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GAO

LONG-TERM ◆ CARE ◆ FORUM

July 13 and 14, 1993

GAO/HRD-93-1-SP

LONG-TERM CARE FORUM

July 13-14, 1993

Discussion Paper

This paper was prepared to generate discussion and frame issues presented at the GAO/Kaiser Family Foundation long-term care forum. All views presented are not necessarily the official views of GAO or the Kaiser Foundation but reflect an attempt to pull together a wide variety of evidence and expert opinion on key issues in long-term care reform.

LONG-TERM CARE REFORM: RETHINKING SERVICE DELIVERY, ACCOUNTABILITY, AND COST CONTROL

What is behind the growing concern with long-term care? The simple answer is demography and dollars. Long-term care is becoming increasingly important as the number of persons who need services grows and expenditures for services to assist them increase. Approximately 10 million Americans of all ages are chronically disabled and dependent on others for assistance in the basic tasks of daily living such as eating, toileting, moving around in the house, shopping, money management, and other activities most Americans take for granted. The number of persons needing help with these things will increase substantially in the future.

As a result of these trends, the Congress is being asked to reconcile simultaneously an increase in long-term care services, an improvement in service quality, and stronger control of costs. Can it be done? Innovative programs in the states and in other countries offer insights into what may be possible as well as point out trade-offs the Congress will face in considering long-term care reform.

Today, the overwhelming majority of care for disabled persons is provided by family and friends, mostly women. In spite of this substantial amount of informal unpaid care, expenditures for formal or paid services nationwide exceeded $58 billion in 1988, about half of which was paid by government and about half paid out-of-pocket.[1] Assuming similar future spending patterns, expenditures for long-term care are projected to more than double by 2018. 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.

At the same time that these projections fuel concern for the future, there is rising dissatisfaction with the current long-term care system, which many people believe is expensive and poorly serving disabled persons. In particular, there is great dissatisfaction with the long-term care program bias in favor of institutional rather than home and community-based services. In response to these issues, innovative programs in the United States and abroad appear to be incorporating several elements in developing a wider range of home and community-based services to meet long-term care needs. These elements include (1) service flexibility sufficient to meet the needs, preferences, and unique circumstances of individuals as much as possible; (2) high standards of organizational accountability to taxpayers for money spent and the quality of services delivered; and (3) effective cost controls to live within budgets decided upon by elected officials.

Long-Term Care System Is Expensive and Inadequate for the Future Because It Was Not Designed to Meet Long-Term Care Objectives

Few experts believe that future long-term care needs can be met, much less paid for, simply by delivering more units of the care we provide now. Today, both care providers and persons needing assistance express widespread frustration with the organization of, access to, and delivery of long-term care services. At the same time, federal and state officials are increasingly concerned about the ability of the public sector to pay for services even now, long before the great demographic changes of the next century occur.

What's the problem with the current long-term care system? There's no simple answer. At the heart of it, however, is that services are not organized with the disabled person in mind as the consumer. Nor is the system organized to achieve well-defined objectives or to maximize effective management of budgets. In addition, the system is biased in favor of institutional and medical approaches

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[1]Congressional Budget Office, Policy Choices for Long-Term Care (June 1991), p. xi.

to care. As a result, disabled persons may get institutional or medical services when other, less intensive, often lower cost services would be more appropriate. And significant gaps exist in nonmedical home and community-based services.

What is at the root of the problem to our approach to long-term care? A major part of the problem is that existing long-term care programs are not a "system" at all but rather a hodgepodge of programs that were designed to meet health care and other needs, not long-term care needs. One important example is Medicaid. Initially intended to pay for low-income persons' medical care, Medicaid has gradually shifted to being 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. Only a small portion of Medicaid has been available for home and community-based care, and stringent regulations have restricted the amount of nonmedical services available. Another example is Medicare, primarily an acute care health insurance program for the elderly. Although Medicare spending for long-term care is limited, Medicare funding for short-stay nursing home care is increasing, and the program is now one of the largest funding sources for home health care services. Several other federal programs--the Older Americans Act, Social Services Block Grant, Supplemental Security Income, and various federal housing and transportation programs--as well as state and local government programs--also have long-term care components.

New Long-Term Care Programs Stress the Importance of Service Flexibility

In contrast to the fragmented, overmedicalized, compartmentalized system described above, some states and countries are developing new, flexible delivery systems that provide services that are more appropriate for and preferred by disabled persons. These flexible systems often begin with an assessment of the individual needs of the disabled person rather than beginning with what existing programs can offer. They then develop a customized set of services unique to the individual's needs and preferences rather than choosing from a menu of standard service packages. This is desirable because individuals often have very different long-term care needs and preferences even when their diagnoses or disabilities are similar. These individual service strategies are also flexible in the way services are delivered because they take into account the role of each individual's natural supports, most importantly family and community resources, in addressing long-term care needs. Many long-term care experts believe this approach results in services that are more appropriate, more effective, often less costly, and greatly preferred by disabled persons.

Innovative long-term care systems address individual needs by emphasizing flexibility in determining the services needed and the

way in which they are provided. They do this in different ways and to different degrees, however. Generally, the program staff, local provider, or other case/care manager seeks to identify what the client needs and wants, the availability of family supports, and ways to use community resources. They accomplish this by spending a considerable amount of time with the person to gain an in-depth understanding of his or her care needs and to have a better sense of the personal history, family situation, and lifestyle of the disabled person. This process of assessment requires considerable effort and on-going evaluation on the part of the provider. But the information gained from this process helps pinpoint the services that will best meet the person's needs.

This approach also helps draw on as many informal supports as possible and minimizes the need to buy what might otherwise normally be available at virtually no cost in the community. For example, neighbors and friends can be emergency backups rather than paying staff to be in or near the home for extended periods of time. Consequently, flexible systems are more likely to achieve better outcomes for both the disabled person and the family and often are less obtrusive.

If increased service flexibility can better meet the unique needs of each disabled individual, can such individualized planning and support services be implemented on a broader scale in the United States? And if so, can the individualized focus of these programs be preserved in the "systems" that will be required to serve hundreds of thousands of disabled individuals?

Program Accountability Needs to Be Improved to Support Flexible Services

Innovations in designing service delivery systems have largely outpaced the development of ways to ensure accountability for federal and state funding. This accountability requires reporting to the taxpayers how their money was used. Under flexible service approaches, how can agencies report what tax money was spent for? How can we gauge what we achieved by spending the money? Without new accountability measures, policymakers and taxpayers may be reluctant to support further expansion of flexible services. In particular, taxpayers must be confident that a strategy to shape services to individual preferences is not the equivalent of a "blank check" for any type or amount of services that may be desired by a disabled person. Taxpayers need to know that the type and quantity of service bought is reasonable.

Some states are in the process of creating new mechanisms to ensure accountability even while meeting current accountability standards. They are attempting to change the typical recordkeeping and accounting systems that relied on standard service packages and defined units of services to accommodate the new, more individualized service approaches. For example, in these

individualized approaches, services may not be provided in predetermined numbers of hours per week but rather are provided when persons need and want them--which can vary by the person and by the day.

Creating new systems for accountability requires rethinking how to achieve it. This will most likely require measuring the impact on those being helped--Are clients more satisfied? Are they more independent? Efforts to address service quality are also pointing in the direction of "customer satisfaction." Under this shift in thinking, less emphasis is placed on past process measures, such as the number of hours of service provided, which are easier to count but may have little bearing on the quality of a disabled person's life. Instead, more emphasis is placed on whether the service helps them do what they could not do alone.

All these questions lead directly to management strategies. What is the most effective management approach to achieve our long-term care objectives? Do we believe that traditional management controls and checks best prevent abuses? Can traditional systems allow adequate flexibility to achieve overall long-term care objectives? Or do we believe that decentralized decisionmaking and accountability are required to meet our objectives even if such an approach requires an overhaul of today's management systems? If so, what are the benefits and risk of change?

Multiple Approaches Used to Control Long-Term Care Costs But Debate Continues on What Works Best

Cost control is perhaps the most pressing long-term care issue for many decisionmakers. The deficit and projected increases in the disabled population make federal and state officials wary of embarking on major reforms until they can assure taxpayers that services can be provided within a manageable budget. Fundamental long-term care reform will require a better understanding of how cost control approaches can be applied and what is required to make them successful in keeping expenditures within budget limits. Multiple approaches to control costs are used in long-term care, but the debate continues on which are the most effective and what the relative emphasis of each should be. Approaches and proposed approaches to control costs in long-term care include

- global budgeting to allocate a fixed amount of money to a program or organization that has discretion over how that money is expended for services;
- capping or setting a ceiling on the total amount that can be spent on the average person for services (capitation) or on a special class of persons with similar needs;
- controlling the supply of services, for example, by

controlling the number or capacity of providers through certification;

- controlling utilization by limiting the number of units of services that can be provided;

- restricting the eligibility of persons who may receive services to persons with certain levels or kinds of disabilities or income levels;

- controlling demand by requiring copayments from persons who receive the services;

- controlling price or reimbursement rates for service;

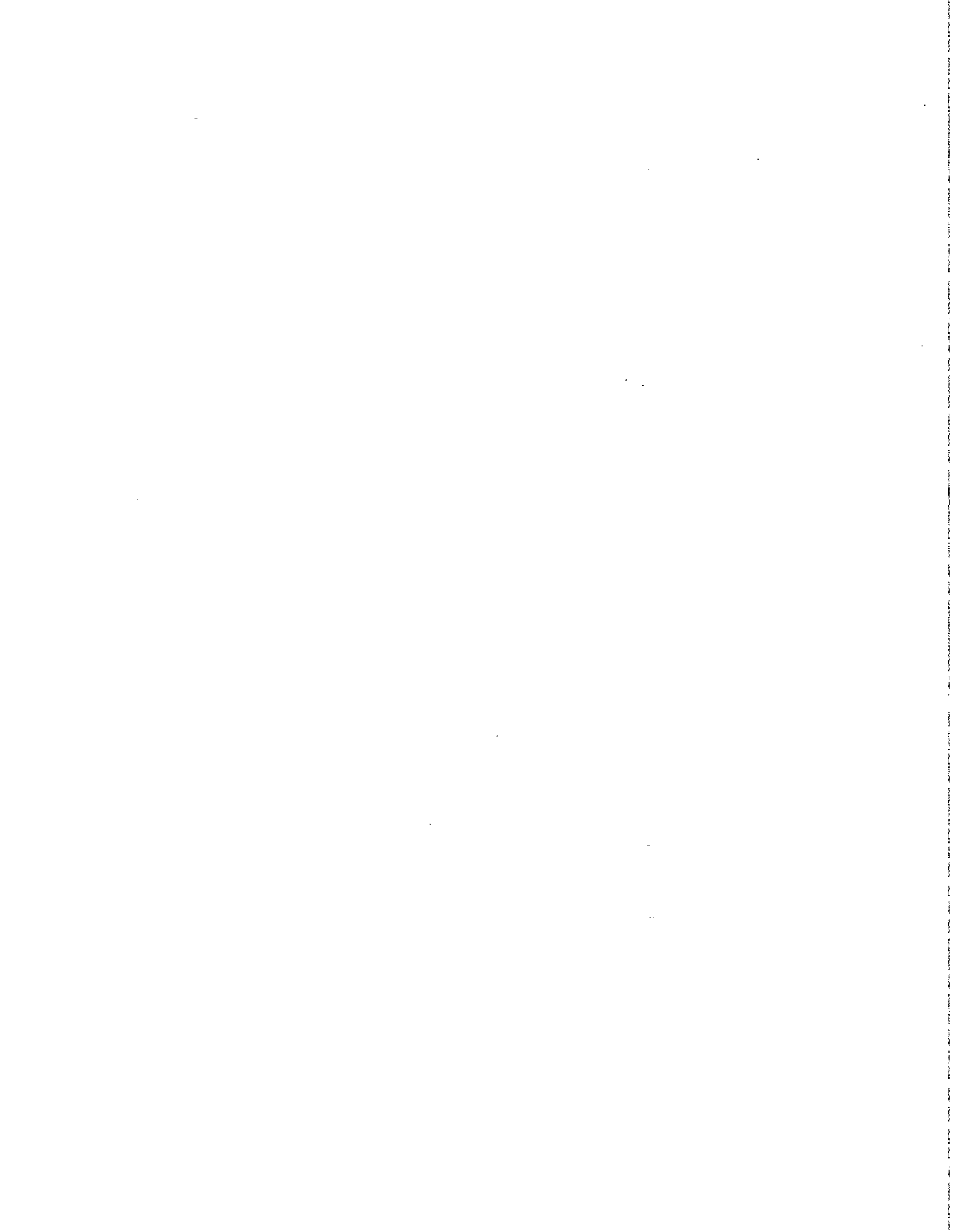
- encouraging the use of private long-term care insurance;

- encouraging and supporting informal caregiving to reduce some of the growing demand for paid government programs;

- using care management to serve as a central point of control or gatekeeper to manage all services provided to person with the intent of providing the appropriate services at the lowest costs; and

- promoting competition of caregiving organizations to decrease costs.

Different cost controls, or combinations of controls, will pose trade-offs that may make them more or less desirable depending upon the service objectives of the long-term care system being examined. In particular, debate needs to focus on the interaction of cost controls and achieving service objectives, such as maximizing flexibility to best meet individual needs. Does increased service flexibility lead to a "woodwork effect" and soaring expenditures? Or can certain strategies to contain costs be successfully implemented in long-term care systems that also provide flexible service delivery? In any case, separating our thinking about cost control strategies from our thinking about service objectives may lead to unintended consequences.



MAJOR CONTRIBUTORS TO THIS DISCUSSION PAPER

HUMAN RESOURCES DIVISION, WASHINGTON, D.C.

Cynthia A. Bascetta, Assistant Director, (202) 512-7207
James C. Musselwhite, Assignment Manager
Connie J. Peebles, Evaluator-in-Charge

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