State Medicaid Programs Offering Personal Care Services

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Two Medicaid programs offer personal care services: (1) the Title XIX Personal Care Services (PCS) optional State plan benefit; and (2) the 1915(c) home and community-based services (HCBS) waivers. By 1998-1999, 26 States offered the PCS optional State plan benefit; 45 offered personal care services via a waiver(s). Nationwide, the former program was larger. The latter was the more popular administrative mechanism, possibly because it more reliably controls growth. States vary dramatically in terms of Medicaid personal care. Medicaid personal care participants per 1,000 State population ranged from 7.33 to 0.04. Per capita expenditures ranged from $91.21 to $0.02.

INTRODUCTION

The purpose of this research was to systematically describe the two predominant means through which Medicaid participants receive personal care services: the Medicaid Title XIX PCS optional State plan benefit; and the Medicaid 1915(c) HCBS waiver program. Our goal was twofold: to offer State and national statistics on the number of Medicaid personal care participants and expenditures; and to describe how the States vary in their implementation of the two programs.

Personal care services are authorized, defined, and periodically updated in the *Federal Register* (1997). Such services are further defined in section 4480 of the *State Medicaid Manual* (Health Care Financing Administration, 1999a). Personal care services (also known in States by other names, such as personal attendant services, personal assistance services, and attendant care services) are covered under a State's Medicaid program and may include a range of human assistance provided to persons with disabilities and chronic conditions of all ages, enabling them to accomplish tasks they would normally do for themselves if they did not have a disability. Thus, personal care prototypically concerns hands-on assistance with activities of daily living (ADLs) (such as eating, bathing, dressing, and bladder and bowel requirements) or instrumental activities of daily living (IADLs) (such as taking medications and shopping for groceries). These services, by definition, cannot solely involve ancillary tasks such as housekeeping or assistance with chores. Recently, CMS made supervision or cuing so that a person can perform tasks by him/herself an allowable service (Health Care Financing Administration, 1999b).

Services must be approved by a physician, or by some other authority recognized by the State. Personal care participants cannot be inpatients or residents of a hospital, nursing facility, intermediate care facility for the mentally retarded (ICF-MR) or institution for mental disease and services can only be rendered by qualified individuals, as designated by each State. Personal care services can be provided in

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the home, outside the home, or in both locations at the option of each State. The reimbursement of legally responsible relatives (e.g., spouses and parents of minor children) as providers of personal care is prohibited. The supervision of providers is left to the State's discretion (*Federal Register*, 1997).

Moreover, CMS definitions are broad enough to give the States significant flexibility in designing personal care programs under Medicaid and little is known about how the States vary in this regard. In sum, personal care is a complex construct, known by a variety of names, overlapping with existing service systems, blurring the lines between skilled and unskilled, and between formal and informal home care. Finally, personal care programs are evolving in different ways across the States, many of which continually make changes in their programs.

BACKGROUND

There are a number of other government programs that support personal care services in the United States, including Title XX Social Security block grants, Title III Older Americans Act funds, State general funds (Kassner and Williams, 1997), Department of Veterans Affairs Aid and Attendance Program and Title II, Section 203 of the Ticket to Work and Work Incentives Improvement Act of 1999. The Medicare and Medicaid home health benefits offer some unskilled assistance as well, but usually on a short-term basis after hospitalization (U.S. General Accounting Office, 1999). Despite the obvious importance of these programs, Medicaid, a joint Federal/State health financing program for low-income individuals, remains the most significant government program offering personal assistance in the United States. It is also the primary payer of long-term care (LTC) more generally (Levit et al., 2000).

Historically, Medicaid has funded services that are delivered in nursing homes and other institutional settings. As a result, Federal statutes and regulations concerning LTC under Medicaid are oriented toward institutional placement and a medical model of care (Harrington et al., 2000b). Most significantly, Medicaid regulations make nursing facilities a mandatory entitlement program, while HCBS alternatives are left to the discretion of each State. The States must offer Medicaid home health care services to individuals who would otherwise be in an institution, and many States offer optional home health services as well. They are also mandated to offer services for children under the Medicaid Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) programs (U.S. Department of Health and Human Services, 1999). These services usually include some personal care. Congress and State legislatures have steadily expanded funding for HCBS, such as personal assistance.

Since 1975, States have had the option of offering personal care services as a Medicaid optional State plan benefit. As the name indicates, the personal care optional State plan benefit offers only personal care services. In this program, the definition of personal care, beyond the basic requirements of the Federal statute and regulations is left to the States (Health Care Financing Administration, 1999a).

The Medicaid HCBS waiver program was established with the passage of Section 2176 of the Omnibus Budget Reconciliation Act (OBRA) of 1981. This legislation created Section 1915(c) of the Social Security Act, which authorized States to exercise the option of providing home and community-based alternatives to institutional care (Miller 1992; Miller, Ramsland, and Harrington, 1999). Because the 1915(c) HCBS waiver program was

created to offer alternatives to institutionalization, program regulations require the HCBS waivers to be limited to those who are eligible for institutional placement. Moreover, the States are allowed to target HCBS waivers to particular populations. Consequently, they are not required to offer HCBS waiver services to all categorically or medically needy groups. (This is called a waiver of comparability.) States have the option of limiting HCBS waiver services to targeted geographic regions (Code of Federal Regulations, 1996). Finally, the States also must specify a limit on the number of individuals who may receive benefits for each HCBS waiver (42 U.S.C. 1396n, Section 1915(c)(4)(A)). (These number limits are commonly referred to as slots.)

Many of the first HCBS waivers were targeted toward the aged and disabled or those with developmental disabilities, but in recent years HCBS waivers have evolved to target Medicaid eligible individuals with a variety of conditions and chronic disorders, such as physical disabilities, acquired immunodeficiency syndrome (AIDS), acquired brain injuries, and other forms of severe disability, including, to a limited extent, chronic mental illness (Miller, Ramsland, and Harrington, 1999; Harrington et al., 2000c).

The HCBS waiver program allows States the opportunity to make available a wide range of LTC services related to personal assistance, including: case management, homemaker/chore services, adult day care, transportation, and respite/companion. Personal care services and other services similarly named, represent formally recognized HCBS waiver services as well. As in the PCS optional State plan benefit, the States have considerable leeway in defining and regulating service. Because of the degree to which different HCBS waiver services overlap with one another, and the extent to which States vary in their definitions of personal care services, it has proven difficult to accurately assess the degree to which 1915(c) HCBS waiver programs offer personal care in the United States.

Financial eligibility for the PCS optional State plan benefit is determined using each State's standard Medicaid eligibility criteria for the categorically and/or medically needy. These criteria are usually more stringent than those used to qualify persons for institutional placement. Under the Medicaid rules, States can use special institutional financial eligibility standards of up to 300 percent of Supplemental Security Income (SSI) to qualify. Medicaid rules also allow the States to adopt the same financial eligibility rules for the HCBS waivers as they use for institutional services. In all but a few States, financial eligibility criteria in the HCBS waiver programs are the same as those for institutional services (LeBlanc, Tonner, and Harrington, 2000). Thus, financial eligibility criteria are typically more restrictive in the PCS State plan benefit than they are in the HCBS waivers (Horvath, 1997; Bruen et al., 1999).

Need criteria for the PCS State plan benefit are left to the discretion of the States and vary accordingly. Need criteria for the HCBS waivers parallel need criteria for institutional placement under Federal statute (42 Code of Federal Regulations 441.302(c)). Consequently, because need criteria for institutional placement vary from State to State, so do criteria for the HCBS waivers (Tonner et al., 2001).

The HCBS waivers are intended to be, by definition, cost effective. The program was designed to provide a cost-neutral alternative to institutional care, requiring the States by Federal statute to keep HCBS waiver costs at or below those of comparable institution-based service. HCBS waiver

services may be formally limited by the States by limiting the number of approved slots. In contrast, the PCS State optional benefit must be statewide and available to all categorically-needy eligibility groups. As a result, the States may be more likely to adopt restrictive financial eligibility and need criteria, require prior authorization for services, and set formal limits on the amount of personal care allowed under the PCS optional State plan benefit than under the HCBS waivers (Harrington et al., 2000b; U.S. General Accounting Office, 1999).

Recent studies have begun to describe the breadth and depth of Medicaid HCBS programs more fully, typically offering statistics on State and national trends (Litvak and Kennedy 1991; Burwell 1999; Miller, Ramsland, and Harrington, 1999), or documenting the statutes and regulations that shape the benefits (Harrington et al., 2000b). In many respects, however, research on personal care in the United States has only just begun.

HCFA Form 64 reports on LTC expenditures allow for year-by-year comparisons of how States allocate their total Medicaid LTC dollars, including statistics on both the PCS optional State plan benefit and the HCBS waivers. Between 1988 and 1998, both the PCS State plan benefit and HCBS waiver programs were growing at a rate surpassing the growth of nursing facility placements (Burwell, 1999). Nonetheless, the amount States spend on institutional care continues to far outweigh, by a factor of 3, what they spend on home and community-based alternatives, of which personal care is one important component (Burwell, 1999). HCFA Form 64 data do not allow one to identify how much of the money spent on HCBS waiver services is allocated for personal care. Nor does it identify the numbers of participants who receive personal care services from Medicaid.

The recent U. S. General Accounting Office (1999) study is one of the few that singles out personal care, both in the PCS optional State plan benefit and in the 1915(c) HCBS waivers, for concentrated analysis of national statistics and State profiles. Additionally, that report offers indepth profiles of four States' approaches to integrating consumer direction into their personal care programs, a topic of growing interest (Beatty et al., 1998; Benjamin et al., 1998; Dautel and Frieden 1999; Doty, Kaspar, and Litwak, 1996; Glickman, Stocker, and Caro, 1997; Micco et al., 1995; Prince, Manley, and Whiteneck, 1995; Scala, Mayberry, and Kunkel, 1996; Richmond et al., 1997). Personal care services are amenable to self-direction. Moreover, it is the service most critical to the vision of the independent living movement (Batavia, DeJong, and McKnew, 1991; Kaye, 1997). Other central aspects of program design such as the definitions and boundaries States place on personal care, are largely unexplored.

METHODS

Data were predominantly collected from telephone interviews with State officials who work closely with these programs. Initial telephone calls to each State's Medicaid Office were typically sufficient for identifying the appropriate persons to be interviewed. It was our goal to locate individuals who work somewhere between the front lines of service delivery and the upper levels of policy planning. In most States, there are a number of individuals knowledgeable about the programs. In States with multiple HCBS waivers, a person able to describe personal care across the waivers was interviewed.

In the statistics on personal care services under the HCBS waivers, participant counts were limited to those services

essentially defined as such (e.g., personal care; personal support). Other HCBS waiver services indirectly related to personal care were excluded (e.g., home health and homemaker or chore services). Insofar as people access these related services, independent of personal care, these data underestimate the numbers of people receiving personal assistance in the HCBS waiver program. States may also offer some personal care services for children under EPSDT programs (U.S. Department of Health and Human Services, 1999), but this program was excluded from the present study due to unavailability of data on participants. Participant data on Medicaid home health services are also not collected by CMS. In any event, data on home health services were considered to be beyond the scope of the present research because they are typically more medically based than personal assistance.

All interviews were conducted between fall 1998 and summer 1999. Ultimately, data were collected from 26 State officials who were knowledgeable about the PCS optional State plan benefit, and 45 officials familiar with personal care services offered in one or more HCBS waivers. Washington DC, had a newly approved waiver that included personal care services but it was not yet operational at the time of the survey. Interviews lasted, on average, between 52 minutes (for the PCS State plan benefit protocol) and 69 minutes (for the HCBS waiver protocol). In five States, in-person interviews were carried out as part of site visits for a related study.

The structured interview protocols were essentially the same for these two Medicaid benefits, including a series of questions regarding service definitions, program structure, service limitations, and provider reimbursement rates. Most survey questions were designed to produce straightforward yes or no responses. Statistics and materials documenting program regulations were collected by mail and FAX.

Finally, data from HCFA Forms 64 and 372 were also used to supplement the survey data. While Form 64 data reflect expenditures for a number of Medicaid programs, Form 372 data concern the HCBS waivers in particular, including both participant and expenditure data that can be broken down by service type. Population statistics from the U.S. Census Bureau (1997) were also used to generate per capita statistics.

It proved difficult at times, even for State officials working closely with the programs, to produce statistical estimates of numbers served. Collection of the HCBS waiver data was particularly difficult in States with multiple HCBS waivers, all or some of which offered personal care or similar services, administered by different agencies. It was sometimes necessary to consolidate data from multiple sources, and rely on Form 372 data and/or rough estimates. Per capita estimates were not adjusted for demographic or other factors that vary across States.

RESULTS

State Personal Care Services Participants and Expenditures

Twenty-six States reported an active PCS optional State plan benefit in 1998-1999. (New Mexico applied in 1999 to CMS to begin the benefit.) Because they report personal care expenditures on Form 64, Florida, Iowa, Kansas, South Carolina, and Vermont are sometimes thought to operate a PCS optional State plan benefit. However, these expenditures reflect personal care for children under EPSDT programs (U.S. Department of Health and Human Services, 1999), not Title XIX optional State plan benefit programs. Arizona offers per-

sonal care to Medicaid-eligible individuals through its 1115 managed care waiver. Therefore, although we present some data on Arizona's Medicaid-funded personal care services, they do not fall under either the PCS optional State plan benefit or the waiver program.

The vast majority of States offered at least some personal care in at least one HCBS waiver. Included in this total of 45 States were Massachusetts and Utah, which had newly added personal care services in a waiver or waiver(s). Participant and expenditure data were not yet available for those two States, however, programmatic data were. The Washington, DC 1915(c) waiver program was newly approved and not yet implemented. Therefore, data on its waivers were not available. In addition to Washington, DC, five States did not offer personal care in their HCBS waiver programs, but each maintained the State PCS optional State plan benefit (Alaska, Michigan, Nebraska, New York, West Virginia). Twenty-five States used only the HCBS waiver mechanism to offer personal care to Medicaid-eligible individuals, and 18 States, plus Washington, DC, Massachusetts, and Utah, used both programs (Table 1).

In total, 467,487 individuals[1] received personal care from the PCS optional State plan benefit program in the most recent fiscal year. The size of this program varied dramatically across the 26 States, with an average of 17,980 participants. Utah and New Hampshire offered the service to less than 200 clients each. In contrast, the heavily populated States of California and New York reached 134,694 and 87,496 Medicaid clients, respectively. Michigan and Texas also had sizable programs, each reporting more than 55,000 participants (Table 1).

Collectively, through the HCBS waivers, 226,164 individuals meeting both Medicaid financial eligibility and institutional level-of-care criteria received personal assistance services in the most recent fiscal year. Of the 210 1915(c) HCBS waivers nationwide, 115 offered personal care as a service. Of those 115, 30 percent were targeted toward people with mental retardation/developmental disability (MR/DD); 30 percent toward the aged, or aged/disabled; 27 percent toward people with physical disability, traumatic brain injury/head injury, children and others; and 13 percent toward people with AIDS.

Taking into account the difficulties of extracting information on personal care from the varied pool of discrete HCBS waiver services, these data showed that the HCBS waivers accounted for a smaller proportion of the Medicaid personal care caseload than did the PCS optional State plan benefit, which by regulation must be offered statewide. However, viewed in its entirety, the HCBS waiver benefit program was larger. According to Form 372 data, 544,497 individuals received some type of HCBS, including personal care from the HCBS waivers in 1997 (Harrington et al., 2000a) (Table 1).

Nine States (Illinois, Kansas, North Carolina, Ohio, Oregon, Texas, Virginia, Washington, and Wisconsin) reported more than 10,000 HCBS waiver personal care clients each, and a number of other States were just below that figure. Yet, 14 States served fewer than 1,000 personal care clients through their HCBS waivers (Table 1).

Adding together participants in these two programs, there were 693,651 total Medicaid personal care participants in the United States in 1998-1999. Approximately one-half (45.2 percent) of the national total was accounted for by three States: California, Texas, and New York. Adding in Michigan and Missouri raises that per-

[1] The same individual might receive personal care under several different Medicaid programs within a given year. Thus, we may overestimate the numbers of participants in each category to an unknown degree.

Table 1

Medicaid Personal Care Participants in the United States: 1998-1999

State	Personal Care State Option	Waivers	Total Medicaid	Participants per 1,000 Population[1]
Total	467,487	226,164	693,651	—
Arkansas	18,198	300	18,498	7.33
Missouri	33,167	394	33,561	6.21
Michigan	55,046	NA	55,046	5.63
Kansas	NA	13,632	13,632	5.24
Oregon	2,483	[2] 13,755	16,238	5.01
Washington	8,854	18,723	27,577	4.91
New York	87,496	NA	87,496	4.82
Texas	59,562	28,079	87,641	4.52
Wisconsin	10,926	11,791	22,717	4.37
California	134,694	[2] 4,383	139,077	4.32
Montana	2,672	647	3,319	3.78
Rhode Island	NA	2,892	2,892	2.93
North Carolina	8,884	10,648	19,532	2.63
Oklahoma	[3] 6,000	2,490	8,490	2.56
West Virginia	[3] 4,500	NA	4,500	2.48
Washington, DC.[4]	1,205	NA	1,205	2.27
New Hampshire	137	[3] 2,500	2,637	2.25
Colorado	NA	[2] 8,514	8,514	2.19
New Jersey	12,810	4,752	17,562	2.18
South Carolina	NA	8,242	8,242	2.18
Maine	1,133	1,151	2,284	1.84
Ohio	NA	[3] 20,000	20,000	1.79
Arizona[5]	NA	8,080	8,080	1.77
South Dakota	808	451	1,259	1.71
Wyoming	NA	794	794	1.65
Alaska	980	NA	980	1.61
Virginia	NA	10,770	10,770	1.60
Idaho	[3] 1,000	916	1,916	1.58
Hawaii	NA	1,823	1,823	1.53
Minnesota	6,487	132	6,619	1.41
New Mexico	NA	[2] 2,380	2,380	1.38
Georgia	NA	9,512	9,512	1.27
Vermont	NA	730	730	1.24
Nevada	853	1,019	1,872	1.12
Maryland	4,499	[3] 200	4,699	0.92
Illinois	NA	10,562	10,562	0.88
Kentucky	NA	3,270	3,270	0.84
Delaware	NA	603	603	0.82
Alabama	NA	3,408	3,408	0.79
Nebraska	1,234	NA	1,234	0.74
Massachusetts[4]	[3] 3,700	NA	3,700	0.61
North Dakota	NA	353	353	0.55
Pennsylvania	NA	6,012	6,012	0.50
Louisiana	NA	2,051	2,051	0.47
Florida	NA	[2] 6,500	6,500	0.44
Indiana	NA	[2] 1,941	1,941	0.33
Tennessee	NA	1,288	1,288	0.24
Mississippi	NA	219	219	0.08
Utah[4]	159	NA	159	0.08
Iowa	NA	132	132	0.05
Connecticut	NA	125	125	0.04
Mean	17,980	5,259	13,601	2.59

[1]Population data from the U.S. Census Bureau (1997).

[2]HCFA Form 372, 1997.

[3]Rough estimate.

[4]Personal care newly added to waiver(s), data not yet available.

[5]Offered through a Medicaid 1115 waiver.

NOTE: NA is not applicable.

SOURCE: Author's tabulations based on structured telephone survey and HCFA Form 372, 1997.

centage to 58 percent. Nearly all of the remaining States reported small numbers of total personal care services participants (Table 1).

Table 1 also shows the number of Medicaid personal care participants per 1,000 population. Ten States (Arkansas, Missouri, Michigan, Kansas, Oregon,

Washington, New York, Texas, Wisconsin, and California) had rates of greater than 4 persons per 1,000 State population. The mean rate for the Nation was 2.59 per 1,000 population. The highest was Arkansas[2] (7.33 per 1,000), followed by Missouri, Michigan, Kansas and Oregon; the lowest States were Tennessee, Mississippi, Utah, Iowa, and Connecticut.

Table 2 presents expenditure data obtained from Forms 64 and 372 along with total and per capita calculations. This shows that $3.4 billion was spent on personal care services in the optional State plan benefit program nationwide, and more than $1.3 billion was spent on personal care in the HCBS waivers, excluding the homemaker/chore services.

Total expenditures for personal care under the 1915(c) HCBS waivers accounted for less than one-half (38 percent) of expenditures for the PCS optional State plan benefit. And the average amount of personal care expenditures through the HCBS waivers ($30,732,166) was much smaller than that of the State plan benefit ($132,464,610), in part because the latter is required to be statewide. A handful of States demonstrated high spending levels. New York's Medicaid program exceeded $1.66 billion in terms of combined personal care services expenditures. In contrast, several States allocated relatively few resources to personal care services. Six States spent less than $1 million in total (Mississippi, Washington, DC, Utah, Rhode Island, Connecticut, and Iowa) (Table 2).

Statistics on per capita expenditures further highlights interstate variation in spending for personal care services. With expenditures of more than $30 per capita, New York, New Hampshire[3], New Jersey, Wisconsin, Washington, and North Carolina were the six States with the greatest per capita spending on personal care. New York had the highest spending level, which was more than $90 per capita. The U.S. average was about $18 per capita. The seven lowest spending States were: Mississippi, Tennessee, Pennsylvania, Rhode Island, Utah, Connecticut, and Iowa (Table 2).

Expenditures per Medicaid participant were highest in Massachusetts, New Hampshire, North Dakota, New York, and New Jersey. They were lowest in Pennsylvania, South Dakota, Iowa, Rhode Island, and Washington, DC. The national average was $6,870 per participant (Table 2).

Formal Limits

Table 3 shows that most of the 26 States offering the PCS optional State plan benefit enforced limits on participants by using either hourly limits or cost caps (ceilings). Of the 26 States 15 had hourly limits; 9 had cost caps that individual clients were not allowed to exceed. All hourly limits are shown as per day limits, although they were sometimes formally written as per week, month, or year. Typically, limits were either in the form of hours or costs exclusively. Only two States (Texas and Washington), and Washington, DC used both.

Under the PCS State plan benefit, hourly limits ranged from an average of 14.5 hours per day in Minnesota to less than a full hour per day (in Oregon). Among States with formal hourly limits, the average was 4.8 hours per day (Table 3). Some officials reported that States have routine mechanisms for granting

[2] Limit personal care services under the PCS optional State plan benefit to the categorically needy (excluding medically needy individuals) (U.S. General Accounting Office, 1999).

[3] New Hampshire's PCS optional State plan benefit program stems from a longstanding program formerly funded with State general funds and limited exclusively to individuals who use wheelchairs and can self-direct their care.

Table 2
Medicaid Personal Care Expenditures in the United States: 1997-1998

State	PCS State Option	PC in Waivers	Total Medicaid PC	Expenditures per Capita[1]	Expenditures per Medicaid PC Participant
Total	3,444,079,859	1,321,483,150	4,765,563,009	—	—
Massachusetts	139,105,479	NA	139,105,479	22.75	37,596
New Hampshire	2,294,653	60,695,389	62,990,042	53.74	23,887
North Dakota	NA	7,166,766	7,166,766	11.18	20,302
New York	1,655,085,940	NA	1,655,085,940	91.21	18,916
New Jersey	169,711,230	129,766,577	299,477,807	37.16	17,053
Minnesota	98,637,571	1,227,364	99,864,935	21.30	15,088
Maine	3,596,006	25,614,444	29,210,450	23.52	12,789
North Carolina	135,870,664	110,332,715	246,203,379	33.13	12,605
Louisiana	NA	25,201,026	25,201,026	5.79	12,287
Idaho	15,238,552	4,719,881	19,958,433	16.51	10,417
New Mexico	NA	[2] 23,500,413	23,500,413	13.63	9,874
Indiana	NA	18,453,155	18,453,155	3.15	9,507
Colorado	NA	71,488,338	71,488,338	18.37	8,397
Wisconsin	65,534,473	114,208,896	179,743,369	34.56	7,912
Virginia	NA	84,297,895	84,297,895	12.51	7,827
Vermont	NA	5,392,984	5,392,984	9.15	7,388
Washington	120,122,810	68,434,955	188,557,765	33.59	6,838
West Virginia	27,845,161	NA	27,845,161	15.34	6,188
Kansas	NA	74,261,662	74,261,662	28.55	5,448
Maryland	24,051,519	1,091,276	25,142,795	4.93	5,351
Illinois	NA	54,927,611	54,927,611	4.58	5,200
Montana	13,365,579	2,589,551	15,955,130	18.16	4,807
Oregon	19,961,594	57,909,764	77,871,358	24.01	4,796
Texas	228,816,135	184,540,107	413,356,242	21.32	4,716
Georgia	NA	43,778,957	43,778,957	5.85	4,602
Mississippi	NA	982,091	982,091	0.36	4,484
Nebraska	5,381,619	NA	5,381,619	3.25	4,361
Alaska	4,246,146	NA	4,246,146	6.96	4,333
Hawaii	NA	7,806,466	7,806,466	6.55	4,282
Wyoming	NA	3,217,359	3,217,359	6.70	4,052
Delaware	NA	2,422,682	2,422,682	3.30	4,018
Michigan	207,957,621	2,384,894	210,342,515	21.51	3,821
South Carolina	NA	30,209,951	30,209,951	7.97	3,665
Arkansas	63,244,424	[2] 1,080,878	64,325,302	25.49	3,477
Tennessee	NA	4,245,022	4,245,022	0.79	3,296
Oklahoma	24,184,928	[2] 1,412,740	25,597,668	7.71	3,015
Missouri	91,636,182	1,668,587	93,304,769	17.25	2,780
Utah	431,427	NA	431,427	0.21	2,647
Ohio	NA	49,490,880	49,490,880	4.42	2,475
Florida	NA	15,604,486	15,604,486	1.06	2,401
California	324,379,099	7,956,733	332,335,832	10.33	2,389
Connecticut	NA	303,256	303,256	0.09	2,418
Alabama	NA	6,572,051	6,572,051	1.52	1,928
Kentucky	NA	6,155,926	6,155,926	1.57	1,883
Nevada	2,025,840	1,396,541	3,422,381	2.04	1,828
Pennsylvania	NA	8,104,963	8,104,963	0.67	1,348
South Dakota	732,931	398,141	1,131,072	1.53	898
Washington, DC	622,276	NA	622,276	1.17	516
Iowa	NA	52,189	52,189	0.02	395
Rhode Island	NA	417,588	417,588	0.42	144
Arizona[3]	NA	NA	—	—	—
Mean	132,464,610	30,732,166	95,311,260	18.11	6,870

[1]Based on population estimates from the U.S. Bureau of Census (1997).

[2]Rough estimate.

[3]Operated through a Medicaid 1115 Waiver.

NOTES: NA is not applicable. PCS is personal care services. PC is personal care.

SOURCE: Data from HCFA Forms 64, and 372, 1997.

exceptions to formal limits. New Jersey, for instance, which had a 25-hour per week limit as the general rule, allowed 26 to 40 hours per week with prior authorization and 40 or more hours per week with central office approval. West Virginia reported a similar policy. Other States, for example, Arkansas and Utah, ignored hourly limits for children. Minnesota allowed some participants to exceed the 14.5 hours per day limit, but most of those clients were eventually placed in the HCBS waiver program because of their high levels of need.

Table 3

Formal Hourly Limits and Cost Caps Placed on Medicaid Participants Receiving Personal Care, in State Plan (SP) and Waivers (WV): 1998-1999

	Hourly Limits				Cost Caps		
State	State Plan	Limit	Waiver	Notes	State Plan	Cap	Waiver
Total	15	NA	8	NA	9	NA	45
Alabama	NA	NA	No	NA	NA	NA	Aggregate
Alaska	No	NA	NA	NA	Yes	$200.0/day	NA
Arizona[1]	NA	NA	No	NA	NA	NA	Individual
Arkansas	Yes	2.3 hours/day	No	NA	No	NA	Mixture
California	Yes	10.1 hours/day	No	NA	No	NA	Aggregate
Colorado	NA	NA	No	NA	NA	NA	Mixture
Connecticut	NA	NA	No	NA	NA	NA	Individual
Delaware	NA	NA	No	NA	NA	NA	Individual
Florida	NA	NA	No	NA	NA	NA	Individual
Georgia	NA	NA	No	NA	NA	NA	Mixture
Hawaii	NA	NA	No	NA	NA	NA	Aggregate
Idaho	Yes	2.3 hours/day	No	NA	No	NA	Individual
Illinois	NA	NA	No	NA	NA	NA	Individual
Indiana	NA	NA	No	NA	NA	NA	Mixture
Iowa	NA	NA	No	NA	NA	NA	Individual
Kansas	NA	NA	Yes	Varies by WV	NA	NA	Mixture
Kentucky	NA	NA	No	NA	NA	NA	Aggregate
Louisiana	NA	NA	Yes	Varies by WV	NA	NA	Mixture
Maine	No	NA	No	NA	Yes	$35.7/day	Mixture
Maryland	No	NA	No	NA	Yes	$90.0/day	Aggregate
Massachusetts	No	NA	No	NA	No	NA	Aggregate
Michigan	No	NA	NA	NA	No	NA	NA
Minnesota	Yes	14.5 hours/day[2]	No	NA	No	NA	Individual
Mississippi	No	NA	No	NA	NA	NA	Aggregate
Missouri	No	NA	No	NA	Yes	$109.4/day	Aggregate
Montana	Yes	5.7 hours/day	No	NA	No	NA	Aggregate
Nebraska	Yes	8.0 hours/day	NA	NA	No	NA	NA
Nevada	No	NA	No	NA	Yes	100% NF	Individual
New Hampshire	No	NA	No	NA	No	NA	Aggregate
New Jersey	Yes	3.6 hours/day	Yes	Varies by WV	No	NA	Mixture
New Mexico	NA	NA	Yes	Varies by WV	NA	NA	Mixture
New York	No	NA	NA	NA	No	NA	NA
North Carolina	Yes	2.9 hours/day	No	NA	No	NA	Individual
North Dakota	NA	NA	No	NA	NA	NA	Mixture
Ohio	NA	NA	No	NA	NA	NA	Mixture
Oklahoma	No	NA	No	NA	Yes	100% NF	Individual
Oregon	Yes	0.7 hours/day	No	NA	No	NA	Mixture
Pennsylvania	NA	NA	Yes	Varies by WV	NA	NA	Mixture
Rhode Island	NA	NA	Yes	Varies by WV	NA	NA	Mixture
South Carolina	NA	NA	No	NA	NA	NA	Aggregate
South Dakota	Yes	1.4 hours/day	No	NA	No	NA	Mixture
Tennessee	NA	NA	No	NA	NA	NA	Aggregate
Texas	Yes	7.1 hours/day	No	NA	Yes	$43.8/day	Mixture
Utah	Yes	2.1 hours/day	Yes	No 24 hour	No	NA	Aggregate
Vermont	NA	NA	No	NA	NA	NA	Aggregate
Virginia	NA	NA	Yes	42 hrs/week	NA	NA	Mixture
Washington	Yes	6.6 hours/day	No	NA	Yes	90% NF	Individual
Washington, DC	Yes	2.8 hours/day	NA	NA	Yes	$116.4/day	NA
West Virginia	Yes	2.1 hours/day	NA	NA	No	NA	NA
Wisconsin	No	NA	No	NA	No	NA	Mixture
Wyoming	NA	NA	No	NA	NA	NA	Individual
Percent of Sample	58	NA	18	NA	35	NA	100
Average	NA	4.8 hours/day	NA	NA	NA	NA	NA

[1] Operated through a Medicaid 1115 waiver.

[2] Average daily limit.

NOTES: Sample size varies by benefit (*N*=26 for SP and *N*=45 for WV). NA is not applicable.

SOURCE: Author's tabulations based on structured telephone survey.

Cost caps in the PCS State plan benefit ranged from $35.70 per day in Maine to $200.00 per day in Alaska. In instances where a State had multiple cost caps that are conditional upon the client's circumstances, the cost caps reported reflect the upper-end of that limit. For instance, in Maryland, cost caps ranged from $10 to $90 per day, varying with four different levels of care (Table 3).

Just 8 of the 45 States with personal care in its HCBS waiver program had set an hourly limit on personal assistance. These hourly limits were, for the most part, variable across individual HCBS waivers, and across HCBS waiver services. Thus, they cannot be reported with any precision. To illustrate, Rhode Island's HCBS waiver for the elderly and disabled enforced a 30-hour per week limit on two services combined: personal care and homemaker/chore services (Table 3).

All HCBS waivers contain cost caps of some kind due to the Federal requirement of cost neutrality. The form of these caps, however, differed across States. Only 14 States established cost neutrality at the aggregate level, thereby avoiding the mandatory enforcement of individual cost caps on any one participant (Table 3). By using aggregate caps under the HCBS waiver program, some HCBS waiver participants were able to receive personal care services beyond the limits generally imposed in the PSC State plan benefit. Some HCBS waiver participants also exceeded the costs of comparable institutional care. All State officials reported that despite such exceptions, the HCBS waivers remained cost neutral.

The remaining 31 States, in comparison, did enforce individual cost caps for personal care participants under at least one HCBS waiver. Of those States 13 imposed cost caps at the individual level in all HCBS waivers. In the remaining 18 States, the policy varied from waiver to waiver, with some using an aggregate cost cap, others requiring an individual cost cap (Table 3).

Reimbursement Rates

The States reimbursed workers providing personal care via agencies as well as those working independently. Agency types included State-licensed home care or personal care agencies, Medicare and Medicaid certified home health agencies, local offices of government agencies, and centers for independent living. Independent providers are individuals working as personal care attendants with no organizational affiliation.

Reimbursement rates for agency providers were similar for the PCS State plan option and the HCBS waivers; independent provider rates were also similar across the two benefits. Agency reimbursement rates averaged about $13 per hour; those for independent providers were about $8-$9 per hour on average. Overall, agency provider rates were, on average, 27 to 39 percent higher than independent provider rates. Officials reported that personal care workers ultimately earned an hourly wage a little over the Federal minimum wage. Health care and other benefits were generally not provided, although three States selectively offered some benefits to personal care workers (Maine, South Carolina, and Washington).[4]

Components of Personal Care Services

State officials were asked to report whether their State considered an array of different services to be a component of personal care under these Medicaid programs.[5] It is important to note that the definition of any given service often differs across individual waivers, and even across HCBS waivers within a State. In the latter case, we integrated varying definitions of personal care in the most inclusive manner possible.

These data show that virtually all States considered assistance with basic ADLs to be the essential component of personal care. In the PCS optional State plan benefit,

[4] Additional information on reimbursement rates for Medicaid personal care providers, both those working through agencies and those working independently is available from Allen J. LeBlanc (address at the end of this article).

[5] Additional information is available from Allen J. LeBlanc.

100 percent of the States included these services under their definition of personal care, and 98 percent did so in the HCBS waiver programs. The same was generally true for homemaker/chore services, with its inclusion in the PCS State plan benefit for all States that operate the program, and in 91 percent of the definitions for the States offering personal care through one or more HCBS waivers. Regarding the latter, most States excluding homemaker/chore services from their definition of personal care did so because such assistance constituted a separate HCBS waiver service.

Transportation services, essentially driving and escorting the client, were allowed in at least 65 percent of the States for attendants working in either program. However, escorting was more frequently allowed than driving because it alleviates some concerns about accident liability. More than one-half of the States operating the PCS optional State plan benefit, and almost 70 percent of those offering personal care through a HCBS waiver, viewed supervisory services, frequently referred to as cuing, as a component of personal care.

Nursing services as a component of personal care present many States with a dilemma. In some States, nurse practice act regulations prohibit the provision of any skilled nursing care under the guise of personal care assistance. Other States allow nurse delegation of nursing tasks to unlicensed personnel that have been trained to carry out certain activities (Kane, 1995). Therefore, it was not surprising to see that roughly one-half of the States omitted this category of service from their programs entirely. States typically viewed bowel and bladder care as acceptable work for personal care attendants.

Other services were much less likely to be formally included in programmatic definitions of personal care. Help with planning or budgeting and communication services, which might entail making telephone calls or writing letters for a client, were more often included in the definition of personal care offered under a HCBS waiver than under the PCS optional State plan benefit. Between 47 percent (for communication services) and 69 percent (for planning or budgeting assistance) of the relevant States did not formally incorporate such assistance under the HCBS waivers, and more than 60 percent neglected them in the State plan benefit. Emergency, short-term support, such as family respite, was typically not considered to be a formalized component of personal care in either program. Emotional support and safety assurance services were even less likely to be viewed as definitive aspects of personal care. However, this is not to say that attendants working in these programs did not provide these kinds of assistance informally. Indeed, many State officials speculated that this is the case.

Generally, HCBS waiver definitions included more services than those used in the PCS optional State plan benefit (5.3 versus 4.7 services on average, respectively, out of a possible 10 service categories). Ten out of 45 States with personal care in an HCBS waiver(s) incorporated 7 or more services in their programmatic definitions, compared with just 3 of the 26 States offering the PCS optional State plan benefit.

Location of Service Delivery

States also regulated where services can be delivered.[6] Although the Medicaid program only places a prohibition on personal care services provided to individuals who are in institutions, 14 of the 26 States (54 percent) offering the PCS optional State plan benefit, and 27 of the 45 (60 percent) with HCBS waivers containing personal care allowed personal care to be delivered outside

[6] Additional information is available from Allen J. LeBlanc.

the client's home. Some States allowed personal care in residential care settings, such as assisted living, group homes for the mentally retarded/developmentally disabled (MR/DD) and personal care homes. Viewed conversely, almost one-half of the States with the PCS State plan benefit limited personal care to the home, and 40 percent of the States with personal care in its HCBS waiver program did the same. (Children, however, are expected to receive EPSDT for needed medical and personal care services when they are in school or in any other setting.)

Greater flexibility in location of services was allowed in the HCBS waivers in comparison with the PCS State plan benefit. The former program more often allowed assistance to be provided in all but one setting (residential care/assisted living). Of the States offering personal care outside the home, the average number of other settings was greater in the HCBS waivers (4.7 locations out of 6 studied) compared with the PCS optional State plan benefit (2.9 locations out of 6 studied).

Respondents from a sizable minority of States (14) reported considering changes concerning the location of personal assistance in either the optional State plan benefit or the HCBS waiver. Generally, these States were considering ways to expand personal care beyond the home, rather than ways to limit it further.

Amount and Types of Providers

As States attempted to implement both the PCS State plan benefit and the HCBS waivers, many respondents reported concerns about the recruitment, sustenance, and monitoring of a personal care provider labor force. Respondents in the majority of the States (61 percent) reported difficulties finding qualified personal care providers.[7]

[7] Additional information is available from Allen J. LeBlanc.

Most typically, the States drew on multiple provider types for direct service workers. The majority of States worked with State-licensed home care or personal care agencies (more than 75 percent of the relevant subsamples: 26 States for the State plan; 45 States for the waivers). Similarly, high percentages relied on Medicare and Medicaid certified home health agencies (65 percent for State plan and 76 percent for waivers). Independent providers, or people working without an agency affiliation, were also used frequently (50 percent for State plan and 60 percent for waivers), according to the officials surveyed. Cited less frequently, but important nonetheless, were local offices of government agencies (e.g., area agencies on aging or regional MR/DD agencies) and centers for independent living.

Monitoring of Personal Care Services

States also have the option of allowing Medicaid participants to self-direct their personal care. Of the relevant States, 50 percent allowed self-direction of personal care under the PCS optional State plan benefit; 60 percent did so under the HCBS waivers.

Case management was the norm in all the States offering personal care through the HCBS waivers (100 percent), as well as in 77 percent of those operating under the PCS optional State plan benefit. In 17 States, participants were allowed the option to refuse the assistance of a case manager, although officials reported that few individuals exercised that option because case managers typically act as gatekeepers to services.

Formalized training of direct care providers was not common. Officials in just 8 percent of the States offering the PCS optional State plan benefit reported that all workers or attendants were

required to undergo training. Only 13 percent of those incorporating personal care under a HCBS waiver reported the same. These estimates were conservative, because States with training requirements under certain conditions were viewed as States that do not formally require training for all workers. Therefore, these data on training requirements may have underestimated the extent to which training occurs. Some States used both agency providers, for whom training may be a pre-requisite for employment, and independent providers who may receive only informal instruction from the client.

Supervision posed a similar problem, in that the States often had contractual arrangements mandating some supervision with some agencies, but also may have had no minimum standard for supervision that must be upheld across all providers. These States were categorized as not having supervision required. Using this conservative interpretation, supervision was reported to be a programmatic requirement in 73 percent of the States administering the PCS State plan benefit, and in 80 percent of those offering personal care through the HCBS waivers.

Two ways of further monitoring these programs were the development of tools for assessing client satisfaction with their personal care services and the creation of organizational procedures designed specifically to assess service quality. Officials from about one-quarter of the States operating the PCS State plan benefit, and just over two-thirds of those offering personal care in the HCBS waivers, described some type of client satisfaction survey. Surveys were typically conducted by telephone or mail, and occasionally face-to-face, or some combination thereof. It is critical to note also that the surveys tended to be limited to specific subpopulations defined by administering government agencies or individual HCBS waivers, and were only sporadically implemented.

Thirty-five percent of States offering the PCS optional State plan benefit, and 78 percent of those with personal care available in the HCBS waivers, incorporated some form of quality assessment into their program management. However, these too were often described as sporadic and limited in scope.

DISCUSSION

Given the size and importance of these two Medicaid personal care services programs, these descriptive data on participants and expenditures serve as a barometer of the current state of national and State investment in personal care services. Despite obvious growth in program size and investment in recent years, personal assistance services and HCBS more generally, still represent small proportions of the $34 billion Medicaid spent on nursing home care and the $10 billion spent on ICF-MR care in fiscal year 1998 (Burwell, 1999).

Yet, even in the absence of comparisons with government spending on services centered in nursing facilities or ICFs-MR, for example, the small numbers of Medicaid-eligible individuals reached with personal assistance nationwide, and in some States in particular, raises concerns. Viewed in light of recent national estimates of need for assistance in the home and community, particularly among low-income individuals (Arno, Levine, and Memmott, 1999; Kennedy and Walls, 1999), the data suggest there may be a large unmet need for personal care in the United States.

The data also suggest that States spent, on average, $6,870 per Medicaid personal care client per year in 1997-1998 (i.e., in

one or both of these benefit programs). In contrast, on average, States spent $19,077 per Medicaid participant on nursing facility care and $72,195 per participant on ICF-MR care in 1997 (Harrington et al., 2000a). Thus, expenditures for personal care services under Medicaid accounted for only a small fraction of expenditures for institutional care under Medicaid. Some portion of this difference is attributable to the fact that Medicaid institutional costs include expenses associated with the provision of room and board, whereas Medicaid prohibits room and board payments for those receiving PCS optional State plan and/or HCBS waiver funds. Nonetheless, this difference is clearly cause for more targeted investigations of costs across the various LTC benefits, as well as for examinations of current spending levels and the associated quality of care.

Currently, there may be growing pressures on the States to re-evaluate their existing Medicaid LTC programs. For example, disability advocates and politicians at the national level continue their efforts to pass legislation removing the institutional bias of Medicaid LTC. MiCASSA or the Medicaid Community Attendant Service and Supports Act of 1999 was introduced in the Senate on November 16, 1999 (ADAPT, 2001). Also, the recent Supreme Court decision in *Olmstead v. L.C.* (1999) provides an important legal precedent encouraging States to offer individuals with disabilities appropriate alternatives to institutional placement and Federal policymakers are already anticipating ways to assist States in providing access to appropriate HCBS (Westmoreland and Perez, 2000). This ruling, based on the anti-discrimination provision of Title II of the Americans with Disabilities Act (1990), does not, however, establish a mandate that the States embrace HCBS alternatives to institutional care. Although it is unclear how legislation and legal mandates such as these will unfold over time, it is abundantly clear that the States will vary in their response.

The participants and expenditures per capita show the dramatic variation across States in investment in programs offering personal care services. Just a handful of States account for the majority of participants reached with services and monies spent. By highlighting such differences, this investigation offers researchers and policymakers the opportunity to learn from some States what might be accomplished, by what means, and at what costs. Other States appear to have some political, economic, and social barriers to expanding personal assistance programs for those with chronic illness and disability (Harrington et al., 2000e, 2000f, 2000g; Newcomer et al., 2000a, 2000b).

Formal limits on service use and low provider reimbursement rates were two primary mechanisms by which States restrict growth of these programs. These data illustrate that hourly limits and cost caps on service use vary within and across the States, and between the two programs types. Additional research is required to gain a better understanding of the factors associated with these kinds of restrictions on personal care. Some waiver policies are readily altered by State officials, while others result from larger environmental forces (e.g., political pressures, economic trends).

Typically, the PCS optional State plan benefit contains more explicit limits on individual clients than the HCBS waivers contain. Under the HCBS waivers, the use of aggregate cost caps afford States the capacity to assist some clients with needs for care that exceed the costs of comparable institutional placement. States using low cost caps enforced at the individual level may limit access to services. In the

long run, these individual cost caps may also be associated with higher rates of institutionalization among Medicaid participants. Among States adopting cost caps in the aggregate, such a practice appears to work effectively, because officials also reported being able to meet the Federal mandate of cost neutrality. Nonetheless, the viability of this strategy over time, as well as any potential problems of its inherent inequities across program participants, remains to be seen. Clearly, the effects of these formal limitations on LTC across the States are also in need of further study.

Provider pay rates are universally low and there are widespread concerns about recruiting and retaining a capable and enduring personal care workforce. The most significant finding is that these rates are universally low, highlighting the widespread concerns about recruiting and retaining a capable and enduring personal care workforce. Low reimbursement rates restrict the supply of personal care attendants and may contribute to a number of related outcomes (e.g., poor service quality, limited access to services). These factors could combine to encourage unnecessary and premature institutional placements among Medicaid participants.

These data also offer a glimpse of the program structures that lie beneath the descriptive statistics on participants, expenditures, limits, and reimbursement rates. Examinations of how the States organize either or both of these programs give analysts the opportunity to gain a better understanding of how seemingly disparate aspects of program structure are associated with the various indicators of program effectiveness and, ultimately, with programmatic change.

Generally speaking, the data suggest that the HCBS waivers are the program of choice among State officials for making personal assistance available to Medicaid-eligible populations. Forty-five States have adopted this strategy, as compared with only 26 implementing the PCS optional State plan benefit. Yet, the data also reveal that the HCBS waivers account for lower expenditure levels and reach fewer people in need than programs operated under the State plan benefit. These differences are not wholly explained by the fact that this study underestimates the full range of HCBS waiver services (Harrington et al., 2000c).

This administrative preference for the HCBS waivers reflects, at least in part, the desire of the States to respond to mounting pressures for program expansion and innovation amidst the omnipresent demand that costs be controlled. For example, the HCBS waivers are slightly more flexible in service definition, location of service, as well as in allowing self-direction. But also, by virtue of their mandate of cost neutrality, the HCBS waivers offer an explicit means of satisfying these paradoxical forces. They also appear to incorporate more explicit program monitoring. Most importantly, however, the HCBS waivers allow States the ability to control program size and growth. Through the HCBS waivers, they can limit services to select target groups, identified by diagnosis, disability, and/or geographic locale.

Because the PCS optional State plan benefit is, by definition, available to all eligible individuals in a given State, it does not allow States the opportunity to make these incremental, typically small, steps toward greater access to personal care. States may have reasons for implementing programs on an incremental basis, such as to better monitor access, utilization, and quality of care. On the other hand, State policy decisions may be driven more by budget limitations than programmatic vision. Considering the demand for services evidenced in waiting lists for HCBS and financial constraints

reported by State Medicaid directors (Harrington et al., 2000d), the latter may be the strongest factor in program design.

Were the States to unanimously adopt the Medicaid PCS optional State plan benefit as a means of providing personal assistance, the result might be improved access to personal care for larger percentages of low-income individuals. Additional study is required to ascertain the relative benefits of strategies geared toward reaching greater numbers of people versus those strategies that might improve service quantity and quality for people already receiving care. If States increasingly rely on the HCBS waivers in the future as a means of offering personal care services, then concerns about access to services may be raised. So long as HCBS waiver services can be limited to selected populations that are eligible for institutional services, the growth of personal care across the country is likely to remain slow and uneven.

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