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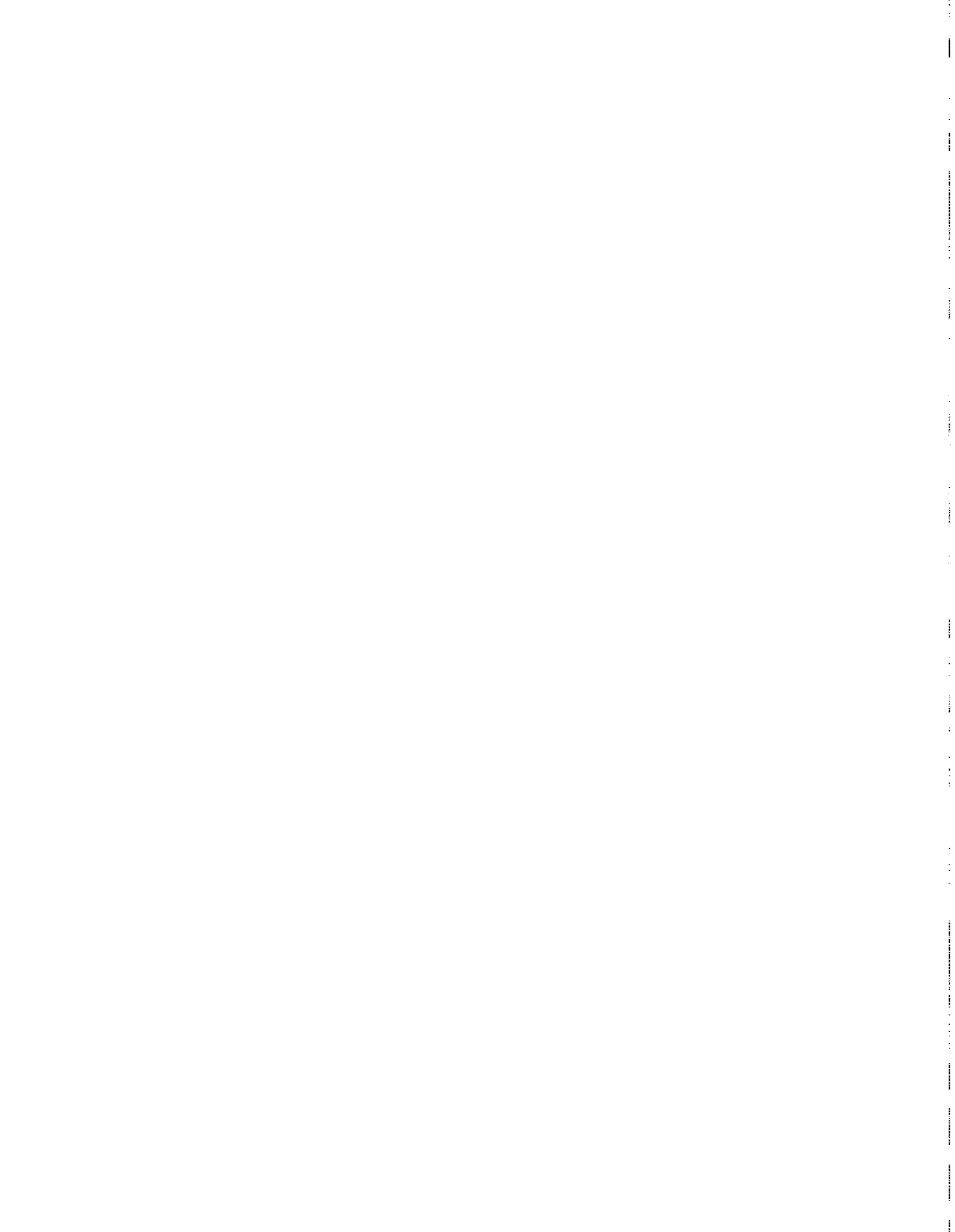
Report to the Chairman, Committee on
Finance, U.S. Senate

March 1994

LONG-TERM CARE

Status of Quality Assurance and Measurement in Home and Community-Based Services







United States
General Accounting Office
Washington, D.C. 20548

**Program Evaluation and
Methodology Division**

B-256835

March 31, 1994

The Honorable Daniel Patrick Moynihan
Chairman, Committee on Finance
United States Senate

Dear Mr. Chairman:

At your request, we are examining aspects of how quality is assured and measured in home and community-based long-term care services for persons with disabilities. Although we will provide further information at a later date, as we arranged with your staff, we present in this report interim findings for such services available to disabled persons who are elderly. These findings address two of the questions you posed:

1. How is "quality" defined for home and community-based long-term care services?
2. What measures are currently used to monitor or assure quality?

By "home and community-based long-term care services," we mean health, personal care, and social services provided over a sustained period to persons who live outside of congregate residential settings and who have lost some capacity for self-care because of a chronic condition or illness. These services include a broad range of supports, from skilled nursing services to assistance with basic activities of daily living (ADLs) (such as bathing, toileting, and dressing) and help with instrumental activities (such as shopping, meal preparation, housekeeping, and laundry). The services may be provided singly, by one or more providers, or in combination, as when a home health aide provides incidental assistance with ADLs.

Since the elderly persons to whom these services are targeted receive them in varied combinations, we have inquired about methods for assuring or measuring the quality of the package of home and community-based long-term care services or the plan of care provided to a particular client. However, we have also identified methods used to assure and measure the quality of one specific type of service—personal care, which generally involves the provision of assistance with basic ADLs in the client's home and is among the most frequently used services in community-based care.

Briefly, our findings indicate the following:

- The complex financing structure that supports home and community-based long-term care services has resulted in the application of different quality assurance requirements to similar services, based on the source of their payment.
- Goals for home and community-based long-term care are articulated differently by administrators, service providers, and customers, with some potential for conflict. This raises the issue of how these goals can be harmonized and what the locus of that function should be. Even case managers may not be ideal for this purpose, because their gatekeeping responsibilities involve them in very close relationships with administrators and providers.
- Goals for personal care services are less formally developed than goals for the network of home and community-based services provided under Medicaid waivers.
- Current quality assurance strategies cannot be judged sufficient to assure the delivery of high-quality services, in part because the undeveloped state of program and outcome measurement prohibits establishing the extent of relationship, if any, between these strategies or requirements and the quality of services rendered. (See page 24.)

Methodology

To develop the information in this report, we performed four types of activities more or less simultaneously:

1. We reviewed the research literature, program documentation, regulations, and findings of recent state surveys conducted by the Administration on Aging, the National Association for Home Care, the National Association of State Units on Aging, and the World Institute on Disabilities.
2. We interviewed experts, federal officials, and organizations representing providers of home and community-based long-term care.
3. We convened a focus group on the topic at the 1993 annual meeting of the Gerontological Society of America.
4. We conducted site visits to interview officials associated with Medicaid and other programs providing home or community-based services in Connecticut, New York, and Wisconsin.

The states we visited were identified to us as ones with progressive programs of quality measurement or integrated administrative structures that could facilitate such measurement.¹

We conducted our work between November 13, 1993, and March 14, 1994, in accordance with generally accepted government auditing standards.

Background

The projected growth in the need for long-term care services, along with a preference among elderly persons for services that allow them to remain at home and in their community, have led to the expansion of noninstitutional long-term care services and have contributed to an increase in public expenditures on home health care. (Table 1 shows historical data on Medicare and Medicaid payment.) This rising expenditure, combined with the vulnerability of the target population and the increasing demand for services, augments the public interest in assuring service quality.

¹Accounts of Medicaid spending for home health care, personal care, and services provided under home and community-based waivers for the aged indicate that these three states collectively accounted for over 70 percent of fiscal year 1991 Medicaid expenditures for the home and community-based long-term care of aged persons.

Table 1: Medicare and Medicaid Payment for Home Health and Nursing Facility Services^a

Fiscal year	Medicare				Medicaid			
	Home health		Nursing facility		Home health ^b		Nursing facility ^c	
	Amount	Percent	Amount	Percent	Amount	Percent	Amount	Percent
1980	\$0.7	2.0%	\$0.3	1.0%	\$0.3	1.4%	\$ 7.9	33.8%
1985	1.8	2.8	0.5	0.8	1.1	3.0	11.6	30.9
1988	1.9	2.4	1.0	1.2	2.0	4.1	14.3	29.3
1989	2.4	2.6	2.8	3.3	2.6	4.7	15.5	28.5
1990	3.7	3.7	1.8	1.8	3.4	5.2	17.7	27.3
1991	5.3	4.5	2.2	1.9	4.1	5.3	20.7	26.9

Source: U.S. Department of Health and Human Services, Health Care Financing Review—1992 Annual Supplement (Baltimore, Md.: 1993); U.S. Bureau of the Census, Statistical Abstract of the United States (Washington, D.C.: varied years).

^aAll amounts are expressed in billions. Percentages indicate the proportion of all annual Medicare or Medicaid expenditures represented by the figure in the corresponding amount column.

^bServices provided at patient's place of residence in compliance with a physician's written plan and include nursing services, home health aide services, medical supplies, equipment, and appliances suitable for use in the home; physical, occupational, and speech therapy; personal care services; and services provided under a home and community-based waiver.

^cNursing facility payments cover both skilled nursing facility services and intermediate care facility services for all other than the mentally retarded.

Current Organization of Services

At present, public programs that finance home and community-based long-term care services include Medicaid, Medicare, Older Americans Act initiatives, social services block grants, and initiatives run with general state revenues. Some of these programs require or encourage recipients to pay a share of the costs.

Home and community-based services are provided through a variety of avenues under Medicaid, which covers physician-ordered home health services and may, at a state's option, provide an entitlement to personal care services prescribed by a physician or authorized under an approved state plan. In addition, programs run under Medicaid waivers pay for a variety of primarily nonmedical support services. However, states may limit eligibility for waiver services to functionally disabled aged or handicapped individuals who are qualified for nursing home placement based on both financial and functional criteria or to elderly persons in certain geographic areas for whom such services can be provided without budgetary impact. State revenues are commonly used to extend this coverage for home and community-based long-term care to individuals

who meet the functional but not the financial criteria established for participants in the Medicaid waiver programs. Medicare, in contrast, finances home-based services that are focused on skilled nursing and therapy rather than nonmedical support services and that appear to be less likely to be used as a form of long-term support.²

Proposed Expansion

In contrast to the existing programs, the administration's health care reform proposal expands home and community-based long-term care services for persons with functional disabilities by introducing a program for home and community-based long-term care that places few limits on the eligible population or states' service selection, although functional eligibility requirements may be more restrictive for new beneficiaries than under some current programs. The proposal also includes some explicit provisions regarding quality. Specifically, each state must specify how it will assure and monitor the quality of services, including

1. safeguarding the health and safety of individuals with disabilities;
2. establishing minimum standards for agency providers and how such standards will be enforced;
3. setting minimum competency requirements for agency provider employees who provide direct service and describing how these will be enforced;

²Both aged and disabled Medicare beneficiaries may receive home health care, including incidental personal care, with no copayment required as long as they are homebound and have a simultaneous need for "intermittent" nursing or skilled therapy. Need for skilled care, not prior hospitalization, is a prerequisite for these benefits, which afford up to 35 hours per week of combined skilled nursing and home health aide services in addition to skilled therapy services for an indefinite period where indicated.

There is some evidence that, at least in the recent past, Medicare home health benefits have not generally been used for long-term care purposes. However, we were told that the Health Care Financing Administration (HCFA) does not routinely report on this issue. A recently published special study conducted under contract to HCFA collected data on this issue from a self-selected group of agencies. The authors approached 235 home health agencies that had earlier indicated willingness to participate in a demonstration project and succeeded in collecting data from 37 percent on the length of home health episodes financed by Medicare for clients who began service in 1986. The study matched these clients with Medicare home health claims received through September 1987. Thus, ignoring delays in claims processing, even a client who began an episode on December 31, 1986, could be associated with up to 9 months of subsequent care. Extrapolating from the sample, the authors estimated that only 17.2 percent of cases beginning episodes in 1986 received continuous care for 90 days or more and only 5.5 percent received care for at least 180 days. (L. G. Branch et al., "Medicare Home Health: A Description of Total Episodes of Care," *Health Care Financing Review*, 14:4 (1993), 59-74.)

4. obtaining meaningful consumer input, including consumer surveys that measure the extent to which participants receive the services described in the plan of care and participant satisfaction with such services;
5. participating in quality assurance activities; and
6. specifying the role of the long-term care Ombudsman and the Protection and Advocacy Agency (under the Developmental Disabilities Assistance and Bill of Rights Act) in assuring quality of services and protecting the rights of individuals with disabilities.

The states are also directed to provide safeguards against physical, emotional, or financial abuse or exploitation. Many of these tactics are controversial among state administrators and experts, who have widely divided views on the utility of survey measures of client satisfaction, the practicality of ombudsman involvement, and the unintended consequences of minimum standards for agency providers.

Meaningful performance review for these services, of course, would require clearly articulated service goals. Under the proposed plan, personal assistance is the only service that must be covered, but matching funds would be available for others. (See table 2.)

Table 2: Services Eligible for Federal Matching Funds Under S. 1757 (1993)

	Service
Mandatory state plan components	Consumer-directed personal assistance Agency-directed personal assistance
Optional state plan components	Case management Homemaker and chore assistance Respite services Adult day services Habilitation and rehabilitation Supported employment Home health services Assistive devices Home modification Any other care or assistive services (approved by the secretary of the Department of Health and Human Services) that the state determines will help individuals with disabilities to remain in their homes and communities

Nature of Services

As indicated in table 2, many different services are provided under the rubric of home and community-based long-term care. This variety has

resulted in some debate regarding the application of medical standards to home care, particularly for persons who need primarily unskilled services to compensate for functional deficits not likely to respond to medical treatment. While some disabled elderly persons living in the community have chronic illnesses for which medical intervention can be beneficial, if only to prevent complications, others have functional deficits resulting from conditions not likely to improve. Nonetheless, even the latter group may require help or instruction on such tasks as meal preparation, housekeeping, and shopping.

Demand

The demand for such services is not limited to persons who live in nursing homes or would seriously consider doing so; more people in need of long-term support live outside nursing homes than in them. For every person age 65 or older residing in a nursing home, there are nearly two living in the community who require some form of long-term support. According to a Brookings Institution report, approximately 4.9 million elderly persons were residing in the community in 1985 (18 percent of the population over age 65) who had ADL limitations. About two thirds of these elderly persons had only moderate impairments—that is, fewer than three ADL limitations. However, some 850,000 elderly persons were severely impaired (which is defined as having a limitation in five or six ADLs).³

The increase in the use of home health services has been driven at least partly by increasing acceptance that most elderly consumers prefer to receive long-term care at home. However, as access to such services has been expanded both in order to satisfy consumer preferences and in the hope of reducing public costs for long-term and hospital care, questions have arisen regarding how the states are assuring and measuring the quality of these services.

Quality

Quality, access, and cost have traditionally made up the three pillars of health care policy. This is so because attempts to improve a program's performance on one dimension, such as cost, may affect its performance on others, such as accessibility or quality. Thus, information on service quality should be interpreted in combination with data on access and cost, and optimal policy choices depend on monitoring all three aspects of service delivery. We use the term quality to refer to "the extent to which service increases the probability of desired outcomes and reduces the

³A. M. Rivlin and J. M. Wiener, Caring for the Disabled Elderly: Who Will Pay? (Washington, D.C.: The Brookings Institution, 1988), p. 6.

probability of undesired outcomes given the constraints of existing knowledge."⁴ Table 3 illustrates various indicators that can be used to define, assure, and measure quality across the various stages and components of care.

⁴Office of Technology Assessment, *Confused Minds, Burdened Families: Finding Help for People with Alzheimer's and Other Dementias* (Washington, D.C.: 1990), p. 159. See also Office of Technology Assessment, *The Quality of Medical Care: Information for Consumers* (Washington, D.C.: 1988). Although "quality" is sometimes defined as the difference between "efficacy," the level of effect that could be achieved under ideal conditions, and "effectiveness," the level of effect that is currently achieved, this definition makes the a priori assumption that effectiveness can easily be measured.

Table 3: Illustrative Framework of a System to Improve the Quality of Home and Community-Based Long-Term Care

Activity	Key questions	Possible goals or measures
Define quality	<p>What goals and outcomes can be identified? Who should be involved in identifying goals and outcomes? To what extent do these goals and outcomes apply across disability categories, functional needs, and diagnostic groups? How are goals and outcomes articulated to stakeholders?</p>	<p>Maintain functional capacity Optimize autonomy and mobility Ensure safety Optimize health Prevent inappropriate institutional placement Satisfy clients Improve quality of life Reduce informal caregiver burden Reduce public costs</p>
Identify indicators of quality	<p>Based on the goals and outcomes identified, what indicators of program implementation or performance can be identified and what additional information is needed to properly interpret these?</p>	<p>Structural indicators Caseload per worker per day Staff certification level Staff knowledge Staff turnover at consumer level</p> <p>Process indicators Frequency of supervision Compliance with medication orders Time between service request and provision Appropriateness of care plan Prescription of inappropriate medications Availability and frequency of informal care</p> <p>Outcome indicators Functioning Change in ADL and IADL status Ability to toilet as needed</p> <p>Safety Falls Burns Financial exploitation</p> <p>Health Appearance of decubitus ulcers Infections Adverse drug reactions Symptom distress Weight gain or loss</p> <p>Client satisfaction Client perception of unmet need Perceived quality of meals Freedom from fear Comfort Sense of control Freedom from unwanted disruption Preference for current living arrangement Duration of preferred living arrangement</p>
Establish review of system and implement feedback	<p>What processes are used for periodic or on-going review of quality indicators? How are review findings used to correct or prevent problems?</p>	<p>Presence of a quality assurance and improvement plan Checks on implementation of plan Evidence of enhanced achievement of desired goals and outcomes</p>

Principal Findings

To preface our discussion of our findings regarding current quality assurance and measurement efforts, it is important to note that states are facing challenges in extending access to home and community-based services to all those in need, with sizable waiting lists reported by the state officials with whom we spoke. Partly as a result, in the three states we visited, work on the measurement of quality is in early stages of development. However, this is not an indication of the relative importance of efforts to measure the quality of home and community-based long-term care. In fact, the measurement of quality provides the data necessary to address questions about performance, efficiency, and appropriateness, which ultimately hold implications for both access and cost.

Since quality is perhaps the most difficult aspect of service delivery to measure, you asked that we describe how quality has been defined, assured, and measured for home and community-based long-term care services as well as the methodological challenges that the states are encountering in their attempts to do so.

We begin by discussing the definition of quality from the viewpoints of service administrators, service providers, and service consumers. We follow this with a description of current quality assurance requirements under Medicare and Medicaid programs providing home and community-based long-term care services and a brief description of methods the states are using to measure the quality of home and community-based long-term care services.

How Quality Is Defined

As noted earlier, we use the Office of Technology Assessment's definition of quality as the extent to which service reduces the probability of poor outcomes and increases the probability of good outcomes within the constraints of existing knowledge. Thus, defining quality for a particular service or program requires identifying goals and operationalizing these in the form of outcomes. Moreover, a coherent program of quality assurance and measurement requires that program goals be articulated well enough to identify the types of performance or outcomes to be assured, measured, or prevented.

The Goals That Are Identified

From our discussions with experts and program officials and our review of pertinent literature, we found that the goals of home and community-based care for the elderly, and therefore the appropriate grounds for assessing its quality, are poorly articulated, especially at the

individual service level. Such goals are, in any case, the subject of some disagreement.

We found that no single set of desired goals and outcomes of home and community-based long-term care has been accepted by the network of organizations representing and serving the aged population. For example, one study asked that persons representing several perspectives rate the relative importance of 21 outcomes of care for which home care providers might be held accountable.⁵ The authors reported substantial agreement on the relative importance of such outcomes as "freedom from exploitation and abuse" and "maintenance or improvement of physical functioning," but even for a particular patient type, substantially less agreement was observed on the relative importance of goals such as client knowledge, regimen compliance, and hospitalization.⁶ Below, we briefly discuss the goals expressed by administrators, providers, and consumers, as they were identified in documents or interviews.

How Goals Are Defined by State Program Administrators

Goals for the Personal Care Option

We visited two states (Wisconsin and New York) offering the personal care option under the Medicaid state plan. In neither did officials readily articulate goals for such services. Similarly, the World Institute of Disability (WID) surveyed states in 1990 regarding the goals established for services under the Medicaid personal care option. The authors described the responses as "not illuminating." In their 1990 site visits to six states offering the personal care option, WID staff found that program goals varied among states but that, in almost all cases, state officials made some

⁵The "outcomes" studied included freedom from abuse; satisfaction with care; client choice and knowledge; affordability; satisfaction with life; physical, cognitive, physiological, and psychological functioning; family knowledge and stress; symptom control; nursing home admission; social activity; morbidity; hospitalization; compliance with exercise, drug, or dietary regimen; physical safety; and death.

⁶R. A. Kane et al., *Quality of Home Care: Concept and Measurement* (Minneapolis, Minn.: University of Minnesota, School of Public Health, Division of Health Services Research and Policy, 1991).

reference to prevention of institutional placement.⁷ Other goals cited by at least one state included encouraging self-determination, authorizing services “only to the extent necessitated by the individual’s functional limitations,” maintaining informal supports, and supporting informal caregivers.⁸

Goals for Other Services

The goals cited by state officials for their waiver programs mentioned reducing inappropriate institutionalization, controlling expenditures, and providing consumers with a choice of living arrangements, control, enhanced dignity, and improved quality of life. Notably, all three of the states we visited had attempted to involve clients in a discussion of goals and service characteristics that would contribute to quality, indicating endorsement of client satisfaction as a program goal. We briefly review below the goals specifically cited for various home and community-based long-term care programs by administrators in the three states.

Connecticut. During our interviews, Connecticut officials indicated that no goals had been developed for particular services, although the state’s home and community-based long-term care programs had the collective goal of keeping people at home in a cost-effective manner. The annual report to the state legislature on the Connecticut Home Care Program for Elders (CHCPE) notes that “The program helps families who are caring for older relatives at home and enables older persons themselves to maintain dignity, control, and an improved quality of life in their later years.”⁹ The goals of the newly consolidated CHCPE were “(1) to create a ‘seamless’ program in which individuals could receive appropriate services according to their needs, without having to negotiate the complexities of various programs and funding restrictions; [and] (2) to control program growth and expenditures.” The goals that state documents indicate have guided decisions about home care in the past and continue to be important include the following:

⁷S. Litvak and J. Kennedy, Policy Issues Affecting the Medicaid Personal Care Services Optional Benefit (Oakland, Calif.: World Institute on Disability, 1991). WID reports that Oregon officials saw the personal care option as incompatible with the goal of reducing the nursing home population, because eligibility for the personal care option under Oregon’s Medicaid program entails meeting an income eligibility limit far lower than that required for Medicaid nursing home eligibility. Thus, Oregon indicated it relies on Medicaid waivers for services that other states have provided under the personal care option and instead uses this option to serve disabled children.

⁸WID specifically noted that no personal care option program surveyed at the time had the goal of enabling participants to work, although it was conceivable, with recent changes in Medicaid eligibility laws, that personal care option recipients could sustain gainful employment without losing their Medicaid eligibility.

⁹Office of the Commissioner, State of Connecticut Department of Income Maintenance, Home Care for a New Era: Annual Report on the Connecticut Home Care Program for Elders to the Human Services Committee and the Appropriations Committee of the General Assembly (Hartford, Conn.: 1993), p. 1v.

- “to establish a continuum of care through which individuals can easily progress as their needs and circumstances change;
- “to develop a balanced long-term care system with a full range of community-based and institutional services;
- “to avoid inequities between state-operated home care programs except where federally imposed restrictions are inconsistent with state policies;
- “to eliminate duplication and overlap of services; and
- “to allow the freedom of choice, to the extent that resources allow, to assure that individuals will not be forced into institutions due to the lack of home care alternatives.”

New York. In presenting work on the quality assurance project for New York's Extended In-Home Services for the Elderly Program, the State Office for the Aging noted that outcomes for the program would include things like “judgement by the case manager that the customer can be maintained safely at home with the service plan, and that the services ordered are delivered as specified.” Neither of these examples, however, goes beyond implementation goals or expectations. Outcome indicators of this nature would not assess whether, for example, the services accomplished anything for the service recipients, nor establish the level of safety and security that service recipients actually experienced while staying at home. Tellingly, a 1993 report of New York State's Task Force on Long-Term Care notes that

“There is no comprehensive mission and policy direction for long-term care for aged and disabled individuals in New York; instead, divergent funding streams out of individual service systems have driven the design and supply of long-term care services.”¹⁰

Wisconsin. In this state, officials readily articulated goals for Medicaid waiver and state programs providing home and community-based long-term care services. However, at least one official did not view service-based goals as appropriate and noted that there was no all-inclusive list of services allowable under the state's Community Options Program. They indicated that the goals of their home and community-based program for the elderly were to provide services at the location of the customer's choice, to involve customers in all service decisions, and to allow people to live with as much independence and dignity as possible. Promotion of client control and respect were mentioned as values guiding their efforts.

¹⁰Task Force on Long Term Care, Reforming Local Access and State Structure for Long-Term Care in New York (Albany, N.Y.: 1993), p. 3.

How Providers Define Goals

From our review of the literature and discussions with some provider organizations, we found that while service providers have begun to identify outcome indicators for home health clients, for clients requiring only assistance with personal care or instrumental ADLs, service goals are relatively ill defined and discussion focuses primarily on the process of service delivery. For example, providers interviewed by the United Seniors Health Cooperative identified the following factors for emphasis in measuring the quality of home care:

- coordination of care;
- appropriateness of the procedure, plan of care, or treatment;
- appropriateness of setting;
- credentials of providers (that is, Do they have the right training and experience to perform the assigned tasks?); and
- skill in performance of treatment or procedure.

In contrast, for patients requiring home medical services, relatively elaborate matrixes of health care outcomes have begun to be identified, although these may not be fully reflected in day-to-day operations.

How Consumers Define Goals

We reviewed a variety of studies in which groups of consumers of home and community-based care were asked about their criteria for quality service. It is important to note that most work with consumers has focused on the characteristics they associate with good or bad services rather than their views of the goals of home and community-based care. Most of the studies involve small groups of home care consumers and are generally limited to consumers who can respond to interview questions. In addition, they address attitudes of consumers in a limited geographic area. In studies of quality in personal care services, consumers cited factors such as

- workers' arrival on scheduled days,
- workers' arrival at the scheduled time,
- working for the scheduled amount of time,
- completion of work,
- service consistency,
- neat and clean appearance,
- care for and protection of the customer's safety (for example, assistance with seatbelts during transportation),
- careful treatment of the customer's property,

- honesty and trustworthiness in dealings with the customer (for example, in completing grocery purchases for the customer),
- courtesy and respect in interactions with the customer,
- responsiveness to the customer's preferences, and
- empathetic and cheerful demeanor.

The United Seniors Health Cooperative has advanced the promotion of three major goals for home care identified through focus groups with consumers: (1) independence, or supporting resumption of ordinary activities and enhanced control; (2) health preservation and improvement; and (3) happiness, or maintaining social engagement and promoting mental health.

To summarize, differences in the definition of goals by these three important stakeholders in home and community-based services may have implications for how quality is assured and measured. Program administrators' goals in many cases are not even formally articulated, much less generally endorsed. Providers' goals are developing, but the differences between the development of medical and personal care outcomes are clear. Among consumers, there appears to be some consensus around goals, but they may be far from the goals of the two other groups with some apparent potential for conflict. However, one important characteristic of the consumer goals noted here is that the majority imply attitudinal changes on the part of service providers rather than service improvements that would necessarily involve additional financial resources to be supplied by administrators or providers.

How Quality Is Assured in Various Service Delivery Systems

The terms "quality assurance" and "quality measurement" are used in a variety of ways. As noted, we have used "quality assurance" to describe prospective processes or requirements—such as licensure, inspections, or training—generally intended to promote a certain level of performance on criteria that might be the subject of a quality measurement program (that is, indicators of the achievement of program goals or the capacity to achieve such goals).

State and federal agencies have implemented a variety of quality assurance strategies. However, the presence of such quality assurance requirements is not sufficient to assure a level of quality. For example, the Quality Assurance Project conducted under New York State's In-Home Services for the Elderly Program found that, although the general quality of communication between case managers and elderly customers was good,

interviews of clients by project staff often revealed problems and incidents that were previously unknown even to case managers. It is important to note that this occurred despite the presence of standards requiring case managers to inform clients to contact them in case of difficulties; the problems in question were only discovered in an independent attempt to measure program quality.

It is also important to note that the complexity of the system through which services are organized and delivered complicates the states' efforts to assure and measure the quality of home and community-based long-term care. Consistent with the structure of federal financial support for these services, the delivery of home and community-based long-term care services is still frequently accomplished through a difficult organizational structure with no single point of entry, although we found evidence of intentions to enhance administrative coordination.¹¹ This lack of integration is noteworthy not only because it may cause confusion for elderly persons trying to gain access to services, and may lead to inequities and administrative duplication in the allocation of long-term care resources, but also because it results in the application of different quality assurance requirements to similar services.

Agencies providing service financed by the Medicare program must meet Medicare's conditions of participation for home health agencies, which incorporate a variety of measures "considered necessary to assure patients' health and safety."¹² These include requirements addressing patients' rights; compliance with federal, state, and local laws; mandated organizational and administrative structures; standards of training and qualifications for personnel; and establishment of a professional advisory group. Agencies and individuals providing service financed under Medicaid must also meet training and qualification requirements, although they differ by specific type of benefit.¹³ Appendix I identifies the variety of

¹¹According to an Administration on Aging survey of state-administered home and community-based services for functionally impaired elderly persons, as of fiscal year 1992, only 16 states had established a single point of entry to such services (integrating at least waiver and state-funded services) and only 13 had implemented this policy statewide. The 16 states reporting a single point of entry were Colorado, Connecticut, Delaware, Illinois, Indiana, Iowa, Louisiana, Maryland, Massachusetts, Ohio, Oregon, Nevada, North Dakota, South Dakota, Virginia, and Wisconsin.

¹²42 C.F.R. 484.1.

¹³For example, for home health services, agency providers of home health aide services must meet the same requirements (including 75 hours of training) that they would under Medicare, while individual providers must meet the requirements for nursing as defined in the state's nurse practice act. For services under the personal care option, qualification and training standards are also invoked, although they are far less specific. Standards vary considerably regarding employment of relatives, nurse or physician supervision, and planning and supervision of services. This variation is confusing insofar as one could receive personal care services, in some circumstances, under each of these options.

quality assurance requirements that the states must impose on personal care when it is financed through various Medicaid benefits and programs. State-funded programs and services financed by the Older Americans Act and title XX may invoke yet another set of requirements, although these may be more or less inclusive than the applicable federal requirements. Specific quality assurance strategies associated with the Medicare and Medicaid waiver programs are summarized below.

Medicare

Medicare has developed several conditions of participation for home health agencies that are designed to assure the health and safety of patients. These requirements apply not only to home health services covered by Medicare but also to home health benefits under Medicaid when these services are provided by agencies or organizations. (See appendix I.)

Medicaid Waiver Programs

In order to receive approval for a Medicaid home and community-based service waiver, the states must assure that necessary safeguards have been taken to protect the health and welfare of individuals who are provided services under the waiver. However, the statute does not prescribe the mechanisms that the states must use to do so. In order to assist the states in learning about approaches other states had taken to assure quality under their waivers, in November 1993 HCFA's Medicaid Bureau summarized the approaches to quality taken by 13 states operating Medicaid home and community-based waiver programs for aged and disabled persons. The 13 states were selected for the sufficiency and variety of material available to the Medicaid Bureau (for example, waiver applications, annual reports, independent assessments, regional office reviews) describing the mechanisms the states had employed to assure the health and welfare of waiver recipients.¹⁴ Thus, these 13 states may have more-developed quality assurance strategies than states not selected. HCFA's review identified three major approaches to quality assurance—use of case management, training, and client involvement—and also addressed quality measurement under the rubric of “program monitoring.”

Case Management as Quality Assurance

A case manager typically develops a plan of care for a waiver client and is required to maintain contact with the client at a fixed frequency that varies among the states, as do caseload limits and average caseloads. All the state programs that were reviewed by the National Association of State Units on

¹⁴The states were California, Colorado, Georgia, Illinois, Maine, Minnesota, New Jersey, Ohio, Oregon, Tennessee, Virginia, Washington, and Wisconsin.

Aging (NASUA) require that a case manager conduct at least some in-home visits. NASUA reports that, in 75 percent of these programs, case managers are required to contact clients, at least by phone, within 3-month intervals. Most of the remaining states require such contact at 6-month intervals. No rationale is apparent for the particular frequencies states have selected, and the effect of differences in frequency of contact has not been reported in the literature we reviewed.

In addition to caseloads and rates of client contact, conflicts of interest may affect case managers' capacity to receive or collect unbiased information on service quality. HCFA's review of 13 states' case management strategies notes that "Case managers review items such as (1) whether providers arrive timely and provide the services outlined in the plan of care; (2) whether there are unmet needs; (3) whether the client is satisfied; and (4) whether the provider met the standards for services."¹⁵ However, in instances in which the case manager is involved in selecting services, it would seem that opinions on these matters would be compromised by the case manager's accountability for care plan costs and role in identifying and selecting providers, as well as clients' probable reluctance to disclose their views to persons seen as service gatekeepers. Moreover, in Wisconsin, an official from the state's ombudsman program indicated that home care clients in the state's Community Options Program generally are not aware of the availability of case managers, who are normally county government employees.

Training Requirements

Training may be used to ensure competence before a provider is authorized to deliver services, to correct deficiencies identified through monitoring, or to enable family members to care for a client in the home. HCFA reported that responsibility for providing or arranging training in the 13 state waivers it reviewed frequently lay with state government agencies or with provider agencies, such as home health agencies. When the states cited factors influencing the selection of training topics, the most frequent factors included provider requests, statewide needs assessments, and monitoring reports. Thus, in this instance some link was apparent between ongoing measurement efforts and the contents of quality assurance activities.

Client Involvement

Client involvement was the third type of strategy that HCFA found the states were using to assure the quality of services in terms of their ability to protect the health and safety of waiver participants. HCFA identified four

¹⁵Health Care Financing Administration, Approaches to Quality under Home and Community-Based Services Waivers (Baltimore, Md.: 1993), p. 63.

major types of client involvement (in addition to the use of client satisfaction surveys, which are addressed later in our report). The four were (1) client involvement in care planning, (2) voluntary attendance at provider training sessions, (3) client participation in policy advisory groups, and (4) mechanisms for handling client complaints.

Some states and subunits have developed advisory councils composed of providers and consumers that may hold hearings or collect information to advise program officials about service quality and other program matters. All three of the states we visited had made some use of this strategy.

Additionally, HCFA reports that "A number of states now permit clients or their representatives to have some input into the development of the plan of care. This is normally done by having the client or representative act as a member of the interdisciplinary team which develops the plan of care."¹⁶ In addition, HCFA reports that most states have the client sign the plan of care, and agencies we interviewed indicated that a copy of the plan of care is usually left in the client's home. The client's signature on the plan of care can help assure state surveyors that the plan reflected in the provider agency's case record has actually been presented to the client. Although some states may not require that providers obtain the client's signature as proof of service delivery, we were told that agencies often adopt this practice for purposes of internal control.

Some state-funded programs, such as the Community Options Program in Wisconsin, have extended client involvement to the point of giving clients the funds necessary to pay care providers directly, but the Medicaid program restricts both this practice and the hiring of family members to provide care.

Finally, HCFA reports that the states collect client complaints, which may be directed to the case manager or to a toll-free hotline. HCFA reports that, very often, states provide clients with printed information on their rights and responsibilities, detailing complaint-handling procedures. The states we interviewed also made reference to the Medicaid fair hearing process as a quality assurance avenue.

State Licensure

Most states require licensure of at least some home care agencies or providers. This can act as a quality assurance mechanism insofar as it bestows a privilege that the state may withdraw if the agency develops a

¹⁶Health Care Financing Administration, p. 72.

pattern of poor performance. Some state licensure requirements exceed federal requirements for participation in Medicare or Medicaid. To exert control on the number and quality of agencies providing home care services, some states have also imposed a requirement that agencies receive a "certificate of need" before beginning operations. The National Association of Home Care Providers conducted a survey of state licensure requirements for home care agencies during the summer of 1992 and found that 39 states applied licensure requirements to Medicare-certified home care agencies, 35 states applied such requirements to non-Medicare-certified home care agencies, and 20 required individual providers of home care (home care aides, homemakers, and personal care aides) to obtain a license. In addition, certificates of need were required in 23 states for Medicare-certified agencies and in 11 states for non-Medicare-certified agencies.

To summarize, our findings illustrate that quality assurance requirements, per se, are insufficient to assure quality services. In any case, the variety of requirements that different programs apply to similar services is consistent with the scant data on the problems the requirements are intended to address and the absence of precise definition of the qualities they are apparently intended to assure.

How Quality Is Measured

We use "quality measurement" in this report to refer to the retrospective quantitative or qualitative assessment of specific criteria of care or service. For example, the percentage of appointments in which the provider arrived within 1 hour of the scheduled time would be a measurable process criterion, while the unnecessary use of emergency services or nursing home beds might be seen as an outcome indicator if an important program goal were the reduction of use.

In the field of acute health care, the service characteristics that are the focus of quality measurement mechanisms have usually been divided into structure, process, and outcome criteria. Where there are multiple goals or multiple stakeholders with different goals, it is important to measure multiple aspects of structure, process, and outcome in order to (1) prevent key stakeholders from rejecting the entire process as irrelevant or counterproductive and (2) develop the capacity to address arguments about the relative importance of key structural and process characteristics to the improvement of outcome measures. Even if this relationship is assessed while designing a quality measurement system, the lack of a relationship between certain variables at that point does not assure that

they will continue to be unrelated. Although the three states we visited had begun to implement measures of home care quality, these measures included few objective indicators of outcomes and lacked a fully articulated system for linking service characteristics to these outcomes.

For some potential goals, defining objective outcomes for which services can be held accountable or identifying measures that are reasonably interpretable as indicators of service quality is methodologically complex. Despite this complexity, the states are pursuing some efforts to monitor the quality of beneficiary outcomes that deserve attention. These include surveys of home health agencies, client satisfaction surveys, on-site inspection and supervision, reviews of client records and care plans, fiscal audits of providers, and focus groups or hearings.

Surveys of Agency Operations

HCFA contracts with states for periodic surveys of home health agencies that receive Medicare payments in order to determine whether they have complied with the standards that HCFA has established for such agencies. The provisions of the 1987 Omnibus Budget Reconciliation Act require that, in assessing the quality of care that home health agencies provide, the states measure how home health care has affected patients' health by assessing whether it has enabled beneficiaries to achieve the highest practicable health status. The law also requires that the states begin to measure quality of care using measures of medical, nursing, and rehabilitative care.

Although HCFA has sponsored research that has resulted in preliminary criteria for measuring the quality of the medical aspects of home health care, officials of HCFA's Health Standards and Quality Bureau acknowledged difficulties in measuring the current effect of home health spending. In addition, HCFA has not yet released a standardized assessment instrument and minimum data set that were required for the Home and Community-Based Care for the Functionally Disabled Elderly Program created under the 1990 Omnibus Budget Reconciliation Act. In an earlier report, we detailed some of the technical weaknesses in HCFA's guidance to the states regarding survey procedures.¹⁷ Unfortunately, we were told that case managers in more than one state had no systematic access to results of state surveys of home health agencies and had little systematic comparative information to draw upon in referring clients to particular providers.

¹⁷U.S. General Accounting Office, Medicare: Assuring the Quality of Home Health Services, HRD-90-7 (Washington, D.C.: October 10, 1989).

Consumer Satisfaction Surveys

State officials appear to endorse patients' satisfaction as an important outcome of home health care. In support of this view, research indicates that satisfied patients are more likely to comply with health care regimens, to participate in their own treatment, and to cooperate with health care providers by disclosing important medical information. However, an alternative interpretation of this research is that satisfied patients are merely more compliant than dissatisfied ones. Indeed, some research suggests that people who are more satisfied with their health care are more satisfied with other aspects of life, suggesting that some measures of health care satisfaction may not be measuring anything linked particularly to health care services. However, measures specific to the types of care received and the conditions of the recipient may be less subject to these criticisms.

Although some states and providers are using client satisfaction surveys to measure experience with home care, the quality of the surveys varies and their results can be difficult to interpret. The population in need of home and community-based care services is methodologically difficult to survey. First, survey respondents are highly dependent on the services they receive in order to remain in the community; they may fear that negative feedback will endanger their ability to continue to receive services. This is consistent with a pattern of differences between overwhelmingly positive written survey responses and findings from trained interviewers in New York and Wisconsin who reported uncovering problems sometimes unknown even to the case manager.

Second, in many cases, the only response available comes from a guardian or a patient's representative, whose views may represent different sets of interests. Since guardians and informal care providers are rarely surveyed separately—although we understood that they are more likely to provide critical comments—survey findings that mix the two types of responses are difficult to interpret. Finally, given the variety of services provided, the sample sizes of the surveys were not always large enough to produce reasonably accurate results about particular providers or services, even if the validity of survey findings had been less problematic.

On-Site Inspection and Supervision

Because of the numerous sites in which home and community-based long-term care is delivered, inspection and direct supervision can be expensive means of monitoring care. Consequently, this technique is not applied with great frequency within the Medicaid programs for which we reviewed regulations. In most states, case managers must make at least

quarterly contact with each client and, for home health aide care provided under Medicaid, a nurse must conduct an in-home visit while the home health aide is present at least once each 60 days. However, the contents and results of this supervision may be highly variable given the lack of specific regulation.

Reviews of Client Records or Care Plans

Providers' billing documents are reviewed against care plans to establish that services ordered have, in fact, been billed. In addition, providers may be audited to assure that services for which the states are billed are documented by appropriate case notes in providers' files. However, audit procedures may be applied as long as 18 months after services are actually rendered, reducing their value as information on ongoing service performance.

Of more importance in this regard is the review of client care plans or records conducted by case managers and, sometimes, by external reviewers to assure that care is appropriately planned and modified to fit patients' needs. We found that in the states we visited, these reviews were implicit—that is, based on the professional knowledge of reviewers rather than on explicit criteria for care. As such, they are probably incapable of assuring that services are equitably authorized or that they consistently meet specific standards. In particular, reviewers lack (1) normative data on the amounts of service authorized for patients within the state's program who have particular levels of functional difficulty and patterns of informal support and (2) explicit standards that might be used to evaluate a patient's care plan.

Other Methods

State officials also identified other methods for gathering information about the quality of services. These included conducting client focus groups or hearings and registering complaints through a toll-free hotline. Although these strategies may be worthwhile for purposes other than measuring quality, they cannot provide either systematic or representative information needed to measure or to understand service quality and how it is changing over time.

In summary, efforts to measure service quality are in early stages of development and appear focused on structural and process indicators rather than indicators of program or service outcomes. Although the state officials we interviewed had attempted to measure client satisfaction through formal surveys, the approaches to and experience with this

strategy varied widely, sometimes yielding results of questionable validity. Moreover, the goals states had identified were not systematically linked to quality measurement strategies, nor were the results of existing measurement and assurance processes consistently used to influence ongoing program operations.

Conclusion

As we noted earlier, it is difficult to establish either the necessity or sufficiency of current quality assurance requirements because of the lack of well developed and systematic measurement of service quality. In this context, it is not surprising that quality assurance strategies applied to the same service are quite varied depending on the source of service financing.

As the Congress considers new programs serving functionally disabled elderly persons, our interim findings suggest careful consideration of provisions for the independent assessment of services in order to develop unbiased information about program performance and quality. We believe that the prospects for independent assessment of quality would be strengthened by (1) better articulated program goals (to permit clear identification of the types of performance or outcomes to be assured, measured, or prevented) and (2) a consistent framework for measuring quality and performance characteristics across service providers. Knowing where to intervene when important outcomes are poor will depend, in part, on having enough information about system characteristics to assess their relationship to outcomes independent of stakeholder perspectives. Without such information, poor performance on outcome indicators may be explained with equal persuasiveness by workers' unions as the consequence of inadequate staffing, by administrators as the consequence of poor staff training, by consumers as the consequence of inadequate amounts of service, or by patients as the result of client characteristics.

With regard to consumer satisfaction surveys, we think it is important to note, first, that it is a very vulnerable and service-dependent population that is being asked to provide potentially negative feedback. The three states we visited were each involved in surveys of clients regarding their receipt of services under Medicaid or other programs. However, this methodology has a weakness with regard to this population, and the states and providers that had attempted to apply it told us that even clients who would reveal problems in the context of an interview did not typically do so on written survey instruments. In summary, although direct inquiries of

consumers may certainly be useful, a survey approach may be expensive and difficult to apply with validity in this population.

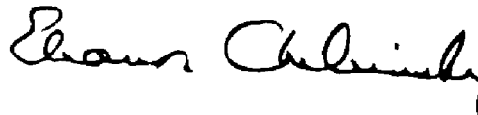
Agency Comments

At your request, we did not ask federal agencies to comment formally on this report. We did obtain their views and they were in general agreement with our findings.

We are sending copies of this report to the Secretary of Health and Human Services, the Administrator of the Health Care Financing Administration, the Assistant Secretary for the Administration on Aging, and other officials. Upon request, we will send copies to others who are interested.

If you have any questions or would like additional information, please do not hesitate to call me, at (202) 512-2900, or Mr. Kwai-Cheung Chan, Director of Program Evaluation in Physical Systems Areas, at (202) 512-3092. Other major contributors to this report are listed in appendix II.

Sincerely yours,



Eleanor Chelimsky
Assistant Comptroller General

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Abbreviations

ADL	Activities of daily living
CHCPE	Connecticut Home Care Program for Elders
HCFA	Health Care Financing Administration
IADL	Instrumental activity of daily living
NASUA	National Association of State Units on Aging
WID	World Institute on Disability

Service-Specific Requirements for Individual and Agency Providers of Medicaid Benefits

Requirement	Benefit or waiver			
	Home health	Personal care	Home and community-based waiver	Home and community-based care for functionally disabled elderly persons
Pertinent statutes and regulations				
Statutory basis	Social Security Act, 1905(a)(7)	Social Security Act, 1905(a)(22)	Social Security Act, 1915(c), (d), (e)	Social Security Act: 1905(a)(23) and 1929(a)(1,3,4,5,8, and 9)
Regulations	42 CFR 440.70(b), 441.15(a), 484.30, 484.36 Public Law 101-508/4721(a)	42 CFR 440.170(f)	42 CFR 440.180(c), (d), (g), (h)	
Eligibility				
Target group	Eligibility does not depend on need for or discharge from institutional care	None specified	For recipients who are not inpatients of a hospital, SNF, ICF, or ICF/MR and who would require the level of care provided in a SNF or ICF if not furnished with home and community-based services; states may narrow the target group ^a	Functionally disabled elderly, as defined in the law; states may narrow the target group
Entry requirement	Provided on physician's orders	Prescribed by a physician	Membership in the target group, as established at state level	Comprehensive functional assessment to determine whether individual is functionally disabled
Plan of care requirements				
Plan required	Plan of treatment	Plan of treatment	Written plan of care	Individual community care plan
Qualifications for reviewer	Physician	Registered nurse	States assure health and well-being of recipients	Qualified community care case manager
Frequency of plan of care review	Every 60 days	Every 60 days	Unspecified	Periodically

(continued)

**Appendix I
Service-Specific Requirements for Individual
and Agency Providers of Medicaid Benefits**

Requirement	Benefit or waiver			
	Home health	Personal care	Home and community-based waiver	Home and community-based care for functionally disabled elderly persons
Locations in which service may be provided				
Private home	Yes	Yes	Yes	No
Facility	Home health services can be provided in an ICF/MR if the services are not required to be provided by the facility	No	Respite care may include payment for placement in a certified facility	Small or large, nonresidential or residential community care settings; unrelated adults residing in setting provided with personal services
Outside a home or facility	The second circuit has held that home health nursing services may be used at any location in the community, but this decision currently applies only in Connecticut, New York, and Vermont	As of fiscal year 1995, as part of home health services or, according to policy, while being transported to receive medical care	Community-based	No
Agency providers, organizations, and facilities				
Requirement to meet Medicare conditions of participation	Yes; conditions of participation for home health agencies	No	No	No
Registered nurse supervision requirements	Yes	Yes	No	No
References to requirements in state law	Yes; medical rehabilitation facility licensed by state	No	No	Yes; state must survey and certify providers; setting must meet applicable state and local requirements
Direction or supervision requirement	Yes; medical rehabilitation facility must be under competent medical supervision	No	No	No

(continued)

**Appendix I
Service-Specific Requirements for Individual
and Agency Providers of Medicaid Benefits**

Requirement	Benefit or waiver			
	Home health	Personal care	Home and community-based waiver	Home and community-based care for functionally disabled elderly persons
Independent and individual providers				
Family members prohibited or restricted	No	Yes; provider may not be a member of the recipient's family	Yes ^b	No
Direction or supervision requirements	Yes; home health aides must be under the supervision of a registered nurse	Yes; service must be supervised by a registered nurse	No	No
References to requirements under state law	Yes; nursing as defined in State Nurse Practice Act	No	For all independent providers, the state must assure that state standards for licensing and certification are met	No
Specific individual provider requirements	Yes; for physical therapist; occupational therapist; speech, hearing, and language services; home health aide (training); and registered nurse providing visiting nurse care	Yes; individual must be qualified to provide services; training requirements for personal care attendants employed by home health agencies	Yes; state must assure adequate standards for all providers and qualifications for individuals developing plans of care	Yes; providers must be competent to provide care

Source: Health Care Financing Administration, Community-Based Care: Options Under Medicaid (Baltimore, Md.: 1993).

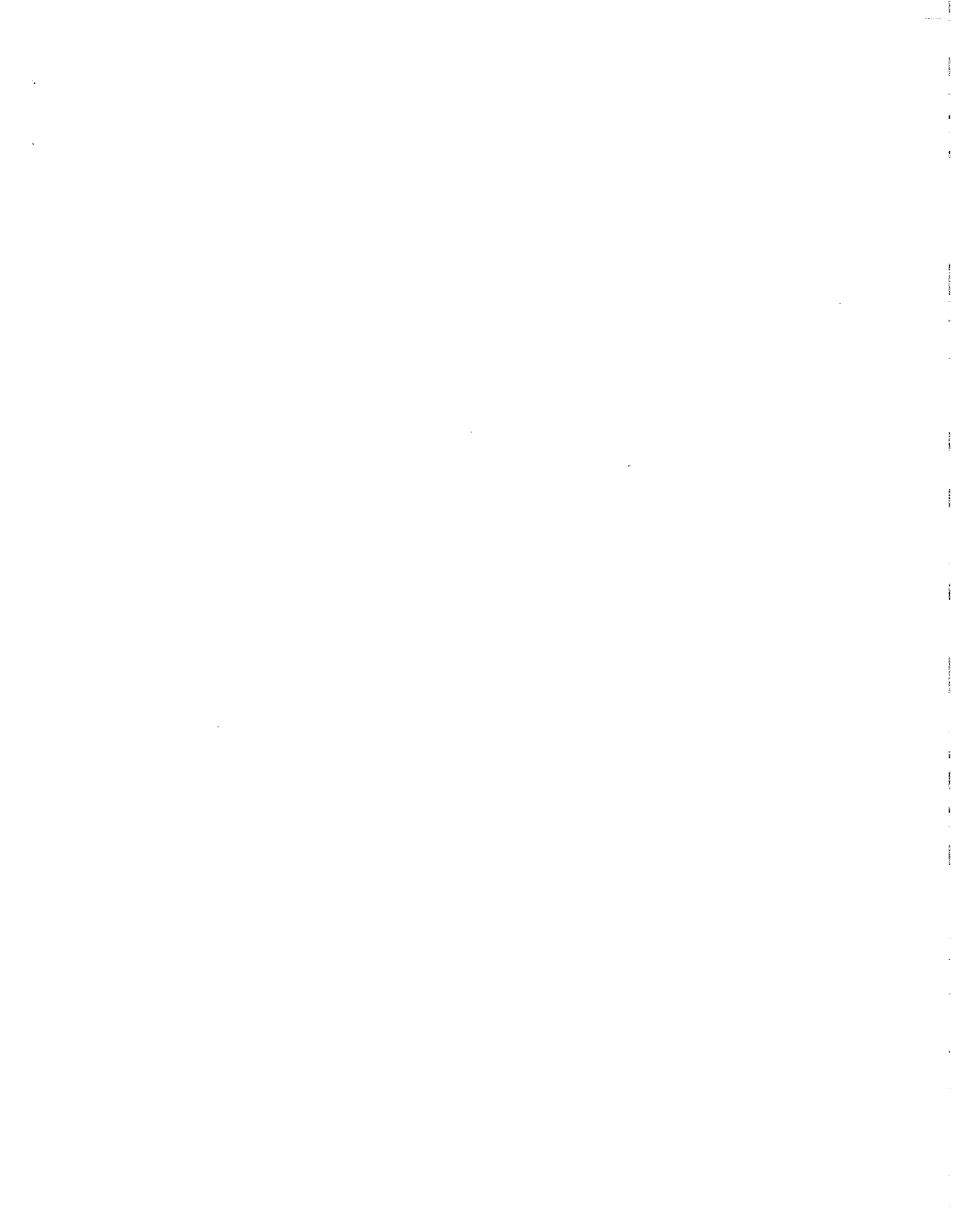
^aSNF = skilled nursing facility; ICF = intermediate care facility; ICF/MR = intermediate care facility for persons with mental retardation.

^bProhibits payment to legally responsible relatives (spouses and parents of minor children) for personal care and other home and community-based services; allows payment for extraordinary requirements and specialized skills under certain conditions.

Major Contributors to This Report

Program Evaluation and Methodology Division

Sushil K. Sharma, Assistant Director
Betty A. Ward-Zukerman, Project Manager
Brett S. Fallavollita, Deputy Project Manager
Penny Pickett, Supervisory Reports Analyst
Venkareddy Chennareddy, Referencer



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