Assisted Living: Recent Developments and Issues for Older Consumers

by Stephanie Edelstein

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Assisted living is marketed as a unique environment that allows older people to age in place, in safety and security, yet many residents will find that their choice fails to meet their long-term needs.

Advertisements for assisted living run through the Senior Living pages of newspapers, magazines, and the Internet. But what is assisted living? What is actually being promised to older people who read these advertisements like the one above? And who makes certain that once they move into the facility advertised, residents will find an environment and services they need or expect?

Assisted living generally includes group or apartment-style living that provides residents with personal care tasks such as bathing, dressing, and taking medications, social and recreational opportunities, and protective oversight and monitoring, all with an emphasis on individual needs and preferences.² There is no uniform definition of assisted living or consensus on what residents should expect or what facilities should provide, and very little legal authority to provide direction to facilities or protection to residents. While states have begun to fill some of these gaps through regulation, their efforts have not yet been tested. This article provides an overview of the questions presented by the emerging assisted living industry, and offers some considerations for guiding consumers in making informed decisions.

I. WHAT IS ASSISTED LIVING?

On a continuum of housing options for older persons, the family home would be at one end, with the greatest opportunity for exercising personal choice and no care or supervision other than that selected by the resident. At the other end is the nursing home, which

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provides twenty-four hour supervision and skilled medical care.\textsuperscript{3} Between the two is a range of choices, some of which overlap, including retirement communities where independent living is the norm, apartment buildings where staff coordinate community-based services,\textsuperscript{4} continuing care retirement communities (CCRCs) where residents move from independent to more supervised housing as their needs change,\textsuperscript{5} board and care homes with round-the-clock supervision,\textsuperscript{6} and assisted living where residents receive assistance with personal care tasks.\textsuperscript{7}

The concept of assisted living has evolved in response to a call for alternatives to the high cost and institutional setting of nursing homes, demands for more personal autonomy, the increase in the number of widows aged sixty-five to seventy-five seeking affordable residential programs, and the desire of older persons to age in place.\textsuperscript{8} Among its varied definitions, perhaps the most comprehensive is:

A residential setting that provides or coordinates flexible personal care services, 24-hour supervision and assistance (scheduled and unscheduled), activities, and health-related services; has a service program and physical environment designed to minimize the need for tenants to move within or from the setting to accommodate changing needs and preferences; has an organizational mission, service programs, and a physical environment designed to maximize residents' dignity, autonomy, privacy, and independence; and encourages family and community involvement.\textsuperscript{9}

Within these parameters, there is a wide variety of living arrangements. Assisted living providers include individuals, religious and other non-profit organizations, public entities, and for-profit corporations.\textsuperscript{10} Some facilities offer only minimal personal assistance and/or light housekeeping; others offer skilled medical care comparable to that available in nursing homes. Some facilities offer special living units and supportive services for residents with medical problems such as Alzheimer's Disease and other dementia. Some facilities use on-site staff to provide services; others simply coordinate and make the services available to residents. Assisted living facilities range in size from very small—fewer than five residents—to quite large—more than several hundred. Depending on the jurisdiction, facilities may be required to provide residents their own living unit, or residents may be permitted to share rooms. Costs vary according to the size of the facility, the needs of the resident, and the services provided.

In a recent report to the U.S. Senate Special Committee on Aging, the U.S. General Accounting Office (GAO) note that assisted living was identified by \textit{Fortune Magazine} as one of the top three potential growth industries for 1997.\textsuperscript{11} However, the GAO cautions that precise numbers for facilities and residents are difficult to obtain because there is no standard definition of assisted living and no systematic means of counting facilities.\textsuperscript{12} The industry itself is less reticent in its optimism. According to the Assisted Living Federation of America (ALFA), assisted living is a $12.2 billion industry, with more than 25,000 facilities that care for up to one million residents nationwide; it is expected to grow to $30 billion by the year 2000.\textsuperscript{13}

Given that the percentage of the population aged sixty-five or older is expected to increase from thirteen percent of the population today to twenty percent of the population in the year 2030, the popularity of assisted living is not surprising.\textsuperscript{14} In the Washington, D.C. metropolitan area alone, plans are underway for the construction of four major assisted-living communities to house more than 10,000 residents, serving a range of those who are active and independent to those who require nursing care. Also planned are more than sixteen smaller projects with services tailored for specific groups, such as persons with Alzheimer's Disease and other forms of dementia.\textsuperscript{15}

There is no doubt that assisted living is a viable housing option for older people seeking a combination of housing and services. The industry's rapid growth attests to the demand. However, while it is important to maintain a delicate balance between resident support and independence, it is absolutely essential that residents receive quality services that meet their medical and social needs. To achieve these goals, states should develop minimum quality standards that protect the health, safety, and legal rights of assisted living residents and establish a viable mechanism for enforcement of those standards. In addition, older consumers should be apprised of the range of available housing options, including assisted living, so that they can make informed choices about where to live and what to expect when they move there.

II. ISSUES IN MARKETING OF ASSISTED LIVING AND CONSIDERATION OF COSTS

Consumers and their families may first encounter the concept of assisted living in print advertisements or through telephone marketing by providers. While there is no dispute as to the right of providers to market their product, there is cause for concern when the industry operates with little oversight and directs its selling to a group of aging, anxious, and often vulnerable individuals.
Newspaper and magazine advertisements have the potential to mislead readers by exaggerating the services offered or downplaying the costs. Assuming that the information it communicates is accurate, an advertisement like the one in the introduction does not appear to be objectionable. However, it should only be taken as an introduction to the facility, and not relied upon as providing sufficient information upon which to make a decision with serious financial and lifestyle consequences. For example, the advertisement makes vague offers of "recreation and personal assistance" without mentioning cost or the extent of the services. It touts a "safe" setting without mentioning staffing. In saying "you'll never want to move again," it may lead prospective residents to assume that they can remain in the facility for the rest of their lives, not revealing that facility policy or state regulation may require discharge if the resident's health needs exceed a certain level.

The marketing techniques promoted in provider literature pose a more serious danger. These leave one with the uncomfortable sense that the importance of making a sale far surpasses the value of helping consumers make informed decisions. The most extreme marketing techniques urge salespeople to wage "guerrilla-style" direct mail and telemarketing campaigns, to avoid set rules, and to "create a sense of urgency" through "relentless, personalized, outrageous mailings and other creative selling initiatives." Other approaches more moderate in tone promote techniques more akin to traditional sales strategies, such as encouraging the development of a referral base of families, health care professionals, guardians, and bank staff and conferring personal attention to create a "warm, fuzzy feeling" that earns the elderly consumer's trust. Techniques that are acceptable between parties of equal bargaining positions may not be appropriate when one party is a large corporate housing provider and the other is an elderly woman concerned about her increasing frailties, anxious not to burden her family, and looking for an affordable place to spend her final years. Even the best intentioned salespeople may indirectly pressure older consumers to make decisions that they do not fully understand and that do not accord with their actual preferences.

Older consumers and their families need to understand the nature of assisted living and the legal rights and responsibilities of providers and residents. States must take responsibility, through promulgation of regulations and application of existing consumer protection laws, for ensuring that marketing and sales pitches are not misrepresentative and that information about assisted living is readily available to consumers. Consumers, in turn, need to visit facilities, interview staff and residents (and their families), check with state licensing agencies, obtain references, and carefully review the residence contract, perhaps in consultation with a lawyer.

The cost of assisted living depends to a great extent on the type of facility (e.g., for-profit or not-for-profit), the accommodations (e.g., the size and occupancy of the unit), and the needs of the resident (e.g., supportive services). Some facilities follow the CCRC payment model, charging a substantial entrance deposit in addition to monthly fees. Others charge only a monthly fee. Whether or not there is an entrance deposit, there is little consistency in what the quoted monthly fee includes. Depending on the facility, the fee might fall within one of the following plans: room only or room and board only with services purchased on an a la carte basis; room, board, and all services at a flat rate; or room, board, and a standard package of services with a surcharge for additional services. The complexity of these plans and the fact that there may be other combinations only emphasize the need for careful examination of the contract and thorough questioning of staff.

Of the sixty-three assisted living residences surveyed in 1993 by the American Association of Retired Persons (AARP), only seven utilized a single rate within the same facility. The lowest median rate for room, board, and services in that AARP survey was $995 per month, and the median highest rate was $1639 per month. Rates have risen in recent years with the advent of new upscale facilities and may be higher still in certain areas of the country. In 1997, monthly fees for assisted living in Florida ranged from $610 for small group homes to $3000 for luxury communities. In the Washington, D.C. metropolitan area, fees for facilities with amenities such as private suites and fine dining, or golf courses and sailing, exceed $5000 per month. In the same area, group homes offer basic housing, meals, and personal assistance at a cost of $776 per month. Assisted living costs are generally paid out-of-pocket by individuals and their families, effectively placing assisted living beyond the reach of most low and moderate-income Americans.

How can assisted living be made affordable? Some residents (usually those in board and care type homes) receive financial assistance from Supplemental Security Income, state supplements for persons with mental or developmental disabilities, or Medicaid home and community-based care waivers. Other sources of payment include Medicare, which may cover skilled nursing care or services provided by licensed home health care agencies, and long-term care insurance for the very limited group of individuals who can afford the high premiums. However, to have any practical impact for providers and consumers, payments under any of these programs must be sufficient to cover the actual expenses of assisted living.
The assisted living industry itself is taking steps toward creating affordable options. According to a study by the National Investment Conference for Senior Living and Long-Term Care Industries, demand is high for housing for persons with household incomes less than $20,000. That study predicts that “the next boom will be in building affordable units—those in the $400 to $1200 a month range.”14 Some industry leaders are beginning to explore this issue. For example, the Enterprise Foundation has launched Enterprise Senior Ventures, Inc., a major initiative to finance and develop assisted living for low income seniors and persons with disabilities.25 In addition, the Robert Wood Johnson Foundation, which focuses on health care issues, and NCB Development Corp., a lender that focuses on non-profit organizations providing services to low- and moderate-income populations, have joined forces with non-profit senior housing and service providers to develop affordable assisted living for very low-income (Medicaid eligible) persons in several states.26 Federal and state governments might enhance these efforts through creative financing, public-private partnerships, and the expansion of tax credit programs. Local jurisdictions could help by mandating that the large, for-profit assisted living developers set aside a certain percentage of their units for low and moderate-income residents.

III. STATE OVERSIGHT AND CONSUMER PROTECTION

Since the emergence of assisted living in the late 1980s, housing and long-term care providers, state officials, consumer advocates, and others have debated the need for its regulation. In a 1996 report, the National Academy for State Health Policy concluded that the differences between board and care and assisted living can be found in assisted living’s philosophy of promoting resident autonomy and privacy, the greater likelihood that residents will live in apartments, and the potential for occupancy by people who require nursing care.27 This description points to the conflict that is at the heart of the discussions on whether to regulate assisted living.

Assisted living providers, promoting resident autonomy and desiring to retain flexibility and avoid extensive regulation like that governing the nursing home industry, contend that the market should direct what services are provided and set the standard for the quality of those services.28 Arguments in support of regulation do not focus on the philosophy of assisted living but rather on resident needs and the services provided. In 1991, the American Bar Association Commission on Legal Problems of the Elderly voiced concern that facilities operating as assisted living provide essentially the same services as board and care, the only difference being increased living space and access to recreational activities—albeit at a higher cost.29 Indeed, a 1993 Research Triangle Institute study found an increasing level of disability among board and care residents and an expanding overlap in the type of services provided in board and care homes and assisted living facilities.30 Cognizant of the history of resident abuse in the board and care and nursing home industries, the ABA Commission has cautioned that, absent government oversight, assisted living residents might, at a minimum, not receive the accommodations or services they have been led to expect during initial discussions and, even more serious, might become victims of abuse or neglect.31

As noted in the National Academy report, the needs of assisted living residents are approaching those of many nursing home residents.32 Indeed, nursing home occupancy rates are declining as many elderly who previously would have entered nursing homes are receiving in-home medical services or moving to assisted living.33 As more assisted living facilities offer skilled nursing services, controversy has arisen regarding where to draw the line between nursing homes and assisted living. The nursing home industry, observing the increase in medical services provided by assisted living facilities without government oversight, has called for the regulation of assisted living.34

These issues have given rise to several compelling questions. Should the emergent models of assisted living be subject to existing board and care rules, or do states need a new statutory and regulatory scheme? Is assisted living a housing model or a medical model? If it is housing, do landlord-tenant laws apply? At what point do resident needs propel a facility beyond a residential model and into the nursing home arena, with its more comprehensive regulations and enforcement mechanisms? Should states limit the kind of care that can be provided to residents of assisted living facilities? What if residents wish to remain in a facility that is not licensed to care for their needs? Who bears the ultimate responsibility for ensuring the quality of care and the safety of residents? To what extent should the market set the standards for quality?

In recent years, recognizing the need for oversight of assisted living, at least two dozen states have created new statutory and regulatory schemes for assisted living.35 These statutes and regulations tend to focus on concrete areas—living accommodations, admission and retention criteria, scope of services, staffing and facility design—rather than addressing the difficult issues of ensuring quality of care. Moreover, even on issues they do address, states vary so widely in their approach that the statutory solutions are difficult to generalize.36
A. STANDARDS FOR ACCOMMODATIONS

The size and occupancy of the living unit has produced substantial debate among consumer advocates, providers, and regulators trying to decide whether there should be a physical distinction between the "old" board and care and the "new" assisted living. Are single occupancy rooms or apartments integral to the concept of assisted living, or are shared rooms acceptable?

In 1995, the Public Policy Institute of the American Association of Retired Persons included single-unit occupancies in its definition of assisted living, thus reflecting the philosophy of personal autonomy. This description, however, is not universally accepted. For example, several states permit two to four residents to share a room; 37 others allow double occupancy at the request of the residents.38

While personal preference should be considered, state definitions of assisted living should not mandate single-occupancy rooms or apartment-style units. Such a requirement could serve to exclude low and moderate-income persons from the protections of new state assisted living laws since they will likely reside in smaller group home facilities.

B. STANDARDS FOR SUPPORTIVE AND HEALTH RELATED SERVICES

While many assisted living residents are active and independent, results from a 1996 survey of 268 facilities (15,000 units) in thirty-five states found the typical resident to be a single or widowed female, average age eighty-four, who needed assistance with three activities of daily living.39 In addition, forty-eight percent of residents had some degree of cognitive impairment and thirty-eight percent used walkers or wheelchairs. In 1995, sixty-seven percent of assisted living facilities offered some degree of nursing care, while in 1997, that figure increased to seventy-five percent of which thirty percent also offered skilled care.41

Yet, despite this demonstrated need for supportive services, little guidance exists to govern what services are to be provided in assisted living and under what circumstances they are to be provided. There are no minimum federal standards, and state standards vary widely. For example, consumers may incorrectly assume that assisted living always includes health-related services such as assistance with medication, monitoring of health and treatment, and medical care. This is not the case. Not all facilities offer health care, and even those facilities that do should be questioned as to precisely what those services are—they could be anything from health and wellness educational programs to comprehensive medical care or, as is more likely, fall somewhere in between.

States without clear standards leave facilities a great deal of room in which to maneuver, creating a burden on consumers who must decipher the contract to determine which services to expect. In the supportive services area, facilities could provide residents only one meal a day, or as many as three meals plus snacks and special meals. Depending on the facility, services could be limited to light housekeeping, or they could extend to regular assistance with basic activities of daily living (dressing, eating, bathing, etc.), instrumental activities of daily living (check writing, shopping, housekeeping, etc.), incontinence care, help with scheduling and traveling to medical appointments, and assistance with medications. On the lighter side, "upscale" facilities offer extras such as golf, ice cream parlors, and bistros. A facility could choose to provide comprehensive twenty-four hour on-site supervision, as well as supportive services and health care. Some assisted living facilities administer medication and coordinate the provision of health care to residents while others provide skilled nursing care.

In some assisted living facilities, services are provided as part of a comprehensive package; in others, community-based services are brought in as needed. The roles seem clearer when the provider is employed by the facility. In the latter arrangement, however, the roles and responsibilities become murky. For example, who is responsible for ensuring that the services are coordinated to meet the needs of the individual resident and that they are monitored for quality? Questions arising from this kind of an arrangement include: should a facility require services to meet certain standards, e.g., certification or licensure? If the resident is responsible for making arrangements on her own, would a requirement that the outside provider be licensed constitute an intrusion into the resident's autonomy? Who bears responsibility for follow-up on care and treatment issues—the resident or the facility? If an outside service provider does not appear when scheduled, is it up to the facility to find a replacement?

Some states have attempted to establish minimum standards for supportive services—those that a facility must provide or ensure to be called assisted living or to be licensed at a certain level of assisted living. In the health care area, several states have amended or begun the process of amending their laws to allow assisted living facilities to offer nursing services. Others permit facilities to obtain a waiver of state licensure rules, provided that the facility can demonstrate how it will meet the particular resident's needs. At the same time, however, state regulations on how services are delivered may conflict with the expectations for assisted living. For example, in most states, a licensed nurse must be responsible for dispensing medication, but state
regulations may not require assisted living facilities to have a licensed nurse as a part of their full-time staff.\textsuperscript{43}

Special care for persons with Alzheimer's Disease and other dementia bears careful examination. Assisted living providers increasingly advertise Alzheimer's and dementia care, either in a discrete unit within a larger facility or in a separate facility. Alzheimer's is a progressive, degenerative disease that damages the brain and causes mental confusion, impaired judgment, and behavioral changes, including aggression in some individuals. If they live long enough, residents with Alzheimer's Disease will become totally bed-ridden and incapable of self-care. How can residents and their families be sure that services offered are actually different from those offered elsewhere in the facility (or at other facilities) and that they are tailored to meet the needs of residents? What do state laws require? Much depends on the state in which the facility is located and whether the state requires a license or certification.

In a recent article analyzing state statutory and regulatory requirements for special care units, Dorothy Siemon and Bruce Vignery observe the inability of states to reach consensus on defining and regulating what constitutes appropriate quality care.\textsuperscript{46} The authors note that states have taken two approaches, neither of which offers much assurance to consumers trying to ascertain precisely what the facility provides or is required to provide. States have tended to focus on physical plant and staffing issues in an effort to promote flexibility and encourage innovation. Additionally, they have provided general guidelines for resident care, along with a requirement that facilities disclose to prospective residents information about issues such as staffing, fees, and guidelines for admission and discharge.\textsuperscript{47} For example, Georgia, Maine, Missouri, Tennessee, and Texas require all facilities that advertise or claim to provide special care to disclose that care during the licensing or certification process.\textsuperscript{48} Nebraska law applies to nursing homes, assisted living, and other residential care facilities.\textsuperscript{49} South Carolina requires disclosure from nursing homes, community care, and adult day care facilities.\textsuperscript{50} Florida law, which covers nursing homes, hospices, assisted living facilities, family foster care, home health agencies, and adult day care facilities, contains broad guidelines as to the kind of information that must be disclosed, but requires that it be filed with the state and be sufficient to distinguish the special care services from those offered to the general resident population.\textsuperscript{51} To encourage states to address this important issue, the Alzheimer's Disease and Related Disorders Association has developed a Model Disclosure Act that would require facilities with special care units to register with the state licensing agency and to disclose specific information about the services to interested consumers.\textsuperscript{52}

Confusion and misperception about the extent of health-related services provided in assisted living can have serious consequences. In one facility in the Washington, D.C. metropolitan area, a resident died following a breakdown in communication between the facility and health care providers on a medication issue. A medical lab had notified the facility of test results with life-threatening implications to the resident, but the facility failed to pass the information along to the resident's physician; the physician delayed visiting the resident, and the resident died. The resident's family had assumed that the facility's medication supervision service included monitoring of medical treatment. While the facility was found not to be responsible for the death of the resident, the situation highlights the danger in failing to clarify exactly what the expectations and responsibilities of the parties are and, specifically, who has the ultimate responsibility for the health of the residents.\textsuperscript{53}

C. ADMISSION AND RETENTION GUIDELINES

State regulations cite nonpayment of rent, failure to comply with facility rules or policies, posing a danger to self or others, or needing care that exceeds the facility's license or capacity to provide, as criteria for admission, discharge, or eviction. Ironically, assisted living residents may have fewer legal rights to contest arbitrary facility decisions that affect their residency than they would have if they lived in either rental housing or a nursing home.\textsuperscript{54}

Regulations may define which services are or are not permitted in assisted living, or may prohibit admission or retention of persons with certain needs or conditions. These needs and conditions include requiring continuous skilled or nursing care for more than fourteen days; requiring intravenous therapy, tube feeding, or a ventilator; being bed-ridden or uncontrollably incontinent; being totally dependent in more than a certain number of activities of daily living; having severe cognitive impairments; behaving in a way that poses a danger to self or others; and requiring physical or chemical restraint, isolation, or confinement to control behaviors. Limitations on initial admission to a facility may be stricter than those for retention once a certain level of need is reached.\textsuperscript{55}

Some states require facilities to provide residents with written notice of an intention to discharge, with a notice period ranging from ten to thirty days.\textsuperscript{56} Few states, however, provide residents with the right to challenge the decision, and, of those that do, all but one permit a resident to request an informal interal meeting or, more rarely, to appeal the decision outside the
facility. Massachusetts is unique in bringing assisted living evictions under the authority of state landlord-tenant law.88

While assisted living residents may not have clear legal rights to challenge facility determinations regarding admission and retention under state housing or regulations, they may have recourse if they qualify for protections under federal law for persons with disabilities. Section 504 of the Rehabilitation Act of 1973 prohibits discrimination on the basis of disability or perceived disability in any program or activity that receives federal financial assistance, including public and subsidized housing programs and nursing facilities that receive Medicare or Medicaid funding. It requires that such programs be accessible to and usable by persons who are "handicapped" or who have disabilities. The Fair Housing Amendments Act of 1988 (FHAA) prohibits discrimination in almost all housing activities or transactions, whether public or private sector, in the provision of services of facilities in connection with a dwelling and in the application of zoning, land use, or health and safety regulations. These laws are complemented by the Americans with Disabilities Act, which, while not specifically covering housing (in fact, specifically excluding entities covered by the FHAA), applies to non-housing functions of a facility, such as meeting rooms, meal sites, adult day care, or long-term care, under Title II (state and local programs) and Title III (public accommodations).

The three statutes use virtually the same definition of "handicap" or "disability." Individuals are protected if they (1) have a "[p]hysical or mental impairment which substantially limits one or more . . . major life activities," such as performing manual tasks, walking, seeing, hearing, and speaking; (2) "have a record of having such an impairment," whether or not the impairment still exists; or (3) are "regarded as having such an impairment," whether or not the perception is accurate. While age alone does not equal disability, the symptoms and conditions of the aging process may cause an individual to meet these definitions. The protections extend to persons who are "frail," described in the Older Americans Act as being sixty years of age or older and unable to perform without assistance (i.e., verbal reminder, physical cue, or supervision) at least two activities of daily living, or who, due to a cognitive or other mental impairment, require substantial supervision because of behavior that poses a serious health or safety hazard to self or others.61

Even under these laws, facilities may deny admission to protected individuals who fail to meet eligibility requirements (e.g., those who cannot afford the fees or require care that the facility is not licensed to provide). Facilities may not, however, use admissions eligibility criteria that screen out otherwise eligible individuals or classes of persons with disabilities. They may not impose rules that deny otherwise eligible residents the opportunity to participate in certain services because of their disabilities (e.g., prohibiting walkers or wheelchairs in common areas of the facility such as the dining room or lobby). And they may not require, without justification, that disabled residents be segregated from other residents (e.g., requiring that they eat in their rooms simply because their disability causes them to eat in a manner that is unappealing to others).

Assisted living providers must make reasonable accommodations (adjustments to rules or procedures) or modifications (changes to the physical premises) upon request, to allow protected individuals to take advantage of the facility's services. The facility must make the requested accommodations or modifications provided that they are reasonable and do not change the nature of the program. If the facility raises safety concerns to justify a transfer or discharge, it must demonstrate actual safety risks that cannot be altered in other ways. Reasonable accommodation and modification provisions could also be utilized by residents as a defense against forced transfer or discharge from a facility because of their medical needs or behavior. A resident who receives such notice could request that the facility make accommodations or modifications to policies or practices to obviate the need for the discharge or transfer.

IV. PERSONAL AUTONOMY AND RESIDENT SAFETY

Assisted living is grounded in the principle that a facility should respond to the individual needs of a resident rather than require her to adhere strictly to rules and policies. Personal autonomy, however, can conflict with resident safety. In an effort to create a balance between the resident's desire for personal autonomy and the provider's responsibility to protect the resident from harm, some assisted living advocates have suggested that the resident and the facility negotiate an agreement in which the resident waives certain services or protections and assumes certain risks; in exchange, the facility is released from liability should the resident be injured as a result of the agreed-upon course of action.

Negotiated risk agreements are most likely to involve issues of daily living such as a resident choosing not to take prescribed medications, deciding to eat sweet desserts against medical advice (e.g., even though diabetic), or opting to leave the grounds for walks (e.g., even though physically frail or cognitively impaired). In theory, the agreements could go further, allowing a
resident to choose to reside in a facility that cannot provide the services necessary to meet the resident's health care needs, and perhaps absolving the facility from injury to the resident as a result of the living situation. Such an agreement would be problematic. First, residents with cognitive impairments may lack the capacity to understand the consequences of such an agreement. Second, consumers and facilities typically have unequal bargaining positions that could lead to exploitation of the consumer who believes that she has no other housing options and thus no choice but to agree to whatever terms the facility proposes. Third, while there has been very little litigation in this area, as a matter of public policy, courts may not look kindly upon a defense based on negotiated risk in an action for damages resulting from a facility's failure to protect a frail, elderly resident.

Negotiated risk can be compared to the process by which physicians obtain informed consent from a patient—by making sure the patient's decision is voluntary and not coerced in any way, by ensuring that the patient is competent to understand the information presented, and by disclosing the amount and type of information that a reasonable, prudent health care professional would have disclosed under similar circumstances (including alternatives). In the assisted living context, however, there is the chance that the resident will not understand all the choices available because the relevant information may not be as clearly definable (e.g., the myriad of supportive service options and because the potential consequences of accepting or rejecting each option may be more difficult for a person of limited capacity to comprehend than a decision to consent to a particular surgical procedure). There is also the opportunity for subtle coercion arising from a fear of not being able to remain in the facility. Finally, there is a concern that relying on surrogates to agree to high-risk circumstances is fraught with potential for abuse.

The issues of resident autonomy and facility liability are better addressed through individual assessments of resident needs and preferences. Many facilities, either by state law or through their own procedures, conduct pre-admission and follow-up assessments of residents in conjunction with the development of a plan for services to be provided. These assessments provide the facility an opportunity to learn the prospective resident's social history, medical history, and service and health care needs and to plan services accordingly. A discussion of a resident's likes, dislikes, and preferences, including any necessary changes to facility rules, could be conducted as part of the assessment and development of an individual care/service plan. Assessments are conducted within the guidelines of the services the facility is licensed and capable of providing and do not allow a facility to avoid legal responsibility. Moreover, the assessment would take into account any cognitive impairments that would reduce the resident's ability to understand the choices and the risks involved. The process of developing alternatives to the standard facility rules to meet a resident's needs could also be considered as a request for accommodations under the Fair Housing Amendments Act or the Americans with Disabilities Act. Those laws also provide the opportunity for discussing resident preferences and facility offerings and for adapting the rules and procedures in order to meet the resident's needs within those parameters.

There is no doubt that people have the legal right to make certain choices about how they live their lives. However, assisted living residents should not be subjected to situations in which they are compelled to agree to unreasonable risks. Perhaps it would be better to look at the issue as an integral part of a collaborative, interactive approach to developing a plan for services and a lifestyle that are acceptable to the resident rather than in terms of negotiation and risk. Service plans and reasonable accommodations allow for the flexibility needed to tailor the changing health and personal needs of the resident. They also presuppose that the choice is not "all or nothing" and that a facility will offer alternatives that may suit the needs and desires of the resident without undermining resident safety. (Offering realistic choices would also allow a resident with some level of cognitive impairment to make an informed decision.) And they do this within the facility's ability and legal responsibilities to meet resident needs according to state regulation and licensure. In the example given above, the facility could offer the diabetic resident an alternative dessert that meets her dietary limitations or assign a staff member to accompany the resident who insists on walking off the grounds, provided that the resident agrees only to go out when accompanied.

V. CONCLUSION

Assisted living is marketed as a unique environment that allows older people to age in place, in safety and security, yet many residents will find that their choice fails to meet their long-term needs. In most states, consumers are left on their own to determine whether a particular facility's accommodations, services, costs, and philosophy will meet their current and future needs. Neither the individual nor the facility can be expected to anticipate every conceivable circumstance that might arise. However, elderly individuals who have moved into assisted living on the assumption that it will be their final residence should not have to vacate simply because the requirements of residency or the services provided by the facility were misunderstood or misrepresented.
In the absence of regulation, one might assume that the residency agreement establishes the rights and responsibilities of the assisted living consumers and the provider. These agreements, however, leave much to be desired. In 1995, the ABA Commission on Legal Problems of the Elderly, at the request of Consumer Reports, examined thirteen assisted living contracts for clarity of language, consistency, adequacy of description of accommodations and services available, and delineation of resident rights and other consumer protections. The contracts ranged from one-page documents lacking any information other than the names and addresses of the parties to multi-page texts replete with information but so poorly organized that they were incomprehensible. With few exceptions, the contracts were found to be vague, confusing, and lacking in the necessary information to bind the facility to specific services, fees, accommodations, staff, or procedures for resident challenges to facility actions. Some states mandate the inclusion of certain provisions in assisted living agreements. However, none require that a particular document be used, that it be provided in a certain format, or that it be approved by the state. A comprehensive, carefully constructed contract setting forth the rights and obligations of the facility would be likely to reduce the move-out rate.

While regulations may establish minimum guidelines and parameters within which assisted living facilities are to operate, few states have mechanisms for monitoring quality or holding providers accountable for poor care. Fewer still provide specific legal protections that would allow residents to challenge a facility decision. Facilities may appreciate a hands-off approach, which allows them flexibility in meeting the needs of individual residents. However, a lack of oversight makes it more likely that facilities will not be held accountable for meeting resident expectations, or worse, that resident safety will be compromised by a failure to meet minimum care standards. All assisted living facilities of whatever size should be required to comply with minimum standards that ensure the safety and well-being of their residents. Moreover, states should establish effective systems for monitoring facility performance and enforcing these standards.

There is no doubt that assisted living is a creative and viable option along the continuum of housing for older persons. Indeed, its popularity signals a change in the perception of what it means to age in place—expanding the boundaries of "place" beyond the four walls of the family home and into a new dwelling within the neighborhood or community. Consumers are attracted to facilities like Springdale in large part due to the supportive services that are offered or that appear to be offered: personalized assistance, recreational facilities, and supervision. However, as discussed in this article, the rapid growth and increasing popularity of this concept has raised and will continue to raise issues of great consequence to the housing, health care, social service, and legal professions, and of course, to consumers. These groups should work together to identify the issues raised by assisted living and to create solutions that balance the interests of all involved and ensure high quality, safe, and affordable housing.

NOTES

1. This advertisement was created by the author to highlight the kind of marketing claims made by assisted living providers. It is not intended to represent advertising by any particular provider.

2. See Elizabeth Clemmer, Assisted Living and Its Implications for Long-Term Care 1-2 (1995); Donna L. Yee, Ensuring Resident-Centered Care in Assisted Living 1 (1994).

3. Nursing homes are certified to provide different levels of care ranging from custodial (room, board and supervision) to skilled nursing services, at a cost of up to $6000 a month. Nursing homes must meet certain standards to participate in the federal Medicare and Medicaid programs and are monitored annually by the states for compliance with these standards. See 42 U.S.C. § 1395 (1997) (Medicare), 42 U.S.C. § 1396 (1997) (Medicaid). See also John J. Regan et al., Tax, Estate & Financial Planning for the Elderly § 15 (1997).

4. Service coordinator programs assist residents in accessing community-based support services to improve their quality of life and prevent premature institutionalization. In federally assisted housing, service coordinators help eligible elderly and nonelderly disabled residents obtain housing. See 12 U.S.C. § 1701(q)(g) (1959) amended by 42 U.S.C. § 8012 (1992). Service coordinators may also be located in other federally funded programs and in some state and local housing programs. In a most interesting development, a handful of private sector landlords, observing the increasing age and frailty of their tenants, have hired in-house service coordinators or contracted with outside agencies to assist them in accessing services. See Susan Lanspery, AAs [Area Agencies on Aging] and "Naturally Occurring Retirement Communities (NORCs)," The Supportive Housing Connection, Nat'l Resource & Pol'y Center on Housing & Long-Term Care, June 1995 (visited Apr. 27, 1998) <http://www-lib.usc.edu/Info/Gero/libpub.htm>.

5. CCRCs have evolved over the last century from what used to be called life care communities, in which religious or fraternal organizations promised total life care in exchange for the resident's assets. The CCRCs of today provide or arrange for housing and health-related services for the life of the
individual, or for a specified period. They house large numbers of residents in separate independent living, assisted living, and skilled nursing units, which are all part of the same general program, but which usually require residents to move from one location to another as their needs change. Thirty-seven states currently regulate CCRCs, with requirements varying from minimal disclosure to comprehensive financial and managerial disclosure and financial reserve requirements. The U.S. General Accounting Office reports that, in a survey of eleven CCRCs, entrance fees ranged from a low of $34,000 for a studio apartment for one person, to a high of $439,600 for a two bedroom home for a couple. See U.S. GEN. ACCT. OFFICE, HEALTH CARE SERVICE: HOW CONTINUING CARE RETIREMENT COMMUNITIES MANAGE SERVICES FOR THE ELDERLY 3 (1997) [hereinafter GAO, HEALTH CARE SERVICE]. In addition, monthly fees range from $1383 for an individual to $4267 for a couple. See DAVID W. SCRUGS, THE CCRC INDUSTRY: 1996 PROFILE 2, 8, 21 (1996).

6 A board and care facility is a publicly or privately operated residence that provides personal assistance, lodging, and meals to two or more adults who are unrelated to the licensee or administrator. See JANE BEYER ET AL., A MODEL ACT REGULATING BOARD AND CARE HOMES: GUIDELINES FOR STATES 1 (1984). Traditionally, board and care has been the affordable option for frail older people requiring supervised living. The board and care category includes adult care homes, senior assisted housing, group assisted living, domiciliary care, congregate care, supportive housing, residential care, and personal care facilities. The size of the facility and the number of people served can range from small group homes housing three to five residents to large facilities of up to one hundred residents, and the fees are just as variable. Board and care facilities are licensed and/or regulated to some degree in every state. However, gaps in enforcement of state laws continue to allow unlicensed and unregulated homes to operate. Even among facilities that do comply with state requirements, the quality of resident care varies markedly. See generally CATHERINE HAVES ET AL., THE REGULATION OF BOARD AND CARE HOMES: RESULTS OF A SURVEY IN THE 50 STATES AND THE DISTRICT OF COLUMBIA 1-7, 11-19 (1993). See also Michael Schuster, Board and Care: How Effective are Licensing Standards?, 27 CLEARINGHOUSE REV. 600, 600-05 (1993); Can Your Loved Ones Avoid a Nursing Home? The Promise and Pitfalls of ‘Assisted Living’, 50 CONSUMER REPS. 656, 656-59 (1995).

7 See ROSALIE A. KANE & KEREN BROWN WILSON, ASSISTED LIVING IN THE UNITED STATES: A NEW PARADIGM FOR RESIDENTIAL CARE FOR FRAIL OLDER PERSONS 1, 1-12 (1993).

8 See YEE, supra note 2.


10 Sunrise Assisted Living, Marriott, Hyatt, and Manor Care all provide assisted living facilities. Marriott, for example, has opened 90 assisted living facilities nationwide, and has 20 more under construction. See MONTGOMERY SUNDAY J., Jan. 11, 1998, at A3.


12 See id. at 1 n.1.


19 See GAO, HEALTH CARE SERVICE, supra note 5, at 3.

20 See KANE & WILSON, supra note 7, at 48.


22 See Levine, supra note 15.

23 States funding some assisted living services through Medicaid waivers and/or other state-funded programs include Arkansas, Colorado, Georgia, Maine, Massachusetts, Minnesota, Missouri, Montana, Nevada, New Mexico, New York, North Carolina, North Dakota, Texas, Washington, and Wisconsin. See GAO, LONG-TERM CARE, supra note 11, at 20-24. See also ROBERT L. MOLLICA & KIMBERLY IRVIN SNOW, STATE ASSISTED LIVING POLICY 17 (1996).
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25 Telephone interview with Stephen H. Gardiner, President of Enterprise Senior Ventures, Inc. (Feb. 10, 1998).


27 See MOLICA & SNOW, supra note 23, at 20.

28 See Lundine & Payne, supra note 21.


30 See GAO, LONG-TERM CARE, supra note 11, at 27.

31 See Coleman & Faibanks, supra note 29.


33 Based on a study by the federal government, the occupancy rates of skilled nursing homes dropped from an average 91.8% to 87.4% from 1985 to 1995, even though the elderly population was growing faster than the number of nursing home beds. See Matthew J. Murer, Assisted Living: The Regulatory Outlook, NURSING HOMES, July-Aug. 1997, at 24.

34 See id. at 24-27.


36 See GAO, LONG-TERM CARE, supra note 11, at 5.


39 Activities of daily living include bathing, dressing, toileting, eating, or medication managing.

40 See GAO, LONG-TERM CARE, supra note 11, at 3.


42 California, for example, requires “residential care facilities” to provide twenty-four hour care and service to those suffering from cognitive impairments or inability to perform activities of daily living, on-site staff, three meals a day, including special dietary accommodations, written contracts or other guarantees of emergency services from a physician or nurse, and appropriate procedures by which to assist residents in the self-administration of prescription medication. See CAL. CODE. REGS. tit. 22, § 58030 (1993).

43 For example, Kansas now permits skilled nursing care or extensive assistance with activities of daily living by appropriate staff. Wisconsin allows up to 28 hours per week of supportive, personal, and nursing services. New Mexico permits periodic nursing care, personal assistance with activities of daily living, and supervision of self-administered medication. See Wagner & Vickery, supra note 41, at 40.

44 Maryland, while in the process of developing regulations that would amend Md. Regs. Code tit. 10 § 07.14, is considering licensing distinctive levels of assisted living based on the level of services provided to residents. Under the licensing program, a facility would be permitted to obtain a waiver in order to retain a resident whose needs had exceeded those for which the facility was licensed upon a showing that the resident’s needs could be met. Still under consideration, these proposals have not yet been published for comment. Md. REGS. CODE tit. 10.70.14.01-03 (1998) would implement Md. CODE ANN. HEALTH-GEN. §§19-301, 302; 19-307, 308; 19.324.1, .2 (1996).

45 Nurse Practice Acts in Oregon and other states permit non-licensed persons to be responsible for dispensing medication under limited circumstances. OR. ADMIN. R. 851-47-000, 851-47-030 (1992). However, a team of University of Minnesota researchers, concerned about the mishandling of medication by residents and staff in assisted living facilities, recently called for minimum standards for the storing and administering of medication. Of the 98 facilities studied by the researchers, 86%
stored medication for residents, 83% reminded residents to take their medication, and 69% administered medication to one or more residents. Six of the 98 facilities reported that a resident had been hospitalized as a result of an adverse drug reaction or medication overdose. Of the 64 facilities participating in follow-up interviews, one third reported that residents were allowed to manage their own medications. Given the potentially frail resident population, the researchers recommend that medication storage and administration be regulated, and that staff responsible for the set up and administration of medications be required to have a minimum level of training. See Susan L. Cooper et al., Drug Use Management in Board and Care Facilities, GERONTOLOGIST, Dec. 1997, at 748.


47 See id. at 225-26.


51 PLA. STAT. ANN. § 400.4117 (West 1997).


55 See Mollica & Snow, supra note 23, at 19. Alaska requires that residents not be bed-ridden, among other conditions. See ALASKA STAT. § 47.33.005 (Michie 1997), ALASKA ADMIN. CODE tit. 7, §§ 75.010 (1995). Idaho will not allow individuals who are in need of assistance with activities of daily living and personal care, to reside in assisted living. See IDAHO CODE §§ 39-3301 (1996), 16 IDAHO APA 3-22-700 (1996). Oregon places no specific limits on residents, but allows facilities to discharge residents whose needs the facility is no longer able to meet. See OR. REV. STAT. §§ 443.400.460, 443.991 (1977), OR. ADMIN. R. §§ 411-56-000. Tennessee allows a facility to retain for 21 days, but not to admit, an individual who needs in-travenous or gastronomy feeding, catheter care, sterile wound care, treatment of stage three or four decubitus ulcers or who, after those 21 days, requires four or more skilled nursing visits per week. See TENN. CODE ANN. §§ 68-11-1404 (1996).


57 California requires providers to give residents a 30-day written notice of the intention to evict or three days upon a determination of good cause by the health department, see CAL. CODE REGS. tit. 22 § 87589 (1993), and although a resident may request a documentary review of a health department order, there is no right to further review. Hawaii provides for a two week notice of the intention to evict, but makes no mention of outside review. See HAW. REV. STAT. §§ 321-15 (1995), HAW. ADMIN. R. §§ 11-100-1 (1986).


60 42 U.S.C. § 3601 (1988). While the FHAA does not specifically prohibit restrictions on group homes for persons with disabilities, the legislative history makes clear Congress intentions. H.R. REP. NO. 100-711, at 24 (1971), 100th CONG., 2d Sess. 24 (June 17, 1988), reprinted in 1988 U.S. CODE CONG. & ADMIN. NEWS, at 2185. In the area of health and safety codes, courts have struck down state and local rules that unduly limit residency by otherwise eligible persons with disabilities. See Potomac Group Home Corp. v. Montgomery County, Md., 623 F. Supp. 1285, 1301 (D. Md. 1993) (holding that fire and safety codes requiring a resident who uses a wheelchair to be able to transfer to the wheelchair and exit the building without assistance violate the FHA by failing to take into account alternative safety measures and the needs and abilities of individual residents). See also Stephanie Edelstein et al., Housing Rights of Group Home and Nursing Home Facility Residents, 29 CLEARINGHOUSE REV. 664, 668 (1995) [hereinafter Edelstein et al., Housing Rights].


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63 See Edelstein et al., Housing Rights, supra note 60, at 664-71; Vicki Gottlich, Protection for Nursing Facility Residents under the ADA, GENERATIONS, Winter 1995, at 43-47.


66 See Klein v. BIA Hotel Corporation, 41 Cal. App. 4th 1133, 1135 (1996). In Klein, children sued a licensed “residential care facility” (assisted living) for the wrongful death of their mother, who had suffered from depression and committed suicide while a resident. The court found that the facility had a duty to exercise a reasonable standard of care in accordance with its license, including monitoring the physical and mental health of its residents and taking reasonable steps to keep residents safe. The court remanded the case to determine whether the facility breached that duty. See also Dorothy Regas Richards, One Way to Spell Liability Relief, CONTEMP. LONG TER. CARE, Sept. 1996, at 64, 66; Steven R. Olson, Linking Service To Standards, PROVIDER, Jan. 1994, at 51.

67 See Dresner & Vignery, supra note 65.

68 Mediation holds potential for helping the facility and the resident reach a satisfactory resolution of issues. For a discussion of mediation in the nursing home arena, see NAOMI KARE & ERICA F. WOOD, KEEP TALKING, KEEP LISTENING: MEDIATING NURSING HOME CARE CONFLICTS (1997).

69 Forty-six percent of residents move out of assisted living and into nursing homes because they need more help than the assisted living facility can provide, 12 percent go into a hospital, and another 12 percent move to a second assisted living or retirement residence. See Susan Fitzgerald, A Cost Effective Quality Alternative, ASSISTED LIVING TODAY, Fall 1995, at 4A (citing a survey by the Assisted Living Federation of America).


71 See id. at 3.

72 Alaska requires that the contract be written, and include the specific services and accommodations to be provided, the rates and the refund policy, the rights, duties and obligations of the resident, and the termination policies and procedures. See ALASKA STAT. § 47.33.005 (Michie 1997), ALASKA ADMIN. CODE tit. 7, § 75.010 (1995). New Hampshire requires a description of the services provided, the facility rules, the bed hold policy, grounds for termination and procedures for involuntary transfer. See N.H. REV. STAT. ANN. § 151.1 (1979).


74 Assisted living specialist Keren Brown Wilson, in a report for the AARP, discusses Oregon’s outcome-oriented regulatory framework that balances resident autonomy and quality care. Wilson proposes (1) a definition of assisted living, (2) minimum licensing standards based on quantifiable requirements, (3) outcome goals in eleven essential areas of resident autonomy, service provision, and physical setting, and (4) a monitoring process to determine compliance with the minimum standards and the outcome goals. See Wilson, supra note 9, at 11.

Mollica & Snow discuss two states’ outcomes, or performance measurements for evaluating quality in assisted living. Washington state is testing an approach by which a state inspector reviews the facility’s complaint history, checks for any concerns expressed by the long-term care ombudsman and residents’ case managers, and conducts on-site interviews with residents and staff. Connecticut requires assisted living services agencies to establish interdisciplinary teams consisting of a physician, a registered nurse, and a social worker, to review facility and resident records and to compare the facilities activities to agency standards. See MOLLICA & SNOW, supra note 23, at 45-47.

In addition, AARP has joined with the Alzheimer’s Association, the American Association of Homes and Services for the Aging, the American Health Care Association, and the Assisted Living Federation of America to create the Assisted Living Quality Coalition (ALQC), with the goal of developing an industry model for assuring quality in assisted living. The ALQC developed recommendations for assessing quality in assisted living and convened meetings in two states—Pennsylvania and Colorado—to share ideas and obtain input on the model and its potential for practical application from organizations, aging and disability advocates, state agencies, and individuals involved at the state and national levels. The coalition has not yet released its final recommendations for quality standards. Information available through American Association of Retired Persons Public Policy Institute, 601 E. Street, Washington, D.C. 20049.