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Report to Congressional Requesters

June 2003

LONG-TERM CARE

Federal Oversight of Growing Medicaid Home and Community-Based Waivers Should Be Strengthened

GAO-03-576

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GAO Accountability • Integrity • Reliability

Highlights

Highlights of GAO-03-576, a report to congressional requesters

Why GAO Did This Study

Home and community-based settings have become a growing part of states' Medicaid long-term care programs, serving as an alternative to care in institutional settings, such as nursing homes. To cover such services, however, states often obtain waivers from certain federal statutory requirements. GAO was asked to review (1) trends in states' use of Medicaid home and community-based service (HCBS) waivers, particularly for the elderly, (2) state quality assurance approaches, including available data on the quality of care provided to elderly individuals through waivers, and (3) the adequacy of federal oversight of state waivers.

What GAO Recommends

GAO is recommending that the Administrator of CMS take steps to (1) better ensure that state quality assurance efforts are adequate to protect the health and welfare of HCBS waiver beneficiaries, and (2) strengthen federal oversight of the growing HCBS waiver programs. Although CMS raised certain concerns about aspects of the report, such as the respective state and federal roles in quality assurance and the potential need for additional federal oversight resources, CMS generally concurred with the recommendations.

www.gao.gov/cgi-bin/getrpt?GAO-03-576.

To view the full product, including the scope and methodology, click on the link above. For more information, contact Kathryn G. Allen at (202) 512-7118.

What GAO Found

From 1991 through 2001, Medicaid long-term care spending more than doubled to over $75 billion, while the proportion spent on institutional care declined. Over a similar time period, HCBS waivers grew from 5 percent to 19 percent of such expenditures—from $1.6 billion to $14.4 billion—and the number of waivers, participants, and average state per capita spending also grew significantly. Since 1992, the number of waivers increased by almost 70 percent to 263 in June 2002, and the number of beneficiaries, as of 1999, had nearly tripled to almost 700,000, of which 55 percent were elderly.

In the absence of specific federal requirements for HCBS quality assurance systems, states provide limited information to the Centers for Medicare & Medicaid Services (CMS), the federal agency that administers the Medicaid program, on how they assure quality of care in their waiver programs for the elderly. States' waiver applications and annual reports for waivers for the elderly often contained little or no information on state mechanisms for assuring quality in waivers, thus limiting information available to CMS that should be considered before approving or renewing waivers. GAO's analysis of available CMS and state waiver oversight reports for waivers serving the elderly identified oversight weaknesses and quality of care problems. More than 70 percent of the waivers for the elderly that GAO reviewed documented one or more quality-of-care problems. The most common problems included failure to provide necessary services, weaknesses in plans of care, and inadequate case management. The full extent of such problems is unknown because many state waivers lacked a recent CMS review, as required, or the annual state waiver report lacked the relevant information.

CMS has not developed detailed state guidance on appropriate quality assurance approaches as part of initial waiver approval. Although CMS oversight has identified some quality problems in waivers, CMS does not adequately monitor state waivers and the quality of beneficiary care. The 10 CMS regional offices are responsible for ongoing monitoring for HCBS waivers. However, CMS does not hold these offices accountable for completing periodic waiver reviews, nor does it hold states accountable for submitting annual reports on the status of waiver quality. Consequently, CMS is not fully complying with statutory and regulatory requirements when it renews waivers. As of June 2002, almost one-fifth of waivers in place for 3 years or more had either never been reviewed or were renewed without a review; for an additional 16 percent of waivers, reports detailing the review results were never finalized. Regional office personnel explained that limited staff resources and travel funds often impede the timing and scope of reviews. While regional office reviews include record reviews for a sample of waiver beneficiaries, they do not always include beneficiary interviews. The reviews also varied considerably in the number of beneficiary records reviewed and their method of determining the sample.

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Abbreviations

CMS	Centers for Medicare & Medicaid Services
FTE	full-time equivalent
HCBS	home and community-based services
HCFA	Health Care Financing Administration
HHS	Department of Health and Human Services
ICF/MR	intermediate care facility for the mentally retarded

GAO
Accountability * Integrity * Reliability

United States General Accounting Office
Washington, DC 20548

June 20, 2003

The Honorable Charles E. Grassley
Chairman
Committee on Finance
United States Senate

The Honorable John B. Breaux
Ranking Minority Member
Special Committee on Aging
United States Senate

Over the last decade, states have increased their support for long-term care services in individuals' homes or in other community-based settings—such as adult day care, adult foster care homes, and assisted living facilities—as an alternative to care in nursing homes and other institutions. For many vulnerable elderly and nonelderly individuals with physical, developmental, or cognitive disabilities, these alternative settings and services are seen as preferable to institutional care. Most state funding of long-term care is through Medicaid, the federal-state health care program for certain low-income individuals. Medicaid home and community-based services (HCBS) waivers, authorized under section 1915(c) of the Social Security Act, are the primary means by which states provide noninstitutional long-term care.[1] Waivers allow states to limit the availability of services geographically, target specific populations or conditions, control the number of individuals served, and cap overall expenditures—actions not usually allowed under the Medicaid statute. The Centers for Medicare & Medicaid Services (CMS)—the federal agency that manages Medicaid—reviews and approves states' requests for these waivers and also is responsible for ensuring that states have necessary safeguards to protect the health and welfare of individuals receiving services through waiver programs.[2]

[1]42 U.S.C. 1396n(c)(2000).

[2]Until June 2001, CMS was known as the Health Care Financing Administration (HCFA). In this report, we continue to refer to HCFA when our findings apply to the organizational structure and operations associated with that name.

Despite the growing use of HCBS waivers, concerns have been raised about the quality of care provided through waivers serving both elderly and nonelderly populations. Newspaper exposés and some state audit reports have chronicled serious health and welfare concerns in waiver programs across the country. Because of continued growth in the numbers of people served through HCBS waiver programs and concerns about the quality of care, you asked us to review (1) trends in states' use of such waivers, particularly for the elderly, (2) state quality assurance approaches for waivers serving the elderly, including available data on the quality of care provided to beneficiaries, and (3) the adequacy of CMS's oversight of state waiver programs for the elderly as well as those for other target populations.

To identify trends in states' use of waivers, we analyzed CMS and state reports that contained data on waiver beneficiaries, expenditures, and services. To identify those waivers that serve the elderly, we compiled a list of HCBS waivers with "the aged" or "aged and disabled" as their target populations. Throughout this report, we refer to this universe of waivers as those "serving the elderly." To assess state quality assurance activities for waivers serving the elderly, we analyzed (1) data on quality assurance approaches from state waiver applications and their most recent annual reports to CMS, (2) the oversight findings reported by states in their annual waiver reports, and (3) CMS regional office waiver reviews and state audits of waivers completed from October 1998 through May 2002.[3] For a more in-depth perspective on states' quality assurance approaches for waivers serving the elderly, we conducted structured interviews with state officials and staff in South Carolina, Texas, and Washington. We selected these states because they operate some of the largest HCBS waivers for the elderly that have been in effect for 5 years or longer. We did not attempt to assess the effectiveness of their quality assurance approaches. To determine the adequacy of CMS oversight of state waiver programs for the elderly as well as those for other target populations, we obtained relevant data from officials at CMS headquarters and conducted structured interviews with all 10 CMS regional offices on their waiver review activities and staffing as of June 2002. See appendix I for a detailed discussion of our scope and methodology. We conducted our review from November 2001 through June 2003 in accordance with generally accepted government auditing standards.

[3]Our analysis of regional office waiver reviews is based on final reports. Reviews that did not have a final report were not included in our analysis.

Results in Brief

Total Medicaid spending for long-term care increased from $33.8 billion in fiscal year 1991 to $75.3 billion in fiscal year 2001, with a growing share spent on services through home and community-based waivers as an alternative to care in institutions such as nursing homes. Expenditures for services through HCBS waivers increased from $1.6 billion in fiscal year 1991 to $14.4 billion in fiscal year 2001, growing from 5 percent of all Medicaid long-term care spending in fiscal year 1991 to 19 percent in fiscal year 2001. Over roughly the same time period, the number of HCBS waivers increased from 155 to 263, with 77 serving the elderly as of June 2002. Every state except Arizona operates at least one waiver for the elderly. From 1992 to 1999, the total number of persons served through waivers nationwide nearly tripled to 688,152 and the number of beneficiaries served by waivers for the elderly more than doubled to 377,083. In two states, Oregon and Washington, HCBS waiver services have replaced nursing homes as the dominant means of providing long-term care to the elderly under Medicaid. Nationally, average Medicaid expenditures per beneficiary in waivers serving the elderly increased from $3,622 in 1992 to $5,567 in 1999; average spending per beneficiary in 1999 ranged from $1,208 in New York to $15,065 in Hawaii, reflecting differences in the type and amount of services provided under different waivers.

No nationwide data are available on states' quality assurance approaches or the status of quality of care for beneficiaries served by waivers for the elderly, but concerns have been identified about the quality of care provided under many of these waivers. Because CMS has not provided detailed guidance to states on federal requirements for HCBS quality assurance systems, the information available to CMS that should be considered before approving or renewing waivers is limited. Thus, state waiver applications and annual waiver reports that we reviewed for waivers serving the elderly often contained little or no information on state quality assurance approaches. For example, 11 applications for the 15 largest waivers serving the elderly identified three or fewer specific quality assurance approaches, and none mentioned important approaches such as complaint systems or enforcement tools. Moreover, 18 of 52 state annual waiver reports that we reviewed contained no information on approaches used to help ensure quality. Where information was provided, the most frequently cited quality assurance approaches included (1) audits or reviews of case management agencies, (2) state agency reviews of waiver providers or direct-care staff, and (3) state licensure, certification, or standards for some waiver providers. Although CMS regional office and state reviews identified few if any specific cases of harm to waiver beneficiaries, the reviews for the majority of waivers serving the elderly

with available relevant detail had one or more problems related to quality of care. Among the most commonly cited problems were (1) failure to provide authorized or necessary services, (2) inadequate assessment or documentation of beneficiaries' care needs in the plan of care, and (3) inadequate case management. For example, one recent CMS regional office review found that more than one-fourth of a state's waiver beneficiaries had received none of their authorized personal care services. However, the consequences for the beneficiaries were not identified in this review. Since many state waiver programs did not have a recent CMS review, as required, or the annual state waiver report lacked the relevant information, the extent of quality-of-care problems is unknown.

CMS guidance to states and oversight of HCBS waivers is inadequate to ensure quality of care for waiver beneficiaries. CMS has not developed detailed guidance for states on appropriate quality assurance mechanisms as part of the waiver approval process, and initiatives under way to generate information on state quality assurance approaches do not address this problem. In addition, the agency has not fully complied with the statutory and regulatory requirements that condition the renewal of HCBS waivers on (1) states submitting required annual reports that include information on state quality assurance approaches and deficiencies identified through state monitoring and (2) CMS's conducting and documenting periodic waiver reviews to determine whether states satisfied requirements for protecting the health and welfare of waiver beneficiaries. Many state annual waiver reports submitted to CMS regional offices for waivers serving the elderly were not timely and lacked required information on quality assurance and state monitoring. As of June 2002, 228 HCBS waivers for all target populations had been in place for 3 years or longer and should have been reviewed by CMS regional offices. However, 42 waivers serving approximately 132,000 beneficiaries either had never been reviewed or were renewed without a review. For 36 additional waivers, reviews were conducted, but the reports summarizing the findings were never finalized, raising a question as to whether any weaknesses were identified and, if so, had been corrected. CMS regional office personnel informed us that limited staff and travel resources impeded the timing and scope of reviews. While regions' reviews included an examination of beneficiary records, we found that the reviews varied considerably in the number of beneficiary records reviewed and their method of determining the sample, raising a question about the extent to which findings could be generalized. In addition, they did not always include beneficiary interviews. Although updated in 2001, CMS guidance for conducting waiver reviews does not address key operational issues

such as an adequate sample size or the sampling methodology to provide a basis for generalizing review findings.

To better ensure that state quality assurance efforts are adequate to protect the health and welfare of HCBS waiver beneficiaries and to strengthen federal oversight, we are recommending that the CMS Administrator (1) establish more detailed criteria regarding the necessary components of an HCBS waiver quality assurance system, (2) require states to submit more specific information about their quality assurance approaches prior to waiver approval, (3) ensure that states provide sufficient and timely information in their annual waiver reports on their efforts to monitor quality, (4) develop guidance on the scope and methodology for federal reviews of state waiver programs, and (5) ensure allocation of sufficient resources for conducting thorough and timely reviews of quality in HCBS waivers and hold regional offices accountable for completing such reviews. Although CMS raised certain concerns about aspects of our report, such as the respective state and federal roles in quality assurance and the potential need for additional federal oversight resources, the agency generally concurred with our recommendations.

Background

The jointly funded federal-state Medicaid program is the primary source of financing for long-term care services.[4] About one-third of the total $228 billion in Medicaid spending in fiscal year 2001 was for long-term care in both institutional and community-based settings. States administer this program within broad federal rules and according to a state plan approved by CMS, the federal agency that oversees and administers Medicaid. Some services, such as nursing home care and home health care, are mandatory services that must be covered in any state that participates in Medicaid. Other services, such as personal care, are optional, which a state may choose to include in its state Medicaid plan but which then must be offered to all individuals statewide who meet its Medicaid eligibility criteria. States may also apply to CMS for a section 1915(c) waiver to provide home and community-based services as an alternative to institutional care in a hospital, nursing home, or

[4]While the purpose of Medicaid is to cover health care and long-term care for low-income persons, including persons who are aged, blind, or disabled, it has become a significant means of funding long-term care for many middle-income persons as well. Many of these persons qualify for Medicaid benefits after a period of "spend-down," during which they deplete their own resources to pay for services.

intermediate care facility for the mentally retarded (ICF/MR).[5] If approved, HCBS waivers allow states to limit the availability of services geographically, to target services to specific populations or conditions, or to limit the number of persons served, actions not generally allowed for state plan services. States often operate multiple waivers serving different population groups, such as the elderly, persons with mental retardation or developmental disabilities, persons with physical disabilities, and children with special care needs.

States determine the types of long-term care services they wish to offer under an HCBS waiver. Waivers may offer a variety of skilled services to only a few individuals with a particular condition, such as persons with traumatic brain injury, or they may offer only a few unskilled services to a large number of people, such as the aged or disabled.[6] The wide variety of services that may be available under waivers includes home modification, such as installing a wheelchair ramp, transportation, chore services, respite care, nursing services, personal care services, and caregiver training for family members. CMS's waiver application form for states includes a list of home and community-based services with suggested definitions. States are free to include as many or as few of these as they wish, to include additional services, or to include different definitions of services from those supplied with the form. See appendix II for a list of services provided through the HCBS waivers serving the elderly and CMS's suggested definitions of these services.

To be eligible for waiver services, an individual must meet the state's criteria for needing the level of care provided in an institution, such as a nursing home, and be able to receive care in the community at a cost

[5]Federal statutory requirements for Medicaid that may be waived include (1) statewideness, which requires that services be available throughout the state, (2) comparability, which requires that all services be available to all eligible individuals, and (3) income and resource rules, which require states to use a single income and resource standard when determining eligibility for Medicaid, with the exception of institutional care. A waiver of this last requirement allows states to use more generous institutional eligibility criteria when determining financial eligibility for waiver services, thus extending eligibility to individuals in the community who would not otherwise qualify for Medicaid.

[6]A recent summary by the National Association of State Medicaid Directors identified 75 discretely defined services in HCBS waiver applications as of June 2000. Individual waivers included as few as one service to as many as 25.

generally not exceeding the cost of institutional care.[7] States are responsible for determining the specific financial and functional eligibility criteria used, conducting the necessary screening and assessment, and arranging for services to be provided. Factors that states use in assessing functional eligibility for nursing home care and for waiver services include the individuals' medical condition and their degree of physical or mental impairment. Other factors that states generally consider, and which may affect the states' ability to provide care in the community at a cost not exceeding that of institutional care or to adequately protect beneficiaries' health and welfare, include the mix of services needed by the individual, the availability of needed services, the cost of services, the need for home modification, and the availability of family members or other caregivers.[8]

In order to receive federal funds for waiver services, a state must submit an application to the Secretary of Health and Human Services (HHS) that identifies the target population, specifies the number of persons that will be served, and lists the services to be included. In addition, states are required to provide certain assurances that necessary safeguards have been taken to assure financial accountability and to protect the health and welfare of beneficiaries under the waiver.[9] Federal regulations specify that the state's safeguards for the health and welfare of beneficiaries must include (1) adequate standards for all providers of waiver services and (2) assurance that any state licensure or certification requirements for providers of waiver services are met.[10] CMS requires that a state's waiver application include documentation regarding the standards applicable for each service provider. If the only requirement for a particular provider is

[7]The average cost of community care under a waiver cannot exceed the average cost of care in an institution.

[8]For example, a person who requires 24-hour care and supervision and has no family or other support in the community may exceed the limits of what the waiver program allows in terms of personal care services. However, the same person who lives with a family caregiver might be eligible to receive several hours of personal care services each day as well as occasional respite care and caregiver training for the family.

[9]A state must provide several additional assurances, including the following: (1) the state will provide for an evaluation of the need for services for individuals, (2) beneficiaries will be informed of available alternatives to the waiver and provided a choice, (3) the average per capita expenditures for waiver beneficiaries will not exceed the amount that the state estimates would have been spent in the absence of the waiver, (4) absent the waiver, beneficiaries would receive the appropriate institutional care that they need, and (5) the state will provide information to CMS annually on the impact of the waiver.

[10]*See*, 42 CFR 441.302(a).

licensure or certification, the state must provide a citation to the applicable state statute or regulation. If other requirements apply, the state must specify the applicable standards that providers must meet and explain how the provider standards will ensure beneficiaries' welfare. Finally, states must annually report on, among other things, how they implement, monitor, and enforce their health and welfare standards and the waiver's impact on the health and welfare of beneficiaries.

Initial waiver applications and amendments to initial waivers are reviewed and approved by CMS headquarters. CMS's 10 regional offices have primary responsibility for reviewing and approving applications to renew waivers and amendments to renewed waivers. If CMS determines that a waiver application meets program requirements, including sufficient documentation to indicate that necessary safeguards are in place to protect the health and welfare of waiver beneficiaries, it will approve an initial waiver for a 3-year period. Subsequently, waivers may be extended for additional 5-year periods.

Section 1915(c)(3) of the Social Security Act provides that, upon request of a state, HCBS waivers may be extended, unless the Secretary of HHS determines that the assurances provided during the preceding term have not been met.[11] Among the assurances that the state makes are that necessary safeguards have been taken to protect the health and welfare of waiver participants and that the state will submit annual reports on the impact of the waiver on the type and amount of medical assistance provided under the state Medicaid plan and on the health and welfare of recipients. Regulations implementing section 1915(c) provide that an extension of a waiver will be granted unless (1) CMS's review of the prior waiver period shows that the assurances the state made were not met and (2) the state fails to provide adequate documentation and assurances to justify an extension.[12] In its explanation of this regulation, HCFA indicated that a review of the prior period is an indispensable part of the renewal process.[13]

[11]42 U.S.C. 1396n(c)(3). Section 1915(c)(3) states "A waiver under this subsection [1915(c)] shall be for an initial term of three years and, upon the request of a State, shall be extended for additional five-year periods unless the Secretary determines that for the previous waiver period the assurances provided under paragraph (2) have not been met."

[12]42 CFR 441.304(a).

[13]*See*, 59 *Fed. Reg.* 37702, 37712 (1994) and 53 *Fed. Reg.* 19950 (1988).

Reviews of waiver programs for which a renewal has been requested are, therefore, expected to occur at some point during the initial 3-year period, and at least once during each renewal cycle. CMS guidance on the reviews calls for on-site visits that include an examination of beneficiary and provider records as well as interviews with state officials. If a state's efforts to protect the health and welfare of waiver beneficiaries are determined to be inadequate, CMS officials told us that the agency can either bar the state from enrolling any new waiver beneficiaries until corrective actions are taken or terminate the waiver.

According to a recent CMS-sponsored review, oversight of waivers is often decentralized and fragmented among a variety of agencies and levels of government, and rarely does a single entity have accountability for the overall quality of care provided to waiver beneficiaries.[14] Some waiver service providers are regulated by state licensing agencies, some are certified by private accreditation organizations, and others operate under terms of a contract or other agreement with a state agency. While the state Medicaid agency is ultimately accountable to the federal government for compliance with the requirements of the waivers, it may delegate administration of the waivers to state units on aging, mental health departments, or other departments or agencies with jurisdiction over a specific population or service. About one-third of waivers for the elderly are administered by an agency or department other than the Medicaid agency, most often the state unit on aging.[15] These agencies may then contract with local networks, agencies, or providers to provide or arrange for beneficiary services.

[14]Maureen Booth and others, *Literature Review: Quality Management and Improvement Practices for Home and Community-Based Care* (Portland, Me.: University of Southern Maine, Edmund S. Muskie School of Public Service, Jan. 10, 2002).

[15]Data gathered by the National Association of State Medicaid Directors identified the location of waiver administration for 56 HCBS waivers for the elderly as of March 18, 2002. Thirty-eight of these were administered either directly by the Medicaid agency or within the same department that houses the Medicaid agency.

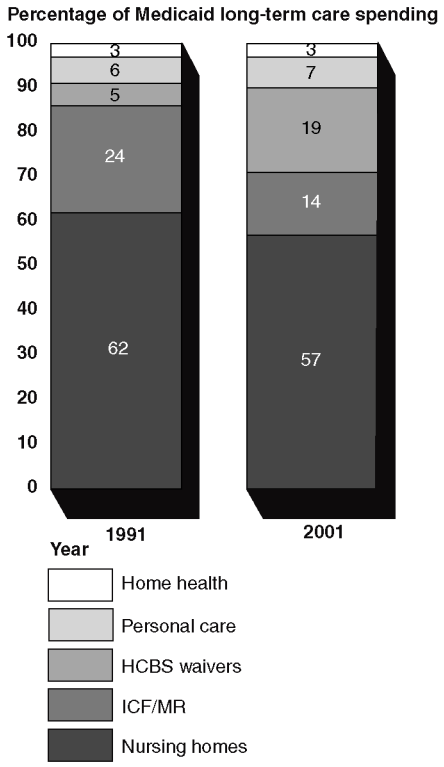
Waivers Are Vehicle for Dramatic Growth in Medicaid Home and Community-Based Services

Medicaid-covered HCBS services have become a growing component of state long-term care systems, with most of the growth accounted for by substantial increases in the number of HCBS waivers and the beneficiaries served through waivers. In a few states, these waivers are beginning to replace nursing homes as the dominant means for providing long-term care to the elderly under Medicaid. Over the past 10 years, total Medicaid long-term care spending has more than doubled—from $33.8 billion in fiscal year 1991 to $75.3 billion in fiscal year 2001. However, the share of spending for institutional care declined from 86 to 71 percent, while the share spent for home and community-based care grew from 14 to 29 percent.

Most of the growth in home and community-based care spending under Medicaid can be accounted for by HCBS waivers. Total Medicaid home and community-based care spending grew from $4.8 billion in fiscal year 1991 to $22.2 billion in fiscal year 2001, while spending for waiver services grew from $1.6 billion in fiscal year 1991 to $14.4 billion in fiscal year 2001. As shown in figure 1, waiver spending grew from 5 percent of all Medicaid long-term care spending in fiscal year 1991 to 19 percent in fiscal year 2001. In all but two states—California and New York—and the District of Columbia, over one-half of Medicaid home and community-based services spending in fiscal year 2001 was through waivers, with a much smaller portion going to nonwaiver mandatory home health care or state plan optional personal care services.[16] See appendix III for a summary of Medicaid long-term care expenditures by type and state.

[16]California and New York fund most of their Medicaid home and community-based services using the state plan personal care services option and home health benefit. The District of Columbia funds most of its Medicaid home and community-based care using the home health benefit.

Figure 1: Percentage Distribution of Medicaid Long-Term Care Expenditures, Fiscal Years 1991 and 2001



Source: CMS.

Note: GAO analysis of HCFA Form 64 data as reported by Brian Burwell, Steve Eiken, and Kate Sredl in *Medicaid Long Term Care Expenditures in FY 2001* (The MEDSTAT Group, May 10, 2002). The figure includes data from 49 states and the District of Columbia.

Both the number and size of HCBS waivers have grown considerably over the past 20 years. Every state except Arizona operates at least one such waiver for the elderly.[17] In 1982, the first year of the waiver program, 6 states operated HCBS waivers. By 1992, 48 states operated a total of 155 HCBS waivers. As of June 2002, 49 states and the District of Columbia operated a total of 263 HCBS waivers, with 77 serving the elderly. The average waiver for the elderly served 3,305 Medicaid beneficiaries in 1992

[17]Arizona operates its Medicaid program as a demonstration project under a section 1115 waiver, which includes long-term care as well as acute health care services. Under section 1115 of the Social Security Act, the Secretary of HHS has broad authority to authorize experimental, pilot, or demonstration projects that are likely to promote objectives of certain federal programs, including Medicaid.

and 5,892 beneficiaries in 1999.[18] In 1999, 15 states served more than 10,000 persons in their waivers for the elderly, an increase from only 4 states in 1992.

The total number of HCBS waiver beneficiaries—elderly and nonelderly—nationwide nearly tripled from 235,580 in 1992 to 688,152 in 1999, the most recent year for which data were available. The number of beneficiaries served in waivers for the elderly more than doubled from 155,349 in 1992 to 377,083 in 1999. Over this same period, the number of Medicaid beneficiaries who used some nursing home care during the year grew by only 2.5 percent from 1.57 million to 1.61 million beneficiaries. By 1999, waivers for the elderly were serving 19 percent of all Medicaid beneficiaries served either in a nursing home or through an HCBS waiver for the elderly, an increase from 9 percent in 1992.[19] In two states, Oregon and Washington, more elderly and disabled Medicaid beneficiaries were served in HCBS waivers in 1999 than were served in nursing homes. Appendix IV includes the number of Medicaid beneficiaries served by HCBS waivers for the elderly and in nursing homes in each state.

In 1999, the average per beneficiary expenditure in HCBS waivers serving the elderly was $5,567, an increase from $3,622 in 1992.[20] However, the average per beneficiary expenditure for such waivers varied widely across states, reflecting differences in the type, number, and amount of services provided under waivers in different states. As shown in table 1, among those states with waivers serving the elderly in 1999, per beneficiary expenditures ranged from an average of $15,065 in Hawaii to $1,208 in

[18]Waiver beneficiary and expenditure data used in this analysis do not cover the same time periods. Waiver expenditure data are available through 2001. Data on waiver beneficiaries and services are available only through 1999. A CMS contractor recently developed a database for HCBS waivers. It is scheduled for installation at CMS in 2003, and it will include waiver beneficiary, service, and expenditure data from annual state reports.

[19]The shift from institutional care to home and community-based services under Medicaid has been most significant for persons with mental retardation or developmental disabilities. In 1992, 28 percent of such beneficiaries who qualified for institutional care were served under HCBS waivers, and by 1999, that proportion had grown to 68 percent.

[20]These average expenditures do not include expenditures for nonwaiver Medicaid services for these beneficiaries. In addition to waiver services, waiver beneficiaries are eligible for the full range of regular Medicaid state plan services. The overall cost to Medicaid for waiver beneficiaries will be higher than the amounts reported here, which only include those services provided under the waiver. In addition, Medicaid covers the cost of room and board for beneficiaries in nursing homes and other institutions, a benefit not generally covered for those receiving services under the waiver.

New York. In Hawaii, one such waiver that provided an average of 85 hours of personal assistance services per month to 91 percent of beneficiaries of that waiver had an average cost of $10,893 per beneficiary. A second Hawaii waiver that provided adult foster care, residential care, or assisted living for waiver beneficiaries had an average cost of $16,958 per beneficiary. In contrast, New York's waiver for the elderly did not include personal care or residential services; the primary benefits included social work services, personal emergency response systems, and home-delivered meals. Appendix V provides summary information on states' HCBS waivers for the elderly, including per beneficiary expenditures.

Table 1: States with Highest and Lowest per Beneficiary Expenditures for State HCBS Waivers Serving the Elderly, 1999

State	Average expenditures per beneficiary	Number of beneficiaries
United States	$5,567	377,083
States with highest per beneficiary waiver spending		
Hawaii	15,065	923
New Mexico	14,151	1,404
North Carolina	13,778	11,159
Alaska	12,015	712
West Virginia	11,213	3,470
States with lowest per beneficiary waiver spending		
Michigan	2,632	6,328
Iowa	2,517	3,994
Missouri	2,224	20,821
Massachusetts	1,919	5,132
New York	1,208	19,732

Source: CMS.

Notes: GAO analysis of annual state waiver report data (HCFA Form 372) as reported by Charlene Harrington in *Medicaid 1915(c) Home and Community-Based Waivers: Program Data, 1992-1999* (San Francisco, Calif.: University of California, San Francisco, August 2001).

All states in this table except Hawaii operated one waiver serving the elderly in 1999. Hawaii operated two waivers, one that served 288 beneficiaries at a cost of $10,893 per beneficiary and a second that served 635 beneficiaries at a cost of $16,958 per beneficiary.

Information on State Quality Assurance Approaches for Waivers Serving the Elderly Is Limited, but Quality Concerns Have Been Identified

No comprehensive nationwide data are available on states' quality assurance systems for or the quality of care provided through HCBS waivers, including those serving the elderly. In the absence of detailed federal requirements for HCBS quality assurance systems, states' waiver applications and annual reports often contained little or no information on the mechanisms used to ensure quality, raising a question as to whether CMS had adequate information to approve or renew some waivers. More than half of the waivers serving the elderly for which we were able to obtain a CMS waiver oversight report, an annual state waiver report, or a state audit report identified oversight weaknesses and quality-of-care problems. Frequently cited quality-of-care problems included (1) failure to provide authorized or necessary services, (2) inadequate assessment or documentation of beneficiaries' care needs in the plan of care, and (3) inadequate case management. We were unable to analyze over one-third of waivers serving the elderly because they lacked a recent regional office review, the annual state waiver report lacked the relevant information, or they were too new to have annual state reports.

States Use a Variety of Waiver Quality Assurance Approaches in Waivers Serving the Elderly, Yet Some States Provide Limited or Incomplete Information to CMS

Although the state waiver applications and annual waiver reports we reviewed for waivers serving the elderly identified more than a dozen quality assurance approaches, many contained little or no information about how states ensure quality.[21] For example, 11 applications for the 15 largest waivers serving the elderly identified three or fewer quality assurance mechanisms and none of these 11 waivers mentioned important approaches, including complaint systems or sanctions. Eighteen of 52 state annual waiver reports that we reviewed contained no information on the mechanisms used to help ensure quality. Moreover, when waiver applications and annual waiver reports did contain some information, the information was often incomplete. Our work in South Carolina, Texas, and Washington identified additional quality assurance mechanisms that were not listed in their waiver applications or annual reports, suggesting that such documents may understate the nature and extent of their oversight

[21]CMS uses the waiver applications, in part, to assess whether the proposed quality assurance mechanisms are sufficient to warrant waiver approval. HCFA Form 372, referred to in this report as the annual state waiver report, is a key source of information on how states have ensured quality until states renew their waivers. In addition to service use and spending data, the annual state waiver report includes information about the state's process for monitoring waiver standards and safeguards and the findings of those monitoring processes—specifically, any deficiencies that were detected during the period covered by the report.

approaches. As a result, CMS's understanding of how these states ensure quality in the waivers may be incomplete.

States Use a Variety of Quality Assurance Mechanisms

Information provided to CMS in state waiver applications and annual reports identified a variety of mechanisms used to protect the health and welfare of beneficiaries in waivers serving the elderly. Table 2 describes 14 quality assurance approaches that states reported using in HCBS waivers for the elderly. Some of these approaches focus on the waiver beneficiary, such as case management or beneficiary satisfaction surveys. Other approaches are focused on providers, including licensure and inspections, corrective action plans, sanctions, and program manuals. States may require that certain providers be licensed or certified or meet other requirements contained in state laws or regulations. Such providers are generally subject to periodic inspections that may include a review of beneficiary records to determine whether the records meet program standards. A third set of quality assurance approaches focuses on waiver program operations, including internal or external evaluations of the waiver program, supervisory reviews of waiver beneficiary assessments and plans of care, and audits or reviews of case management agencies.

Table 2: Quality Assurance Mechanisms States Reported Using in HCBS Waivers Serving the Elderly

Quality assurance mechanism	Description
Beneficiary-oriented mechanisms	
Case management	Case management includes assessing the beneficiary's needs, developing the plan of care, arranging for the delivery of services, monitoring the beneficiary, and conducting periodic reassessments of the beneficiary's needs and modifying the plan of care as needed.
Beneficiary satisfaction surveys or interviews	A survey instrument or other tool is used to measure waiver beneficiaries' views about their waiver services and the extent to which services are meeting their long-term care needs.
On-site visits of beneficiaries	On-site visits may be conducted by program officials other than the beneficiary's case manager to observe services being provided and gather information about the care provided.
Complaint systems	Systems to accept, investigate, and track the status of waiver beneficiaries' or others' complaints regarding the waiver program.
Provider-oriented mechanisms	
Licensure, certification, or other state standards	States require that certain providers be licensed, certified, or meet other requirements contained in state law or regulation. Providers are generally subject to periodic inspections that

Quality assurance mechanism	Description
	include a review of beneficiary records to determine if they meet program standards.
Provider or direct care staff reviews or audits	State program officials conduct reviews of waiver providers or individual caregivers to determine whether waiver-specific requirements were met. Such reviews involve reviews of beneficiary records and other provider documentation as well as individual beneficiary interviews.
Corrective action plans	List of actions that the provider agrees to take to return to compliance with federal or state standards.
Sanctions and penalties	Depending on the severity of the violation, actions available to penalize the provider for not complying with federal or state standards.
Training and technical assistance	Ongoing, continuing education for case managers and waiver providers to ensure competency in delivering and monitoring the care of waiver beneficiaries.
Program manuals	Distribution of rules, policies, procedures, or standards to waiver providers.
Program-oriented mechanisms	
Case management agency review or audit	Reviews of agencies responsible for case management of the HCBS waiver, including a review of a sample of case managers' records to ensure timeliness and completeness.
Supervisory review of beneficiary assessments or plans of care	Review conducted by case managers' supervisors or at the state level of documents related to waiver beneficiaries' assessed needs and identified services.
Analysis of automated waiver program data	Review or monitoring of electronic version of client data, such as assessments, reassessments, and care plans.
Internal or external evaluation of waiver program	Program review of the procedures for waiver beneficiary assessments, development of plans of care, and delivery of waiver services; review may be conducted by state agency officials or by contractor.

Source: CMS.

Note: GAO analysis of the most recent waiver application for the 15 largest HCBS waivers serving the elderly and the most recent annual state reports for 52 waivers serving the elderly submitted to CMS regional offices as of July 2002.

States Provide CMS Limited Information about Their Quality Assurance Approaches

Because CMS has not provided detailed guidance to states on federal requirements for HCBS quality assurance systems, the waiver applications and annual reports submitted by states to CMS for waivers serving the elderly often contained little or no information on state mechanisms for ensuring quality, raising a question as to whether CMS had adequate information to approve or renew some waivers.

- Waiver applications. Our review of the most current waiver applications for the 15 largest waivers serving the elderly found that many states provided CMS limited information about how they plan to protect the health and welfare of beneficiaries.[22] Eleven of the 15 states cited three or fewer quality assurance mechanisms. For example, New York's application only contained information about the state licensure and certification requirements for its waiver services. None of these 11 applications included well-recognized quality assurance tools such as complaint systems, corrective action plans, sanctions, or beneficiary satisfaction surveys. The remaining 4 states each identified six to eight quality assurance approaches, including at least one of these four important tools. As shown in table 3, the two mechanisms most frequently cited by states were (1) licensure for some HCBS waiver providers, such as home health agencies and residential care providers, and (2) case management.

Table 3: Quality Assurance Mechanisms Frequently Cited in Waiver Applications and Current Annual State Reports for HCBS Waivers Serving the Elderly

Quality assurance mechanism	Waiver application: number of states citing mechanism (n=15 largest state waivers for the elderly)	Annual state report: number of states citing mechanism[a] (n=40 states)
Case management agency reviews or audits	8	30
Waiver provider or direct-care staff reviews or audits	1	24
Licensure, certification, or other state standards	15	22
Waiver beneficiary satisfaction surveys or interviews	2	21
Case management	12	20
Training and technical assistance	0	20
On-site visits of waiver beneficiaries	1	16
Complaint systems	1	13
Supervisory review of waiver beneficiary assessments or plans of care	7	11
Corrective action plans	2	9
Sanctions and penalties	1	7

[22]We reviewed waiver applications for the 15 largest state waivers for the elderly based on the number of beneficiaries. These waivers were from the following states: Colorado, Florida, Georgia, Illinois, Kentucky, Missouri, New York, North Carolina, Ohio, Oregon, South Carolina, Texas, Virginia, Washington, and Wisconsin. In 1999, these waivers ranged in size from 10,514 beneficiaries in Virginia to 27,978 beneficiaries in Texas.

Quality assurance mechanism	Waiver application: number of states citing mechanism (n=15 largest state waivers for the elderly)	Annual state report: number of states citing mechanism[a] (n=40 states)
Analysis of automated waiver program data	1	4
Internal or external evaluations of waiver program	0	4
Waiver program manuals	0	4

Source: CMS.

Note: GAO analysis of the most recent waiver application for the 15 largest HCBS waivers serving the elderly and the most recent annual state reports for 52 waivers serving the elderly submitted to CMS regional offices as of July 2002.

[a]We reviewed 70 annual state waiver reports from 49 states and the District of Columbia. Fifty-two of these annual reports from 40 states contained some information about states' monitoring processes for HCBS waivers serving the elderly. States may have more than one HCBS waiver serving the elderly.

- Annual waiver reports. Compared to waiver applications, annual state waiver reports identified more quality assurance mechanisms for waivers serving the elderly. The quality assurance mechanisms states' annual reports cited most frequently included (1) audits of case management agencies, (2) reviews of provider or direct-care staff, (3) licensure and certification of providers, (4) beneficiary satisfaction surveys or interviews, (5) case management, and (6) training and technical assistance. As shown in table 3, these six mechanisms were mentioned by at least half of the 40 states that provided such information.[23] However, as was the case with most of the 15 waiver applications we reviewed, complaint systems, corrective action plans, and sanctions were identified less frequently. For example, only 13 of the 40 states identified complaint systems for waivers serving elderly beneficiaries as a monitoring tool in their annual waiver reports.[24] Responding to beneficiary complaints is a key element in protecting vulnerable nursing home residents and home

[23]As of June 2002, there were 77 waivers serving the elderly. However, our analysis includes 2 additional waivers for the elderly that had been terminated or not renewed as of that date because the states were able to provide us with their most recent annual report.

[24]Only 1 of the 15 waiver applications we reviewed indicated that the state had a complaint system for the providers under its waiver. For a discussion of the role of complaint systems, see U.S. General Accounting Office, *Nursing Homes: Sustained Efforts Are Essential to Realize Potential of the Quality Initiatives*, GAO/HEHS-00-197 (Washington, D.C.: Sept. 28, 2000) and U.S. General Accounting Office, *Medicare Home Health Agencies: Weaknesses in Federal and State Oversight Mask Potential Quality Issues*, GAO-02-382 (Washington, D.C.: July 19, 2002).

health beneficiaries. Moreover, 18 of the elderly waiver reports (26 percent) from 12 states did not include a description of the process for monitoring the standards and safeguards under the waiver, as required on the reporting form.

State officials in South Carolina, Texas, and Washington informed us they use a wider range of quality assurance mechanisms in their waiver programs than were described in either their waiver application or their annual state waiver report. Officials in Washington informed us they use 12 of the 14 mechanisms identified in table 3, yet they included only 2 of these on their application and 3 in their most recent annual report. For example, Washington operates a complaint system for waiver providers but did not refer to this approach in its waiver application or annual report. On the other hand, only Washington included reviews or audits of case managers or case management agencies in its application or annual report, yet all three states provided information on their use of this quality assurance tool during our interviews. States' formal reports to CMS on their quality assurance mechanisms may therefore understate the nature and extent of their oversight approaches.

State Oversight and Quality Issues in Waivers Serving the Elderly Have Been Identified by CMS Regional Offices and States

Although information on the quality of care provided in the 79 waiver programs serving the elderly is limited, state oversight problems were identified by CMS regional offices or states in 15 of 23 waivers and quality-of-care problems in 36 of 51waivers that we were able to examine.[25] We were unable to analyze findings related to 28 waivers serving the elderly for various reasons: they lacked a current regional office review or a waiver review report was never finalized,[26] the annual state waiver report lacked the relevant information, or the waivers were too new to have an annual state report. Because of incomplete information and the absence of

[25]Our analysis of state oversight issues is based on 23 discrete waivers that had either a regional office review or a state audit. State auditors are responsible for reviewing state programs and may include Medicaid HCBS waiver programs as a part of these audits. Annual state waiver reports do not address state oversight weaknesses. Our analysis of quality-of-care issues is based on 51 discrete waivers that had either a regional office review or an annual state report. As of June 2002, there were 77 waivers serving the elderly. However, our analysis of state oversight and quality-of-care problems included 2 additional waivers for the elderly that had been terminated or not renewed as of that date because they had had a regional office review during the October 1998 through May 2002 time period we examined.

[26]Regional office review reports that did not have a final report were not included in our analysis.

current reviews for many of the active waivers, the extent of quality-of-care problems is unknown.

State Oversight Weaknesses

CMS regional office reviews or state audits identified weaknesses in state oversight for waivers serving the elderly in 15 of the 23 waivers we examined. In some cases, the waiver programs did not have essential oversight systems or processes in place. For example, in the case of a Virginia assisted living waiver that had over 1,250 beneficiaries, the Philadelphia regional office found several state oversight problems, including (1) no system in place to track the completion of the required annual resident assessments, (2) insufficient monitoring to ensure that beneficiaries were cared for in settings able to meet their needs, (3) insufficient monitoring to ensure that state standards were met for basic facility safety and hygiene, and (4) failure to inspect medication administration records sufficiently to ensure that medication was being dispensed safely and by qualified staff. The regional office identified serious lapses in Virginia's oversight of the waiver and the protection of beneficiaries, resulting in both medical and physical neglect of waiver beneficiaries. On the basis of the regional office review findings, HCFA allowed the waiver to expire in March 2000. In other cases, states may have had an oversight system or process in place, but they were determined to be inadequate. Five state audit agency reports we reviewed identified inadequate monitoring systems in state waiver programs. For example, Connecticut had a policy in place for monitoring and evaluating its HCBS waiver program, but, from January 2000 through March 2001 it conducted no quality assurance reviews of the agencies it contracted with to coordinate and manage services for waiver beneficiaries.

Quality-of-Care Related Problems

CMS regional office reviews and states' annual waiver reports identified quality-of-care related problems in 36 of 51 HCBS waiver programs for the elderly that we were able to examine. Specifically, they found weaknesses in the delivery of key elements of home and community-based services that could affect waiver beneficiaries' health and welfare (see table 4). Typically, the reports did not provide sufficient detail to demonstrate the impact of these weaknesses on waiver beneficiaries. Consequently, few, if any, specific cases of beneficiary harm were identified.

Table 4: Frequently Cited Quality-of-Care Problems Identified by CMS Regional Offices or States in HCBS Waivers Serving the Elderly

Problem area	Example	Number of 51 waivers in which problem was identified
Provision of authorized or necessary services	Beneficiary not receiving services identified as being needed.	20
Plan of care	Beneficiary's care needs not addressed in plan of care.	20
Case management	Case manager for HCBS waiver program not providing ongoing assessment and monitoring of waiver beneficiaries or inadequate follow-up of changes in beneficiaries' care needs.	20
Staffing	Insufficient number of staff to provide adequate care or staff not having appropriate credentials or training to provide care.	12
Assessment	Beneficiary's needs not assessed or reassessment not completed in a timely manner.	11
Documentation of service delivery	Incomplete record of waiver services provided to beneficiary.	8
Training	Case managers identified as needing additional training on Medicaid eligibility.	8
Quality assurance or quality of care	HCBS waiver program lacked a formal quality assurance system; poor quality of care or services were identified.	7
Medication	Unable to document that facilities providing care to waiver beneficiaries dispensed medication safely and by qualified staff.	4

Source: CMS.

Notes: GAO analysis of CMS regional office final waiver review reports for HCBS waivers serving the elderly issued from October 1998 to May 2002 and the most recent annual state waiver reports for 51 waivers serving the elderly.

Fifteen waivers serving the elderly had no problems identified in their regional office reviews or annual state reports; the remaining 36 waivers had problems related to quality of care. When both the CMS regional office and the state identified a waiver as having the same type of problem, we counted that problem only once.

The most frequently identified quality-of-care problems in waivers serving the elderly involved failure to provide authorized or necessary services, inadequate assessment or documentation of beneficiaries' care needs in the plan of care, and inadequate case management.

- Provision of authorized or necessary services. Identified problems included (1) services identified in plans of care not rendered, (2) inadequate nutrition provided to waiver beneficiaries, and (3) discontinuation of services without adequate notice to beneficiaries. For example, CMS's Dallas regional office found that significant numbers of Oklahoma waiver beneficiaries did not receive personal care services from their direct-care provider—4,303 beneficiaries (27 percent) received none of their authorized personal care services and 7,773 beneficiaries (49 percent) received only half of their authorized services. While the consequences for beneficiaries were not identified in this review, failure to

provide authorized needed services may result in harm and could affect the continued ability of beneficiaries to be cared for at home.

- Plan of care. Issues included plans of care that (1) insufficiently addressed the needs of waiver beneficiaries, (2) were not completed or updated appropriately, and (3) were missing from beneficiaries' files. In the review of one of the Florida waivers, CMS's Atlanta regional office staff found several instances where needs identified through individual assessments, including significant changes in waiver beneficiaries' conditions, were not addressed in the plan of care, a situation that could lead to beneficiaries not receiving the necessary services. Without an appropriate plan of care to direct the type and amount of services to be delivered, the waiver beneficiary may not receive an adequate level of care.
- Case management. Examples of case management problems included case managers who (1) were unaware of beneficiaries having lapses in delivery of care, (2) were not always aware of procedures or protocols for reporting abuse, neglect, or exploitation, (3) failed to complete resident assessments—service plans were either incomplete or inappropriate, and updates to plans of care were late, or (4) did not always appear to have a clear understanding of service definitions or requirements of the waiver or Medicaid program.

CMS Guidance to States and Oversight Of HCBS Waivers Are Inadequate to Ensure Quality Care

CMS has not developed detailed guidance for states on appropriate quality assurance approaches as part of the initial waiver approval process. Moreover, although CMS oversight has identified some quality problems, it does not adequately monitor HCBS waiver programs or the quality of care provided to waiver beneficiaries for waivers serving the elderly as well as those serving other target populations.[27] CMS does not hold its regional offices accountable for conducting and documenting periodic waiver reviews, nor does CMS hold states accountable for submitting annual reports on the status of quality in their waivers. As of June 2002, about one-fifth of the 228 waivers in place for 3 years or more had either never been reviewed or were renewed without a review.[28] We found that the reviews varied considerably in the number of beneficiary records

[27]Because CMS regional offices have responsibility for oversight of all HCBS waivers, including those serving the elderly, our analysis included all HCBS waivers as of June 2002.

[28]As of June 2002, CMS regional offices had oversight responsibility for 263 HCBS waivers. These waivers included other population groups as well as those serving the elderly. Of this total, 228 had been in place for 3 years or more and should have had a regional office review; 70 of these 228 waivers served the elderly. Nine waivers serving the elderly had not been in place for 3 years or more and therefore were not included in this analysis.

examined and the method of determining the sample, potentially limiting the generalizability of findings. According to CMS regional office staff, the allocation of staff resources and travel funding levels have at times impeded the scope and timing of their reviews. In addition, some regional office staff told us that limited travel funds have resulted in the substitution of more limited desk reviews for on-site visits and in the conduct of reviews with one staff member when two would have been preferable.

CMS Lacks Detailed Guidance for States on the Necessary Components of a Quality Assurance System

CMS has a number of initiatives under way to generate information and dialogue on quality assurance approaches, but the agency's initiatives stop short of (1) requiring states to submit detailed information on their quality assurance approaches when applying for a waiver or (2) stipulating the necessary components for an acceptable quality assurance system. CMS recognizes that insufficient attention has been given to the various mechanisms that states could and should use to monitor quality in their waiver programs. As described in appendix VI, the initiatives CMS has under way include identification of strategies that states are currently using to monitor and improve quality in home and community-based care, distribution of a guide on quality improvement and assessment mechanisms for states and regional offices, and provision of a variety of technical assistance and resources to states. The agency also has implemented a new HCBS waiver quality review protocol for use by regional offices in assessing whether state waivers should be renewed.[29] Regional office staff told us that some states have begun to modify their approaches to quality assurance in HCBS waivers based on the use of the new waiver review protocol. For example, Washington officials established a new quality assurance unit within the agency that oversees its waiver for the elderly. In May 2002, CMS also introduced a voluntary application template for its new consumer-directed HCBS waiver that asks for a detailed description of states' quality assurance and improvement programs, including (1) the frequency of quality assurance activities, (2) the dimensions monitored, (3) the qualifications of quality assurance staff, (4) the process for identifying problems, including sampling

[29]This protocol was developed to provide a standardized and comprehensive set of procedures for regional office staff to follow when conducting periodic waiver reviews. See Department of Health and Human Services, HCFA, *HCFA Regional Office Protocol for Conducting Full Reviews of State Medicaid Home and Community-Based Services Waiver Programs* (Washington, D.C.: Department of Health and Human Services, Dec. 20, 2000).

methodologies, (5) provisions for addressing problems in a timely manner, and (6) the system for handling critical incidents or events. While these CMS activities are intended to facilitate the development of HCBS-related quality assurance approaches, they do not constitute a consistent set of minimum requirements and guidance for states' use to obtain approval for their HCBS programs.

CMS Is Not Holding Regional Offices or States Accountable for Oversight of HCBS Waiver Quality

In addition to the lack of detailed guidance for states, CMS is not holding its own regional offices or states accountable for oversight of the quality of care provided to individuals served under HCBS waivers. CMS regional offices are expected to conduct periodic waiver reviews to determine whether states are protecting the health and welfare of waiver beneficiaries. Annual state reports are required by statute, and CMS regulations indicate that they are intended to play a key role in determining whether a waiver should be renewed.[30] We found that regional offices are neither conducting waiver reviews prior to renewal nor obtaining complete annual state reports in a timely manner. As a result, CMS has not fully complied with the statutory and regulatory requirements that condition the renewal of HCBS waivers on states fulfilling their assurances that necessary safeguards are in place to protect the health and welfare of waiver beneficiaries.

CMS Regional Offices Often Are Not Conducting Timely Reviews of State HCBS Waivers

Most CMS regional offices have not conducted timely reviews of the state agencies administering waivers serving the elderly and other target populations or completed reports to document the results of their reviews. Periodic on-site reviews are used to determine, among other things, whether a state is ensuring the health and welfare of waiver beneficiaries. Guidance from CMS headquarters instructs the regional offices to conduct reviews before the first renewal of a waiver at the end of 3 years and within 5 years for subsequent waiver renewals.

Eighteen percent of all HCBS waivers (42 of 228) that have been in place for 3 years or more as of June 2002 either have never been reviewed by the regional offices or had not been reviewed prior to their last waiver renewal. Approximately 132,000 beneficiaries were served by these 42 waivers in 1999. Fourteen of the 42 waivers—serving approximately 37,000 waiver beneficiaries in 1999—have had 10 or more years elapse without a regional office review (see table 5). CMS's Dallas regional office was

[30] *See*, 50 *Fed. Reg.* 10013, 10016-17 (1985).

responsible for 9 of these 14 waivers. Over a 10-year period, a regional office should have conducted at least two reviews for each waiver. The New Mexico AIDS Waiver, initially approved in June 1987, has been in place the longest without ever being reviewed—15 years. CMS officials were aware that regional offices had not reviewed some waivers but were unaware of the extent of the problem.

Table 5: HCBS Waivers That Had 10 Years or More Elapse without Ever Having a Regional Office Review or without a Review Prior to the Last Waiver Renewal, as of June 2002

State	Target population	Number of waiver beneficiaries[a]	Number of years without a CMS regional office review
No regional office waiver review ever conducted			
Dallas regional office			
New Mexico	Persons with AIDS	60	15
Oklahoma	Persons with mental retardation	2,550[b]	14
Texas	Medically dependent children	895[b]	14
Louisiana	Elderly and persons with disabilities	393	12
New Mexico	Medically fragile children	152	11
Texas	Persons with mental retardation and related conditions	1,047	11
Texas	Persons with mental retardation	4,956[b]	10
Texas	Persons with mental retardation	224[b]	10
Louisiana	Elderly and persons with disabilities	113	10
Seattle regional office			
Idaho	Elderly and persons with disabilities	1,000	12
Idaho	Persons with mental retardation and developmental disabilities	512	12
No regional office waiver review conducted prior to last waiver renewal			
Kansas City regional office			
Iowa	Elderly	3,994	11
Missouri	Elderly	20,821	10
San Francisco regional office			
Hawaii	Persons with AIDS	66	12

Source: CMS.

Note: GAO analysis of data provided by CMS, June 2002.

[a]The number of HCBS waiver beneficiaries is based on 1999 HCFA Form 372 data. See Harrington, Aug. 2001.

[b]Author's estimate. See Harrington, Aug. 2001.

As of June 2002, based on an analysis of the most recent regional office review that occurred prior to October 2001 for each of the waivers, we found that 23 percent of the review reports (36 of 158) in over half of the regional offices had not been finalized.[31] CMS requires its regional offices to prepare a final report on each HCBS review to document their findings, recommendations, and the state response. Without such a final report, there is no formal document to indicate whether a state has fulfilled the required assurances, including those related to the health and welfare of waiver beneficiaries. The New York regional office did not finalize 11 of its 12 reviews, dating back to 1998, and the San Francisco regional office did not finalize 7 of its 13 reviews, 1 of which was for a review that occurred in 1990. Without a final report documenting the review results, CMS cannot be assured that, if problems were identified, they were appropriately addressed.

CMS Does Not Obtain Timely and Complete State Annual Waiver Reports

Many state annual waiver reports submitted to CMS regional offices are neither timely nor complete. During the interval between regional office reviews, the required annual state waiver reports provide key information on how states monitor beneficiaries' quality of care and on any quality-of-care related problems. According to regional office officials, states routinely fail to submit these annual reports within the required time frame—within 6 months after the period covered. In August 2000, officials in CMS's Philadelphia regional office reported that they had current annual state reports for less than half (11 of 28) of the waiver programs in their region. Our review of the most recent annual state reports for 70 of 79 HCBS waivers serving the elderly confirmed that producing these reports remains a problem: (1) reports for more than a third of the waivers were at least 1 year late—the most recent report from one of Louisiana's HCBS waivers was for calendar year 1997, (2) reports for approximately one-fourth of the waivers provided no information on whether deficiencies had been identified through the monitoring processes,[32] and (3) five reports indicated that deficiencies had been identified but provided no

[31]In our analysis, we included only those reviews that had taken place prior to October 2001, allowing 9 months from the time the regional office conducted the waiver review to final report issuance—from October 2001 to June 2002. CMS allows up to 4 months from the time the regional office completes all waiver review activities to issuance of a final report documenting the review findings.

[32]As noted earlier, about one-quarter of annual state reports for waivers serving the elderly did not include information requested concerning the approaches used to monitor quality assurance.

additional information about the nature of or response to the problems. [33] CMS headquarters has no central repository for annual state reports but is in the process of establishing a centralized database for state report information sometime in 2003, a development that could facilitate ongoing monitoring of the timeliness and completeness of these reports.

Extent of Oversight Weaknesses Evident in 15 Largest Waivers Serving the Elderly

Our analysis of CMS's oversight activities for the 15 largest HCBS waivers serving the elderly demonstrates the extent of oversight weaknesses. Overall, 8 of the 10 CMS regional offices provided inadequate oversight for 13 of these 15 largest state waivers for the elderly, which, in 1999, served about 215,000 beneficiaries—over half (57 percent) of the total elderly waiver beneficiary population at that time (see table 6). We found that

- Four of the 15 HCBS waivers were not reviewed in a timely manner by the CMS regional office—none of the 4 had reviews for 8 or more years and yet were renewed.[34]
- Four of the 15 waivers had no waiver review final report completed by the regional office. Two of the reviews occurred in 1999, and for the remaining 2 waivers the regional office could not tell us the date of the reviews or whether a final report was available.
- Four of the 15 waivers lacked a timely annual state report to the regional office. As of April 2002, the most recent annual report for these 4 waivers was either for the waiver period ending August 1999 (1 waiver) or September 2000 (3 waivers).
- Seven of the 15 waivers had annual state reports that were incomplete because they either lacked information on their quality assurance mechanisms or on whether deficiencies had been identified.

[33]Eight of the remaining 9 waivers were new and had not yet had an annual report submitted. The CMS Atlanta regional office did not provide a current annual report for 1 waiver. As of June 2002, there were 77 waivers serving the elderly. However, our analysis includes 2 additional waivers for the elderly that had been terminated or not renewed as of that date because the state was able to provide us with their most recent annual report.

[34]These 4 waivers are a subset of the 42 HCBS waivers in place for 3 years or more that either were never reviewed by the regional offices or were not reviewed prior to their last renewal.

Table 6: Status of CMS and State Monitoring for the 15 Largest HCBS Waivers Serving the Elderly

State	Number of waiver beneficiaries[a]	CMS waiver review not timely or report not finalized	Annual state report not timely or documentation insufficient[b]
New York regional office			
New York	19,732	X	X
Philadelphia regional office			
Virginia	10,514		X
Atlanta regional office			
South Carolina	14,361	X[c]	X
Georgia	14,018		X
Florida	13,762		X
Kentucky	13,339		X
North Carolina	11,159	X[c]	X
Chicago regional office			
Ohio	26,135		
Illinois	17,396[d]	X	X
Wisconsin	13,900	X	
Dallas regional office			
Texas	27,978	X	X
Kansas City regional office			
Missouri	20,821	X	
Denver regional office			
Colorado	11,481	X	
Seattle regional office			
Oregon	26,410		X
Washington	25,718		

Source: CMS.

Note: GAO analysis of data provided by CMS, June 2002 and the most recent annual state waiver reports. The 15 largest HCBS waivers serving the elderly are based on the number of beneficiaries.

[a]The number of HCBS waiver beneficiaries is based on 1999 HCFA Form 372 data. See Harrington, Aug. 2001.

[b]The annual report is required by statute and CMS directs states to (1) submit such reports within 6 months after the period covered, and (2) include information on how the state implements, monitors, and enforces its health and welfare standards and the waiver's impact on the health and welfare of beneficiaries.

[c]The CMS regional office could not provide the date that the last waiver review was conducted or specify whether a report had been finalized.

[d]Author's estimate. See Harrington, Aug, 2001.

Scope and Duration of Regional Office Waiver Reviews Are Limited

The limited scope and duration of periodic regional office waiver reviews raise a question about the confidence that can be placed in findings about the health and welfare of waiver beneficiaries. CMS regional offices conduct reviews using guidance provided by headquarters. The guidance instructs regional office staff to review beneficiary records; interview waiver beneficiaries, primary direct-care staff of waiver providers, and case managers; and observe waiver beneficiaries and the interaction between the beneficiary and direct-care staff. This guidance was updated in January 2001 when use of the new HCBS waiver quality review protocol became mandatory. However, the new protocol does not address important operational issues such as

- an adequate sample size or sampling methodology for the beneficiary record reviews and interviews to provide a basis for generalizing the review findings;
- whether the sample should be stratified according to the different groups served under the waiver (i.e., for a waiver serving both the elderly and the disabled, selecting a stratified sample based on the proportion of persons aged 65 and over and those aged 18 to 64 with disabilities); and
- the appropriate duration of an on-site review, taking into consideration the number of sites and beneficiaries covered in the waiver.

Our analysis of regional office review reports for 21 HCBS waivers serving the elderly found that the reviews varied considerably in the number of beneficiary records evaluated and their method of determining the sample, potentially limiting their ability to generalize findings from the sample to the universe of waiver beneficiaries.[35] Specifically, we found a wide range of sample sizes in 15 of the 21 regional office reviews that included such information. The sample sizes for record reviews ranged from 14 beneficiaries (of 73 served) in the Boston regional office review of the Vermont waiver to 100 beneficiaries (of 24,000 served) in the Seattle regional office review of the Washington waiver. (See app. VII for a summary of the sample sizes in the regional office reviews.) Eleven of the 15 CMS waiver review reports included information on the specific number of beneficiaries interviewed or observed during the review; however, we could not determine whether beneficiary interviews or observations had been conducted in other waiver reviews. The method by which the beneficiary record review samples were selected varied, with

[35]We requested that regional offices provide us with final reports for HCBS waivers serving the elderly issued from October 1998 to May 2002. Eight of the 21 reviews we analyzed were completed after CMS's new HCBS waiver quality review protocol was implemented.

some regional offices using randomized sampling methods, some basing their sample on geographic location, and others reporting no method of sample selection.

For most of these same 15 waivers serving the elderly, we found that the regional staff typically spent 5 days conducting the waiver review—regardless of the number of waiver beneficiary records sampled or the overall size of the waiver. However, the Seattle regional office staff conducted only three reviews in the past 4 years, targeting its largest HCBS waivers. For example, the regional office has spent 3 to 4 weeks per waiver for the on-site portion of the review and another week for state agency interviews and review of documents. Generally, the number of beneficiary records reviewed and beneficiaries interviewed is dependent on (1) the number of days allocated to the waiver review by a regional office and (2) the number of regional office staff members available.

Limited Regional Office Resources Available for Oversight of HCBS Waivers

The limited number of assigned staff and available clinical specialists, coupled with insufficient travel funds allocated to regional office oversight of HCBS waivers, have contributed to the timeliness and scope problems we identified. According to regional offices, the level of attention given to HCBS waiver oversight, including periodic reviews when waivers come up for renewal, is at the discretion of regional office management and competes with other workload priorities.[36] In August 2000, some regional office officials formally communicated to HCFA headquarters their concern that the agency was not devoting sufficient resources to properly monitor the quality of HCBS waiver programs. Regional office officials responsible for waiver oversight told us that the number of staff available for waiver oversight has not kept pace with the growth in the number of waivers and beneficiaries served and that resource issues remain a key challenge for waiver oversight.

[36]Headquarters officials are responsible for establishing waiver policy and the 10 regional offices have responsibility for waiver oversight. Both headquarters and the regional offices answer separately to the Administrator without any formal reporting links. In earlier work, we reported that these organizational reporting lines complicated coordination and communication, weakened oversight, and blurred accountability when problems arose. See U.S. General Accounting Office, *Medicare Contractors: Further Improvement Needed in Headquarters and Regional Office Oversight*, GAO/HEHS-00-46 (Washington, D.C.: Mar. 23, 2000) and U.S. General Accounting Office, *Nursing Homes: Sustained Efforts Are Essential to Realize Potential of the Quality Initiatives*, GAO/HEHS-00-197 (Washington, D.C.: Sept. 28, 2000).

We found that CMS regional offices differed substantially in the number of staff assigned to waiver oversight and the extent to which staff with clinical or program expertise were assigned to waiver oversight. According to Dallas, Denver, and Philadelphia regional office staff, the level of resources allocated by the regional offices for such reviews dictated the number of waiver beneficiary records reviewed or beneficiary interviews conducted. Six of the 10 regional offices had two or fewer full-time-equivalent (FTE) staff assigned to monitoring HCBS waivers (see table 7).[37] Moreover, we found that the number of regional office staff assigned to monitoring HCBS waivers bore little relationship to the waiver workload. For example, the Chicago regional office had six FTE staff to monitor 34 HCBS waivers with 131,902 waiver beneficiaries, while the Dallas regional office had one-and-a-half FTE staff for 28 HCBS waivers with 63,614 waiver beneficiaries. Until a few years ago, one person in the Philadelphia regional office was assigned to oversee HCBS waivers—despite growth in the number and size of the region's HCBS waivers over the past decade.[38]

[37]We asked the regional offices to distinguish between staff assigned to HCBS waiver oversight and staff who may be temporarily assigned, such as those borrowed from another division for their specific expertise.

[38]In 1992, the Philadelphia regional office was responsible for oversight of 16 waivers serving approximately 17,000 waiver beneficiaries. By 1999, the regional office had responsibility for 23 waivers serving over 48,500 waiver beneficiaries. As of 2002, the regional office's total number of waivers had grown to 33. Since early 2000, this regional office has hired or reassigned approximately three additional staff to focus on waiver oversight.

Table 7: Number and Specialty of CMS Regional Office Staff Assigned to Oversee HCBS Waivers

CMS regional office	Number of HCBS waivers (number of waivers for the elderly)	Number of HCBS waiver beneficiaries[a] (number of elderly waiver beneficiaries)	Number of FTE staff assigned to oversee waivers	Specialist staff assigned to oversee waivers
Boston	26 (9)	45,390 (20,190)	1	No
New York	15 (3)	69,390 (24,319)	<2[b]	No
Philadelphia	33 (8)	48,537 (18,554)	4.1	No
Atlanta	43 (15)	122,120 (78,669)	<3.5[b]	Yes[c]
Chicago	34 (10)	131,902 (73,935)	6	No
Dallas	28 (9)	63,614 (47,454)	1.5	No
Kansas City	23 (4)	59,253 (33,873)	1.4	Yes[d]
Denver	29 (7)	32,866 (15,420)	4	Yes[e]
San Francisco	15 (6)	51,068 (10,829)	2	No
Seattle	17 (6)	64,012 (53,840)	.4	No

Source: CMS.

Note: GAO analysis of data provided by CMS, June 2002.

[a]The number of HCBS waiver beneficiaries is based on 1999 HCFA form 372 data. See Harrington, Aug. 2001.

[b]Staff are not working full-time on HCBS waivers.

[c]One qualified mental retardation professional and one qualified mental health professional.

[d]One individual who is both a registered nurse and a qualified mental retardation professional.

[e]One registered nurse and one part-time qualified mental retardation professional.

As shown in table 7, 3 of the 10 regional offices had specialists assigned to waiver oversight, such as registered nurses or qualified mental retardation professionals.[39] When asked to identify one of the greatest improvements that could be made in federal waiver oversight, 3 of the 10 regional offices identified the direct assignment of specialist staff. CMS's waiver review protocol specifies that the participation of clinical and other specialist staff is important to assessing issues related to beneficiaries' health and welfare. However, many regional offices indicated that they had to "borrow" specialist staff from other departments within the region in order to conduct their waiver reviews. The Seattle and Boston regional offices provide contrasting examples of the role played by regional office management in obtaining clinical staff to conduct reviews. According to Seattle regional office staff, it has been a challenge to obtain specialist

[39]Two of these three regions indicated that they had intentionally hired someone with a clinical specialty for waiver reviews.

staff on the waiver review teams. For 4 to 5 years, the region did not conduct any HCBS waiver reviews. In the past 4 years, it has only conducted three reviews—regardless of the number of waivers due for review. The region has four waivers that have never been reviewed, two dating back to 1989. According to the staff, the prior regional administrator did not target resources for HCBS waiver reviews, and it was difficult to obtain clinical and other specialist staff from other departments to assist in conducting reviews. Although it has no specialist staff assigned to waivers, Boston regional office officials informed us that conducting HCBS waiver reviews has been a management priority, as evidenced by the fact that the region always includes a registered nurse or other relevant specialist on the review team. We noted that the Boston regional office has conducted timely reviews of all of its waivers.

When asked to identify the greatest challenges related to HCBS waiver oversight, 4 of the 10 CMS regional offices identified insufficient travel funding. Regional office staff indicated that there appears to be no correlation between the amount of travel dollars made available by the regional offices for the reviews and the review schedule set forth by CMS headquarters. Moreover, they told us that they had to compete for limited travel resources with the regional office staff responsible for overseeing nursing homes. Regional office responses to inadequate travel funds have included (1) conducting a "desk review" without visiting state agency officials, providers, and waiver beneficiaries, (2) limiting the number of days allotted for the review, (3) reducing the number of staff assigned to conduct the review, or (4) not reviewing a particular waiver at all. In the New York regional office, a lack of travel funds led to desk reviews for 9 of 15 waivers. According to the Philadelphia regional office's final report for a Virginia HCBS waiver, some cases that should have been pursued were not reviewed because only 1 week had been allotted for fieldwork, and 2 of the 18 cases selected for field review were dropped because there was insufficient time to conduct the review. In 2001, the Chicago regional office conducted a limited on-site review of a Michigan HCBS waiver serving over 6,000 beneficiaries. During the review, three case files were examined and one beneficiary was interviewed. According to Denver regional office officials, travel budget problems have meant that the reviews are conducted by one staff member when two would be preferable.

Conclusions

HCBS waivers give states considerable flexibility to establish customized programs offering long-term care services for specific populations, such as elderly persons, persons with mental retardation, or children with special needs. While maintaining this flexibility is important, insufficient emphasis has been placed on balancing flexibility with measures to ensure accountability. At present, states may obtain a waiver serving the elderly with a limited explanation of how they plan to monitor quality, and CMS has not held states accountable for submitting complete and timely annual waiver reports detailing their quality assurance activities. Moreover, CMS has not fully complied with the statutory and regulatory requirements that condition the renewal of HCBS waivers on whether the state has fulfilled its assurances that necessary safeguards are in place to protect the health and welfare of waiver beneficiaries. The current size and likely future growth in HCBS waiver programs that serve a vulnerable population—particularly elderly individuals eligible for nursing home placement—make it even more essential for states to have appropriate mechanisms in place to monitor the quality of care.

While CMS requires periodic reviews of state waiver programs to help ensure that beneficiaries' health and welfare are adequately protected, many have been renewed without such a review. In addition, guidance on how these waiver reviews should be conducted does not address important operational issues such as sample size and sampling methodology. Consequently, there is little relationship among the amount of time spent on-site conducting waiver reviews, the number of beneficiary records reviewed, and the number of beneficiaries served. CMS expects its regional offices to interview and observe waiver beneficiaries to obtain a first-hand perspective on care delivery and the adequacy of case management, but beneficiary interviews are not a component of all regional office reviews. Moreover, staff resources and travel funds currently allocated to conduct waiver reviews are insufficient. Without necessary attention from CMS, these guidance and resource issues will only be exacerbated by the expected future growth in the number of persons served through HCBS waiver programs. CMS has a number of initiatives directed towards improving quality and quality assurance for home and community-based waiver programs. They do not, however, address the specific oversight weaknesses we have identified in this report, such as the lack of detailed criteria or guidance for states regarding the necessary components of a quality assurance system to help ensure the health and welfare of waiver beneficiaries.

Recommendations for Executive Action

To ensure that state quality assurance efforts are adequate to protect the health and welfare of HCBS waiver beneficiaries, we recommend that the Administrator of CMS

- develop and provide states with more detailed criteria regarding the necessary components of an HCBS waiver quality assurance system,
- require states to submit more specific information about their quality assurance approaches prior to waiver approval, and
- ensure that states provide sufficient and timely information in their annual waiver reports on their efforts to monitor quality.

To strengthen federal oversight of the growing HCBS waiver programs and to ensure the health and welfare of HCBS waiver beneficiaries, we recommend that the Administrator

- ensure allocation of sufficient resources and hold regional offices accountable for conducting thorough and timely reviews of the status of quality in HCBS waiver programs, and
- develop guidance on the scope and methodology for federal reviews of state waiver programs, including a sampling methodology that provides confidence in the generalizability of the review results.

Agency and State Comments and Our Evaluation

We provided a draft of this report to CMS and South Carolina, Texas, and Washington, the three states in which we obtained a more in-depth perspective on states' quality assurance approaches. (CMS's comments are reproduced in app. VIII.) CMS affirmed its commitment to its ongoing responsibility, in partnership with the states, to ensure and improve quality in HCBS waivers. The agency stated that the federal focus should be on assisting states in the design of HCBS programs, respecting the assurances made by states, improving the ability of states to remedy identified problems, providing assistance to states to improve the quality of services, and thereby assisting people to live in their own homes in communities of their choice. CMS generally concurred with our recommendations to improve state and federal accountability for quality assurance in HCBS waivers but raised concerns about our definition of quality, how best to ensure quality in state waiver programs, the appropriate state and federal oversight roles, and the resources and guidance required to carry out federal quality oversight.

Definition of Quality

CMS stated that the draft report's definition of quality in waivers was too narrow because it ignored a wide variety of activities used to promote quality. Furthermore, CMS cited the availability of a broad array of waiver services with choice over how, where, and by whom services are delivered as important to beneficiaries' quality of life. According to CMS, growth in the number of persons served by HCBS waivers was evidence of beneficiary satisfaction. (See CMS's "General Comments," 2 and 3.)

Rather than defining quality ourselves, we reported the approaches states used to assure quality in their waiver programs. By analyzing state applications for waivers serving the elderly and state annual waiver reports, we identified a broad array of state quality assurance activities, including licensing and certification of providers and beneficiary satisfaction surveys (see tables 2 and 3). We disagree with CMS's assertion that beneficiaries' preference for services that allow them to remain in the community can be equated with satisfaction for the services delivered. Even assuming that beneficiary satisfaction alone is a reliable indicator of quality, CMS offered no empirical evidence to support its position. Only about half of the state annual waiver reports we reviewed indicated that states measured beneficiary satisfaction with services. Moreover, our review of quality-of-care problems identified in waiver programs serving the elderly demonstrated that failure to provide needed or authorized services was a frequently cited problem. For example, as we noted in the draft report, a CMS review found that 27 percent of beneficiaries served by one state's HCBS waiver for the elderly did not receive any of their authorized personal care services, and 49 percent received only half.

Quality Assurance Approaches

CMS commented that the draft report failed to recognize that HCBS programs require a different approach to quality than their institutional alternatives and "leaves the distinct impression that the most effective way to assure and improve quality is through the process of inspection and monitoring." CMS asserted that design of an HCBS waiver, as opposed to monitoring its implementation, is the most important contributor to quality, and the agency's recent efforts have focused on working with states to improve design decisions and design options. (See CMS's "General Comments," 4 and 7.)

We disagree with CMS's characterization of our findings. Our report recognizes the importance of maintaining states' considerable flexibility in ensuring quality in HCBS waivers but concludes that insufficient emphasis has been placed on balancing this flexibility with measures to ensure the accountability called for by both statute and regulations. Contrary to

CMS's comments, we did not recommend an additional or increased federal oversight role or the adoption of oversight systems such as those used for institutional providers. Our analysis and conclusions were based on the criteria established in both statute and regulations that entail federal oversight of waivers and that condition federal approval and renewal of waivers on states' demonstrating to CMS that they have established and are fulfilling assurances to protect the health and welfare of waiver beneficiaries. We found that CMS currently receives too little information from states about their quality assurance approaches to hold them accountable, raising a question as to whether the agency has adequate information to approve or renew some waivers. While we agree that waiver design is important to ensuring quality, a state's implementation of its quality assurance approaches is equally, if not more, important. In its protocol for reviewing states' HCBS waivers, CMS gives equal emphasis to both the design and implementation of quality assurance mechanisms. Despite its concerns, CMS generally concurred with our recommendation to develop and provide states with more detailed criteria regarding the necessary components of an HCBS waiver quality assurance system. CMS cited its current effort to provide such guidance and indicated that it would work to more clearly define its criteria and expectations for quality.

State and Federal Roles in Ensuring Quality

CMS commented that "the report lends itself to the conclusion that the federal government ought to be the primary source of quality monitoring and improvement, and fails to recognize that the federal statutes convey respect for state authority and competence in the administration of HCBS programs." (See CMS's "General Comments," 6.) We agree that the states and the federal government have distinct quality monitoring roles but believe that CMS has mischaracterized our description of those roles as defined in statute and regulations. In addition, we believe that CMS has understated the importance of federal oversight.

The report describes states' statutory and regulatory responsibility to (1) include information in their waiver applications on their approaches for protecting the health and welfare of HCBS beneficiaries and (2) report annually on state quality assurance approaches and deficiencies identified through state monitoring. We reported that waiver applications contained limited information on state quality assurance approaches and that many state annual waiver reports were neither timely nor complete. Eleven of the 15 applications for the largest waivers serving the elderly included none of the following well-recognized quality assurance tools: complaint systems, corrective action plans, sanctions, or beneficiary satisfaction

surveys. Annual reports for more than a third of 70 waivers serving the elderly were at least 1 year late, and one-quarter of such reports did not indicate whether deficiencies had been identified, as required. CMS acknowledged the need for more comprehensive information from states at the time of application and at subsequent renewals. Consistent with our recommendation, CMS agreed to revise and improve the application process and annual state waiver report to include more information on states' quality approaches and activities.

The report also describes CMS's statutory responsibility for ensuring that states adequately implement their quality assurance approaches—a responsibility operationalized in policy guidance to the agency's regional offices. Waiver reviews are expected to occur at least once during the initial 3-year waiver period and during each 5-year renewal cycle. We did not propose an expanded federal quality assurance role. We reported that, in some cases, CMS had an insufficient basis for determining that states had met the required assurances for protecting beneficiaries' health and welfare. As of June 2002, almost one-fifth of all HCBS waivers in place for 3 years or more had either never been reviewed or were renewed without a review; 14 of these waivers had 10 or more years elapse without a regional office review. Some CMS waiver reviews have uncovered serious state oversight weaknesses as well as quality-of-care problems. For example, the review of one state's waiver found both medical and physical neglect of beneficiaries because of serious lapses in state oversight, resulting in a decision to let the waiver expire. The full extent of such problems is unknown because many state waivers lacked a recent CMS review. CMS did not comment directly on our conclusion that the agency is not fully complying with statutory and regulatory requirements when it renews waivers. The agency suggested it would be far more efficient and equally effective for federal waiver reviews to focus on only one waiver in cases where there are multiple waivers in a state serving subsets of the same target group and using the same quality assurance system; however, CMS's own guidance to its regional offices calls for each waiver to receive at least one full review during a given waiver cycle, with each waiver receiving at least some level of review.[40]

[40]The only exceptions mentioned in CMS guidance apply to model waivers and those waivers serving fewer than 200 participants when the regional office determines there is a high probability that no significant quality problems exist by (1) combining the review of a smaller waiver with a larger waiver in the same state or (2) conducting an initial mini-review with the understanding that a more extensive review could follow if quality assurance problems are detected during the mini-review.

Resources and Guidance for Federal Oversight

CMS commented that the draft report's recommendations to hold regional offices accountable for conducting thorough and timely reviews of quality in HCBS waiver programs, including a sampling methodology that provides confidence in the generalizability of the review results, would require a huge new investment or redirection of federal resources. Specifically, CMS commented that the report "does not address the significant resources that would need to be found or redirected to implement its recommendations" and "fails to acknowledge the lack of appropriated funds for HCBS quality." The agency stated that such funds would have to come from CMS's operating budget. CMS also pointed out that it had already taken steps organizationally to ensure that enough resources are devoted to quality and that they are appropriately positioned within CMS. (See CMS's "General Comments," 5, 8, and 9.)

CMS's existing waiver review protocol directs regional offices to select a sample of waiver beneficiaries for activities such as interviews and observations, but it does not adequately address sampling methodology. We found that sample selection methods varied with some regional offices selecting random samples, some basing their sample on geographic location, and others reporting no methodology for sample selection. Given that the regional offices are already generalizing their findings to the waiver program as a whole, we believe explicit and uniform sample selection guidance is imperative. At the same time, we believe that, as CMS suggested, samples may appropriately be targeted to certain types of participants or services so that, over time, greater assurances are provided about the quality of care. In response to our recommendation to develop guidance on the scope and methodology for federal reviews of state waiver programs, CMS said it is committed to developing additional policy guidance.

We did not recommend significant increases in appropriated funds for conducting waiver reviews. Rather, our draft report recommended that CMS ensure allocation of sufficient resources and hold regional offices accountable for conducting thorough and timely reviews of the status of quality in HCBS waiver programs. The CMS Administrator is responsible for assessing whether existing funding levels are adequate to satisfy statutory and regulatory requirements, including periodic regional office review of the states' assurances. The Administrator may indeed conclude that, to carry out these oversight responsibilities for the growing numbers of frail beneficiaries who prefer and rely on these services, there may be a need to reallocate existing funds or to request additional funds. CMS also noted that it had recently redeployed and reorganized headquarters staff to incorporate the quality function into each program area, including the

operational unit that oversees HCBS waivers. Despite CMS's concerns about the need for significant funding increases, the agency noted the importance of further investments to advance both state and federal capability to assure quality in waiver programs.

Additional CMS Comments

CMS commented that the draft report had numerous technical inaccuracies, but cited only one and provided no additional examples or technical comments to accompany its written response (CMS's "General Comments," 1). Although CMS stated that our characterization of federal requirements concerning waiver renewals was inaccurate, its suggested changes and our report language were essentially the same. To avoid any confusion, however, we have added the statute's specific language to the background section of the report. CMS further commented that our report should recognize that the Congress created an enforcement mechanism that places great reliance on a system of assurances. Our draft report made that point while also describing CMS's responsibility, as specified in its implementing regulations, to determine that each state has met all the assurances set forth in its waiver application before renewing a waiver.

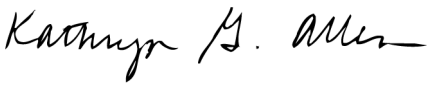
CMS stated that the draft report failed to acknowledge the steps it has already taken to ensure quality. (CMS's "General Comments," 10.) To the contrary, the draft report described each of the efforts CMS referred to as under way to monitor and improve HCBS quality and addressed each activity: the waiver review protocol, the HCBS quality framework, the development of tools to assist states, development of the Independence Plus template, and the national technical assistance contractor. However, we found that CMS's waiver review protocol does not address key issues relating to the scope and methodology of federal oversight reviews. Moreover, the use of the Independence Plus template, which requires more specific information on states' quality assurance approaches, is voluntary rather than mandatory.

State Comments

In its written comments, Texas stated that it supports proper federal oversight of HCBS waivers but stressed the need to maintain flexibility in designing waivers to meet the unique needs of residents requiring community care. The state believes that such flexibility should not be lost in establishing more specific quality assurance criteria.

As arranged with your offices, unless you publicly announce its contents earlier, we plan no further distribution of this report until 30 days after its issue date. At that time, we will send copies of this report to the Administrator of the Centers for Medicare & Medicaid Services and appropriate congressional committees. We also will make copies available to others upon request. In addition, the report will be available at no charge on the GAO Web site at http://www.gao.gov.

Please contact me at (202) 512-7118 or Walter Ochinko at (202) 512-7157 if you have questions about this report. Other contributors to this report included Eric Anderson, Connie Peebles Barrow, and Kevin Milne.



Kathryn G. Allen
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Appendix I: Scope and Methodology

This appendix describes our scope and methodology, following the order that our results are presented in the report.

Data on HCBS Waivers. To identify the universe of state HCBS waivers as of June 2002, we asked the CMS regional offices to identify each waiver, including the target population and the waiver start date. The regional offices identified a total of 263 waivers. Using this information and other data, we identified 77 waivers serving the elderly. To identify trends in Medicaid long-term care and Medicaid waiver spending, we analyzed data covering fiscal years 1991 through 2001 from HCFA reports (HCFA Form 64) compiled by The MEDSTAT Group. To identify trends in the overall number of Medicaid waiver beneficiaries, number of elderly waiver beneficiaries, average waiver size, and average per beneficiary expenditures for waivers serving the elderly, we analyzed data from state annual waiver reports (HCFA Form 372) covering fiscal years 1992 through 1999 in a database compiled by researchers at the University of California, San Francisco.[1]

State Quality Assurance Mechanisms. In the absence of comprehensive, readily available information on HCBS quality assurance mechanisms that states use, we analyzed the information available in a subset of state waiver applications and annual state waiver reports for waivers serving the elderly. Specifically, we analyzed (1) initial and/or renewal applications for the 15 largest waivers serving the elderly as of 1999 and (2) annual state waiver reports from 70 of the 79 waivers serving the

[1]See Harrington, Aug. 2001. Researchers collected HCFA Form 372 reports for most HCBS waivers from 1992 through 1999. In some cases, where the annual reports were not available, state officials provided estimates of the relevant data. In other cases, where annual reports were not available and where state officials were unable to provide an estimate, University researchers developed their own estimates for the missing data on the basis of trend information for the particular waiver. For 1992, participant and expenditure data were estimated for 21 of 155 HCBS waivers; 8 of these were waivers serving the elderly. For 1999, participant and expenditure data were estimated for 20 of 214 HCBS waivers; 3 of these were waivers serving the elderly. Where participant or expenditure data for individual states are based on such estimates, we have indicated so in the text. In addition, based on information provided by CMS, we identified 7 of the 238 waivers in this database that had been misclassified. Four waivers listed as serving the aged or aged and disabled actually served other population groups; and 3 waivers listed as serving other population groups served either the aged or aged and disabled. Our analyses reflect the actual target populations for these 7 waivers.

elderly.[2] The waiver applications are used by CMS, in part, to assess whether the quality assurance mechanisms in place warrant waiver approval. The annual waiver reports are required to provide a description of the process for monitoring the standards and safeguards under the waiver and the results of state monitoring. Of the 70 state annual waiver reports that we analyzed, 52 contained some information about states' monitoring processes. Eight of the remaining 9 annual waiver reports were new waivers for which the state had not yet submitted an annual report, and for 1 waiver, a regional office did not provide a copy of the annual state report.

State Oversight and Quality of Care. To assess state oversight issues in waivers serving the elderly, we examined regional office waiver review reports for 21 waivers and state audit reports related to 5 waivers, the only reports we were able to analyze, for a total of 23 discrete waivers.[3] To assess quality-of-care problems in waivers serving the elderly, we reviewed 51 waivers for which we were able to analyze regional office final reports and annual state reports. Regional office waiver review reports identified problems in 19 waivers, and annual state reports identified problems in 22 waivers, for a total of 36 discrete waivers.[4] These reports identified no quality-of-care problems in the remaining 15 waivers. We were unable to analyze findings from 28 additional waivers because they either (1) lacked a recent regional office waiver review completed during the period of October 1998 through May 2002 or an annual state waiver report, (2) the annual state waiver report did not address whether deficiencies had been identified, or provided no information on the deficiencies found, or (3) the

[2]As of June 2002, there were 77 waivers serving the elderly. However, our analysis of quality-of-care problems includes 2 additional waivers serving the elderly that had been terminated or not renewed as of that date because they had had a regional office review during the October 1998 through May 2002 time period we examined.

[3]Five state audit agencies—Connecticut, Delaware, Kansas, Louisiana, and Montana—provided audit reports of waiver programs serving the elderly. Three of the regional office reviews and three of the state audit reports covered the same waivers.

[4]Five of the regional office reviews and five of the annual state reports in which problems were identified covered the same waivers.

waivers were too new to have had a regional office review or to provide an annual state report.[5]

CMS Oversight. To determine the adequacy of CMS regional office oversight of states' waiver programs, we asked all 10 CMS regional offices to provide the following information for each of the waivers for which they were responsible, including both waivers for the elderly as well as those serving other target populations: (1) the waiver start date, (2) the current waiver time period, (3) the fiscal year the waiver was last reviewed, and (4) whether or not the waiver review report was finalized. Of the 263 waivers, 228 had been in place for 3 years or more and therefore should have had a regional office review. The other 35 waivers were less than 3 years old and would not have yet qualified for a review as of June 2002. For information on sample sizes and duration of the reviews, we analyzed CMS's HCBS waiver review final reports for waivers serving the elderly that were issued during the period of October 1998 through May 2002. Fifteen of the 21 waiver review reports that we received included information on the number of waiver beneficiary records reviewed and on the duration of the reviews. Some review reports also provided the number of beneficiaries that were interviewed or observed. We also discussed regional office oversight activities with CMS headquarters' staff.

[5]As of June 2002, there were 77 waivers serving the elderly. However, our analysis of state oversight and quality-of-care problems includes 2 additional waivers for the elderly that had been terminated or not renewed as of that date because they had had a regional office review during the October 1998 through May 2002 time period we examined.

Appendix II: Suggested CMS Definitions of Home and Community-Based Services in Waivers Serving the Elderly

Table 8 contains a list of services provided through the HCBS waivers serving the elderly and the suggested CMS definitions. However, states may provide alternative definitions in their waiver applications.

Table 8: Services States May Include in Their Medicaid Home and Community-Based Services Waiver

HCBS waiver service	Suggested CMS definition
Case management	Services that will assist individuals who receive waiver services in gaining access to needed waiver and other state plan services, as well as needed medical, social, educational, and other services, regardless of the funding source for the services to which access is gained.
Homemaker services	Services consisting of general household activities (e.g., meal preparation and routine household care) provided by a trained homemaker, when the individual regularly responsible for these activities is temporarily absent or unable to manage the home and care for him- or herself or others in the home.
Personal care services	Assistance with activities of daily living, such as eating, bathing, dressing, or personal hygiene. This service may include assistance with preparation of meals, but does not include the cost of the meals themselves.
Respite care services	Services provided to individuals unable to care for themselves; furnished on a short-term basis because of the absence of or need for relief for those persons normally providing the care. These services may be provided in such locations as a nursing home, hospital, or waiver beneficiary's home.
Adult day health services	Services furnished 4 or more hours per day on a regularly scheduled basis, for 1 or more days per week, in an outpatient setting, encompassing both health and social services needed to ensure the optimal functioning of the individual. Meals provided as part of these services do not constitute a "full nutritional regimen" (three meals per day). Physical, occupational, and speech therapies indicated in the individual's plan of care will be furnished as component parts of this service.
Environmental accessibility adaptations	Those physical adaptations to the home, required by the individual's plan of care, that are necessary to ensure the health, welfare, and safety of the individual or that enable the individual to function with greater independence in the home, and without which the individual would require institutionalization. Adaptations may include installation of ramps and grab-bars, widening of doorways, modification of bathroom facilities, or installation of specialized electric and plumbing systems necessary to accommodate the medical equipment and supplies that are necessary for the welfare of the individual.
Skilled nursing services	Services listed in the plan of care that are within the scope of the state's Nurse Practice Act and are provided by a registered professional nurse or licensed practical or vocational nurse under the supervision of a registered nurse licensed to practice in the state.
Transportation	Service offered to enable individuals served on the waiver to gain access to waiver and other community services, activities, and resources specified by the plan of care.
Specialized medical equipment and supplies	Specialized medical equipment and supplies include devices, controls, or appliances, specified in the plan of care, that enable individuals to increase their abilities to perform activities of daily living or to perceive, control, or communicate with the environment in which they live.
Chore services	Services needed to maintain the home in a clean, sanitary, and safe environment. These services include heavy household chores such as washing floors, windows, and walls, tacking down loose rugs and tiles, and moving heavy items of furniture in order to provide safe entry and exit.

HCBS waiver service	Suggested CMS definition
Personal emergency response systems	Electronic devices that enable certain individuals at high risk of institutionalization to secure help in an emergency. The individual may also wear a portable "help" button to allow for mobility. The system is connected to the person's telephone and, once a "help" button is activated, the telephone is programmed to signal a response center staffed by trained professionals.
Adult companion services	Nonmedical care, supervision, and socialization provided to a functionally impaired adult. Companions may assist or supervise the individual with such tasks as meal preparation, laundry, and shopping but do not perform these activities as discrete services.
Attendant care services	Hands-on care, of both a supportive and health-related nature, specific to the needs of a medically stable, physically handicapped individual. Supportive services are those that substitute for the absence, loss, diminution, or impairment of a physical or cognitive function.
Adult foster care services	Personal care and services; homemaker, chore, attendant care, and companion services; and medication oversight (to the extent permitted under state law) provided in a licensed (where applicable) private home by a principal care provider who lives in the home. Adult foster care is furnished to adults who receive these services in conjunction with residing in the home. Typically, there is a limit to the total number of individuals living in the home.
Assisted living services	Personal care and services, homemaker, chore, attendant care, and companion services; medication oversight (to the extent permitted under state law); and therapeutic social and recreational programming, provided in a home-like environment in a licensed (where applicable) community care facility, in conjunction with residing in the facility. This service includes 24-hour on-site response staff to meet scheduled or unpredictable needs in a way that promotes maximum dignity and independence, and to provide supervision, safety, and security.
Private duty nursing	Individual and continuous care (in contrast to part-time or intermittent care) provided by licensed nurses within the scope of state law. These services are provided to an individual at home.
Extended state plan services	Includes physician services, home health care services, physical therapy services, occupational therapy services, speech, hearing and language services, and prescribed drugs—services available through the approved state plan but without limitations on amount, duration, and scope.

Source: CMS.

Note: Definitions contained in current streamlined Medicaid 1915(c) waiver application format, OMB form 0938 0449.

Appendix III: Medicaid Long-Term Care Expenditures, by Type and State, Fiscal Year 2001

State	Medicaid long-term care expenditures (in millions)	Percent of expenditures by service or setting				
		Institution[a] care		Home and community-based care		
		Nursing homes	ICF/MR	HCBS waivers	Personal care[a]	Home health[b]
Alabama	$927	73%	7%	17%	0%	4%
Alaska	156	46	0	48	5	0
Arizona	15	n.a.	n.a.	n.a.	n.a.	n.a.
Arkansas	647	57	15	15	10	4
California	5,066	51	8	10	27	3
Colorado	768	47	2	42	0	10
Connecticut	1,842	56	13	23	0	8
Delaware	195	57	16	24	0	3
District of Columbia	253	63	31	1	0	6
Florida	2,648	64	11	21	1	3
Georgia	1,099	69	10	16	0	4
Hawaii	210	71	4	25	0	1
Idaho	258	46	24	23	5	3
Illinois	2,533	59	26	14	0	1
Indiana	1,307	63	23	11	0	4
Iowa	756	49	27	17	0	6
Kansas	887	54	8	34	1	3
Kentucky	935	60	10	17	0	13
Louisiana	1,677	69	21	8	0	1
Maine	411	49	11	37	1	2
Maryland	1,061	66	6	20	3	6
Massachusetts	2,450	58	9	21	10	3
Michigan	2,385	73	1	17	8	1
Minnesota	1,916	47	11	32	7	3
Mississippi	646	64	26	8	0	2
Missouri	1,677	62	11	18	9	0
Montana	215	52	10	27	11	0
Nebraska	579	64	8	23	1	3
Nevada	162	57	18	17	4	4
New Hampshire	358	59	1	38	1	1
New Jersey	3,192	69	13	10	6	2
New Mexico	410	40	4	39	16	0
New York	13,469	47	16	15	14	8
North Carolina	2,037	43	20	22	11	4
North Dakota	251	60	19	20	0	1
Ohio	3,643	64	22	13	0	2
Oklahoma	811	53	14	29	5	0
Oregon	1,058	51	1	45	3	0

State	Medicaid long-term care expenditures (in millions)	Percent of expenditures by service or setting				
		Institution[a] care		Home and community-based care		
		Nursing homes	ICF/MR	HCBS waivers	Personal care[a]	Home health[b]
Pennsylvania	5,114	72	10	17	0	1
Rhode Island	420	58	2	39	0	1
South Carolina	789	47	21	28	0	3
South Dakota	237	66	8	25	0	1
Tennessee	1,203	65	19	15	0	0
Texas	3,288	49	22	21	8	0
Utah	241	38	23	37	0	1
Vermont	191	44	1	49	2	3
Virginia	1,010	52	19	29	0	0
Washington	1,427	43	9	36	11	1
West Virginia	531	55	9	28	5	4
Wisconsin	1,813	53	11	27	6	3
Wyoming	113	35	13	48	0	4
U.S. Total	**75,288**	**57**	**14**	**19**	**7**	**3**

Source: CMS.

Notes: GAO analysis of HCFA Form 64 data as reported by Brian Burwell, Steve Eiken, and Kate Sredl in *Medicaid Long Term Care Expenditures in FY 2001*, The MEDSTAT Group, May 10, 2002. Arizona does not have any HCBS waivers as it operates its Medicaid program as a demonstration project under a section 1115 waiver. Percentages in table may not add to 100 due to rounding.

[a]Personal care is an optional Medicaid state plan service.

[b]Home health care is a mandatory Medicaid state plan service.

Appendix IV: Number of Beneficiaries Served by HCBS Waivers for the Elderly and in Nursing Homes, by State, 1999

State	Number of Medicaid beneficiaries		Percent of beneficiaries served by waivers for the elderly
	Served by HCBS waivers for the elderly	Served in nursing homes	
Alabama	5,826	24,576	19.2%
Alaska	712	929	43.4
Arizona[a]	not applicable	not applicable	not applicable
Arkansas	8,158	20,699	28.3
California	8,671[b]	117,843	6.9
Colorado	11,481	18,918	37.8
Connecticut	8,978	38,862	18.8
Delaware	734	3,109	19.1
District of Columbia[c]	not applicable	4,359	not applicable
Florida	16,915	91,985	15.5
Georgia	14,018	39,720	26.1
Hawaii	923	4,274	17.8
Idaho	1,000	5,014	16.6
Illinois	17,396	81,791	17.5
Indiana	2,338	47,988	4.6
Iowa	3,994	21,882	15.4
Kansas	6,701	17,644	27.5
Kentucky	13,339	27,739	32.5
Louisiana	872	35,508	2.4
Maine	1,395	9,236	13.1
Maryland	132	27,920	0.5
Massachusetts	5,132	60,044	7.9
Michigan	6,328	44,180	12.5
Minnesota	7,838	38,925	16.8
Mississippi	2,540	23,909	9.6
Missouri	20,821	39,762	34.4
Montana	1,514	5,549	21.4
Nebraska	2,357	16,487	12.5
New Hampshire	1,367	7,147	16.1
New Jersey	4,587[b]	51,747	8.1
New Mexico	1,404	7,074	16.6
Nevada	1,235	3,821	24.4
New York	19,732	139,509	12.4
North Carolina	11,159	42,382	20.8
North Dakota	347	5,570	5.9
Ohio	26,135[b]	92,133	22.1
Oklahoma	9,042	25,758	26.0

State	Number of Medicaid beneficiaries: Served by HCBS waivers for the elderly	Number of Medicaid beneficiaries: Served in nursing homes	Percent of beneficiaries served by waivers for the elderly
Oregon	26,410	12,031	68.7
Pennsylvania	2,383	72,481	3.2
Rhode Island	2,304	13,297	14.8
South Carolina	14,361	17,458	45.1
South Dakota	522	5,950	8.1
Tennessee	511	37,311	1.4
Texas	27,978	95,812	22.6
Utah	574	5,513	9.4
Vermont	1,014	3,745	21.3
Virginia	11,835	27,746	29.9
Washington	25,718	24,620	51.1
West Virginia	3,470	11,788	22.7
Wisconsin	13,900	41,341	25.2
Wyoming	982	2,609	27.3
Total U.S.	**377,083**	**1,616,663**	**18.9%**

Source: CMS.

Notes: GAO analysis of (1) annual state waiver report data (HCFA Form 372) as reported by Harrington, Aug. 2001, and (2) data on beneficiaries in nursing homes from Centers for Medicare & Medicaid Services, *MSIS Statistical Report for Fiscal Year 1999*.

[a]Arizona does not have any HCBS waivers for the elderly as it operates its Medicaid program as a demonstration project under a section 1115 waiver.

[b]Author's estimate. See Harrington, Aug. 2001.

[c]In 1999, the District of Columbia did not have any HCBS waivers for the elderly in operation.

Appendix V: Number of HCBS Waivers for the Elderly, Beneficiaries, Expenditures, and per Beneficiary Expenditures by State, 1999

State	Number of HCBS waivers for the elderly	Number of beneficiaries served by waivers for the elderly	Total expenditures	Average expenditures per beneficiary
Alabama	1	5,826	$37,488,861	$6,435
Alaska	1	712	8,554,566	12,015
Arizona[a]	0	not applicable	not applicable	not applicable
Arkansas	1	8,158	24,788,949	3,039
California[b]	3	8,671	26,128,332	3,013
Colorado	1	11,481	57,968,202	5,049
Connecticut	1	8,978	54,432,244	6,063
Delaware	1	734	6,528,330	8,894
District of Columbia[c]	0	not applicable	not applicable	not applicable
Florida	4	16,915	80,073,234	4,734
Georgia	1	14,018	48,483,972	3,459
Hawaii	2	923	13,905,438	15,065
Idaho	1	1,000	6,300,645	6,301
Illinois	1	17,396	46,272,565	2,660
Indiana	1	2,338	15,477,320	6,620
Iowa	1	3,994	10,052,900	2,517
Kansas	1	6,701	40,359,505	6,023
Kentucky	1	13,339	44,471,778	3,334
Louisiana	3	872	8,402,786	9,636
Maine	1	1,395	14,751,242	10,574
Maryland	1	132	678,589	5,141
Massachusetts	1	5,132	9,849,893	1,919
Michigan	1	6,328	16,655,463	2,632
Minnesota	1	7,838	34,845,022	4,446
Mississippi	1	2,540	11,645,303	4,585
Missouri	1	20,821	46,311,315	2,224
Montana	1	1,514	14,454,089	9,547
Nebraska	1	2,357	13,813,410	5,861
New Hampshire	1	1,367	11,977,955	8,762
New Jersey[b]	2	4,587	46,294,225	10,092
New Mexico	1	1,404	19,868,387	14,151
Nevada	2	1,235	5,179,673	4,194
New York	1	19,732	23,845,013	1,208
North Carolina	1	11,159	153,752,548	13,778
North Dakota	1	347	3,328,323	9,592
Ohio[b]	1	26,135	134,200,340	5,135
Oklahoma	1	9,042	34,905,750	3,860
Oregon	1	26,410	168,138,603	6,366

State	Number of HCBS waivers for the elderly	Number of beneficiaries served by waivers for the elderly	Total expenditures	Average expenditures per beneficiary
Pennsylvania	1	2,383	13,752,684	5,771
Rhode Island	2	2,304	11,650,696	5,057
South Carolina	1	14,361	63,652,223	4,432
South Dakota	1	522	1,376,800	2,638
Tennessee	2	511	4,536,477	8,878
Texas	1	27,978	266,376,586	9,521
Utah	1	574	1,672,476	2,914
Vermont	2	1,014	8,988,080	8,864
Virginia	3	11,835	80,772,354	6,825
Washington	1	25,718	194,129,285	7,548
West Virginia	1	3,470	38,908,487	11,213
Wisconsin	1	13,900	114,878,732	8,265
Wyoming	1	982	4,420,108	4,501
U.S. Total	**64**	**377,083**	**$2,099,299,758**	**$5,567**

Source: CMS.

Note: GAO analysis of annual state waiver report data (HCFA Form 372). See Harrington, Aug. 2001.

[a]Arizona does not have any HCBS waivers for the elderly as it operates its Medicaid program as a demonstration project under a section 1115 waiver.

[b]With the exception of the number of waivers for the elderly, the data for this state are based on author's estimates. See Harrington, Aug. 2001.

[c]In 1999, the District of Columbia did not have any HCBS waivers for the elderly in operation.

Appendix VI: CMS HCBS Quality Initiatives

CMS has undertaken a series of initiatives to generate information and dialogue on existing systems of quality assurance in HCBS waivers and to provide a range of assistance to states in this area. Approximately $1 million was budgeted for these HCBS quality initiatives in fiscal year 2001 and $3.4 million in fiscal year 2002. Through its HCBS quality initiatives, CMS intends to more closely assess the status of quality assurance efforts currently in place and to provide direct assistance to states in this area. CMS's initiatives include (1) developing a conceptual framework for defining and measuring quality, (2) creating tools for states to adapt and use in assessing quality, such as model consumer experience surveys, and (3) providing technical assistance and resources for quality assurance and improvement. These initiatives, while important, do not address the lack of detailed requirements for states on the necessary components of an acceptable quality assurance system or the weaknesses in regional office oversight of state HCBS waivers that we identified elsewhere in this report.

Quality Framework and Expectations. CMS sponsored the development of a framework for quality in home and community-based services that focuses on outcomes in several key areas including beneficiary access to care, safety, satisfaction, and meeting beneficiary needs and preferences.[1] The next phase involves identifying strategies that states are currently using to monitor and improve quality within these key areas. While the expectations contained in the quality framework have not been specified in CMS regulations, they are reflected in the application template for CMS's new consumer-directed HCBS waiver, Independence Plus.[2] States' use of the template for the Independence Plus waiver is voluntary. The template asks states for a detailed description of their quality assurance and improvement programs—something not currently required as part of the general HCBS waiver application. Guidance for using the template notes that the description should include (1) information on the frequency of quality assurance activities, (2) the dimensions that will be monitored, (3) the qualifications of persons conducting quality assurance activities,

[1]The quality framework was developed with input from a variety of organizations and individuals including national aging and developmental disabilities organizations, CMS officials from headquarters and regional offices, and state directors for Medicaid, aging and developmental disabilities.

[2]Independence Plus is CMS's new demonstration program for family or individual-directed community-based services. Under this consumer-directed care model, beneficiaries are provided greater decision-making authority regarding their service needs, their provider of services, and how quality of care will be assessed.

(4) the process for identifying problems, including sampling methodologies, (5) provisions for assuring that problems are addressed in a timely manner, and (6) the system to receive, review, and act on critical incidents or events.

Quality Assurance Mechanisms. CMS is also developing quality assessment and improvement mechanisms for states. For example, to develop a guide for states and CMS regional offices, a contractor reviewed the literature on quality measurement and improvement in home and community-based care, convened an expert panel, and conducted interviews with state officials. As of April 2003, the guide was undergoing final clearance within CMS. It is expected to include (1) benchmarks for effective quality assurance programs in home and community-based care, (2) a discussion of the knowledge and mechanisms needed to design, implement, and assess quality activities in home and community-based care, and (3) suggestions for addressing limitations and problems in assuring quality in home and community-based care. Another contractor has developed and field-tested consumer experience surveys for use in waiver programs for the elderly and for persons with developmental disabilities. This contractor is also developing a set of performance indicators for states to use in guiding development and assessing quality in new self-directed HCBS waivers.

Technical Assistance and Resources. Other CMS efforts focus on providing technical assistance and resources to states. One contractor has assembled a team of professionals with expertise in home and community-based services that can serve as a resource for both states and the CMS regional offices.[3] Services available from these teams are expected to include conducting targeted reviews of waiver programs; providing suggestions to states regarding their quality assurance activities; consulting with CMS staff regarding quality aspects of specific waivers; and providing resource materials on quality assurance monitoring and improvement tools. This contractor is also assessing the types of data currently gathered by a sample of states that is, or could be, used for quality measurement and improvement; compiling information on selected data-driven state quality efforts; and providing technical assistance to the states. Finally, CMS sponsored a national conference on HCBS quality

[3]The MEDSTAT Group is managing the overall contract with CMS.

measurement and improvement in May 2002. This day-and-a-half-long conference—attended by state officials, CMS staff, and others—offered training and information on strategies and techniques for quality assurance and improvement in home and community-based care.

Appendix VII: Beneficiary Samples for and Duration of Regional Office Reviews of 15 State Waivers Serving the Elderly

State	Target population	Number of waiver beneficiaries	Beneficiary samples[a]		Duration of on-site review (days)
			Record reviews	Interviews or observation	
Boston regional office					
Connecticut	Elderly	7,300	21	21	5
Vermont	Residential care	73	14	14	5
Philadelphia regional office					
Virginia	Consumer-directed personal attendant services	99	15	[b]	[c]
Virginia	Elderly and persons with disabilities	9,000	20	[b]	5
Virginia	Assisted living waiver	1,166	39	20	5
Dallas regional office					
Oklahoma	Elderly and persons with disabilities	10,000	40	5	5
Kansas City regional office					
Kansas	Frail elderly	4,500	17	11	4
Nebraska	Elderly and adults and children with disabilities	2,357	25	14	4
Denver regional office					
Montana	Elderly and persons with physical disabilities	1,514	36	18	5
North Dakota	Elderly and persons with disabilities	390	36	17	5
South Dakota	Elderly	638	28	17	5
Wyoming	Elderly and persons with physical disabilities	850	38	22	5
San Francisco regional office					
California	Disabled, frail, and elderly	16,335	19	10	10
Seattle regional office					
Oregon	Elderly and persons with disabilities	36,000	52	[b]	22.5
Washington	Elderly and persons with disabilities	24,000	100	[b]	22.5
Average		7,615	33	15	8

Source: CMS.

Note: GAO analysis of CMS regional office final waiver review reports for HCBS waivers serving the elderly that included information on sample size for beneficiary record reviews or interviews, issued from October 1998 to May 2002.

[a]Fifteen of the 21 CMS regional office waiver review reports for HCBS waivers serving the elderly included information on sample size of the regional office reviews of waiver beneficiary records. This appendix provides a summary of the 15 waiver review reports that included this information. The number of waiver beneficiaries is based on those reported in the regional offices' waiver review reports. To the extent that the information was included in the waiver review reports, we have provided details on the number of beneficiaries interviewed or observed during the reviews.

[b]The regional office review contained no information on beneficiary interviews or observations.

[c]This waiver review was conducted at the regional office rather than on-site at the relevant state agencies.

Appendix VIII: Comments from the Centers for Medicare & Medicaid Services

DEPARTMENT OF HEALTH & HUMAN SERVICES

Centers for Medicare & Medicaid Services

Administrator
Washington, DC 20201

DATE: JUN 13 2003

TO: Kathryn G. Allen
Director, Health Care—Medicaid
and Private Health Care Issues

FROM: Thomas A. Scully
Administrator

SUBJECT: GAO Draft Report, *Long-Term Care: Federal Oversight of Growing Medicaid Home and Community-Based Waivers Should Be Strengthened*, (GAO-03-576)

We appreciate the opportunity to review and comment on the above-referenced draft report and its recommendations. The Administration has undertaken a number of quality initiatives, including initiatives in the area of home and community-based services (HCBS). We take the issue of quality in home and community-based services (HCBS) very seriously, but have significant concerns with the draft report's assumptions, focus, technical accuracy, and recommendations.

Attached are our specific comments to the report. We look forward to working with GAO on this and other issues in the future.

Attachment

The Centers for Medicare & Medicaid Services' Comments to GAO's Draft Report, *Long-Term Care: Federal Oversight of Growing Medicaid Home and Community-Based Waivers Should Be Strengthened,* (GAO-03-576)

General Comments

1. The draft report has numerous technical inaccuracies or mischaracterizations of CMS' efforts. The most significant was the inaccurate statement on page 8 where the report states that, "HCBS waivers may be extended." In fact, section 1915(c) of the Social Security Act (the Act) gives the Secretary of HHS the authority to approve and extend waivers, *at the request of the state.* The Act says that the Secretary *shall* approve and extend waivers (unless assurances have not been met). Congress obviously places great weight on the state assurances. In so doing, Congress conveys deference to the states that are closest to those being served. We therefore believe the GAO report itself should recognize that Congress created an enforcement mechanism that places great reliance on a system of assurances.

2. The draft report failed to recognize that the states, families, and individuals who are aged or have a disability are greatly satisfied with the current programs, as evidenced by the considerable expansion in the number of people who have elected to be served under state HCBS programs. We are disappointed that the report failed to acknowledge the positive and vital contribution that Medicaid HCBS waiver programs make to the quality of life of persons who are at risk of more costly and more restrictive institutional care. We note, for example, that a recent AARP survey of elderly individuals found that "spending time with family and friends tops the list of important activities for maintaining one's quality of life (96%); second is religious or spiritual activities (82%)..." HCBS waivers allow individuals to remain with their families and in their communities where they may continue these activities that are so critical to their quality of life. No doubt these are the major reasons why Medicaid HCBS waiver programs have become the service program of choice for more than 800,000 vulnerable persons. We do not believe that the report appropriately acknowledges this fact. The report also ignores the wide variety of activities at the state and community levels to promote quality, including the licensing and credentialing of professionals.

3. The report is narrow in its definition of and focus on quality. Families and individuals participating in HCBS waivers inform us that some of the most important factors associated with quality are: *availability of a flexible array of supports and services* that can be tailored to each individual's needs and preferences; *choice and control* over how, where and by whom such services are delivered; *access and timeliness of services* in the community; and *ability to maintain relationships* with families and friends. In short, the report overlooks the centrality of these quality concepts relating to flexibility and timeliness--and focuses instead on a narrow and regulatory approach to quality. We believe choice and access are among the most important quality indicators. The "cash and counseling" waivers have demonstrated that fact. Putting individuals and their families in control of the resources spent on their behalf promotes choice and access.

4. The report leaves the distinct impression that the most effective way to assure and improve quality is through the process of inspection and monitoring. This assumption fails to recognize the pioneering work of the Institute of Medicine (e.g., IOM, *Crossing the Quality Chasm, 2001)* or the established literature of Edwards Deming and others. The Institute on Medicine report addressed quality in the fields of both acute and long-term health care when it wrote: "…care must be delivered by systems that are carefully and consciously designed to provide care that is safe, effective, patient-centered, timely, efficient, and equitable. Such systems must be designed to serve the needs of patients, and to ensure that they are truly informed, retain control and participate in care delivery whenever possible, and receive care that is respectful of their values and preferences." W. Edwards Deming put these concepts forward more succinctly in his "14 Points:"

   > "Cease dependence on inspection to achieve quality. Eliminate the need for inspection on a mass basis by building quality into the product in the first place."

   The design of an HCBS waiver is therefore the most important contributor to quality. This observation accounts for the fact that recent CMS efforts to improve quality have focused on working with states to improve design decisions and design options. One example is the recent *Independence Plus* waiver template, a design option for states that increases choice and control by HCBS waiver participants. This template not only includes more specific expectations for quality assurance systems, but also more fundamentally builds quality upon the foundation of individual choice, control, and responsiveness. Another example is the recent State Medicaid Director Letter (#01-006) emphasizing the need to ensure adequacy of HCBS services. A third example is the recent provision of $125 million in "Real Choice Systems Change" grants to states to improve fundamental capability of community-based systems. These efforts to improve design of HCBS programs promise greater improvement in quality than any proliferation of Federal monitoring reports.

5. The report fails to note the steps CMS has already taken organizationally to ensure quality is built into all of our program areas, including HCBS waivers. While design is the most important factor for quality, we also note that CMS is not minimizing the need for a quality focus or, specifically, for quality reviews of HCBS waivers. In fact, we have recently enhanced both. We note that the Center for Medicaid State Operations (CMSO) has recently redeployed staff and reorganized to incorporate the quality function into each program area. Previously, quality was a stand-alone function grouped less appropriately with financing and data systems. By redeploying staff from the stand-alone group, we have ensured that a concern for quality is incorporated into each of our program components, including the one that oversees the HCBS waiver programs.

   Given that program design is the most important contributor to quality, given that we have already taken steps organizationally to ensure that enough resources are devoted to quality and that they are appropriately positioned within CMS, we have serious concerns that additional monitoring could detract from both the design and design improvement work that we undertake

with the states.

6. The report lends itself to the conclusion that the Federal government ought to be the primary source of quality monitoring and improvement, and fails to recognize that the Federal statutes convey respect for state authority and competence in the administration of HCBS programs. Federal statutes locate the responsibility for quality assurance with the states. Section 1915(c) of the Act requires that states provide an assurance that the health and welfare of waiver participants will be protected. The CMS approves no waiver that fails to contain such an assurance. We therefore maintain that the proper role of Federal reviews is not to substitute, replicate, or in any other way duplicate state quality assurance mechanisms. Instead, the purpose of Federal information gathering and review is to identify any issues with the state quality assurance and quality improvement systems. Review of state systems may also be conducted by means other than by Federal staff, such as peer reviews and contract review.

   These differences in the proper role of Federal review have broad implications that place us at odds with some of the conclusions in the GAO draft report. For example, the draft faults CMS for not undertaking "…sampling methodology to provide a basis for generalizing review findings." However, it may be more important for CMS to target small (unrepresentative) samples in specific areas of concern, and then engage the states to examine a representative sample for the purpose of determining the extent of any problems identified.

   The draft report similarly criticizes CMS for not conducting a review of every waiver. Yet many states have multiple waivers serving subsets of the same target group, all served by the same state quality assurance system. If the purpose of federal review is to focus on state quality assurance systems, and multiple state waivers are served by the same system, it would be far more efficient while equally effective for federal review to focus on just one of the waivers through the protocol review process and monitor the requirements of waivers through other means. Such considerations are important in a world of scarce resources.

7. The draft report fails to recognize that HCBS programs are significantly different in intent and focus than the institutions for which they are alternatives, thus requiring a different approach to quality. The HCBS programs are intended to allow people to live in their own homes or with families. The major services, such as personal assistance and respite, are delivered in a person's own home. We are hesitant to embrace a strategy that would have Federal inspectors marching through a "representative sample" of waiver participants' private homes. We believe a better strategy is to give individuals greater control over the management of resources.

8. The draft report fails to acknowledge the lack of *appropriated* funds for HCBS quality. The conclusions and recommendations would require a huge new investment of Federal

resources. While the report notes that "limited regional resources" affect CMS' oversight capabilities, it does not acknowledge the magnitude of the resource issue in a comparative sense. In particular, the report fails to acknowledge that financial resources for assuring quality in nursing homes and ICF/MR facilities have a *line-item appropriation*, with an estimated $170 million (Federal share) devoted to facility survey and certification. There is no line-item appropriation for HCBS quality, so the resources spent on assuring quality must come from the operating budget. While new investments will be required, we would argue that the most effective deployment of resources would not be made in the duplicative, retrospective review process advocated by the report.

9. The draft report does not address the significant resources that would need to be found or redirected to implement its recommendations. While CMS is criticized for not conducting a review of every waiver, there is no acknowledgement that, given the volume of HCBS waivers, conducting a review of every HCBS waiver by means of a statistically valid sampling of waiver participants would require hundreds of additional Federal staff. Omitting reference to the scale of the additional staffing necessary to implement this recommendation is especially troubling when we believe, as stated above, it is actually program design that is the more important determinant of quality outcomes for HCBS waiver participants. Thus, the report neglects the extent to which additional staffing resources would be necessary to implement a narrow, regulatory approach to quality, when additional staffing could be more appropriately redirected to support the more comprehensive approach to quality (i.e., one that focuses on program design and on the ability to remedy identified problems).

10. The report fails to acknowledge CMS' efforts to assist states with HCBS quality. To illustrate our work in HCBS quality, we provide below a list of some of the activities, products, tools, and technical assistance to states that we have recently implemented:

    - Development of the HCBS *Protocol,* a mandatory review protocol for CMS regional offices to use when conducting waiver reviews. The CMS required mandatory use of the *Protocol* in January 2001 to assure consistency in the Federal review process. The *Protocol* is also used by states voluntarily to guide them in their development of quality assurance/improvement systems.
    - Development and Dissemination of the HCBS Quality Framework, a common frame of reference for designing HCBS waivers, with quality built into the design.
    - Development of Tools to Assist States in the development of quality approaches, including the Participant Experience Survey and HCBS Quality Work Book.
    - Development of the *Independence Plus* template, with specific requirements to assure quality.
    - National Technical Assistance Contractor, a contract with nationally recognized organizations that provide technical assistance to states on a variety of quality issues.

    The contractors provide assistance to states in development of their quality improvement systems, problem remediation, analysis of quality issues, and other technical assistance activities. To date, 15 states have utilized the expertise and resources of the national contractor.

In summary, CMS is committed to its on-going responsibility, in partnership with the states, to assure and improve quality in HCBS waivers. However, we strongly believe that the focus should be on assisting states in the design of HCBS programs, respecting the assurances made by states, improving the ability of states to remedy identified problems, providing assistance to states to improve the quality of services, and thereby assisting people to live in their own homes in communities of their choice.

GAO Recommendation

To ensure that state quality assurance efforts are adequate to protect the health and welfare of HCBS waiver beneficiaries, we recommend that the Administrator of CMS

- develop and provide states with more detailed criteria regarding the necessary components of an HCBS waiver quality assurance system.

CMS Response

The CMS has provided guidance to both states and CMS regional offices on the necessary components of a waiver quality assurance system, through documents such as the *Framework* and the *Protocol.* As with any continuous quality improvement process, we recognize the need for on-going guidance. Toward that end, CMS has already conducted and/or plans to conduct numerous technical assistance sessions for both states and regional offices throughout 2003 and 2004. We question the need and advisability of prescribing uniform, detailed Federal criteria for more than 270 waivers that cover populations as diverse as HIV/AIDs and the frail elderly, and can serve caseloads ranging from 100 to more than 30,000.

However, we will work in consultation with our state partners to define more clearly our broad criteria and expectations for quality through the further refinement of the *Quality Framework.*

GAO Recommendation

To ensure that state quality assurance efforts are adequate to protect the health and welfare of HCBS waiver beneficiaries, we recommend that the Administrator of CMS

- require states to submit more specific information about their quality assurance approaches prior to waiver approval; and
- ensure that states provide sufficient and timely information in their annual waiver reports on their efforts to monitor quality.

CMS Response

We recognize the need for more comprehensive information from states at the time of application and at subsequent renewals. We view this as an effective, appropriate, and economical Federal

role. The CMS acknowledged this need when it developed the *Quality Framework* and required submission of a quality assurance and improvement plan as part of *Independence Plus* applications.

The CMS is committed to working with our regional offices and state partners to receive and review information about quality as part of the waiver approval, renewal, and annual reporting process. Toward that end, CMS will revise and improve the application process and annual state waiver report to include quality information from the state's quality program.

GAO Recommendation

To strengthen Federal oversight of the growing HCBS waiver programs and to ensure the health and welfare of HCBS waiver beneficiaries, we recommend that the Administrator

- ensure allocation of sufficient resources and hold regional offices accountable for conducting thorough reviews of the status of quality in HCBS waiver programs; and
- develop guidance on the scope and methodology for Federal reviews of state waiver programs, including a sampling methodology that provides confidence in the generalizability of the review results.

CMS Response

We would remind GAO that there is no line-item appropriation for HCBS quality as there is for institutional quality, and any additional resources targeted to the Federal quality assurance or quality improvement efforts must be taken from CMS operating funds for administration of the waivers.

The GAO's recommendation regarding sampling methodology has serious cost implications. We question whether the allocation of scarce resources for what could be scores or hundreds of additional Federal employees to conduct reviews with representative samples is the best use of operating funds. We have therefore advised our regional offices to use the samples they conduct to gain greater familiarity with the states' waiver operations, or target areas of concern, and not to consider them representative samples.

While we may disagree with the draft GAO recommendations on certain methodologies that might be taken to assure quality in home and community-based services, we have no disagreement on the importance of doing so, or on the advisability of making further investments to advance both state and Federal capability for both quality assurance and quality improvement systems. The CMS is committed to developing additional policy guidance for regional offices on the scope and frequency of Federal reviews and to examine other models for quality assurance and improvement.

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