MEDICAID 1915(c) HOME AND COMMUNITY BASED WAIVERS:
PROGRAM DATA, 1992-1999

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Introduction

This website provides program data regarding the Medicaid 1915(c) home and community based (HCBS) waiver program for the period 1992-1999. This work is part of a larger study on the home and community based service program being conducted for The Kaiser Commission on Medicaid and the Uninsured. The site contains two main parts. Part 1 presents five pages of text that introduce the HCBS waiver program and describe the data sources and methods used to compile this report. Part 2 contains eight tables that present data concerning participants, expenditures and services by waiver, and by state, for the years 1992 through 1999. Further information on these data and the waiver program can be found in the sources listed at the end of Part 2.

PART ONE

Medicaid 1915(c) HCBS Waivers: An Introduction

For most of the 20th century, the bulk of formal (paid) long-term care (LTC) was provided in institutions (e.g. nursing homes). Little use was made of home and community-based services (HCBS) such as personal care, home delivered meals and independent living. Still, the only Federal Medicaid LTC benefits required of states are those provided by institutions, and home health services provided to those who would otherwise be in an institution.1,2,3

Since Congressional authorization in 1981, the Medicaid 1915(c) HCBS waiver program offers to the states, federal matched funding to expand HCBS and accelerate movement away from LTC services provided from institutions. This optional program allows the Department of Health and Human Services to ‘waive’ certain Medicaid statutory requirements so that states can receive federal funds to expand HCBS and reduce existing institutional care in three main ways. First, states can target HCBS towards specific geographical areas (i.e. a county), populations (e.g. the elderly), and conditions (e.g. traumatic brain injury). Second, they can provide HCBS services not otherwise covered by the Medicaid program (e.g. respite care, home modifications, case management, homemaker services, personal care, and adult day care). Third, states can set a limit on the numbers of waiver ‘slots’ available in order to control program costs.1,2,3
As a Medicaid program, the 1915(c) waiver initiative encourages states to expand and target the provision of HCBS services toward the elderly and those with disabilities who would otherwise be in an institution.\textsuperscript{2,3} Since it began in 1981, the 1915(c) HCBS waiver program has been growing in participants and expenditures. In 1982, the program spent $3.8 million on 6 waivers, and another 35 states had submitted waivers.\textsuperscript{3,4} In 1984, federal funding began for disabled children and in 1987, adults and children with AIDS began receiving HCBS waiver services.\textsuperscript{3,5} By 1997, there were 221 waiver programs in operation and total expenditure had risen to over $8.1 billion.\textsuperscript{3} By 1999, all states, except Arizona had one or more 1915(c) waiver programs for LTC services. Arizona operates its Medicaid LTC program under a capitation arrangement using an 1115 waiver.\textsuperscript{3}

**Data Sources**

While it was known that Medicaid 1915(c) HCBS waiver spending was increasing, little was know about the participants, expenditures and services in waiver programs across the states.\textsuperscript{5} Since 1994, researchers at the University of California, San Francisco have been funded by HCFA and more recently by the Kaiser Family Foundation to collect and report these data.\textsuperscript{6,7}

The primary source of data on 1915(c) waiver programs is the Health Care Financing Agency (HCFA) Form 372 on which states are required to file annual reports on their waiver programs. Two separate reports must be submitted to HCFA for each waiver. The “initial” 372 reports are due six months after the end of the reporting year for the waiver (different waivers have different reporting years). One year later (18 months after the end of the waiver year), states are required to submit “lag (final) reports” which include all revisions, adjustments, refunds, cost settlements, disallowances, and other changes. Another source of waiver expenditure data (but not participant data) is the HCFA Form 64 on which states submit annual claims to Medicaid for payment. This data source reports higher waiver expenditures than Form 372 data. While certain problems associated with Form 64 data are acknowledged\textsuperscript{8}, the reasons for the discrepancies with Form 372 expenditure data are unknown. It is likely, however, that Form 372 program reports may be more accurate than the Form 64 payment request data.
Methods

Since 1994, a University of California, San Francisco research team (led by Charlene Harrington) has collected Form 372 data for each waiver from every state. The data collection builds upon an initial effort in 1994 by the team to collect Form 372 reports from the states for 1992 onward. Since then, each year, every state Medicaid program was called by telephone and sent faxes to collect HCBS waiver data. In earlier years, the need to reconstruct historical files from the states required a great effort. Each year since then, between 3-5 calls were made by study researchers in order to collect the 372 reports for the previous year and any outstanding reports. Thus, the HCBS waiver data presented here represent the best available reports and the most recent complete data set of actual participants and expenditures.

Once the HCFA Form 372 reports were obtained, the data were coded and entered into a SAS database. State officials were asked to estimate data when the Form 372s were unavailable. Where states did not provide estimates, missing data were estimated by the researchers, based upon the trend line for each waiver. Some of the 372 reports collected each year contain discrepancies between waiver expenditures by service and total waiver expenditures. In these cases, calls were made to the states to rectify the problem. When responses were not forthcoming, edits were made by the investigators to correct errors and identify missing data. When service-level expenditure data were not reported, no effort was made to estimate such data -- see expenditure tables later in Part 2 of the report. The tables show estimates with an asterisk designation.

From the 372 reports, the classification of waivers by target group is not always straightforward since some states gave the waivers names that do not include the name of the target group. In order to classify the waiver by target group, we matched each waiver number with the name of the target group that the state reported to HCFA in their initial waiver request. Then, we categorized the target groups into eight categories.

Reporting of service categories are determined by each state. Participants by service are duplicated since most participants receive more than one category of service. Since waivers may offer many different services and because states do not have common names for these services, coding the service data was a challenge. A list of 30 separate service codes was compiled from a review of the 1992 data. Then waiver services were coded in the category that appeared to be most similar to the coding category. A miscellaneous category is used for those services not covered by the categories. The 30 service categories were collapsed into six categories for purposes of presentation in this report.
PART TWO

HCBS Waivers: Program Data, 1992 Through 1999

In 1992, there were 155 waivers and this increased to 214 in 1999. During this period, some states consolidated their total number of waivers while others expanded their total number of waivers. The eight tables shown in this section provide detailed information regarding these and other trends in the waiver program. Table 1 shows the total participants in each 1915(c) home and community based waiver in the US by state for each year from 1992 through 1999. There were 235,580 total participants in 1992 and this increased to 688,152 in 1999, or by 192 percent. Two Form 372 reports contained zero amounts for annual participant and expenditures. Because this indicates the waivers were either not operational or were consolidated into another state waiver, we report these data and do not estimate using the methods described for missing 372 reports.

Table 2 shows the total 1915(c) waiver expenditures for each waiver in each state from 1992 through 1999. The total expenditures increased from $2.16 billion in 1992 to $10.55 billion in 1999, or by 387 percent.

Table 3 shows the average 1915(c) waiver expenditures for each participant in each waiver from 1992 through 1999. The average expenditures per waiver participant in the states increased from $9,187 in 1992 to $15,331 in 1999, or by 67 percent.

Table 4 shows the participants per 1,000 population in each 1915(c) HCBS waiver in the US for each year from 1992 through 1999. There was an average of 0.94 participants per 1,000 population in 1992 and this increased to 2.52 participants per 1,000 in 1999, or by 168 percent.

Table 5 shows the expenditures per capita in each 1915(c) HCBS waiver in the US by state for each year from 1992 through 1999. There was an average of $8.65 per capita in 1992 and this increased to $38.69 per capita in 1999, or by 347 percent.

Table 6 shows the total number of waiver participants in each waiver that used one of six services in 1999. Participants could use more than one service. There were 258,293 participants that used case management, 79,787 that used residential care/assisted living or foster care, 380,474 that used respite, home health, or personal care services, 180,883 that used habilitation or day care, 46,398 that used nursing or other therapy services, and 389,907 participants that used other services in 1999. Twenty one waiver reports did not include service data.
Table 7 shows the total expenditures by waiver and service category in 1999. There was $376.5 million spent on case management, $909.7 million spent on residential care/assisted living or foster care, $2.2 billion spent on respite, home health, or personal care services, $4.2 billion spent on habilitation or day care, $155.5 million spent on nursing or other therapy services, and $508.4 million spent on other services. Twenty one waiver reports did not include service data.

Table 8 shows the average waiver expenditures per participant in each waiver spent on one of six services in 1999. There was an average of $1,458 spent on case management, $11,402 spent on residential care/assisted living or foster care, $5,758 spent on respite, home health, or personal care services, $23,220 spent on habilitation or day care, $3,352 spent on nursing or other therapy services, and $1,304 spent on other services per participant. Twenty one waiver reports did not include service data.

SUMMARY

In summary, the 1915(c) home and community based service waiver program is growing in all states. The total number of waivers increased from 155 in 1992 to 214 in 1999, or by 38 percent. There was a steady increase in waiver participants and expenditures across the seven-years of data reported. For more analysis of these programs, see Harrington, et al., LeBlanc et al., Kitchener et al., Miller et al., and Newcomer et al.

REFERENCES


