Medicaid State Plan Personal Care Services: Trends in Programs and Policies

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Abstract. Policymakers face mounting pressures from consumer demand and the 1999 *Olmstead* Supreme Court decision to extend formal (paid) programs that deliver personal care to the elderly, chronically ill, and disabled. Despite this, very little is known about the largest program that delivers personal care: the Medicaid State Plan personal care services (PCS) optional benefit. This paper presents the latest available national program (participant and expenditure) trend data (1999-2002) on the Medicaid PCS benefit and findings from a national survey of eligibility and cost control policies in use on the program. The program trends show that, over the study period, the number of states providing the Medicaid PCS benefit grew by four (from 26 to 30), and national program participation, adjusted for population growth, increased by 27%. However, inflation-adjusted program expenditures per participant declined by 3% between 1999 and 2002. Findings from the policy survey reveal that between 1999 and 2002 there was a marked decline in the range of services provided, and by 2004, almost half the programs operated a cap on the hours of services provided.

Keywords: Medicaid, state plan personal care services, formal care, programs, policy

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INTRODUCTION

While the majority of long-term care (LTC) in the United States is provided informally (unpaid, usually by family and friends), policymakers face mounting pressure to extend formal (paid) home and community-based services (HCBS) that allow consumers to live independently rather than in institutions such as nursing homes (Kitchener & Harrington, 2004). In 1999, the pressure increased with the Supreme Court ruling in the *Olmstead* case, which held that failure of public programs to offer HCBS alternatives to institutional care constitutes discrimination under the Americans with Disabilities Act (Rosenbaum & Teitelbaum, 2004). Subsequent enforcement litigation bought against certain states provides further impetus for change (Kitchener, Ng, Miller, & Harrington, 2005). Despite these pressures, successive studies report that the development of HCBS funded by Medicaid (the largest single payer of LTC) remains uneven and limited by factors including policies that commit 70% of the program's LTC expenditures to institutions (Eiken, Burwell, & Schaefer, 2004; GAO, 1999; Harrington, LeBlanc, Wood, & Satten, 2002).

Beyond national analyses of HCBS and case studies of initiatives in selected states, limited attention has been given to personal care services that many elderly and disabled persons need to remain independent (Stone, 2001). Notably, very little is known about the largest program delivering community-based personal care; the Medicaid State Plan Personal Care Services (PCS) optional benefit, which allows states to fund non-medical assistance with activities of daily living (ADLs) such as bathing and eating, and instrumental ADLs (IADLs), such as shopping and preparing meals (LeBlanc, Tonner, & Harrington, 2001).

The information deficit concerning the Medicaid PCS program persists despite the need for policymakers to respond to the *Olmstead* integration mandate and two other developments.

First, research evidence has increased awareness of the negative outcomes that arise from high levels of unmet need for personal care including: underemployment and lost productivity (Richmond, Beatty, Tepper, & DeJong, 1997); compromised safety (Desai, Lentzner & Weeks, 2001); increased risk of institutionalization (Muramatsu & Campbell, 2002); and higher probabilities of adverse consequences on 29 out of 34 measures including going hungry, losing weight, and dehydration (LaPlante, Kaye, Kang, & Harrington, 2004). Second, mounting political willingness to expand Medicaid personal care is indicated in the Presidents' New Freedom Initiative (NFI), the National Governors Association LTC initiative, and most specifically, the re-introduction of Medicaid Community-Based Attendant Services and Supports Act (MiCASSA) which seeks to guarantee access to personal care for persons eligible for nursing home care (Harkin & Spector, 2005).

This paper draws from a unique longitudinal national dataset to provide two sets of information on the development of the Medicaid PCS program for policy makers and other stakeholders. First, we present the latest available national participant and expenditure data (1999-2002) for the Medicaid PCS program and compare them with trends in the next two largest programs that provide formal personal care: (1) Medicaid 1915(c) waivers, and (2) Older Americans Act (OAA) Title III. Second, we report the findings from national surveys of policies used on the Medicaid PCS program (1999-2004) including cost controls and provider reimbursement. The remainder of this paper contains four main sections which: (1) introduce the Medicaid state plan PCS benefit, (2) describe the data sources and methods, (3) present the findings, and (4) discuss policy implications.

Medicaid State Plan PCS in the Patchwork of Formal Community-Based Personal Care

*The Patchwork***.** In the United States, formal community-based personal care is paid by a loosely-coupled collection of private sources (out-of-pocket expenses and the limited indemnity and employer-based insurance markets) and governmental programs (Lutzky, Corea, & Alexcih, 2000). Medicaid is the primary payer of community-based personal care, spending $8.9 billion compared to the $110 million paid by the Older Americans Act (OAA) Title III. Within certain OAA constraints (e.g., services must be statewide and delivered to persons aged 60 and over), state units of aging (SUAs) set their own eligibility criteria for Title III services (Kassner, 2001). Formal community-based personal care is also funded through programs for which few data are available and which are not studied here, including: The U.S. Department of Veterans Affairs' Housebound and Aid and Attendance Allowance Program, the Medicare home health benefit, Title XX Social Security Block Grants (Kitchener et al., 2005), and a growing number of state-only funded programs (Summer & Ihara, 2004).

In addition to the strategy of providing Medicaid personal care through state plan PCS and 1915(c) waivers, some states have used 1115 demonstration waivers and Centers for Medicaid and Medicare (CMS) Systems Change Grants (Kitchener et al., 2005). Medicaid 1115 demonstration waivers are policy experiments that provide flexibility for the provision of services that would not otherwise be matched by federal funding and allows eligibility for those who would otherwise not be eligible for the Medicaid program. Among the best known examples are Arizona's waiver, which offers HCBS (including personal care) to those who are Medicaid-eligible, and the Cash and Counseling initiative which, in Arkansas, Florida, and New Jersey, allows the payment of cash in lieu of a service package to permit spouses and parents of minor children to be paid caregivers, and to permit participants to purchase goods and services not

covered by Medicaid (Foster, Randall, Phillips, Schore, & Carlson, 2003). Among the various forms of CMS Systems Change Grants, between 2001 and 2003, Community-Integrated Personal Care and Supports grants were awarded to 26 states at an average $700,000 per state (Kitchener, Willmott, & Harrington, 2004b). Because less than 20% of the funds can be used for direct services, initiatives concentrated on issues such as developing single points of entry into state systems (e.g., Rhode Island) and workforce development (e.g., Oklahoma).

Medicaid State Plan PCS. Since 1975, all states have had the option of offering PCS as a Medicaid state plan benefit and hence, receive federal matching funds for the services provided. The definition of PCS given in the CMS Medicaid Manual affords states considerable discretion in determining the amount, duration, and scope of covered services: "a range of human assistance provided to persons with disabilities and chronic conditions of all ages, which enables them to accomplish tasks they would normally do for themselves" (see LeBlanc et al. 2001). One outcome of this discretion is that the name of the PCS benefit and the services covered varies widely across the nation to include: personal attendant services, personal assistance services, and attendant care services.

While Medicaid PCS cannot solely involve housekeeping or chores, it does cover both hands-on assistance with ADLs and IADLs (actually performing a personal care task for a person) and 'cuing' (directing, encouraging, etc) so that the person performs the task for him/herself (LeBlanc et al. 2001). Typically, state plan PCS are approved unless federal review finds them to be contrary to statutory requirements and this has allowed, for example, New York State's benefit to include personal emergency response systems (PERS) that clients use to summon help (Meiners et al., 2005). In all state PCS programs, however, services must be authorized for the participant by a physician in accordance with a plan of treatment or (at the

option of the state) otherwise authorized in accordance with a service plan approved by the State (e.g., by a registered nurse [RN]).

In comparison to personal care delivered in Medicaid 1915(c) waivers, the PCS benefit must be made available to all categorically eligible groups statewide, it may include the medically needy (those who spend down to the state standard because of medical expenses), and states typically employ more stringent eligibility criteria (LeBlanc et al., 2001). While 'legally responsible' relatives (i.e., spouses and parents of minor children) are prohibited from serving as formal PCS providers, findings from a study of the California program indicate that allowing participants to hire relatives, friends, and neighbors increases client satisfaction and helps address the limited supply of attendants (Benjamin, 2001).

Despite consumer demand and federal matching funds, development of the Medicaid state plan optional PCS benefit was slow initially, with only 10 states having an active program in 1979 (Doty, Kasper, & Litvak, 1996). Slowly, and largely beyond the gaze of analysts, the PCS program has become the largest public-funding mechanism for formal community-based personal care used by the elderly and by younger, physically disabled persons. Among the few national studies of the PCS program, an analysis of 1999 data reported significant differences among the 26 states with active benefits including: hours provided per day (average 4.8, range 0.2-14.5) and per capita expenditures ranging from $0.02 to $91.21 (LeBlanc et al., 2001). Case studies of selected Medicaid PCS programs have illustrated other differences in operating policies including: the provision of services outside the participant's residence, and the hiring of independent providers not employed by licensed agencies (Benjamin, 2001; Doty et al., 1996; Kane & Kane, 1997; Mollica, 2001).

Beyond the research findings summarized above, there is very little up-to-date national information on the development of Medicaid PCS programs across the states. Thus, this study was designed with two main aims: (1) to present the Medicaid PCS program's latest national participant and expenditure trends, and (2) to present and analyze the program's policy trends.

METHODS

Data Sources

This study used a unique dataset compiled from an annual national survey of Medicaid state plan PCS programs. Each year since 2001, a standardized instrument was used to survey the state official responsible for each PCS program. The instrument (available from the authors) gathered program (participant and expenditure) data and information on a set of policy issues. By March 2005, after follow-up telephone calls and emails, responses were received for 31 of the 32 PCS programs reporting in 2002 (97%) and 26 of the 32 (82%) programs reporting in 2003 and 2004.

Analysis

PCS program (participant and expenditures) data were coded using a standardized protocol and entered into an Excel database to allow four sets of descriptive state and national analyses to be produced for the period 1999-2002: (1) unduplicated participants and expenditures by state program, (2) unduplicated participants per 1,000 population, (3) consumer price index (CPI)-adjusted expenditures per participant, and (4) CPI-adjusted expenditures per capita. Data from the PCS policy surveys were coded using a standardized protocol and entered into an Excel database. These data were analyzed descriptively to examine the eligibility, cost control, and other policies employed by states in 2002-2004. Data from a previous survey by the authors on 1999 PCS policy were also analyzed.

FINDINGS

Table 1 illustrates the major and growing role of Medicaid PCS within the patchwork of formal community-based personal care provision. By 2002, the national Medicaid PCS program had grown 30% over four years to represent 61% of formal personal care participants and 62% of personal care expenditures.

Table 1

Although the Medicaid PCS state plan program is the largest provider of formal personal care in the country, only 32 states offer the service in their state plans, although two of these states (Delaware and Rhode Island) did not provide the services during the study period. Between 1999 and 2002, the adoption of the Medicaid PCS state plan benefit by four states (Florida, New Mexico, North Dakota, and Vermont) helped increase national program participants per 1,000 population by 27% with an 18% annual increase in 2002 alone (Figure 1). After national average expenditures per participant are adjusted for inflation (i.e., in constant 2002 dollars), there was an annual increase of 12% in 2001 and a similar rate of annual decline in 2002. Over the study period, inflation-adjusted PCS program expenditures per participant declined by 3%. These national figures mask significant inter-state variations in Medicaid PCS program development. For example, in 2002, while the national average participants per 1,000 population was 2.37, states such as California (8.11), Missouri (7.25), and Arkansas (5.86) had the highest participation rates while Oregon (0.57), Utah (0.09), and New Hampshire (0.03) had the lowest program participation rates among active programs. Significant inter-state variation also existed for program expenditures per participant with New Hampshire ($22,780), New Mexico ($18,899), and New York ($18,010) spending the most per participant while Oregon ($195), Utah ($235), and South Dakota ($1,111) spent the least.

Figure 1

While the large size (and not per participant spending) of the California program is well recognized, recent participant growth in the Missouri and Arkansas programs is worthy of note and further study. In terms of expenditure rates, it is interesting that one of the newer PCS programs (New Mexico) has the second highest per participant expenditures whereas the well-established Oregon and Utah programs report among the lowest standardized measures of both program size and expenditures.

With 31 of the 32 PCS programs responding to the policy survey in 2002, more than 65% of state Medicaid PCS programs are administered through state offices such as the Department of Health while less than a quarter of the states administered the PCS program through county offices (Table 2). Private organizations such as the Visiting Nurses Association administered less than 10% of programs in PCS states. The physically disabled and the elderly are the largest groups served by the PCS program in 2002 and 2004. There has been no significant change in the percentages of states that serve a particular client group in the state plan PCS programs.

Table 2

Although more than 60% of PCS programs enrolled Medicare certified home health agencies as providers in both 1999 and 2002, only 46% of states enrolled such agencies in their PCS program in 2003 and 2004. Licensed home health and personal care agencies were the largest group of enrolled PCS providers in 1999, 2003 and 2004. The number of states that allowed independent providers to provide PCS services declined from 42% in 1999 to less than 10% in 2002, 2003, and 2004.

Table 3

Most states allow non-physicians such as RNs and social workers to conduct needs assessments and service authorization but only a quarter of PCS states utilize tools such as surveys to identify and track needs of program participants that are not met (Table 4). About half the states have established guidelines and scoring systems to assess needs of potential PCS participants while more than two-thirds of states have established criterion for the authorization of PCS services. There was very little change over the three most recent survey years.

Table 4

Although PCS programs must serve all categorically needy persons in a state that provides the program, states can choose to limit service costs by capping the maximum amount that can be spent per participant or by limiting the number of hours for which each participant may be authorized. In 1999, more than 90% of PCS states utilized cost and service caps, almost 50% utilized such caps from 2002-2004, and more than 40% of states limited the number of service hours available to participants. In 2002, the hourly cap per day for each state plan PCS recipient ranged from 0.14 hours in Nevada to 6.67 hours in Texas.

In 1999 and from 2002 to 2004, most PCS programs provided personal care services to assist participants with both ADLs and IADLs (Table 5). However, between 1999 and 2002, there was a marked decline in states providing medical transportation, case management and other services such as escort services under the state plan personal care program. Only one state reported allowing assistive technology to be covered under Medicaid state plan PCS (AK).

Table 5

Between 1999 and 2004, there was a slight (8%) increase in programs that provided personal care services in community settings (e.g., shops) in addition to the client’s residence and a more marked (19%) increase in the number of programs providing services in the

workplace. In an unusual finding, the Florida program serves only persons living in residential care/assisted living facilities.

Between 1999 and 2002, states requiring formal training for State Plan PCS providers increased from 8% to 45% while states providing a case manager to every PCS participants declined from 77% to less than 50%. In 2002, a little more than half the PCS states allowed clients to hire and fire their care providers and more than 70% required state supervision of care providers (Table 6). Most PCS state officials either stated that health care and sick leave benefits varied by provider or that they did not know if personal care workers in their state received such benefits. That said, nearly one quarter of all states reported that PCS workers did not receive health care and sick leave benefits. More than a third of states that provide State Plan PCS report shortages of care providers.

Table 6

Although the average reimbursement rate for agencies providing State Plan PCS increased by more than 8% between 1999 and 2002, it increased by 6% from 2002 to 2003 and declined slightly in 2004 (Figure 2). On the other hand, even as care provider reimbursement increased by 5% between 1999 and 2002, there was a 0.7% annual increase in 2003, and there was no change in 2004.

Figure 2

DISCUSSION AND CONCLUSION

Policymakers face mounting pressures to expand access to Medicaid personal care from developments such as the President's NFI, which includes the goal of transitioning institutionalized persons into home and community-based settings (The White House, 2002); consumer demand; the 1999 *Olmstead* ruling; and the National Governors Association LTC

initiative to extend access to formal home and community-based services such as personal care that allow consumers to live independently rather than in institutions. Despite these pressures, almost 70% of Medicaid LTC expenditure is committed to institutions such as nursing homes, ICF-MR/DDs, and hospitals (Eiken et al., 2004).

This study reports that the Medicaid optional state plan PCS benefit is the largest program delivering community-based personal care, serving 61% of all personal care consumers and spending 62% of total personal care expenditures in 2002. It is also shown that between 1999 and 2002, as the number of states providing PCS programs increased by 4 (from 26 to 30), program participants adjusted for population increased by 27%. However, inflation-adjusted program expenditures per participant did not keep pace and, in fact, declined by 3% between 1999 and 2002.

Findings from the national survey of policies used on PCS programs reveal some possible explanation for the national expenditure trends. For example, it is revealed that between 1999 and 2002, there was a marked decline in the range of services provided (e.g., transportation) and by 2004, almost half the programs operated a cap on the hours of services provided. While Medicaid state plan PCS programs are required to provide services to all Medicaid-eligible recipients, the survey findings report that no single target group such as MR/DD or the elderly/disabled is covered by all 32 state programs. In one surprising finding, this study reports that the Florida PCS program only serves clients living in residential care/assisted living facilities. Given that this type of provider is typically associated with serving the elderly, further investigation is required to determine the implications of this policy for the younger disabled population. However, despite these findings and the fact that 43 states reported budget deficits

in 2003, (KFF, 2003), the variety of cost controls used in PCS programs has declined since 1999 with most states utilizing service hour caps instead of alternatives such as dollar amount limits.

Beyond the national trends in PCS program and policy development, significant inter-state variation persists. The examination and understanding of such differences require consideration of states' broader systems of Medicaid LTC and supports (e.g., including HCBS waivers), which lay beyond the scope of this study that concentrated on the under-researched PCS program. This study does, however, signal that a key distinction among states operating the PCS benefit was the split between programs that did and did not allow non-physicians (e.g., RNs) to assess need and approve services.

Targeted future state-level research into the expenditure and participation trends of Medicaid state plan PCS benefits and the continued monitoring of the policies and cost controls reported in this study is needed to assist policymakers as they seek to address the existing unmet need for personal care (LaPlante et al., 2004). The increase in the number of PCS program participants and the increase in the number of states providing the benefit demonstrate strong and increasing demand for formal publicly-funded personal care, while states struggle with budget deficits. The capacity of states to address these issues will likely be stretched further as pressure mounts to assure the quality of State Plan PCS and integrate service delivery with other HCBS programs and initiatives such as waivers and Cash and Counseling.

REFERENCES

Allen, S. M., & Mor, V. (1997). The prevalence and consequences of unmet need: Contrasts between older and younger adults with disability. *Medical Care, 35*, 1132-1148.

Batavia, A. I., DeJong, G., & McKnew, L. B. (1991). Toward a national personal assistance program: the independent living model of long-term care for persons with disabilities. *Journal of Health Politics, Policy, & Law, 16*(3), 523-45.

Benjamin, A. E. (2001). Consumer-directed services at home: a new model for persons with disabilities. *Health Affairs*, *20*(6), 80-95.

Burwell, B., Sredl, K., & Eiken, S. (2003). *Medicaid Long-Term Care Expenditures in FY 2002.* Cambridge, Massachusetts: The Medstat Group.

Congressional Budget Office. (1998). *Cost estimates for MiCASSA legislation*. Originally introduced by former Speaker of the House Newt Gingrich in 1997. Unpublished. Washington, DC.

Dautel, P., & Frieden, L. (1999). *Consumer choice and control: Personal attendant services and supports in America.* Report of the National Blue Ribbon Panel on Personal Assistance Services. Houston TX: Independent Living Research Utilization Program.

Desai, M., Lentzner, H., & Weeks, J. (2001). Unmet need for personal assistance with activities of daily living among older adults. *The Gerontologist, 41*, 82-88.

Doty, P., Kasper, J., & Litvak, S. (1996). Consumer-directed models of personal care: Lessons from Medicaid. *The Milbank Quarterly, 74*(3), 377-409.

Eiken, S., Burwell, B., & Schaefer, M. (2004) *Memo on long-term care expenditures, FY 1998 to 2003.* Cambridge, Massachusetts: The Medstat Group. May.

Foster, L., Randall B., Phillips, B., Schore, J., & Carlson, B. (2003). Improving the quality of Medicaid personal assistance through consumer direction. *Health Affairs*, web exclusive. Accessed on August 2, 2004. Website address:

http://content.healthsaffairs.org/cgi/content/full/hlthaff.w3.162v1/DC1.

Harrington, C., LeBlanc, A.J., Wood, J., & Satten, N. (2002). Met and unmet need for Medicaid home and community services in the States. *Journal of Applied Gerontology, 21*(4), 524-550.

Harkin, T., & Spector, A. (2005). *Medicaid Community Attendant Services and Supports Act of 2005 (MiCASSA).* S.1298. Washington, DC: U.S. Congress.

Heffler, S., Levit, K., Smith, S., Smith, C., Cowan, C., Lazenby, H., & Freeland, M. (2001). Health spending growth up in 1999; faster growth expected in the future. *Health Affairs*, *20*(2), 193-203.

Hudson, R. B. (1996). Social protection and services. In Robert H. Binstock & Linda K. George (Eds.) *Handbook of aging and the social sciences, 4th Edition*. San Diego, California: Academic Press.

Kaiser Commission on Medicaid and the Uninsured (KFF) (2003), *Medicaid Spending Growth: A 50-State Update for Fiscal Year 2003.* Washington DC: The Kaiser Family Foundation.

Kane, R. A., & Kane, R. L. (1997). *Long-term care: principles, program and policies*. New York: Springer.

Kassner, E., & Williams, L. (1997). *Taking care of their own: State funded home and community based care programs for older persons*. Washington, DC: American Association of Retired Persons.

Kassner, E. (2001). *The role of the Older Americans Act in providing long-term care*. Washington, DC: Public Policy Institute, American Association of Retired Persons.

Kitchener, M., &. Harrington, C. (2004). U.S. Long-term care: A Dialectic analysis of institutional dynamics." *Journal of Health and Social Behavior, 45* (Extra issue), 87-101.

Kitchener, M., Willmott, M., & Harrington, C. (2004a). *Home and community based services: Medicaid research and demonstration waivers*. University of California, San Francisco: The National Center for Personal Assistance Services.

Kitchener, M., Willmott, M., & Harrington, C. (2004b). *Federal systems change grants to states and territories: 2001-2004*. University of California, San Francisco: The National Center for Personal Assistance Services. Accessed on December 16, 2004. Website address: http://pascenter.org/systemschange/.

Kitchener, M., Ng, T., Miller, N., & Harrington, C. (2005). Medicaid home and community-based services: National program trends. *Health Affairs, 24*(1), 206-212.

LaPlante, M. P., Harrington, C. & Kang, T. (2002). Estimating paid and unpaid hours of personal assistance services in activities of daily living provided to adults living at home. *Health Services Research, 37*(2), 397-415.

LaPlante, M. P., Kaye, H. S., Kang, T, & Harrington, C. (2004). Unmet need for personal assistance services: Estimating the shortfall in hours of help and adverse consequences. *Journals of Gerontology: Social Sciences, 59B*(2), S98-S108.

LeBlanc, A. J., Tonner, M. C., & Harrington, C. (2000). Medicaid 1915(c) home and community based services waivers across the states. *Health Care Financing Review, 22*(2), 159-174.

LeBlanc, A. J., Tonner, M. C., & Harrington, C. (2001). State Medicaid programs offering personal care services. *Health Care Financing Review, 22*(4), 155-173.

Litvak, S. (1992). Financing personal assistance services: Federal and state legislative and revenue enhancing options. *Journal of Disability Policy Studies, 3*, 93-106.

Lutzky, S., Corea, J., & Alexcih, L. (2000). *A survey of employers offering group long-term care insurance to their employees*. Washington, DC: Department of Health and Human Services.

Mahoney, K., Simon-Rusinowitz, L., Loughlin, D., Desmond, S., & Squillace, M. (2004). Determining personal care consumers' preferences for a consumer-directed cash and counseling option: Survey results from Arkansas, Florida, New Jersey, and New York elders and adults with physical disabilities. *Health Services Research, 39*(3), 643-663.

Meiners, M, .Loughlin, D., Sadler, M., & Mahoney, K. (2005). *Clarifying the definition of personal care: Findings on the purchase of equipment, goods and services under the Cash and Counseling Demonstration and Evaluation in Arkansas and New Jersey.* University of Maryland Center on Aging and Boston College. (Draft final report).

Mollica, R. (2001). *Personal care services: A comparison of four states*. Washington, DC: American Association of Retired Persons.

Muramatsu, N., & Campbell, R. (2002). State expenditures on home and community-based services and use of formal and informal personal assistance: A multilevel analysis. *Journal of Health and Social Behavior, 43*, 107-124.

Nosek, M., & Howland, C. (1993). Personal assistance: The hub of the policy wheel for community integration of people with severe physical disabilities. *Policy Studies Journal, 21(4)*, 1-9.

Older Americans Act of 1965, as amended in 2000. (U.S. Code Title 42, 35) Accessed on December 16, 2004. Website address: http://www.access.gpo.gov/uscode/title42/chapter35.html

Richmond, G., Beatty, P., Tepper, S., & DeJong, G. (1997). The effect of consumer directed personal assistance services on the productivity outcomes of people with disabilities. *Journal of Rehabilitation Outcomes Measurement, 1*(4), 48-51.

Rosenbaum, S., & Teitelbaum, J. (2004). *Olmstead at five: Assessing the impact*. Washington, DC: Kaiser Commission on Medicaid and the Uninsured. Accessed December 16, 2004. Website address: http://www.kff.org/medicaid/7105a.cfm.

Summer, L., & Ihara, E.S. (2004). *State-funded home and community based service programs for older people*. Washington, DC: American Association of Retired Persons.

Stone, R. I. (2001). Providing long-term care benefits in cash: Moving to a disability model. *Health Affairs, 20*(6), 96-108.

The White House. (May 2002), *New Freedom Initiative: A Progress Report.* Accessed 2 February 2004. Website address: www.cms.hhs.gov/newfreedom

Tritz, K. (2004) *Report for Congress: Long-term care consumer directed services under Medicaid*. (Order code RL32219). Washington DC: Congressional Research Service.

U.S. Administration on Aging. *Title III and Title VII state program report tables 1997-2002*. National aging program information system. Accessed December 16, 2004. Website address: http://www.aoa.gov/prof/agingnet/NAPIS/SPR/spr.asp

U.S. General Accounting Office (GAO). (1999). *Adults with severe disabilities: Federal and State approaches for personal care and other services*. Report to U.S. Congressional requesters. GAO/HEHS-99-101. Washington, DC.

Velgouse, L., & Dize, V. (2000). A review of State initiatives in consumer directed long-term care. *Generations,* 28-33.

Verbrugge, L. M., Rennert, C., & Madans, J. (1997). The great efficacy of personal and equipment assistance in reducing disability. *American Journal of Public Health, 87*, 384-392.

Wiener, J., Tilly, J., & Alecxih, L. M. (2002). Home and community based services in seven states. *Health Care Financing Review, 23*(4), 89-114.

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TABLE 1. Personal Care (PC) Programs Summary Data, 1999-2002

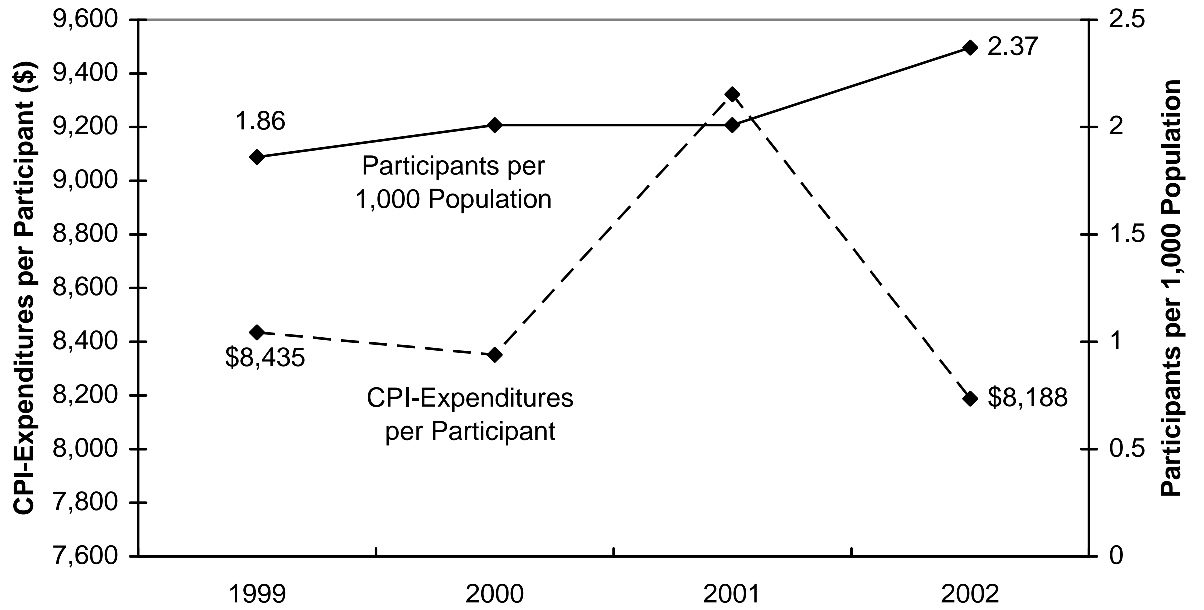
Program/Measure	1999	2000	2001	2002	Change 99-02	% of Total Personal Care (2002)
Medicaid State Plan PCS [1]						
Programs (states)	28	29	29	32	14%	
Participants	526,578	568,431	571,896	683,099[c]	30%	61%
Expenditures($m)	$4,113	$4,544	$5,248	$5,594[d]	36%	62%
PC in Medicaid Waivers [2]						
PC-waivers (total waivers)	131 (218)	137 (227)	150 (232)	158 (252)	21% (16%)	
Participants	269,709	291,021	314,708[a]	351,733[b]	30%	31%
Expenditures($m)	$2,309	$2,612	$3,015[a]	$3,354[b]	45%	36%
Total Medicaid PC						
Participants	796,287	859,452	886,604	1,034,832	30%	93%
Expenditures($m)	$6,422	$7,155	$8,263	$8,947	39%	99%
Older American Act Title III [3]						
Programs (states)	42	42	40	38	-9.5%	
Participants	107,499	105,499	80,265	83,471	-22%	7%
Expenditures($m)	$129	$131	$101	$110	-15%	1%
Total PC						
Participants	903,786	964,901	966,869	1,118,303	24%	100%
Expenditures($m)	$6,551	$7,286	$8,364	$9,057	38%	100%

SOURCES: [1] UCSF Annual Survey of State Medicaid State Plan PCS programs (1999-2002).
[2] UCSF Annual Waiver Program Survey (1999-2002).
[3] Older American Act Title III funding for Personal Care Service

NOTES: Estimated data: [a] 1 NH & 1 SC waiver; [b] waivers by state CA 1, LA 1, ND 1, NH 1, SC 1; [c] MO & VT; [d] VT

All states except AZ operate 1915(c) waivers. AZ operates an 1115 waiver.

FIGURE 1. Medicaid State Plan PCS Standardized Program Trends, 1999-2002



SOURCES: UCSF Annual Survey of State Medicaid State Plan PCS programs (1999-2002). Population data taken from US Census Bureau Population Estimate (1999-2002) http://www.census.gov. (23 May 2004).

NOTE: CPI-adjusted expenditures reported in constant 2002 dollars.

TABLE 2. Medicaid State Plan PCS Administration and Groups Served, 2002-2004

	2002 (N= 31)	2003 (N=26)	2004 (N=26)
Administration			
State	20 (65%)	18 (69%)	17 (65%)
County	6 (19%)	6 (21%)	6 (21%)
Other	2 (6%)	2 (8%)	2 (8%)
Client Groups Served			
Physically disabled	27 (21%)		24 (21%)
Elderly	27 (21%)		24 (21%)
Mental health	24 (19%)		21 (18%)
Children	21 (16%)		19 (17%)
MR/DD	25 (20%)		22 (19%)
Others	4 (3%)		4 (4%)

SOURCE: UCSF Annual Survey of State Medicaid State Plan PCS programs (2002-2004).

TABLE 3. Medicaid State Plan PCS Enrolled Provider Entities, 1999, 2002-2004

	1999 (N=26)	2002 (N=31)	2003 (N=26)	2004 (N=26)
Medicare certified home health agencies	16 (62%)	21 (68%)	12 (46%)	12 (46%)
Licensed home health & personal care agencies	17 (65%)	19 (61%)	16 (62%)	16 (62%)
Centers for independent living	2 (8%)	5 (16%)	5 (19%)	5 (19%)
Independent providers (no agency affiliation) with fiscal intermediary	11 (42%)	2 (6%)	2 (8%)	2 (8%)
Independent providers (no agency affiliation) without fiscal intermediary	n/a	8 (26%)	6 (23%)	6 (23%)
Persons legally responsible for client (using state only money)	n/a	2 (6%)	2 (8%)	2 (8%)
Other family members & friends, not legally responsible for client	n/a	9 (29%)	8 (31%)	8 (31%)
Foster care/residential/assisted living etc	n/a	7 (23%)	6 (23%)	6 (23%)
Others (e.g., Personal Care Intermediate Service Organizations)	6 (23%)	4 (13%)	3 (12%)	3 (12%)

SOURCE: UCSF Annual Survey of State Medicaid State Plan PCS programs (2002-2004). 1999 data LeBlanc et al. (2000).
NOTE: n/a: the 1999 survey did not provide such information.

TABLE 4. Medicaid State Plan PCS Need Assessment, Authorization & Cost Controls, 1999, 2002-2004

	1999 (N=26)	2002 (N=31)	2003 (N=26)	2004 (N=26)
Need Assessment, Authorization				
Non-physicians assess client's needs for State Plan PCS	n/a	25 (81%)	22 (85%)	22 (85%)
Need assessment based on a scoring system such as ADLs	n/a	17 (55%)	14 (54%)	14 (54%)
After assessment, non-physicians authorize State Plan PCS	n/a	21 (68%)	18 (69%)	18 (69%)
Specific criteria used for the authorization decision	n/a	21 (68%)	18 (69%)	18 (69%)
State tracks unmet needs, that is, services (e.g., respite) or extra hours of care that are needed by clients but not currently available	n/a	8 (26%)	7 (27%)	7 (27%)
Cost Controls				
Max. cost per recipient	9 (35%)	1 (3%)	1 (4%)	1 (4%)
Max. hours per recipient per period	15 (58%)	14 (45%)	11 (42%)	11 (42%)
Ave. hourly cap per recipient day	3.8	3.2	3.1	3.1

SOURCE: UCSF Annual Survey of State Medicaid State Plan PCS programs (2002-2004). 1999 data LeBlanc et al. (2000).
NOTE: n/a: the 1999 survey did not provide such information.

TABLE 5. Medicaid State Plan PCS Allowed Services & Delivery Sites, 1999 & 2002-2004

	1999 (N=26)	2002 (N=31)	2003 (N=26)	2004 (N=26)
Allowed Services				
Assist directly with ADLs	26 (100%)	28 (90%)	25 (96%)	25 (96%)
Assist directly with IADLs	26 (100%)	27 (87%)	24 (92%)	24 (92%)
Medical transportation	17 (65%)	8 (26%)	6 (23%)	6 (23%)
Non-medical transportation	n/a	5 (16%)	5 (16%)	5 (16%)
'Cuing' or monitoring	14 (54%)	14 (45%)	12 (46%)	12 (46%)
Emergency support/respite	5 (19%)	5 (16%)	4 (15%)	4 (15%)
Animal assistance (e.g., guide dogs)	n/a	4 (13%)	3 (12%)	3 (12%)
Assistive technology (AT)	n/a	1 (3%)	1 (4%)	1 (4%)
Case management	20 (77%)	8 (26%)	8 (31%)	8 (31%)
Task delegated by nurse (e.g., injections)	n/a	8 (26%)	7 (27%)	7 (27%)
Other (e.g., escort)	13 (50%)	9 (29%)	7 (27%)	7 (27%)
Delivery Sites (in addition to residence)				
Work site	6 (23%)	13 (42%)	11 (42%)	11 (42%)
Other (e.g., shops, banks)	13 (50%)	16 (52%)	15 (58%)	15 (58%)

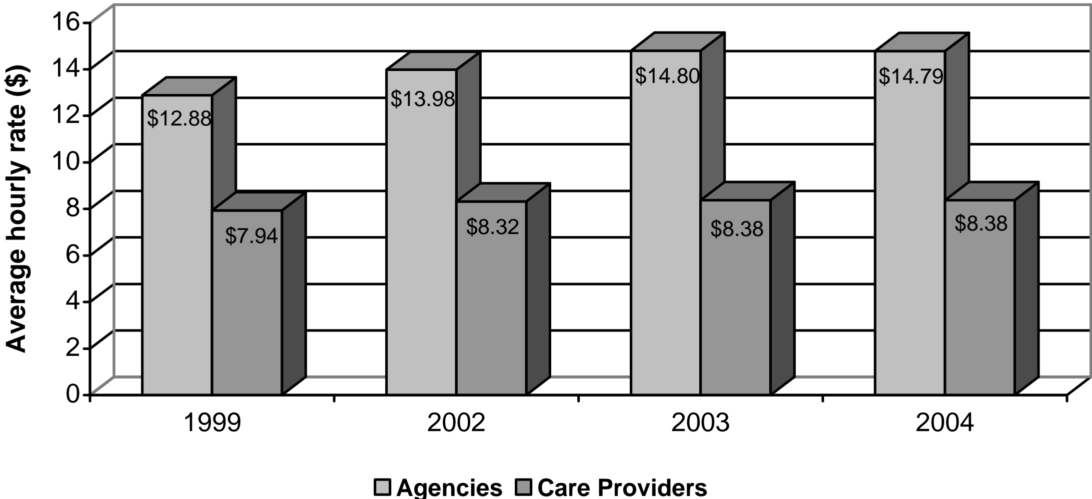
SOURCE: UCSF Annual Survey of State Medicaid State Plan PCS programs (2002-2004). 1999 data LeBlanc et al. (2000).
NOTE: n/a: the 1999 survey did not provide such information.

TABLE 6. Medicaid State Plan PCS Care Provider Regulations, 1999 & 2002-2004

	1999 (N=26)	2002 (N=31)	2003 (N=26)	2004 (=26)
State requires formal training for care providers	2 (8%)	14 (45%)	13 (50%)	13 (50%)
State requires certification of care providers	n/a	9 (29%)	9 (35%)	9 (35%)
State requires supervision of care providers	19 (73%)	22 (71%)	19 (73%)	19 (73%)
State allows client to hire & fire care providers	n/a	17 (55%)	15 (58%)	15 (58%)
State requires criminal background check for care providers	n/a	18 (58%)	16 (62%)	16 (62%)
Every client has a care plan	n/a	23 (74%)	20 (77%)	20 (77%)
Every client has a case manager	20 (77%)	15 (48%)	13 (50%)	13 (50%)
Care providers do not receive health care benefits	n/a	5 (16%)	4 (15%)	4 (15%)
Care providers do not receive sick leave	n/a	7 (23%)	5 (19%)	5 (19%)
Shortage of care providers	n/a	11 (34%)	10 (38%)	10 (38%)

SOURCE: UCSF Annual Survey of State Medicaid State Plan PCS programs (2002-2004). 1999 data LeBlanc et al. (2000).
NOTE: n/a: the 1999 survey did not provide such information.

FIGURE 2. National Average Medicaid PCS Care Provider Rates, 1999 & 2002-2004



SOURCE: UCSF Annual Survey of State Medicaid State Plan PCS programs (2002-2004). 1999 data LeBlanc et al. (2000).