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LONG-TERM CARE REFORM

Program Eligibility, States' Service Capacity, and Federal Role in Reform Need More Consideration

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SUMMARY

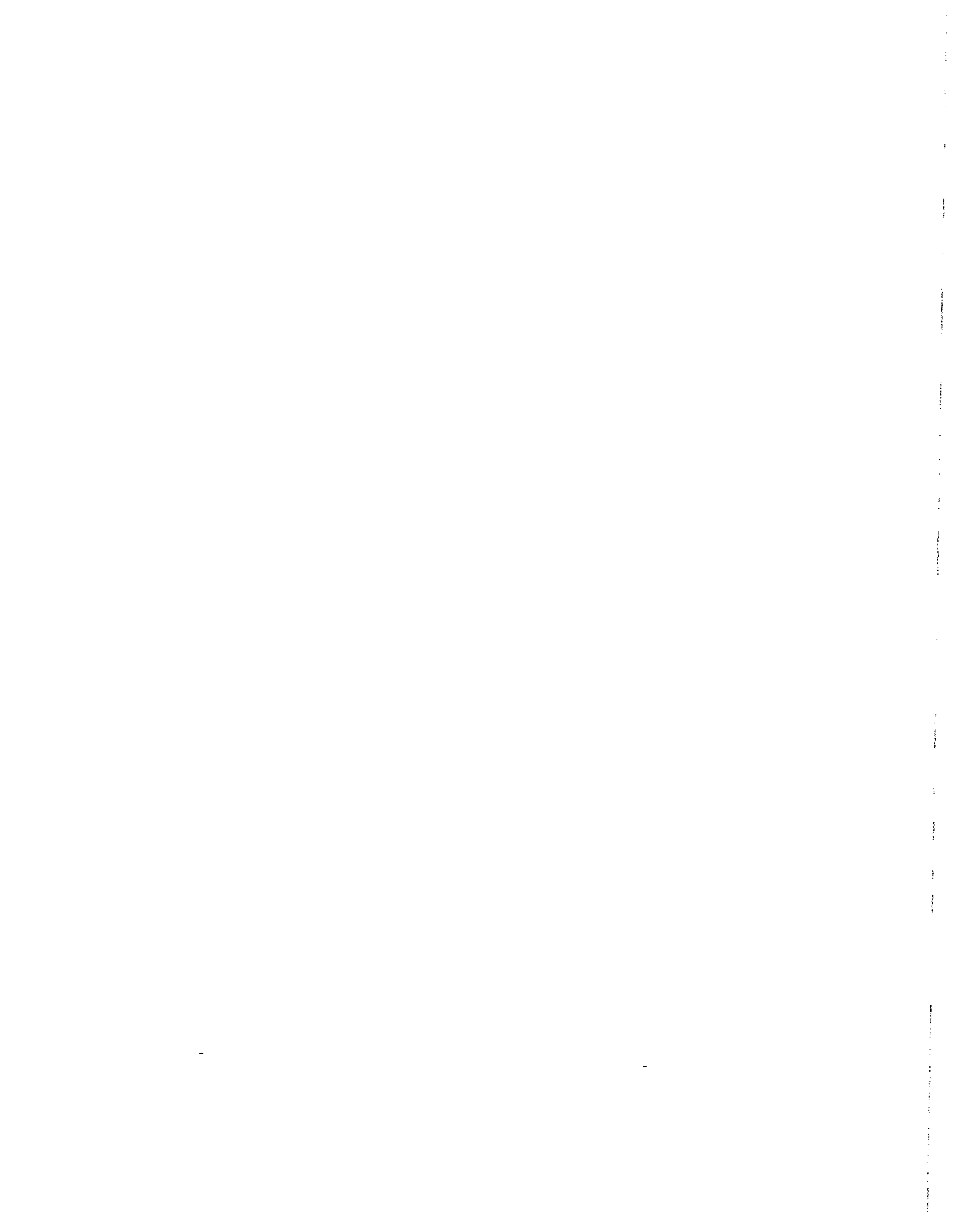
Demographic pressures, rising expenditures, and dissatisfaction with services provide a compelling rationale for long-term care reform. Currently there are several legislative proposals that seek to either improve existing federal long-term care programs, create new programs, or expand the role of the private sector. At the Subcommittee's request, GAO's testimony covered three aspects of the home and community-based services portion of the Health Security Act, the Administration's reform proposal. These aspects are eligibility, states' service capacity, and the federal role in this legislation.

The Administration's proposal, which entitles states to a capped amount of dollars to provide home and community-based services, includes eligibility criteria as to who may receive those services. These criteria need additional consideration, including how eligibility will be determined during the phase-in of federal funding. Modifications to the plan could include more latitude to the states in eligibility determination and updating eligibility criteria over time, as well as phased-in eligibility requirements or guidance to states on service priorities until the full allotment of funding is available.

Program administration and service delivery under the proposal is left to the states to organize as they choose. Today, state long-term care infrastructures vary considerably, and states have differing capacities for providing more services, serving additional people, and absorbing new program dollars. To avoid unintended program outcomes, states with less developed infrastructures will need technical assistance to assure program funds are well spent and that service capacities are improved.

At present, no entity has been given federal responsibility for implementation. Furthermore, the federal role in implementing the Administration's proposal needs clarification given the legislation's innovative approach. Two defining elements of an appropriate role are (1) the need to distinguish good and bad variations in state programs and (2) the capacity of the federal government to recognize and encourage good variation while discouraging the bad. Encouraging flexibility while avoiding unintended outcomes could be facilitated by technical assistance for and monitoring of the implementation process.

Passage of any long-term care reform legislation is the first step of a long process and not the final word on how the nation meets long-term care needs. This legislation would require a different federal role, largely one of partnership with the states in the design, administration, and monitoring of programs. If the Health Security Act is adopted, additional consideration should be given as to the specifics of this federal role, as well as better guidance to the states on eligibility determination and how states with less capacity can be assisted in wisely using program funds.



Madam Chair and Members of the Subcommittee:

I am pleased to be here today to discuss long-term care reform. As you know, there is a growing sense that such reform is needed because of changing demography, rising costs, and dissatisfaction with current services. In response to these concerns, the Administration has proposed long-term care reform as part of the Health Security Act. Other long-term care proposals also have been introduced or will be introduced soon in Congress.

Several principles of long-term care reform are common to leading state and international long-term care initiatives. These principles include (1) emphasizing home and community-based services, (2) basing access on a person's ability to carry out everyday activities, (3) permitting flexibility in the services provided to individuals, (4) decentralizing decisionmaking for services as close as possible to the person receiving care, and (5) controlling costs.

With these principles in mind, my remarks today will focus on three aspects of the Administration's proposal concerning eligibility determination, service capacity, and the federal role in implementing the legislation.

BACKGROUND

Growing long-term care need, long-term care spending, and dissatisfaction with services are driving the need for reform. About 11 million persons of all ages are chronically disabled and depend on others for assistance in the basic tasks of daily living. This includes persons of all ages: persons with limitations in activities of daily living, persons with cognitive disabilities, persons with mental retardation, and children. These needs are expected to increase in the future.

Though most persons receive all their care free from family and friends, society spends about $108 billion dollars for services. Federal and state government spending is about $70 billion. Almost all the remaining $38 billion is paid for by families. Costs are expected to increase dramatically in the future. The majority of long-term care spending is for institutional care.

Persons receiving care and their families are dissatisfied with the services currently offered. At the core of their frustration lies a belief that services are often difficult to access and not matched well with the diverse needs and preferences of disabled individuals. This results from fragmented funding streams that, rather than the individual needs and preferences of disabled persons, often determine available services.

The Administration's proposal, prompted by these challenges, would provide $38 billion dollars in new federal funding per year for a new federal-state program of home and community-based

services, to be phased in from 1996 to 2003. Funding would be provided by a federal match to states more generous than they currently receive under Medicaid. The proposal provides states a fixed budget for home and community-based services but provides no entitlement to services to individuals. States are given broad flexibility to design and administer programs to serve persons of all income ranges. States are required, however, to use a uniform eligibility instrument to be supplied by the Secretary of Health and Human Services, offer personal assistance services, and provide a plan for review by the Secretary. In addition, the proposal would liberalize Medicaid nursing home eligibility, provide tax credits to defray the costs of personal assistance services for persons with disabilities who work, and both encourage and regulate private long-term care insurance.

You asked us to comment on the Administration's proposal for home and community-based services regarding issues frequently encountered in the launching of a new federal program: (1) How do persons become eligible for program benefits? (2) What is the capacity to provide the benefits? and (3) What is the federal government's role in assuring successful implementation of the program? We are providing comments on these issues based on long-term care work we have completed and other work underway (see attachment I).

ELIGIBILITY ISSUES POSE SEVERAL CHALLENGES

One of the most challenging elements of the Administration's long-term care proposal, or indeed any reform proposal, is eligibility determination. The Administration's home and community-based services proposal specifies that persons of all income levels and ages will be eligible for services. Eligible groups, who would be assessed with a uniform instrument, include persons with limitations in three or more activities of daily living, individuals with cognitive disabilities, individuals with severe or profound mental retardation, and severely disabled children.

Knowledge of how to determine eligibility for home and community-based services is still evolving. To help ensure desired program outcomes, additional attention needs to be given to how the Administration's program determines program eligibility and how eligibility will be determined during the phase-in of federal funding from 1996 to 2003.

Administration Could Address Eligibility Challenges by Providing States Latitude and Priorities for Phase-in Period

Determining eligibility for services in any broad-based long-term care program is complex. The need for long-term care cannot

easily be determined on the basis of a diagnosis or illness. For example, knowing that a person has arthritis or mental retardation does not indicate whether the person has a long-term care need. Furthermore, not all persons with the same impairment need long-term care. The better indicator is long-term inability to perform age-appropriate, everyday tasks of living.

The greatest challenge of eligibility determination is the difficulty in providing fair and consistently accurate evaluations of functional impairment for individuals of different age groups and with different underlying limitations. If an adult is not able to use the bathroom, bathe, and dress, there may be a need for long-term care. Yet we cannot measure a toddler's long-term care needs by assessing his or her ability to do the same things. Similarly, persons of the same age with different underlying limitations need to have their eligibility determined differently. A person who is paralyzed may not be able to get in and out of bed while a person with severe mental retardation might be able to do so. Yet both may have long-term care needs; the former for physical assistance, the latter for supervision or cueing to enable him or her to move about and perform other everyday activities in a safe and appropriate way.

Currently, there is a lack of good indicators for the diverse functional impairments that can result in long-term care needs, a lack of practical measures of the extent of impairment, and a lack of knowledge of how best to weigh impairment across diverse individual needs. All of these elements are necessary for fair and accurate eligibility determination in a program serving persons of different ages with diverse disabilities. To address this knowledge gap, additional thought needs to be given to the specifics of how eligibility will be determined, especially for persons with cognitive impairment, severe mental retardation, and children. Modifications to the Administration's plan, including more latitude to the states in eligibility determination and updating criteria over time, could help compensate for limited knowledge.

Furthermore, any new legislation should not lock in imperfect measures for long-term care need used now, but rather should be prepared to change how we measure need as knowledge increases. To provide the states with some latitude, legislative language may be needed to designate that a percentage of residual program funds may be used for persons with severe long-term care needs who do not otherwise meet the eligibility criteria specified. Information provided back by the states on this population could be used to further refine eligibility criteria. Ideas of this type have been discussed by a panel of national experts on eligibility convened by the Office of Technology Assessment.

Full Eligibility and Partial Funding During Phase-in Could Be Problematic

The relationship between the eligibility determination process and the receipt of services during the phase-in period between 1996 and 2003 appears to create a great mismatch between the number of persons who may seek services and the resources available to provide them. Under the proposal, all eligible may present themselves for services in fiscal year 1996, but only a fraction of the fully phased-in funding is available. This could potentially create short-term and medium-term demands for services, including the initial screening, service assessment, and development of the individualized care plan, far beyond the fiscal ability of states to provide them.

We see nothing in the proposal to deal with this apparent imbalance, which could last until fiscal year 2003, when the proposal is fully funded. Given limited funds, particularly in the first several years, either phasing in eligibility requirements--for example, by income or disability levels--or providing states with guidance on other service priorities until the full allotment of funds is available, would seem appropriate.

Reconciling this apparent phase-in imbalance is particularly important because the program does not provide an entitlement to individuals for service. Making this absolutely clear to implementing agencies and persons who may need services is essential to the success of the program. Implementation could be greatly complicated if this program, sometimes called a "capped entitlement," was perceived as an open-ended entitlement to service, such as Medicare. In fact, states may need to use waiting lists and other methods to deal with demands when they exceed resources.

STATES VARY IN LONG-TERM CARE CAPACITY AND EXPERTISE

Program design, administration, and service delivery under the Health Security Act are left to the states to organize as they believe appropriate, subject to federal approval of their state plans. This means that the ultimate success of the program will be defined, in large part, by the states' capacities to deliver services.

Today, state long-term care infrastructures, including providers, agencies, and administrative expertise, vary considerably. As a result, they have differing capacities for providing more services, serving additional people, and absorbing new program dollars. This unevenness may result in the less than ideal use of new program funds for home and community-based care, or a lack of services available to fulfill individualized care

plans. To avoid these unintended outcomes, states with less developed infrastructures will need technical assistance to assure program funds are well spent and that service capacities are improved. In addition, it may be useful to include a provision providing that states that cannot initially spend all the funds allocated to them are not penalized.

Uneven State Long-Term Care Infrastructures Have Implications for Program Implementation

Historical differences in the use of federal programs, state and local funding, and legislation between the states have resulted in an uneven long-term care infrastructure nationwide. No comprehensive nationwide data exist, however, on the range of capacity and infrastructure development both within and between states. Some states have devoted considerable state and local resources to developing programs and services for both elderly and nonelderly persons with severe functional impairments. They have often spent their own dollars, capitalized on Medicaid program options to add services and reach new populations, or done both, as well as built service delivery capacity where certain services did not exist. Even among these states, significant variation exists in the range of services offered and the volume of people served. Finally, some states offer very few services and serve few people. Variations also exist within states--between rural and urban areas and in different locations.

Agency staff in less experienced states, if they assume responsibility for the new home and community-based services program, may well lack the administrative expertise to arrange for cost-effective and appropriate services for large populations. They may have little information and experience regarding program design and implementation, including negotiating contracts with providers, and determining appropriate levels and mixes of services for recipients. Some areas may lack sufficient staff to undertake these new administrative roles. Indeed, some local agencies currently have only a handful of staff with any responsibility or expertise in long-term care. In the worst case, this lack of experience may translate into fraud and waste of new public funding. Even in the absence of deliberate abuse, however, the possibility exists that new funds would not be effectively spent.

Some states additionally lack a well-developed network of providers with the service capacity to handle the scope and depth of potential demand under the proposed plan. A wide range of services are allowable under the proposed legislation, including respite care, adult day services, and supported employment. Many states may have few or no providers of these services in some areas. Furthermore, states may be lacking in a trained workforce available to fill jobs as the home and community-based services

industry grows. An underdeveloped provider network would mean that individual care plans calling for certain services could not be realized, even when funds are available. Furthermore, even well-developed and diverse infrastructures may not have sufficient capacity to accommodate the volume of new demand.

Varying Capacity Among States Likely to Result in Different Case Management Roles

Because of flexibility in the Administration's proposal regarding case management and varying state capacities, the role of case management will probably continue to be very different from state to state. The proposal requires states to provide many key case management functions even though case management in the broader sense is an optional service. More specifically, the required functions are eligibility determination, needs assessment and reassessment, development of an individualized care plan, and determination of how services in that plan are to be obtained. These functions would be required for persons receiving support whether through vouchers, cash, or agency-provided services. Other permitted but not required case management functions include arranging of service providers and services, monitoring of service provision and quality, and cost control.

Although case management in some form is widely available in aging programs among the states, its definition and scope vary. Some programs use case managers to refer clients to services, while others define case management as a more intensive function that includes approving services and guaranteeing their provision. Not all persons with disabilities, however, need or want intensive case management services, or they may only need these services for a short period of time as they learn to perform this role themselves. However, core case management functions, especially identifying sources for obtaining services and cost-control activities, will require administrative expertise and knowledge about area services and the capacity to manage them. Because case management capacity and models vary significantly among the states, the role of intensive case management is likely to differ under the proposal. These differences are appropriate given our understanding of case management, the wide-ranging needs of populations, and services.

Provisions for Unexpended Funds Should Be Considered

Provisions allowing states that choose to participate in the program to carry over unspent funds to later years should be considered. States without strong service networks or significant administrative capacity may not be able to expend all available funds at first or spend them appropriately. These states should not be penalized. Currently, no explicit mechanism exists in the

legislation for handling dollars not spent by states by the end of the fiscal year. Such a mechanism may afford more latitude to the states by not encouraging inappropriate spending beyond the capacity of the state infrastructure merely to maintain access to these dollars.

Despite the significant federal dollars involved--a total of $38 billion when the program is fully implemented--and the attractive federal match, ranging from 78 to 95 percent, it is not clear whether all states will choose to take full advantage of the new funds available. However, cost estimates for the legislation are premised on full participation by all 50 states. No provision exists for reallocating the funds of any state that opts not to participate, or not to participate fully.

NEED TO BETTER DEFINE FEDERAL ROLE AND HOW IT IS FULFILLED

The federal role in the Administration's long-term care proposal needs better definition given the proposal's innovative approach to implementation. The federal role spelled out in the legislation is primarily to provide a uniform eligibility assessment instrument to the states and to monitor state plans. The federal role in monitoring implementation of the proposal is unclear. As yet, the Administration has not specified where responsibility for implementation and oversight of the proposal's long-term care provisions will reside, nor the availability of resources at the federal level to carry out monitoring and technical assistance tasks.

At present, we know more about what the federal role is not than what it is. Because the proposal is built on state flexibility in administering home and community-based services, the federal role is not categorical control, as in Medicaid. At the same time, the proposal is not a traditional block grant without strings attached because it requires the states to do certain things, such as only serve persons meeting specific eligibility criteria.

More thought needs to be given to what the federal role is and how it will be carried out while preserving state flexibility to accomplish program objectives. A central goal of any federal involvement should be to preserve flexibility and maintain accountability through technical assistance and continual monitoring and feedback.

Federal Involvement Should Preserve Innovation and Avoid Adverse Outcomes

Two key elements in defining the federal role in the Administration's proposal are (1) the need to recognize which

variations in state programs are good and which are bad and (2) the capacity of the federal government to recognize and encourage the good and discourage the bad. Additional thought is needed in the Administration's proposal as to how the federal government will recognize and encourage good variations and recognize, prevent, and correct bad variations. Encouraging flexibility while avoiding unintended outcomes could be facilitated by technical assistance for and monitoring of the implementation process. Highly regulatory approaches, even if well intended, are more likely to make good state variations more difficult without giving high assurance of preventing bad ones.

Why is variability desirable in long-term care programs? Variations are needed because of differences in communities and the preferences of those being served. For example, an impaired person needing transportation services in an urban area may access public transportation. In a rural area, paratransit services may be provided instead. In either community, an impaired individual may prefer to carpool for transportation with a neighbor rather than use formal transport. The service is different in each case but the need is met.

Some types of variations in state programs can be bad. These variations may result in discrimination in providing services; inefficient operation of programs; poor management information; and waste, fraud, and abuse. Flexible program operation, therefore, needs to incorporate accountability mechanisms to prevent state variations of this sort without preventing the good variations that are desired. An important part of this responsibility in the proposal lies with elected state officials and advisory groups. At the same time, the federal government needs to work with state governments and others to encourage better reporting mechanisms and evaluation of program implementation.

Information Dissemination and Technical Assistance Could Help States With Less Capacity

The federal government could play a key role in identifying long-term care practices that work well and in helping other states use this information. An important dimension of this effort would be dissemination of information to improve service capacities and accountability mechanisms. The most effective use of such information could be achieved through technical assistance to help states apply lessons learned to their specific situation. Peer assistance, such as programs that sponsor technical assistance from knowledgeable persons in state and local governments and the research community, may be particularly appropriate for those states struggling with administrative and capacity challenges already successfully addressed by others. The federal government could serve as a resource clearinghouse for this localized

expertise, by facilitating travel, arranging consultation, and promoting electronic information exchange between state officials.

Providing this assistance will require coordination of action from various federal agencies in the Department of Health and Human Services, such as the Assistant Secretary for Planning and Evaluation, the Administration on Aging, and the Health Care Financing Administration, and other federal departments, such as the Department of Education (Assistant Secretary for Special Education and Rehabilitative Services), the Department of Transportation, the Department of Veterans Affairs, the Department of Labor, and the Department of Housing and Urban Development.

Continuous Monitoring and Feedback Could Provide Needed Data on Best Practices

The federal government can also do much to achieve good outcomes by working with states in the design and administration of programs. Indeed, the federal government should be prepared to learn from the leading states because they have been the originators of long-term care innovation. The federal government, in partnership with the states, should be monitoring implementation to detect problems, providing technical assistance where needed, helping to develop new measures of accountability in flexible programming, and changing guidance as appropriate. We believe that the federal government's monitoring role in program implementation should be recognized explicitly in legislation. Current wording seems to focus more on federal monitoring of planning activities than on the implementation of the program.

While the proposed flexibility in program design is both desired by persons with disabilities and generally consistent with the principles of leading state and international long-term care programs, it also underscores our relative lack of data about what works best. Research and experience are currently both insufficient to proscribe standard service packages and financing mechanisms as well as ideal program design. Ongoing monitoring and feedback on problems and successes with implementation, however, could provide the necessary data for midcourse corrections as knowledge expands. This assessment should take place immediately, in order to provide early warning of any major barriers to implementation, and over the medium- and long-term as programs mature. Monitoring the different impacts of case management and other service delivery models, for example, on client satisfaction, outcome, and costs, can begin to fill data gaps. This information could be used to continually refine guidance on which methods of service delivery work best under what circumstances.

CONCLUSIONS

Passage of any long-term care reform legislation is the first step of a long process and not the final word on how the nation meets its long-term care needs. Knowledge about determining long-term care needs and services, derived largely from the experience of innovative states, suggests thus far that state flexibility is the best way to meet widely diverse needs of individuals and communities. This flexibility requires a new, different federal role, largely one of partnership with the states in the design, administration, and monitoring of programs. The federal government can learn from the leaders and help facilitate the development of services and accountability measures as needed, regardless of which reform proposal is adopted.

If the Administration's proposal is to be the blueprint for long-term care reform, this new federal role should be more clearly articulated. Furthermore, additional thought should be given on guidance to the states concerning eligibility determination and how states with less capacity can be assisted in wisely using program funds. Such modifications could help achieve the overarching reform principles spelled out in my introduction.

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Madam Chair, this concludes my statement. I will be happy to answer any questions.

RELATED PRODUCTS

SELECTED REPORTS ON LONG-TERM CARE

Long-Term Care: Demography, Dollars, and Dissatisfaction Drive Reform (Testimony, 4/12/94, GAO/T-HEHS-94-140).

Long-Term Care: Support for Elder Care Could Benefit the Government Workplace and the Elderly (Report, 3/4/94, GAO/HEHS-94-64).

Long-Term Care: Private Sector Elder Care Could Yield Multiple Benefits (Report, 1/31/94, GAO/HEHS-94-60).

Older Americans Act: Title III Funds Not Distributed According to Statute (Report, 1/18/94, GAO/HEHS-94-37).

Health Care Reform: Supplemental and Long-Term Care Insurance (Testimony, 11/9/93, GAO/T-HRD-94-58).

Long-Term Care Insurance: High Percentage of Policyholders Drop Policies (Report, 8/25/93, GAO/HRD-93-129).

VA Health Care: Potential for Offsetting Long-Term Care Costs Through Estate Recovery (Report, 7/27/93, GAO/HRD-93-68).

Medicaid Estate Planning (Letter, 7/20/93, GAO/HRD-93-29R).

Long-Term Care Reform: Rethinking Service Delivery, Accountability, and Cost Control (Discussion Paper, 7/13-14/93, GAO/HRD-93-1-SP).

Long-Term Care Insurance: Tax Preferences Reduce Costs More for Those in Higher Tax Brackets (Report, 6/22/93, GAO/GGD-93-110).

Massachusetts Long-Term Care (Letter, 5/17/93, GAO/HRD-93-22R).

Long-Term Care Case Management: State Experiences and Implications for Federal Policy (Report, 4/6/93, GAO/HRD-93-52).

Long-Term Care Insurance Partnerships (Letter, 9/25/92, GAO/HRD-92-44R).

Long-Term Care Insurance: Actions Needed to Reduce Risks to Consumers (Testimony, 6/23/92, GAO/T-HRD-92-44). Reports on same topic (3/27/92, GAO/HRD-92-66 and 12/26/91, GAO/HRD-92-14). Testimonies on same topic (5/20/92, GAO/T-HRD-92-31 and 4/11/91, GAO/T-HRD-91-14).

Long-Term Care Insurance: Better Controls Needed in Sales to People With Limited Financial Resources (Report, 3/27/92, GAO/HRD-92-66).

Board and Care Homes: Elderly at Risk from Mishandled Medications (Testimony, 2/7/92, GAO/T-HRD-92-45).

Services for the Elderly: Longstanding Transportation Problems Need More Federal Attention (Report, 8/29/91, GAO/HRD-91-117).

Long-Term Care: Projected Needs of the Aging Baby Boom Generation (Report, 6/14/91, GAO/HRD-91-86).

Administration on Aging: Autonomy Has Increased but Harmonization of Mission and Resources Is Still Needed (Testimony, 6/11/91, GAO/T-PEMD-92-9).

Administration on Aging: More Federal Action Needed to Promote Service Coordination for the Elderly (Report, 4/23/91, GAO/HRD-91-45).

CURRENT LONG-TERM CARE WORK (Anticipated product issue date)

Review of interstate funding formulas for Title III funds under the Older Americans Act and whether they accurately reflect state needs (HEHS, May 1994).

Review of how quality has been defined by various stakeholders in home and community-based long-term care, and what measures are used to monitor and assure quality (PEMD, Spring 1994).

Review of long-term care systems in other countries, reform efforts underway, and implications for the United States (HEHS, May 1994).

Review of state Medicaid home and community-based service programs, their accomplishments, and implications for national long-term care reform efforts (HEHS, May 1994).

Survey of state agencies for lessons learned with regards to eligibility, services, and cost containment and implications for national long-term care reform (HEHS, June 1994).

Review of demographic and other factors affecting the current and future demand for long-term care, diversity among different groups with long-term care needs, and implications for national reform efforts (HEHS, September 1994).

Review of current programs and services for providing long-term care, innovative approaches, and implications for national long-term care reform efforts (HEHS, Fall 1994).

Review of current public and private responsibilities for long-term care financing, cost containment mechanisms employed, pressures for reform, and key policy questions (HEHS, Fall 1994).

Review of geriatric assessment practices in publicly funded home and community-based long-term care programs (PEMD).

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