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Report to the Ranking Minority Member, Special Committee on Aging, U.S. Senate

September 1994

LONG-TERM CARE REFORM

States' Views on Key Elements of Well-Designed Programs for the Elderly

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Health, Education, and
Human Services Division

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September 6, 1994

The Honorable William S. Cohen
Ranking Minority Member
Special Committee on Aging
United States Senate

Dear Senator Cohen:

Today, about 7 million elderly persons need long-term care. Many more will need long-term care in the future as the elderly population continues to grow. The elderly prefer home and community-based services rather than nursing home care, and approximately 75 percent of those needing long-term care live outside nursing homes. To a great extent, care for elderly persons with disabilities is provided today by family and friends, mostly women.

Total long-term care spending for the elderly in 1993 was estimated to be $79.2 billion, $20.6 billion of which was for home and community-based services. Assuming the continuation of current spending patterns under current law, it is estimated that total expenditures will more than double by 2020. But the future demand for government spending may grow at an even faster rate because the rising number of women in the workforce, smaller family size, more frequent divorce, and geographic dispersal of families are likely to decrease the ability of informal caregivers to provide the same proportion of unpaid care.

A number of proposals to reform long-term care have been introduced in the Congress as part of the health care reform debate. While these proposals cover various long-term care populations and services, almost all include home and community-based services for the elderly as a major component of their reform strategies.[1] To help inform this debate, you asked us to survey state agencies on aging and state Medicaid agencies to obtain their views on how best to design and administer public programs to provide home and community-based long-term care services for the elderly. Through these agencies, many states have been innovators in trying to develop programs that more effectively identify persons in need, determine the types of services needed, and control costs.

[1]The current long-term care reform debate covers persons of all ages—children, adults, and the elderly—with severe physical or cognitive disabilities or both. However, our work and its results are limited to the elderly population.

Results in Brief

Congressional deliberations on long-term care reform have focused on key program components—who should receive services, what services should be provided, and how costs can be controlled. Another topic of debate is how responsibility for long-term care should be shared between the public and private sectors. This report offers insight on how the states view these issues for the elderly.

Collectively, the state agencies' responses showed significant agreement on key components of well-designed programs. First, state agencies agreed that an elderly person's ability to perform activities of daily living (ADL)[2] is the best way to identify persons with the greatest need for services. However, ADLs are not uniformly defined by the states, and most of the states use ADLs in combination with other indicators to determine need. The other best indicators of need are cognitive disability and access to care from family. For determining service needs, state agencies generally agreed that case/care management,[3] a standard assessment instrument, and involvement of the elderly person in the process are most useful. Second, state agencies reported that the largest proportion of elderly persons with severe disabilities need nonmedical services, such as personal care. Third, state agencies agreed that a variety of cost control methods are effective, although there was less consensus about which specific methods are most effective. The most frequently identified cost-control method was case/care management, followed by limits on total individual costs, capitation with providers at risk,[4] and fixed program allocations.

State agencies believed that encouraging a greater private sector role could reduce government long-term care spending for the elderly. For example, many state agencies believed that government interventions could increase the use of private long-term care insurance and private residential care alternatives, which might reduce government long-term care spending for the elderly. State agencies agreed that informal or family care could reduce government long-term care spending. However, they did

[2]ADLs generally include bathing, dressing, eating, using the toilet, continence (bowel or bladder control or both), getting in or out of a bed or chair, and mobility.

[3]Case management generally is a process that assists people in defining their service needs, locating and arranging services, and coordinating the services of multiple providers. Case managers may also be responsible for containing costs by controlling client access to services, especially high-cost services.

[4]Capitation with providers at risk is a financing arrangement in which an organization receives a fixed amount of money for each person who is enrolled in a care program in exchange for guaranteeing the services needed by each person for a fixed period of time. In addition, the organization receiving the payments is financially responsible for the costs of such services if total costs exceed per capita payments.

not believe that government interventions would be likely to increase the use of this approach.

Background

State governments, through their respective state agencies on aging and Medicaid agencies, administer most home and community-based services for the elderly and have been leaders in developing strategies to provide more appropriate, integrated, and flexible services to meet the long-term care needs of individuals with severe disabilities and to identify methods to control costs. Some states have also been involved in efforts to establish public/private efforts to meet long-term care needs. As a result, state agencies' views based on these experiences may help inform the congressional debate on long-term care reform.

The two types of agencies we surveyed—state agencies on aging and Medicaid agencies—have different perspectives on administering public programs and providing home and community-based services to elderly persons with severe disabilities. State agencies on aging provide a broad range of general aging and advocacy services, such as congregate programs, home meals, and ombudsman programs, for persons 60 years of age and older, targeting services to those most in need. Medicaid agencies, on the other hand, administer the Medicaid program that was intended to pay primarily for low-income persons' medical care but has also become the primary public funding source for long-term care. Evolving from the medical model, Medicaid's primary long-term care role has been to pay for nursing home care. Medicaid agencies also administer funding for some coverage of nonmedical home and community-based services to persons with severe disabilities. Compared with Medicaid agencies, state agencies on aging tend to administer or oversee a larger number of other federal and state-only funded home and community-based service programs for the elderly. Also, almost half of the state agencies on aging administer or oversee at least some part of Medicaid home and community-based program funds for their states.

Scope and Methodology

This study focuses on states' experiences in providing home and community-based services to elderly persons with severe disabilities. This group includes those whose physical impairments are so great that they are unable to carry out essential everyday activities without assistance from others and those whose cognitive impairments are so great that they need frequent or continuous supervision. Because younger persons with

disabilities were not included in the scope, the survey results do not apply to them.

To do our work, we surveyed state agencies on aging and state Medicaid agencies in the 50 states and the District of Columbia. We asked the agencies questions related to what they believed would be the best approaches in providing home and community-based long-term care services to elderly persons who are severely disabled, considering limited resources. We also asked the state agencies for a copy of the assessment instruments they used to identify persons in need of home and community-based long-term care services. As agreed to with your staff, we did not ask the state agencies to report their current methods and practices for administering and designing home and community-based services to elderly persons. Also, we did not independently verify state agency responses to the survey since the survey focused on the state agencies' views.

In designing the survey we drew on our previous long-term care work,[5] reviewed the literature, and interviewed experts. We then pretested the survey instrument with state agencies and made revisions as needed. We mailed the survey on May 20, 1994. We received responses from all 51 state agencies on aging and from 50 of 51 state Medicaid agencies. (See app. I for the survey tables and frequencies.) We received assessment instruments from 28 state agencies on aging and 29 state Medicaid agencies.

State Agencies Generally Agreed on Key Components of Home and Community-Based Service Programs for the Elderly

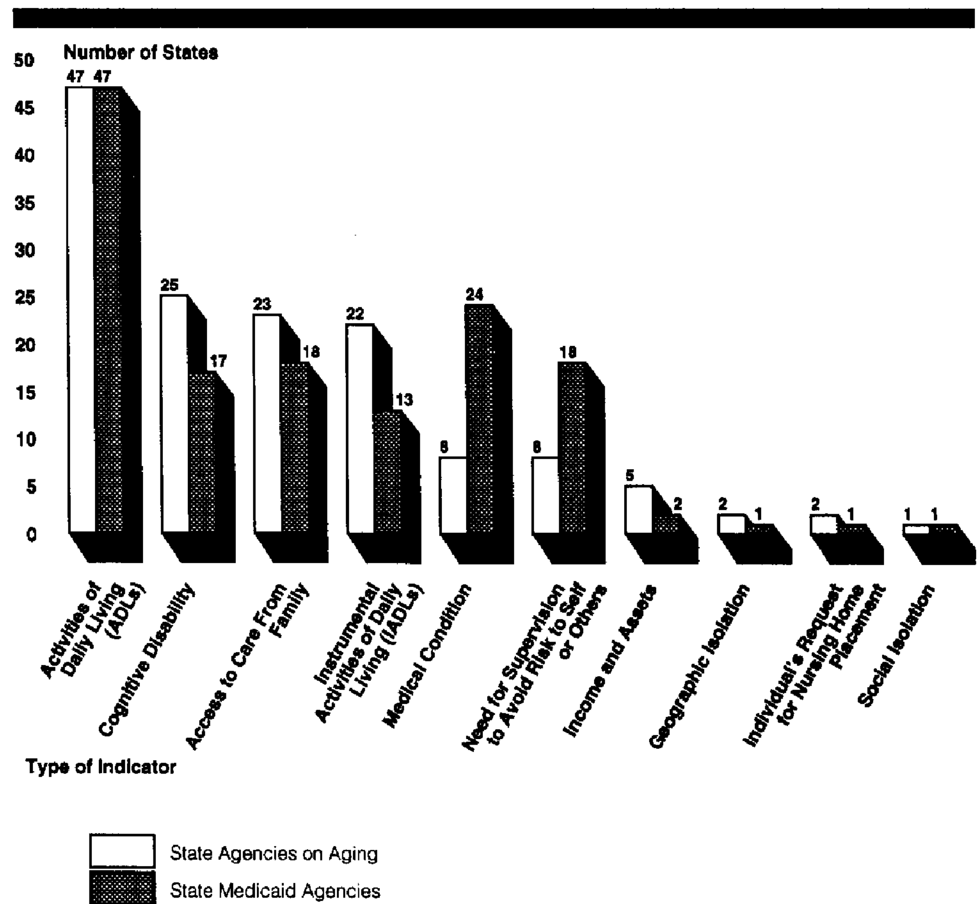
State agencies we surveyed generally agreed on key components of home and community-based service programs for elderly persons who are severely disabled. These agencies generally agreed on key aspects of how a public program would best determine which elderly persons are most in need of home and community-based services and how a public program would best identify services to meet these persons' needs. They also shared common views about the types of services needed by the elderly who are severely disabled. Finally, although they reported that a variety of cost-control methods are effective, there was less consensus about which methods are most effective.

[5]A forthcoming report, Long-Term Care: Other Countries Tighten Budgets While Seeking Better Access (GAO/HEHS-94-154), looks at other countries' experiences with similar service and cost-control issues in providing home and community-based long-term care. For other related products, see p. 32.

An Elderly Person's Ability to Perform ADLs Is the Leading Indicator of Need

State agencies on aging and state Medicaid agencies almost unanimously agreed that an elderly person's ability to perform ADLs is the leading indicator for public programs to use in determining need for home and community-based services, although ADLs are not uniformly defined by the states (see fig. 1). Moreover, most of the state agencies' assessment instruments we received in response to our survey used ADLs in combination with other indicators to determine need.

Figure 1: Best Indicators to Identify Elderly Persons With Severe Disabilities Who Have the Greatest Need for Home and Community-Based Services



Note: Maximum number of respondents: 51 state agencies on aging, 50 state Medicaid agencies. Respondents each identified their top three indicators.

Source: GAO survey of state agencies (July 1994).

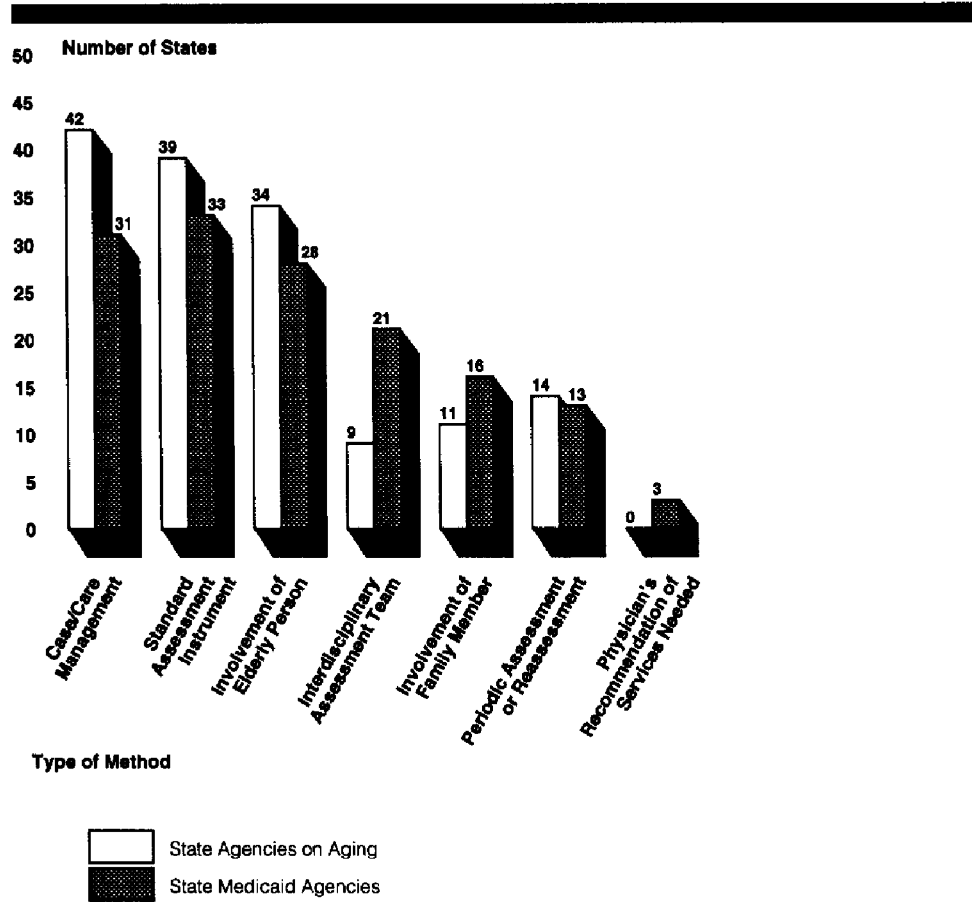
Many state agencies also regarded an individual's cognitive disability and access to care from family as the best indicators of need. State agencies believed that several other indicators are important to identify need for services among the elderly, although agreement was less marked and varied between aging and Medicaid agencies. These indicators included an individual's (1) ability to perform instrumental activities of daily living (IADL),[6] (2) medical condition, and (3) need for supervision to avoid risk to self and others. Other indicators mentioned much less frequently included an individual's income and assets, geographic isolation, request for nursing home placement, and social isolation.

Three Methods Are Most Useful for Determining Service Needs

State agencies on aging and Medicaid agencies generally agreed that three methods are most useful for public programs when determining which services elderly persons with severe disabilities need. These methods are (1) case/care management, (2) a standard assessment instrument, and (3) involvement of the elderly person in the process of determining services (see fig. 2). State agencies on aging, however, more often identified these methods as most useful than did state Medicaid agencies. Some state agencies also believed that other methods are most useful, including (1) interdisciplinary assessment teams, (2) involvement of the elderly person's family, and (3) periodic assessment of needs. Only three agencies reported that a physician's recommendation is one of the most useful methods of determining need.

[6]IADLs generally include preparing meals, doing laundry, doing heavy work, grocery shopping, managing money, taking medicine, making telephone calls, doing light work, and going places beyond walking distance.

Figure 2: Most Useful Methods to Determine Home and Community-Based Services Needed by Elderly Persons With Severe Disabilities



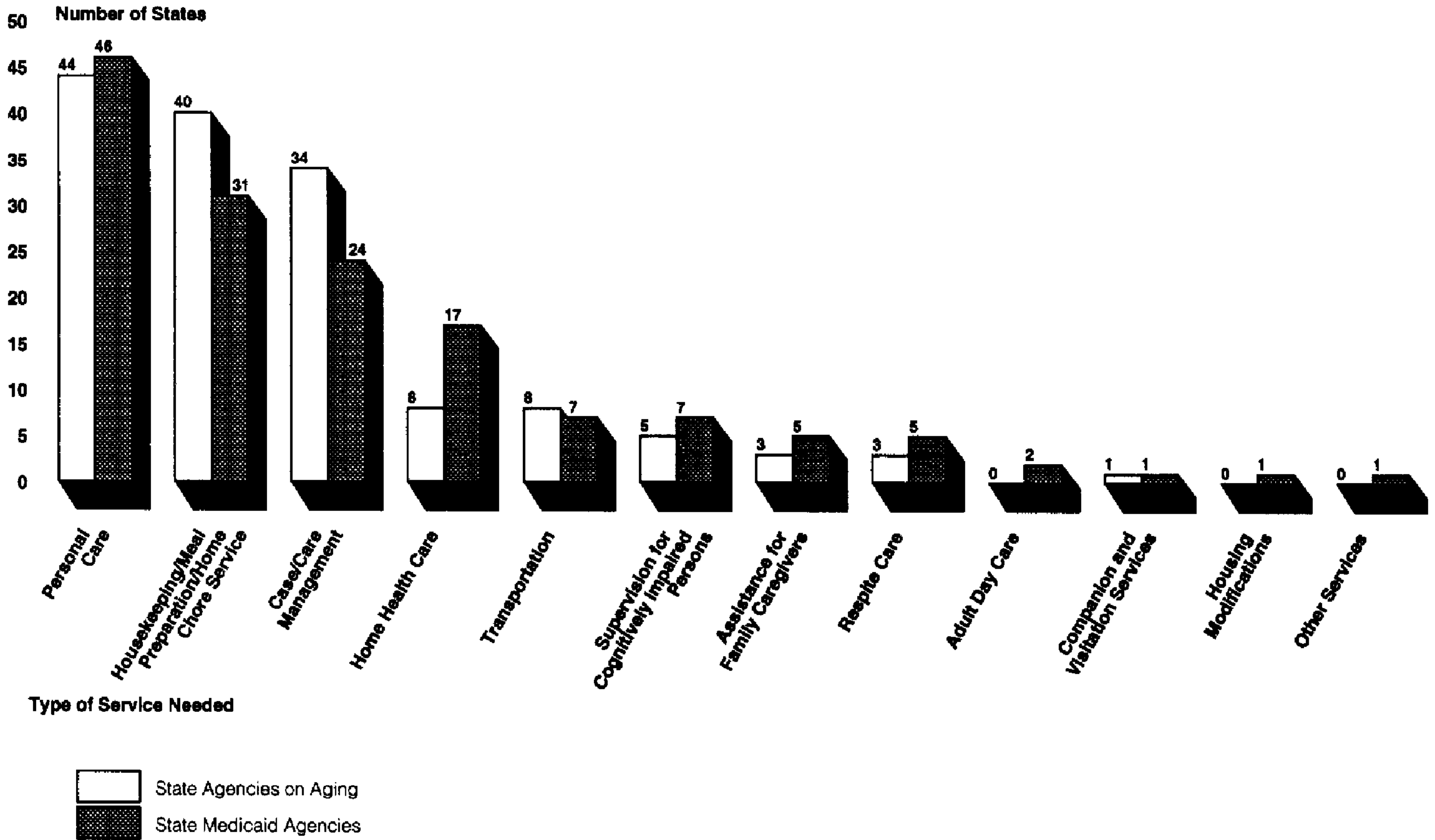
Note: Maximum number of respondents: 51 state agencies on aging, 50 state Medicaid agencies. Respondents each identified their top three methods.

Source: GAO survey of state agencies (July 1994).

The Largest Proportion of Elderly Persons With Severe Disabilities Need Nonmedical Services

State agencies reported that the largest proportion of elderly persons with severe disabilities need nonmedical services. State agencies most often cited (1) personal care; (2) housekeeping, meal preparation, and other home chore services; and (3) case/care management as the services needed by the largest proportion of elderly persons with severe disabilities (see fig. 3). Other services mentioned by several states included home health care, transportation, supervision for cognitively impaired persons, respite care, and assistance for family caregivers such as training, counseling, or support groups. Adult day care, companion and visitation services, and housing modifications were mentioned much less often.

Figure 3: Home and Community-Based Services Needed by the Largest Proportion of Elderly Persons With Severe Disabilities



Note: Maximum number of respondents: 51 state agencies on aging, 50 state Medicaid agencies. Respondents each identified their top three services.

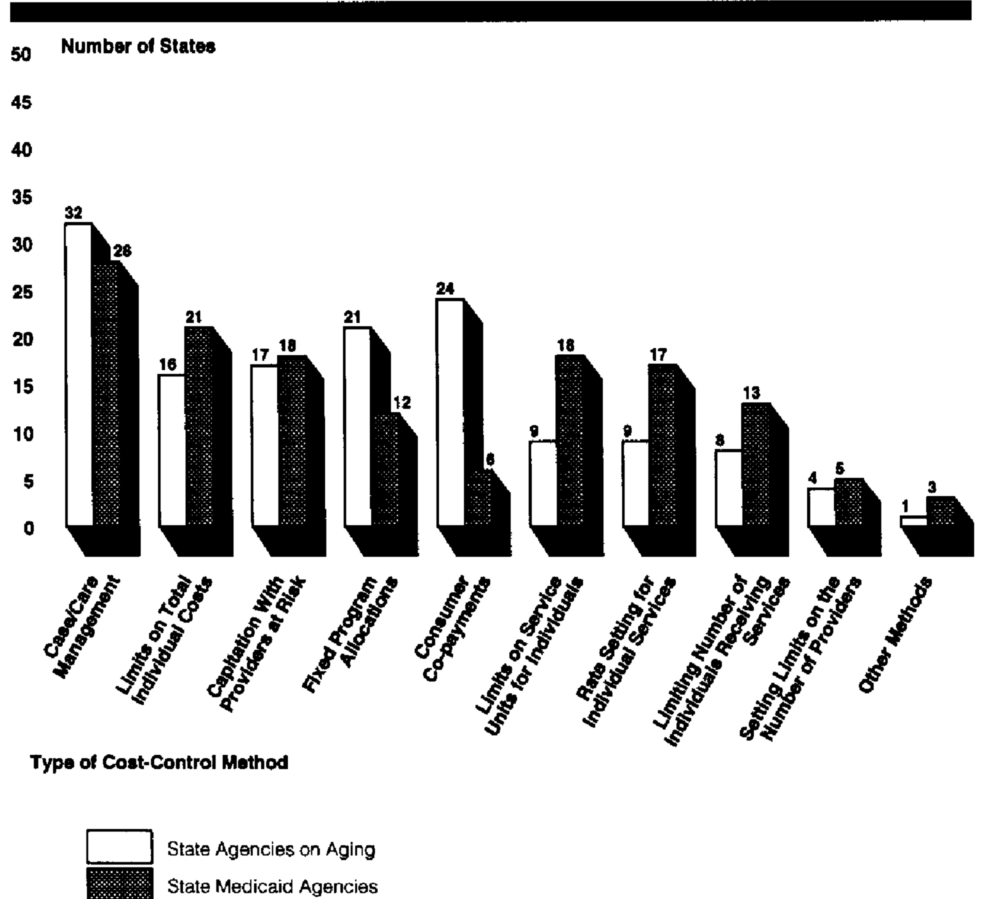
Source: GAO survey of state agencies (July 1994).

Views of State Agencies Showed Less Consensus About Which Cost-Control Methods Are Most Effective

Views of the state agencies showed less consensus about which methods are most effective for controlling spending on home and community-based services for the elderly. The most frequently identified cost-control method was case/care management (see fig. 4). Other frequently identified cost-control methods included limits on total individual costs, capitation with providers at risk, fixed program allocations, and consumer co-payments. In addition, some state agencies identified limits on the number of service units for an individual,[7] rate setting for individual services, and limiting the number of individuals receiving services as the most effective methods for controlling costs. A few states also reported that setting limits on the number of providers and other methods would be most effective for controlling costs.

[7]Limits on service units cap the number of hours or days of care a person may receive in a defined period of time. These caps may limit the total cost of care for any single individual and help limit total costs of care for the types of services included.

Figure 4: Most Effective Cost-Control Methods for Home and Community-Based Services Needed by Severely Disabled Elderly Persons



Note: Maximum number of respondents: 51 state agencies on aging, 50 state Medicaid agencies. Respondents each identified their top three methods.

Source: GAO survey of state agencies (July 1994).

The views of state agencies on aging and state Medicaid agencies differed more on cost-control methods than in the other areas we surveyed. State agencies on aging reported more frequently than state Medicaid agencies that (1) case/care management, (2) consumer co-payments, and (3) fixed program allocations would be effective cost-control mechanisms. State Medicaid agencies reported more frequently that (1) limits on total individual costs, (2) limits on the number of service units to individuals, (3) rate setting for individual services, and (4) limiting the number of

individuals receiving services would be most effective for controlling costs.

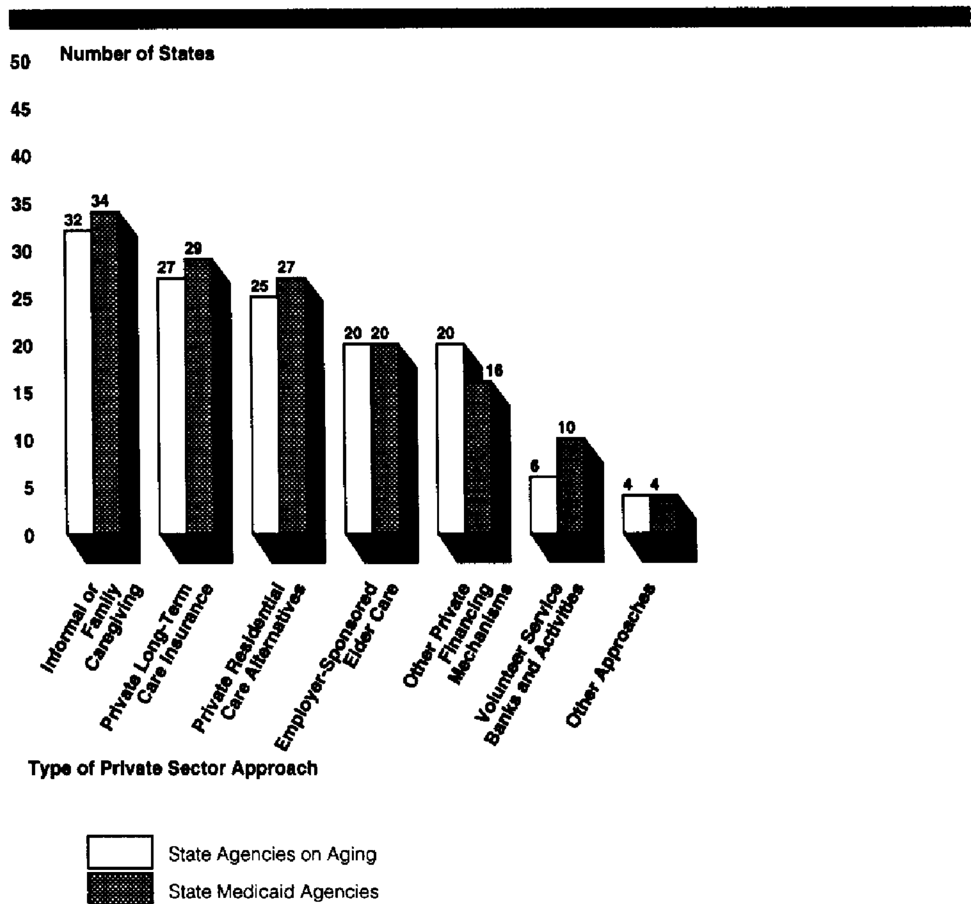
State Agencies Believed Private Sector Role Could Probably Reduce Government Costs and Government Interventions Might Increase Private Sector Activity

State agencies believed that the private sector role could probably reduce government long-term care costs for nursing home and home and community-based services. Since we did not ask to what extent the various private sector approaches could help to reduce publicly funded services, our results do not address the potential magnitude of cost reductions. State agencies also reported that government interventions—other than additional funding—might increase the use of a number of private sector approaches to long-term care.

State agencies reported most frequently that informal or family caregiving—a common private sector approach—could reduce total government long-term care spending for the elderly (see fig. 5 and tables 1 and 2). Four other approaches were also mentioned with some frequency: (1) private long-term care insurance, (2) private residential care alternatives, (3) employer-sponsored elder care, and (4) other private sector financing mechanisms. Other private sector financing mechanisms included reverse annuity mortgages,[8] long-term care medical individual retirement accounts (IRA), and life insurance conversions. Some state agencies also believed that volunteer service banks and activities as well as other private sector approaches could reduce government spending for long-term care.

[8]Reverse annuity mortgages permit elderly homeowners to take out loans, which they receive in the form of monthly payments, based on the equity in their homes. At the time of the homeowner's death, the loan is repayed through the sale of the house.

Figure 5: Most Effective Private Sector Approaches to Reduce Government Long-Term Care Spending for Elderly Persons With Severe Disabilities



Note: Maximum number of respondents: 51 state agencies on aging, 50 state Medicaid agencies. Respondents each identified their top three approaches.

Source: GAO survey of state agencies (July 1994).

Table 1: State Agencies on Aging Views on Effectiveness of Private Sector Approaches to Reduce Government Spending for Nursing Home and Home and Community-Based Services

	Would an increase in the use of the approach reduce government spending for long-term care services?				
Approach	**Definitely yes**	**Probably yes**	**Probably no**	**Definitely no**	**No basis to judge**
Informal or family caregiving	27	10	13	1	0
Employer-sponsored elder care programs for employees who are caregivers	5	31	13	0	2
Private, long-term care insurance	12	27	7	2	3
Other private financing mechanisms such as reverse annuity mortgages, long-term care medical IRAs, and life insurance conversions	5	29	9	1	6
Residential care alternatives, such as continuing care retirement communities,[a] and other private, assisted living options	12	26	11	1	1
Volunteer service banks and other volunteer activities to provide services	2	17	24	2	6
Other	4	2	0	0	0

Note: Maximum number of respondents: 51 state agencies on aging.

[a]Continuing care retirement communities (CCRC) are organized to provide independent residential units and social and health services in one setting. This may include nursing home care in or near the community. Residents usually pay entry and monthly fees to CCRCs to receive care for the rest of their lives.

Source: GAO survey of state agencies (July 1994).

Table 2: Medicaid Agencies' Views on Effectiveness of Private Sector Approaches to Reduce Government Spending for Nursing Home and Home and Community-Based Services

	Would an increase in the use of the approach reduce government spending for long-term care services?				
Approach	**Definitely yes**	**Probably yes**	**Probably no**	**Definitely no**	**No basis to judge**
Informal or family caregiving	28	15	5	1	1
Employer-sponsored elder care programs for employees who are caregivers	11	27	8	1	3
Private, long-term care insurance	18	26	4	0	2
Other private financing mechanisms such as reverse annuity mortgages, long-term care medical IRAs, and life insurance conversions	6	32	9	0	3
Residential care alternatives, such as continuing care retirement communities, and other private, assisted living options	15	24	11	0	0
Volunteer service banks and other volunteer activities to provide services	7	22	12	0	9
Other	5	2	0	0	1

Note: Maximum number of respondents: 50 state Medicaid agencies.

Source: GAO survey of state agencies (July 1994).

State agencies also reported that government interventions—other than additional funding—might increase the use of a number of private sector approaches in long-term care (see tables 3 and 4). Government interventions include consumer education and information, technical assistance, quality assurance, avoidance of overly restrictive regulation, and national standards. Private long-term care insurance was most often cited as an approach that government could encourage without spending additional funds. Other approaches reported with some frequency were private residential care alternatives, other private financing mechanisms, employer-sponsored elder care, volunteer service banks and activities, and informal or family caregiving.

Table 3: State Agencies on Aging Views on Government Interventions to Increase the Use of Private Sector Approaches

	How likely is it that government intervention would increase use of the approach?					
Approach	**Very likely**	**Somewhat likely**	**As likely as not**	**Somewhat unlikely**	**Very unlikely**	**Don't know**
Informal or family caregiving	5	16	8	9	12	0
Employer-sponsored elder care programs for employees who are caregivers	11	14	14	7	1	4
Private, long-term care insurance	15	21	6	5	2	2
Other private financing mechanisms such as reverse annuity mortgages, long-term care medical IRAs, and life insurance conversions	10	21	8	4	2	4
Residential care alternatives, such as continuing care retirement communities, and other private, assisted living options	13	18	14	4	0	2
Volunteer service banks and other volunteer activities to provide services	7	14	9	10	5	6
Other	4	1	0	1	0	0

Note: Maximum number of respondents: 51 state agencies on aging.

Source: GAO survey of state agencies (July 1994).

Table 4: Medicaid Agencies' Views on Government Interventions to Increase the Use of Private Sector Approaches

	How likely is it that government intervention would increase use of the approach?					
Approach	**Very likely**	**Somewhat likely**	**As likely as not**	**Somewhat unlikely**	**Very unlikely**	**Don't know**
Informal or family caregiving	4	8	16	11	10	1
Employer-sponsored elder care programs for employees who are caregivers	6	26	10	3	2	3
Private, long-term care insurance	9	29	6	2	1	3
Other private financing mechanisms such as reverse annuity mortgages, long-term care medical IRAs, and life insurance conversions	9	24	8	3	2	4
Residential care alternatives, such as continuing care retirement communities, and other private, assisted living options	18	15	11	3	2	1
Volunteer service banks and other volunteer activities to provide services	7	12	12	10	3	6
Other	3	2	0	0	0	1

Note: Maximum number of respondents: 50 state Medicaid agencies.

Source: GAO survey of state agencies (July 1994).

Conclusion

The views of state agencies on aging and Medicaid agencies showed wide agreement on key components of well-designed programs. State agencies agreed that an elderly person's ability to perform ADLs is the best way to identify persons with the greatest need for services, although states do not uniformly define ADLs. To determine service needs, state agencies generally agreed that case/care management, a standard assessment instrument, and involvement of the elderly person in the process are most useful. State agencies reported that the largest number of severely disabled elderly persons need nonmedical services, such as personal care. State agencies agreed that a variety of cost control methods are effective, although there was less consensus about which specific methods are most effective. Regarding the private sector role in long-term care, state agencies believed the private sector role could probably reduce government costs, and government interventions might increase private sector activity.

We did not obtain agency comments since our work was focused on the state agencies' views rather than their current program practices.

As agreed with your office, unless you publicly announce its contents earlier, we plan no further distribution of this report for 3 days. At that time, we will send copies of this report to other congressional committees and members with an interest in this matter; the Secretary of Health and Human Services; the Assistant Secretary for Aging; the Administrator, Health Care Financing Administration; the Assistant Secretary for Planning and Evaluation; Directors of State Agencies on Aging; Directors of State Medicaid Agencies; and to others upon request.

Should you or your staff have any questions about this report, please call me on (202) 512-7215. Other major contributors are listed in appendix II.

Sincerely yours,

Jane L. Ross
Associate Director,
Income Security Issues