

AN OVERVIEW OF ASSISTED LIVING: 2004

Assisted living provides housing and services to individuals who need some long-term assistance but who do not require complex medical services. Assisted living in the United States is based on European models that aim to enable older persons to live as independently as possible in a homelike environment, while getting the assistance they need. Assisted living is distinguished from more institutional approaches by its philosophy emphasizing residents' independence and choice. The extent to which the philosophy is followed varies, depending on state regulations and the policies and practices of individual residences.

Assisted living residences began to appear in the United States in the mid-1980s, and their number greatly expanded during the 1990s. By the mid-1990s, assisted living had become the most rapidly growing form of residential long-term supportive services in the United States.¹

The growth of assisted living has provided a new option for long-term services that is much more desirable to consumers than a nursing home. AARP's *Beyond 50 2003: A Report to the Nation on Independent Living and Disability* found that the majority of people age 50 and older prefer to receive any needed assistance at home, either from family and friends or from an agency.² When individuals need or want services away from home, assisted living is strongly preferred over a nursing home. At the same time, the rapid growth of assisted living has raised several issues of concern to consumers, providers, and regulators.

This issue brief summarizes the findings of some of the major multi-residence, multi-state studies on assisted living in the United States

and examines their implications for state policymakers and consumers of long-term supportive services. The issue brief begins with a description of the philosophy of assisted living and a discussion of the definition of assisted living. Next, it examines four topics:

- the characteristics of residents and services provided;
- the degree to which assisted living residences carry out the assisted living philosophy;
- the costs and affordability of assisted living; and
- quality and consumer protection.

The paper then reviews current efforts to promote affordability and quality in assisted living, explores future demand for assisted living, and presents conclusions with implications for relevant public policy.

A limitation of the available research is that the units of analysis vary, as each study defines assisted living somewhat differently and some studies include a broader range of residential housing settings. Currently, the National Center for Health Statistics is attempting to create a uniform classification system, or typology, for long-term care residences.³ This typology may improve the sampling methodologies of future studies and facilitate cross-state comparisons.

The Philosophy of Assisted Living

Most descriptions of assisted living include a *philosophy of assisted living*. Although state laws and assisted living providers vary in what they consider to be essential features of this philosophy, four tenets are usually included:⁴

(1) Meeting consumers' scheduled and unscheduled needs—Assisted living responds to residents' scheduled and unscheduled needs by providing awake staff 24-hours a day, assistance with personal and supportive services, some health services, meals, and housing. Assisted living provides social activities and unscheduled assistance not available through home care, which typically provides only a few scheduled hours of services a day. Assisted living usually does not provide the more intensive medical and nursing care provided in a nursing home.

(2) Maximizing consumers' independence, autonomy, and dignity—Through its policies, procedures, and culture, assisted living aims to support residents' right to live as independently as possible, to make choices about the services they receive and about their lifestyles, and to be treated with dignity.

(3) Minimizing the need to move when a resident's needs for services increases (sometimes called "aging in place")—Assisted living aims to minimize the need for a resident to move by providing services that respond to his or her changing needs.

(4) Providing a homelike environment—Assisted living fosters a homelike environment by providing private living areas (typically private rooms and baths or small apartments), allowing residents to bring their own furniture and decorations, and avoiding an institutional look.

Diverse stakeholders support such a philosophy. In 2003, the Assisted Living Workgroup, initiated by the U.S. Senate Special Committee on Aging and described in more detail later in this paper, recommended a set of "core principles" of assisted living that embodied the four tenets

described above.⁵ Workgroup participants represented assisted living consumers, providers, health care professionals, accrediting organizations, the disability community, and aging and long-term care organizations.

Increasing numbers of states are including a statement of an assisted living philosophy in their regulations. A 2002 study by Robert Mollica of the National Academy for State Health Policy surveyed state officials about their states' assisted living policies.⁶ In 2002, 28 states reported that they include a philosophy of assisted living in their regulations, up from 22 states in 1998 and 15 in 1996. Oregon was the first state to adopt a specific philosophy for assisted living. Their regulations state, "Assisted living promotes resident self-direction and participation in decisions that emphasize choice, dignity, privacy, individuality, independence and homelike surroundings."

Even when states include a statement of an assisted living philosophy in their laws and regulations, residences may vary considerably in the extent to which they put the philosophy into practice. While some states have detailed regulations to ensure that the philosophy is realized, others leave it up to the residences to develop environmental features and policies consistent with the philosophy.⁷

A later section of this paper reviews the extent to which assisted living residences and state regulations support an assisted living philosophy, focusing on the four tenets described above.

Definition

Definitions of assisted living vary from state to state and sometimes among providers within a state. As a result, consumers are

often confused about what to expect in places that are advertised as offering assisted living services. A 2003 study by O’Keeffe and colleagues for the U.S. Department of Health and Human Services examined assisted living in six states. In each state except Oregon, stakeholders said that public confusion about residential care options was a problem in their state,⁸ primarily because the term “assisted living” was used to market residences that differed widely in the type of housing and services offered. In contrast, in Oregon, the only state in the study that limited the use of the term “assisted living” to residential settings with private apartments, no respondents mentioned public confusion about the different types of residential services.

As of 2004, 36 states and the District of Columbia used a term such as assisted living residences, assisted living communities, or assisted living facilities in a licensing statute or regulation.⁹ Some of these states, like Oregon, define assisted living as a distinct model of residential services, while other states use “assisted living” as an umbrella term that covers quite different types of residential care settings.¹⁰ The remaining states have no legal definition of assisted living, although residences may use it as a marketing term. Instead, laws and regulations in these states use a variety of terms for these residences, including residential care homes, personal care homes, shelter care facilities, adult residential care homes, enriched housing programs, and homes for the aged, to name a few.

* In its 2003 report, the Assisted Living Workgroup used the term “assisted living residence” in preference to “facility,” to emphasize the housing and residential aspects of living, rather than the more institutional aspects (The Assisted Living Workgroup, April 2003.)

Most states that do use the term in their laws or regulations define assisted living as a building in which services are provided. A few states, however, license it as a service. For example, in Connecticut, “assisted living services agencies” may provide care in a “managed residential community” or in subsidized senior housing. In Minnesota, a licensed “assisted living home care provider” may provide care in one or more registered “housing with services establishments.” Connecticut, Minnesota, and New Jersey fund “assisted living services” in subsidized housing.

Because of the inconsistency in states’ definitions and standards and lack of a nationally used typology, the term assisted living is now often used as a generic term for any residential long-term services setting that is not licensed as a nursing home.¹¹ A more detailed, consistent definition might help consumers make more informed decisions when choosing an appropriate long-term supportive services setting. On the other hand, a too-narrow definition might limit the ability of providers to offer variety and choice and to include new and innovative services and features.

Although definitions vary, most states require that assisted living provide or arrange for personal and supportive services 24 hours a day, some health care, meals, activities, and housing, in a group residential setting.¹²

The intensity of services, the range of disabilities for which services are provided, the type of living arrangements, and many other aspects vary a great deal, often within as well as between states. Most assisted living residences provide private rooms or apartments, a communal dining area, and common areas for socialization and activities. Although most residences have

from 11 to 50 beds, two-thirds of residents live in larger residences (those with more than 50 beds).^{†13} The majority of assisted living residences (55 percent) are free-standing. The remainder share a campus with some other type of residential setting, such as a nursing home, rehabilitation center, board and care home, independent living apartments, or continuing care retirement community. About half are non-profit, and about half are for-profit; very few are government-run.¹⁴

A 1999 study by Hawes, Rose, and Phillips, conducted for the U.S. Department of Health and Human Services as part of an ongoing series of studies on assisted living, documented the wide range of privacy and services offered in residences known as assisted living.^{15‡} The study categorized residences according to the levels of privacy and services as follows:

- *High privacy* meant that at least 80 percent of residents' units were private.
- *Minimal privacy* meant having one or more rooms shared by three or more residents.
- *Low privacy* residences included all those in between high and minimal privacy.
- *High services* residences had a full-time RN on staff and provided the following: nursing care if needed, help with at least two activities of daily living, 24-hour

staff, housekeeping, and at least two meals a day.

- *Minimal services* was defined as not offering help with even two ADLs.
- *Low services* residences were those that offered more than minimal but less than high services.

As Hawes and colleagues noted, there is disagreement over what combination of privacy and services most embodies the concept of assisted living.¹⁶ In a follow-up study in 2000, Hawes and colleagues focused on the 41 percent of assisted living residences that provided high privacy, high services, or both (hereafter referred to as high service or high privacy residences).¹⁷ The researchers selected these residences "because they seemed to most effectively exhibit key elements of the philosophy of assisted living." This paper frequently refers to these residences, which most closely reflect the philosophy and definition of assisted living referred to in the text.

I. Residents and Services

The resident needs that can be met and the services provided in assisted living vary greatly from residence to residence. These differences reflect the differences in state regulations and the services a residence chooses to provide.

Resident Characteristics

In 2000, Hawes and colleagues found that the typical high service or high privacy assisted living resident was a widowed woman in her mid-eighties (see Table 2).¹⁸ This is consistent with the characteristics of assisted living residents reported in other studies.¹⁹ Assisted living has less racial diversity than adult foster homes, board and care homes, or nursing homes, with nearly all assisted living residents being White.²⁰

[†] Some studies measure residence size in terms of "beds," while others count resident "units," i.e., resident rooms or apartments. Although some units include more than one bed, the majority of assisted living units are single occupancy.

[‡] To be included in the study, a residence had to: 1) serve the elderly, 2) have 11 or more beds, and 3a) refer to itself or advertise itself as providing "assisted living," or 3b) offer, at a minimum, two meals, 24-hour staff, housekeeping, and assistance with two of the following: medications, bathing, or dressing.

This may be due to economic factors, discrimination, or cultural differences.

Table 2: Characteristics of High Service or High Privacy Assisted Living Residents

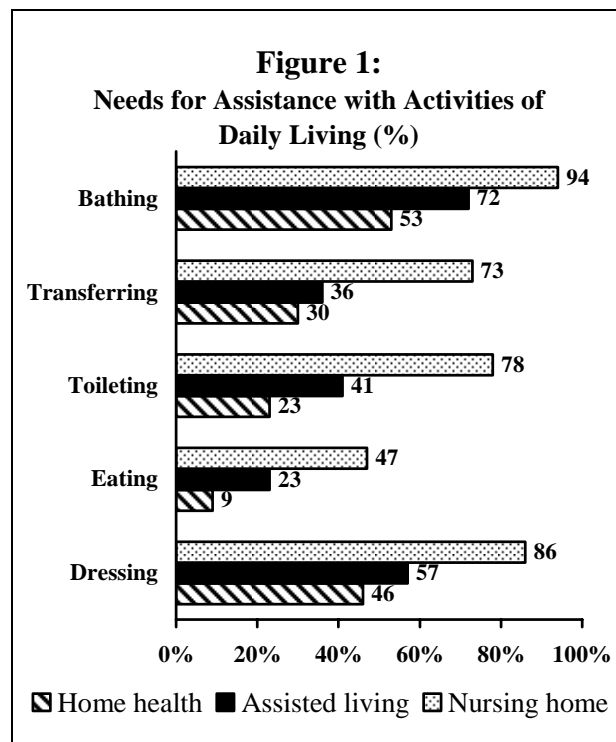
Average age	85
Women	79%
White	99%
Marital status	
Widowed	71%
Married	12%
Divorced/separated	7%
Never married	10%

Source: Hawes et al., 2000

Although assisted living residents have a wide range of needs, most need more assistance than persons receiving home health services and less assistance than nursing home residents (see Figure 1). Only eight percent of high service or high privacy assisted living residents say they receive supervision or assistance with three or more activities of daily living (ADLs), such as bathing or dressing.²¹ By comparison, two-thirds of nursing home residents receive assistance with three or more ADLs.²² Although 44 percent of assisted living residents have some cognitive impairment, only 24 percent have a diagnosis of Alzheimer's disease or other dementia,²³ compared to 42 percent of nursing home residents.²⁴ In high service or high privacy assisted living, 77 percent of residents receive help with taking medications.²⁵

Services for Residents with Alzheimer's Disease and Other Cognitive Impairment

The ability of assisted living residences to meet the needs of persons with Alzheimer's or other cognitive impairment is particularly important, given that almost half of the residents have these conditions and many residences advertise providing services to those with such conditions.



Source: National Center for Assisted Living (2001). The figure compares data from NCAL's Survey of Assisted Living Facilities, 2000; HCFA's 2000 OSCAR report; and the 1996 National Home and Hospice Care Survey. Prepared by AARP Public Policy Institute, 2001 for Donald L. Redfoot and Sheel M. Pandya, *Before the Boom: Trends in Long-Term Supportive Services for Older Americans with Disabilities*, (Washington, DC: AARP Public Policy Institute, October 2002).

Sixty-two percent of high service or high privacy assisted living residences say they provide or arrange for specialized dementia care.²⁶ Entire residences or units dedicated to serving residents with Alzheimer's or other dementia are less common, comprising five percent of high service or high privacy assisted living residences. Sixteen percent have a special care unit for residents with these conditions. Hence, the majority of assisted living residents with dementia do not live in a special care unit.

Despite the large number of assisted living residents with dementia, no consistent standards exist to ensure that the residences that serve them provide the services, trained

staff, and environment to meet their needs. In 2002, 36 states reported having specific requirements for residences that serve residents with Alzheimer's disease or other dementias, up from 28 states in 2000.²⁷ Requirements in these states address one or more of the following areas: training, staffing, activities, environment, and disclosure. Only five states (Maryland, Missouri, North Carolina, Texas, and West Virginia) had requirements addressing all five areas.

A 2003 study by Sheryl Zimmerman of the University of North Carolina at Chapel Hill, conducted for the Alzheimer's Association, examined services for residents with dementia in assisted living and nursing homes.²⁸ The results suggested that many residents in both settings would benefit from more services than they were receiving:

- 54 percent of residents with dementia were observed to have low food intake;
- 51 percent were observed to have low fluid intake;
- 40 percent of residents with recognized pain received no pain medication, and nearly a third were not receiving ongoing professional care;
- only 28 percent of residents with depression were receiving professional treatment—The researchers noted that depression was associated with behavioral problems, suggesting that recognizing and treating depression might help to alleviate these problems.

These findings may be useful to states in establishing quality standards for assisted living residences that serve residents with dementia.

II. The Degree to Which Assisted Living Residences Carry Out the Assisted Living Philosophy

The assisted living philosophy describes assisted living as a new model of residential long-term services that differs from traditional models by being more responsive to consumers' preferences. Older models (such as board and care homes, rest homes, and domiciliary care homes) provide room and board and limited supportive services and protective oversight. In contrast, residences that embody the assisted living philosophy provide a higher level of services and aim to maximize residents' independence, autonomy, dignity, and privacy. Some residences fall in between these two ends of the continuum; for example, a residence may provide higher levels of service but may not have adopted the assisted living philosophy.

Even among the high service or high privacy residences, the degree to which assisted living residences carry out the assisted living philosophy is inconsistent. State licensing requirements may support or hinder the fulfillment of the assisted living philosophy.

Meeting Residents' Scheduled and Unscheduled Needs

The degree to which an assisted living residence meets a resident's scheduled and unscheduled needs varies a great deal, depending on the needs of the resident, the services the residence chooses to provide, and the services required or prohibited by the state.

Among the high service or high privacy residences in the 2000 Hawes study, nearly all provided or arranged for services to meet the scheduled needs of residents, such as assistance with bathing, transportation for

outings, nursing supervision and monitoring, and medication reminders, as well as planned recreational activities.²⁹ (See Table 3).

More variation existed with respect to meeting residents' unscheduled needs. Between 50 and 80 percent of high service or high privacy assisted living residences provided assistance with toilet use, locomotion, basic incontinence care, assistance with transferring, and temporary nursing care. An additional 23 percent of residences reported being willing to arrange for temporary nursing care with an outside provider.

The 2000 Hawes study suggests that resident satisfaction is mixed concerning meals, transportation, and activities.³⁰ Just over half the residents surveyed (54 percent) said they always had a choice among entrees, and 20 percent said that they never had such a choice. Two-thirds (66 percent) said the food was usually or always tasty and well-seasoned. About half (51 percent) said that the residence usually or always offered activities that they enjoy, and just under half (46 percent) said the residence usually or always provided transportation for things they enjoy. Only 41 percent said that staff usually or always asked about their activity preferences.

Most states specify some basic services that assisted living residences must provide, such as assistance with personal supportive services, transportation, laundry, recreational activities, arranging health related services, housekeeping, medications management, monitoring, and three meals a day.³¹ Residences may choose to offer additional services beyond the minimum services required by the state.³²

Table 3: Percent of High Service or High Privacy Assisted Living Residences that Provide or Arrange for Various Services

Service	% Residences	
	Provided	Arranged
3 meals a day	99%	1%
Planned activities	99%	1%
Assistance w/ bathing	98%	2%
Transportation for outings	85%	11%
Nursing supervision/ monitoring	84%	8%
Medication reminders	86%	1%
Assistance w/ toilet use	80%	2%
Assistance w/ locomotion	82%	2%
Incontinence care	79%	2%
Assistance w/ transferring	65%	1%
Temporary nursing	54%	23%
Assistance w/ eating	51%	3%

Source: Hawes et al., 2000.

Many states also prohibit assisted living from providing certain services. For example, many states do not allow 24-hour skilled nursing services to be provided in assisted living. In these states, residences are required to discharge residents who develop a need for services beyond those the residence is allowed to provide.

A few states stand out as allowing the broadest range of services to be provided in assisted living.³³ New Jersey allows skilled nursing services in assisted living that are prohibited in many states (e.g., advanced stage pressure sores, ostomy care, and 24-

hour nursing supervision). Oregon has no specified discharge criteria based on service needs. In these states, individuals can receive a high level of services in assisted living, just as they could in their own homes.

Maximizing Residents' Independence, Autonomy, and Choice

A critical tenet of the philosophy of assisted living is support for residents' independence, autonomy, and choice. AARP's *Beyond 50: 2003* report highlighted the importance of this component of the assisted living philosophy. In a national survey conducted for the report, loss of independence was the most common worry or concern that persons 50 and older with disabilities reported having about the future.³⁴ Twenty-eight percent of respondents mentioned loss of independence as one of their biggest worries or concerns, with little difference by age group or level of disability.

What does it mean to be "independent"? As Judith E. Heumann (co-founder, World Institute on Disability) put it, "Independent living is not doing things by yourself; it is being in control of how things are done."³⁵ The Merriam-Webster dictionary defines independence as "not subject to control by others."³⁶

In assisted living, residents' independence and choice can be supported through the residences' policies and procedures, such as resident involvement in their service plans. Recent studies by Hawes and colleagues and the National Center for Assisted Living suggest that assisted living residences are mixed in the extent to which their policies support residents' independence and choice (see Table 4).³⁷ Areas where residences were most likely to support resident choice included residents' right to have personal

furniture (99 percent) and to furnish their own rooms or apartments (90 percent).³⁸ Rules were more likely to be restrictive regarding whether residents could drink alcohol, smoke, have a pet, or have overnight guests.³⁹

Table 4: Assisted Living Residences with Policies Supporting Consumer Autonomy and Choice

Residence policy	% Residences
Bring own furniture*	99%
Furnish own room*	90%
Tobacco allowed**	65%
Alcohol allowed**	52%
Small pet allowed**	49%
Residence pet provided**	40%
Overnight guests allowed**	54%
Shared responsibility agreements available*	29%

* Source: Hawes et al., 2000. Percentages apply to high service or high privacy residences.

** Source: NCAL, 2001

When used appropriately, *shared responsibility agreements* (sometimes termed *negotiated risk*, *managed risk*, or *shared risk*) are another way to support residents' preferences and choices. As described in a proposed Assisted Living Workgroup (ALW) recommendation,[§] shared responsibility agreements are "a tool for communication."⁴⁰ Shared responsibility agreements document the discussions and agreements between the resident and provider regarding the residents' preferences and how they will be accommodated in the community. They may be used when the resident wishes to take a course of action that has a high risk of adverse outcomes.

[§] The Workgroup did not reach two-thirds majority agreement on the shared risk agreement recommendation. Fifteen organizations signed a supplemental position supporting the recommendation, and twelve signed a supplemental position opposing it.

The proposed ALW recommendation included the following process for a shared responsibility agreement:

- identify the cause for concern,
- identify the probable consequences of the resident's choice,
- make clear what the resident wants,
- describe possible alternatives,
- set forth the final agreement,
- decide what staff will be notified of the agreement and how often follow-up is necessary, and
- sign the agreement.

Although shared responsibility agreements may be used as part of a residence's risk management program, the proposed ALW recommendation opposed their use as waivers of liability. Liability determinations depend on many factors, and the presence of a shared responsibility agreement may or may not affect a court's decision.⁴¹ Regardless of a shared responsibility agreement, the residence still must act with reasonable care, caution, and judgment. Shared responsibility agreements are *not* appropriate for resident preferences that would violate a state law or licensure regulation or community standard of services, which a court would use to evaluate whether a provider was negligent in providing services.

Examples of resident choices for which shared responsibility agreements have been used successfully include:⁴²

- smoking by residents;
- deviations from a recommended diet, where medical conditions such as diabetes are involved; and
- walking and freedom of movement by residents prone to wandering, falls, or getting lost easily.

Shared responsibility agreements are relatively uncommon in assisted living, with

only about 29 percent of high service or high privacy residences having such agreements.⁴³ As of 2002, nineteen states included a shared responsibility process in their state laws or regulations for assisted living.⁴⁴ These states differed in their requirements regarding shared responsibility agreements.

State laws and regulations governing assisted living residents' rights also affect residents' independence and autonomy. Examples of such rights include the right to have visitors, the right to control one's own personal finances, the right to choose a health care provider outside the residence, and the right to file a complaint or grievance.

States vary considerably in the rights guaranteed to assisted living consumers, how residents are informed of their rights, and how these rights are enforced. In a General Accountability Office (GAO, formerly the General Accounting Office) study of assisted living in four states, 73 percent of residences said they provide prospective residents with a written statement of residents' rights and responsibilities.⁴⁵ Two-thirds (65 percent) of residences said they provide a written description of complaint or grievance procedures. In cases where residences did not provide this information, the report did not specify whether this was a matter of residences' not providing information required by state regulations or of state regulations not requiring the information.

Minimizing the Need to Move

Minimizing the need to move is another critical component of the assisted living philosophy. A 2001 AARP survey of New Yorkers age 50 and older found that staying in the same assisted living residence and

getting all the care needed instead of moving to a nursing home was important to 91 percent of respondents.⁴⁶ Eight in ten (80 percent) said that it was very important. Similarly, in a 2002 survey of 803 AARP members from Connecticut, 88 percent said that staying in the same residence and getting all the care needed instead of moving to a nursing home was “important” or “very important.”⁴⁷

Supporting residents’ preference to age in place can be a problematic goal. A resident’s ability to stay in assisted living depends on how much the resident is willing and able to pay for additional services, what services the assisted living residence is willing and able to provide, and state requirements for discharging residents.

Ensuring that residents are informed about limitations on their ability to age in place is also a challenge. The 2000 Hawes study on high service or high privacy assisted living residences found that consumers often incorrectly believed that they would be able to remain in assisted living for the rest of their lives, regardless of circumstances. Nearly all assisted living residents (98 percent) and 89 percent of family members believed that the resident would be able to stay in the assisted living residence for as long as they wished.⁴⁸ In reality, however, the researchers concluded, “Residents could be assured of aging in place if they remained relatively healthy and affluent.” Residences tended to require residents to leave when they “reached a point where they needed assistance in transferring from a bed to a chair, developed judgment problems or severe memory loss, or began to exhibit troublesome behavioral symptoms.”

Many residents are able to remain in assisted living for the rest of their lives. However,

approximately the same proportion of residents eventually move to a nursing home for more services. A 2000 study of residents leaving assisted living found that, among residents who left, 34 percent died in the assisted living residence or shortly after discharge, and another 34 percent moved to a nursing home or rehabilitation center. (Of the remaining residents, 15 percent moved to another assisted living residence or other residential supportive services setting, five percent moved to some other setting, and 12 percent were discharged with their status unknown.) Among those who moved to another setting, the need for more services was the most commonly cited reason for leaving (see Table 5).⁴⁹

Table 5: Reasons for Leaving Assisted Living (among residents who left for another setting)

Needed more care	78%
Location closer to loved ones	14%
Dissatisfied with care	12%
Dissatisfied with price	11%
Other dissatisfaction	11%
Ran out of money	9%
Other/unknown reason	9%

Source: Phillips et al., *Residents Leaving Assisted Living*, 2000. Results total more than 100 percent because respondents could give more than one answer.

The ability to age in place depends on a residence’s discharge policies, which are set by the provider within the limits established by state regulations. As shown in Table 6, nearly all high service or high privacy assisted living residences will a resident who have urinary incontinence that he or she can manage without assistance.⁵⁰ On the other hand, almost no residences will retain an individual who is physically aggressive or bedfast.

Table 6: High Service or High Privacy Assisted Living Residences That Would Retain a Resident, By Condition

Condition	% Residences
Has urinary incontinence the resident can manage without assistance	93%
Uses a wheelchair	80%
Is incontinent and can't manage supplies	60%
Needs transfer assistance	52%
Is physically aggressive	3%
Is bedfast	3%

Source: Hawes et al., 2000.

Most states require assisted living residences to discharge residents who acquire certain medical needs or conditions. Examples of discharge triggers in these states include having certain acute or chronic conditions, needing continuous nursing care, having communicable diseases, being a danger to oneself or others, and needing restraints. States using discharge triggers include: California, Delaware, Florida, Idaho, Illinois, Maryland, Mississippi, Nevada, New Mexico, South Carolina, Tennessee, Virginia, Washington, and West Virginia.⁵¹

Some of these states have a waiver approach that may allow some residents to age in place after they develop conditions that would normally trigger discharge. For example, Maryland regulations allow an assisted living residence (called an assisted living program in Maryland) to apply for a Resident-Specific Level of Care Waiver. If approved, the waiver enables the residence to continue to serve a specific resident who has developed a need for services beyond those the residence is licensed to provide.⁵² To obtain a waiver, the residence must demonstrate that it is able to meet the needs

of that resident and that the needs of other residents will not be jeopardized. A residence can receive waivers only for a limited number of residents (between 20 and 50 percent of bed capacity, depending on the licensure level of the residence).

In 2001, three states (Michigan, Mississippi, and Texas) passed legislation that allows a resident to remain in assisted living as long as the resident, the resident's physician, and the provider all agree in writing that the resident's needs can be safely met.⁵³

Other states have also enacted legislation that strongly supports aging in place. Oregon and Hawaii are among the states with the broadest policies.⁵⁴ These states allow residents to remain in assisted living despite functional decline as long as the residence is willing and able to meet their needs. Residences may decide what services to provide beyond the basic services mandated by the state.

Some states (Arizona, Arkansas, Idaho, Maine, Maryland, Mississippi, Missouri, and Vermont) have two or more levels of licensure for assisted living.⁵⁵ For example, in Maryland, residents are assigned to one of three levels based on an assessment of their conditions and service needs. In these states, residents who develop significant medical needs can generally remain in their assisted living residence only if the residence is licensed at the highest level of services. In states with a level of services approach, requirements for staffing patterns, staff training, and building features may vary by level of licensure.

Homelike Environment

A fourth tenet of the assisted living philosophy is providing a homelike environment. From the perspective of

consumers, having a private room, just as they would in their own homes, is among the most important features of assisted living. In a 1998 AARP survey of Oregon assisted living residents, 94 percent rated “private room and bath” as “very important.”⁵⁶ Residents rated “private room and bath” higher than any of the other 11 features rated, including “a safe place to live,” “access to medical care,” and “good food.”

The increase in the number of semi-private rooms being occupied by only one person suggests that demand for private rooms may be increasing. In a 2000 Assisted Living Federation of America survey, residences reported an average of 33 percent of semi-private rooms being occupied as private rooms in 1999, up from 20 percent in 1998 and 17 percent in 1997.⁵⁷

Assisted living may provide a homelike environment by avoiding the hospital-like design elements traditionally found in nursing homes, such as nursing stations, and by providing private rooms. Assisted living is distinguished from other long-term services settings in that most residents live in private rooms. In Hawes and colleagues’ 2000 study, 81 percent of high service or high privacy assisted living residents had a private room.⁵⁸ Private bathrooms were less common, with 35 percent of residents sharing all or part of a bathroom.

Although most residents prefer private accommodations, many residents with modest incomes share a room because they cannot afford the higher cost of a private room. Most states do not require private rooms for Medicaid reimbursement for services, and Medicaid does not cover the cost of housing.⁵⁹

Private rooms are more often a result of market demand than state regulations.⁶⁰ As of 2002, only 19 states had at least one residential long-term services licensing category for which the state required private rooms (shared only at the request of residents).⁶¹ States were more likely to require private rooms in residences licensed as “assisted living” than in residences licensed under other terms, such as congregate housing, residential care, or personal care homes.

III. Costs and Affordability

Because of their high cost and lack of public subsidies, assisted living residences are often unaffordable for persons with low or moderate incomes.

Costs

The average cost of assisted living exceeds the incomes of many older persons. Hawes and colleagues’ 1999 study found that the average monthly rate was \$2,000 for high service or high privacy residences.⁶² More recently, an April 2004 review by Health Policy Tracking Services found that estimates of the average cost of assisted living ranged from approximately \$2,100 to \$2,900 a month.⁶³

The cost of assisted living varies considerably, depending on the location of the residence, the type of accommodations (e.g., private or shared room), and the services the resident needs or wants.

Sources of Payment

Unlike nursing homes, assisted living is never covered by Medicare, Medigap, or other Medicare supplemental insurance. Although private long-term care insurance may cover assisted living, less than 10

percent of persons age 65 and over and an even lower percentage of persons age 55 to 64 have purchased a policy, according to a 2002 GAO study.⁶⁴ As discussed below, public subsidies for assisted living are limited.

As a result, assisted living residents usually pay privately. As of 1998, three out of four residents were using their own income or assets to pay for assisted living, with sixteen percent receiving assistance from family members.⁶⁵

Public Subsidies to Individuals

Limited public subsidies for low-income assisted living residents are available through the federal SSI program, state supplements to SSI, the federally and state-financed Medicaid program, and, in some states, food stamps.⁶⁶ Many states provide supplements to SSI to cover room and board and sometimes personal care. However, these supplemental payments are often insufficient to cover the cost of assisted living.

Mollica's 2002 study reported that 41 states had approval to cover services in assisted living and other residential care through Medicaid.⁶⁷ Approximately 102,000 residents were receiving Medicaid coverage of assisted living services in 2002, out of approximately 910,000 assisted living residents. This compares with just under 60,000 residents receiving Medicaid coverage of assisted living services in 2000.⁶⁸

States reported great variation in the number of participants served through Medicaid.⁶⁹ States with low Medicaid participation included Mississippi (15 participants), Pennsylvania (41), Rhode Island (30), and Wyoming (40).⁷⁰ States with high

participation included North Carolina (28,098 participants), Florida (9,990), Missouri (7,300), and Washington (5,180).

Although Medicaid coverage increased significantly from 2000 to 2002, it remains limited for several reasons:

- Medicaid reimburses only for *services* in assisted living; the beneficiary must still pay for room and board. SSI payments are insufficient to cover room and board in most assisted living residences.
- Assisted living residences are not required to participate in a state's Medicaid program, and the percentage of residences participating varies significantly by state. In Hawes and colleagues' 2000 study, only about one in nine high service or high privacy assisted living administrators (11 percent) said that they would accept Medicaid if it were available.⁷¹
- In most states, Medicaid coverage of assisted living is provided through a waiver, which requires that applicants need a nursing home level of care to qualify for benefits. Many individuals who need assisted living services cannot receive assistance through Medicaid because they do not meet this medical eligibility requirement.
- States can limit the number of persons served in the community through Medicaid waivers, whereas Medicaid coverage of nursing homes is an entitlement—all qualified applicants must be served.
- Medicaid has strict financial criteria. Applicants must have low incomes and very limited assets to be eligible for benefits. Many individuals have incomes too high to qualify for Medicaid, yet too low to afford to pay privately for assisted living.

Recent state budget crises have put pressure on states to control Medicaid spending, according to a September 2003 report by the Kaiser Commission on Medicaid and the Uninsured.⁷² However, the report noted that, of the Medicaid cost containment actions implemented in fiscal year 2003 and planned for fiscal year 2004, only a small share were aimed at controlling spending for long-term services and supports. During this time, 24 states expanded the number of home- and community-based waivers or expanded the number of waiver “slots,” that is, the number of persons who can be served in these programs. At the same time, 16 other states restricted the number of slots, decreased benefits covered under the waiver, instituted waiting lists, or used other means to control costs in these programs. On the other hand, officials from several states said that their states would continue efforts to expand Medicaid coverage of home- and community-based services as a consumer-preferred, lower-cost alternative to nursing home care.

The high cost and lack of public funds have serious implications for older persons. Assisted living residents often have to sell their assets, spend their savings, or get help from family members to pay for their stay. Many moderate or low-income older persons who cannot afford assisted living either live at home without needed services or to go to a residential supportive services setting that provides a lower level of services and privacy. Residents who pay privately and then run out of money may have to move to a nursing home, where Medicaid is an entitlement, if they cannot obtain Medicaid coverage for assisted living.

IV. Assuring Quality and Consumer Protection

Because the federal government does not license or monitor assisted living, quality standards and methods of assuring quality vary from state to state.^{**} This variation has implications for the quality of services and the adequacy of information disclosed to residents.

Methods for Assuring Quality and Consumer Protection

A variety of methods are available for assuring quality and consumer protections in assisted living. These include: state monitoring and enforcement systems, consultations with providers, disclosure of quality information to consumers, the Long Term Care Ombudsman Program, and private right of action laws. Many states use a combination of these methods.

States enforce quality standards through periodic inspections and by investigating complaints. In most states, regulators respond to violations with penalties or plans of correction. Penalties usually vary, depending on the severity of the violation and may include fines, denial of Medicaid reimbursement, a ban on new admissions until violations are corrected, suspension or revocation of the residence's license, or imprisonment. Plans of correction are written descriptions of how and when the residence will correct the violation(s); they may be written by the residence or imposed by the state.

The 2002 Mollica study asked state licensing officials what worked to make their monitoring and enforcement systems

^{**} Nursing homes, in contrast, are subject to federal laws and regulations.

effective.⁷³ The most frequently mentioned strategies included:

- making follow-up visits when survey findings or complaints indicated areas of concern;
- having a range of remedies available;
- making unannounced visits; and
- progressive enforcement based on the facility's history and response.

In some states, the Long-Term Care Ombudsmen Program, authorized by the Older Americans Act, is another resource for promoting quality in assisted living. The ombudsmen advocate for residents and investigate and resolve complaints.⁷⁴ The program provides ombudsmen for residents of nursing homes and other long-term supportive services residences in every state. However, both state licensing agencies and ombudsmen offices sometimes lack the staff and resources necessary to ensure that complaints are resolved and violations of state standards are corrected.

To strengthen residents' complaint procedures, Georgia has established a range of remedies specifically for assisted living residents.⁷⁵ Massachusetts has created a separate ombudsman program dedicated to assisted living residents.

Private right of action laws provide an additional mechanism for enforcing quality standards in assisted living in some states. A private right of action exists when a statute authorizes a person aggrieved by particular actions or inactions listed in the statute to bring a lawsuit. In addition to compensating for injuries, a private right of action can supplement traditional government regulatory enforcement with private oversight and enforcement. With a private right of action, long-term supportive services consumers can sue a provider or the government for breach of statutory or

regulatory rights, duties, or responsibilities. Such breaches are one of several claims that may be used in a lawsuit filed against an assisted living residence. As of 2000, 16 states and the District of Columbia had enacted a private right of action for assisted living residents.⁷⁶

States have undertaken a variety of additional quality improvement strategies to supplement their monitoring and enforcement systems:⁷⁷

- *Consultation with providers.* In 2000, Washington established a staff of quality consultants to assist providers with complying with state regulations on a voluntary basis.⁷⁸ Evaluations of the program documented improvements in provider compliance as well as in resident health and safety. However, the state stopped funding the program due to budget cuts.
- *Reviewing and revising quality standards.* As mentioned elsewhere in this paper, several states have revised their assisted living regulations in recent years. Other states have formed committees or held meetings to review quality standards and consider revisions. Examples of reviewing or revising quality standards include: meeting with providers to develop minimal standards for assessment, adding dementia disclosure requirements, proposing legislation to increase required training for medication aides, and forming a committee to review level of care criteria.⁷⁹
- *Providing information to consumers:* One example of a state's efforts to provide information to consumers is the Colorado licensing agency's web site (www.cdphe.state.co.us/hf/static/pcbhrf).

htm), which makes available the results of survey findings and complaints for each assisted living residence in the state. Florida created a website that allows consumers to search for a residence by location, price, and available services (www.floridaaffordableassistedliving.org/).⁸⁰ Texas developed a standardized disclosure statement that enables consumers to better compare residences.

Quality Problems

Two major studies and recent news reports have documented the most frequently occurring quality problems in assisted living residences. A 1999 GAO study found that more than one-fourth of the residences reviewed in four states were cited by state licensing, ombudsmen, or other agencies for five or more quality- or consumer protection-related violations during 1996 and 1997.⁸¹ The study identified four frequently observed problems:

- providing inadequate or insufficient services to residents;
- having insufficient, unqualified, and untrained staff;
- making medication errors; and
- not following admission and discharge policies required by state regulation.

More recently, Mollica's 2002 survey of state licensing officials identified similar concerns.⁸² The areas ranked as having the most frequent deficiencies and complaints were:

- medications (48 percent of responding states said that problems with medications occurred frequently or very often);
- staff quality and qualifications (41 percent);
- insufficient staff (36 percent);
- records (32 percent);

- care plans (24 percent);
- inadequate care (21 percent); and
- admission/discharge (15 percent).

In May 2004, investigative reports by *USA Today* and the *Washington Post* revealed similar quality problems, including, for example failing to meet staff training requirements, having too few employees, neglecting to obtain criminal background checks on employees, making medication errors, and admitting or retaining residences who needed more care than the residence was equipped to provide.⁸³ The reports also pointed out that many residences provide excellent quality care.

Staffing

Staffing problems are a major factor affecting quality in assisted living, as well as other long-term services settings. In the 1999 GAO study, state officials attributed many of the observed problems in assisted living to problems with staffing, including insufficient numbers of staff, inadequate staff training, high staff turnover, and low pay rates. More recently, in the 2003 O'Keeffe study on assisted living in six states, almost every person interviewed expressed concerns about the quality and quantity of staffing in assisted living and other residential care settings.

Few studies have focused on staffing issues in assisted living. A 2001 study by Robyn Stone and Joshua Wiener reviewed the research on staffing in nursing homes and home care.⁸⁴ This research suggests that, although wages and benefits are important, worker autonomy, responsibility, and relationships with supervisors are the most significant predictors of lower turnover rates. Staff retention is also affected by how society values the job, economic conditions, and public policies—including policies

related to long-term services, regulation, labor, welfare, and immigration.

The 2000 Hawes study suggests that high service or high privacy assisted living residents are frequently dissatisfied with staffing levels, training, and retention.⁸⁵ Just over half (52 percent) reported that staff always took the time to stop and listen to them, and the same proportion (52 percent) said that staff training and supervision were very good. Only 42 percent of residents responded that adequate numbers of staff were always available, and just 28 percent reported that the residence was very successful in retaining good staff.

On the other hand, most residents said they were pleased with their interactions with staff.⁸⁶ Four in five residents (79 percent) said that staff always treated them with dignity and respect, and the majority (61 percent) said that staff were always “affectionate and caring” in their interactions with them.

Training for assisted living staff is typically quite limited.⁸⁷ Hawes and colleagues found that three-quarters of personnel working with residents (excluding licensed nurses) were required to attend pre-service training or orientation. For those who received required training, the most common amount of training was only 1 to 16 hours. Just 11 percent completed such training before the start of work.^{††} The study also found that most staff were not knowledgeable about what constituted normal aging.

^{††} In contrast, federal law requires aides in nursing homes to complete a minimum of 75 hours of training and to pass an exam before they can provide direct services to residents. Many states require additional training beyond the 75 hours required by federal law.

States are mixed in their requirements for staff and administrator training. Mollica’s 2002 study reviewed states’ (including Washington, D.C.) regulations for initial training of direct care staff in assisted living:⁸⁸

- 7 states required completion of a state-approved training course;
- 10 states specified both the topics that must be included in training and a minimum number of training hours—the minimum hours required ranged from 1 to 40;
- 29 states specified topics only;
- 2 states had general requirements (e.g., staff must “be qualified by training”); and
- 3 states had no training requirements.

In addition, 23 states included requirements for ongoing training of staff.⁸⁹ Thirty-three states required training on services for residents with dementia.⁹⁰

A growing number of states are requiring criminal background checks of prospective assisted living direct service staff and administrators.⁹¹ Health Policy Tracking Services reported that, in 2002, nine states enacted new screening requirements or expanded existing ones. Currently, 40 states require statewide criminal background checks, and 26 of these states bar employment if certain offenses are found. Eight of these states require national background checks, and another nine require a national check under specific circumstances, such as when an applicant has recently moved to the state.

State initiatives to recruit and retain more direct service workers include:

- wage and benefit “pass through” legislation, which increases Medicaid reimbursement earmarked for wages and benefits;

- minimum staffing regulations; and
- job training and welfare resources.

Disclosure

Inaccurate or incomplete contracts (sometimes called “resident agreements”) are another frequently identified problem in assisted living. To make informed choices about assisted living, consumers need accurate information about such factors as the costs, the services provided, residents’ rights and responsibilities, and the conditions that would trigger discharge. However, GAO’s 1999 study concluded that residences “are not routinely providing prospective residents with information sufficient for them to select the setting most appropriate for their needs.”⁹² The study identified four key problems:

- Marketing material, contracts, and other written material provided by residences were often incomplete and were sometimes vague or misleading.
- Only about half of the residences reported that they provided prospective residents with such key written information as the amount of assistance residents can expect to receive with medications, the circumstances under which the cost of services might change, or when residents might be required to leave if their health needs increase.
- Only about one-third provided a description of the qualifications of staff or information on the services that are not available.
- Only 25 percent of the residences routinely provided contracts, an important source of information about a residence, to prospective residents before they decided to apply for admission.

More recently, Mollica’s 2002 study suggested that many states lacked laws and

regulations that would require assisted living contracts to provide consumers with key information needed to make informed decisions. Most states require that contracts include a statement of the services provided in the basic service package (46 states) and the cost of basic services (41 states).⁹³ However, depending on the provision, approximately half or fewer of the states require that contracts include information on the services that are available for additional charges, the cost of additional services, the process for changing rates, the refund policy, or admission and discharge criteria (see Table 7). Residences may choose to provide such information, however, even if the state does not require it.

Table 7: State Requirements for Assisted Living Contracts

Information required in contract	Number of states
Services provided in the basic service package	46
Cost of basic services	41
Refund policy	27
Services available for additional charges	26
Cost of additional services	26
Process for changing rates	24
Admission and discharge criteria	22

Source: Mollica, 2002.

V. Recent Efforts to Promote Quality and Affordability

The federal government and the states, consumers and advocates, assisted living providers, and others have initiated a variety of efforts to promote quality and affordability in assisted living. Although this Issue Brief cannot discuss all these efforts, a few noteworthy initiatives are described.

The Assisted Living Workgroup

In 2001, the U.S. Senate Special Committee on Aging held a hearing on assisted living. After the hearing, staff from the Committee met with a diverse group of assisted living stakeholders to ask them to work together on developing recommendations for ensuring quality in assisted living. As a result of this meeting, nearly fifty national organizations formed the Assisted Living Workgroup (ALW). The organizations represented direct services staff, providers, consumer advocates, regulators, state and local government, health care professionals, the disability community, and accrediting organizations.

The ALW began to meet and develop recommendations in fall, 2001. A final report of the ALW's recommendations, *Assuring Quality in Assisted Living: Guidelines for Federal and State Policy, State Regulation, and Operations*,⁹⁴ was presented to the Committee at a hearing on April 29, 2003.

As a next step, the ALW recommended that states hold public meetings attended by diverse stakeholders, to consider the recommendations of the ALW, as well as other issues related to assisted living in their state. To continue and expand the work of the ALW, eleven organizations that participated in the ALW have formed an organizing committee to develop a "Center for Excellence in Assisted Living" (CEAL). The CEAL will be composed of diverse stakeholders and will foster high quality, affordable assisted living by disseminating research and information and providing technical assistance. The CEAL will focus primarily on developing resources for states, and secondarily for providers and consumers.

Programs to Help Assisted Living Become More Affordable

Medicaid reimbursement for services is the primary means of subsidizing the cost of assisted living. However, several other programs have been established that subsidize the construction of affordable assisted living residences. Providers often use a combination of these funding sources.

The federal Department of Housing and Urban Development (HUD) has two programs that subsidize developers, allowing them to provide assisted living at a lower cost to consumers. For the newer program, the Assisted Living Conversion Program, HUD allocated \$50 million per year for fiscal years 2000 to 2002 to provide grants to help owners of non-profit low-income senior housing apartments, most of which have religious affiliations, to convert dwelling units into assisted living apartments.⁹⁵ The HUD program does not specify the level of services required beyond room, board, and continuous protective oversight. Instead, it specifies that Assisted Living Conversion Program residences must be state or locally licensed and regulated as assisted living. One-bedroom units must include a kitchen, bathroom, and living/dining area. Efficiency units with a bedroom, living, and dining area are also eligible. Owners must assist residents with the costs of services, either directly or through a third party, such as Medicaid, SSI payments, or the State or Area Agency on Aging.⁹⁶

Another HUD program, Section 232 of the Federal Housing Administration's mortgage insurance program, was extended by the 1992 Housing Act to include assisted living residences.⁹⁷ (Section 232 already covered nursing homes and board and care homes.) Section 232 offers federal mortgage

insurance, allowing developers to obtain favorable loan terms. The program can lower mortgage costs, but the lowering of these costs is not sufficient to make assisted living affordable to people with low incomes without additional subsidies.

Another option for making assisted living services available to persons with low incomes is to provide these services to subsidized housing residents.⁹⁸ New Jersey provides a good example. Since the late 1970s, the state has provided services in subsidized housing through its state-funded Congregate Housing Services Program (CHSP), a program that funded services at 65 sites as of January 2002. CHSP programs primarily fund service coordination and meals, rather than a full range of assisted living services. In 1994, the state received a grant from the federal Administration on Aging for a demonstration program to expand services in subsidized housing. As a result of the demonstration program, the state created a new licensing category, Assisted Living Programs, which allows HUD-subsidized housing for older persons to provide assisted living services without expensive retrofitting to meet the building standards required of newly built assisted living residences. The state also dedicated Medicaid waivers to fund services. As of January 2002, the program included 15 providers at 24 sites serving about 75 older persons with low incomes.

Another effort to promote affordable assisted living is the Coming Home Program, sponsored by National Cooperative Bank (NCB) Development Corporation in partnership with The Robert Wood Johnson Foundation. In February 2001, The Coming Home Program awarded 3-year grants of up to \$300,000 to nine states to foster affordable assisted living for

low-income older persons.⁹⁹ (The nine states are Alaska, Arkansas, Iowa, Florida, Maine, Massachusetts, Washington, Wisconsin, and Vermont. NCBDC also has a separate program in Illinois.) The program provides states with technical assistance on state policy issues, a revolving loan fund, and assistance to local sponsors who wish to develop affordable assisted living. The Coming Home program focuses on rural areas, where fewer assisted living residences are available.

A new federally sponsored nursing home relocation program assists nursing home residents who wish to move and whose needs could be met in assisted living or at home. In 2001 and 2002, the Centers for Medicare and Medicaid Services provided grants to 23 states for nursing home relocation programs.¹⁰⁰ Program staff visit nursing home residents to see if their condition has improved or if new resources are available that might enable them to move, help residents select an appropriate setting, and help them make the transition. The program pays for the reasonable costs of transition to the community, including security deposits, essential furnishings and moving expenses, and deposits for utility access.

VI. Future Demand for Assisted Living

Assisted living is now growing less rapidly than during the 1990s, as markets have become more competitive in some areas of the country.¹⁰¹ Increased competition may lead to positive outcomes for consumers. Residences that face more competition are likely to have lower rates and to offer more private rooms than residences that face less competition.¹⁰²

The extent of future demand for assisted living is uncertain. Several factors will

affect the extent of growth, including population growth among Americans age 75 and older, the health and financial status of this age group, and competition from other service settings.

In the immediate future, between the year 2000 and 2010, little growth will occur in the 75 to 85 age group, historically the main market for assisted living.¹⁰³ However, the 85 and older population will continue to grow at a rapid rate during this time. In the more distant future, between 2020 and 2050, rapid growth is predicted both among 75 to 84 year-olds and among people aged 85 and older. The National Center for Assisted Living estimated that, if growth in assisted living were to be based on increase in the 75 and older population alone, ignoring all other factors, the number of assisted living beds would increase from 987,000 in 2000 to more than 1,900,000 in 2030.¹⁰⁴ However, medical advances and healthier lifestyles may reduce the proportion of older persons who need assistance with daily activities.

VII. Policy Implications

Recent research on assisted living suggests several challenges for policymakers:

One challenge is to ensure that assisted living residences (and other long-term service settings) provide services and an environment consistent with what consumers want. A step that states could take is to review or revise their regulations to make them consistent with the assisted living philosophy. For example, states could: include the philosophy in the definition of assisted living; require sufficient services to meet residents' needs;

specify a process for shared responsibility agreements; enact a bill of residents' rights that protects residents' independence and autonomy; allow residents to remain in assisted living when their needs change, provided that the residence can meet their needs; and require assisted living residences to provide private rooms.

Promoting a more homelike environment in assisted living may lead to changes in other long-term services and supports settings. In response to competition from assisted living residences, some nursing home providers have also started to offer more homelike environments and individualized services.¹⁰⁵

A second challenge is to ensure that individuals with limited financial resources have access to needed services in the setting they prefer. Options include expanding Medicaid coverage of assisted living and expanding other programs that make assisted living more affordable.

A third challenge is to ensure quality of assisted living services. To do this, states will need to expand current efforts to improve quality and ensure that these efforts are adequately funded. Areas where state regulations are often weak include staff training, disclosure of information to consumers, and services to meet the needs of residents with cognitive impairment. The report of the Assisted Living Workgroup provides a resource that can be useful to policymakers as they consider ways to improve assisted living quality and affordability in their states. Additional research is needed to better understand the effectiveness of various approaches to improving quality.

Written by Bernadette Wright, Ph.D.
AARP Public Policy Institute, October 2004

601 E Street, NW, Washington, DC 20049

© 2004, AARP

Reprinting with permission only.

<http://www.aarp.org/ppi>

References

- ¹ Catherine Hawes, Miriam Rose, and Charles D. Phillips, *A National Study of Assisted Living for the Frail Elderly: Results of a National Survey of Facilities* (Washington, DC: Prepared for U.S. Department of Health and Human Services (HHS), 1999), Report.
- ² Gibson, Mary Jo, et al., *Beyond 50.03: A Report to the Nation on Independent Living and Disability*, Washington, DC: AARP, 2003.
- ³ Han, Beth, Al Sirrocco, and Robin Remsburg. "Developing a Typology of Long-Term Care Residential Places: The First Step." Document prepared for Expert Meeting on Typology of Long-Term Care Residential Places, January 12 – 13, 2004, Social & Scientific Systems, Inc., Silver Spring, MD.
- ⁴ Catherine Hawes, Charles D. Phillips, and Miriam Rose, *High Service or High Privacy Assisted Living Facilities, Their Residents and Staff: Results from a National Survey* (Washington, DC: HHS, 2000).
- ⁵ The Assisted Living Workgroup, *Assuring Quality in Assisted Living: Guidelines for Federal and State Policy, State Regulations, and Operations*. A Report to the US Senate Special Committee on Aging, April 2003, <http://www.aahsa.org/alw.htm>, accessed May 12, 2003.
- ⁶ Mollica, Robert L., *State Assisted Living Policy 2002*, Portland, ME: National Academy for State Health Policy, November 2002.
- ⁷ Elizabeth Devore, *Assisted Living* (Health Policy Tracking Services, 2001), Issue Brief.
- ⁸ O'Keeffe, Janet, Christine O'Keeffe, and Shulamit Bernard. *Using Medicaid to Cover Services for Elderly Persons in Residential Care Settings: State Policy Market and Stakeholder Views in Six States*. Washington, DC: U.S. Department of Health and Human Services, Assistant Secretary for Planning and Evaluation, Office of Disability, Aging and Long-Term Care Policy, December 2003.
- ⁹ Tanner, Rachel, "Assisted Living," Health Policy Tracking Service, April 1, 2004, Issue Brief, <http://www.hpts.org>, accessed August 31, 2004. The following 36 states used the term assisted living: Alabama, Alaska, Arizona, Arkansas, Colorado, Connecticut, Delaware, Florida, Hawaii, Idaho, Illinois, Iowa, Kansas, Kentucky, Louisiana, Maine, Maryland, Massachusetts, Minnesota, Montana, Mississippi, Nebraska, Nevada, New Jersey, North Carolina, North Dakota, Oklahoma, Oregon, Rhode Island, South Dakota, Tennessee, Texas, Utah, Virginia, West Virginia, and Wyoming.
- ¹⁰ O'Keeffe et al., 2003.
- ¹¹ See, for example, Jennifer R. Frytak and others, "Outcome Trajectories for Assisted Living and Nursing Facility Residents in Oregon," *HSR: Health Services Research* 36, no. 1 (2001).
- ¹² Lewin-VHI Inc., *National Study of Assisted Living for the Frail Elderly: Literature Review Update* (Washington, DC: Prepared for The Office of the assistant Secretary for Planning and Evaluation & Administration on Aging, U.S. Department of Health and Human Services, 1996).
- ¹³ Hawes, Rose, and Phillips, 1999.
- ¹⁴ Hawes, Phillips, and Rose, *High Service or High Privacy Assisted Living Facilities*, 2000.
- ¹⁵ Hawes et al., 1999.
- ¹⁶ Ibid.
- ¹⁷ Hawes et al., 2000.
- ¹⁸ Ibid.
- ¹⁹ Morgan, Leslie A., Ann L. Gruber-Baldini, and Jay Magaziner. "Resident Characteristics." In *Assisted Living: Needs, Practices, and Policies in Residential Care for the Elderly*, edited by Sheryl Zimmerman, Philip D. Sloane, and J. Kevin Eckert. Baltimore: The Johns Hopkins University Press, 2001; National Investment Conference (NIC) and Assisted Living Federation of America (ALFA), *National Survey of Assisted Living Residents: Who Is the Customer?* (Annapolis, MD, 1998), Report.
- ²⁰ Morgan et al., 2001.
- ²¹ Hawes et al., 2000. The levels reported by residents and their proxy respondents are considerably lower than estimates reported by administrators. In those interviews, administrators estimated that 24 percent of their residents had received assistance with three or more ADLs during the preceding seven days. The five ADLs include dressing, locomotion, transfer, toilet use, and eating. NCAL's survey of facilities found higher percentages of assisted living residents needing assistance than did Hawes et al., although both studies reported considerably fewer residents needing assistance in assisted living than in nursing homes. National Center for Assisted Living (NCAL), *Facts and Trends: The Assisted Living Sourcebook* (Washington, D.C., 2001).
- ²² Enid Kassner and Robert W. Bectel, *Midlife and Older Americans with Disabilities: Who Gets Help?*

A *Chartbook* (Washington, DC: Public Policy Institute, AARP, 1998).

²³ NIC and ALFA, 1998.

²⁴ Sheel Pandya, *Nursing Homes* (Washington, D.C.: Public Policy Institute, AARP, 2001), Fact Sheet.

²⁵ In some cases, this reported level of assistance could be a product of facility policy (i.e., that all medications are centrally stored and distributed by staff), rather than resident need (Hawes et al., 2000).

²⁶ Hawes et al., 2000.

²⁷ Mollica 2002. The 36 states are: Alabama, Arizona, Arkansas, California, Colorado, Florida, Georgia, Idaho, Iowa, Kansas, Maine, Maryland, Massachusetts, Minnesota, Mississippi, Missouri, Montana, Nebraska, Nevada, New Mexico, North Carolina, North Dakota, Ohio, Oklahoma, Oregon, Rhode Island, South Carolina, South Dakota, Tennessee, Texas, Utah, Vermont, Virginia, Washington, West Virginia, Wisconsin, and Wyoming.

²⁸ Alzheimer's Association, November 24, 2003.

"Residents with Alzheimer's May Receive Inadequate Care in Nursing Homes and Assisted Living," press release, <http://www.alz.org/Media/newsreleases/current/study112303newsrelease.pdf>, accessed December 23, 2003; conversation with Sheryl Zimmerman, December 23, 2003; full study forthcoming in *The Gerontologist*, late 2004.

²⁹ Hawes et al., 2000.

³⁰ Ibid.

³¹ "Seniors Housing State Regulatory Handbook," Washington, D.C.: American Seniors Housing Association, 2002.

³² Mollica 2002.

³³ Ibid.

³⁴ Mary Jo Gibson, *Beyond 50.03: A Report to the Nation on Independent Living and Disability*, Washington, DC: AARP, 2003.

³⁵ Ibid.

³⁶ <http://www.m-w.com/cgi-bin/dictionary?book=Dictionary&va=independent>, accessed May 29, 2003.

³⁷ Hawes et al., 2000; NCAL, 2001.

³⁸ Hawes et al., 2000.

³⁹ NCAL, 2001.

⁴⁰ ALW, 2003.

⁴¹ Kenneth L. Burgess. "Negotiated Risk Agreements in Assisted Living Communities." Fairfax, VA: Assisted Living Federation of America (ALFA), June 2002.

⁴² Ibid.

⁴³ Hawes et al., 2000.

⁴⁴ Mollica 2002. The 19 states are: Alaska, Arkansas, Connecticut, Delaware, Florida, Hawaii,

Illinois, Iowa, Kansas, Maine, Massachusetts, New Jersey, Ohio, Oklahoma, Oregon, Texas, Utah, Vermont, and Washington.

⁴⁵ U.S. General Accounting Office (GAO). *Assisted Living: Quality-of-Care and Consumer Protection Issues in Four States*. Washington, DC: GAO, 1999. GAO/HEHS-99-27.

⁴⁶ Rachele Cummins, *New York Assisted Living Facility Survey: Summary Report* (Washington, D.C.: AARP, 2001).

⁴⁷ Bridges, Katherine, *AARP Connecticut Assisted Living Survey*, Washington, DC: AARP, 2002.

⁴⁸ Hawes et al., 2000.

⁴⁹ Charles D. Phillips, Catherine Hawes, Kathleen Spry, and Miriam Rose, *Residents Leaving Assisted Living: Descriptive and Analytic Results from a National Survey* (Washington, D.C., 2000), Report prepared for U.S. Department of Health and Human Services and Public Policy Institute, AARP.

⁵⁰ Hawes et al., 2000.

⁵¹ Mollica 2002.

⁵² Maryland regulations, "Assisted Living Programs, Title 10.07.14."

⁵³ Health Policy Tracking Services, *Summary of Law # Ms H 1478* (accessed July 31 2001), available from <http://www.hpts.org/>; ALFA (Assisted Living Federation of America), *Assisted Living Federation of America Applauds New Texas Reforms, Press Release, June 21, 2001* (2001, accessed June 27 2001),

<http://www.alfa.org/public/articles/details.cfm?id=325/>; Gregory J. Bator and Kathleen Muphy, "Informed Choice: National Implications," in *ALFA National Conference & Expo* (Washington, DC: ALFA, 2001).

⁵⁴ Ibid.

⁵⁵ Mollica 2002.

⁵⁶ Rosalie A. Kane, Mary Olsen Baker, Jennifer Salmon, and Wendy Veazie, *Consumer Perspectives on Private Versus Shared Accommodations in Assisted Living Settings* (Washington, D.C.: Public Policy Institute, AARP, 1998), #9807.

⁵⁷ ALFA (Assisted Living Federation of America), PriceWaterHouseCoopers, and NIC (National Investment Center), *ALFA's Overview of the Assisted Living Industry* (Fairfax, VA: ALFA, 2000).

⁵⁸ Hawes et al., 2000.

⁵⁹ Kane et al., 1998.

⁶⁰ Mollica 2002.

⁶¹ The 19 states were: Alaska, Arizona, Arkansas, California, Connecticut, Delaware, Florida, Hawaii, Iowa, Kansas, Kentucky, Louisiana, Maine, New Jersey, Oregon, Texas, Utah, Washington, and Wisconsin.

⁶² Hawes et al., 1999.

⁶³ Tanner, 2004.

⁶⁴ GAO, "Long-Term Care: Aging Baby Boom Generation Will Increase Demand and Burden on Federal and State Budgets," (GAO-02-544T). Testimony before the Special Committee on Aging, U.S. Senate, March 21, 2002.

⁶⁵ ALFA and NIC, 1998.

⁶⁶ Mollica 2002.

⁶⁷ Ibid.

⁶⁸ Mollica 2002.

⁶⁹ Ibid.

⁷⁰ Robert Mollica, personal communication, July 25, 2003.

⁷¹ Hawes et al., 2000.

⁷² Smith, Vernon, Rekha Ramesh, Kathy Gifford, Eileen Ellis, and Victoria Wachino. "States Respond to Fiscal Pressure: State Medicaid Spending and Growth and Cost Containment in Fiscal Years 2003 and 2004: Results from a 50-State Survey." Washington, DC: Kaiser Commission on Medicaid and the Uninsured, September 2003. <http://www.kff.org/medicaid/loader.cfm?url=/comspot/security/getfile.cfm&PageID=22126>, accessed December 22, 2003.

⁷³ Mollica 2002.

⁷⁴ Barbara L. English, *Assisted Living: Background and Issues* (Washington, D.C.: Congressional Research Service (CRS), 2001), Report for Congress.

⁷⁵ GAO, "Assisted Living, Examples of State Efforts to Improve Consumer Protections." Washington, DC: GAO, April 2004.

⁷⁶ Bruce Vignery and Dorothy Siemon, *Ensuring Assisted Living Quality through the Courts: State Policy Issues Regarding a Consumer Private Right of Action* (Washington, DC: AARP, Public Policy Institute, 2000).

⁷⁷ Mollica 2002.

⁷⁸ GAO, 2004.

⁷⁹ Mollica 2002.

⁸⁰ GAO, 2004.

⁸¹ GAO, 1999.

⁸² Mollica 2002. Data were reported by 34 states. Information was unavailable from several states.

⁸³ Fallis, David S, "As care declines, cost can be injury, death," *Washington Post*, May 23, 2004, Page A01; Appleby, Julie, "Good centers keep elderly active, safe," *USA Today*, May 25, 2004, Pg. A11; McCoy, Kevin and Appleby, "Many facilities accept people who are too ill," *USA Today*, May 27, 2004, p. A06; McCoy and Appleby, "Problems with staffing, training can cost lives," *USA Today*, May 26, 2004, Pg B01.

⁸⁴ Robyn I. Stone and Joshua M. Wiener, *Who Will Care for Us? Addressing the Long-Term Care Workforce Crisis* (Washington, DC: The Urban

Institute and the American Association of Homes and Services for the Aging, 2001).

⁸⁵ Ibid.

⁸⁶ Hawes et al., 2000.

⁸⁷ Ibid.

⁸⁸ Mollica 2002, p. 145.

⁸⁹ Ibid.

⁹⁰ Ibid, p. 137.

⁹¹ Tanner, 2004.

⁹² GAO, 1999.

⁹³ Mollica 2002.

⁹⁴ The Assisted Living Workgroup, 2003.

⁹⁵ U.S. Department of Housing and Urban Development (HUD), "Assisted Living Conversion Program (ALCP) for Eligible Multifamily Housing Projects," *Federal Register* 66, no. 38 (2001).

⁹⁶ "Multi-Family Housing - Program Description – HUD," <http://www.hud.gov/offices/hsg/mfh/progdesc/alcp.cfm>, accessed July 29, 2003.

⁹⁷ Donald L. Redfoot, "Long Term Care Reform and the Role of Housing Finance," *Housing Policy Debate* 4 (1994).

⁹⁸ Robert Wilden and Donald L. Redfoot, *Adding Assisted Living Services to Subsidized Housing: Serving Frail Older Persons with Low Incomes* (Washington, D.C.: AARP Public Policy Institute, 2002).

⁹⁹ NCB Development Corporation, *Affordable Assisted Living: Backgrounder*, accessed September 12, 2003; available from [http://www.ncbdc.org/ncbdc/contents.nsf/docname/AALbackgrounder2001pdf/\\$file/AAL2001Backgrounder.pdf](http://www.ncbdc.org/ncbdc/contents.nsf/docname/AALbackgrounder2001pdf/$file/AAL2001Backgrounder.pdf); <http://www.ncbdc.org/>, accessed September 12, 2002.

¹⁰⁰ Mollica 2002.

¹⁰¹ ASHA (The American Seniors Housing Association), "Senior Housing Construction Down in 2000," (Washington, D.C.: 2000).

¹⁰² NIC and ALFA, 1998.

¹⁰³ Donald L. Redfoot and Sheel M. Pandya, *Before the Boom: Trends in Long-Term Supportive Services for Older Americans with Disabilities* (Washington, D.C.: AARP Public Policy Institute, October 2002), #2002-15.

¹⁰⁴ NCAL, 2001.

¹⁰⁵ Dembner, Alice. "With new style, a nursing 'home': Residents hail role in daily decisions." *The Boston Globe*, Jan 26, 2004.