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LONG-TERM CARE

Availability of Medicaid Home and Community Services for Elderly Individuals Varies Considerably

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Contents

Abbreviations

ADL	activities of daily living
CMS	Centers for Medicare & Medicaid Services
HCBS	home and community-based services
IADL	instrumental activities of daily living

GAO
Accountability * Integrity * Reliability

United States General Accounting Office
Washington, DC 20548

September 26, 2002

The Honorable John B. Breaux
Chairman, Special Committee on Aging
United States Senate

Dear Mr. Chairman:

The aging baby boom generation is anticipated to greatly expand the demand for long-term care services, with some estimates projecting that spending for long-term care for the elderly could nearly quadruple by 2050. Medicaid, the joint federal-state health-financing program for low-income individuals, is currently the largest payer for long-term care services and is anticipated to face substantial increases in spending as demand for long-term care increases.[1] While coverage of nursing home care has traditionally accounted for the bulk of Medicaid long-term care expenditures, the high costs of such care and many individuals' preference to receive care in their homes as long as possible has led many states to expand their Medicaid programs to provide additional home and community-based services for those who would otherwise be eligible for nursing home care.

Home and community-based services for elderly individuals with disabilities can include in-home care involving personal care attendants to provide hands-on care with activities such as bathing and eating, household support for activities such as laundry and meal preparation, or custodial supervision to ensure the safety of someone requiring ongoing monitoring. Community options can include adult day care, which provides temporary care in a group environment, and permanent care in alternative residential settings, such as assisted living facilities or adult foster care, for those who are not able to remain in their home but who do not require nursing home care.

Because most home and community-based services are optional elements of state Medicaid programs, states have discretion in what services are

[1]See U.S. General Accounting Office, *Long-Term Care: Aging Baby Boom Generation Will Increase Demand and Burden on Federal and State Budgets*, GAO-02-544T (Washington, D.C.: Mar. 21, 2002).

covered, who may be eligible, and what services they receive. Additionally, local case managers, who screen Medicaid-eligible individuals to determine what services they qualify for based on their level of disability, often have discretion to customize care plans based on the individual's needs, preferences, and availability of care services, including unpaid care provided by family members or other informal caregivers.

The Senate Special Committee on Aging has been examining the current provision of long-term care to further discussion of what role the public sector should play in assuring that long-term care needs will be met for the impending surge of persons who will need care—the aging baby boom generation. In light of this, you asked us to examine how the availability of Medicaid-covered home and community-based care that is available for elderly individuals with disabilities varies both across and within states. Specifically, we addressed

1. the extent to which home and community-based services were available within selected states' programs for Medicaid-covered long-term care services for the elderly;

2. the Medicaid-covered long-term care services that local case managers would offer for two hypothetical elderly individuals with disabilities based on the levels of unpaid informal care provided by family members; and

3. the extent to which care offered to the same hypothetical individual with the same level of informal support varied among the selected states.

To answer these objectives, we selected four geographically diverse states—Kansas, Louisiana, New York, and Oregon— that varied in the extent of spending for Medicaid home and community-based services for individuals who are elderly and disabled. In each of these states, we interviewed state Medicaid officials and reviewed information about home and community-based services covered by their Medicaid programs. Based on data the states reported on Medicaid expenditures to the federal Centers for Medicare & Medicaid Services (CMS) for 1999, the most recent year for which data were available, we also estimated the amount each of these states spent on several categories of long-term care services for the elderly.

To obtain information about the availability of long-term care for our hypothetical elderly individuals with disabilities in these states, we

conducted interviews with 4 case managers responsible for Medicaid home and community-based services in each state—a total of 16 case managers.[2] We asked the case managers to prepare detailed care plans for six hypothetical situations we presented to them using the same assessment tools and professional expertise that they would with Medicaid-eligible clients they served. The six hypothetical situations represented two elderly persons with certain disabilities and each with three different scenarios illustrating different levels of informal care available from family members. In each scenario, the two elderly persons would have been eligible for nursing home care, but preferred to receive home or community-based services when possible. If the state had a waiting list that would preclude the case managers from immediately offering Medicaid home and community-based services to new clients, we asked them to assume that the hypothetical individuals had exited the waiting list and could receive these Medicaid-covered services. Although some case managers also identified non-Medicaid services that the hypothetical clients could receive or seek, such as Medicare home health services, programs offered through the Older Americans Act, or state or locally subsidized programs, other relevant services may have been available that the Medicaid case managers did not include in their care plans. We did not evaluate the adequacy or appropriateness of the care plans offered by the case managers for meeting the long-term care needs of our hypothetical individuals.

The first hypothetical person was a woman who had difficulty performing everyday activities due to physical limitations, while the second was a man who had difficulty due to cognitive limitations. Specifically, our hypothetical individuals were the following:

Abby: an 86-year-old woman with debilitating arthritis who is chair-bound and whose husband, who had previously cared for her, recently died.

- Scenario 1: Abby lives with her daughter who provides most of Abby's care but is overwhelmed by also caring for the daughter's infant grandchild.
- Scenario 2: Abby lives with an elderly sister who provides most of Abby's care, but the sister has limited strength making her unable to provide all care.

[2]In each state, we selected two case managers in a county with a small town (less than 15,000 people) and two in a county with a large city (at least 250,000 people) based on a list of all local Medicaid case managers provided by state or county officials.

- Scenario 3: Abby lives alone, and her working daughter visits Abby once each morning to provide care for about 1 hour per day.

Brian: a 70-year-old man cognitively impaired with moderate Alzheimer's disease, who has just been released from a skilled nursing facility after recovering from a broken hip.

- Scenario 1: Brian lives with his wife who provides most of his care and she is in fair health.
- Scenario 2: Brian lives with his wife who provides some of his care and she is in poor health.
- Scenario 3: Brian lives alone because his wife has recently died.

Appendix 1 provides additional description of these hypothetical Medicaid clients, including their specific limitations and needs for additional care services.

We performed our work from June through September 2002 in accordance with generally accepted government auditing standards.

Results in Brief

Differences in how states exercised their flexibility in designing their Medicaid long-term care programs, including the resources devoted to them, affected the extent to which home and community-based services were available to elderly individuals with disabilities. The states we reviewed—Kansas, Louisiana, New York, and Oregon—had all opted to cover home and community-based services for at least some Medicaid-eligible elderly individuals with disabilities. These services represented larger shares of New York's and Oregon's total Medicaid long-term care expenditures for the elderly than those of Kansas and Louisiana. All Medicaid-eligible elderly individuals needing long-term care services could receive home and community-based services in New York and Oregon. Most new clients could not immediately receive Medicaid-covered home and community-based care in Kansas, which initiated a waiting list in April 2002, or in Louisiana, which had more than three times as many persons on its waiting list as were being served as of July 2002.

Medicaid case managers in these four states offered care plans for our two hypothetical individuals that relied largely on Medicaid-covered home and community-based services that in most situations would provide enough hours of in-home care that the case managers would not recommend that the individuals move to a nursing home or other residential care setting. They typically recommended that Abby, an 86-year-old chair-bound

woman with debilitating arthritis, could stay in her home with varying amounts of hands-on assistance with personal care (such as bathing) and household support (such as meal preparation) to supplement the care provided by her family. However, the amount of in-home care that the case managers offered varied significantly. For example, in the scenario in which Abby lives with her daughter, case managers offered from 4.5 hours per week to 40 hours per week of in-home care. For Brian, a 70-year-old man with moderate Alzheimer's disease, the case managers typically recommended that he could remain at home with varying amounts of additional in-home support if his wife was also available to provide informal unpaid care and supervision. For example, if Brian lived with his wife who was in poor health, they would offer from 6 hours per week to 35 hours per week of in-home care. If Brian lived alone, however, they usually recommended that he move to a nursing home or an alternative residential setting, such as an assisted living facility, to ensure his safety, although two case managers said they could offer him as much as 24-hour-a-day care in his home.

The home and community-based care that case managers offered to Abby or Brian sometimes differed due to state policies or practices that shaped the availability of their Medicaid-covered services. In Kansas and Louisiana, neither Abby nor Brian would have been immediately able to receive Medicaid home and community-based services due to a waiting list for certain services. Some states also had caps or other practices that limited the amount of Medicaid-covered in-home care that could be offered, as the following examples illustrate.

- In Louisiana, case managers were limited in the number of hours of in-home care they could offer due to a cap of $35 per day at the time we conducted our work;
- In Kansas, case managers often offered fewer hours of in-home care than were offered in other states, which may have been in part influenced by Kansas's supervisory review of more costly care plans and cost-consciousness among the case managers who recognized that lower costs per client could enable more clients to be served; and,
- In New York and Oregon, case managers did not have similar cost restrictions in offering in-home hours, with one case manager in each state offering as much as 24-hour-a-day care.

When out-of-home placements were recommended, Oregon's case managers consistently recommended adult foster care or assisted living facilities, whereas case managers in the other states more often recommended nursing home care.

We received oral comments from officials of the four states on a draft of this report. In response to our findings, they noted that fewer hours of in-home care in one state or community did not necessarily translate into unmet health and welfare needs for individuals; that limits on the number of individuals served or resources available for home and community-based care were in some cases due to state funding constraints and cost-effectiveness requirements relative to nursing home care; and that the local availability of long-term care workers and other services vary significantly and influence the care plans that case managers offer to individuals seeking care.

Background

Long-term care includes many types of services needed when a person has a functional disability, whether physical or cognitive. Individuals needing long-term care have varying degrees of difficulty in performing some activities of daily living without assistance, such as bathing, dressing, eating, toileting, and moving from one location to another. They may also have trouble with instrumental activities of daily living, which include such tasks as preparing food, housekeeping, and handling finances. They may have a mental impairment, such as Alzheimer's disease, that necessitates supervision to avoid harming themselves or others or need assistance with tasks such as taking medications. Although a chronic physical or mental disability may occur at any age, the older an individual becomes, the more likely a disability will develop or worsen.

Assistance for such needs takes many forms and takes place in varied settings, including institutional care in nursing homes or alternative community-based residential settings such as assisted living facilities, in-home care services, and unpaid care from family members or other informal caregivers. Approximately 64 percent of all elderly individuals with a disability relied exclusively on unpaid care from family or other informal caregivers; even among almost totally dependent elderly—those with difficulty performing five activities of daily living—about 41 percent relied entirely on unpaid care.[3]

Long-term care is financed through a variety of sources, primarily public programs. Nationally, spending from all public and private sources for

[3]Calculations based on Korbin Liu et al, *Changes in Home Care Use by Older People with Disabilities: 1982-1994*, prepared for the AARP Public Policy Institute (Washington, DC.: AARP, Jan. 2000).

long-term care for all ages totaled about $137 billion in 2000, accounting for nearly 11 percent of all health care expenditures.[4] Medicaid, the joint federal-state health-financing program for low-income individuals, continues to be the largest funding source for long-term care. In 2000, Medicaid paid 46 percent (about $63 billion) of total long-term care expenditures. Individuals' out-of-pocket payments represented the second largest source of payments for long-term care—a larger part of long-term care spending than for other types of health care services such as physicians and hospitals. These out-of-pocket payments accounted for 23 percent (about $31 billion) of total long-term care expenditures in 2000. Medicare, private insurance, and other public or private sources financed the remaining shares of these expenditures.

States share responsibility with the federal government for Medicaid, paying on average approximately 43 percent of total Medicaid costs. Within broad federal guidelines, states have considerable flexibility in determining who is eligible and what services to cover in their Medicaid program. Among long-term care services, states are required to cover nursing facilities and home health services for Medicaid beneficiaries. States also may choose to cover additional services that are not mandatory under federal standards, such as personal care services, private-duty nursing care, and rehabilitative services. For services that a state chooses to cover under its CMS-approved state Medicaid plan, enrollment for those eligible cannot be limited but benefits may be. For example, states can limit the personal care service benefit through medical necessity requirements and utilization controls.

States may also cover Medicaid home and community-based services (HCBS) through waivers of certain statutory requirements under section 1915(c) of the Social Security Act, thereby receiving greater flexibility in the provision of long-term care services.[5] These waivers permit states to adopt a variety of strategies to control the cost and use of services. For example, states may obtain CMS approval to waive certain provisions of the Medicaid statute, such as comparability, which generally requires states to make all services available to all eligible individuals statewide.

[4]Based on our analysis of data from the CMS Office of the Actuary and The MEDSTAT Group. These figures include long-term care for all people, regardless of age. Amounts do not include expenditures for nursing home and home health services provided by hospital-based entities, which are counted with other hospital services.

[5]42 U.S.C. § 1396n(c) (2000).

With a waiver, states can target services to individuals on the basis of certain criteria such as disease, age, or geographic location. Further, states may limit the numbers of persons served to a specified target, requiring additional persons meeting eligibility and need criteria to be put on a waiting list. Limits may also be placed on the costs of services that will be covered by Medicaid. To obtain CMS approval for a HCBS waiver, states must demonstrate that the cost of the services to be provided under a waiver (plus other state Medicaid services) is no more than the cost of institutional care (plus any other Medicaid services provided to institutionalized individuals). These waivers permit states to cover a wide variety of nonmedical and social services and supports that allow people to remain at home or in the community, including personal care, personal emergency response systems, homemakers' assistance, chore assistance, adult day care, and other services.

Medicare—the federal health financing program covering nearly 40 million Americans who are aged 65 or older, disabled, or have end-stage renal disease—primarily covers acute care, but it also pays for limited post-acute stays in skilled nursing care facilities and home health care. Medicare spending accounted for 14 percent (about $19 billion) of total long-term care expenditures in 2000. During the early and mid-1990s, Medicare became an increasingly significant funding source for individuals receiving continuing home health care, including home health aide services that may at times substitute for other long-term care services. The adoption of an interim payment system in 1997 to better control spending growth was followed by a sharp reduction in the number of home health visits and spending covered by Medicare. A new home health prospective payment system was implemented in October 2000 that was intended to more closely align Medicare payments with patient needs. While it provides funding that allows a higher number of home health visits per user than under the interim payment system, it also provides incentives to reward efficiency and control use of services. The number of home health visits declined from about 29 visits per episode immediately prior to the prospective payment system being implemented to 22 visits per episode during the first half of 2001.[6] Most of the decline was in home health aide visits.

[6]U.S. General Accounting Office, *Medicare Home Health Care: Payments to Home Health Agencies Are Considerably Higher Than Costs*, GAO-02-663 (Washington, D.C.: May 6, 2002).

Selected States Varied in Expenditures for and Design of Medicaid Home and Community Services

Each of the states we reviewed—Kansas, Louisiana, New York, and Oregon—covered home and community-based services in their Medicaid programs, but differed in how much of their Medicaid spending for long-term care for the elderly they dedicated to home and community-based care and how they designed their programs for these services. In general, Kansas and Louisiana spent a smaller portion of their Medicaid long-term care expenditures on home and community-based services than the other two states, and many of these services had recently not been available to new clients because both states had waiting lists. New York had the highest Medicaid spending on long-term care services for the elderly, with per capita spending nearly two-and-a-half times the national average. In addition, most of New York's home and community-based services were covered through its state Medicaid plan, making the services available to all eligible Medicaid beneficiaries. Oregon spent much less on nursing home care than other states, with a higher share of its long-term care expenditures for the elderly dedicated to home and community-based care.

The four states we reviewed allocated different proportions of Medicaid long-term care expenditures for the elderly to federally required long-term care services, such as nursing facilities, and to state optional home and community-based care, such as in-home personal support, adult day care, and other home and community services. (See table 1.) New York's expenditures for Medicaid long-term care services (including nursing facilities, home health, personal support, and other care) for the elderly was $2,463 per person aged 65 or older in 1999—much higher than the national average of $996.[7] While nursing home care represented 68 percent of New York's expenditures, New York also spent more than the national average on long-term care services provided at the state's option, such as personal support services. Kansas and Louisiana spent near the national average of $996 per person aged 65 or older ($935 and $1,012, respectively), but nursing home care accounted for a higher portion of these expenditures in Louisiana (93 percent) than the national average (81 percent). Oregon spent $604 on Medicaid long-term care services per elderly individual. In contrast to the other states, Oregon spent much less

[7]Medicaid expenditures for these long-term care services for the elderly include both federal and state shares and are in relation to the state or national population aged 65 or older. Also, we adjusted Medicaid expenditures for a state's health care costs as a percentage of the national average health care costs for 1997 to 1999 to at least partially account for geographic cost differences.

per capita on nursing home care, and spent a larger portion for other long-term care services such as care in alternative residential settings.

Table 1: Medicaid Expenditures in Four States for Long-Term Care Services for the Elderly per State Population Aged 65 or Older, 1999

	Kansas		Louisiana		New York		Oregon		U.S.	
	$ per capita	% of total	$ per capita	% of total	$ per capita	% of total	$ per capita	% of total	$ per capita	% of total
Services required under federal law										
Nursing facility	737	79	938	93	1,665	68	352	58	806	81
Home health	14	2	3	0	153	6	0	0	24	2
Services covered at state option										
Personal support	174	19	9	1	502	20	10	2	88	9
Other care services (includes adult day care and alternate residential care settings)	10	1	62	6	143	6	242	40	77	8
Total	**935**		**1,012**		**2,463**		**604**		**996**	

Notes: Per capita expenditures represent the ratio of Medicaid expenditures for services for the elderly to the state population aged 65 or older.

We adjusted Medicaid expenditures for the state's health care costs in relation to national average health care costs for 1997 to 1999 to at least partially account for geographic cost differences.

Percentages may not add to 100 and expenditure categories may not add to the total due to rounding.

Sources: GAO calculations based on CMS Medicaid expenditure data; Bureau of the Census, *Population Estimates for the U.S., Regions, and States by Selected Age Groups and Sex: Annual Time series, July 1, 1990 to July 1, 1999 http://eire.census.gov/popest/archives/state/st-99-09.txt* (downloaded Sept. 13, 2002); and health care services cost data from the Department of Labor's Bureau of Labor Statistics and the Department of Housing and Urban Development.

The states also differed in how they designed their home and community-based services, influencing the extent to which these services were available to elderly individuals with disabilities. In some instances, as the following examples illustrate, not all services were available to all clients, with Kansas and Louisiana having waiting lists for HCBS waiver services for new clients.

- Kansas: Most home and community-based services for the elderly in Kansas were offered under HCBS waivers. These services included in-home help such as personal care, household support, night supervision, assistive devices (such as shower seats), personal emergency response systems, adult day care, and respite care. As of June 2002, 6,300 Kansans were receiving these HCBS waiver services. Because Kansas recently initiated a waiting list for these services in April 2002, they were not

currently available to new recipients, with 290 people on the waiting list as of June 2002.

- Louisiana: Most home and community-based services available in Louisiana for the elderly and disabled were offered under HCBS waivers, allowing the state to limit the number of recipients and cap the dollar amount available per day for services. One waiver, which includes such services as personal care, environmental modifications to the home (such as wheelchair ramps), and personal emergency response systems, served approximately 1,500 people in July 2002 with a waiting list of 5,000 people. The dollar cap on services provided through this waiver increased in September 2002 from $35 per day to $55 per day. The other waiver, which is exclusively for adult day health care,[8] served approximately 525 people, with 201 individuals on the waiting list as of July 2002.
- New York: New York relied less on HCBS waivers for home and community-based care for the elderly and disabled than other states because these services were largely available through the state Medicaid plan. Although New York had higher spending on Medicaid long-term care services per capita than the other states in 1999, including about $500 per capita on personal support services for the elderly, spending for HCBS waiver services was a small part of Medicaid spending—$9 per elderly person.[9] As a result, home and community-based services were largely available to all eligible Medicaid beneficiaries needing them through the state Medicaid plan without caps.[10] Services offered through the state plan included in-home help, such as hands-on assistance and household support, and personal emergency response systems. Through a waiver, New York also offers such services as home-delivered meals, adult day care, environmental modifications, and nutritional counseling.
- Oregon: Oregon had HCBS waivers that covered in-home care, environmental modifications to homes, adult day care, respite care, and care in alternate residential settings such as assisted living facilities and adult foster homes. Oregon's waiver services did not have a waiting list and were available to elderly and disabled clients based on functional need, and served about 12,000 elderly and disabled individuals as of June

[8]In Louisiana, "adult day health care" for the elderly and disabled is distinguished from "adult day care" for individuals with mental retardation or developmental disabilities. For the purposes of this report, "adult day care" is used to describe care for the elderly and disabled to be consistent with terminology across states.

[9]HCBS waiver services served about 25,000 New Yorkers as of July 2002.

[10]In New York, spending on HCBS waiver services provided in-home cannot exceed 75 percent of Medicaid's average annual nursing home costs for most individuals, but these costs may be up to 100 percent of average annual nursing home costs for individuals with certain diagnoses, including Alzheimer's disease.

2002. Oregon has established a priority system for providing services based on eligible Medicaid beneficiaries' needs with assistance for activities of daily living. Were a waiting list to become necessary in Oregon, officials told us that the state would allocate services based on its priority categories so that those categorized as being more dependent on assistance would receive help first.

Table 2 summarizes the home and community based services offered in the four states we reviewed either through their Medicaid state plan or a home and community-based services waiver. Generally, many home and community-based services are covered in each of the states, but in Kansas and Louisiana they may be limited in their level of coverage and the number of individuals served.

Table 2: Medicaid Home and Community-Based Long-Term Care Services for Elderly in Four States

Home and community-based services (includes services offered in state plans and through waivers)	**Kansas**	**Louisiana**	**New York**	**Oregon**
In-home help with daily activities				
Personal care, providing hands-on assistance with activities of daily living such as eating, bathing, dressing, using the toilet, and grooming	❍	❍	●	●
Household support, providing assistance with instrumental activities of daily living, such as housekeeping and meal preparation	❍	❍	●	●
Home-delivered meals			●	●
Standby assistance during day or night	❍	❍		●
Adaptive items or changes to facilitate independence, mobility, or safety				
Environmental modifications, such as wheelchair ramp, or assistive devices or technology, such as bathtub lift or shower seat	❍	❍	●	●
Personal emergency response system	❍	❍	●	●
In-home medical care or counseling				
Periodic nursing evaluation	❍	●	●	●
Home health services/medical equipment assistance	●	●	●	●
Nutritional counseling			●	
Case management	●	❍	●	●
Help outside of home				
Adult day care	❍	❍	●	●
Help provided in community residential settings, such as assisted living facility, adult foster care, boarding home	❍		●	●
Transportation		●[a]	●	●
Moving assistance			●	
Care for Caregiver				
Respite care in-home or out of home	❍		●	●

● Available services

❍ State had a waiting list for these services as of June 2002

Note: Services are only included in the table if the state Medicaid plan or HCBS waivers cover these services specifically for the elderly and/or disabled. In some cases, other services (such as respite care or transportation) may not be specifically included in the state plan or the waiver but could be provided indirectly through personal care attendants or other support services that are covered.

[a]In Louisiana, the HCBS waiver covers transportation to medical appointments only.

Source: GAO interviews with state Medicaid officials and review of state Web sites, 2002.

Case Managers Predominately Offered Medicaid In-Home Care Services, but Number of Hours Offered Varied

Most often, the 16 Medicaid case managers we contacted in Kansas, Louisiana, New York, and Oregon offered care plans for our hypothetical clients—Abby, an 86-year-old chair-bound woman with debilitating arthritis, and Brian, a 70-year-old man with moderate Alzheimer's disease—that aimed at allowing them to remain in their homes. The number of hours of in-home care that the case managers offered and the types of residential care settings recommended depended in part on the availability of services and the amount of informal family care available. In a few situations, especially when the individual did not live with a family member who could provide additional support, case managers were concerned that the client would not be safe at home and recommended a nursing home or other residential care setting.

Most case managers offered in-home services for Abby and Brian except for the one scenario when Brian lives alone and requires constant supervision to ensure his safety due to his moderate Alzheimer's disease. Several case managers noted that they would attempt to honor individuals' preferences to remain at home unless it was unsafe to do so. For Abby, most case managers offered in-home personal care (hands-on assistance with activities such as bathing, toileting, and eating), household support (such as preparing meals and laundry), and other supplemental services (such as household modifications or an emergency response system) that would supplement the care she received from her family. When Abby lived with her daughter or elderly sister, all but 1 of the 16 case managers offered in-home care. When Abby lived alone with her daughter able to come by only once per day before going to her job, 12 case managers still offered in-home services to provide most of her care while 4 recommended that she relocate to a nursing home or other residential care setting. Similarly, in the scenarios when Brian lived with his wife, all but one case manager offered in-home care services for Brian. Most of the care plans continued to rely on Brian's wife to provide much of the supervision of Brian's safety and reminders for him to bathe, eat, and use the bathroom, but the care plans also offered additional in-home support to provide some hands-on care and household support. However, when Brian would otherwise have to live alone, 13 of the 16 care plans would have him move to a nursing home or other residential care setting. (See table 3.)

Table 3: Number of Care Plans that Recommended that the Individual Remain at Home or Move to a Different Residential Setting

Amount of informal care available	Number of plans in which individual remains at home	Number of plans in which individual moves to a residential care setting
Abby (86-year-old chair-bound woman with debilitating arthritis)		
Scenario 1: Abby lives with her daughter (who also cares for infant grandchild)	15	1
Scenario 2: Abby lives with her sister (who has limited strength)	16	0
Scenario 3: Abby lives alone (her daughter visits once a day)	12	4
Brian (70-year-old man with moderate Alzheimer's disease)		
Scenario 1: Brian lives with his wife (wife in fair health)	16	0
Scenario 2: Brian lives with his wife (wife in poor health)	15	1
Scenario 3: Brian lives alone	3	13

Source: GAO interviews with case managers in Kansas, Louisiana, New York, and Oregon.

When the case managers recommended that the individuals remain at home, the number of hours of in-home services offered varied. The care plans generally provided more paid in-home care when less informal family support was available, especially when Abby or Brian lived alone, as shown in the following examples.

- When Abby lived with her daughter who was overwhelmed due to also caring for an infant grandchild, the case managers recommending in-home care offered a median of 28 hours per week. However, the number of hours of in-home care in this scenario varied by case manager from 4.5 hours to 40 hours per week. In this scenario, four case managers recommended that Abby attend adult day care—which serves to both provide additional hours of care to Abby and provide her daughter with some respite.[11]

[11]Many of the care plans recommending that Abby or Brian remain at home also recommended other supplemental services, including Medicaid-covered personal emergency response systems or assistive devices for bathtubs such as grab bars or transfer seats; Medicaid and/or Medicare home health care; or other federal or state-subsidized services such as meal deliveries or transportation services.

- When Abby lived with an 82-year-old sister who had difficulty helping with some tasks due to limited strength, the case managers offered a median of 16 hours per week, with a range across case managers of 6 to 37 hours per week. In this scenario, one case manager also recommended that Abby receive most of her care (56 hours per week) through adult day care.
- When Abby lived alone with her daughter visiting for an hour each morning, the number of offered hours of in-home care was highest—a median of 32 hours per week and as many as 49 hours per week.

For Brian, the number of hours of care offered more consistently reflected the amount of informal help that was available to him, as the specific examples illustrate.

- When Brian lived with his wife who was in fair health, the case managers offered a median of 18 hours per week of in-home care, ranging from 11 to 35 hours per week. Two case managers also offered adult day care in addition to or instead of in-home care.
- If Brian's wife were in poor health, the case managers offered in-home care for a median of 22 hours per week, ranging from 6 to 35 hours per week. One care manager recommended that Brian move to a residential care facility.
- When Brian lived alone, two of the three care managers who had Brian remain at home offered round-the-clock in-home care—168 hours per week.

Table 4 summarizes the numbers of hours of in-home care offered by care managers for each scenario.

Table 4: Number of Hours of In-Home Care Offered For Individuals Remaining At Home

Amount of informal care available	Median amount of in-home help offered (hours per week)	Range in amount of in-home help offered (hours per week)
Abby (86-year-old chair-bound woman with debilitating arthritis)		
Scenario 1: Abby lives with her daughter (who also cares for infant grandchild)	28	4.5 to 40
Scenario 2: Abby lives with her sister (who has limited strength)	16	6 to 37
Scenario 3: Abby lives alone (her daughter visits once per day)	32	12 to 49
Brian (70-year-old man with moderate Alzheimer's disease)		
Scenario 1: Brian lives with his wife (in fair health)	18	11 to 35
Scenario 2: Brian lives with his wife (in poor health)	22	6 to 35
Scenario 3: Brian lives alone	168	35 to 168

Source: GAO interviews with case managers in Kansas, Louisiana, New York, and Oregon.

Consistent with the hypothetical individuals' preferences to remain at home as long as possible, case managers less often recommended that the hypothetical individuals move out of their homes to a nursing home or an alternative residential care setting such as an assisted living facility, adult foster home, or adult boarding home. The case managers typically recommended the individual move only if they believed that she or he would be unsafe in their homes or, in two instances, if they were concerned that the family caregiver was at risk due to the demands of providing extensive informal care. Of the 16 case managers, 13 recommended that Brian move to a residential care setting if he lived alone, with most noting that they were concerned about his safety living at home alone or were unable to provide a sufficient number of hours of in-home supervision. Four case managers also recommended that Abby needed to move if she did not have a family member or paid caregiver who could remain with her at nighttime and assist her with using the toilet or in an emergency. In two instances when the hypothetical individuals did have a family member living with them, case managers were concerned that providing care would be too demanding either for Abby's daughter (who also had an infant grandchild to care for) or Brian's wife (who was in poor health) and recommended that the client move to an adult foster home. For example, one case manager was concerned that Brian's wife, who was

in poor health, would ultimately also need care if she continued to provide Brian with most of his support.

In some situations, two case managers in the same locality offered notably different care plans. For example, across the eight localities where we interviewed case managers, four case managers offered in-home care while their local counterpart recommended a nursing home or alternative residential setting for Abby when she lived alone. This contrast also occurred three times when Brian lived alone and once each when Abby lived with her daughter and Brian lived with his wife who was in poor health. In a few cases, the case managers in the same locality both offered in-home care but offered significantly different numbers of hours. For example, one case manager offered 42 hours per week of in-home care for Abby when she lived alone, while another case manager in the same locality offered 15 hours per week of in-home care for this scenario.

Appendix II provides a summary of the care plans provided by each case manager for each of the six hypothetical scenarios.

Case Managers in Some States Offered More In-Home Care, Alternative Residential Settings, or Other Supplemental Services

The care plans the case managers offered for the hypothetical individuals, Abby and Brian, sometimes varied as a result of state-specific policies or practices for Medicaid home and community-based services. In particular, neither Abby nor Brian would be able to immediately receive HCBS waiver services in Kansas and Louisiana due to a waiting list. When case managers developed care plans based on HCBS-waiver services for our hypothetical individuals, Louisiana's cap on the amount of dollars that could be spent per day limited the number of hours of in-home care that could be offered in scenarios where Abby or Brian needed more extensive care. Also, Kansas's case managers may have been more cost-sensitive due to state review thresholds and their awareness that maintaining lower average costs per client may help other clients to be served. When out-of-home placements were recommended, case managers in Oregon consistently recommended alternatives to nursing homes (either adult foster care or assisted living) whereas case managers in Louisiana were more likely to recommend a nursing home. Other state-specific differences in the care plans included that Louisiana case managers did not offer adult day care in any of the care plans, and New York and Louisiana case managers often considered how Medicare home health services would expand or offset the Medicaid home and community-based services offered.

Waiting Lists in Two States Would Prevent New Clients from Immediately Receiving Medicaid Home and Community-Based Waiver Services

As new clients, our hypothetical elderly individuals with disabilities would not have been able to immediately receive most Medicaid home and community-based services in Kansas or Louisiana due to waiting lists for the HCBS waiver services. As a result, our hypothetical individuals would often have fewer services available to them, only those available through other state or federal programs, until Medicaid HCBS waiver services became available or they would have to receive Medicaid-covered nursing home care. The average length of time individuals wait for Medicaid waiver services was not known in either state. However, one case manager in Louisiana estimated that elderly persons for whom he had developed care plans had spent about a year on the waiting list before receiving services. In Kansas, as of July no one had yet come off the waiting list, which was instituted in April 2002.

When case managers in Kansas developed care plans based only on what services were currently available from sources other than Medicaid home and community-based services, they tended to offer fewer in-home hours and to recommend out-of-home placements twice as often as they did when the waiver services were available. Service availability also varied more widely across the state when case managers could not offer Medicaid HCBS waiver services. For example, in one area of the state, in-home help was offered using Older Americans Act funds while in another area those services were not available due to budget constraints.[12]

According to Louisiana officials, since Medicaid HCBS waiver services have a waiting list, persons needing immediate assistance who call the state help line may be referred to local councils on aging or they can contact another organization that would help them complete an application for nursing home care. In general, however, the case managers we interviewed in the four states indicated that few services were typically available outside of the Medicaid program.

Number of Hours of In-Home Care Varies Partly Due to State Policies

The number of hours of in-home care offered to our hypothetical individuals through Medicaid could be as much as 168 hours per week (24 hours per day) in New York and Oregon while case managers in Kansas and Louisiana offered at most 24.5 and 37 hours per week, respectively.

[12]Funding from the Older Americans Act provides for supportive in-home and community-based services, including such services as nutrition, transportation, senior centers, health promotion, and homemaker services. 42 U.S.C. §§3001-3058ee (2000).

The number of hours of in-home care offered was often lowest in Kansas, and in Louisiana case managers tended to change the amount of in-home help offered little even as the hypothetical scenarios changed, such that our hypothetical individuals presumably would require more assistance because there was less unpaid care available from family caregivers. (See table 5.) This variation reflects several factors case managers took into consideration when determining the amount of care to offer. These factors included the local availability of personal care attendants and other care services, the cost of the care that was allowed under their state's Medicaid program, and the state's review requirements for approving care plans.

Table 5: Range in Amount of In-Home Care Offered for Individuals Remaining at Home, by State

	Offered in-home care (hours per week)			
Amount of informal care available	**Kansas**	**Louisiana**	**New York**	**Oregon**
Abby (86-year-old chair-bound woman with debilitating arthritis)				
Scenario 1: Abby lives with her daughter (who also cares for infant grandchild)	5 to 22	28 to 37	4.5 to 40	7[a]
Scenario 2: Abby lives with her sister (who has limited strength)	6 to 14	24.5 to 37	15 to 35	9 to 16
Scenario 3: Abby lives alone (her daughter visits once per day)	12 to 24.5	24.5 to 35	42 to 49	15 to 42
Brian (70-year-old man with moderate Alzheimer's disease)				
Scenario 1: Brian lives with his wife (in fair health)	11 to 14.75	21 to 35	11 to 20	16 to 25
Scenario 2: Brian lives with his wife (in poor health)	14 to 21	21 to 28	6 to 35	22 to 29
Scenario 3: Brian lives alone	N/A[b]	N/A[b]	168[c]	35 to 168

Note: Table does not include adult day care services.

[a]Only one case manager offered in-home care for this scenario. Two other Oregon case managers recommended that Abby stay at home and the family caregiver become licensed for a relative foster home and receive a payment that she could use to hire in-home or respite care for an unspecified number of hours.

[b]All four case managers recommended care in a residential care setting, such as a nursing home or assisted living facility.

[c]Only one case manager offered in-home care for this scenario. The other New York case managers recommended a residential care setting.

Source: GAO interviews with case managers in Kansas, Louisiana, New York, and Oregon.

The number of hours of in-home care case managers in Louisiana could offer was limited by a dollar cap on waiver services of $35 per day at the time we conducted our work.[13] Case managers in Louisiana tended to offer

[13]The cap was increased from $35 per day to $55 per day effective September 1, 2002. The cap includes the cost of in-home care as well as a case management fee. According to a state official, Louisiana's daily cap for in-home HCBS waiver services reflects the state's budget constraints as well as the need to be cost-effective relative to nursing home care.

as many hours of care as they could offer under the cost limit. Therefore, as the amount of informal care changed in the different scenarios, the hours of in-home help offered in Louisiana did not change as much as they did in the other states. For example, when Brian's wife was in poor health, the case managers in Kansas, New York, and Oregon usually either offered more in-home care (from 1.5 to 13.5 additional hours per week) or else offered more help through adult day care than they offered when his wife was in better health. In contrast, case managers in Louisiana did not prescribe any more hours of in-home care per week when Brian's wife was in poor health because they could not cover more hours within the cap.

Case managers in Kansas often offered the fewest hours of in-home care across all of the states we reviewed. The state had a review process whereby higher cost care plans were more extensively reviewed than lower cost care plans. Case managers recognized that Kansas's Medicaid HCBS waiver program and other state programs providing long-term care services had recently been largely closed to new clients due to budget constraints. As one Kansas case manager told us, offering fewer hours of care may reflect the case managers' sensitivity to the waiting list and an effort to serve more clients by keeping the cost per person low.

In contrast, case managers in New York and Oregon did not indicate similar cost concerns in offering in-home care hours. When the costs of services were above the cost limit for waiver services in New York, case managers could offer most in-home care through services provided in the state plan, which were not subject to a cost limit. Further, while three case managers in Oregon expressed concern about finding live-in help or providers for lower-paying custodial services, one case manager in New York and one in Oregon offered the most in-home care possible—24 hours a day, 168 hours a week.

When Residential Care Was Recommended, Oregon Relied on Alternatives Other Than Nursing Homes

When recommending that our hypothetical individuals could be better cared for in a residential care setting, case managers offered alternatives to nursing homes to varying degrees across the states, with those in Louisiana relying most heavily on nursing home care and those in Oregon using exclusively alternative residential settings. Case managers in Louisiana recommended nursing home care in three of the four care plans for Abby or Brian in which care in another residence was recommended. A Louisiana state official noted that care in alternative residential care settings is generally not covered through the Medicaid waiver. In contrast, case managers in Oregon never recommended nursing home care for our hypothetical individuals. Instead, case managers in Oregon exclusively

recommended either adult foster care or an assisted living facility in the five care plans recommending care in another residence. (See table 6.)

Table 6: Number of Care Plans Where Nursing Home or Alternative Residential Setting was Recommended

	Type of residential care setting (number of care plans)			
	Kansas	**Louisiana**	**New York**	**Oregon**
Residential care settings	Nursing home (2) Assisted living (3)	Nursing home (3) Group home (1)	Nursing home (3) Boarding home (2)	Nursing home (0) Assisted living (1) Adult foster care (4)
Total out-of-home placements	**5**	**4**	**5**	**5**

Source: GAO interviews with case managers in Kansas, Louisiana, New York, and Oregon.

Case managers in Oregon twice recommended that our hypothetical individuals obtain care in other residential care settings when case managers in other states would have had them stay at home. Case managers in Kansas, Louisiana, and New York only recommended out of home placement for Abby or Brian in scenarios when they lived alone. In Oregon, however, two different case managers recommended that Abby and Brian move into an adult foster home in scenarios when they lived with a family member, expressing concern that continuing to provide care to Abby or Brian would be detrimental to the family.

States Also Varied in Use of Adult Day Care and Medicare Home Health Services

State differences also were evident in how case managers used other services to supplement in-home or other care. For example, across all care plans the case managers developed for Abby and Brian (24 care plans in each state), adult day care was offered four times in New York and Oregon and three times in Kansas. When adult day care was offered in the other states, it often served to provide additional hours of care for Abby or Brian as well as some relief for their caregiver. However, none of the care plans developed by case managers in Louisiana included adult day care despite

the state's Medicaid waiver for these services.[14] Case managers may not have offered adult day care services because Louisiana covers these services under a separate HCBS waiver from the waiver that covers in-home assistance and, in general, individuals cannot receive services from two separate waiver programs concurrently.

Case managers in New York and Louisiana also often considered the effect that the availability of Medicare home health services could have on the Medicaid in-home care. For example, one case manager in New York noted that she maximizes the use of Medicare home health before using Medicaid home health or other services. Several of the case managers in New York included the amount of Medicare home health care available in their care plans, and these services offset some of the Medicaid services that would otherwise be offered. In Louisiana, where case managers faced a dollar cap on the amount of Medicaid in-home care hours they could provide, two case managers told us that they would include the additional care available under Medicare's home health benefit in their care plans, thereby increasing the number of total hours of care that Abby or Brian would have by 2 hours per week. While six Kansas and Oregon case managers also mentioned that they would refer Abby or Brian to a physician or visiting nurse to be assessed for potential Medicare home health care, they did not specifically include the availability of Medicare home health care in the number of hours of care provided by their care plans.

Concluding Observations

Many states have found that offering home and community-based services through their Medicaid programs can help low-income elderly individuals with disabilities remain in their homes or communities when they otherwise would be likely to go to nursing homes. States differ, however, in how they designed their Medicaid programs to offer home and community-based long-term care options for elderly individuals and the level of resources they devoted to these services. As a result, as demonstrated by the care plans offered by case managers for our hypothetical elderly individuals in four states, the same individual with certain identified disabilities and needs would often receive different types and intensity of home and community-based care for their long-term care needs across states and even within the same community. These

[14]The Louisiana adult day care waiver served approximately 525 people with a waiting list of 201 people as of July 2002.

differences often stemmed from case managers' attempts to leverage the availability of both publicly financed long-term care services as well as the informal care and support provided to individuals by their own family members.

States' Comments

We requested comments on a draft of this report from Kansas, Louisiana, New York, and Oregon officials. On behalf of these states, we received oral comments from the Program Manager, Kansas Department of Aging; the Waiver Manager, Louisiana Bureau of Community Supports and Services; the Health Program Administrator, Bureau of Long-Term Care, Office of Medicaid Management, New York Department of Health; and the Manager of Community-Based Care Licensing, Office of Licensing and Quality of Care for Seniors and People with Disabilities, Oregon Department of Human Services.

Two states commented on our findings concerning the extent of services case managers offered to our hypothetical individuals. The Kansas official noted that our finding that the Kansas case managers' care plans often offered among the fewest hours of in-home care does not necessarily reflect that the care plans would not meet their health and welfare needs. She emphasized that Kansas case managers are trained to enssure that the care plans are sufficient to meet clients' health and welfare needs and that the state reviews the care plans to provide further assurances that they are sufficient. We clarified the report to indicate that we did not evaluate the adequacy or appropriateness of the care plans offered by the case managers in meeting the hypothetical individuals' long-term care needs. The Louisiana official commented that the state was covering as many eligible enrollees in its HCBS waivers as funding allowed, and that Louisiana's daily cap for in-home HCBS waiver services reflects the state's budget constraints as well as the need to be cost-effective relative to nursing home care, which had a reimbursement rate of about $85 per day as of September 2002.

Two states commented on the importance of individuals' preferences and the local availability of long-term care service providers in shaping case managers' care plans. The Oregon official commented that case managers will develop their care plans to best reflect the preferences of their clients to receive care in their home or in community-based settings. The New York official commented that the availability of certain long-term care services, such as workers to provide in-home care and adult day care settings, varies within the state and can be an additional factor influencing the number of hours of in-home care offered in case managers' care plans.

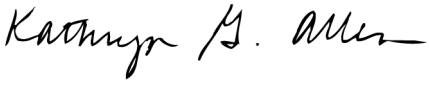
Officials from the four states also provided technical comments that we incorporated as appropriate.

We did not seek comments on this report from CMS because we did not evaluate CMS's role or performance with respect to the availability of Medicaid home and community-based services.

As agreed with your office, unless you publicly announce this report's contents earlier, we plan no further distribution until 30 days after its date. At that time, we will send copies of this report to other interested congressional committees and other parties. We will also make copies available to others on request. Copies of this report will also be available at no charge on GAO's Web site at http://www.gao.gov.

Please call me at (202) 512-7118 or John E. Dicken at (202) 512-7043 if you have any questions. Major contributors to this report include JoAnne R. Bailey, Romy Gelb, and Miryam Frieder.

Sincerely yours,



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

Appendix I: Summary of Hypothetical Individuals Presented to Case Managers

To obtain information about the availability of long-term care for our hypothetical elderly individuals, we asked 16 Medicaid case managers in Kansas, Louisiana, New York, and Oregon to prepare detailed care plans for two elderly persons with physical or cognitive disabilities. For each hypothetical individual, we presented the case managers with three different scenarios illustrating different levels of informal care available from family members. The first hypothetical person was a woman, "Abby," who had difficulty performing everyday activities due to physical limitations, while the second was a man, "Brian," who had difficulty due to cognitive limitations. We contacted each case manager and presented detailed information, as summarized below, regarding the hypothetical individuals' conditions, needs for assistance, and availability of informal unpaid care from family. We also provided any clarifying information that the case managers requested to be able to develop the care plans. With this information, the case managers used state-specific uniform assessment instruments and their professional expertise to develop care plans as they would with other Medicaid-eligible clients.[1]

Summary of Abby

The first hypothetical Medicaid-eligible individual we presented was Abby, an 86-year-old woman with physical limitations due to debilitating arthritis. She also has type II diabetes. Specifically, Abby is chair-bound, has developed a pressure ulcer, and has some degree of difficulty with all activities of daily living (ADL) and instrumental activities of daily living (IADL) tasks as well as with taking an oral medication.[2] She also needs her glucose levels checked daily to monitor her diabetes. She is alert and oriented, without any cognitive impairment. Her prognosis is for little or no recovery, with decline in her current condition possible. Abby's husband, who served as her primary caregiver, recently died.

We presented three scenarios to the case managers in which Abby's conditions and needs for assistance remained the same, but the availability of unpaid informal care provided by her family varied:

[1]We presented information about the hypothetical individuals by phone, whereas case managers would typically assess clients in person.

[2]ADLs include grooming, dressing upper and lower body, bathing, toileting, transferring (such as to and from a bed or wheelchair), walking (ambulation), and eating. IADLs include planning and preparing meals, transportation, laundry, housekeeping, shopping, and using a telephone.

- Scenario 1: Abby has moved in with her 51-year-old daughter who also cares for her own infant grandchild.[3] Abby's daughter provides assistance with Abby's ADL and IADL needs, but the daughter reports feeling overwhelmed caring for both her mother and grandchild. In addition, the daughter is unable to help with Abby's diabetes testing because she does not know how to do so.
- Scenario 2: Abby has moved in with her 82-year-old sister who provides assistance with Abby's ADL and IADL needs. However, the sister has limited strength and therefore is unable to provide assistance with some ADLs and IADLs, such as helping Abby to the toilet and transferring her to and from her wheelchair. During the week, the sister is also unable to fully meet Abby's needs for bathing, laundry, and housekeeping. In addition, the sister cannot assist Abby with her diabetes testing.
- Scenario 3: Abby lives alone, and her 51-year-old daughter visits once each morning for 1 hour to provide assistance but is unable to provide additional assistance at other times because she works two jobs and lives in another home. As a result, Abby does not receive assistance with grooming and dressing her upper and lower body. During the day and night, she does not receive assistance with planning and preparing meals, toileting, eating, and transferring to and from her wheelchair to the toilet or bed. Each week, she does not receive assistance with transportation, bathing, laundry, and using the telephone in case of an emergency. In addition, the daughter is unable to assist with Abby's diabetes testing.

Summary of Brian

The second hypothetical Medicaid-eligible individual we presented to the case managers was Brian, a 70-year-old man with moderate Alzheimer's disease who has been in a skilled nursing facility for 90 days following hospitalization for a hip fracture.[4] During his stay in the skilled nursing facility, he has become physically weakened and will need physical therapy. Brian takes medication for his hip fracture and for anxiety and temporarily uses a cane when walking, but otherwise is in good physical health. Brian needs supervisory help with most ADLs and IADLs and taking his oral medication—that is, he can perform tasks such as eating and toileting if he is reminded and monitored. Due to dementia resulting from Alzheimer's disease, he is alert but not oriented and is unable to shift attention and recall directions more than half the time. Further, he is

[3]In this scenario, Abby's granddaughter is a single mother who works long hours and therefore depends on her mother (Abby's daughter) for child care.

[4]Brian is not a military veteran and is therefore not eligible for health or long-term care services covered by the Department of Veterans Affairs.

confused during the day and evening, but not constantly. He cannot be left unsupervised.

As with the first hypothetical individual, we presented three scenarios to the case managers in which Brian's conditions and needs for assistance remained the same, but the availability of unpaid informal care provided by his family varied:

- Scenario 1: Brian lives with his 65-year-old wife, who is his primary caregiver and is in fair health but has recently suffered health problems.[5] She supervises Brian with all ADLs and she performs many of his IADLs herself, but is having increasing difficulty doing these tasks due to her declining health. During the day, she would like additional assistance reminding Brian to toilet and bathe as well as with planning and preparing meals and transportation. Each week, she would like additional assistance with laundry, housekeeping, and shopping.
- Scenario 2: Brian's 65-year-old wife is in poorer health than described in scenario 1, and can offer supervisory help with ADLs but cannot perform most IADLs. As a result, Brian does not receive all of the reminders he needs for bathing and toileting nor all of the assistance he needs with planning and preparing meals, transportation, laundry, housekeeping, and shopping.
- Scenario 3: Brian lives alone because his wife recently died. He needs constant supervision with most ADLs and help with several IADLs. He cannot be left unsupervised and does not receive reminders for bathing, dressing, grooming, toileting, eating, and taking his medications. He also does not receive assistance with planning and preparing meals, transportation, shopping, laundry, and housekeeping.

[5]In this scenario, Brian's wife has a history of high blood pressure and type II diabetes, and she underwent an angioplasty in the past 6 months.

Appendix II: Summary of Care Plans Offered by 16 Case Managers

We obtained care plans from 16 Medicaid case managers in Kansas, Louisiana, New York, and Oregon that detailed the long-term care services that they would offer to two hypothetical Medicaid-eligible elderly individuals—Abby, an 86-year-old woman with debilitating arthritis and who was chair-bound, and Brian, a 70-year-old man with moderate Alzheimer's disease. Each case manager developed six care plans, representing three different levels of unpaid informal care provided to Abby and Brian by their family. The case managers we contacted were specifically responsible for Medicaid home and community-based services. While most also were familiar with other local public services available, clients could receive different care options if they sought care through other approaches, such as physician referrals or contacting local councils on aging. The care plans were based on the information presented by telephone to the case managers we selected to interview in a small town (a population of less than 15,000 people) and a large city (a population of more than 250,000 people) in each of the four states and should not be generalized to indicate what care plans other case managers in these localities or other states would likely offer. We did not evaluate the adequacy or appropriateness of the care plans offered by the case managers for meeting the long-term care needs of our hypothetical individuals.

Tables 7 through 12 summarize key components of the care plans offered by each of the case managers, designated in the tables as case managers A through P, for each of the six care plans.[1] The tables summarize the number of in-home hours of care offered by the case manager or whether a nursing home or other alternate residential care setting was recommended. The tables also provide other aspects of care offered to Abby or Brian, including whether the care manager would offer adult day care to supplement or replace in-home or other care, whether the case manager noted the availability of a nurse or home health services available from Medicare and/or Medicaid, and examples of other services (such as personal emergency response systems, assistive devices such as transfer

[1]While some case managers suggested alternative care plans or noted that clients could choose among different care options, the care plans summarized in this report represent the care plans that the case managers identified as the best alternative or indicated were most likely to be selected by clients who generally preferred to remain at home if possible. The recommended care plans represented the services offered at the time of the assessment, could be subject to supervisory review, and could be reassessed if the plan did not meet the individuals' care needs or if the individuals' conditions or availability of informal care changed.

seats, or companionship services) that may be offered through Medicaid or other federal, state, or local programs.

Table 7: Care Plans for Abby, an 86-Year-Old Chair-Bound Woman With Debilitating Arthritis Who Lives with Her Daughter (Scenario 1)

Case manager	Amount of in-home care offered (hours per week)	Other housing – nursing home or alternate housing	Adult day care (hours per week)	Medicare or Medicaid nurse or home health care	Other Medicaid services	Other non-Medicaid services
A		Adult foster home				
B	Relative foster home[a]			Medicaid	• Grief counseling	• Companionship • Caregiver support for daughter • Respite care for daughter
C	Relative foster home[a]		24	Medicaid		
D	7			Medicaid	• Home-delivered meals	
E	40			Medicare	• Respite care	
F	32			Medicare	• Lift/transfer seat for bathing	• Wheelchair ramp
G	4.5			Medicaid		• Senior companion • Home-delivered meals
H			18	Medicare		
I	5		12	Medicare		
J	22			Medicaid	• Personal emergency response system	• Respite care
K	12			Unspecified[b]	• Personal emergency response system	• Adult diapers • Home meal delivery
L			8	Medicaid		• Senior companion
M	28			Medicare	• Personal emergency response system	
N	35			Unspecified[b]	• Personal emergency response system	• Home-delivered meals
O	37			Medicare	• Personal emergency response system	• Home-delivered meals • Family counseling
P	35					• Companionship

[a]The care plan recommended that the family caregiver become licensed for a relative foster home to allow Abby to remain living in the home and the family caregiver would receive payment that could be used to hire additional in-home or respite care for an unspecified number of hours.

[b]The care plan recommended a referral for home health care but did not specify whether this service would by covered through Medicare or Medicaid.

Note: Abby's daughter also cares for an infant grandchild and, though meeting the care needs of both her mother and grandchild, reports feeling overwhelmed by her responsibilities.

Source: GAO interviews with case managers in Kansas, Louisiana, New York, and Oregon.

Table 8: Care Plans for Abby, an 86-Year-Old Chair-Bound Woman With Debilitating Arthritis Who Lives With Her Sister (Scenario 2)

Case manager	Amount of in-home care offered (hours per week)	Other housing – nursing home or alternate housing	Adult day care (hours per week)	Medicare or Medicaid nurse or home health care	Other Medicaid services	Other non-Medicaid services
A	9			Medicaid		• Transportation • Caregiver support for sister
B	Relative foster home[a]			Medicaid	• Grief counseling	• Companionship
C	16			Medicaid		
D	14			Medicaid	• Personal emergency response system • Home-delivered meals	
E	35			Medicare	• Assistive devices	• Home-delivered meals
F	15			Medicare and Medicaid	• Lift/transfer seat for bathing • Wheelchair ramp	
G	17			Medicaid	• Personal emergency response system	
H	28			Medicare	• Adult diapers • Personal emergency response system	• Equipment to help with eating
I	10			Medicaid		• Home-delivered meals
J	6		56		• Personal emergency response system	
K	14			Unspecified[b]	• Personal emergency response system	• Adult diapers • Home-delivered meals
L	6			Medicaid	• Minor home repairs	• Transportation
M	24.5			Medicare	• Personal emergency response system • Wheelchair ramp	
N	36.5			Unspecified[b]	• Personal emergency response system	• Home-delivered meals
O	37			Medicare	• Personal emergency response system	• Home-delivered meals
P	28					• Companionship

[a]The care plan recommended that the family caregiver become licensed for a relative foster home to allow Abby to remain living in the home and the family caregiver would receive payment that could be used to hire additional in-home or respite care for an unspecified number of hours.

[b]The care plan recommended a referral for home health care but did not specify whether this service would by covered through Medicare or Medicaid.

Source: GAO interviews with case managers in Kansas, Louisiana, New York, and Oregon.

Table 9: Care Plans for Abby, an 86-Year-Old Chair-Bound Woman With Debilitating Arthritis Who Lives Alone (Scenario 3)

Case Manager	Amount of in-home care offered (hours per week)	Other housing – nursing home or alternate housing	Adult day care (hours per week)	Medicare or Medicaid nurse or home health care	Other Medicaid services	Other non-Medicaid services
A	15			Medicaid		• Caregiver support for daughter • Grief support for Abby
B	42			Medicaid	• Personal emergency response system • Grief counseling	• Companionship
C	36			Medicaid	• Personal emergency response system	
D		Adult foster home	8	Medicaid		• Large-button speaker phone
E		Boarding home		Medicare and Medicaid		
F	49			Medicare and Medicaid	• Personal emergency response system • Lift/transfer seat for bathing	• Wheelchair ramp
G		Nursing home				
H	42			Medicare	• Adult diapers • Personal emergency response system	• Equipment to help with eating
I		Assisted living facility		Medicaid		
J	24.5			Medicare and Medicaid	• Personal emergency response system	
K	21			Unspecified[a]	• Personal emergency response system	• Adult diapers
L	12			Medicaid		• Transportation • Home-delivered meals
M	24.5			Medicare	• Personal emergency response system • Wheelchair ramp	
N	34			Unspecified[a]	• Personal emergency response system	
O	30			Medicare	• Personal emergency response system	• Home-delivered meals
P	35					• Home-delivered meals • Companionship

[a]The care plan recommended a referral for home health care but did not specify whether this service would by covered through Medicare or Medicaid.

Note: Abby's working daughter visits once each morning for 1 hour to provide informal care for Abby.

Source: GAO interviews with case managers in Kansas, Louisiana, New York, and Oregon.

Table 10: Care Plans for Brian, a 70-Year-Old Man With Moderate Alzheimer's Disease Who Lives With His Wife in Fair Health (Scenario 1)

Case manager	Amount of in-home care offered (hours per week)	Other housing – nursing home or alternate housing	Adult day care (hours per week)	Medicare or Medicaid nurse or home health care	Other Medicaid services	Other non-Medicaid services
A	18			Medicaid	• Home-delivered meals	
B	16			Medicaid	• Counseling	• Caregiver support group
C	25		16			
D	25				• Bath/shower grab bar	
E	20			Medicare	• Home-delivered meals • Personal emergency response system	
F	11			Medicaid		
G	14.5					
H			30			
I	11					• Home-delivered meals
J	14.75			Medicare		• Home-delivered meals • Respite (2 hr/week) • Caregiver support group
K	13					• Companionship
L	14			Medicare		• Caregiver support group • ID bracelet (in case Brian wanders)
M	21			Medicare		• Caregiver support group
N	34				• Personal emergency response system	• Home-delivered meals • Housekeeping
O	25					
P	35			Medicaid		

Source: GAO interviews with case managers in Kansas, Louisiana, New York, and Oregon.

Table 11: Care Plans for Brian, a 70-Year-Old Man With Moderate Alzheimer's Disease Who Lives With His Wife in Poor Health (Scenario 2)

Case manager	Amount of in-home care offered (hours per week)	Other housing – nursing home or alternate housing	Adult day care (hours per week)	Medicare or Medicaid nurse or home health care	Other Medicaid services	Other non-Medicaid services
A	26.5			Medicaid	• Home-delivered meals	
B	22			Medicaid	• Counseling	• Caregiver support group
C		Adult foster home	24		• Home-delivered meals	
D	29					
E	35				• Home-delivered meals • Personal emergency response system	
F	24.5					• Home-delivered meals
G	16		15			
H	6		30			
I	15					• Home-delivered meals
J	21			Medicare		• Home-delivered meals
K	19					
L	14			Medicare	• Personal emergency response system	• Caregiver support group • ID bracelet (in case Brian wanders)
M	21			Medicare and Medicaid		• Caregiver support group
N	28				• Personal emergency response system	• Home-delivered meals • Housekeeping
O	25			Medicaid		
P	27.5			Medicaid		

Source: GAO interviews with case managers in Kansas, Louisiana, New York, and Oregon.

Table 12: Care Plans for Brian, a 70-Year-Old Man With Moderate Alzheimer's Disease Who Lives Alone (Scenario 3)

Case manager	Amount of in-home care offered (hours per week)	Other housing – nursing home or alternate housing	Adult day care (hours per week)	Medicare or Medicaid nurse or home health care	Other Medicaid services	Other non-Medicaid services
A	35			Medicaid	• Home-delivered meals • Counseling	
B		Assisted living facility				
C		Adult foster home				
D	168					
E		Boarding home				
F	168					
G		Nursing home				
H		Nursing home				
I		Assisted living facility				
J		Assisted living facility				
K		Nursing home				
L		Nursing home				
M		Nursing home				
N		Nursing home				
O		Group home				
P		Nursing home				

Source: GAO interviews with case managers in Kansas, Louisiana, New York, and Oregon.

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