

Extended remarks
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Mr. Chairman and members of the Committee, it is a privilege to speak with you today about what I believe is one of the most important developments in our nation's long term care system - the emergence of assisted living. I also want to commend Senator Wyden and the General Accounting Office for initiating a review of two critical aspects of assisted living: quality of care and consumer expectations.

With funding from the Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, the National Academy for State Health Policy (NASHP) conducted two studies of state assisted living licensing and Medicaid reimbursement policy. NASHP is a non-profit organization, based on Portland Maine, that was formed to help states learn from one another and to provide a forum for state officials to work together in a multi-disciplinary, cross agency manner on health and long term care issues. The results of the studies highlight the diversity among states, the flexibility and creativity of approaches, and the interest of states in promoting a residential, consumer-centered model for accessing long term care services.

GAO studied four states: California, Florida, Ohio and Oregon. Our study found that 25 states, including Florida and Oregon, have regulations with an assisted living category. The remaining states do not use the term but some, like Ohio, have updated their rules. Since the GAO study was completed, new regulations were adopted in Oregon and proposed changes were issued in Florida. Thirty-two states, including Florida and Oregon, cover services in assisted living settings under Medicaid while coverage is being considered in California and Ohio.

Philosophy

States are very concerned about balancing quality of care, consumer preferences and appropriate oversight. Assisted living in many states represents a more consumer focused model which organizes the setting and the delivery of service around the resident rather than the facility. States which emphasize consumers use terms such as independence, dignity, privacy, decision-making, and autonomy as a foundation for their policy. Statutes, licensing regulations, and Medicaid requirements in 22 states, up from 15 states in 1996, contain a statement of their philosophy of assisted living. States which have adopted or proposed this philosophy are Arizona, Delaware, Florida, Hawaii, Illinois (demonstration program), Iowa, Kansas, Kentucky, Louisiana, Maine, Maryland, Massachusetts, Nebraska, New Jersey, New Mexico, Oregon, Rhode Island, Utah, Vermont, Virginia, Washington and West Virginia. Massachusetts includes their language in a section that allows the Secretary of Elder Affairs to waive certain requirements for bathrooms as long as the residences meet the stated principles.

Oregon's definition states that: "Assisted living promotes resident self-direction and participation in decisions that emphasize choice, dignity, privacy, individuality, independence and home-like surroundings." Florida's statute states the purpose of assisted living is "to promote availability of appropriate services for elderly and disabled persons in the least restrictive and most home-like environment, to encourage the development of facilities which promote the dignity, individuality, privacy and decision-making ability...." The laws also state that facilities should be operated and regulated as residential environments and not as medical or nursing facilities. The regulations require

that facilities develop policies which allow residents to age-in-place and which maximize independence, dignity, choice, and decision-making of residents.

New Jersey amended its rules to emphasize the values of assisted living and introduce managed risk. Facilities must provide and coordinate services "in a manner which promotes and encourages assisted living values." These values are concerned with the organization, development, and implementation of services and other facility or program features so as to promote and encourage each resident's choice, dignity, independence, individuality, and privacy in a home-like environment. The values promote aging-in-place and shared responsibility.

Although the philosophy of assisted living is increasingly found in state policy, facilities must take additional steps to operationalize it. Aspects of assisted living that might be considered to convert philosophy to action include the living units required or provided, whether living units may be shared by choice, use of a shared-risk process to develop a service plan and training for facility staff on the principles of assisted living. Eight of the twenty-two states with a statement of the philosophy of assisted living also require apartment units. Rules in four states have mixed requirements, allowing bedrooms in some arrangements and apartments in new construction. Fifteen of the states allow sharing (apartments or bedrooms) only by choice of the residents. Ten states use a shared risk process for developing tenant service agreements or service plans. Connecticut, which licenses assisted living service agencies and not facilities, does not have a statement of philosophy, but residences must offer apartments, and sharing is allowed only by choice. Two other states, Ohio and Oklahoma, have a shared-risk provision and no statement of philosophy. Four states include a philosophy of assisted living but do not address the remaining areas which would operationalize the philosophy. Eleven states require that the training curriculum for staff must cover the principles of assisted living.

Occupancy

States with newer regulations tend to allow facilities to serve residents who need more care than under older board and care rules. Several states now allow people to live in residential settings who previously could only be served in nursing homes as long as the facilities have the staffing capacity to serve them. The broadest policies have been developed in Arizona, Delaware, Kansas, Maine, Nebraska, New Jersey, and Oregon. Draft rules in Hawaii and Vermont also allow facilities to serve higher acuity residents. Florida has a list of conditions that residents in Extended Congregate Care settings may or may not have and in Ohio, residents needing part time or intermittent nursing care may remain for 120 days.

State regulations set the parameters governing who may be served, but they allow facilities themselves to determine whom they will serve within those parameters. This flexibility may cause confusion among consumers who are aware of the state's regulations and might expect to receive care as their needs increase yet find the facility's policy may not allow residents with certain conditions to remain.

Policies governing occupancy can be grouped in five areas: general statements, health related conditions, functional measures, Alzheimer's disease and dementia and behavior. Rules in many states specify a list of prohibited conditions. Other states require that tenants have stable and predictable health conditions. A few states limit the number of days residents with certain health care needs may be retained. Regulations may also include a combination of these approaches.

Resident agreements

Including a philosophy of assisted living and allowing residents to receive a higher level of care support

aging-in-place. While this a welcome development, it is also raises expectations. Consumers move into a facility expecting to remain when their health or functional capacity declines and they need more care. Unfortunately, this expectation may not be realized if the facility decides not to provide the full level of service allowed by state rules. State rules usually set the parameters for admission and retention while owners themselves set the policy for their facility. It is critical that facilities clearly disclose to prospective residents the services they provide and the circumstances under which a person may have to move to another setting.

State regulations include requirements for the residency agreements or contracts with residents. There are several common elements the basic services provided, the monthly fee for the basic service package, additional services available, the cost of these services, resident rights and the circumstances under which residents may have to move.

The agreements include a description of the fee or charges to be paid, the basis of the fee or what is covered, who will be responsible and the method, and time of payment. Refund policy is also covered by agreements in many states. Rules covering agreements specify the amount of advance notice tenants must be given when rates are changed. A thirty-day notice is usually required. Policies governing the management of resident funds, when applicable, may also be included in resident agreements.

Service provisions generally describe the services to be provided that are covered by the basic fee and any additional services that might be available. Maryland's rules require disclosure in the agreement of the level of care that the facility is licensed to provide and the level of care needed by the resident at the time of admission. Wisconsin requires that the qualifications of staff who will provide services are included in the agreement and whether services are provided directly or by contract. The resident agreement in Colorado includes a care plan which outlines functional capacity and needs.

Resident rights and the provisions that allow staff to inspect living quarters, with the resident's permission, are also required by some states. Other states require that a copy of residents' rights provisions must be provided to each resident, without including it as part of the resident agreement. Grievance procedures may also be included in the agreement or provided separately to residents.

Terms of occupancy may also address provision of furnishings and the policy concerning pets. Other terms often include admission policy and descriptions of the reasons for which a resident may be involuntarily moved as well as the time frame and process for informing the resident and arranging for the move. Policies concerning shared occupancy must be included in agreements under Maryland's rules as well as procedures which will be followed when a resident's accommodations are changed. The changes could be due to relocation, change in roommate assignment, or an adjustment in the number of residents sharing a unit. Agreements may also include the facility's "bed hold" policy when residents temporarily enter a hospital, nursing home, or other location.

Agreements in Colorado must disclose whether the facility has an automatic sprinkler system. Rules in Maine do not allow the resident agreement to contain any provision for discharge which is inconsistent with state rules or law or imply a lesser standard of care than is required by rule or law. Agreements in Maine must also include information on grievance procedures, tenant obligations, resident rights, and the facility's admissions policy.

Kansas requires that citations of relevant statutes and copies of information on advance medical directives, resident rights, and the facility's grievance procedure must be given to residents before an agreement is signed.

Kansas specifies that the agreement must be written in clear and unambiguous language in 12 point type. Draft rules in Maryland direct that the agreement must be a clear and complete reflection of commitments agreed to by the parties and the actual practices that will occur in the facility. The language must be accurate, precise, easily understood, legible, readable, and written in plain English. Wisconsin's rules require that the format of agreements make it easy to readily identify the type, amount, frequency, and cost of services.

Most state rules do not address revising or updating resident agreements. However, Alabama includes the period covered by the agreement. Wisconsin's rules provide that agreement must be reviewed and updated when there is a change in the comprehensive assessment, or at the request of the facility or the resident. Updates are otherwise made as mutually agreed by the parties.

Negotiated risk

Sixteen states have adopted or proposed a negotiated risk process to involve residents in care planning and to respect resident preferences which may pose risk to the resident or other residents. Agreements are typically developed as a joint effort between the resident, family members (when appropriate), the case manager, and facility staff. The purpose of this process is to define the services that will be provided to the resident with consideration for preferences of the resident as to how services are to be delivered. The agreement lists needs and preferences for a range of services and specific areas of activity under each service. To many regulators, negotiated service agreements operationalize a philosophy that stresses consumer choice, autonomy, and independence over a facility-determined regimen that includes fixed schedules of activities and tasks that might be more convenient for staff and management of an efficient "facility." It places residents' needs and preferences ahead of the staff and administrators and helps turn a "facility" into a home.

Oversight

States rely on several strategies to monitor quality: training requirements, background checks, regular inspections and complaints. Several states have developed additional staffing, disclosure and training requirements for facilities serving residents with Alzheimer's disease. Case managers in Medicaid home and community based services waiver programs also monitor quality for Medicaid beneficiaries.

New approaches are likely to emerge to promote quality. Our survey identified 17 states that were interested in developing outcome measures for assisted living. Although the interest is high, much work needs to be done. Developing outcome measures requires collection of data and devising measurable indicators for people with chronic conditions. Two states, Maine and Vermont, will collect data from which such measures might be developed. Officials in Washington developed a review guide for inspectors that is intended to monitor quality of care and how the philosophy of assisted living is being implemented. Facility quality improvement programs are required under rules in Connecticut and draft rules in Vermont.

Affordability

Many state leaders are concerned about affordability. Several surveys have found that over 50% of the assisted living facilities charge a monthly fee for private pay residents that is \$2,000 a month or lower. This is very affordable for state Medicaid programs and well below the cost of a nursing home.

By early 1999, 32 states covered services in residential settings, either assisted living or board and care licensing categories, through Medicaid. Coverage is planned in the District of Columbia, Hawaii and

Utah while Connecticut and Louisiana are implementing demonstration programs. Nebraska has implemented a grant program to facilitate conversion of excess nursing home capacity to assisted living and other community based alternatives.

States typically use the Home and Community Based Services Waiver (1915 (c)) to finance care, however, regular state plan services are used in five states. The basis of coverage is important. There are important differences between waiver services and state plan services. Waiver services are available only to Medicaid beneficiaries who would be eligible to enter a nursing home if they applied. This test is not required for beneficiaries using state plan services.

States set limits on the funds that can be spent through waiver programs while state plan services are entitlements. Under waivers, states may use the optional eligibility category under home and community based waiver service programs that allows beneficiaries with incomes less than 300% of the federal SSI benefit (\$1500 a month in 1999), to be eligible and receive all Medicaid services. In the absence of this provision, people who live at home and have too much income to qualify for Medicaid would be forced to enter a nursing home and quickly "spend down" their income and assets to qualify. Using this option, states can pay for services in assisted living settings and other in-home and community services to give people options to nursing home admission. Residents pay for the room and board costs and Medicaid covers the services.

In addition, new programs are emerging to create affordable assisted living using tax credits and tax exempt bonds. The Robert Wood Johnson Foundation has funded the NCB Development Corporation to develop affordable assisted living using these and other mechanisms. The proposed HUD budget would convert some 202 projects to assisted living and use Section 8 vouchers in these settings.

Challenges facing States

As assisted living grows, states face enormous challenges to promote diversity and choice, to make it affordable, to promote quality, and to develop appropriate and effective oversight strategies that value consumer preferences and focus on outcomes. These are not easy challenges. As I talk to state policy makers, they often say they want to avoid the experience with nursing homes, and strategies that produce cookie cutter designs, institutional settings, over-medicalized services and loss of privacy, dignity and independence. Developing an outcome oriented, consumer-focused regulatory and oversight system is not easy. However, states are the laboratory where change can be tested. States welcome this challenge. They are committed to improving our long term care system, to creating a system that offers consumers real choices and to ensuring that the choices will be supported with appropriate oversight to ensure that services are of the highest quality.

Thank you.