

States must offer home health services as a part of their Medicaid program to all beneficiaries who are entitled to nursing facility services. Under Medicaid, a physician must order home health services as part of a care plan that is reviewed periodically and includes part-time or intermittent nursing services; home health aide services; and medical supplies, equipment, and appliances suitable for use in the home. Home health aide services must be provided by a home health agency and can include personal care.

PCS Benefit

States may, at their option, choose to offer the PCS benefit as part of their Medicaid program. Medicaid defines the PCS benefit as services that are (1) authorized for an individual by a physician in accordance with a plan of

[3]Examples of other definitions of disability include (1) measures of physical activities such as walking, lifting, reaching; (2) serious sensory impairments; (3) serious symptoms of mental illness; and (4) inability to work.

treatment;[4] (2) provided by an individual who is qualified to provide such services and who is not a member of the individual's family;[5] and (3) furnished in a home or, if the state chooses, in another location.[6] States may limit the PCS benefit through two mechanisms: medical necessity and utilization control.

HCBS Waivers

HCBS waivers provide states greater flexibility in program design, permitting the adoption of a variety of strategies to control the cost and use of services. Thus, states may "waive" certain provisions of the Medicaid statute, such as (1) "statewideness," which requires that the services be available throughout the state (a waiver allows services to be provided only in particular geographic locations); (2) comparability, which requires that all services be available to all eligible individuals (a waiver allows states to target services to individuals on the basis of certain criteria determined by the state, such as disease, condition, and age); and (3) the community income and resource rules for the medically needy (a waiver allows states to use institutional eligibility rules—which are more generous than community rules—for individuals residing in the community).[7] To receive an HCBS waiver, states must demonstrate that the cost of the services to be provided under a waiver (plus other state Medicaid services) is no more than the cost of institutional care (plus any other Medicaid services provided to institutionalized individuals). Waivers permit states to cover a wide variety of nonmedical and social services and supports that allow people to remain in the community, including personal care, personal call devices, homemakers' assistance, chore assistance, adult day health care, and other services that are demonstrated as cost-effective and necessary to avoid institutionalization.

Medicare, a federal program that provides health insurance to Americans 65 and older as well as to certain disabled individuals, offers a home health benefit that can include in-home services provided by an aide. To be eligible for Medicare home health, a beneficiary must be confined to the home, be under the care of a physician who establishes a plan of care, and

[4]Under Medicaid, states may also approve "service plans," which are similar to physician-prescribed treatment plans.

[5]"Family member" is defined as a legally responsible relative (42 C.F.R. sec. 440.167(b)). This includes spouses of recipients and parents of minor recipients, including any stepparents who are legally responsible for minor children. Adult children are not included in this definition.

[6]The PCS benefit is not available to Medicaid-eligible individuals who are hospitalized or reside in a nursing facility, an intermediate care facility for people with mental retardation, or an institution for mental disease.

[7]For example, under institutional eligibility rules, the parents' income is not counted when determining their child's eligibility for Medicaid. The parents' income is counted under the community rules.

have a need for at least one of the following: intermittent skilled nursing care, physical therapy, speech therapy, or continuing occupational therapy. Finally, the beneficiary must receive services under a plan of care that is reviewed periodically. A physician can prescribe a home health aide only if all the coverage conditions are met. Any home health aide services must consist primarily of personal care activities; chores, housekeeping, and other services must be incidental to the personal care services performed and not add to the time of the visit.

Under the PCS benefit and HCBS waivers, some states have allowed consumers of personal care to direct their own services, a concept known as consumer direction. Consumer direction includes a range of potential activities. At a minimum, consumer direction entails some degree of decision-making on the part of consumers regarding their service needs, who should provide their care, and their evaluation of the quality and appropriateness of the services received. Consumer direction differs from the traditional, agency-based system of personal care in which people with disabilities have little control over the choice of caregivers, staff schedules, and policies regarding what services will be provided. At its best, consumer direction can tailor services to meet the expressed needs and personal preferences of consumers; thus, it involves helping define the services to be delivered and making important decisions about caregiving. While Medicaid enabling legislation does not authorize cash payments to beneficiaries, states can allow consumers to direct their own care through hiring, training, and supervising their personal care attendants. States with consumer direction may also establish processes that permit consumers to assist in payroll management, tax filings, and other fiscal responsibilities.

Over Two Million Adults With Severe Disabilities Live in the Community

We estimate that approximately 2.3 million adults living in the community have severe disabilities and require considerable help from another person to perform multiple ADLs or IADLs. There are a variety of methods and definitions for identifying individuals with severe disabilities. Our estimate is based on NHIS data and includes adults with both physical and cognitive impairments who required personal care in a home- or community-based long-term care setting.[8] Adults with severe disabilities were less likely to work, had less education, and had less income than the general population. Adults aged 18 to 64 with severe disabilities were also much more likely to have public health insurance coverage, primarily through

[8]We selected NHIS in part because it allowed individuals to provide an indication of the amount of assistance they required.

Medicare and Medicaid, than those of similar age in the general population.

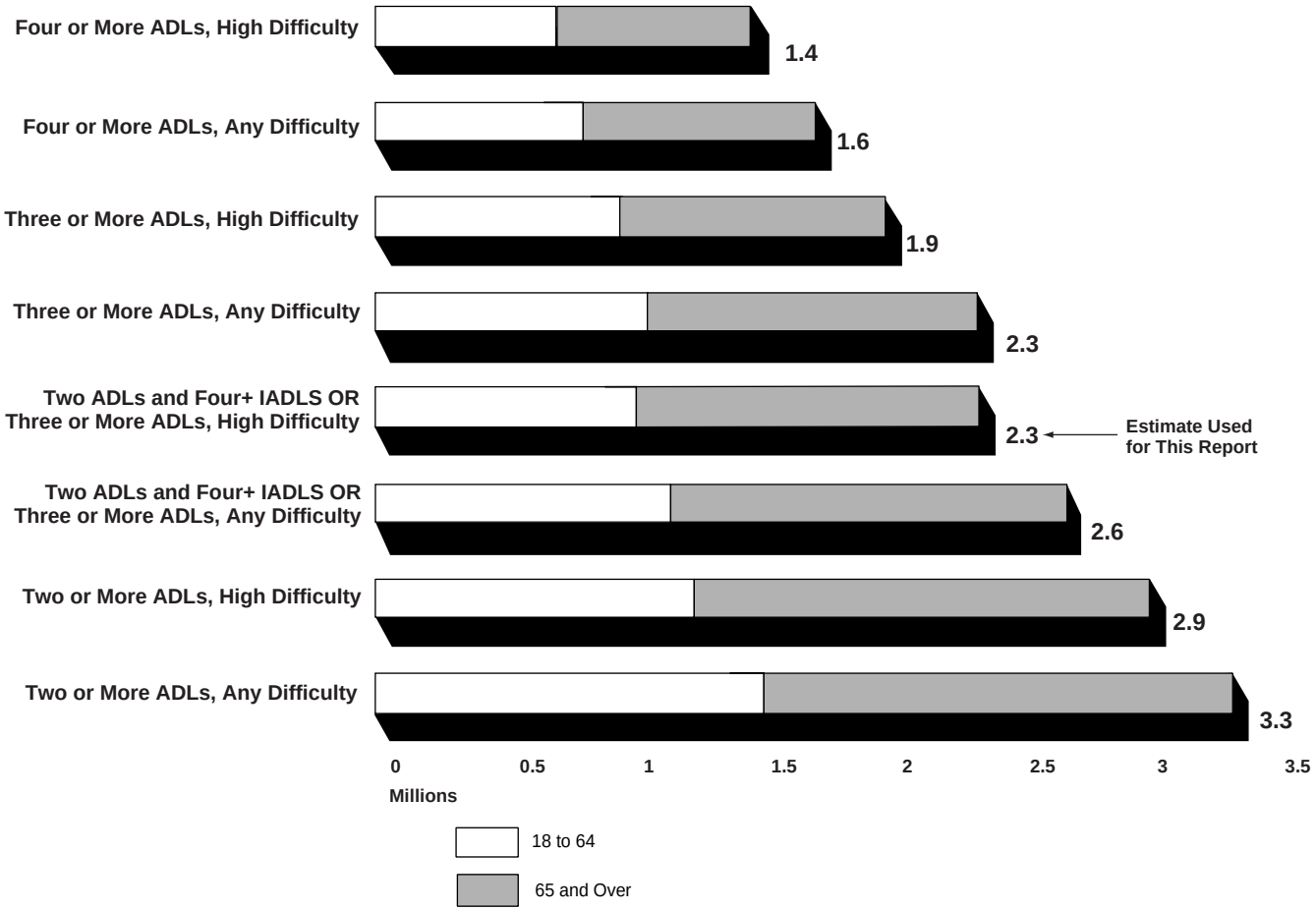
No Consensus Definition of Severe Disability Exists

There is no consensus on what constitutes a severe disability. Individuals differ in the number of functional areas in which they require assistance (expressed by ADLs or ADLs in combination with IADLs) and the level of difficulty they have in performing the activity. Using NHIS, we estimated that the number of individuals with severe disabilities ranged from 1.4 to 3.3 million, depending upon the definition of severity used (see fig. 1). For purposes of demographic analysis, we selected a definition of adults that focused primarily on individuals' ability to perform ADLs but also included an IADL component. Specifically, we defined an adult with severe disabilities as an adult who has either a lot of difficulty with or is unable to perform either

- three or more ADLs or
- two ADLs and four IADLs.[9]

[9]Our definition focuses on adults living in the community; thus, individuals with severe disabilities residing in nursing homes or other institutions are excluded from this analysis.

Figure 1: Estimates of Number of Adults With Severe Disabilities, 1994-95



Note: We identified two levels of difficulty in performing ADLs and IADLs: (1) "any difficulty," which means an adult reported some difficulty, a lot of difficulty, or being unable to perform a requisite number of activities, and (2) "high difficulty," which means an adult reported a lot of difficulty or being unable to perform activities.

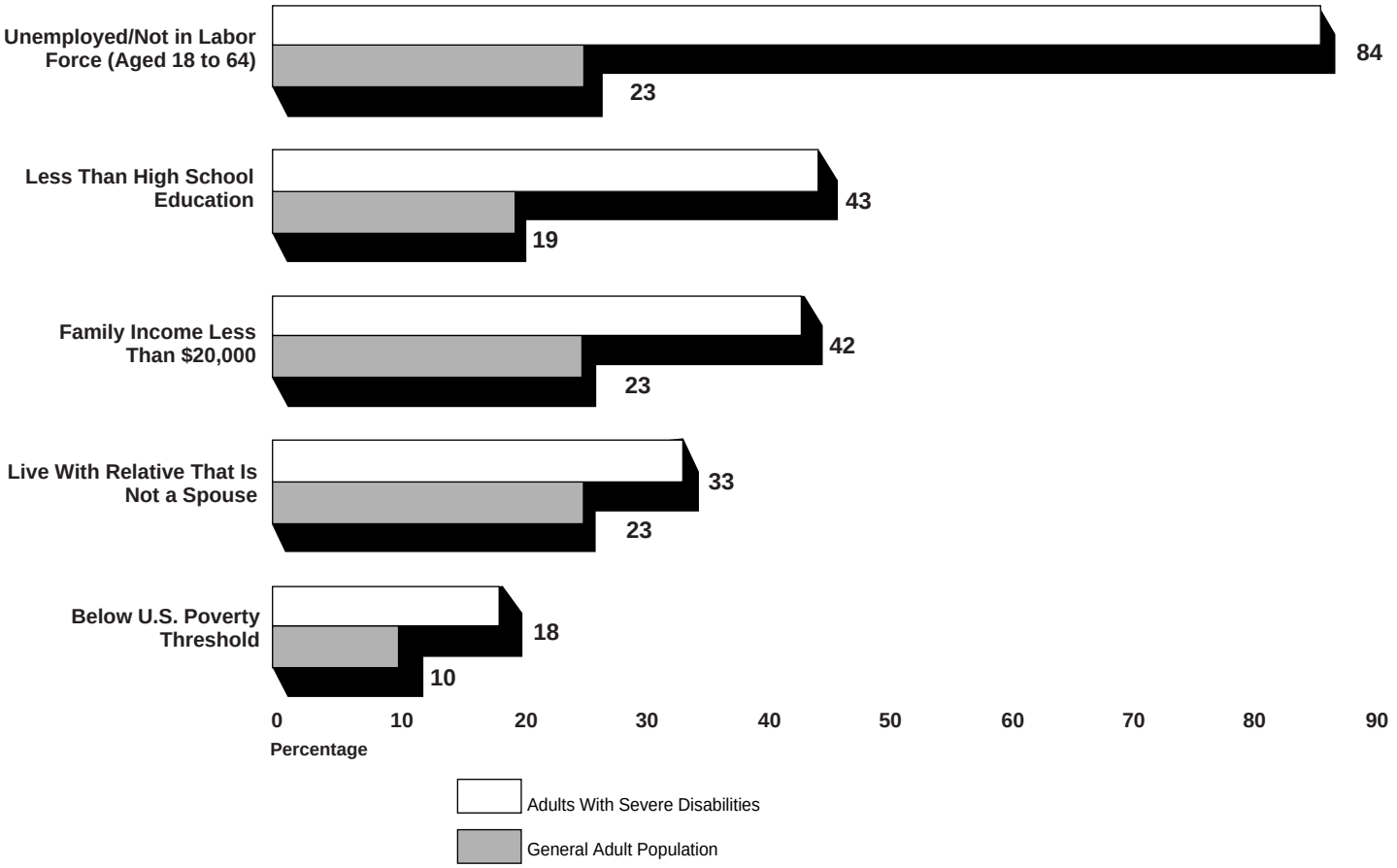
Source: NHIS 1994-95 data.

Adults With Severe Disabilities Had Lower Employment, Education, and Income

Adults with severe disabilities were considerably less well off than the rest of the general population in several key areas, as summarized in figure 2. Working age adults (18 to 64) with severe disabilities were far less likely to work, with 84 percent reporting that they were either out of work or did not participate in the workforce. Additionally, adults 18 and over with

severe disabilities were more likely to have less than a high school education, live in a family with an income of less than $20,000 per year, and live with a relative that is not a spouse. Furthermore, adults 18 and over with severe disabilities were almost twice as likely to live below the U.S. poverty threshold than nondisabled individuals.

Figure 2: Selected Characteristics of Adults With Severe Disabilities Compared With Those of the General Population, 1994-95



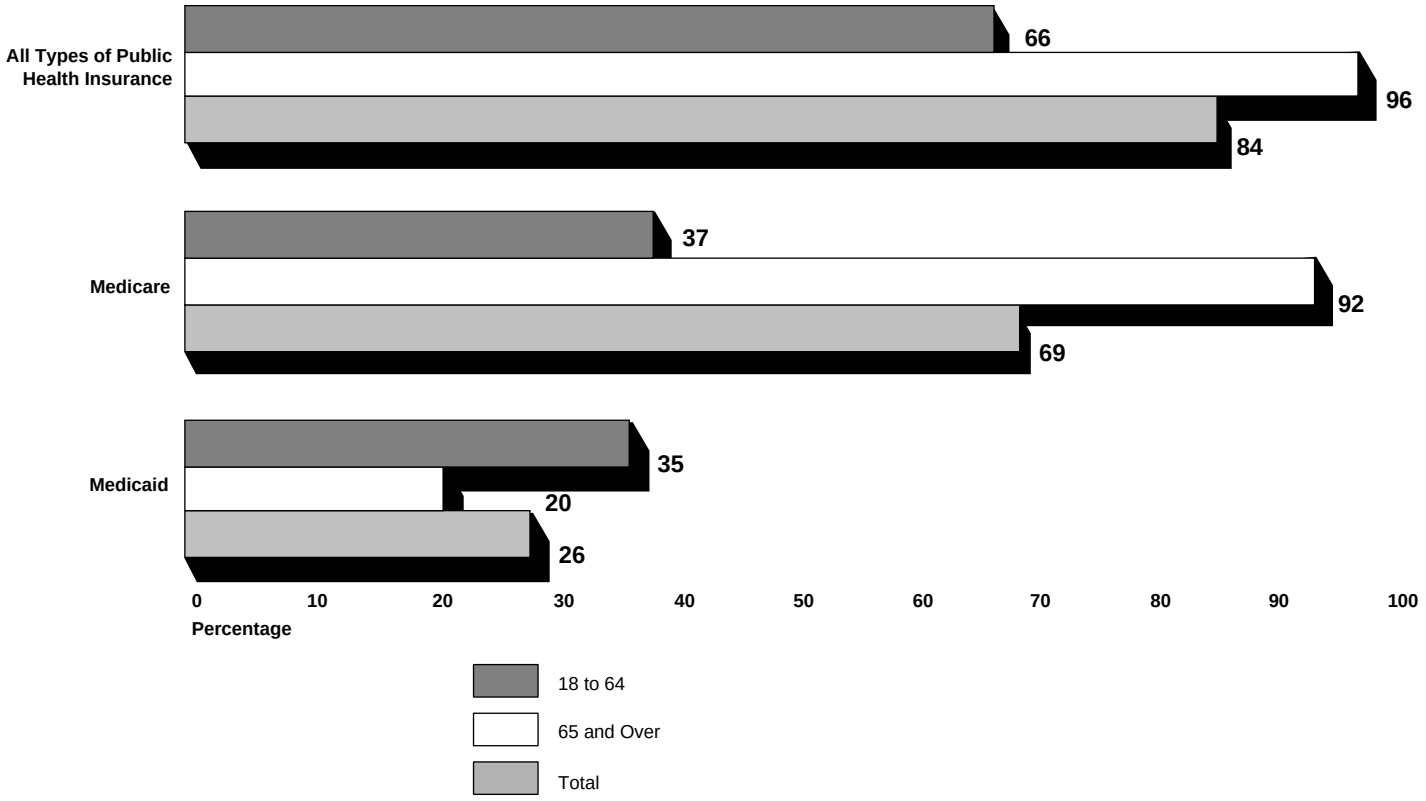
Source: NHIS 1994-95 data.

Most Adults With Severe Disabilities Qualified for Public Health Insurance Coverage

Most adults with severe disabilities reported receiving public health insurance coverage, primarily Medicare and Medicaid. Of our estimated 2.3 million adults with severe disabilities, 1.9 million, or 84 percent, reported having some form of public health insurance, as shown in figure 3. Because almost everyone aged 65 or older is eligible for Medicare, age was a significant factor in health insurance coverage. While younger adults with severe disabilities were less likely to have public health coverage than those 65 and over, they were far more likely to have public coverage than those of a similar age in the general population. Because disability is one eligibility criterion for both programs, an adult aged 18 to 64 with severe disabilities was 7 times as likely to receive Medicaid coverage and over 18 times as likely to receive Medicare[10] than the nondisabled general population.

[10]In 1998, 5.2 million individuals below the age of 65 with disabilities qualified for Medicare, accounting for approximately 13 percent of program beneficiaries.

Figure 3: Adults With Severe Disabilities Covered by Public Health Insurance, 1994-95



Notes: Public health insurance includes Medicare, Medicaid, military, veterans', and Indian Health Services coverage. Approximately 2 percent reported military health coverage.

Medicare and Medicaid coverage categories are not mutually exclusive; a person can qualify for both programs at the same time.

Source: NHIS 1994-95 data.

Many Federal Programs Provide Assistance to Adults With Disabilities

We identified two groups of federal programs that provide assistance to individuals with disabilities—a term that is applied in a variety of ways.[11] The first group uses various definitions of disability as a central criterion for eligibility and consists of 30 programs with estimated expenditures totaling $110 billion in fiscal year 1999. The second group uses disability as one of many potential criteria for program participation and consists of 40 programs, including Medicare and Medicaid, for which age, income, or both also serve as bases for eligibility.[12] Medicaid is the most significant source of federal funds for providing personal care services to individuals with disabilities. The provision of personal care services under Medicare is limited to its home health benefit, the use of which has been growing over the past decade.

$110 Billion in Federal Programs Is Targeted Exclusively for Individuals With Disabilities

For fiscal year 1999, the federal government will obligate an estimated $110 billion across 30 programs and services that specifically offer benefits to individuals with disabilities.[13] The three largest programs—Social Security Disability Insurance,Veterans Compensation for Service-Connected Disabilities, and Supplemental Security Income—offer cash benefits to eligible individuals and account for over 86 percent of this total. One program within the 30, the Department of Veterans Affairs (VA) Aid and Attendance program, explicitly offers personal care services through a cash allowance and provides an additional cash allowance to eligible veterans if their disabilities make it impossible to perform basic ADLs without the assistance of another person.[14] Figure 4 shows the distribution of the $110 billion by budget function.

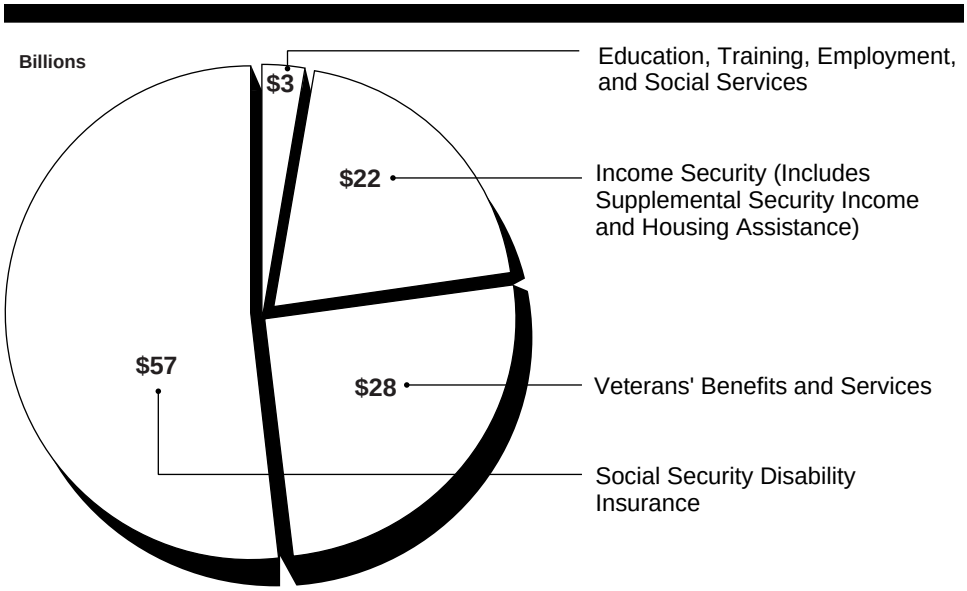
[11]The eligibility criteria for federal programs are not consistent with the definition we used to estimate the number of adults with severe disabilities. For federal programs, disability can be linked to an individual's ability to work, rather than the need for assistance with ADLs and IADLs. While these two definitions are not mutually exclusive, they are not necessarily the same. In fact, many of these federal programs are likely to serve very different populations than those represented in our estimate of 2.3 million. For example, one program offers independent living services to individuals with visual impairments, and another offers employment training to individuals with physical or mental impairments that impede employment.

[12]We have not included expenditures for these 40 programs because the broader eligibility criteria did not allow us to determine the amount of expenditures that could be attributed to individuals with disabilities.

[13]This estimate includes 77 percent of the expenditures of the Supplemental Security Income program, which is the percentage of individuals with disabilities served by this program. Supplemental Security Income is an income- and resource-tested cash assistance program for low-income individuals who are aged, blind, or disabled.

[14]For more information on consumer-directed personal care offered under this program, see Consumer-Directed Personal Care Programs: Department of Veterans Affairs and Medicaid Experience (GAO/HEHS-98-50R, Jan. 16, 1998).

Figure 4: Distribution of the Estimated $110 Billion Designated Specifically for Individuals With Disabilities, by Budget Function, Fiscal Year 1999



Source: General Services Administration, Catalogue of Federal Domestic Assistance (Washington, D.C.: GSA, Dec. 1998).

Appendix II summarizes the 30 programs for which disability is a condition of participation, and appendix III lists the broader array of 40 programs that include disability as one of many potential eligibility criteria.

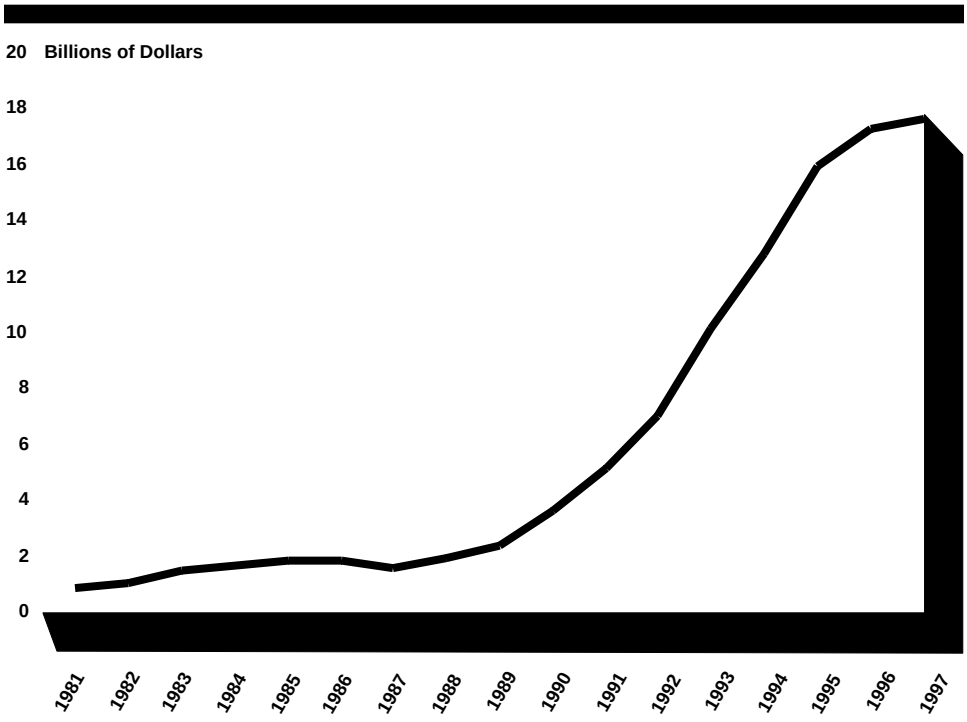
Medicare Home Health Has Become a Significant Source of Funds for Community-Based Care

Although Medicaid is the most significant source of federal funds for providing personal care services to people with disabilities, the Medicare home health benefit—particularly the long-term use of a home health aide—has become an important source of nonskilled personal care for individuals with disabilities and the elderly. This benefit, originally established for beneficiaries recovering from illness or injury after a hospitalization, has been used by an increasing number of beneficiaries as a source of custodial care for chronic conditions.[15] This shift toward more long-term care services has been a major contributor to the 20-percent average annual growth in Medicare home health costs between 1981 and

[15]See Medicare Home Health: Success of Balanced Budget Act Cost Controls Depends on Effective and Timely Implementation (GAO/T-HEHS-98-41, Oct. 29, 1997).

1997. Figure 5 shows the dramatic increases in Medicare home health expenditures.[16]

Figure 5: Medicare Home Health Expenditures, 1981-97



Source: Health Care Financing Administration (HCFA), Office of the Actuary.

Longer-term use of the home health benefit, particularly for home health aide services, has increased Medicare spending. In 1989, the proportion of home health users receiving more than 30 visits was 24 percent. In 1996, this proportion had increased to 49 percent, indicating that the program was serving a larger proportion of longer-term patients. Moreover, 55 percent of beneficiaries receiving home health care in 1997 had not been recently hospitalized, another indication that those receiving care were not in need of short-term acute care (such as following a hospital stay), but of longer-term care for chronic conditions, which are often associated with disability. For 1996, over 48 percent of all Medicare visits

[16]From 1995 through 1997, the rate of growth of the Medicare home health benefit slowed, and Medicare home health expenditures declined in 1998. The amount of the decline is uncertain, however, since these expenditures have not been finalized.

were made by home health aides and, as shown in table 1, 5 percent of home health aide users received about 41 percent of those visits.

Table 1: Beneficiaries' Use of Medicare Home Health Aides, 1996

Number of visits per user	Percentage of total users	Percentage of home health aide visits
1-9	22.2	0.2
10-29	28.9	2.1
30-49	13.0	3.4
50-99	14.6	9.6
100-149	6.7	10.7
150-199	4.7	12.9
200-249	2.8	10.3
250-299	2.0	9.9
300+	5.0	40.8
Total	**100.0**	**100.0**

Note: Percentages may not total 100 because of rounding.

Source: Medicare Payment Advisory Commission.

Most Medicaid Personal Care and Related Services Are Optional Benefits Offered by States

Under Medicaid, states have three approaches for providing personal care, two of which may be offered at the discretion of the state. First, states must offer the Medicaid home health services benefit (including home health aides), which may provide unskilled personal care services. Second, states may choose to provide the PCS benefit, which offers unskilled personal care services as a part of the states' Medicaid benefit package. Third, HCBS waivers, which were first introduced in 1981, give states the option of providing personal care and other related services if they choose to do so. HCBS services operate under markedly different rules than the home health and PCS benefits, which must be offered to all eligible individuals. In particular, HCBS waivers allow states to limit geographic availability, target specific populations or conditions, limit the number of individuals served, and cap waiver expenditures.

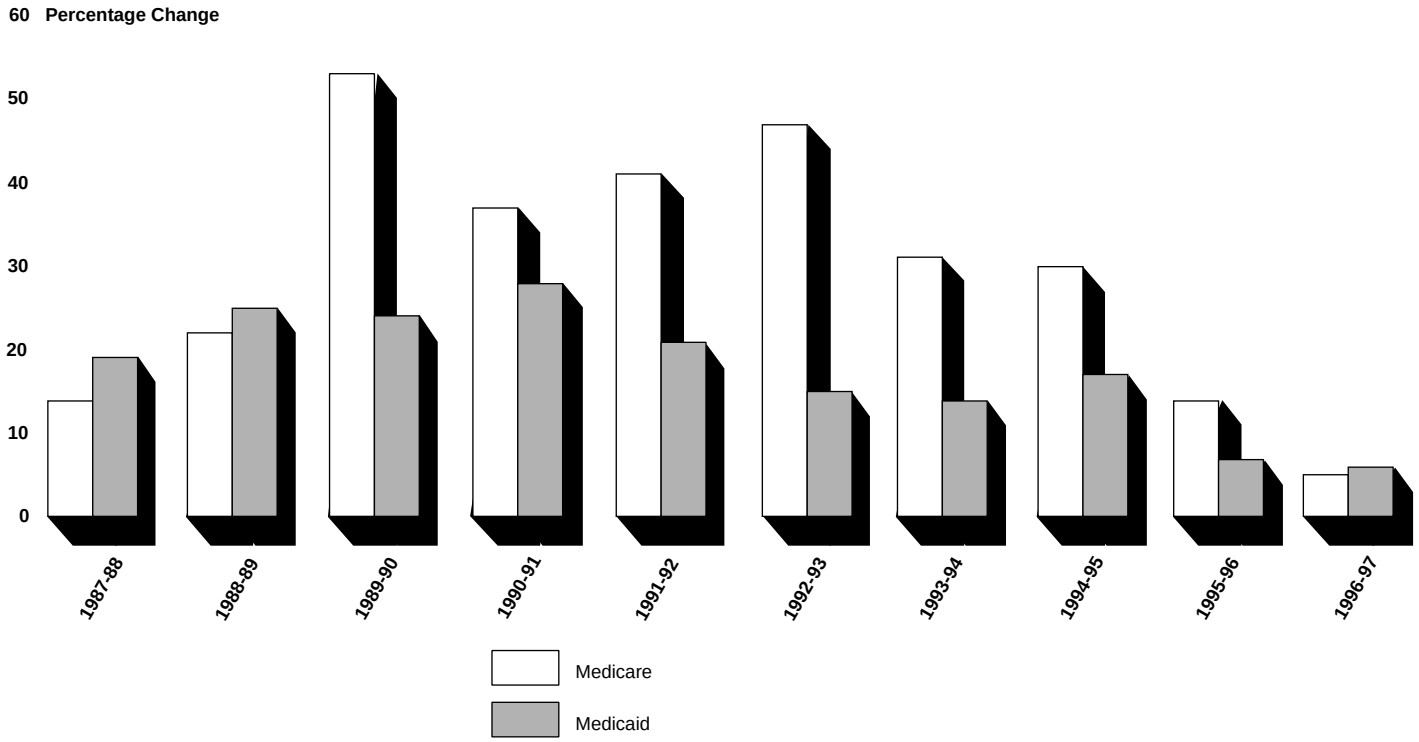
The popularity of HCBS waivers is evidenced by their growth rate: from 1987 to 1998, expenditures under HCBS waivers grew at an average annual rate of 31 percent, compared with 16 percent for home health and 10 percent for the PCS benefit. Appendix IV summarizes the growth of each of the three Medicaid approaches to personal care and provides information on how states use them to provide community-based care.

Finally, recent court challenges to service provision limits and to the selective nature of some personal care waiver programs have raised serious concerns about the continued viability of HCBS waivers. These pending cases have raised concerns among a few states that waiver costs will increase; if so, there may be additional costs for the federal government as well.

Medicaid Home Health Has Grown Modestly Compared With Medicare

In contrast to the very rapid growth in the Medicare home health benefit since the late 1980s, expenditures under Medicaid home health have increased more modestly. A physician must order Medicaid home health in accordance with a plan of care that is reviewed periodically and details the use of services required. A prescribed care plan may or may not include the services of a home health aide, but the home health benefit must make available medical services (such as nursing services), supplies, equipment, and appliances suitable for use in the home. Between 1987 and 1997, expenditures for Medicaid home health grew at an average annual rate of 17 percent, compared with 26 percent for Medicare home health. Figure 6 shows annual changes in expenditures for the two programs during this period.

Figure 6: Comparison of Growth in Medicare and Medicaid Home Health Expenditures, 1987-97



Source: HCFA.

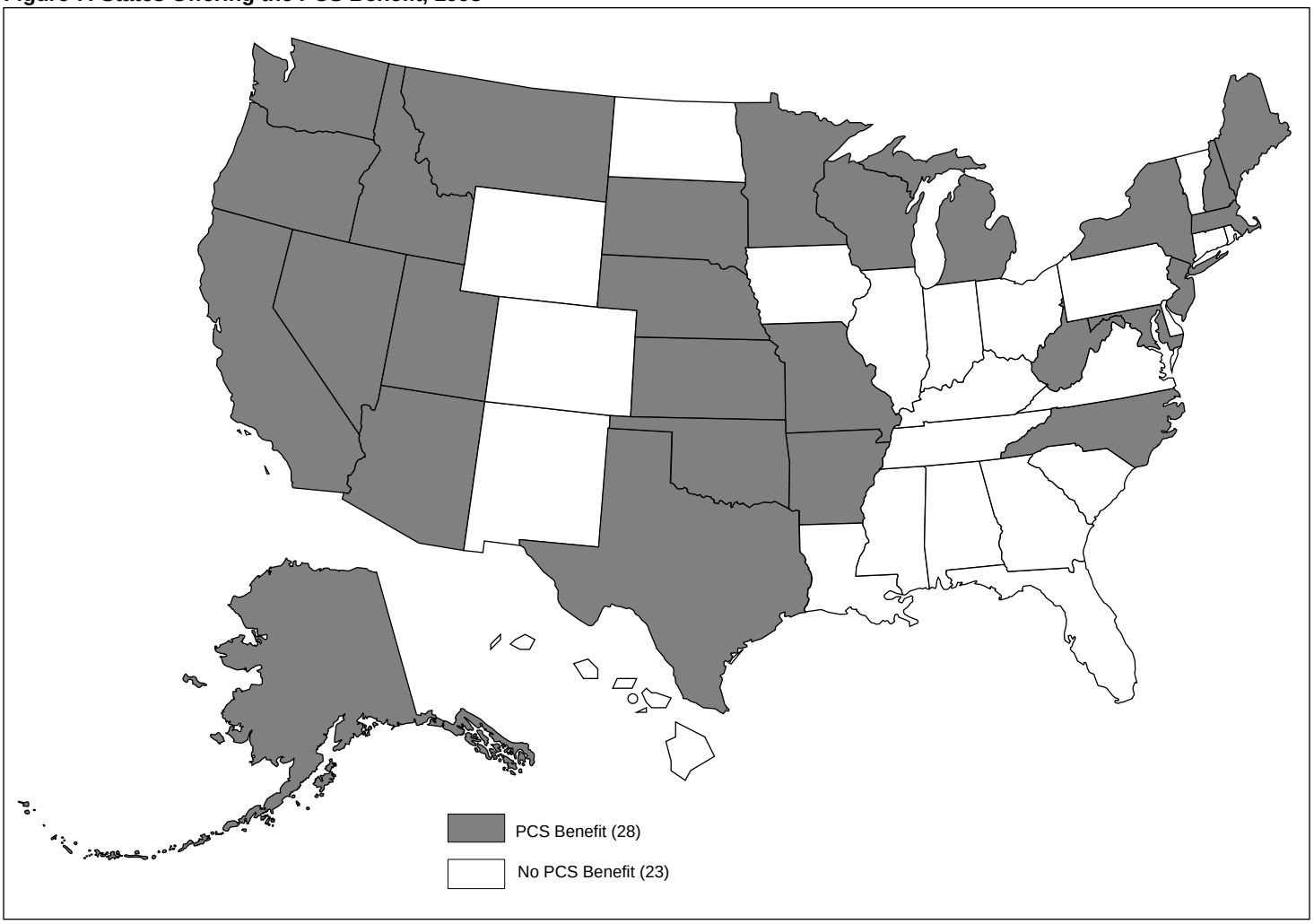
States are permitted to use medical necessity and utilization control methods to manage the use of Medicaid home health services. For example, California requires prior authorization for more than one visit in a 6-month period and will approve a maximum of 30 visits at a time. Florida limits visits to 60 per year, except by prior authorization.[17] Other states limit the hours of service provided each day; require preauthorization if the services are not in conjunction with a recent hospitalization; or impose limits on the type of services provided, such as nurse, therapy, or home health aide visits.

[17]While Medicaid services for home health can range from those of a home health aide to more skilled services (for example, physical, occupational, or speech therapy or nursing services), expenditures are not tracked by the type of home health visit made.

Medicaid PCS Benefit Requires Statewide Service Provision but Allows Service Limits

Of the Medicaid approaches offering personal care, the PCS benefit is offered by the fewest states; accordingly, it has had the slowest average annual growth: 10 percent from 1987 to 1998. About three-fifths of the states and the District of Columbia had elected to use the PCS benefit under Medicaid as of 1998, as shown in figure 7. Once elected, the PCS benefit must be provided to all eligible individuals with a demonstrable need for personal care, a factor that may prevent additional states from adopting this benefit.

Figure 7: States Offering the PCS Benefit, 1998



Note: Arizona operates a personal care program as part of a separate section 1115 waiver; because HCFA includes these expenditures as part of its PCS benefit totals, Arizona is identified as a PCS state in this map.

Source: Medicare and Medicaid Guide (Chicago, Ill.: Commerce Clearing House, Inc.).

States offering the PCS benefit are afforded some flexibility in order to contain costs or target services to particular populations. For example, states are allowed to set their own criteria for establishing who needs the PCS benefit and may use a wide variety of assessment instruments or other

procedures to determine who receives services. Variations in the use of the PCS benefit are apparent across states, reflecting these implementation differences. For example, California relies on the PCS benefit primarily as a means of providing personal care services to individuals with long-term care needs, whereas Oregon targets this benefit toward an acute-care, more medically based service. Other states establish eligibility for the PCS benefit by identifying functional impairment. For example, Maine and New Hampshire limit eligibility to individuals with chronic or permanent disabilities, while Florida limits the PCS benefit to children. Table 2 shows PCS benefit expenditures and their proportion of each state's total Medicaid home and community expenditures for fiscal year 1998.

Table 2: States' Use of the PCS Benefit, Ranked by Percentage of Total Medicaid Community-Based Expenditures, Fiscal Year 1998

State	Percentage of community-based expenditures	FY 1998 PCS benefit expenditures
California	59.10	$324,379,099
Arkansas	49.36	63,244,424
Idaho	42.46	15,238,552
New York	41.90	1,655,085,940
Michigan	39.95	207,957,621
Texas	35.33	228,816,135
New Jersey	33.51	169,711,230
Montana	32.41	13,365,579
Missouri	28.84	91,636,182
North Carolina	28.20	135,870,664
Washington	27.79	120,122,810
Massachusetts	22.05	139,105,479
Arizona	19.98	266,642
West Virginia	18.56	27,845,161
Minnesota	18.49	98,637,571
Wisconsin	15.08	65,534,473
Oklahoma	15.03	24,184,928
Alaska	12.11	4,246,146
Maryland	10.39	24,051,519
Nevada	9.53	2,025,840
Oregon	6.77	19,961,594
Nebraska	5.58	5,381,619
Florida[a]	3.82	14,136,021
Kansas	3.74	8,213,577
Maine	3.06	3,596,006
District of Columbia	2.73	366,038
Vermont[a]	2.15	1,527,670
New Hampshire	2.10	2,294,653
South Dakota	1.55	732,931
South Carolina[a]	0.81	1,177,397
Utah	0.66	431,427

[a]These states do not offer the PCS benefit to adults but report expenditures because of services provided to children under the Early and Periodic Screening, Diagnostic, and Treatment program.

Source: HCFA.

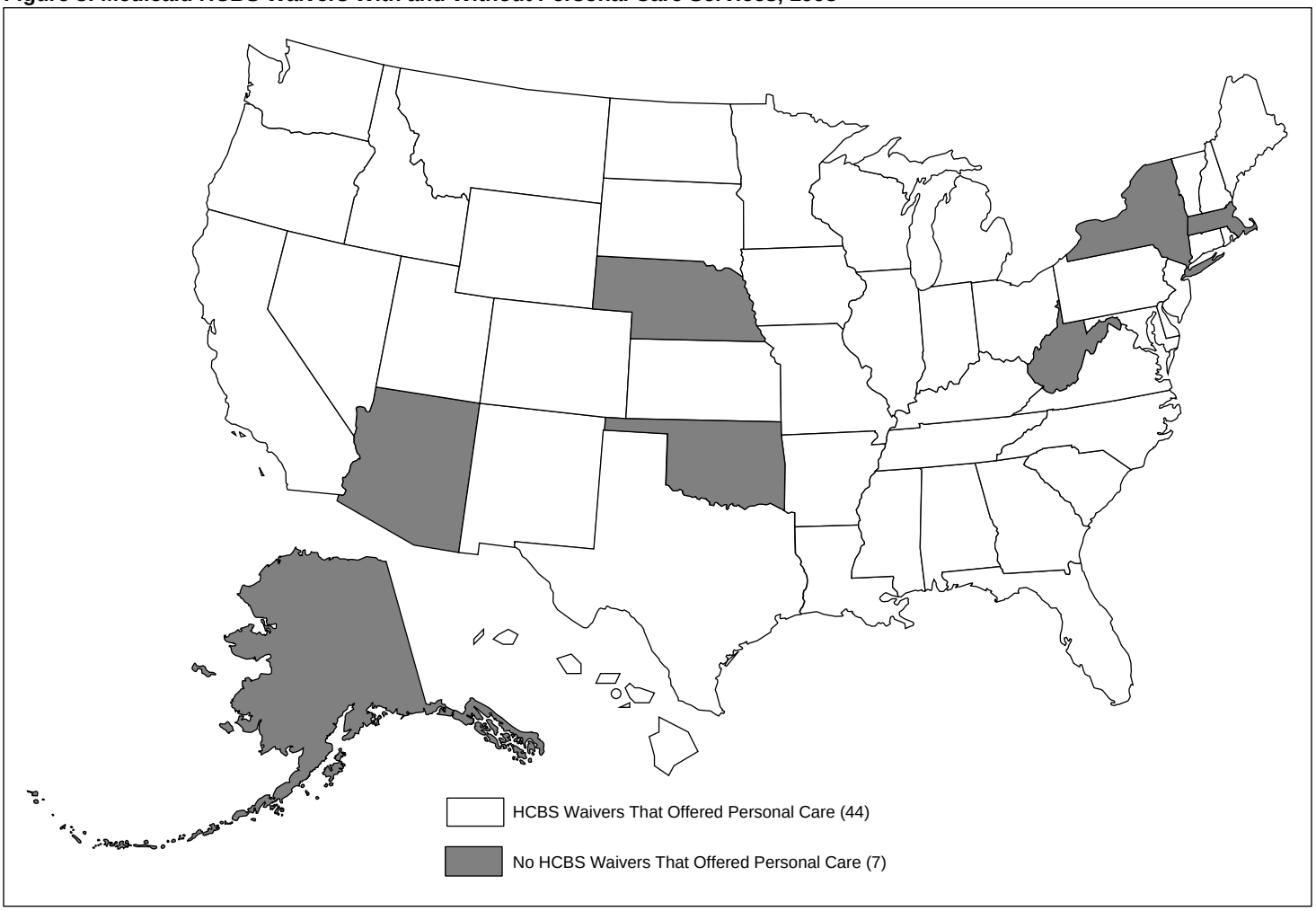
States also control utilization of the PCS benefit by requiring prior authorization, establishing limits on the duration of services, or both. For example, of the 27 states and the District of Columbia, 7 require prior authorization for personal care services and 15 limit the hours or units of service provided.[18] (App. V summarizes approaches states take to limit services under the PCS benefit through the use of assessment tools and limits on services.)

States Make Use of Controls and Flexibility Afforded by HCBS Waivers

The enactment of HCBS waivers gave states more flexibility in program design and more control over expenditures. HCBS waivers allow states to target services to specific populations, geographic areas, or both. HCBS waivers also allow states to set expenditure caps, limit services to a specific number of individuals, and—similar to the PCS benefit—impose limits on the number of hours of services provided. From 1987 to 1998, HCBS waivers grew at an average annual rate of 31 percent, increasing in popularity and use among states. In contrast to the PCS benefit, which 23 states did not offer, HCBS waiver expenditures were reported by almost every state in 1998, and all but 8 of these states had at least one waiver that offered personal care services (see fig. 8). Only two states used the PCS benefit for the majority of their Medicaid community-based expenditures, while 40 states channeled over half of their community-based Medicaid expenditures through HCBS waivers. (App. V summarizes HCBS waivers that offered personal care.)

[18]Of the 14 states and the District of Columbia with service limits, 7 do not allow these limits to be exceeded, while the remaining 8 allow exceptions with prior authorization.

Figure 8: Medicaid HCBS Waivers With and Without Personal Care Services, 1998



Source: American Public Human Services Association.

Using a database compiled by the American Public Human Services Association (APHSA), we estimated that 118 of the over 200 HCBS waivers provided personal care to almost 331,000 individuals.[19] The estimate of the number of recipients is likely to be an undercount, because as many as 16 waivers did not cite the number of enrollees. States had anywhere from

[19]Personal care is only 1 of over 25 different types of services offered under HCBS waivers. Because data on the costs associated specifically with personal care services within each waiver are not readily available, information on HCBS waivers and spending encompasses many related services.

one to six HCBS waivers offering personal care that varied greatly in the number of clients served and per capita cost, as shown in table 3. For example, the number of clients served ranged from a high of 35,000 under one waiver to a low of 9 under another. Additionally, one-half of the waivers identified served fewer than 1,000 individuals, indicating that most HCBS waivers were relatively small. Waivers that offered personal care were most likely to provide related services, such as respite services, environmental modifications, personal emergency response systems, and adult day health programs.

Table 3: Range of Attributes of HCBS Waivers Offering Personal Care Services, 1998

Attribute	Low	High	Average
Clients served per waiver	9	35,000	3,250
Per capita costs	$663	$270,000	$20,769
Waivers per state	1	6	2.68

Source: APHSA.

HCBS waivers are also likely to target a specific population or group of individuals. For example, over 50 percent of HCBS waivers offering personal care focused on (1) the elderly, people with physical disabilities, or both and (2) individuals with developmental disabilities; together, these two populations accounted for over 80 percent of consumers for HCBS waivers with personal care. Table 4 summarizes HCBS waivers with personal care by their target populations and number of consumers.

Table 4: Selected Characteristics of HCBS Waivers With Personal Care, 1998

Target population	Number of waivers	Percentage of waivers	Number of consumers	Percentage of consumers
Elderly, people with disabilities, or both[a]	30	25.4	174,969	52.8
People with disabilities	15	12.7	17,631	5.3
People with HIV/AIDS[b]	12	10.2	13,726	4.1
Elderly	9	7.6	11,617	3.5
People with developmental disabilities	35	29.7	112,221	33.9
People with traumatic brain injury	13	11.0	916	0.3
Other	4	3.4	387	0.1
Total	**118**	**100.0**	**331,467**	**100.0**

[a]States did not identify HCBS waiver populations consistently, so we created two categories of HCBS waivers for individuals with disabilities: one that identified only disability and one that served the elderly, people with disabilities, or both.

[b]Human immunodeficiency virus/acquired immunodeficiency syndrome.

Source: APHSA.

State Efforts to Target Services Have Been Challenged Legally

Recent litigation in federal courts has raised the possibility that the use of functional assessments in conjunction with HCBS waivers as a basis for denying services to reduce or constrain costs may no longer be legally permissible in some circumstances under the Americans With Disabilities Act of 1990 (ADA).[20] These cases raise questions about whether federal matching funds would be made available to meet added costs resulting from increased services that are outside a state's Medicaid plan.

The ADA prohibits the exclusion of an individual with a disability from participating in public programs or receiving public benefits by reason of the person's disability. Department of Justice regulations implementing this provision require that "a public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities."[21] Justice has recently reiterated that the "most integrated setting" standard applies to states,

[20]42 U.S.C. 12131-12134. Sec. 12132 of the act states that " . . . no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity."

[21]See 28 C.F.R. 35.130(d).

including state Medicaid programs. The court cases reflect the application of this provision to specific state programs for individuals with disabilities.

Courts in both Georgia and Pennsylvania have applied Justice regulations and found that institutional placement may violate the ADA if the placement does not constitute the most integrated setting appropriate to the needs of the individual. While only binding in the circuits involved, the court decisions have potentially broader implications for all states and their ability to place limits on the number of people that participate in waiver programs. On July 29, 1998, HCFA sent a letter to state Medicaid directors informing them of the following three Medicaid cases relating to the ADA and the most integrated setting standard.

In L.C. By Zimring & E.W. v. Olmstead,[22] patients in a state psychiatric hospital in Georgia filed suit challenging their placement in an institutional setting rather than in a community-based treatment program. The circuit court found that the placement in an institutional setting appeared to violate the ADA because it constituted a segregated environment, and that community placement could be required as a "reasonable accommodation" to the needs of the individuals. While the court emphasized that the state cannot justify the denial of community placement because of a lack of funding, it also acknowledged that the state need not provide these services if doing so would fundamentally alter the state's program.[23] This case was remanded to the lower court for a determination of whether a fundamental alteration of the state program would occur as a result of the community placements.[24] On a separate issue, this case was argued before the Supreme Court on April 21, 1999. The Court limited its review to the issue of whether the ADA compels the state to provide treatment for mentally disabled people in a community placement when appropriate treatment can also be provided to them in a state institution.

[22]L.C. By Zimring & E.W. v. Olmstead, 138 F.3d 893 (11th cir.), rehearing and suggestion for rehearing en banc denied, 149 F. 3d 1197 (11th cir.), cert. granted, 119 S.Ct. 617, order amended, 119 S.Ct. 633 (1998).

[23]See 28 C.F.R. 35.130(b)(7). "A public entity shall make reasonable modifications . . . unless the public entity can demonstrate that making the modifications would fundamentally alter the nature of the service, program or activity."

[24]In its ruling, the circuit court put forward some issues the lower court should consider in determining if the state is meeting its burden of establishing that a fundamental alteration of the program would occur if community-based treatment was provided. One issue, among others, is whether the additional expenditures needed to treat the plaintiffs in the community would be unreasonable given the demands on the state mental health budget.

In Helen L. v. DiDario,[25] a Medicaid nursing home resident alleged that the Pennsylvania Department of Public Welfare violated the ADA by requiring her to receive services in a nursing home rather than in her own home through a state-funded personal care program for which she qualified. The court held that the state's failure to provide services in the "most integrated setting" appropriate to the individual's needs violated the ADA. Additionally, the court found that the provision of personal care to the plaintiff would not fundamentally alter any state program because the services were already within the scope of an existing program.

In Easely v. Snider,[26] individuals with disabilities in Pennsylvania filed a lawsuit, through their representatives, challenging a requirement that they be mentally alert in order to participate in the state's personal care program. The court determined that given the essential goal of the program to foster independence for individuals limited by only physical disabilities, including individuals incapable of controlling their own legal and financial affairs in the program would constitute a fundamental alteration of the program. Therefore, the mental alertness requirement was found to be valid and not to violate the ADA.

Of these three cases, only the last appears to uphold states' authority to limit the availability of Medicaid-funded services. In our interviews, state officials from both California and Maine expressed concern about the implications of these cases, as well as about Justice's "most integrated setting" standard. State officials' concerns center on states' ability to limit participation in their waiver programs. Maine officials noted that it is crucial that the state have the authority to define eligibility for services and to implement programs consistently with financial budgets, especially given the large number of individuals who have ADL limitations.

State Approaches to Consumer Direction Reflect Similar Goals and Challenges

States have introduced consumer direction into their personal care programs as a means of ensuring that these services are tailored to the expressed needs and personal preferences of individual consumers. Putting the consumer in the "driver's seat" is challenging for both individuals with disabilities and states. Officials we interviewed compared the skills required for consumer direction to those needed to run a small business. Overall, 31 states appear to offer some degree of consumer-directed personal care. The four states in our sample—California, Kansas,

[25]Helen L. v. DiDario, 46 F.3d 325 (3rd cir.), cert. denied, 516 U.S. 813 (1995).

[26]Easley v. Snider, 36 F.3d 297 (3rd cir.), rehearing and rehearing en banc denied, 36 F.3d 297, 306 (3rd cir. 1994).

Maine, and Oregon—have extensive interest in or experience with consumer-directed personal care. Despite differences in their consumer-direction models, all four states have confronted similar issues surrounding the availability and quality of consumer-directed services: (1) ensuring a qualified pool of personal caregivers for what are typically relatively low-wage positions that often attract individuals with little or no training and (2) balancing state concerns regarding consumer safety with the consumers' right to self-direct their own care.

Consumer Direction Can Be Analogous to Operating a Small Business

Consumer direction entails some degree of decision-making on the part of consumers about the specific services they need and want and about whether individual caregivers are appropriate for the job and capable of delivering those services satisfactorily. Thus, at a minimum, consumer direction means that the consumer defines the services to be delivered and makes employment decisions about caregivers. In contrast, under the traditional system of personal care delivered by a home health or other agency, people with disabilities are typically constrained by the agency's choice of caregivers, the schedules of these staff, and agency policies limiting available services. Consumers and state officials both told us that self-direction is analogous to operating a small business, in that consumers may have to select, hire, train, and manage their own caregivers. (See fig. 9.)

Figure 9: Self-Direction Can Be Analogous to Operating a Small Business

Select and Hire Personal Caregivers

- Prepare job descriptions for the services required.
- Decide how to advertise for and recruit job applicants, including through word of mouth, churches, colleges, newspapers, and bulletin boards.
- Screen job applicants either by phone or in person, checking references and interviewing applicants that appear qualified.

Train and Manage Personal Caregivers

- Provide necessary training and management for personal caregivers to assist with self-care and daily living tasks.
- Plan and coordinate schedules of possible multiple caregivers to ensure needed coverage.
- Monitor absences and tardiness; collect, approve, and submit time sheets to state or local authorities for payment; in some cases, oversee deduction and withholding of payroll and income taxes; and ensure paychecks are provided.
- Develop contingency plans to use when the personal caregivers are ill, have a personal emergency, or will be absent for other reasons.
- Evaluate job performance, including responsiveness to consumer direction.
- Discharge the caregivers if performance is not acceptable.

Depending in part on the nature and degree of the disability, the consumer may have to retain the services of multiple personal caregivers to provide sufficient hours of care to meet ongoing needs as well as to respond to emergencies. For example, a consumer may need assistance in both the morning and evening, a situation that would probably result in the need for more than one caregiver. In one case, we were told that a person with quadriplegia required the services of 12 different personal caregivers over the course of a week. An employed individual with disabilities with whom we met told us that he has five different caregivers. In Maine, 479 consumers collectively employ over 2,000 personal caregivers.

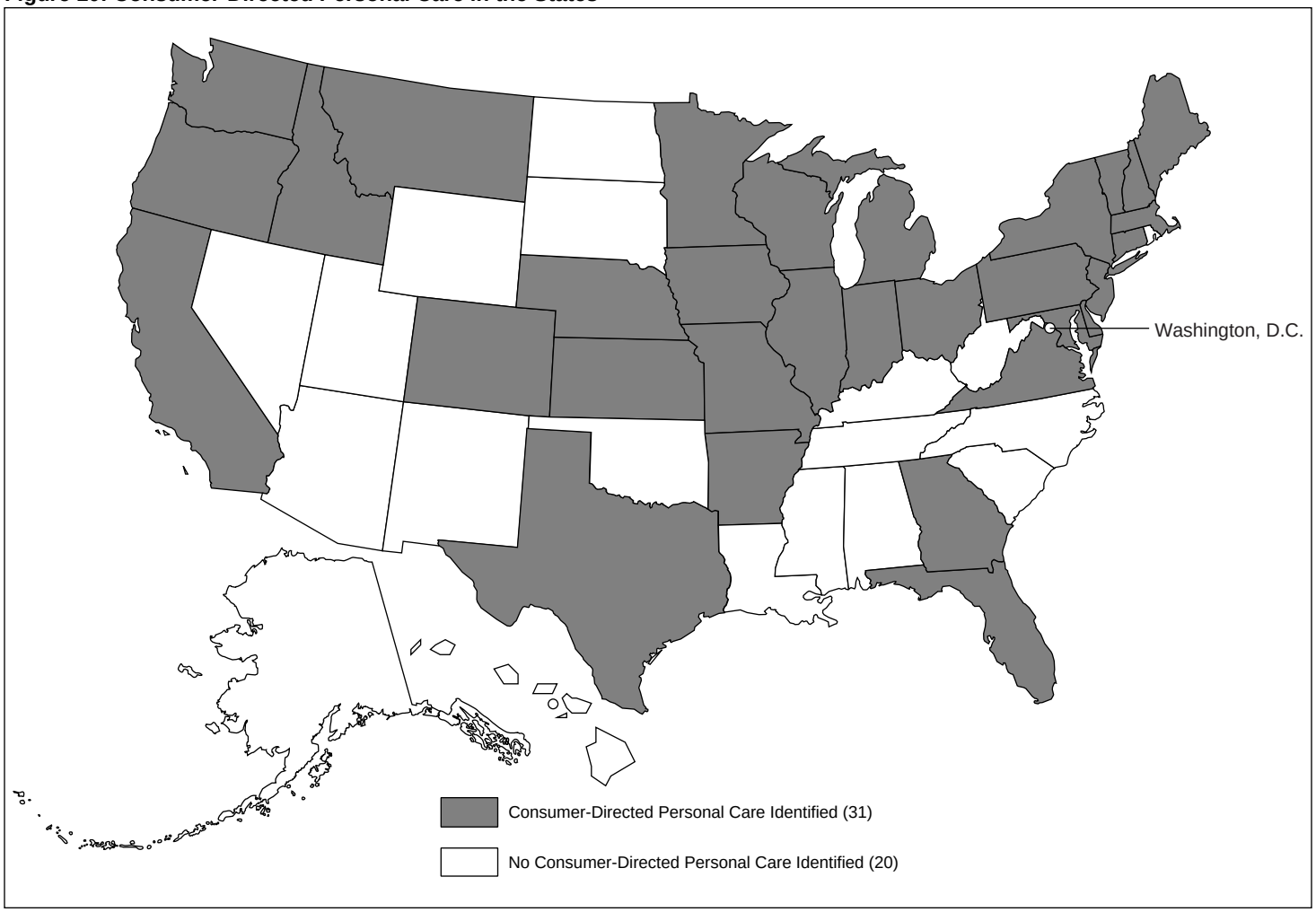
Over Half the States Include Some Consumer Direction for Personal Care Services

We identified 31 states, shown in figure 10, that offered consumer-directed personal care, primarily under Medicaid. A review of the literature shows that states have different approaches to consumer direction. For example, consumer direction in one state may mean that a consumer participates in preparing a service plan and can assist in recruitment. In other states and programs, consumers may also screen caregivers, negotiate compensation,

and train caregivers.[27] To date, little systematic evaluation of the effectiveness of and costs associated with consumer-directed personal care has taken place; a demonstration is under way, however, that should provide insights on this approach to community-based personal care services. The Robert Wood Johnson Foundation, in cooperation with the Department of Health and Human Services (HHS), is sponsoring a four-state demonstration and evaluation of the cost-effectiveness and appeal of a consumer-directed approach to personal care services in Medicaid. Appendix VI summarizes the implementation progress of this demonstration in Arkansas, Florida, New Jersey, and New York.

[27]See Susan A. Flanagan and Pamela S. Green, Consumer-Directed Personal Assistance Services: Key Operational Issues for State CD-PAS Programs Using Intermediary Service Organizations (Washington, D.C.: Department of Health and Human Services, Oct. 24, 1997), app. V-1, exhibit D, pp. 8-12.

Figure 10: Consumer-Directed Personal Care in the States



States in Our Sample Approach Consumer Direction Differently

The four states that we visited offer several different approaches to consumer direction that vary in the consumers targeted and the extent to which consumers have a choice about self-direction. In addition, these states offered different supportive services to help consumers manage their care and oversee their caregivers, as well as different levels of consumer participation in the payroll process.

California

Under California's county-based system, 96 percent of personal care (and related services) is self-directed, with consumers having various levels of access to supportive services. State officials told us, however, that regulations require that all counties evaluate consumers regarding their

ability to self-direct and, if counties determine consumers are incapable, they are referred for special assistance. Of California's 58 counties, 16 offer service delivery models other than self-direction that are based upon county assessments of consumers' needs. In these 16 counties, consumers may also select providers from either the contracting agency or the counties' contracted providers. Twenty-three counties offer supported individual provider services, which use state funds to provide additional administrative and support services for consumers using independent providers. Supported individual provider services enhance service delivery through recruitment, provider list development and maintenance, orientation classes, supervision assistance, and consumer-to-independent-provider matching services. In addition, six counties have opted to form public authorities,[28] which are enhanced independent provider models, and provide additional client assistance and increased compensation for providers.[29] In other counties, few such services are available.

Kansas

The degree of self-direction in Kansas ranges from a low of 10 percent of people with developmental disabilities to a high of 70 percent of those with physical disabilities. The frail elderly fall in between, with 30 percent self-directing their care. Consumers choosing self-direction manage all aspects of their care except paying personal caregivers, which is generally the responsibility of community organizations that serve as payroll agents. Consumers are given lists of payroll agents from which they may choose. Consumers may consult with Centers for Independence for help with determining how comfortable they are with living independently in the community and with self-direction.

Maine

Maine gives consumers an initial choice regarding self-direction. Consumers choosing to self-direct must then decide between two models. Under one model, all consumers must agree to participate in the most extensive consumer-directed program we reviewed, which requires clients to be responsible for training and developing job descriptions for their caregivers as well as for performing actual payroll management functions. These consumers receive a voucher check twice a month from the state based on time sheets that they submitted.[30] Personal caregivers are hired by the consumers and trained on the job by the consumers to assist with

[28]Public authorities are relatively new; the San Francisco Public Authority first met in Oct. 1995, and Los Angeles passed its ordinance in Oct. 1997.

[29]In California, counties exercise control over many aspects of personal care. Not only do they administer the personal care program, they are also responsible for 17.5 percent of costs and decide what supportive services will be available to consumers.

[30]A voucher check is a two-party check that the consumer signs over to the caregiver.

daily activities. Under the second model, consumers may choose between more limited self-direction and agency provision of service.

Oregon

In Oregon, consumer-directed providers, over whom clients have ultimate hiring and firing authority, provide over 91 percent of in-home services. These providers are paid directly by a state agency, and, thus, consumers have minimal involvement in the payroll process. However, consumers of Medicaid in-home care do verify that the authorized hours of work were performed by signing workers' time sheets. In Oregon, case managers play a significant role in ensuring a successful community-based placement. Consumers work with case managers to obtain the set of services that best meets their functional needs. Oregon reports a staffing standard of one case manager for each 69 in-home clients—approximately one-half of the staffing standard for nursing facility clients. Case managers can also arrange for in-home agency providers to assist in case of an emergency. Finally, Oregon has a "Client Employed Provider Guide for Employees" that helps clients select, hire, and direct caregivers. The four states' approaches are summarized in table 5.

Table 5: Variation in Consumer Direction of Personal Care in Four States

State	Populations served	Consumer direction available	Supportive services available[a]	Payroll done by consumer
California	People with physical disabilities and the frail elderly	Yes, in all 68 counties; 16 counties have additional service delivery modes.	Yes, in at least 23 counties[b]	Less than 1 percent
Kansas	People with physical disabilities and developmental disabilities and the frail elderly	Optional	Yes	No
Maine	People with physical disabilities and the frail elderly	Mandatory under one model; optional under other model	Yes, but limited under one model	Yes, under one model
Oregon	People with physical disabilities and developmental disabilities, the frail elderly, and people with mental illness	Optional	Yes	No

[a]Supportive services include assistance in recruiting and hiring, training, and day-to-day management of caregivers.

[b]California services are decentralized to the county level and thus vary in the degree of available supportive services.

States Recognize Multiple Factors Influencing the Quality of Personal Care

Despite differences in their models of consumer direction, the four states we visited share concerns about ensuring the quality of care and safeguarding individuals with disabilities. There is a general consensus among state officials, consumers, and advocates that working conditions—including low wage levels and lack of fringe benefits—often make it very difficult to recruit and retain qualified caregivers.[31] Despite these states' commitment to transfer authority over key aspects of personal care to the consumer, there is less consensus among these same groups on whether and how other quality control measures, such as background checks and service monitoring, should be implemented. Each

[31]Additionally, state officials, consumers, and advocates reported that it is often difficult to arrange for backup when caregivers do not show up for work.

state recognizes the special challenges posed by monitoring services delivered in a home-based setting and by serving a population that includes consumers who have mental impairments. Furthermore, little consensus existed among state officials, consumers, and advocates regarding the degree to which government should actively protect consumers with disabilities.

Compensation of Caregivers Has Implications for Quality of Care

Among the concerns most often raised by state officials, consumers, and advocates in three of the four states we visited are the low wages and limited fringe benefits available to caregivers and the implications of these factors for the quality of care consumers receive. Any decision about caregiver compensation inevitably must be made in a context of funding limitations. The quantity of services available is related in large part to the cost of those services—and labor is by far the largest component of the cost of personal care.

Three of the four states told us that they were uncomfortable with caregiver pay levels, indicating that low wages could reduce the quality and consistency of care. Only in Kansas did there seem to be general agreement that personal caregiver wage rates were adequate. At the time of our visits, the hourly wages for personal care when provided under consumer-directed (nonagency) arrangements were as follows:

- California paid $5.75,
- Kansas paid varying wages,
- Maine paid $6.25, and
- Oregon paid $6.50 to $6.72.[32]

In California, counties have the option of increasing the personal caregiver's hourly wage using local revenues, without any state contribution to the increase. Only San Francisco has augmented the wage level—to $7. Several other counties are currently considering increases. In addition, California has chosen to use state revenues to pay relatives for providing personal care to people who are otherwise eligible for Medicaid reimbursement.[33] One study, which found positive outcomes for consumers self-directing their caregivers, estimated that over 40 percent of consumer-directed personal care providers in California are family

[32]Oregon has a tiered payment system reflective of clients' care needs. At the time of our visit, Oregon rates were $6.50 per hour for minimal assistance with ADL and IADL care needs and $6.72 per hour for full assistance with ADL care. As of Feb. 1, 1999, Oregon increased its rates to $7.80 and $8.02, respectively.

[33]HCFA generally prohibits Medicaid payments to spouses or parents of beneficiaries who provide care.

members.[34] Family members are more likely to undertake such a responsibility, in part, for altruistic reasons, and thus the low compensation may be more appropriately viewed as a recognition of this fact rather than as an actual salary.

In Kansas, under the HCBS waiver for people with physical disabilities, caregivers are paid between $8.25 and $13.25 per hour. The specific amount is determined by the consumer and his or her independent living counselor and reflects in part the severity of the consumer's disability. These amounts are essentially ceilings; caregivers are typically paid at lower levels. For example, for personal care arranged through the Topeka Independent Living Center, wages range from $7 to $10. Part of the reason for the difference between these rates and the maximum allowed by the state is that the Center pays for workers' compensation and unemployment insurance from the remainder of the state allowance. The frail elderly waiver reimburses between $12.00 and $13.25, depending on the level of care the consumer requires; the waiver for people with developmental disabilities offers a flat hourly rate of $10.40. These amounts are then subject to withholding and insurance, resulting in the caregiver's receiving approximately $6 to $8.

Few fringe benefits—such as workers' compensation, health insurance, and paid leave—are available for personal caregivers. Of the four states we visited, only California offers workers' compensation to all personal caregivers; Kansas offers selective coverage, depending in part on the choice of the consumer or vendor agency. In California, active consideration is being given to providing health insurance coverage; San Francisco began providing health insurance coverage in March 1999, and a few counties are also exploring health insurance options. None of the four states offers sick or vacation leave to consumer-directed personal caregivers.

In two of the four states—Oregon and California—labor unions are attempting to organize the states' personal care workforces with the goal of improving wage and benefit levels. The unions face special challenges because of the extent of consumer direction, which results in a highly decentralized workforce. Of the two states, greater organizing progress has been made in California where, as of February 1999, personal caregivers in six counties, including Los Angeles, voted in favor of representation by the Service Employees International Union. In Oregon,

[34]A.E. Benjamin, R.E. Matthias, and T.M. Franke, Comparing Client-Directed and Agency Models for Providing Supportive Services at Home, report for the Assistant Secretary for Planning and Evaluation, HHS (Los Angeles, Calif.: Sept. 30, 1998).

the Oregon Public Employees Union, with the help of its umbrella organization, the Service Employees International Union, has submitted legislation to form a Home Care Providers Commission. One of the main functions of this commission would be to collectively bargain on behalf of client-employed providers.

Views Differ on Monitoring Service Quality

State and local agencies charged with paying for and regulating personal care confront special challenges because of the basic characteristics of self-directed personal care, including the setting in which care is delivered and the nature of both the clientele and the workforce. Moreover, state efforts to intervene to protect consumers have engendered controversy across subgroups of the disability population and their advocates, some of whom view government oversight as intrusive.

As a service delivered in individuals' homes, in diffuse settings, personal care is by nature more difficult to monitor than care delivered in a centralized setting to multiple individuals (for example, in a nursing home or adult day care center). Consumer direction further complicates the task of oversight because it leads to considerable variation and adjustment to individual circumstances, resulting in a less standardized "product." In addition, consumer-directed personal care requires closer monitoring than services provided through agencies, which are often obligated to ensure the qualifications and performance of their employees.

Finally, at least some of the adult disabled and elderly populations have degrees of mental impairment that restrict or prohibit their ability to oversee their own affairs and may require some sort of special protection. Older consumers are sometimes at special risk because of dementia and depression, which can accompany the aging process. But some younger adults with disabilities also experience limitations in mental capacity, such as those associated with mental retardation and certain other developmental disabilities.

Officials, Consumers, and Advocates See the Need to Balance Safety With Autonomy

Recognizing their responsibility for protecting the most vulnerable consumers of personal care—especially the elderly and mentally impaired—state and local government officials with whom we spoke were generally inclined to support broad intervention strategies to protect consumers. Other things being equal, these officials seemed to prefer erring on the side of too much rather than insufficient protection. Although none of the four states we contacted was considering imposing licensure or certification requirements or demanding credentials for personal caregivers, efforts are being made to train personal caregivers as

a quality assurance measure in some of the states we visited. The importance of training is exemplified by caregivers' frequent need to assist consumers in rising from beds or chairs or in moving about their homes. Without training in lifting or transferring techniques, workers may injure themselves or the people for whom they are caring.

To some extent, a pivotal issue in the consumer protection debate is tolerance of risk to the consumer's personal safety. Some consumers and advocates are more willing to tolerate risk if it allows greater personal autonomy, while others believe that protection of vulnerable consumers must take priority.[35] Those on both sides of the issue seem willing to concede, however, that exceptions can and should be made, and individual circumstances should ultimately govern policy. Maine officials noted concerns about the liability of caregivers who provide services in accordance with consumers' instructions that may not meet quality or safety standards. In this regard, Maine officials stated that nurses have raised similar concerns.[36]

Conclusions

Our review of federal and state approaches to providing personal care in home- and community-based settings suggests that the willingness and capacity to do so exist. Increasingly, states are taking advantage of the flexibility available through the use of Medicaid HCBS waivers to design and target programs to individuals with disabilities that meet unique state needs. The personal care programs we examined in California, Kansas, Maine, and Oregon reflect the diversity of approaches and can serve as useful models for other states that may wish to expand the delivery of services in noninstitutional settings and emphasize consumer participation in directing services to meet their own care needs.

Agency and State Comments

HCFA and the four states we visited were given an opportunity to review a draft of this report. They generally agreed with our description of individuals with disabilities and the federal programs providing services. HCFA identified several areas in which the report could be clarified. As a result, we revised language addressing (1) home health services under

[35]In particular, the subject of criminal background checks for personal caregivers is a controversial issue. Advocates for younger adults with physical disabilities see this idea as unnecessary and overly intrusive, while state officials and other advocates see it as imperative to protect vulnerable consumers. Within these groups there is also skepticism about the efficacy of background checks given the incompleteness of criminal justice databases. Other difficulties surrounding the issue include the expense of such background checks as well as reluctance at the state and local levels to fund them.

[36]In this case, nurses are not supervising the caregiver but are providing in-home nursing care.

Medicare and Medicaid and (2) the PCS benefit option under Medicaid. We incorporated other technical comments from both HCFA and the states as appropriate.

We are sending copies of this report to the Honorable Donna E. Shalala, Secretary of Health and Human Services; the Honorable Nancy-Ann Min DeParle, Administrator of HCFA; appropriate congressional committees; and other interested parties.

If you or your staff have any questions about this report, please call me at (202) 512-7118 or Walter Ochinko, Assistant Director, Health Financing and Public Health Issues, at (202) 512-7157. Other major contributors are listed in appendix VII.

Kathryn G. Allen
Associate Director, Health Financing
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Abbreviations

ADA	Americans With Disabilities Act of 1990
ADL	activities of daily living
AIDS	acquired immunodeficiency syndrome
APHSA	American Public Human Services Association
ARC	AIDS-related complex
CCDE	Cash and Counseling Demonstration and Evaluation
HCBS	home- and community-based services
HCFA	Health Care Financing Administration
HHS	Department of Health and Human Services
HIV	human immunodeficiency virus
HUD	Department of Housing and Urban Development
IADL	instrumental activities of daily living
NHIS	National Health Interview Survey
PCS	personal care services
VA	Department of Veterans Affairs

Objectives, Scope, and Methodology

To estimate the number of people with severe disabilities, we reviewed several national surveys, including the Medical Expenditure Panel Survey, the Survey of Income and Program Participation, and the Medicare Current Beneficiary Survey. We selected the 1994 and 1995 National Health Interview Surveys (NHIS) for analysis in part because individuals were asked to report the level of difficulty they had in performing activities of daily living (ADL) and instrumental activities of daily living (IADL), thus providing some measure of the severity of their conditions. NHIS also provided information regarding individuals' need for personal care and related assistance with ADLs and IADLs, as well as data on individuals' ability to work. NHIS data report on noninstitutionalized individuals; thus, our sample excludes individuals residing in nursing homes or other institutions.

By combining 2 years of NHIS data, we were able to increase the sample size and decrease the sampling standard error of our estimates. Because our estimate of the number of individuals with severe disabilities is based on a sample of the population, it is subject to sampling errors. The highest standard error (a measure of sampling error) of our population estimates was +/- 1.6 percent of total estimates. For our comparison of the demographics of individuals with severe disabilities with those of the general population, the percentage sampling error was within a 95-percent confidence interval. Finally, we did not verify the accuracy of the survey data; however, NHIS is a recognized national survey instrument with established procedures in place to ensure a reasonable level of reliability of estimates. We consulted with national research organizations and interest groups regarding a definition of individuals with severe disabilities, obtaining input on the advisability of including both ADL and IADL components. Despite the fact that NHIS specifically asks about supervision of ADLs, research and advocacy organizations believed that an IADL component was necessary to better ensure that individuals with mental or cognitive impairments were represented in our sample.

On the basis of these discussions and our research, we defined an adult with severe disabilities as an individual who reported either a lot of difficulty with performing or inability to perform either (1) three or more ADLs or (2) two ADLs and four IADLs. In some cases, individuals with mental impairments, such as developmental disabilities, mental illness, and other conditions, can physically perform ADLs, IADLs, or both, but supervision or oversight is necessary to ensure that self-care is safely, consistently, and appropriately performed. Although we relied on a definition that included IADLs, our estimates maintained a predominant focus on ADLs because of

their close tie to personal care needs. In this regard, the definition applied for this report is more heavily weighted toward individuals with physical impairments.

To identify federal programs for which people with disabilities are likely to qualify, we reviewed the December 1998 Catalog of Federal Domestic Assistance (Washington, D.C.: General Services Administration, Dec. 1998) for program descriptions containing variations of the terms "disability" and "handicap." The catalog is a governmentwide compendium of federal programs, projects, services, and activities that provide assistance or benefits to the American public. It contains financial and nonfinancial assistance programs administered by departments and other entities of the federal government. We included in our program count cash assistance, grant, and direct service programs for which adults with disabilities are eligible. Grants and activities for children were excluded because our focus was on adults. In addition, we did not include research, affirmative action and advocacy, and architectural barriers and compliance programs because they do not involve the direct provision of cash, benefits, or other services to people with disabilities.[37]

We subsequently divided the identified grants and activities into two groups: (1) those for which disability was the primary condition of program participation and (2) those for which program participation did not depend solely on an individual's having disabilities.[38] We compiled estimated federal expenditures for the first group to arrive at a total federal commitment of $110 billion for fiscal year 1999. We did not determine the amount of estimated expenditures for the second group because eligibility for these programs did not depend only on disability.

To identify the amount and type of personal care provided under Medicaid and Medicare, we reviewed both existing research and Health Care Financing Administration (HCFA) expenditure reports. For the Medicaid home health and personal care services (PCS) benefits, we used HCFA 64

[37]Our search yielded several grants and activities that were not directly related to individuals with disabilities. For example, some programs contained a generic statement regarding the illegality of discriminating against individuals with disabilities. We did not include such programs in our count.

[38]The Supplemental Security Income program provides cash benefits to individuals with disabilities or those who are aged. Because 77 percent of the participants in this program have disabilities, we included this percentage of expenditures in our calculations of federal commitments to individuals with disabilities.

and 2082 data sources on expenditures and recipients.[39] Using the Commerce Clearing House, Inc., Medicare and Medicaid Guide, we identified states offering the PCS benefit and grouped them by the eligibility categories and service limits imposed by each state. To identify home- and community-based service (HCBS) waivers, we used an August 1998 database maintained by the American Public Human Services Association (APHSA). We then summarized available cost and recipient data on HCBS waivers. However, not all waivers in the database had cost data and recipient counts; hence, data on HCBS waivers are likely to represent an undercount of consumers and expenditures. To identify states with consumer-directed services, we reviewed the APHSA database of waivers, conducted a literature search, and contacted research and advocacy organizations.

To examine how a select group of states directs personal care services to those most in need and how these states have implemented consumer direction, we conducted an extensive literature review and held discussions with research and advocacy organizations. We selected our state sample with the purpose of identifying a range of considerations, including states that

- were identified as leaders in offering consumer-directed personal care;
- offered HCBS waivers with personal care, with a broad range in per capita spending;
- made significant use of the PCS benefit under Medicaid; and
- targeted a mixture of populations, such as the aged, those with disabilities, and those with mental disabilities.

Our objective was to select states representing a broad diversity of approaches to personal care and consumer direction. Thus, we selected California in part because of its extensive use of the PCS benefit, and Oregon because of its extensive use of an HCBS waiver. Maine and Kansas afforded additional variety in their use of multiple HCBS waivers and differences in their use of the PCS benefit. During our fieldwork, we met with state and local agencies, interest groups, consumers, and unions representing or seeking to represent caregivers in order to obtain a variety of perspectives on the services and programs offered in each state. In our discussions, we focused on strategies for monitoring services and

[39]HCFA 64 is a quarterly Medicaid expenditure report that summarizes data submitted by the states. HCFA 2082 is an annual statistical report with data on Medicaid eligibles, recipients, services, and expenditures derived from the states and summarized by HCFA. We did not verify the accuracy of HCFA expenditure reports.

targeting client populations, and we asked each group and organization to highlight areas of concern regarding consumer-directed services.

Federal Programs Directed Specifically at Individuals With Disabilities

Using a compilation of 237 programs from the Catalog of Federal Domestic Assistance, we identified 30 programs, services, and activities that target individuals with disabilities. These programs are identified below by budget function and estimated fiscal year 1999 expenditures. Three programs—Social Security Disability Insurance, Supplemental Security Income, and Veterans Compensation for Service-Connected Disability—account for 86 percent of the funds obligated.

Education, Training, Employment, and Social Services

Budget Subfunction 503—Research and General Education Aids

Books for the Blind and Physically Handicapped ($48.1 million). Provides library services to the blind and physically handicapped by offering cassette players and books on cassettes, on disks, and in Braille.

Budget Subfunction 506—Social Services

Rehabilitation Act: Independent Living Centers ($46.1 million). Provides grants for establishing and operating statewide networks of centers for independent living to help people with severe disabilities function more independently in family and community settings. Core services provided must include information and referral services, training in independent living skills, peer counseling, and individual and system advocacy. The governing board and the majority of staff and individuals in decision-making positions must be individuals with disabilities.

Rehabilitation Act: Independent Living State Grants ($22.3 million). Provides grants to help states promote a philosophy of independent living, consumer control, peer support, self-help, self-determination, equal access, and individual and system advocacy. Independent living funds are used to support the statewide Independent Living Council and to maximize the leadership, empowerment, independence, and productivity of individuals with disabilities, as well as the integration and full inclusion of individuals with disabilities into mainstream American society.

Rehabilitation Act: Independent Living Services for Older Individuals Who Are Blind ($11.2 million). Provides project grants to authorized state agencies to provide rehabilitation services to individuals

aged 55 and over who are blind, or whose severe visual impairments make competitive employment extremely difficult to attain, but for whom independent living in their own homes or communities is feasible. Services provided include (1) those designed to help correct or modify visual disabilities, (2) eyeglasses and other visual aids, (3) services and equipment to enhance mobility and self-care, and (4) training in Braille.

Rehabilitation Services—Vocational Rehabilitation Grants ($2.3 billion). Assists states in providing vocational rehabilitation services and goods, including assessment, counseling, vocational and other training; job placement; reader services for the blind; interpreter services for the deaf; medical and related services; prosthetic and orthotic devices; rehabilitation technology; transportation to vocational rehabilitation sites; maintenance during rehabilitation; and other goods and services necessary for an individual with a disability to prepare for and engage in competitive employment.

Rehabilitation Act: American Indians With Disabilities ($17.6 million). Provides project grants to governing bodies of American Indian tribes for vocational rehabilitation services for Indians with disabilities who reside on federal or state reservations to prepare them for suitable employment. Projects funded are for services over and above those provided by the Rehabilitation Act Basic Support Program, which is administered by the states, and include on-the-job training through tribal industries; support for self-employment in food services, crafts, and other enterprises; and special vocational and academic training through tribal colleges. Projects generally require 10-percent matching funds in cash or in kind.

Rehabilitation Act: Special Projects and Demonstrations for Providing Vocational Rehabilitation Services to Individuals With Severe Disabilities ($18.9 million). Provides grants to states and public and other nonprofit organizations for projects and demonstrations that expand or improve vocational rehabilitation and other rehabilitation services for individuals with disabilities—especially those with the most severe disabilities. Projects may also be conducted to meet the special needs of individuals that are unserved or underserved.

Developmental Disabilities Projects of National Significance ($5.3 million). Provides grants and contracts for the development of national and state policy that enhances the independence, productivity, and integration and inclusion into the community of people with

developmental disabilities. Project grants have been used to educate policymakers, fund federal interagency initiatives, enhance minority participation in public and private sector initiatives on developmental disabilities, and provide technical assistance and data collection and analysis. Funded projects include the provision of personal assistance services to individuals with disabilities.

Rehabilitation Act: Service Projects ($5.9 million). Provides grants to state vocational rehabilitation agencies and public nonprofit organizations for projects and demonstrations that hold promise for expanding or improving vocational and other rehabilitation services for individuals with severe disabilities over and above the services provided by the Rehabilitation Act Basic Support Program. Projects provide financial assistance for vocational rehabilitation services to migratory agricultural or seasonal farmworkers and for projects that initiate integrated programs of recreation for individuals with disabilities.

Rehabilitation Act: Projects With Industry ($22.1 million). Awards grants to employers, labor unions, for-profit and nonprofit organizations, institutions, and state vocational rehabilitation agencies to create and expand job and career opportunities for individuals with disabilities in the competitive labor market by joining with private industry to provide job training and placement, as well as career advancement services. A 20-percent match is required.

Rehabilitation Act: Supported Employment Services for Individuals With Severe Disabilities ($38.2 million). Provides formula grants for time-limited services leading to supported employment for individuals with the most severe disabilities. Funds are used to provide (1) services complementary to title I of the Rehabilitation Act, (2) skilled job trainers who accompany workers for intensive on-the-job training, (3) systematic training, (4) job development, (5) follow-up services, (6) regular observation or supervision at training sites, and (7) other services needed to support an individual in employment.

Senior Companion Program ($35.2 million). Provides grants to state and local agencies and private nonprofit organizations to afford income-eligible people, aged 60 and older, the opportunity to provide personal assistance and companionship to other seniors through volunteer service; provide nonmedical personal support to adults who, without support, might be inappropriately placed in long-term care facilities; help people who have been discharged from health care facilities and other

institutions; and provide companionship to people with developmental disabilities and other special needs. The grants may be used for Senior Companion stipends, transportation, physical examinations, insurance, and meals; staff salaries, fringe benefits, and travel; equipment and space; and so on.

Technology-Related Assistance State Grants ($30 million). Provides grants to states to help them develop and implement comprehensive, consumer-responsive statewide programs of technology-related assistance for individuals of all ages with disabilities. States may provide assistance to statewide community-based organizations or directly to individuals with disabilities.

Income Security

Budget Subfunction 604—Housing Assistance

Shelter Plus Care ($65 million). Provides project grants to states, units of local governments, Indian tribes, and public housing agencies to provide rental assistance, in connection with other supportive services funded from sources other than this program, to homeless people with disabilities. Rental assistance is available for tenant-based, sponsor-based, project-based, and single-room occupancy for homeless individuals.

Supportive Housing for Persons With Disabilities (also appears under subfunction 371 for mortgage credit) ($174 million). Provides capital advances to finance the construction, rehabilitation, or purchase of buildings for supportive housing for people with disabilities for use as group homes. Project rental assistance is also used to cover any part of the Housing and Urban Development (HUD)-approved operating costs of a facility that is not met from project income.

Multifamily Housing Service Coordinators (also appears under subfunction 451 for community development) ($6.5 million).[40] Provides project grants to owners or managers of conventional public housing projects to hire service coordinators to link elderly and disabled assisted housing residents with supportive or medical services in the general community; prevent premature and unnecessary institutionalization; and assess individual service needs, determine

[40]Represents expenditures for FY 1998; estimated expenditures for FY 1999 were not available.

eligibility for public services, and make resource allocation decisions that enable residents to stay in the community longer.

Budget Subfunction 609—Other Income Security

Supplemental Security Income ($21.4 billion).[41] Provides cash payments to ensure a minimum level of income to people who are aged 65 or older or who are blind or disabled. Eligibility is based on an assessment of the individual's monthly income and resources, U.S. residency, and citizenship or alien status.

Social Security

Budget Subfunction 651—Social Security

Social Security Disability Insurance ($57.3 billion). Replaces part of the earnings of qualified disabled workers under age 65 who are unable to engage in any substantial gainful activity because of a medically determinable physical or mental impairment that has lasted or is expected to last at least 12 months, or to result in death. The program provides monthly cash benefits to eligible disabled people and eligible auxiliary beneficiaries, such as certain family members, throughout the period of disability. Costs of vocational rehabilitation are also paid for certain beneficiaries.

Veterans' Benefits and Services

Budget Subfunction 701—Income Security for Veterans

Veterans Compensation for Service-Connected Disability ($15.3 billion). Compensates veterans for disabilities incurred or aggravated during military service according to the average impairment of earning capacity such a disability would cause in civilian occupations. Benefits are paid from when the injury occurred or disease was contracted as well as from the time a preexisting injury occurred or disease was contracted in the active military.

Veterans Pension for Non-Service-Connected Disability ($2.3 billion). Assists wartime veterans in need whose

[41]Represents expenditures for only the disabled Supplemental Security Income program population. Total program estimated expenditures for FY 1999 are $27.8 billion.

non-service-connected disabilities are permanent and totally prevent them from obtaining substantial gainful employment. Veterans who have had 90 days or more of honorable active wartime service in the armed forces or who were released or discharged with less than 90 days of service because of a service-connected disability are eligible. Income restrictions are prescribed, and pensions are not payable to those whose estates are so large that it is reasonable that they could be used for maintenance.

Budget Subfunction 702—Veterans Education, Training, and Rehabilitation

Vocational Rehabilitation for Disabled Veterans ($403 million). Provides all services and assistance necessary to enable service-disabled veterans and those receiving treatment for a service-connected disability pending discharge to achieve maximum independence in daily living and, to the maximum extent feasible, to become employable and to obtain and maintain suitable employment.

Veterans' Specially Adapted Housing ($14.7 million). Assists certain severely disabled veterans in acquiring suitable housing units with special fixtures and facilities made necessary by the nature of the veterans' disabilities. For veterans with permanent, total, and compensable disabilities related to service, the Department of Veterans Affairs (VA) provides 50 percent of the cost to the veteran of the housing unit, land, fixtures, and allowable expenses up to a maximum grant of $43,000. The program also provides funds for certain adaptations and equipment not to exceed a maximum grant of $8,250.

Automobiles and Adaptive Equipment for Certain Disabled Veterans and Members of the Armed Forces ($26.2 million). Provides financial assistance to certain service members and veterans with disabilities toward a one-time payment for an automobile or other conveyance and an additional amount for adaptive equipment deemed necessary to ensure the eligible person will be able to operate or make use of the automobile or other conveyance. Provides financial assistance to veterans with honorable service and service members on duty who have a service-connected disability due to the loss or permanent loss of use of one or both feet, the loss of one or both hands, or a permanent impairment of vision of both eyes to a prescribed degree.

Budget Subfunction 703—Hospital and Medical Care for Veterans

Veterans Outpatient Care ($8.0 billion). Provides medical and dental services on an outpatient basis, including examination; treatment; certain home health services; podiatric, optometric, and surgical services;

medicines; and medical supplies to veterans who are 50-percent or more service-connected disabled. Pre-bed care, posthospital care, and care to obviate the need for hospitalization for any condition must be furnished to veterans rated 30- or 40-percent service-connected disabled and those whose annual income does not exceed the pension rate of a veteran in need of regular aid and attendance. Several other groups of veterans also qualify for these benefits, and veterans whose eligibility falls within the discretionary category who agree to make a copayment can be furnished outpatient care, services, or both on a facilities- and resource-available basis.

Veterans Prescription Service ($1.6 billion). Provides eligible veterans (that is, veterans receiving Veterans Outpatient Care benefits) and certain dependents and survivors of veterans with prescription drugs and expendable medical supplies. Veterans receiving medications on an outpatient basis from VA facilities for treatment of a non-service-connected disability or condition are required to make a copayment of $2 for each supply of medication for 30 days or less. Veterans receiving medications for the treatment of a service-connected condition and veterans rated 50-percent or more service-connected disabled are exempt from this copayment requirement.

Blind Veterans Rehabilitation Centers and Clinics ($59.8 million). Provides personal and social adjustment programs and medical or health-related services for eligible blind veterans at selected VA medical centers maintaining centers for rehabilitation of the blind.

Veterans Prosthetic Appliances ($395.4 million). Provides through purchase or fabrication prosthetic and related devices, equipment, and services to disabled veterans to enable them to live and work as productive citizens. This assistance includes replacement and repair of devices; training in the use of artificial limbs; and provision of artificial eyes, wheelchairs, aids for the blind, hearing aids, braces, orthopedic shoes, eyeglasses, crutches and canes, medical equipment, implants, medical supplies, and automotive adaptive equipment.

Budget Subfunction 704—Veterans Housing

Veterans Housing—Direct Loans for Certain Disabled Veterans (amount not available). Provides direct loans of up to $33,000 to permanently and totally disabled veterans if (1) they are eligible for a VA Specially Adapted Housing grant, (2) a loan is necessary to supplement the

grant, and (3) home loans from a private lender are not available in the area where the property is located.

Budget Subfunction 705—Other Veterans Benefits and Services

Disabled Veterans' Outreach Program ($80 million). Provides formula grants to be used only for salaries and expenses and reasonable support of Disabled Veterans' Outreach Program specialists who shall be assigned only those duties directly related to meeting the employment needs of eligible veterans—that is, developing and promoting on-the-job training and apprenticeship positions within VA programs; providing outreach assistance to local employment service offices; promoting maximum employment opportunities for veterans; and providing job placement, counseling, testing, and job referral to eligible veterans, especially disabled veterans of the Vietnam era.

General Government

Budget Subfunction 805—Central Personnel Management

Rehabilitation Act: Federal Employment for Individuals With Disabilities (amount not available). Encourages federal agencies to provide employment opportunities to individuals with physical, cognitive, or mental disabilities in positions for which they qualify.

Other Federal Programs With Disability as a Criterion for Eligibility

Forty federal programs include disability as one of many potential criteria for program participation. Within these 40 programs, Medicare and Medicaid are the most significant sources of federal funds that provide personal care services to individuals with disabilities.

Commerce and Housing Credit

Budget Subfunction 371—Mortgage Credit

Rural Rental Housing Loans. Provides loans to construct or purchase and substantially rehabilitate rental or cooperative housing or to develop manufactured housing projects that generally consist of two or more family units and any appropriate related facilities suitable for rural areas. Occupants must be low- or moderate-income families, the elderly, or individuals with disabilities. Loans may not be made for nursing, special care, or institution-type homes.

Mortgage Insurance Rental Housing for the Elderly. HUD insures lenders against loss on mortgages approved under section 231 of the National Housing Act to finance construction or rehabilitation of detached, semidetached, walk-up, or elevator-type rental housing designed for occupancy by the elderly or individuals with disabilities and consisting of five or more units.

Mortgage Insurance Rental and Cooperative Housing for Moderate Income Families and Elderly. HUD insures lenders against loss on mortgages approved under section 221 of the National Housing Act to finance construction or rehabilitation of detached, semidetached, row, walk-up, or elevator-type rental housing containing five or more units and designed for occupancy by moderate-income families, the elderly, and individuals with disabilities.

Budget Subfunction 376—Other Advancement of Commerce

Small Business Loans. Provides guaranteed loans to low-income small business owners; businesses located in areas of high unemployment; nonprofit sheltered workshops; and small businesses owned, being established, or being acquired by individuals with disabilities who are unable to obtain financing in the private credit marketplace.

Transportation

Budget Subfunction 401—Ground Transportation

Capital Assistance Program for Elderly Persons and Persons With Disabilities. Provides financial assistance in meeting the transportation needs of elderly people and people with disabilities where public transportation services are unavailable, insufficient, or inappropriate.

Education, Training, Employment, and Social Services

Budget Subfunction 502—Higher Education

TRIO Student Support Services. Provides grants to institutions of higher education for low-income, first-generation college students or students with disabilities who are in need of academic support in order to pursue a program of postsecondary education. Funds may be used to provide personal and academic counseling, career guidance, instruction, mentoring, and tutoring.

Budget Subfunction 504—Training and Employment

Job Training Partnership Act. Provides formula grants to states for establishing programs to prepare economically disadvantaged youth and adults facing serious barriers to employment for participation in the labor force by providing job training and other services that will result in increased educational and occupational skills, increased employment and earnings, and decreased welfare dependency. Not less than 65 percent of the recipients shall be in one or more of the following categories: deficient in basic skills, recipients of cash welfare payments, school dropouts or students 1 or more years below grade level, individuals with disabilities, homeless or runaway youth, and youth who are pregnant or parenting.

Employment Service. Provides formula grants to states to support a nationwide network of public employment offices to place people in employment by providing a variety of placement-related services. These services are available without charge to job seekers and to employers seeking qualified individuals to fill job vacancies. Workers and veterans with disabilities are entitled to special employment services.

Veterans' Employment Program. Provides grants to states to develop programs to meet the employment and training needs of veterans with service-connected disabilities, veterans of the Vietnam era, and veterans recently separated from military service.

Budget Subfunction 506—Social Services

Social Services Block Grant. Provides formula grants to enable each state to furnish the social services best suited to the needs of the individuals residing in the state. Federal block grant funds may be used to provide services for one of the following five goals: (1) prevent, reduce, or eliminate welfare dependency; (2) help individuals achieve or maintain self-sufficiency; (3) prevent neglect, abuse, and exploitation of children and adults; (4) prevent or reduce inappropriate institutional care; and (5) secure admission or referral for institutional care when other forms of care are not appropriate.

Developmental Disabilities University Affiliated Programs. Provides grants to defray the cost of administration and operation of programs that (1) provide interdisciplinary training for personnel concerned with developmental disabilities; (2) demonstrate community services activities, which include training and technical assistance and may include direct services; (3) disseminate findings related to the provision of services; and (4) generate information on the need for further service-related research.

Special Programs for the Older Americans Act, Title III, Part C, Nutrition Services. Provides formula grants to states to support nutrition services, including providing nutritious meals, nutrition education, and other appropriate nutrition services for older Americans in order to maintain their health, independence, and quality of life. Meals may be served in a congregate setting or delivered to the home to eligible individuals aged 60 and over and to individuals under age 60 if they are handicapped or disabled and reside with and accompany an older individual.

Health

Budget Subfunction 551—Health Care Services

Medical Assistance Program. The Medicaid program provides formula grants to states to provide financial aid for medical assistance on behalf of cash assistance recipients; children; pregnant women; individuals who are

aged, blind, or disabled and who meet income and resource requirements; and other categorically eligible groups. States can elect to provide similar coverage to medically needy people who, except for income and resource limitations, would be eligible for cash assistance. Financial assistance is provided to states to pay for Medicare premiums and copayments and deductibles of qualified Medicare beneficiaries meeting certain income requirements. More limited financial assistance is available for certain Medicare beneficiaries with higher incomes.

Medicare

Budget Subfunction 571—Medicare

Medicare Hospital Insurance. Provides hospital insurance protection for covered services to people aged 65 or older, certain people with disabilities, and individuals with chronic renal disease. Hospital insurance benefits are paid to participating and emergency hospitals, skilled nursing facilities, home health agencies, and hospice agencies to cover the prospective payment amount or reasonable cost of medically necessary services furnished to individuals entitled under this program. People under age 65 who have been entitled for at least 24 months to Social Security disability benefits, or for 29 consecutive months to Railroad Retirement benefits on the basis of disability, are eligible for hospital insurance benefits.

Medicare Supplementary Medical Insurance. Provides supplementary medical insurance to all people aged 65 or older; certain people with disabilities, whether insured under Medicare Hospital Insurance or not, may voluntarily enroll for this supplemental insurance. Medicare generally pays 80 percent of the approved amount (fee schedule, reasonable charges, or reasonable cost) for covered services in excess of the annual $100 deductible. Covered services include doctors' services, lab and other diagnostic tests, X-ray and other radiation therapy, outpatient services, therapy, ambulance services, home health services, and provision of durable medical equipment.

Income Security

Budget Subfunction 601—General Retirement and Disability Insurance (Excluding Social Security)

Social Insurance for Railroad Workers.[42] Provides monthly Social Security benefits, rail industry pensions, permanent and occupational disability benefits, federal windfall benefits, supplemental annuities, and sickness and unemployment benefits to workers and their families.

Longshore and Harbor Workers' Compensation. Provides compensation for disability or death resulting from injury, including occupational disease, to longshore workers, harbor workers, and certain other eligible employees engaged in maritime employment on the navigable waters of the United States and adjoining pier and dock areas.

Coal Mine Workers' Compensation. Provides monthly cash benefits to coal miners who are totally disabled from coal workers' pneumoconiosis (black lung disease) and to widows and other surviving dependents of miners who have died of this disease.

Special Benefits for Disabled Coal Miners. Provides monthly cash benefits to coal miners who have become totally disabled by coal workers' pneumoconiosis or other chronic lung diseases arising from coal miner employment and to widows and other surviving dependents of miners who have died of these diseases.

Budget Subfunction 604—Housing Assistance

Supportive Housing Program. Provides project grants designed to promote the development of supportive housing and services to help people make the transition from homelessness to living as independently as possible. Program funds may be used in part to provide for transitional housing for up to 24 months and permanent housing in conjunction with appropriate supportive services to maximize the ability of people with disabilities to live as independently as possible.

Economic Development and Supportive Services Program. Provides project grants to enable public housing agencies and Indian tribes in partnership with nonprofit or for-profit agencies to (1) facilitate economic development opportunities and supportive services to assist residents to become economically self-sufficient and (2) assist the elderly and people

[42]This federal program was also classified under budget subfunction 603 for unemployment compensation.

with disabilities to live independently and prevent premature or unnecessary institutionalization.

Operating Assistance for Troubled Multifamily Housing Projects. Provides loans to the elderly and people with disabilities to restore or maintain the physical and financial soundness of eligible housing projects, as well as to assist in the management and maintenance of the low- to moderate-income character of certain projects approved for assistance under the National Housing Act or the Housing and Urban Development Act of 1965.

Rural Rental Assistance Payments. Provides rental assistance to reduce the rents paid by low-income senior citizens or families, domestic farm laborers, and citizens with disabilities occupying eligible rural rental housing whose rents exceed 30 percent of an adjusted monthly income and whose income does not exceed the limit established for the state.

Rural Rental Housing Section 538 Guaranteed Loans. Provides guaranteed loans to encourage the construction of new rural, multifamily rental housing and appropriate related facilities, generally consisting of two or more family units. Occupants must have low to moderate incomes, be elderly, or have disabilities. Income cannot exceed 115 percent of the median income. Guaranteed loans may not be made for nursing, special care, or industrial-type housing.

Public and Indian Housing. Provides funding to authorized local public housing agencies for the operation of cost-effective, decent, safe, and affordable dwellings for lower-income families, the elderly, and families with people with disabilities.

Budget Subfunction 605—Food and Nutrition Assistance

Food Stamps. Provides low-income households the ability to improve their diets by increasing their food purchasing ability. Food stamp benefits vary on the basis of family size, income, and level of resources. Food stamps may be used in participating retail stores to buy food for home consumption; by certain elderly people and people with disabilities and their spouses who cannot prepare their own meals and receive meals delivered to them by authorized meal delivery services; and by people who are elderly, disabled, or both and their spouses to purchase meals in establishments providing communal dining for the elderly.

Nutrition Program for the Elderly (Commodities). Provides food for use in the preparation of congregate or home-delivered meals by nutrition programs for the elderly. This program is designed to improve the diets of the elderly and to increase the market for domestically produced foods acquired under surplus removal or price support operations. Meals may be served in a congregate setting or delivered to the home to eligible individuals aged 60 and over and, in certain cases, under age 60 if the individual is handicapped or disabled and resides with and accompanies an older individual.

Child and Adult Care Food Program. Assists states, through grants-in-aid and other means, to initiate and maintain nonprofit food services programs for children, the elderly, and adults with impairments in nonresidential day care facilities. The program is generally limited to children 12 years old and younger, individuals with disabilities, functionally impaired adults at least 18 years old, and adults 60 years of age and older. Meals must meet minimum requirements of the U.S. Department of Agriculture.

Budget Subfunction 609—Other Income Security

Family Support Payments to States. Provides cash payments directly to eligible needy families with dependent children through the Temporary Assistance for Needy Families program and to needy people who are aged, blind, or disabled in Guam, Puerto Rico, and the Virgin Islands. The program also provides child care, so that individuals can participate in approved education and training activities and accept or maintain employment, and temporary emergency assistance to families with children.

Social Security

Budget Subfunction 651—Social Security

Social Security Retirement Insurance. Provides monthly cash benefits to eligible retired workers and their eligible family members to replace part of the earnings lost as a result of retirement. Retired workers aged 62 and over who have worked the required number of years under Social Security are eligible for monthly benefits. Also, certain family members can receive benefits, including (1) a wife or husband aged 62 or older; (2) a spouse at any age, if a child who is under age 16 or is disabled is in his or her care and is entitled to benefits on the basis of the worker's record;

(3) unmarried children under age 18; (4) unmarried adult offspring at any age if disabled before age 22; and (5) divorced wives or husbands aged 62 or older who were married to the worker for at least 10 years.

Veterans' Benefits and Services

Budget Subfunction 702—Veterans Education, Training, and Rehabilitation

All-Volunteer Force Educational Assistance. Provides educational assistance to those who have served on active duty after June 30, 1985. This program also assists in the recruitment and retention of highly qualified personnel in the active and reserve armed forces by extending the benefits of higher education to those who may not otherwise be able to afford it. Physical or mental disability that is not the result of the individual's own willful misconduct can extend the 10 years after release from service that veterans have to complete their education. Veterans must serve 2 years before they are eligible for basic educational assistance. Participants who have not completed the required obligated service must have been discharged for a service-connected disability.

Post-Vietnam-Era Veterans' Educational Assistance. Provides educational assistance to people entering the armed forces after December 31, 1976, and before July 1, 1985, to help them obtain an education they might otherwise not be able to afford. This program was also designed to promote and assist the all-volunteer military program of the United States by attracting qualified people to serve in the armed forces. Post-Vietnam-era veterans must have served honorably on active duty for more than 180 continuous days beginning on or after January 1, 1977, or have been discharged after that date because of a service-connected disability.

Survivors and Dependents Educational Assistance. Provides partial support to the following individuals who are seeking to advance their education: qualifying spouses, surviving spouses, or children between ages 18 and 26 of (1) deceased veterans or veterans who, as a result of their military service, have a permanent and total (100-percent) service-connected disability or (2) service personnel who have been listed for a total of more than 90 days as currently missing in action or as prisoners of war. Assistance in the form of monthly payments for up to 45 months to be used for tuition, books, subsistence, and so on is available

for 10 years from the date of the veteran's disability rating or the date of death of a veteran classified with a total service-connected disability.

Budget Subfunction 703—Hospital and Medical Care for Veterans

Veterans Medical Care Benefits. Provides hospital outpatient medical and dental services, medicines, and medical supplies to enrolled veterans in a VA medical care facility. Eligible veterans include, among others, those that require treatment for a service-connected disability, have a service-connected disability rated at 50 percent or more, have a compensable service-connected disability rated at less than 50 percent, or are former prisoners of war.

Budget Subfunction 704—Veterans Housing

Veterans Housing Guaranteed and Insured Loans. Provides VA-guaranteed or -insured loans to assist eligible veterans, certain service personnel, and certain surviving spouses of veterans who have not remarried in obtaining credit to purchase, construct, or improve homes on more liberal terms than are generally available to nonveterans. Eligible veterans include those with a service-connected disability.

Veterans Housing Manufactured Home Loans. Provides VA-guaranteed or -insured loans to assist eligible veterans, certain service personnel, and certain surviving spouses of veterans who have not remarried in obtaining credit to purchase a manufactured home on more liberal terms than are generally available to nonveterans. Eligible veterans include those with a service-connected disability.

Native American Veteran Direct Loan Program. Provides direct loans to certain Native American veterans, certain service personnel, and certain surviving spouses of Native American veterans who have not remarried to purchase or construct homes on trust lands. Eligible veterans include those with a service-connected disability.

Administration of Justice

Budget Subfunction 754—Criminal Justice Assistance

Public Safety Officers' Benefits Program. Provides a $141,556 death benefit to the eligible survivors of a federal, state, or local public safety officer whose death is the direct and proximate result of a personal

(traumatic) injury sustained in the line of duty. The program also provides a $141,556 disability benefit to a federal, state, or local public safety officer whose permanent and total disability is the direct and proximate result of a personal injury sustained in the line of duty.

General Government

Budget Subfunction 805—Central Personnel Management

Federal Employment Assistance for Veterans. Provides assistance to veterans in obtaining federal employment. A 5-point preference is given to veterans separated under honorable conditions who served on active duty in the armed forces of the United States during certain periods of time or who have a campaign or expeditionary medal. A 10-point preference is given to disabled veterans and certain wives or husbands, widows or widowers, and mothers of veterans. Retired members of the armed forces have not been considered eligible for preference since October 1, 1980, unless they are veterans with disabilities or they retired below the rank of major or the equivalent.

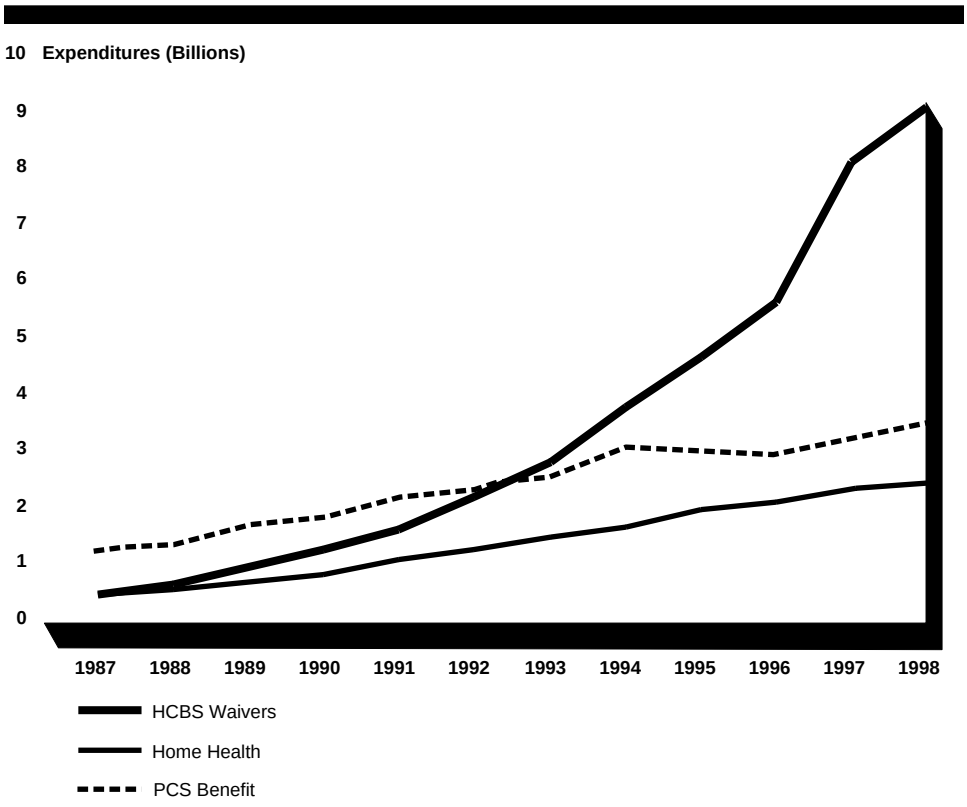
Budget Subfunction 999—Miscellaneous

Weatherization Assistance for Low-Income Persons. Provides formula grants to states to improve the thermal efficiency of dwellings of low-income people, particularly individuals who are elderly or handicapped, by the installation of weatherization materials, such as attic insulation, caulking, weatherstripping, and storm windows, and by furnace efficiency modification in order to conserve needed energy and to aid those people least able to afford higher utility costs.

Medicaid Expenditures for Personal Care and Related Services

Medicaid's provision of personal care and in-home services has evolved considerably over the years, particularly as the use of HCBS waivers as a means of providing community-based services has grown. For fiscal year 1998, expenditures for Medicaid community-based services—home health, the PCS benefit, and HCBS waivers—totaled $14.8 billion. From 1987 to 1998, expenditures grew at an average annual rate of 16 percent for Medicaid home health, 10 percent for the PCS benefit, and 31 percent for the HCBS waivers (see fig. IV.1). HCBS waivers account for about 62 percent of all community-based expenditures under Medicaid, compared with 15 percent for home health and 23 percent for the PCS benefit. Table IV.1 shows each state's total Medicaid spending for community-based care and expresses the proportion of total spending for each of the three benefits.

Figure IV.1: Growth in Medicaid Expenditures for Personal Care and Related Services, 1987-98



Source: HCFA.

Table IV.1: Medicaid Community-Based Expenditures, Fiscal Year 1998

State	Fiscal year 1998 expenditures (millions)	Percentage of total expenditures		
		PCS benefit	HCBS waivers	Home health
Alabama	$141	[a]	83.72	16.28
Alaska	35	12.11	84.59	3.30
Arizona[b]	1	19.98	[a]	80.02
Arkansas	128	49.36	35.04	15.60
California	549	59.10	25.86	15.04
Colorado	266	[a]	80.52	19.48
Connecticut	410	[a]	72.73	27.27
Delaware	38	[a]	80.72	19.28
District of Columbia	13	2.73	[a]	97.27
Florida	370	3.82[c]	67.74	28.44
Georgia	180	[a]	75.41	24.59
Hawaii	27	[a]	93.61	6.39
Idaho	36	42.46	45.09	12.45
Illinois	291	[a]	95.53	4.47
Indiana	97	[a]	53.65	46.35
Iowa	119	[a]	63.16	36.84
Kansas	219	3.74	90.29	5.97
Kentucky	183	[a]	46.94	53.06
Louisiana	89	[a]	75.18	24.82
Maine	117	3.06	84.86	12.07
Maryland	232	10.39	67.10	22.51
Massachusetts	631	22.05	63.43	14.52
Michigan	520	39.95	54.35	5.69
Minnesota	533	18.49	71.94	9.56
Mississippi	23	[a]	46.35	53.65
Missouri	318	28.84	68.71	2.45
Montana	41	32.41	64.03	3.56
Nebraska	97	5.58	78.43	15.99
Nevada	21	9.53	55.86	34.61
New Hampshire	109	2.10	94.36	3.54
New Jersey	506	33.51	49.37	17.12
New Mexico	117	[a]	96.58	3.42
New York	3,950	41.90	36.85	21.24
North Carolina	482	28.20	57.57	14.23
North Dakota	39	[a]	95.53	4.47
Ohio	321	[a]	86.25	13.75

(continued)

State	Fiscal year 1998 expenditures (millions)	Percentage of total expenditures		
		PCS benefit	HCBS waivers	Home health
Oklahoma	161	15.03	84.20	0.77
Oregon	295	6.77	93.09	0.14
Pennsylvania	590	[a,c]	90.57	9.43
Rhode Island	150	[a]	97.05	2.95
South Carolina	145	0.81[c]	88.34	10.85
South Dakota	47	1.55	92.18	6.27
Tennessee	87	[a]	99.52	0.48
Texas	648	35.33	64.67	[a]
Utah	66	0.66	95.42	3.93
Vermont	71	2.15[c]	92.04	5.81
Virginia	205	[a]	96.00	4.00
Washington	432	27.79	69.56	2.66
West Virginia	150	18.56	67.10	14.34
Wisconsin	435	15.08	72.70	12.21
Wyoming	48	[a]	91.11	8.89
Total	**$14,780**	**23.47**	**61.52**	**15.01**

[a]State did not report expenditures in this benefit category.

[b]Arizona offers personal care services through a section 1115 waiver demonstration program; HCFA assigned expenditures from this waiver to the PCS benefit.

[c]State does not offer the PCS benefit to adults; expenditures under this benefit represent personal care services provided to children under the Early Periodic Screening, Diagnostic, and Treatment program.

Source: HCFA.

States' Use of Home Health, the PCS Benefit, and HCBS Waivers

Under Medicaid, states have three approaches for providing personal care, two of which may be offered at the discretion of the state. First, states must offer the Medicaid home health services benefit (including home health aides), which may provide unskilled personal care services. Second, states may choose to provide the PCS benefit, which offers unskilled personal care services as a part of the states' Medicaid benefit package. Third, HCBS waivers give states the option of providing personal care and other related services if they choose to do so.

All candidates for personal care and other long-term care services are given individualized assessments, frequently coupled with environmental evaluations that take into account the candidates' informal and community support. The objective is to ensure that (1) services are focused primarily on those with the greatest need, (2) personal care is targeted to prevent institutionalization as a first priority, and (3) only those with no feasible alternative are admitted to nursing homes. How states approach assessments can vary, primarily in the degree of professional discretion afforded to the assessor. Thus, some states use an assessment instrument that produces a numeric score, which essentially determines the level of care that the state will provide. Other states rely exclusively on the professional judgment of the individual assigned to undertake the assessment.

States impose different limits on these services that are somewhat dependent on the states' use of home health, the PCS benefit, or HCBS waivers. Under home health and the PCS benefit, states may limit services through medical necessity or utilization controls. HCBS waivers provide a much wider array of means to limit services that includes targeting populations, limiting geographic availability (statewideness), and capping expenditures. In all cases, imposing limits on services can help states to control costs.

Home Health

States must offer home health services as a part of their Medicaid program to all beneficiaries who are entitled to nursing facility services. Under Medicaid, a physician must order home health services as part of a care plan that is reviewed periodically and includes part-time or intermittent nursing services; home health aide services; and medical supplies, equipment, and appliances suitable for use in the home. Home health aide services must be provided by a home health agency and can include the provision of personal care. States may also choose to provide physical, occupational, and speech pathology and audiology as optional services.

States can elect to limit the number of visits, the number of hours, or the dollar amount of certain services provided under the Medicaid home health program. Table V.1 shows the states' major limitations. Sixteen states specify no limitations, and most states allow established limits to be exceeded with prior authorization.

Table V.1: Limits Imposed Under the Medicaid Home Health Benefit

State	Limits
Alabama	104 visits per recipient per calendar year
Alaska	[a]
Arizona	[a]
Arkansas	50 visits for any combination of home health nurse or aide services without prior authorization
California	More than one visit in 6 months is subject to prior authorization and to a physician-approved treatment plan requirement. A maximum total of 30 visits may be approved at any one time, valid for a period not exceeding 120 days.
Colorado	Covered visit is 2-1/2 hours. No more than five home health visits are covered per day. Simultaneous visits by two or more individuals count as one visit.
Connecticut	Prior authorization is required after the first two visits for intermittent nursing services when no home health agency exists in the area; for home health aide services in excess of 20 hours per week; and for physical, occupational, speech pathology, and audiology services.
Delaware	[a]
District of Columbia	36 visits per year unless prior authorization is obtained; services of a home health aide are limited to 4 hours per day except by prior authorization.
Florida	60 home health visits per year; 4 visits per day by a registered nurse; or 1 visit per day by a licensed practical nurse except by prior authorization
Georgia	75 nursing or home health visits per recipient per calendar year
Hawaii	One visit per day during the first 2 weeks; three visits during the next 5 weeks; one visit per week for the following 7 weeks, and one visit every 60 days thereafter; additional services require prior authorization.
Idaho	100 per recipient per calendar year; prior authorization is required for all medical equipment that costs more than $100 purchased by the department.
Illinois	Prior authorization is required except when services are provided by independently practicing physical, occupational, or speech therapists or by community health agencies.
Indiana	30 hours/sessions/visits in a 30-day period unless prior authorization is obtained

(continued)

State	Limits
Iowa	[a]
Kansas	Home health aide services are limited to one visit per day, and physical, occupational, speech therapy, and restorative aide services are limited to 6 months from the first date of service.
Kentucky	Prior authorization is required for durable medical equipment that costs $150 or more.
Louisiana	50 nursing and home health aide visits and 50 physical therapy services per year, except for recipients of Early and Periodic Screening, Diagnostic and Treatment program services
Maine	[a]
Maryland	One visit of less than 4 hours per type of service per day, eight visits per month for physical or speech pathology, four visits per month for occupational therapy, and 12 home health aide services per month; services and medical supplies that cost more than $900 per month require prior authorization.
Massachusetts	Prior authorization is required for home health aide services exceeding 120 hours in a calendar month when services exceeded 120 hours in each of the 2 preceding months.
Michigan	[a]
Minnesota	Prior authorization is required, unless a professional nurse determines an immediate need, for up to 40 visits per calendar year and for certain medical supplies and equipment.
Mississippi	Patients are limited to a combined total of 50 visits per fiscal year, medical equipment that costs less than $150 must be purchased, and a determination must be made whether to rent or purchase equipment that costs more than $150.
Missouri	100 visits per patient per year
Montana	100 home health visits and 75 skilled nursing visits per recipient per fiscal year; home health aide services are not provided for an individual receiving personal care services.
Nebraska	40 hours per week and 8 hours per day
Nevada	[a]
New Hampshire	Prior authorization is required to purchase durable medical equipment exceeding certain cost limits as well as portable and in-home oxygen equipment.
New Jersey	Personal care assistant services are limited to 25 hours per week.
New Mexico	[a]
New York	[a]
North Carolina	Prior authorization is required for durable medical equipment.
North Dakota	[a]
Ohio	[a]

(continued)

State	Limits
Oklahoma	12 home health visits per year
Oregon	[a]
Pennsylvania	15 visits per month after 28 days of unlimited visits, one fee per visit regardless of services provided, and 1 visit per month for prenatal care
Rhode Island	Prior authorization is required for more than eight visits per month and for all medical supplies, equipment, and appliances.
South Carolina	75 home health agency visits per fiscal year
South Dakota	[a]
Tennessee	[a]
Texas	50 nurse and home health aide visits per recipient per year without prior authorization
Utah	Housekeeping or homemaking services and occupational therapy are not covered.
Vermont	Routine services are covered for 4 months with a physician's certification.
Virginia	32 home health agency or registered nurse visits or home health aide services and 24 rehabilitative therapy services ordered annually without prior authorization
Washington	Approval is required when the home health service duration or monthly payment will exceed the program's limits.
West Virginia	[a]
Wisconsin	30 visits by a registered aide, registered nurse, licensed practical nurse, or therapist without prior authorization; home health aide visits requiring more than 4 hours of continuous care require prior authorization.
Wyoming	[a]

[a]No limitation specified.

Source: Medicare and Medicaid Guide, Commerce Clearing House, Inc.

PCS Benefit

Twenty-seven states and the District of Columbia offer personal care under the PCS benefit, which is an optional benefit under the Medicaid program. Nine states[43] provide personal care services to only the categorically needy, which include low-income children; pregnant women; aged, blind, or disabled people meeting Supplemental Security Income program requirements; and individuals who are eligible to receive

[43]For three of these states (Arkansas, Oklahoma, and Washington), limiting personal care services to the categorically needy is a departure from policies on other benefits in their Medicaid programs, which are offered to both categorically needy and medically needy individuals.

federally assisted income maintenance payments. Such individuals must generally meet income and resource standards established for public assistance. The remaining 18 states and the District of Columbia provide personal care to both categorically needy and medically needy individuals. The latter group comprises those individuals whose income, resources, or both exceed the levels for the categorically needy, but who cannot afford to pay their medical bills. To control utilization of personal care services, states usually require prior authorization, establish concrete limits on the duration of services, or both. Table V.2 lists the control techniques used by each state. A few states have targeted eligibility for the PCS benefit by identifying a population or functional impairment for which they will provide assistance. For example, New Hampshire limits eligibility to individuals with chronic disabilities who use a wheelchair, and Florida limits personal care to children with disabilities.

Table V.2: Limits Imposed Under the Medicaid PCS Benefit

State	Limits
Alaska[a]	One assessment and treatment plan per 12 months
Arizona[a]	[b]
Arkansas[c]	Services cannot exceed 72 hours per month without prior approval.
California	Services must not exceed 283 hours per month.
District of Columbia	Services cannot exceed 4 hours per day or 1,040 hours in 12 months without prior authorization.
Idaho[a]	16 hours per week
Kansas	Prior authorization is required for up to 24 hours per day.
Maine	Available to individuals with chronic or permanent disabilities who are able to self-direct a personal care attendant
Maryland	Services are provided at one of four intensity levels of care subject to prior authorization.
Massachusetts	Prior authorization is required.
Michigan	[b]
Minnesota	Prior authorization is required.
Missouri[a]	Need assessment to be completed every 6 months
Montana	40 hours per week unless prior authorization is obtained
Nebraska	40 hours per week unless prior authorization is obtained
Nevada[a]	Prior authorization is required.
New Hampshire	Recipients must be chronically wheelchair-bound.
New Jersey	25 hours per week or up to 40 hours per week with prior authorization
New York	6 months for one of three levels of services with prior authorization unless exceptions are authorized for up to 12 months

(continued)

State	Limits
North Carolina	80 hours per month and covered only if no home health aide services are provided on the same day
Oklahoma[c]	Departmental approval is required.
Oregon	Prior authorization is required.
South Dakota[a]	120 hours per calendar quarter
Texas	Lesser of 50 hours per week or the rate of the average nursing facility; prior authorization is required and a plan of treatment must be reviewed.
Utah	60 hours per month and covered only if no home health aide services are provided on the same day
Washington[c]	[b]
West Virginia	Limited on a per-unit, per-month basis; prior authorization is required for additional hours of care.
Wisconsin	Prior authorization is required for more than 250 hours per calendar year; housekeeping tasks are limited to one-third of the time spent in the recipient's home.

[a]Provide personal care services to only the categorically needy.

[b]No limitation specified.

[c]Provide most Medicaid services to both categorically needy and medically needy, but limit personal care services to categorically needy.

Source: Medicare and Medicaid Guide, Commerce Clearing House, Inc.

HCBS Waivers

Forty-three states and the District of Columbia provide personal care under an HCBS waiver; 24 states and the District of Columbia offer both the Medicaid PCS benefit and one or more HCBS waivers. While HCBS waivers offer broader opportunities to limit or target services, the availability of national data on them is limited. The APHSA database of HCBS waivers, however, does track waivers by target populations and number of clients served (see table V.3).

Table V.3: Clients Served by Medicaid HCBS Waivers With Personal Care, 1997

Waivers' target populations[a]	Number of clients
Alabama	
Mentally retarded or developmentally disabled people	3,290
Aged and disabled people	6,316
Disabled people	362
Arkansas	
Disabled adults who are 21 to 64	60
California	
Mentally retarded or developmentally disabled people who are technology-dependent	35,105
Aged and disabled people	8,314
People with HIV/AIDS[b]	2,792
Colorado	
Aged and disabled people	5,843
People with HIV/AIDS	101
Chronically mentally ill people who are over 18	79
People with traumatic brain injury	70
Developmentally disabled people who are 18 and older	[c]
Connecticut	
Disabled people who are 18 to 64 and need help with 2+ ADLs	[c]
People with traumatic brain injury who are 18 to 64	[c]
Delaware	
People with HIV/AIDS-related conditions	174
District of Columbia	
Mentally retarded or developmentally disabled people who are 22 and older	75
People who are 65 and older	[c]
Florida	
Aged and disabled people who are 18 and older	16,943
Mentally retarded or developmentally disabled people	10,302
Aged and disabled people who are 18 and older	1,380
People with AIDS	8,000
Mentally retarded or developmentally disabled people who are over 18	116
Elderly people	[c]
Georgia	
Aged and disabled people	16,500
Mentally retarded or developmentally disabled people	2,109
Disabled adults who are 24 to 64[d]	121

(continued)

Waivers' target populations[a]	Number of clients
Hawaii	
Mentally retarded or developmentally disabled people	512
Aged and disabled people	338
People with AIDS/ARC[e]	104
Iowa	
People with HIV/AIDS	29
Mentally retarded people (including children)	4,530
People with traumatic brain injury who are 30 to 64	30
Mentally retarded or developmentally disabled people and mentally retarded children with disabilities	374
Elderly people	2,236
Idaho	
Aged and disabled people 21 and older	1,429
Mentally retarded or developmentally disabled people 21 and older	415
Illinois	
Disabled people	12,021
People with HIV/ARC/AIDS	984
Mentally retarded or developmentally disabled adults	5,224
People who have been disabled by an acquired traumatic brain injury	[c]
Indiana	
Aged and disabled people	2,467
Mentally retarded people and those with related conditions	1,201
Kansas	
Aged and disabled people	3,150
Physically disabled people who are 16 to 64	1,880
People with traumatic brain injury[d]	160
Kentucky	
Aged and disabled people	11,500
Adults and children with traumatic brain injury	[c]
Louisiana	
Mentally retarded or developmentally disabled people	2,095
People with loss of sensory motor function	103
Aged and disabled people	222
Maryland	
Mentally retarded or developmentally disabled people	3,600
Maine	
Elderly people	554

(continued)

Waivers' target populations[a]	Number of clients
Physically disabled people	204
Disabled people who are 18 to 60	13
People with traumatic brain injury	[c]
Michigan	
Aged and elderly people	2,804
Minnesota	
Elderly people	6,582
Mentally retarded people and those with related conditions	5,657
Disabled people under 65	2,751
People with acquired traumatic brain injury	290
Missouri	
Mentally retarded or developmentally disabled people	5,860
People with HIV/AIDS	140
Disabled people and developmentally disabled people who are 21 to 64[d]	[c]
Mississippi	
Disabled people who are 21 to 64	100
Mentally retarded or developmentally disabled people	325
Montana	
Aged and disabled people	1,158
Mentally retarded or developmentally disabled people	652
North Carolina	
Mentally retarded or developmentally disabled people	3,201
North Dakota	
Mentally retarded or developmentally disabled people	1,792
Aged and disabled people	366
People with traumatic brain injury who are 18 to 64	9
New Hampshire	
Mentally retarded or developmentally disabled people	1,303
People with acquired traumatic brain injury who are 22 and older[d]	27
New Jersey	
Mentally retarded or developmentally disabled people	5,242
People 18 to 65 who incurred traumatic brain injury after age 16[d]	153
New Mexico	
People with AIDS/ARC	60
Aged and disabled people	1,200
Mentally retarded or developmentally disabled people	1,500

(continued)

Waivers' target populations[a]	Number of clients
Nevada	
Frail elderly people 65 and older	898
Elderly people in group care	72
Ohio	
Aged and disabled people	17,000
Aged and disabled people under 60	3,904
Mentally retarded or developmentally disabled people	2,512
Mentally retarded or developmentally disabled people 18 and over	[c]
Oregon	
Aged and disabled people	19,471
Pennsylvania	
Physically disabled people	[c]
Elderly people	675
Rhode Island	
Elderly people 65 and over	600
Physically disabled people[d]	80
South Carolina	
Aged and disabled people	7,658
People with HIV/AIDS	637
Mentally retarded people and those with related conditions	2,288
People with traumatic brain injury and spinal cord injury	161
Adults who are technology-dependent (ventilator-dependent)[d]	27
South Dakota	
People 18 and over who are quadriplegic	39
Tennessee	
Aged and disabled people	306
Mentally retarded or developmentally disabled people	2,200
Aged and disabled people	150
Texas	
Aged and disabled people	9,945
Aged and disabled people 21 and older	[c]
Utah	
Physically disabled people	[c]
Virginia	
Aged and disabled people	7,442
Mentally retarded and developmentally disabled people	1,685
Aged and disabled people 18 and over	[c]
People with HIV/AIDS who are symptomatic	636

(continued)

Waivers' target populations[a]	Number of clients
Chronically ill children with traumatic brain injury and adults with traumatic brain injury[d]	178
Vermont	
Mentally retarded people and those with related conditions	1,419
Aged and disabled people	780
Washington	
Aged and disabled people	17,013
Mentally retarded or developmentally disabled people	[c]
Developmentally disabled people who are inappropriately placed	[c]
People with HIV/AIDS	69
People with traumatic brain injury[d]	16
Wisconsin	
Aged and disabled people	10,670
People who are developmentally disabled	6,936
Mentally retarded and developmentally disabled people	90
Wyoming	
Developmentally disabled people	611
Aged and disabled people	700
Total	
118 waivers	**331,467**

[a]Only HCBS waivers offering personal care or attendant care to adults were included in our state analysis of HCFA waivers and auxiliary services.

[b]Human immunodeficiency virus/acquired immunodeficiency syndrome.

[c]Data not reported in the APHSA Summary of 1915 (c) HCBS waivers.

[d]HCBS waivers considered Model Waivers under the Medicaid program.

[e]AIDS-related complex.

Source: APHSA.

Cash and Counseling Demonstration and Evaluation

The Cash and Counseling Demonstration and Evaluation (CCDE) project represents one of the first systematic evaluations of consumer-directed personal care. Sponsored by the Robert Wood Johnson Foundation, in cooperation with the Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, the CCDE is expected to evaluate the advantages and disadvantages of offering consumers the choice of receiving personal care services under Medicaid via a direct cash allowance in lieu of state payments to service providers. The University of Maryland Center on Aging is directing and coordinating the demonstration, overseeing the evaluation, and providing technical assistance to the demonstration states—Arkansas, Florida, New Jersey, and New York.

Uniform Requirements

The CCDE has established a rigorous experimental protocol. The research questions seek to identify whether there are significant differences between interested consumers who are randomly assigned to receive cash allowances and those with agency-delivered services in the following areas:

- types and amounts of services,
- program and administrative costs, and
- consumer satisfaction and quality of care.

Additionally, the CCDE plans to identify the counseling services offered to consumers with cash payments to determine which consumers take advantage of additional supports, such as instruction in how to train providers and manage payroll. Consumers will also be asked to assess the value of the counseling services they receive under the CCDE. The evaluation will also examine the effects of the demonstration on informal caregivers and paid workers.

The four states participating in the CCDE have agreed to take part in a rigorous evaluation process and to enroll at least 3,500 individuals in their programs. The manner in which individuals enter each state's program will be the same as the current process: individuals will continue to receive an assessment (or reassessment) that takes into account existing formal and informal supports, such as care regularly provided by family members. Any unmet needs for personal assistance will be identified and will become the basis for a care plan. Once deemed eligible for the program, individuals will be randomly assigned to either a control group or a

treatment group (cash option).[44] In the control group, the consumer will receive services as traditionally provided in each state's Medicaid program.

Those assigned to the cash option group will "cash out" their benefits as defined by their care plans—in effect, the cost of their service needs will be converted to a cash payment that they will be able to use to purchase services directly. Consumers in the cash option group will then pay caregivers directly or will choose to have a fiscal intermediary perform the payroll function.[45] Consumers will not be required to spend all the money on personal attendants and will be able to save some of it for emergencies or costly items, such as environmental modifications or assistive devices. Additionally, the demonstration will waive Medicaid rules that prohibit the hiring of legally responsible relatives, allowing family members to become paid caregivers.

Counseling services, which are an integral part of the CCDE, will be offered to meet an array of needs. For example, counseling services will help consumers decide whether to use a fiscal intermediary or obtain training and counseling on how to be an employer. Earlier on, the Robert Wood Johnson Foundation contracted with Health Services Research Institute, which prepared an employer and taxation booklet tailored to the four states. Additional counseling services may include assisting consumers with screening providers, finding emergency or substitute arrangements, managing tax forms and insurance paperwork, and even locating home modification subcontractors.

Variations in Implementing the CCDE

There is variation in how the four CCDE states plan to implement this demonstration, including their (1) approach to personal care under Medicaid, (2) use of a fiscal intermediary and counseling services, and (3) outreach and enrollment efforts.

Arkansas, New Jersey, and New York are implementing the CCDE through their PCS benefit, for which each state has slightly different service limits

[44]Consumers interested in directing all aspects of their care—including cash management—must first pass a skills test. In the event a consumer is not totally capable of self-direction, he or she has the opportunity to select a representative decisionmaker to act on the consumer's behalf.

[45]While several models exist, a fiscal intermediary generally manages any legal requirements associated with the employment of the caregiver, often through payroll management and tax filings. For a description of other intermediary models, see Flanagan and Green, Consumer-Directed Personal Assistance Services: Key Operational Issues for State CD-PAS Programs Using Intermediary Service Organizations, Final report for the Department of Health and Human Services by The MEDSTAT Group (Washington, D.C.: Oct. 24, 1997).

and authorization requirements. Florida's personal care will be provided through HCBS waivers, including one that targets elderly individuals and those with physical disabilities and another that includes children and adults with developmental disabilities. Both waiver populations will participate in the CCDE evaluation. The other three states will include a mix of older and younger adults with physical disabilities.

The four CCDE states also differ in the way they plan to implement fiscal intermediary and counseling services. Arkansas divided the state into four regions and asked each to select an entity that would provide both counseling and fiscal intermediary services. The regional selections varied and included an area Office on Aging, a rehabilitation center, and a center for developmental disabilities. New York, which will be the last state to implement the CCDE, also plans to combine counseling and fiscal intermediary services. Florida and New Jersey have selected one organization to serve as the fiscal intermediary on a statewide basis and separate entities to provide their counseling services.

Outreach and enrollment efforts by states reflect the concern that all consumers have the opportunity to select a cash option.[46] In New Jersey and Arkansas, the same organizations that provide personal care services under the CCDE also enroll individuals for the traditional personal care benefit. Because these organizations have a vested interest in provider-based care, states had some concern that they might steer individuals away from the cash option. To address this concern, Arkansas hired a series of nurse coordinators to assist with enrollment, while New Jersey added the enrollment activities to the contract of the organization that had successfully handled the state's Medicaid managed care contract. In Florida, the organizations and individuals who provide care management services under the traditional system will also handle outreach and counseling under the cash option. Special care is being given to separate care management and counseling functions. New York's plans for enrollment and outreach had not been fully developed at the time of our work.

[46]Selecting a cash option does not ensure that a consumer gets to be a part of the cash option group, since half of the consumers interested in cash and counseling are randomly assigned to a control group.

Progress to Date

The states participating in the demonstration are implementing their programs over time. Once receiving overall approval for the CCDE,[47] Arkansas was the first to implement the demonstration and began enrolling clients during early December 1998. New Jersey, Florida, and New York plan to begin implementation later in 1999.

In an effort to assess consumers' preliminary interest in a cash approach to consumer-directed personal care, the University of Maryland Center on Aging conducted a telephone survey in the CCDE states. Consumers were asked if they would be interested in a cash option for personal care services. Results from these surveys indicated an interest among consumers ranging from 32 percent in Arkansas (from a sample of Medicaid personal care clients) to 58 percent in Florida (from a sample of participants in the state's aging and disabled waiver program).[48] Table VI.1 summarizes the extent of consumer interest in a cash model across the four states.

Table VI.1: Consumer Interest in a Cash Model

State	Percentage of consumers interested in cash option[a]
Arkansas	32
Florida	
Physically disabled waiver	58
Developmentally disabled waiver	40 adults; 79 children
New Jersey	42
New York	40

[a]These percentages include both consumers answering for themselves and surrogates answering for the consumers.

In addition to determining consumer interest in or preference for a cash model, the survey also asked participants if they wanted assistance or

[47]After the states received approval for their projects from HCFA in early Oct. 1998, states had to obtain waivers from the Supplemental Security Income program. Program waivers were necessary because the demonstration allows participants to carry funds forward month to month, which could violate resource limits under the program.

[48]For more detailed information on the Arkansas survey results, see L. Simon-Rusinowitz and others, "Determining Consumer Preferences for a Cash Option: Arkansas Survey Results," Health Care Financing Review, Vol. 19, No. 2 (winter 1997).

training for seven different tasks associated with the cash option, including

- deciding how much to pay a worker,
- managing payroll taxes,
- conducting background checks,
- arranging for backup care,
- finding a caregiver,
- interviewing a prospective caregiver, and
- firing a caregiver.

Most consumers interested in the cash option expressed a need for each of the supportive services. Overall, consumers attached the most importance to deciding worker's pay, managing the payroll and conducting background checks, and less interest in the remainder of the tasks.

Results of the telephone survey shaped some of the design of the CCDE. In particular, 80 to 90 percent of respondents expressed interest in a fiscal intermediary; thus, choosing an intermediary for payroll assistance became a critical component for states' demonstrations. Additionally, the survey showed the need for counseling services and training, particularly among consumers who wanted assistance with the seven tasks noted above. This result underscores the integral role that counseling plays in the demonstration.

To provide sufficient time for consumer enrollment and experience, the participating states will be expected to conduct their demonstration programs for at least 24 months. Final reports on the CCDE are expected to be available 3 years and 3 months after the state starts its demonstration. This period of time allows for 1 year of open enrollment, 1 year of tracking consumers, and the remaining year and 3 months for data collection and analysis. Throughout the demonstration, however, interim reports are planned and will be issued as they are completed. Additionally, researchers will conduct a series of in-depth, qualitative interviews intended to provide a snapshot of the individual's experience with the cash option. A demonstration researcher indicated that there may be 25 qualitative interviews per state, which will primarily involve the consumer, principal family member, paid caregiver, and a counselor.

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