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ABSTRACT

Federal Medicaid long-term care regulations do not require states to offer home and community-based service (HCBS) alternatives; rather, they are offered at the discretion of each state. The two most significant Medicaid HCBS programs are the Medicaid 1915(c) HCBS waiver programs and the Medicaid Title XIX personal care services (PCS) optional state plan benefit. This report summarizes the most current data on HCBS, combining data from Health Care Financing Administration sources with data collected by the University of California, San Francisco. This report presents estimates of program participants and expenditures, including breakdowns by specific populations and types of service. Findings from the data include: (1) the total number of participants in the 1915(c) HCBS Medicaid waiver program more than doubled between 1992 through 1997 to 561,510 people; (2) expenditures have grown more than \$5.7 billion since 1992 for the waivers; (3) expenditures per Medicaid waiver participant grew 52 percent from 1992 to 1997; (4) on average, waiver participants nationwide were allotted approximately \$14,016 each in 1997; (5) waivers primarily assist those with mental retardation and adults with disabilities who have aged; and (6) in 1997, the most used category of service remained respite/home health or personal care. (Contains 17 references.) (CR)





NATIONAL INSTITUTE ON DISABILITY AND REHABILITATION RESEARCH

REPORT 16

Disability Statistics Report

Medicaid Home and Community-Based Services

OCTOBER 2001

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Medicaid Home and Community-Based Services

by

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October 2001

National Institute on Disability and Rehabilitation Research U.S. Department of Education



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INTRODUCTION

Medicaid is a joint federal-state health financing program for low-income individuals. Historically, federal Medicaid long-term care statutes and regulations have reflected an institutional bias and an orientation toward a medical model of care. As a result, Medicaid long-term care has been nearly synonymous with institutional long-term care. Services have typically been offered in skilled nursing facilities (SNFs) and intermediate care facilities for the mentally retarded (ICF/MRs).

Federal Medicaid long-term care regulations make institutional placement a mandatory program entitlement in all states. In contrast, home and community-based service (HCBS) alternatives are not mandatory entitlements; rather, they are offered at the discretion of each state. The two most significant Medicaid HCBS programs are (1) the Medicaid 1915(c) HCBS waiver program and (2) the Medicaid Title XIX personal care services (PCS) optional state plan benefit. These two programs are the focus of this report.

Congress established the Medicaid 1915(c) HCBS waiver program in 1981 under Section 1915(c) of the Social Security Act (Miller 1992, Miller et al. 1999). This benefit offers a broad array of services, including case management, home health services, personal care, and skilled nursing assistance. Waiver services are available only to Medicaid participants who have been deemed eligible for institutional placement due to their service needs. States can target specific populations for waiver services and limit services in a waiver to a previously established number of participants or to participants living in a previously identified geographic area. By 1997, all states except Arizona and the District of Columbia had one or more 1915(c) HCBS waivers for long-term care services. Nationwide, 234 waivers targeting a variety of populations were in effect by 1999. Arizona operates its Medicaid long-term care program under a capitation arrangement, using a waiver program other than the 1915(c). Washington, D.C., did not begin its 1915(c) waiver program until 1999 (LeBlanc et al. 2000b).

Since 1975, states have had the option of offering personal care, often referred to as personal assistance, as part of their Medicaid benefit package, (i.e., as an optional state plan benefit). As the name indicates, the Title XIX PCS optional state plan benefit offers only personal care, which has various definitions but typically includes assistance with activities of daily living (e.g., bathing, dressing, and eating) and with instrumental activities of daily living (e.g., shopping and cooking). Services falling under the headings of personal care or personal assistance are critical components of HCBS from any viewpoint; however, these services are especially significant to those living with chronic illness and disability because they help facilitate, on a longterm basis, independent living and greater social participation. In essence, they enable many to avoid unwanted and unnecessary institutionalization. Under the state plan benefit, such services must be made available statewide and to all individuals meeting financial and need-based eligibility criteria. These criteria are less stringent than those used for waiver services. Unlike the 1915(c) waiver program, the PCS optional state plan benefit does not require that participants have care needs severe enough to mandate institutional placement. As of 1998-99, 26 states had adopted this benefit as part of their state plans (LeBlanc et al. 2000a).



Until now, it has been difficult to describe the population receiving Medicaid HCBS, as well as the expenditures associated with service provision. In-depth data regarding the 1915(c) waiver program (Harrington et al. 2000a, 2000b, 2000c; LeBlanc et al. 2000b; Miller et al. 1999) and the Title XIX PCS optional state plan benefit (Burwell 1999; LeBlanc et al. 2000a; U.S. Government Accounting Office [USGAO] 1999) have been compiled and made available only recently. This report summarizes the most current data on Medicaid HCBS, combining data from Health Care Financing Administration (HCFA) sources with data collected by the University of California, San Francisco (UCSF). This report presents estimates of program participants and expenditures, including breakdowns by specific populations and types of service.

Finally, it should be noted that home health care services are also a component of Medicaid HCBS. Medicaid regulations stipulate that home health care, like 1915(c) waiver services, are available only to Medicaid participants who would otherwise be in an institution (Harrington et al. 1999a). Thus, to qualify for home health assistance, individuals must demonstrate an institutional-level need for care. Moreover, although home health services may include some unskilled assistance, the services usually involve skilled nursing care on a short-term basis after a hospitalization. Therefore, despite the fact that home health care takes place in the home, in many ways it resembles the care provided in institutions as closely as it does HCBS. Little is known about the numbers of Medicaid home health participants and the resulting expenditures, as described in this report.



DATA SOURCES

Data for this report came from HCFA forms 372 and 2082, plus a survey fielded by UCSF. Census estimates of state and national population sizes were used to calculate per capita estimates where appropriate.

The states are required to report annually on their 1915(c) HCBS waiver programs by filing HCFA Form 372, but HCFA does not systematically organize the information from this form into a central database. Data regarding the Title XIX PCS optional state plan benefit are drawn from an original data collection carried out at UCSF.

HCFA Form 2082 data, also reported annually by the states, offers information on both institutional and HCBS Medicaid long-term care programs. In terms of HCBS, Form 2082 data combines information on home health services with information on other types of HCBS. Because home health data are indistinguishable from the 1915(c) waiver and the PCS state plan benefit data in Form 2082, we cannot provide separate estimates for home health.



METHODS

1915 (c) Waivers

Funded by HCFA, the researchers collected data from Form 372 on waiver participants, services, and expenditures for the years 1992 through 1997 (Harrington et al. 2000b). States were asked to estimate data when Form 372s were unavailable. In areas where states did not provide estimates, the missing data for participants and expenditures were imputed based upon the trend line for each waiver. Of the total waivers operational over the six-year period, 23 percent lacked Form 372 data. Six percent of these cases were estimated by the states, and 12 percent by the investigators. (See Harrington et al. 2000b for more details.)

The classification of waivers by target group was not straightforward because some states gave the waivers names that did not include the name of the target group. To classify the waivers by target group, we matched each waiver number with the name of the target group that the state reported to HCFA in its initial waiver request. Then, we categorized the target groups into the following eight categories:

- mentally retarded/developmentally disabled;
- aged/elderly;
- aged/disabled;
- disabled/physically disabled;
- children:
- AIDS/ARC (AIDS-related complex);
- mental health; and
- traumatic brain injury (TBI).

Some of these category names are ambiguous and can be interpreted in slightly different ways across states. For example, the categories "aged/elderly" and "aged/disabled" clearly overlap. Generally, these two categories differ in that the latter refers to people with disability who have aged into later life, while the former refers to elderly individuals who have acquired long-term care needs due to the onset of an illness or an accident. Other labels, such as ARC, reflect outdated language commonly used at the inception of a waiver.

Form 372 data on specific waiver services are "duplicated count," because most participants received services from more than one category. (Data on participants and expenditures are "unduplicated.") Because waivers often offered many different services, and because states did not have common names for these services, coding the service data was a challenge. Starting with a review of the 1992 data, the investigators constructed a list of 30 separate service codes. These 30 codes were ultimately reduced to the following six for this report:

- case management;
- residential care, assisted living, or foster care;
- respite, home health, or personal care;
- habilitation or day care;
- nursing or other therapy services; and
- other, including vocational training, transportation, home maintenance and modification, medical supplies, nutritional services and home meals, emergency response, and mental health services.



Title XIX PCS Optional State Plan Benefit

Detailed 1998-99 data regarding the Title XIX PCS optional state plan benefit were requested via telephone from state officials working closely with the program. (See LeBlanc et al. 2000a for details.)

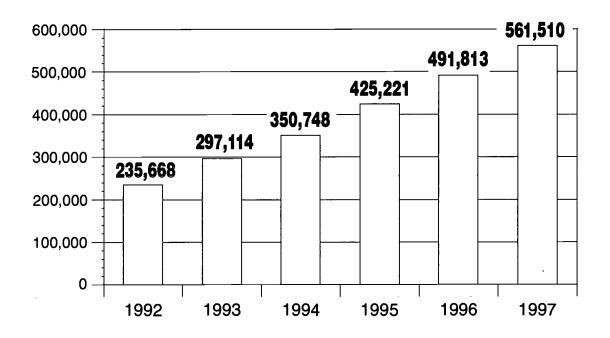


FINDINGS

Figures 1 through 12 present data on the 1915(c) HCBS Medicaid waiver program.

Figure 1 shows the total number of participants in the program for the United States for each year from 1992 through 1997. By 1997, more than 560,000 Medicaid-eligible individuals with an institutional-level need for long-term care received waiver services across the nation. The program more than doubled over the six-year period, with an average annual growth rate of 19 percent per year.

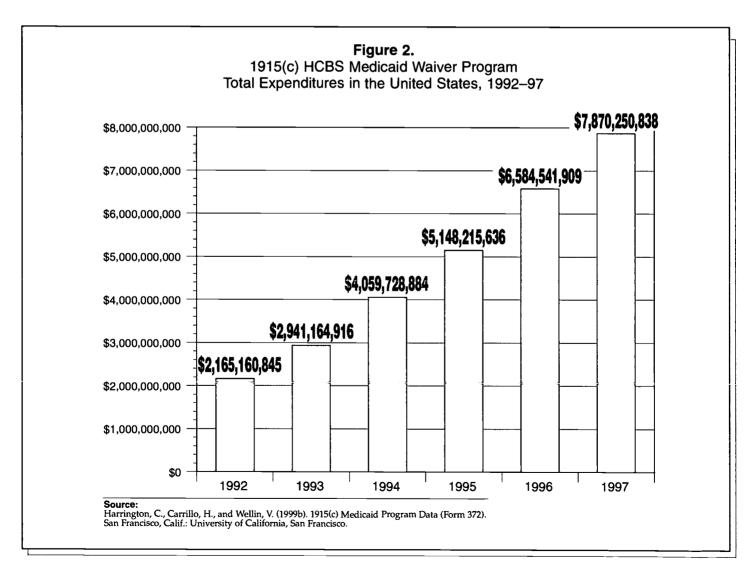
Figure 1.
1915(c) HCBS Medicaid Waiver Program
Total Participants in the United States, 1992–97



Source:
Harrington, C., Carrillo, H., and Wellin, V. (1999b). 1915(c) Medicaid Program Data (Form 372). San Francisco, Calif.: University of California, San Francisco.



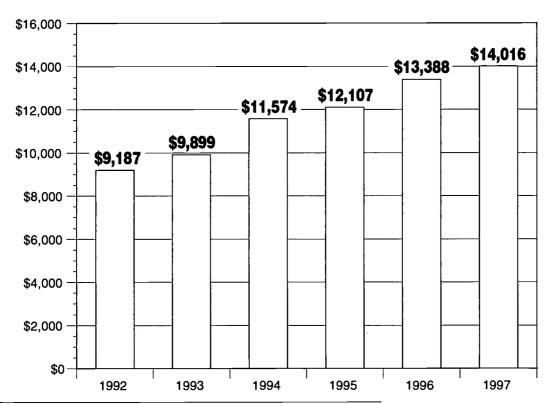
Figure 2 illustrates the national expenditures for the waivers over the same six-year time frame. Expenditures have grown more than \$5.7 billion since 1992, with an average annual growth rate of 22 percent. The largest annual increases in expenditures for the Medicaid waiver program were between 1992 and 1993 (36 percent) and between 1993 and 1994 (38 percent).





In Figure 3, one can observe the average expenditures per Medicaid waiver participant over the six-year period. Spending per participant increased each year. Expenditures per participant grew 52 percent from 1992 to 1997 (to \$14,016), with an average annual growth rate of 9 percent. The largest annual increases in spending were between 1993 and 1994 (17 percent) and 1995 and 1996 (11 percent).

Figure 3.
1915(c) HCBS Medicaid Waiver Program
Total Expenditures per Participant in the United States, 1992–97



Source: Harrington, C., Carrillo, H., and Wellin, V. (1999b). 1915(c) Medicaid Program Data (Form 372). San Francisco, Calif.: University of California, San Francisco.



._ 14

The next three figures are geographic illustrations of the numbers of Medicaid waiver participants per 1,000 population (Figure 4), the expenditures per capita (Figure 5), and the expenditures per participant (Figure 6) across the United States in 1997. In each figure, the states are grouped roughly into quartiles, distinguished by gradations in color. The states that rank in the top 25 percent in participants, total spending, and spending per participant are colored with the darkest shade, and the bottom 25 percent are colored with the lightest.

Figure 4 shows the states by the number of Medicaid waiver participants per 1,000 population, which provides an indicator of the number of people served after adjusting for the size of the state. For the entire United States, there were 2.10 Medicaid waiver participants per 1,000 population in 1997 (not shown). This figure illustrates the large amount of variation between states in the number of waiver participants (ranging from .62 to 7.91 per 1,000).

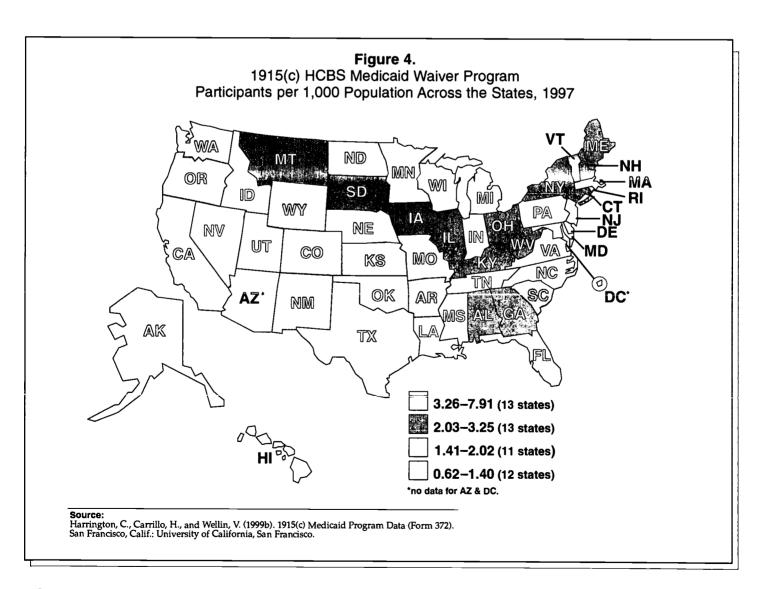




Figure 5 shows the states in terms of their total Medicaid waiver expenditures per capita in 1997, also providing a population-adjusted statistical estimate. Here, too, one can observe large variations across the states (with a low of \$3.94 and a high of \$96.22). The national average was \$29.40 in 1997.

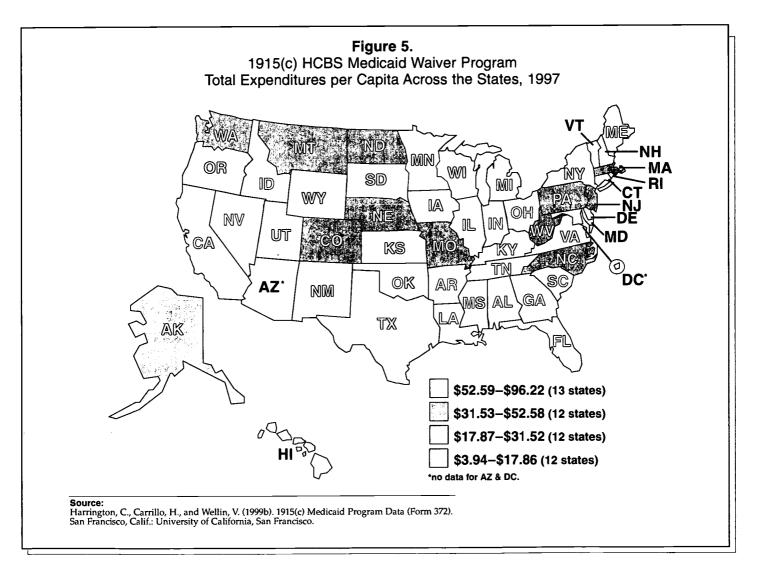
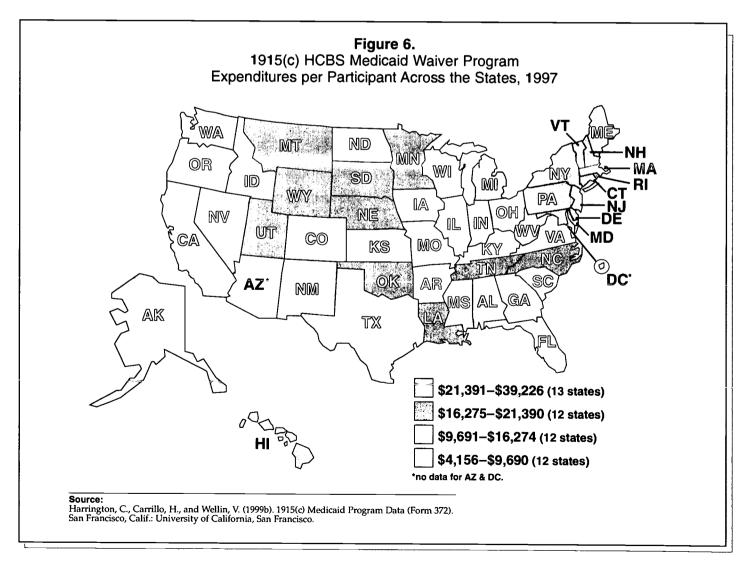


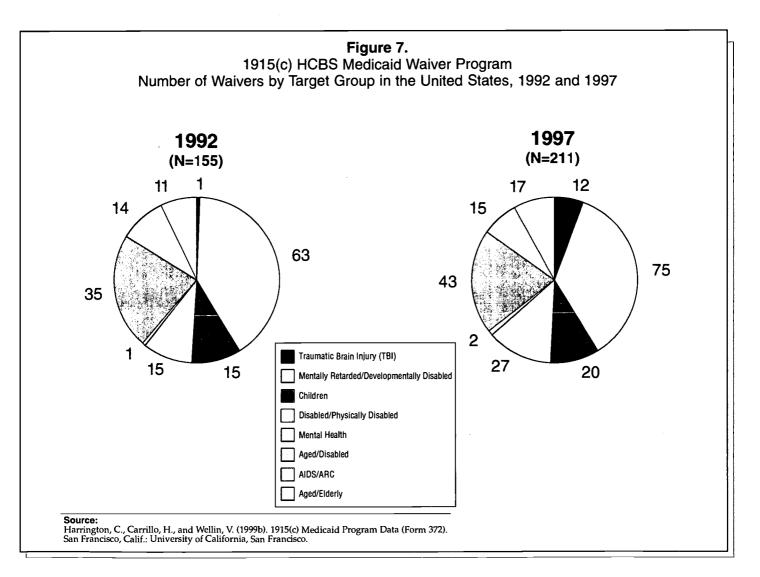


Figure 6 shows state expenditures per Medicaid waiver participant. On average, waiver participants nationwide were allotted approximately \$14,016 each in 1997, although the state-by-state comparisons reveal sizeable differences.





Because each individual waiver is limited to a specific population, it is important to consider for whom waivers are typically designed. Figure 7 illustrates the number of waivers per target group in both 1992 and 1997. In 1992, there were 155 active waivers; in 1997, there were 211. The figures show an increase in waivers for each targeted population over the six years, although for some groups the numbers remained quite low. For example, mental health waivers increased from one to just two. Also, there were fewer than 20 waivers for people with AIDS and the aged/elderly in 1997. There were only 12 TBI/head injury waivers nationwide by then, but this is an increase from just one waiver in 1992. In contrast, the number of AIDS waivers has grown by only one over the six-year span.





These data also reveal that waivers primarily assist two groups: the mentally retarded/developmentally disabled (MR/DD) and the aged/disabled, which differs from the aged/elderly (see page 5). Those two target populations accounted for 64 percent of all waivers in 1992 and 56 percent in 1997. The number of waivers for the disabled/physically disabled rose substantially, becoming the third most common waiver and accounting for 13 percent of all waivers by 1997.

The participants served in each of these target groups are illustrated in Figure 8. Although the overall number of program participants has more than doubled over the six-year period, the proportional breakdown of participants across target groups did not change dramatically. In both 1992 and 1997, most participants were in one of two groups: the MR/DD or the aged/disabled. In 1997, however, a great deal more (39 percent) of the waiver caseload was concentrated in the MR/DD population.

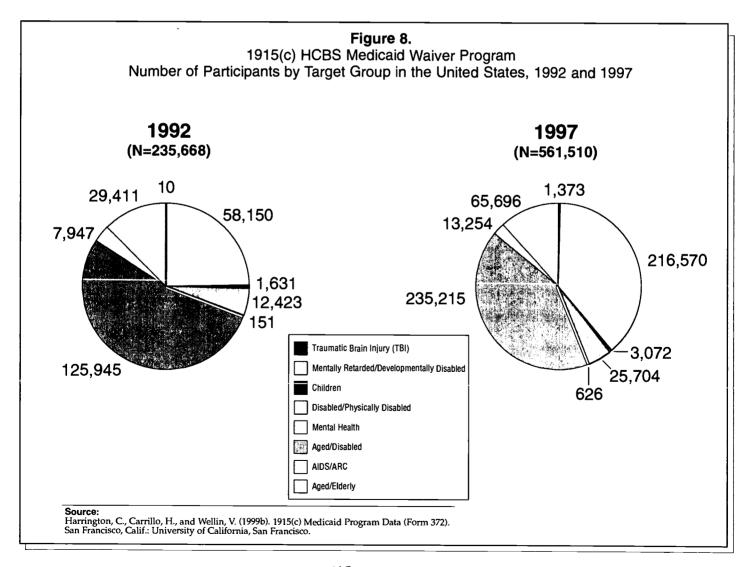
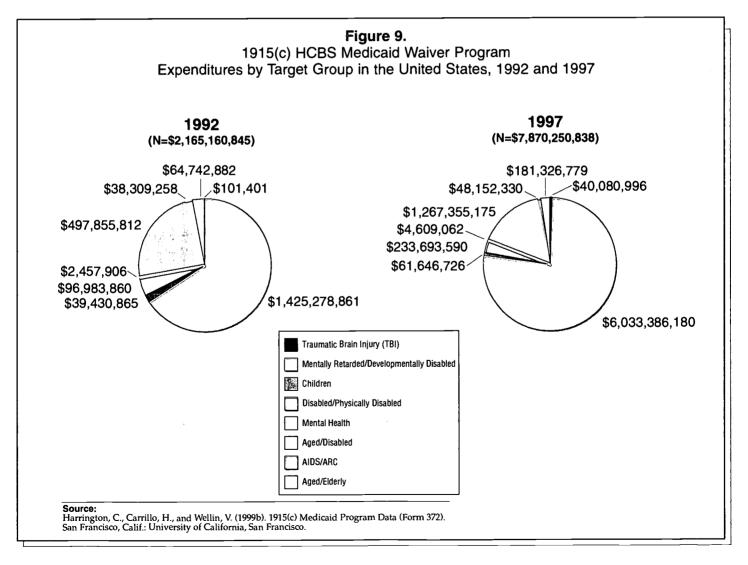




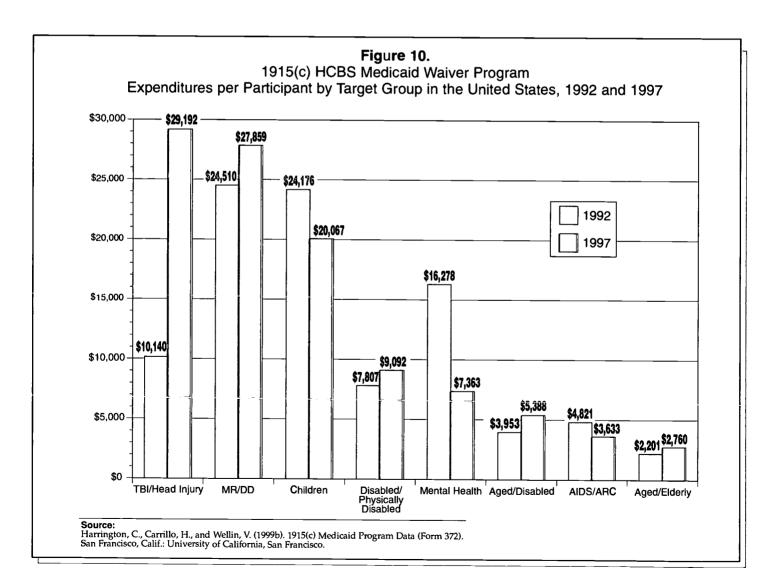
Figure 9 demonstrates that the MR/DD population received the largest proportion of spending for both years, accounting for 76 percent of Medicaid waiver spending by 1997. The aged/disabled accounted for the second largest share of expenditures in 1992 and 1997.





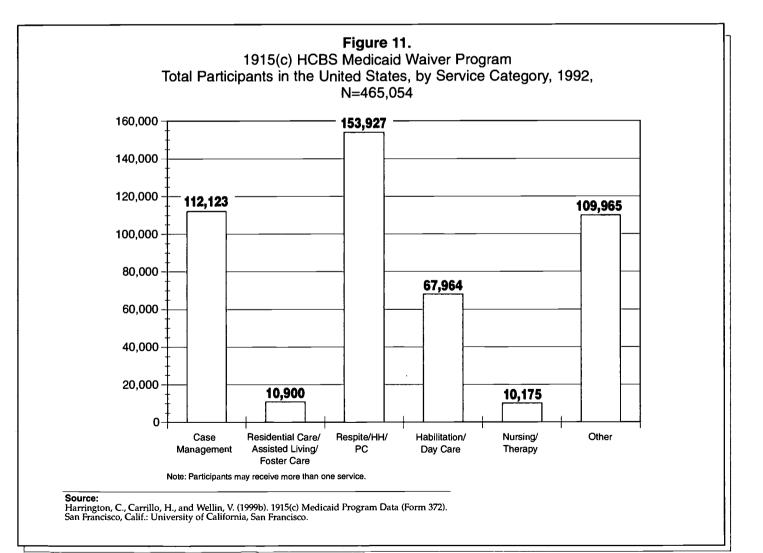
Expenditures per participant vary a great deal by target group, as shown in Figure 10. In 1992, the MR/DD and children populations both received more than \$24,000 per participant. Those with mental illness received \$16,278 on average, but this statistic is based on a very small number of Medicaid waiver participants. By 1997, participants with TBI/head injuries accounted for the highest per participant expenditures. Individuals with MR/DD and children with long-term care needs remained high in per participant expenditures relative to the other target groups through 1997.

Figure 10 also illustrates changes in spending within each target population. Expenditures rose over the six-year span in the following categories: TBI/head injury (dramatically, at 188 percent), MR/DD, disabled/physically disabled, aged/disabled, and the aged/elderly. Expenditures declined for children, mental health, and AIDS/ARC.



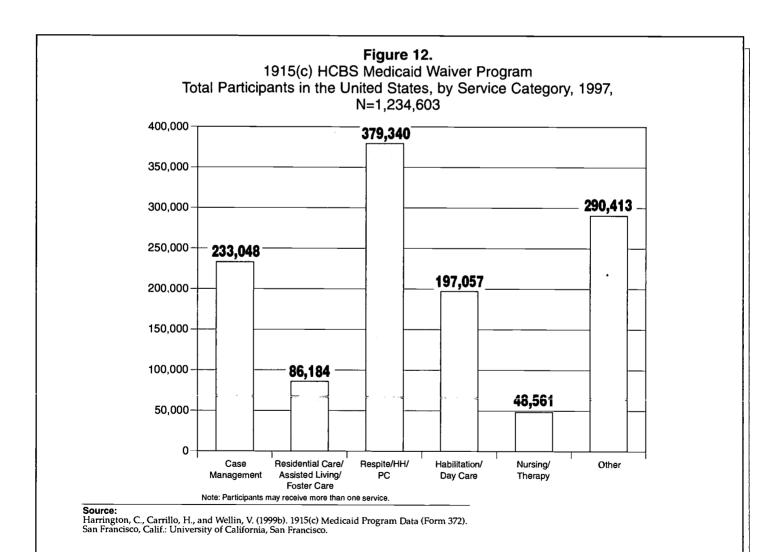


Figures 11 and 12 show the number of participants receiving various services, listed by category, for 1992 (below) and 1997 (page 18). In 1992, 33 percent of participants used a service from the respite/home health/personal care category, making it the largest service area of the program. Nearly one-quarter received case management and services included in the "other" category. Fifteen percent received habilitation/day care. A very small proportion received residential care/assisted living/foster care or nursing care (Figure 11).





Despite the large increase in total participants over the six-year period, the proportion of the waiver population receiving each category of service was quite stable. In 1997, the most heavily used category of service (31 percent of all participants) remained respite/home health or personal care (Figure 12).





Figures 13 through 17 concern Medicaid personal care services, comparing those offered under the PCS state plan benefit with those made available via the waivers. Figures 13 and 15 reflect annual participant estimates for 1998–99; Figures 14 and 16 reflect annual expenditure estimates for 1997–98. Figure 17 combines these estimates from different years to calculate the approximate annual expenditures per participant across the states for one year during the 1997–99 time period.

Figure 13 shows that in terms of program participants, the PCS state plan benefit reached more individuals nationwide with personal assistance than did the waivers. Personal care participants via the waivers accounted for about half of the PCS optional state plan caseload (Figure 13). It is important to point out that these 467,487 PCS state plan benefit participants all resided in one of the 26 states that offer the benefit.

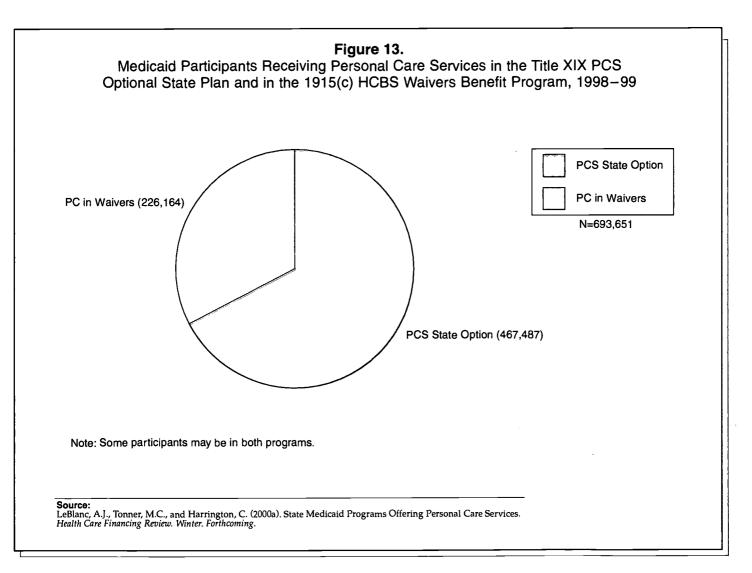
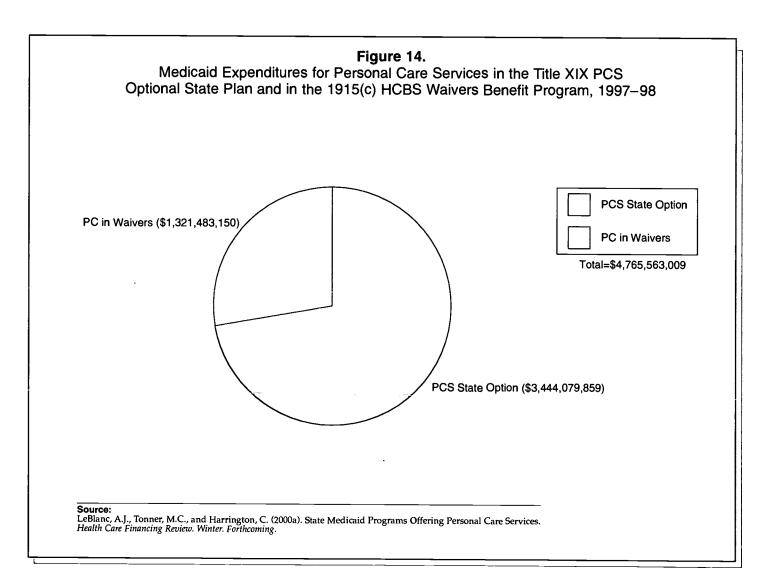




Figure 14 demonstrates that personal care in the waivers accounted for a smaller proportion of the total U.S. Medicaid personal care expenditures (38 percent). Although this is evidence that the state plan benefit is larger in terms of expenditures for personal care, it must be viewed in light of the fact that the waivers offer an array of HCBS, of which personal care is only one. In addition, just 26 states administer the PCS optional state plan benefit.





Figures 15, 16, and 17 provide graphic illustrations of each state's investment in Medicaid personal care offered in both the waivers and the optional state plan benefit. Arizona, which offers personal care through a Medicaid 1115 waiver, is omitted from these figures. In terms of participants per 1,000 population (Figure 15), expenditures per capita (Figure 16) and expenditures per participant (Figure 17); the states vary dramatically. The states range from .04 to 7.33 in Medicaid personal care participants per 1,000 population (mean = 2.12, not shown); \$.02 to \$91.21 in Medicaid personal care expenditures per capita (mean = \$18.11, not shown); and \$144 to \$37,596 in Medicaid expenditures per personal care participant (mean = \$6,870, not shown).

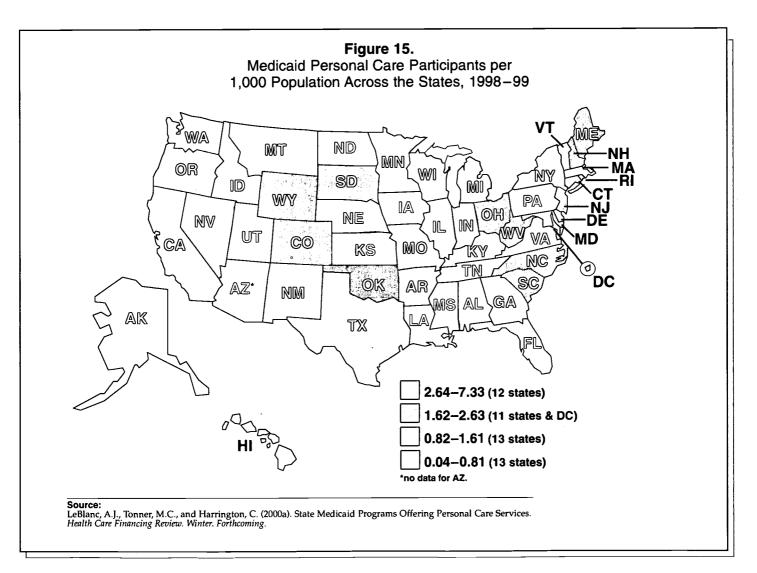




Figure 16.

Medicaid Personal Care Expenditures per Capita
Across the States, 1997–98

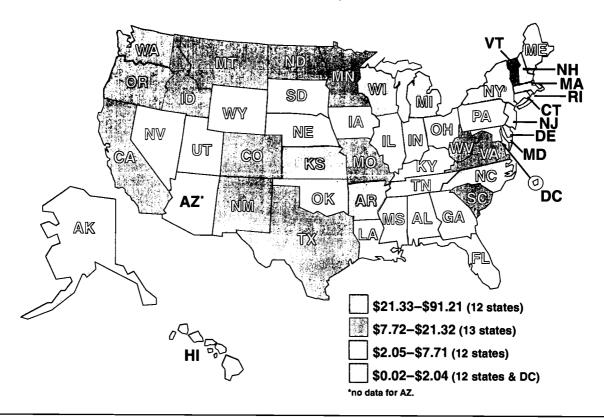
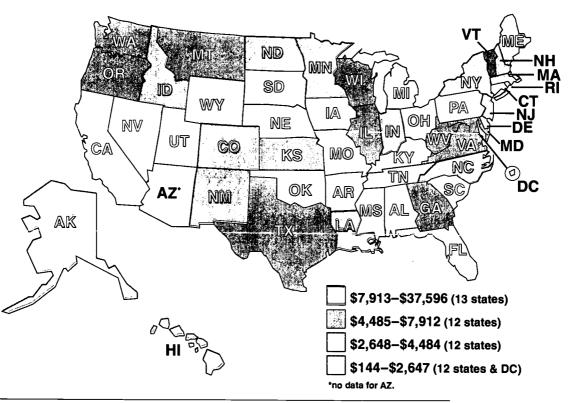


Figure 17.

Medicaid Expenditures per Personal Care Participant
Across the States, 1997–99



Source:

LeBlanc, A.J., Tonner, M.C., and Harrington, C. (2000a). State Medicaid Programs Offering Personal Care Services. Health Care Financing Review. Winter. Forthcoming.



Home health services represent an important component of Medicaid HCBS, but we lack detailed data on this category of service. In the next three figures, with data from HCFA Form 2082, Medicaid home health services are included in comparisons of Medicaid HCBS with Medicaid institution-based programs for 1992 and 1997, in terms of participants (Figure 18), expenditures (Figure 19), and expenditures per participant (Figure 20). For these comparisons, HCBS include data regarding home health, waiver, and PCS state plan benefit services.

Figure 18.

Medicaid Long-Term Care Participants by
Home Health & Other Home & Community-Based Care,
SNF, and ICF/MR Service Categories, 1992 and 1997



Source:

Harrington, C., Swan, J.H., Wellin, V., Clemena, W., and Carrillo, H. (2000c). State Database on Long-Term Care: Programs and Market Characteristics, 1978–98. Data prepared for the Health Care Financing Administration.

San Francisco, Calif.: University of California, San Francisco. Available at: http://www.hcfa.gov/medicaid/ltchomep.htm.

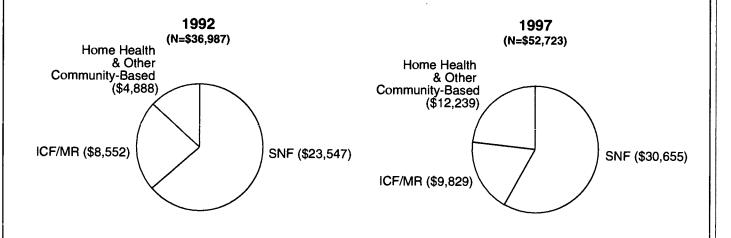


In the six years from 1992 to 1997, the relative proportion of Medicaid participants receiving some type of HCBS grew. While they accounted for 35 percent of Medicaid long-term care program participants in 1992, individuals receiving HCBS accounted for 52 percent in 1997 (Figure 18). In terms of expenditures, however, HCBS amounted to less than a quarter of overall costs in 1997 (Figure 19).

Figure 19.

Medicaid Long-Term Care Expenditures by
Home Health & Other Home & Community-Based Care,
SNF, and ICF/MR Service Categories, 1992 and 1997

(In millions)



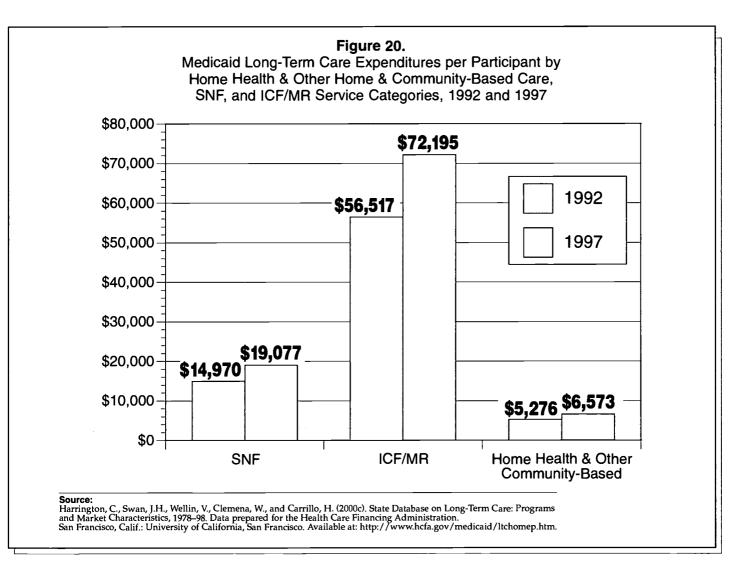
Source

Harrington, C., Swan, J.H., Wellin, V., Clemena, W., and Carrillo, H. (2000c). State Database on Long-Term Care: Programs and Market Characteristics, 1978–98. Data prepared for the Health Care Financing Administration.

San Francisco, Calif.: University of California, San Francisco. Available at: http://www.hcfa.gov/medicaid/ltchomep.htm.



More dramatic are the comparisons illustrated in Figure 20, where expenditures per Medicaid HCBS participant are much smaller than expenditures per Medicaid SNF and ICF/MR participants—for both years of data.





SUMMARY

In summary, Medicaid benefits offering home and community-based service (HCBS) alternatives are growing across the states. When home health is also counted as an HCBS, the number of HCBS participants approximates the number of people who receive institutional placement in either a nursing home or an intermediate-care facility for the mentally retarded (ICF-MR). However, researchers must strive to uncover more data on the number of Medicaid home health participants and expenditures in relation to those for other services. Researchers must also further explicate the differences and similarities between home health and other HCBS.

Regardless, in terms of total expenditures and expenditures per participant, Medicaid HCBS still are less costly than Medicaid institutional care (cf. Burwell 1999). To some extent, this finding suggests that HCBS may be the more economical long-term care alternative because they do not require board and care costs. Alternatively, the lower costs could be evidence that the states do not provide sufficient funding for these HCBS programs. For example, the average annual spending on a Medicaid personal care participant was just \$6,870, according to a recent estimate (LeBlanc et al. 2000a).

Moreover, these data clearly illustrate how these two Medicaid benefit programs are expanding unevenly, varying dramatically from state to state. There are tremendous differences across the states in their implementation of these critical programs (cf. Harrington et al. 2000d, 2000e, 2000f; Newcomer et al. 2000a, 2000b). Increasing political pressures from disability advocates and legal precedents—for example, the U.S. Supreme Court ruling in Olmstead v. L.C., (199 S. Ct. 2176, 1999), which requires states to offer appropriate alternatives to institutional placement when reasonably possible—are currently directing a great deal of attention on the future of these programs.



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