Assisted Living at the Crossroads: Principles for Its Future

A Discussion Paper by

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The Jessie F. Richardson Foundation is a not-for-profit organization advocating innovation and quality in housing and long-term care. It can be reached at 9803 SE Ramona Street, Portland, Oregon 97266, phone 503.720.9000, Facsimile 503.698.5375.
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Executive Summary

Background

Assisted living evolved, in large part, because older people wanted to avoid nursing homes and their families also wished to spare them the regimented, abnormal lifestyle associated with life in typical nursing homes. Assisted Living seemed to offer an alternative that could provide or arrange necessary care in settings that preserved privacy, dignity, choice, and normal life styles.

Since its origin in the mid 1980's, the growth in assisted living, largely as a private-pay option, has been shaped by the interaction of three forces: provider visions and goals; consumer goals and responses; and state policies, which can encourage, discourage, and shape the services and settings. At present, assisted living is characterized by great intra-state and inter-state variation in physical plants, service configurations, and the extent to which their residents mirror the health conditions and functional limitations that would qualify them to enter a nursing home.

Decisions in the public and private sector will profoundly shape assisted living's future. Rapid growth, critical media scrutiny, growing public payment, Congressional attention, industry stress, and quality concerns have created a climate where change is likely to occur and public oversight is likely to increase. While protecting consumers against confusing market claims and poor care, it is imperative to respond with a strategy that keeps assisted living's original promise of a better way to live with long-term care needs.

Essential Elements of Assisted Living

This Discussion Paper identifies essential elements of assisted living and describes the extent to which they are met in current assisted living settings. Even if some entities now called assisted living fail to embody them, assisted living has three major attributes (the 3-legged stool on which assisted living rests) that arguably define its very essence: a residential physical environment that resembles private homes; a philosophy that gives priority to consumer choice, independence, dignity, and preferred life-style; and a capability to muster routine and specialized services to meet individual need. Any regulatory and quality monitoring process applied to assisted living should preserve and, better, promote these essential characteristics.

Residential environment. The residential environment includes at a minimum a room and full bath that is unshared unless the resident explicitly wishes, resident control over the use of this space,
accessibility features to enhance residents' functionality and mobility with assistive devices including wheelchairs. Public space must similarly be designed to permit access to indoor and outdoor spaces. (Beyond that assisted living settings may and often do have many other autonomy-enhancing, life-enriching features that are not available to nursing-home residents under current regulatory expectations.) To maintain residential character, residents should be free of the effects of disruptive behavior of other residents in public spaces or intruding in their private space.

**Philosophy.** The philosophy of promoting consumer control and choice in daily life and care and enhancing what residents would consider a "normal" good quality of life is encompassed in some state regulations already. However, tensions are unresolved between respecting preferences versus protecting safety, and require fresh thought about regulatory expectations, including regulations that prohibit aging in place by defining who is "appropriate for a setting." The essentials of implementing the philosophy are that: residents preferences are known; attempts are made to honor resident priorities and help them implement their preferences; and residents are, as much as their abilities allow, in control of their lives, their schedules, and their own space in their rooms or apartments.

**Service capability.** Achieving a service capability that results in Individualized care has proven challenging, especially at a cost that public and most private payers can afford. Much training of personnel, along with a conducive work climate, is needed to achieve truly individualized care. Use of universal workers and delegation of nurse services have been used in assisted living to make individualized service capability more feasible, but these advances may be undercut by hasty promulgation of prescriptive staffing standards for assisted living settings. Essential elements in service capacity include offering or arranging: competent initial assessments of needs and preferences; individualized service planning; kind, capable, and responsive personal care 24 hours a day, 7 days a week; 3 meals a day; housekeeping; identification of changes in residents' physical functioning and condition; arrangements for specialized assessments and interventions; and responses to emergency situations. The provider must also offer or arrange routine nursing services, including medications management, but "nursing services" should not be construed as services that can only be performed by a registered or licensed nurse.

**Challenges**

This Discussion Paper identifies challenges that must be addressed to maintain and improve the quality of assisted living while preserving the essential qualities that made it sought out be consumers.

- resolving the tension between enhancing autonomy and preferred
quality of life while protecting safety. This plays out concretely around determining how to deal with incidents such as falls and accidents, and other adverse outcomes, including weight loss and bed sores. An expectation of no adverse events is unreasonable in any setting, let alone one that mirrors the private home, but, beyond unambiguous examples on either side, differentiating outcomes that result from poor care from unpredictable outcomes is difficult. Moreover, providers, regulators, and advocates may be reluctant to allow consumers to decide to take risks in order to enjoy their lives, even though hard information about the likelihood and severity of many of these risks is scant. Negotiated risk agreements, whereby an informed consumer knowingly and formally agrees to shoulder risks and providers articulate the steps they will take to minimize those risks are one vehicle that could help resolve this tension, but more explication is needed about how they might operate within a framework of quality improvement and quality assurance.

Determining the conditions under which a consumer can remain in the assisted living setting. Aging in place has been an ideal of assisted living, but it is hard to realize in the face of perceived safety risks. Some jurisdictions prohibit consumers with specified functional problems or needs from remaining in assisted living, and some providers prefer an ideal that they disclosure retention criteria rather than aim to keep residents who want to stay. A recent Michigan Supreme Court decision led to a state statute prohibiting enforced removal of residents from assisted living settings if they and their interested family want them to stay, the provider is willing to keep them, and the primary care provider affirms that health needs will not be jeopardized in the setting. This ruling may offer a promising guideline for other jurisdictions.

Meeting the consumers' needs and wishes for individuality and for community. People have a need for both individuality and belonging to a community, though the emphasis placed on each varies according to the person. At the individual level, this raises a tension between mandated activity programs versus mandated individual attention. A related issue is how to balance the interests of the community of residents with those of particular individuals. Setting up special areas for dementia or for heavy care may be responsive to some concerns of residents and families about the effects of encroaching disability levels on community life, but undercuts aging in place.

Establishing expectations that coincide with willingness to pay. Most state public payment systems and many privately paying consumers have inadequate financial resources to pay for an ideal assisted living setting and services. Separating the costs of shelter and board from services and care is an important contribution of assisted living, but most public subsidy programs attribute an unrealistically low rate for shelter and meals, often pegging it at what Supplemental Security Insurance (SSI)
allows for room and board. Overall, the public's expectations surpass its collective ability or willingness to pay, and yet stakeholders have a hesitancy to set priorities, or to permit consumers to choose tradeoffs that might place standard views of safety second. This is particularly true when consumers exhibit any evidence of cognitive impairment. Older consumers are more realistic in their demands for a normal good quality of life than are advocates, regulators, providers, and even their own family members, though they may emphasize different priorities.

✓ accepting limitations and sharing responsibility. A goal of zero tolerance for adverse health outcomes has proven impossible to achieve in nursing homes, undermines the spirit of assisted living, and is especially difficult to enforce because assisted living's essential components include social features directed at broad social and psychological well-being. The Discussion Paper summarizes two concepts bounded choice and shared responsibility which may assist stakeholders, including citizens at large, in necessary discussions about what outcomes are expected of assisted living and the responsibilities of all parties for bringing them about.

Strategies for Action

Considerable pressure is mounting for national standard-setting, or at least for requirements that states meet specific standards in a model statute before using federal funds for assisted living. Given the developmental state of the field, a slow approach to prescriptive mandates would be prudent while the field is developing. Any action at present should surely be at the state level, but we favor states treading slowly in their own prescriptive mandates. Model state statutes seem less useful than learning from accumulated experience with diverse state approaches that presently prevail, a strategy we recommend.

It is fruitful to consider how assisted living might be regulated if it were viewed as more like home care than like nursing homes. We also suggest that regulations and their enforcement can be used to enhance non-regulatory quality assurance strategies such as consumer information and empowerment, on the one hand, and provider-initiated quality improvement efforts on the other. The Discussion Paper concludes by discussing in greater detail a dozen suggestions.

• Strive for approaches, guidelines and standards that pay significantly greater attention to quality of life.
• Consider how regulations and monitoring could affect achieving the essential features of assisted living and resolving the major challenges described in this paper.

• Critically examine existing state assisted living regulations and enforcement practices for their effects on the preceding goals.

• Consider whether there has been unnecessary spillover of existing nursing home rules into assisted living, and at least for a time evolve assisted-living oversight as independently as possible from nursing-home oversight.

• Develop actions that states can take to enhance consumer information and understanding of assisted living.

• Determine how negotiated risk contracting and individualized care planning can be encouraged by and be compatible with regulation.

• Keep the focus on the values inherent in assisted living with training and dissemination of "best practices" all geared to developing competence in the promotion of those values.

• Find ways to address subsidies for shelter costs.

• Incorporate into any standard setting activity an analysis of impact related to monetary costs, resident autonomy, resident rights, and livability.

• Refine ways to measure the outcome of assisted living and conduct research targeted at improving assisted living capabilities.

• Determine how to support active family involvement in care in assisted living.

• Encourage community dialogue and consensus building.
Assisted Living at the Crossroads:
Principles for Its Future

Why at a Crossroads?

Assisted living as a form of long-term care is at a critical juncture, where decisions taken in the public and private sector will profoundly shape its future. From little more than an idea in the mid 1980's (Wilson, 1990), this service sector grew to about 11,500 settings caring for well over 500,000 residents by 1999 (Wunderlich & Kohler, 2001). Unlike the comparable growth of nursing homes in the 1960's, which was largely fueled by Medicaid payment mechanisms for low income people, assisted living expanded largely through a private-pay market. Although as of July 2000, thirty (30) states provided some public funding under Medicaid waivers and other mechanisms for low-income people to receive care in assisted living settings, in no state did Medicaid assist in payment for more than 25% of the clientele and in many states the proportion is much lower (Mollica, 2000). Medicaid helps pay for almost 70% of nursing home residents nationwide (Feder & Neifeld, 2000), whereas, according to a 1998 study, only 19% of assisted living residents use any other source of payment (for example, Medicaid, SSI supplements, or insurance to supplement their own or family resources (Wylde 1998). Because assisted living was initially a private pay phenomenon, regulatory oversight lagged behind development. Now with the large numbers of citizens served and growing public payment, the interest in quality standards and oversight is mounting.

Moreover, with the expansion of assisted living, serious concerns and challenges have arisen about its quality. The alarm has been sounded by consumer advocates such as nursing home ombudsmen and by state regulators who have a general responsibility for regulating health and long-term care. The worry has been fanned by media reports. Since September 2000, lengthy and largely critical reports on assisted living have appeared in the Philadelphia Inquirer (Tofani, 2000), Consumer Reports (Lieberman, 2001), the Washington Post (Goldstein, 2001a, 2001b), the New York Times (Steinhauer, 2001), the Portland Oregonian (Barnett & Walth, 2001a, 2001b, 2001c), the Charlotte Observer
(Alexander & Kelley, 2001a, 2001b), and Time Magazine (Goldstein, 2001), to name a few. Collectively, this coverage alleges both neglectful and insufficient care, as well as financial and resident retention practices that mislead the public. At the same time, many of these and other stories affirm that older people and their families like assisted living, wish to stay there even when state regulators assert they should leave for more protected settings, and on the whole report high satisfaction. For example, a U.S. and World News article (Shapiro, 2001), the previously cited Time story (Goldstein, 2000), an article in the Los Angeles Times (Rosenblatt, 2001) and one in the New York Times (Oser, 2001) emphasize assisted living's positive appeal to consumers.

Congress reacted to the quality concerns, ordering a General Accounting Office report (GAO, 1999a); based on a four-state study, the report fell short of suggesting federal oversight but raised concerns about how well consumers are informed about assisted living and the nature of typical contracts between providers and consumers. The Senate Committee on Aging held hearings in 1999 and 2001 to examine whether a federal presence is needed in assisted living regulation, and, if so, what form it should take. Subsequent to the congressional hearings held in spring 2001, the Senate Aging Committee requested interested parties including industry representatives and consumer representatives to meet to develop some suggested guidelines for assisted living and report to the Committee on its progress in the Spring of 2002. Committee members recognized that federal regulation had failed to solve many quality problems in nursing homes, yet expressed uncertainty about viable alternatives. Apart from the Senate Aging Committee, a number of individual congressional members have sought venues through other committees to hold hearings on assisted living as it effects their districts.

The combination of rapid growth, media scrutiny, growing public payment, Congressional attention, and quality concerns has created a climate where change is likely to occur. Assisted living providers, themselves faced by a crisis in obtaining liability insurance and, in some instances, a problem with the bottom line, may modify their goals, perhaps dropping heavier care or a commitment to aging in place. Some regulators and advocates have begun to call for using the standards that apply in nursing homes to judge quality in assisted living.

The solutions so far advanced in policy circles seem to revolve around a limited repertoire derived from almost four decades of
experience in regulating nursing homes. These strategies as they have been refined over the years have led to improvements in nursing home care, though problems related to health and safety have far from disappeared (GAO, 1998, 1999b, 1999c; OIG, 1999a, 1999b). But although regulatory oversight may help check the most egregious problems in quality, more than three decades of nursing-home regulation have failed to render nursing homes places where older people care to live or where relatives willingly send them.

Assisted living evolved to solve a problem with nursing home care that was strongly felt by consumers and their families. Although holding no brief for poor care, we are concerned that in any rush to regulatory protection, the very essence of what assisted living sought to achieve for its consumers will be lost. Moreover the very definition of poor or unacceptable care and results and of good care in all settings needs to be re-examined in the light of the powerful attractions of assisted living to consumers. This Discussion Paper articulates issues that public authorities and private groups should consider when determining "what is to be done about assisted living." Undoubtedly, there will and should be a push to balance the tension between consumer autonomy and public safety inherent in all long-term care, and to send signals to the assisted living industry to make mid-course corrections. But without overarching principles for defining and seeking quality, the best of what assisted living offers may be lost. We offer no clear answers. In many instances, we ourselves are uncertain about the best way to proceed. Rather we urge dialogue and no premature foreclosure on who assisted living should serve or how it should be staffed or organized.

Background: Evolution of Assisted Living

Assisted living is the product of idealism, pragmatism, entrepreneurial impulses, and consumer hope. The result: a bewildering array of programmatic forms, all bearing the label assisted living. The problems assisted living sought to address are well documented: the sterility and rigidity of nursing homes and the dread and despair they evoke in prospective or actual users. The indignities of one-size-fits-all solutions, the loss of privacy, the loneliness and lack of meaning that nursing home life can inculcate are a recipe for avoidance by consumers (and, incidentally, many health professionals) and guilt for family members who accept so-called "placement" of their relatives. Years ago, Elaine Brody (1973) likened the nursing home to the Procrustean bed of the mythic hosteller who stretched or cut the legs of his victims to fit his one-size bed. This chilling metaphor is still apt. Some commentators believe that regulatory efforts to improve quality of care in nursing homes ultimately reduced quality of life.

One of the first articulations in public policy of assisted living as it has come to be understood began in Oregon in the mid 1980's, with the opening of two congregate residential settings, each composed of more than 100 self-contained apartments. These settings were built to nursing home standards in terms of corridor widths and
disability-friendly physical environments, and aspired to serve people with the physical and cognitive disabilities that would have rendered them likely candidates for nursing homes. The state of Oregon conducted a demonstration project in 1986 to determine whether Medicaid-waiver clients could be well-served in these settings, and, having reassured itself, moved rapidly with task forces and public input to create regulations to encourage and shape a new long-term care form. The evolution of this model has been well-documented (Kane al, 1990; Wilson, 1993). The hallmarks of Oregon-style assisted living are: privately-occupied (unless by choice), apartments with full bathrooms (typically with roll-in showers) and kitchenettes; three daily meals served in a congregate dining room as part of the basic price; and an expectation that people with the full range of long-term care needs be accommodated. From the beginning, Oregon provided Medicaid coverage for the service components of assisted living for those financially eligible (room and board to be paid out of income). This model focused on creating broad access in terms of serving people with acuity similar to those eligible for nursing homes.

A national evaluation of Oregon assisted living was conducted using a longitudinal data to compare 600 assisted living residents in 38 settings to an equal number of nursing home residents in 31 facilities. Based on data collected in 1995 and 1996, multi-variate analysis controlling for resident characteristics showed that being in an assisted living setting versus being in a nursing home made no difference in some of the health-related outcomes of greatest concern to advocates: functional status, pain and discomfort, and mental health symptoms of depression and anxiety (Frytak, et al., 2001). Thus, setting did not account for patterns of change in arenas thought sensitive to the greater nursing availability in nursing homes. Other analyses under way show that the assisted living setting was associated with greater family involvement (Gaugler & Kane, in press;), social well-being, and resident satisfaction.

At about the same time, a private-pay, high-acuity model of assisted living was evolving on the east coast. Inspired by service settings in the Netherlands, these communities are comprised of relatively small private studio apartments or 2-bedroom suites (with private rooms and shared living room, kitchen and bath; well-planned public space; and significant attention to socialization to encourage a family atmosphere. Using a signature building style, this model became branded as Sunrise Assisted Living. Subsequent entrants into assisted living often chose elements of either the Oregon approach or the Sunrise model, ultimately leading to many competing hybrid models with varying levels of service and amenities designed to serve a broad array of individuals with differing care needs and income levels.

Assisted living development accelerated after 1994 when the interest of Wall Street and other investors who provided capital for growth was captured. This resulted in a proliferation of congregate residential care settings for care, sometimes licensed by states.
(typically under residential care facility provisions) and sometimes not licensed at all. As the term assisted living gained recognition, and with the prospect of third-party coverage for its services, the existing board home and residential care industry renamed itself assisted living. For example, the Adult Congregate Care Facilities in Florida, which are more numerous and serve more Floridians than nursing homes, became called Assisted Living Facilities. Many of these failed to meet the environmental standards that some see as intrinsic to assisted living, and indeed Florida state regulation prohibited them from seeking a service standard comparable to nursing homes. Similarly, a large rest home industry in North Carolina was grand-fathered in as assisted living. Some states use the term assisted living for very small family homes that other states call adult foster homes or some similar term. Residential care units attached to or on the campus of nursing homes also began to and in some states were required to call themselves assisted living; rarely were such nursing-home-based entities comprised as private apartments (though often they had private rooms and bathrooms), and typically the providers aspired to moving residents through a continuum of care rather than permitting (let alone encouraging) the option to "age in place" in the assisted living wing. In Continuing Care Retirement Communities, the middle level between independent living and nursing homes may be designated assisted living, depending on the state. Some states even license home-care services going into designated congregate settings as assisted living. The Assisted Living Federation of America broadened its representation in recognition of this variety by merging with the National Residential Care Association and National Association of Senior Living. The term, assisted living, is now so ubiquitous that entities such as HUD, Fannie Mae, and the United States Veterans' Administration incorporate it into their routine lending or contracting cycles. In sum, a combination of self-designation by providers and official designation by legislators and regulators has vastly expanded assisted living and rendered its boundaries unclear.

Although some data have been published about the characteristics of the industry, the variation has made describing it uncertain at best (ALFA. 2000; Hawes, Phillips, & Rose, 2000; Hawes, Rose & Phillips, 1999, Wylde, 1998). Precise numbers are hard to come by, though some trends seem clear. Ownership is largely for profit (75%). Indeed, not-for-profits, perhaps due to financial limitations or to the need to garner consensus about a change in direction, were slower to adopt assisted living. By now, however, 25% of the settings are nonprofit, with considerable state variation in that proportion. For example, the Minnesota Health and Housing Alliance, which is the affiliate of the national nonprofit trade association American Association of Homes and Services for the Aged has more housing-with-services members than nursing home members, and recently produced a position statement endorsing for all of long-term care many of the principles of privacy and consumer-centered care associated with assisted living (MHHA, 2000).
Although large multi-facility providers are highly visible, ownership is largely made up of single or small regional providers. In 2000, the largest 25 providers in the United States accounted for 23% of the properties and 16% of the operational capacity. Of the national companies, some are public companies devoted solely to assisted living (Assisted Living Concepts, Alterra, Sunrise Assisted Living), others have their roots in the hospitality industry (Marriott, Hyatt), and still others were spun off of or brought key management from the nursing home industry (Balanced Care, Emeritus, Atria). And among the national companies, some were privately held and others were publically traded. The first dedicated assisted living company went public in 1994, and by the year 2000, there were 14 publicly-traded companies offering assisted living, three of which also provide nursing-home care (Price Waterhouse, presented by companies going public provided the capital that spread the assisted living models after more than a decade of very modest growth, particularly the high acuity, high amenity models represented by both the Oregon and Sunrise models. But it also brought injudicious growth, restive stock holders seeking quick returns on their investment, prices for services too high for persons with modest incomes, and financial trouble for many of the companies.

The result of all the activity since the mid-1980s means that assisted living enters its adolescence with extraordinary variation within and across states, including in: size, physical environments, target clientele, typical staff patterns, usual length of stay, price, and public subsidy. Because assisted living services are viewed as home and community-based care rather than nursing home care, it is feasible for states to subsidize these services under Medicaid waivers and other programs, leaving the room and board for the consumer to pay out of income. Some assisted living residents truly approximate tenants renting apartments in housing with services; others occupy what would be recognized more as rooms in boarding houses with services attached; and still others (though fewer) can be said to be living in institutions unworthy to fall under the home and community based care classification because they resemble traditional nursing homes. Level of tenant need also varies enormously, which in turn makes it difficult to promulgate staffing and other requirements. Table 1 illustrates schematically the implications of various tenant characteristics for service requirements. The actual services provided or arranged must be sensitive to the functional abilities, cognitive abilities, and medical needs of the residents. The table shows the wide range of needs that can be found in assisted living. The table uses illustrative ADL and IADL impairment levels to characterize functional dependency. In actuality some states may limit assisted living from serving residents with some of those needs.
### Table 1. Service Implications of Various Tenant Levels of Impairment

<table>
<thead>
<tr>
<th>Tenant Impairment</th>
<th>Low (Hospitality Model)</th>
<th>Moderate</th>
<th>High (Nursing Home Replacement)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical Impairment</td>
<td>Level of physical impairment minimally impacts ability to perform self-care, e.g.:</td>
<td>Level of physical impairment adversely impacts ability to perform self-care, e.g.:</td>
<td>Level of physical impairment significantly adversely impacts ability to perform self-care, e.g.:</td>
</tr>
<tr>
<td></td>
<td>✷ T 0-1 ADL(^a) dependencies</td>
<td>✷ 2-3 ADL dependencies</td>
<td>✷ 4 or more ADL dependencies</td>
</tr>
<tr>
<td></td>
<td>✷ 1-2 IADL(^b) dependencies</td>
<td>✷ 3-4 IADL dependencies</td>
<td>✷ 5 or more IADL dependencies</td>
</tr>
<tr>
<td></td>
<td>✷ needs assistance with 2-3 IADLS</td>
<td>✷ needs assistance with 3-4 IADLS</td>
<td>✷ needs assistance with 5 or more ADLs</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>✷ needs assistance with 6 or more IADLS</td>
</tr>
<tr>
<td>Cognitive Impairment</td>
<td>Level of cognitive functioning adequate to survive independent of 24-hour supervision</td>
<td>Level of cognitive functioning impacts ability to survive independent of ongoing oversight (e.g., mild dementia)</td>
<td>Level of cognitive functioning significantly adversely impacts ability to survive independent of ongoing oversight (e.g, mid-to late-stage dementia)</td>
</tr>
<tr>
<td>Medical/Acute Care Needs</td>
<td>✷ Chronic health problems may be present and treatment may be ongoing; No need for ongoing specialized equipment/procedures</td>
<td>✷ Chronic health problems are typically present and treatment ongoing; Minimal need for ongoing specialized equipment/procedures to intervene</td>
<td>✷ Medical/acute health care needs typically present and need ongoing treatment; Need for ongoing specialized equipment or procedures to intervene.</td>
</tr>
</tbody>
</table>


\(^a\) ADLs (Activities of Daily Living) include: eating, dressing, bathing, toileting, transferring, continence, and walking.

\(^b\) IADLs (Instrumental Activities of Daily Living) include: managing money, using the telephone, shopping, housekeeping, cooking, managing medications, doing laundry and using transportation.
The variation in assisted living continues to be largely shaped by three forces: 1) the goals, vision, and business projections of providers entering the market; 2) state regulations that permit, prohibit, or require certain characteristics of the industry, and may influence the size necessary for viable projects; and 3) consumers' purchasing behavior in various markets, which, for example, may have nudged some assisted living providers into accommodating higher acuity than they originally intended, or have influenced others to cap disability levels or to segregate people with dementia or heavy care needs to better attract or retain well older people. Despite its many guises, assisted living is far from being the unregulated entity sometimes portrayed in the media, assisted living is shaped and constrained by the rules of the states (and to some extent localities) where it operates. The setting is, to a far greater extent than any private home, regulated by building codes typically far more stringent than other public use buildings. Further, whether it is through licensing of services only or licensing of a setting with services, assisted living is already held to a set of standards set by the states. These standards often already more heavily influence provider behavior than consumer preferences or business goals.

A societal response is needed to channel positively all the developments of the last decade so as to keep assisted living's original promise to consumers while protecting them against confusing marketing claims and poor care. Because many consumers could be considered vulnerable adults, and many are or become cognitively impaired, states correctly perceive a public obligation to protect assisted living consumers, regardless of their payment source. We argue that states are also obliged to protect what is good in assisted living and to preserve or at least consider the merits of the reforms assisted living set out to make. At this writing, the Supreme Court Olmstead decision is about two years old, and states are now struggling to evolve plans for long-term care in the most integrated, least restrictive settings for people with disabilities of all ages. Many seniors needing care have downsized their homes and wish to shed routine responsibilities for home maintenance. For them, assisted living could be an integrated community setting like other apartment buildings. Or, with hasty policy mis-steps, assisted living could become another institution barely distinguishable from conventional nursing homes. This latter result would indeed represent a failure in the post-Olmstead age.

Three-Legged Stool of Assisted Living

Assisted living has many definitions. The most agreed-upon points are that it is a group residential setting that is not licensed as a nursing home and where personal care, household services, and routine nursing services are provided or made available for persons with functional impairments (Kane & Wilson, 1993). Some would add "in a homelike setting" to the definition and some would add elements of a philosophy that promotes choice and independence in the consumer's
living situation, but these additions reflect an ideal of some more than an achieved characteristic of all entities called assisted living. In a 2001 attempt to arrive at a definition, the ALFA Executive Committee approved the following language: "Assisted Living is a residential setting that offers choices in personal care and health related services." This definition is so all-encompassing and vague that it offers little insight into the essence of assisted living, or how it differs from a standard nursing home, on the one hand, or an independent living apartment complex on the other.

Figure 1 likens assisted living to a 3-legged stool, each leg of which is essential to the idealized concept (Kane, Kane, & Ladd 1998). The first leg is a residential setting in both the resident’s private space and the shared public space; the second leg is a philosophy that promotes dignity, choice, independence, privacy, individuality, and "normality" in everyday life; and the third leg is a service capacity to meet recurrent, routine needs for help (some of which can and some of which cannot be scheduled) and an ability to arrange for more specialized services that may be needed intermittently. Each part of the tripod is essential to an ideal of assisted living, and regulatory and policy reform will need to consider each.

![Figure 1: Three-Legged stool of Assisted Living](source: Modified from Kane, Ladd, & LDD, 1998.)
Residential Environment

Critics of assisted living, especially in the media, sometimes dismiss environmental amenities in assisted living as though pleasant surroundings and furnishings in cheerful, functional apartments with ordinary residential features like refrigerators, stovetops, and microwaves are mere marketing ploys that are beyond the point of what care is all about. On the contrary, we hold that these physical environments are intrinsic to the theory of assisted living. They are expected to promote functional abilities, meaningful activity, sense of familiarity and security, and well-being. In other words, the residential environment can and should be designed to further both good functional outcomes and good quality of life.

As already stated, physical environments vary in assisted living, and some fail to meet the ideal expectations for privacy, function-enhancing, and life-enriching features. Shortfalls are found especially in extant residential care facilities grand-fathered in as assisted living, and even more particularly in programs designed originally to serve SSI recipients. However, assisted living, on the whole, has done a good job on re-designing physical environments, and has set a new standard for privacy and normal residential environments for people with major long-term care needs. Not surprisingly, the assisted living industry is reluctant to impose expensive environmental standards on its members that some would find difficult to meet, and only a handful of states have been assertive in limiting the use of the term assisted living to private occupancy apartments. Still, the Assisted Living Quality Coalition (a consortium of the Alzheimer's Association, the American Association of Homes and Services for Aging, the American Association of Retired Persons, the American Senior Housing Association, and the Assisted Living Federation of America) emphasize and encourage environmental features that are radically different from nursing homes (Assisted Living Quality Coalition, 1996). It is unlikely that the clock will be turned back on new environmental expectations. Increasingly, as nursing-homes replenish their stock, they are moving at least to private rooms and bathrooms, as well as to smaller rooms and cluster areas that are more residential in nature.

"Privacy except by choice" has few overt opponents, although many express concern over the cost for both public and private pay consumers. Available cost data would suggest privacy is achievable, but many issues remain unresolved. Of greatest concern is the use of Supplementary Security Insurance (SSI) standards to set room and board rates, a topic to which we will return later. But, there are also reported concerns about the possible negative impact of privacy on social isolation and on the physical well-being of those with dementia. Given the priority privacy is given by actual consumers, this is an area worthy of more serious attention if it is to be held forth as core to assisted living.
Tension also arises, however, over other environmental features. For example, some stakeholders doubt that older people with severe physical disabilities or memory problems should have access to ordinary environmental features such as hot water that could scald, showers where they could slip, light bulbs and sockets, ample storage space where various personal supplies can be stashed; cooktops and microwaves, cutting knives, wine and beer, and the like in their apartments; or unsupervised access to patios and other outdoor spaces. Collective thought is needed about whether it is necessary or proper to deprive residents of such niceties lest they injure themselves, especially since people with disabilities in their own home have no such publically imposed strictures. This dilemma introduces a fundamental question that will recur as regulation and quality in assisted living is considered. Is an assisted living apartment more like home, where even the most paternalistic professional would be loath to reshape the consumer's environment (though they may urge moving to a nursing home for a "safer" setting.)? Or, is assisted living more like a nursing home, where residents are protected as much or more than preschool children (who, after all, have access to swings and monkey bars) and where the new resident is often provided with written state rules prohibiting extension cords, most electrical devices, candles, and other things that are taken for granted in private homes? Is a mid-point position possible so that individualized modifications might render environments safer for the few without being sterile for all? What level and type of disability justifies such intrusiveness? And, if accidents occur at the same rate as they do in private homes, is the assisted living community to be judged as having quality problems?

**Philosophy**

The discussion of environment leads to philosophy. The validity of the underlying principles of assisted living choice, dignity, privacy, independence, individualization, normal life styles seems widely recognized, and has come to be espoused in many state statutes, either for assisted living or for long-term care in general. The principles are more easily enunciated, however, than implemented. There is disagreement about the ability to achieve these principles when consumers have significant health problems, severe physical disabilities, or are cognitively impaired. There is also disagreement about the priority that should be given to these values if they lead to what professionals or families see as unnecessary risks or seem to jeopardize health and safety.

In practice, the enhanced physical environments enable many of the values over and above the obvious one of privacy. More choice of routine, use of space, and activities, and more exercise of desired independence is made possible. Some of the principles seem better observed in practice than others. The notion of choice and autonomy in initial service planning is typically quite well implemented. On the other hand, true individualization has been hard to achieve. To truly individualize a service plan requires a determined mind-set, a set of
skills, and significant organizational flexibility. Both providers and regulators would do well to consider what sorts of expectations and training might promote such individualization. To take a trivial example, some states mandate that snacks be served centrally at several times between meals, undermining the likelihood that individualized service planning build in the availability of snack food that residents most enjoy in their own refrigerators and cupboards, along with a care-plan that ensures any necessary assistance or cuing to be sure that the resident is able to enjoy the snack. A more powerful example would be a regulatory or provider stance that permits absolutely no leeway for the resident to execute decisional autonomy in situations having any potential for adverse consequences when the resident has any documented memory loss or cognitive impairments. The irony should not be lost that these individuals have seldom had their civil rights restricted legally by virtue of being adjudicated incompetent to make decisions. Certainly, few advocates for older people consciously view residents as institutional inmates without full civil rights except those given explicitly to them by special rule; the rhetoric and principles of advocacy programs often say quite the contrary! Yet, in practice that loss of rights and "institutionalized" status is what occurs when vulnerable people are subject to far-reaching, professionally-controlled plans for care, and when their lives are dominated by restrictive rules or lived out in socially impoverished environments.

Thus, the philosophy of assisted living is sorely pressed around two issues. First, is the tension around protecting safety, which is felt as an imperative by providers, families, and regulators alike. Striking the balance between safety and autonomy is difficult because little creative thought has been devoted to how to give reasonable attention to safety while preserving autonomy. Indeed, research knowledge about the likelihood of various risks and the efficacy of orthodox approaches to reduce risks is virtually non-existent.

A second, related issue is when, if ever, residents should be deemed "inappropriate for assisted living," required to move out, or encouraged to live in a more protected setting. The slogan "aging in place" was at one time elevated to a principle of assisted living, expressed in a view that residents should not be required to leave assisted living against their will unless they needed the intensity of a hospital or had absolutely no ability to benefit by assisted living (e.g. those who are comatose or in vegetative states). Certainly, the principles of choice, independence, and individualization suggest that aging in place is desirable. However, staff members need the skills to be able to provide or arrange the services needed, as well as to minimize behavior that might disturb others in group settings. Also regulators would need to abandon rules that require residents to leave their homes in assisted living under certain conditions, for example, being unable to transfer, being incontinent, being confused and prone to wander.
Over the past several years, regulators in various states have required that specific residents leave assisted living against their will though the provider has been willing to retain them, and multiple court cases have been joined testing the right of individuals to stay in settings when the state deems it necessary for them to leave. Typically, the state position prevails in court, and some providers believe the ideal of "aging in place," should be substituted for an ideal the facilities should clearly disclosure before move-in the conditions under which they will not promise to retain residents. A twist on this is found in some state regulations where the facility must determine upfront what kind of assisted living "level" it wishes to offer, and meet accelerating regulations for each level.

A Michigan court case in the Year 2000 (Wallace v. Michigan Department of Consumer Services) was decided the other way, i.e. in favor of the resident and family, resulting in a new Michigan law stating three conditions for the resident to stay: resident and key family members understand risks and conditions and wish to stay; the provider is willing to continue care; and the primary care physician believes the health care can be managed appropriately in the setting. Thus, different ideas are circulating, including: a strong endorsement of "aging in place;" a strong endorsement of providers deciding and disclosing the conditions under which residents can stay; a view that regulators should establish various structural and process standards under which residents of varying disabilities can stay; and the promising model embodied in the Michigan statute. Before further regulations are cast, these competing approaches need careful attention.

**Service Capability**

Perhaps the most difficult part of the assisted living vision to achieve is the needed service capability, especially at times of shortages of skilled workers in all types of long-term care. It is useful to divide services into two types: 1) routine services almost always needed in assisted living; and 2) specialized services.

**Routine services.** Routine services, whether delivered by assisted living staff or separate outside contractors or vendors, include personal care (e.g., bathing, dressing, toilet assistance, transferring, and assistance with eating), ambulation assistance, medication assistance and management, safety supervision and reminders for persons with cognitive impairment, and household services, such as cleaning and laundry. Some such services for example, cleaning, laundry, medications, transferring, and usually bathing (except for unexpected incontinence) can typically be scheduled. Other help cannot be as readily scheduled, such as providing general supervision for safety purposes, dealing with acute illnesses such as heart attacks and strokes, or handling emergencies such as falls and accidental injuries.

To meet routine needs and still deliver affordable care in homelike,
autonomy-enhancing residential settings, many assisted living providers have championed such concepts as: the universal worker, which allows of multiple tasks to be performed by a single worker who also comes to know the resident; and delegation of nursing services, which allows for nursing services to be performed by non-licensed personnel without close nurse supervision as long as a nurse has taught them how to perform the service and certifies that they know how. The nurse delegation issues, particularly important for cost-effective medication management, remain an area of some controversy. A state-wide study in assisted living settings in Washington state showed that those assisted living settings opting to use nurse delegation had fewer nursing errors and problems than those choosing not institute nurse delegation programs. The hypothesized explanation for the results is that in assisted living programs without nurse delegation, nurses were often largely out of the loop and care staff were not knowledgeable about the regimens they administered without delegation training (Young et al., 1998).

To preserve the philosophy of assisted living while delivering the care, other strategies have included individualized, negotiated service plans, and negotiated risk agreements. The latter (sometimes interchangeably called negotiated risk contracts, managed risk contracts, or managed risk agreements) are signed agreements between providers and consumers and other involved parties that state that an informed consumer chooses to accept risks associated with his or her care in order to maximize certain preferences. Consumers who prefer to partially or fully take their own medicines, who prefer not to adhere to a diet or medication regimen, who decline to use walkers or wheelchairs are examples of those who may be candidates for such managed risk contracts. All these ways of handling services are differentially implemented, understood, and endorsed across the assisted living industry and by external regulators, payers, or advocates. Something as simple as a universal worker may be contentious because it involves a tradeoff between specialized skills and credentials versus the ability to deliver on a wide range of services even in a small setting where a large, differentiated staff could not be supported. Given the present experimentation with different forms to deliver service and the shortage of service personnel in general, it would seem to be important to be reflective before imposing staff ratios and patterns based on the status quo. At the same time, much thought is needed to the kind of recruitment and on-the-job training needed to support the wide range of roles routinely required of care staff in assisted living. A recent study with a large national sample of assisted living facilities and residents found that facilities employing nurses were less likely to discharge residents to higher care settings (Hawes, Phillips, & Rose, 2000). This finding offers an important hint that the organization must be geared to plan chronic care and deal with emergency health situations. The findings should not be extrapolated, however, to lead jurisdictions to mandate specific nursing levels or ratios or precise arrangements to achieve that capability, given the promise of some of the extant models that have developed heightened capacity of line
staff and employ delegation practices that appear to utilize the time of expensive licensed nurses effectively.

**Specialized services.** The challenge of providing specialized services and care is one that assisted living shares with nursing homes. From time to time, residents will need dentists, physical therapists, occupational therapists, speech therapists, psychologists, spiritual advisors, audiologists, optometrists, oculists, podiatrists, alcohol specialists, nutritionists, among others. Like seniors in their own homes or in nursing homes, they may have their own dentists and other health specialists, pastors, psychotherapists, and so on. But, also like many other seniors in the community, they may have no access or only spotty access to the help that would be useful or even lack awareness of what specialized services might help.

Assisted living settings should be able to provide the early warning assessments that specialized services are needed, and linkages to those services. This requires training of assisted living staff. Realistically, however, in some communities, even after the need is recognized, finding the appropriate professional is impossible, and in other instances, paying that person is a challenge. To meet the need for specialized services, it will be necessary to counteract confusion, poor communication, conflicting wishes among resident and various family members, lack of resources, and, sometimes, unwillingness to expend resources. Community physicians and other community professionals also need to be part of this solution. Certainly it is more challenging to perceive the need for and bring professional services to assisted living than to nursing homes, which are largely modeled on hospitals and which may have in-house physicians and therapists, but it should be less difficult than doing so in the context of home care. Depending on the mix of residents in assisted living, many may need active management of health conditions, but no evidence at present suggests that the care should literally be on-site, or that a nursing-home style medical director model is either necessary or even a good idea.

**Essential Components**

Assisted living settings can adopt a variety of ways to achieve the three elements of the assisted living tripod, and given the variation in resources and prices among assisted living settings, different approaches are to be expected. Moreover, continuing creativity should lead to new ideas about how to construct the residential environment, how to create the service capability, and how to put the philosophy in action. Below we suggest some minimum expectations that could be established for each

**Essentials for residential environment.** In this area, the expectations pertain to structure (the actual physical environment) and process (the way that environment is used). Private space should include a bedroom and full bathroom that is unshared unless the resident wishes, and individual temperature controls. The space should be designed to enhance functionality and mobility for people using
assistive devices including wheelchairs. The resident should have control over the use of this private space. Public space must similarly be designed to permit access to indoor and outdoor spaces.

The above essentials are minimum only. Private spaces could and often are comprised of apartments, which themselves vary in number of bedrooms, features in the kitchen, cable television, and the like. Similarly the public space could include a range of features, such as gymnasiums and swimming pools, gardens, porches, and solariums, and the like. These details should be a matter of consumer discretion, since they too vary in the type of housing they wish and can afford. The landlord's obligation for the property includes keeping the environment pest-free, assuring it is properly heated, cooled, and lighted, and that appliances and fixtures are in working order. The consumer's obligation is to pay the rent and keep the property in reasonable condition.

Resident control over the use of the environment is not easy to guarantee. To take a few trivial example, some states require that all garbage pails must be metal: apparently, somewhere it was decided that plastic, wicker, and wood create unacceptable hazards. Similarly, it is not unusual that if the residents' private quarters fail to meet some third party's standards for safety or cleanliness, living space may be cited as too cluttered, containing unsafe objects (such as unsecured over the-counter medications such as aspirins, unsecured cleaning products or cosmetics, or windows without screens). Multiply this by many other examples, and the degrees of freedom of the resident in her space disappears.

Not all states require the standard of privacy and function-enhancing features suggested as minimum and some have rules that restrict resident use of environment. These should be revisited. Obviously, new environmental mandates make compliance difficult for existing programs, and mandates for private rooms are less practical if the room and board price is pegged artificially low. However, this topic is so important to consumers that it must be faced directly. (If privacy and wheelchair accessibility became mandated as a standard, it would be reasonable to grandfather in those already holding the license without meeting the standard).

Essential service capacity. The essential capabilities here are: ability to perform or arrange a competent initial assessment of needs (not just medical) and preferences and develop an individualized plan; the ability to provide kind, capable, and responsive care 7 days a week and 24 hours a day. It also includes the ability to identify changes in physical functioning and condition and to arrange for specialized assessments and interventions; the ability to provide or arrange meals and housekeeping; the ability to respond to emergency situations, and the ability to provide or arrange routine nursing services, including medications management. (We sharply differentiate generic nursing services from services of a registered nurse; "nursing
services," therefore, should not be construed as services that can only be performed by a registered or licensed nurse.) It may be unhelpful to establish a staff-to-resident ratio or requirements for people with specific training (e.g., nurses) or job descriptions (e.g., activity director) to attempt to secure this capacity. Indeed, it would be more useful to consider how we would know that an individualized care planning capacity is in place, what evidence we would seek for its results, and what are the key components for competency-based training.

Essentials for implementing the philosophy. The essential signs that the philosophy has been implemented are: residents preferences are known; attempts are made to honor resident priorities and help them implement their preferences; and residents are, as much as their abilities allow, in control of their lives, their schedules, and their private space. Rules for conduct in private space should be minimized, and no bedtimes or meal-times should be imposed on the individual (though a resident choosing a late bedtime who needs substantial help may need to compromise on the details of the way help is given). Private environments may be made safer for persons with cognitive impairment (for example, by disconnecting or removing appliances), but the burden should be on providers and regulators to show it is necessary to restrict a resident rather than on the resident and her family to prove she can use the ordinary tools and equipment found in most households.

Major Challenges

Maintaining and improving the 3-legged stool that, we argue, makes assisted living a desirable long-term care option while providing some assurance of quality presents some major challenges, which we discuss next. Our goal in laying out these inter-related topics, is to present the complexity of addressing these challenges in meaningful ways.

Balancing Safety With Autonomy and Quality of Life

The tension between providers', regulators', and even families' perceptions of safety, on the one hand, and consumer perceptions of quality of life and personal choice, on the other, are palpable in assisted living, as in all of long-term care. In nursing homes, the thrust is and always has been towards perceived safety. Although quality of life is valued in nursing-home regulations, it is always qualified by the caveat "as is consistent with health and safety." The Pioneer Network in Long-Term Care, a group that is actively advocating for culture change in nursing homes, recommends changing that balance, and takes as a principle that "risk is a part of normal adult life (Lustbader, 2000)." However, regulatory momentum seems to be in the opposite direction with broadened definitions of abuse and neglect. Given this backdrop, the assisted living challenge is to determine the kind of practices that will be permissible, the outcomes that are tolerable, and the kind of regulatory oversight needed to promote the positive values of assisted living. The order of thinking must be altered to give quality of life much higher priority, while
offering reasonable confidence to consumers and their families that care needs will be met, and that care will not be neglected under the guise of consumer choice.

The tension plays out around many specific topics. For example, consider incidents and accidents, perhaps the most common of which is a fall, with or without injury. The occasional fall and particularly the first fall in a person with no known risk factors who trips over the leg of a table-mate's chair during dinner may be understood as an unpredictable and unavoidable accident. The fall in an effort to get up from a toilet seat where a frail older person was placed and left unattended for a significant time almost certainly is an instance of poor care. But in between these extremes are infinite variations with many nuances. Some people who may be at risk of falling prefer to use canes and walkers rather than wheelchairs. Some people who do not want to wait for the arm of an attendant, insist on going outside alone, prefer clothing that decreases their safety of movement, or insist on walking where there are no sidewalks or paved surfaces. Should they be prohibited from this freedom on penalty of eviction? (If evicted, they may move into a community setting with no help at all, or to a nursing home where they may lose the opportunity or even the desire to move around.) What about the person with Parkinson's disease who falls with regularity, sometimes with injuries that draw blood? What about the person with several broken hips to her credit? Should they be "grounded" from walking without assistance? Required to move? If the answer is "no," what should a regulator look for to determine whether monitoring the need for and delivery of care is adequate? A note in the chart that shows staff is aware of the condition? A negotiated risk agreement that identifies the risk and proposes a strategy to reduce the possibility of injury, and may be a sign that family were informed and involved in decision-making, particularly if consumer is cognitively impaired. Should we assume ambulation independence a sign of good care as long as no injuries ensue, but bad care when injuries occur? If rates of both the good things (in this case, ambulation rates) and the bad things (falls, and fall with injury) are calculated, but if these are used to compare assisted living programs (as is now the case for fall rates in nursing homes), can case mix be appropriately taken into account given the variation within and across assisted living settings and, if so, how?

Similar examples could be promulgated for other common problems in long-term care such as weight loss, skin condition, "elopement" of wanderers. We know, for example, that short of force-feeding, some older individuals do lose weight because of appetite loss and drastic reduction in food intake. Again what constitutes evidence of good care? Signs that the person has a medical consultation to rule out disease as a reason for weight loss? Determination of whether a treatable depression is at the root of the problem? Evidence of efforts to entice the resident to eat by an individualized plan to tempt her with favorite foods? Proof of tasty, well-prepared meals? If these efforts fail to bring about weight gain, must the resident be force fed or evicted? As for skin condition, is there any room for
toleration of decubitus ulcers in patients with specific conditions, such as diabetes or end-stage cancers or end of life in general, when system shutdowns lead to skin breakdown? Regarding "elopement," should a resident prone to eloping be refused as a potential resident for fear of liability or sanction if such an event occurs?

Fear of sanctions, liability and public censure act as powerful incentives to give priority to safety even when the resident is mentally competent to exercise autonomy. If the resident has substantial cognitive impairment, balancing safety and autonomy is more difficult. The resident is considered vulnerable and her ability to make truly autonomous decisions at all is in doubt. Although practitioners know that many perhaps most--people with Alzheimer's disease or stroke-related dementia have preferences that they can make known verbally or non-verbally, providers, regulators and families alike are extremely reluctant to risk accusations of neglect, abuse and poor care. We do not know what evidence of these preferences held by people with dementia would be convincing enough to allay concerns about poor quality of care. Nor have we addressed the extent to which surrogates, such as family or friends should be empowered to decide about risk-taking based on their presumed knowledge of the individual's likes and dislikes. Should States legitimize negotiated risk agreements developed by surrogates on behalf of the consumer who is substantially confused? Should negotiated risk agreements entered into by sufficiently competent consumers be revoked if the consumer deteriorates cognitively to the point that she no longer understands the consequences of the risks she previously assumed? What other strategies might be developed to facilitate the exercise of autonomy among those cognitively impaired? What mixture of process standards and outcome expectations should be developed?

Under commission from the Assisted Living Federation of America, Burgess prepared a legal analysis and a cautious endorsement of providers using negotiated risk vehicles in what he saw as an unsettled area of law (Burgess, 2000). It is clear that more work would need to be done in this area if this strategy is to be an effective tool for better balancing autonomy and safety concerns. At that time, fifteen (15) states included negotiated risk agreements in their assisted living rules. Yet little consensus can be found on how such vehicles should be used in a quality assurance system, how negotiated risk would be combined with a "comparative outcomes" approach to quality assessment, or what training is needed for personnel using them and regulators inspecting them after the fact (Wilson, Burgess, & Hernandez, in press). In the meantime, it is clear that people with some cognitive impairments are the ones who may be at greatest risk when they exercise their remaining independence. These individuals are frequently found in assisted living settings, and excepting them from opportunities for choice would seem unduly restrictive at a time when persons with moderate and severe mental retardation have gained the right to much increased autonomy. A way needs to be found to build upon the preferences the person with Alzheimer's disease is still able to express, any documented history
of their lifelong preferences, and the views of their legally empowered guardians or surrogate decision-makers to apply benefits of negotiated risk contracting to them as well.

Reconciling Individual and Community Perspectives

Meeting residents' individuality and social needs. Assisted living ideally serves an individual's need to exercise personal preferences, pursue interests and activities meaningful to them within their abilities, and enjoy a zone of privacy where they can be alone, together with family or friends, and surrounded by their own possessions. Assisted living also ideally helps meet an individual's need for community, where they have a cushion against isolation, can associate with others, and can experience group activities ranging from informal dining experiences and casual encounters to activities planned by the assisted living community. All people have needs for solitude and for society and affiliation, though some may emphasize one pole over the other.

Assisted living programs can help people meet their needs for affiliation and social involvement through internal activity programs, efforts to help residents maintain their connections to external communities (e.g. church, civic clubs, sports interests, family activities), and encouraging meaningful resident-staff and resident-resident relationships. This is by no means easy, but helping residents experience their individuality is even more difficult, calling for individualized discussions of resident interests, life experiences, and preferences, and determining ways to help them carry these out. Although service planning and care planning tends to establish resident choices, the ability to choose is within limited boundaries, and developing truly individualized plans to facilitate what interests a resident calls for creativity, attention, and skill. Moreover, promoting individualism conflicts with promoting community.

From a regulatory viewpoint, attendance at activities is often emphasized and equated with pleasant socialization. Resident's needs for stimulation and community should not be ignored, but the planned group activity is often a simplistic solution. This is another arena where consideration is needed regarding what constitutes acceptable levels of activity and social involvement, as well what constitutes enough privacy and solitude.

Our plea for increasing the capacity for individualized approaches seems to go against the current trend for guidelines and standardized care protocols. The point that should be emphasized, in our opinion, is that protocols are desirable for medical and health-care interventions, but not for people's very lives. It makes complete sense to have protocols for proper administration of medications or for transferring a person in and out of bed. A protocol for when people should get in and out of bed and how they should spend their waking hours when not receiving care is counterproductive to a philosophy that respects individual wishes and preferences.
Individual interests versus community interests. Inescapably, assisted living has elements of group living, similar to any apartment complex or neighborhood where tenants must behave within boundaries acceptable to their neighbors. In fact, these group-living constraints are exaggerated because the assisted living residents will usually eat together and often encounter each other in the public spaces and at activities. Actually, the setting takes on the larger role of community precisely because contact with the larger world typically shrinks as impairment levels increase. The rights of one resident to remain in the community may conflict with the desires of other residents for a serene environment and perhaps with those other residents' property rights. Residents who are cognitively intact may be intolerant of those who are cognitively impaired, and especially those whose behavior creates disturbances, or is menacing, or frightening. Little attention has been given to teasing out the priorities that should be given in these situations. Surely, group pressure should not be used to ease out a resident who looks ill, eats in an unappetizing way, or otherwise reminds the community members of their own mortality. Yet, staff must surely bear major responsibility for structuring the day and monitoring the behavior of residents with dementia so they will not be disturbing to other residents (whether in integrated assisted living settings or special units for dementia). Move-out policies are often a matter of regulation. At times, assisted living is criticized for retaining residents "who should not be there," and at times it is criticized for evicting a resident. Without knowing the answers, we think the issues of how to enhance socialization, how to enhance individuality, and how to regard the community versus the individual need attention before criteria are developed to judge the adequacy of the program.

Mainstreaming versus stratification. One way of managing negative community feelings about other residents is to develop specialized units for dementia or for people with very heavy care needs, or both. This also renders it more efficient to provide supervision and disability-appropriate activity for the person with dementia, and to provide nursing care for those with high levels of disability. Locked units permit concerns about wandering to be broadly addressed, and the ability to address such issues is not to be lightly dismissed. But clearly such special care units have their limitations as a solution. First there is the problem with selection and retention criteria with both the level of confusion, as well as the existence of other physical or health related problems. Then too, segregation may undercut the vision of assisted living as a place to which a tenant has moved voluntarily and can stay as long as she desires. In efforts to assure safety the environment, the special care units may eliminate many of the very things that make assisted living residential. It certainly undercuts the importance of establishing, decorating, and becoming attached to one's own place. And while it may make it more efficient to deliver specifically designed care, it doesn't necessarily make it easier for staff to deliver it in such a way as to meet the even modest expectations of consumer families. What
combination of selection criteria, size, design, program structure and staff element would best demonstrate the efficacy of special care units? And in what circumstances would integrated units serve as well or better? A single answer is unlikely to emerge because size and complexity of the building will influence the value of a specialized dementia unit, and because the community need for such segregation is highest when residents do not have private rooms. It would be useful to develop criteria to influence practice based on increased knowledge of the circumstances under which residents with and without dementia thrive.

Establishing Expectations Consistent with Willingness to Pay

Great expectations. We as a society are conflicted over what we say we want and what we are able or willing to pay for it. This conflict is evident in every domain--public education, health care, urban renewal, public transportation, parks and recreation, national forests, preservation of wildlife and habitats, eradication of disease and so forth. Crudely put, we often exhibit champagne taste on a beer budget. This is true for many in their private lives where the assumption of debt to pay for items we believe we need to live a quality life is the American way. It is also true for matters of public social policy where lawmakers have a penchant for creating unfunded mandates, as opposed to asking taxpayers to pay for what they say they want or to set priorities and build consensus where choices are tough to make.

Health policy is a good example of this problem. While it is widely acknowledged that the United States has excellent health care available, it is also recognized that access varies and a multi-tiered system operates where many people have little access to the best. For a select few with unlimited financial resources or excellent private insurance plans without co-pays, prior authorizations or stringent criteria for specialist use, the latest in treatment approaches and medications are readily available, and satisfaction levels are generally high. Far greater numbers of individuals and families are in less satisfying circumstances. For those with health insurance, the amount and type of coverage has been an arena of serious concern. Reduced access to specialists, new treatment approaches, and newer drugs are greeted with dismay, but so too is an increase in co-pays. Oddly, in many states, those who qualify for Medicaid have fewer limits on the amount and type of care they get compared to those with private insurance, but to be eligible for Medicaid the individual must have a very low income and have largely exhausted financial assets. On the other hand, because Medicaid rates are usually below market rates, the number of participating providers may be limited. And because someone else is paying, the system is designed to be difficult to use. Finally, many have no coverage under either Medicaid or private insurance. Thus, except for a few at both end of the income spectrum, the likelihood of achieving their expectations for the miracle of modern medicine is severely constrained.
In long-term care, including assisted living, the issues are uncomfortably similar—great expectations and modest means. If anything the conflict is exacerbated, both because the population is perceived to be vulnerable and, in the case of nursing homes, a greater percentage of the care is paid for by Medicaid and Medicare. Furthermore, regulatory requirements are built around health expectations, since shelter, food, and the like are only narrowly health matters. (Food must be nutritious and prepared and served according to safety standards rather than by well-vetted chefs.) If more were mandated as a basic minimum in the shelter and board area, these provisions would raise costs further and impact state budgets for all settings where care is subsidized. The question of shelter costs, while recognized, has not been given seriously explored, in part, because of cost implications. As it is, regulatory requirements related to staff and program may not be accompanied by funding to accomplish the goals. When faced with unfunded mandates, we often seek to shift the burden to other payers private pay consumers, private insurance or even taxpayers, who absorb the cost of tax exemptions given not-for-profit providers. Policy-makers tend to finesse the issue of whether to pay more or change expectations by calling for doing more with less.

Doing more with less. Over the past two decades several strategic approaches have been used to work within limited means. In acute care, generic drugs and treatment guidelines aim to generate efficiency. In assisted living, universal workers (that is, care assistants who are trained on the job for a wide variety of functions) and nurse delegation (that is, policies by which nurses teach and delegate non-licensed personnel to do nursing tasks) are two approaches currently used for doing more for less. Neither can be used in nursing homes without specific waivers, and in some states nurse practice acts or agency licensing requirements need to be adapted to permit their use in assisted living.

Other technologies such as sophisticated management information systems using hand-held wands for bedside recording, insulin pumps, incontinence products with moisture alerts, talking medication reminders, interactive television, “smart” furnishings that enhance functioning and monitor vital signs, high-tech bathtubs that permit easy transfer, and fingerprint identification security systems all are available and may someday be priced in such a way to help continue to do more for less.

But, there is a limit to what can be done, particularly to counter certain fixed costs such as those associated with housing (shelter) and food in long term care. While expectations have continued to rise such as the clear preference for private living space, increasing building code requirements for safety, the availability of choices in food entrees and extended hours for food service—how to pay for these is not as amenable to the types of strategies we discussed in the previous paragraphs. Public policy makers have largely ignored the effect of rising expectations that have been market-driven by
consumers themselves, contending they are simply a cost of doing business. Such arguments are specious, given that the business is conducted in a setting governed by extensive requirements.

Ducking true costs of shelter and food. In all residential care settings including nursing homes, the true costs of shelter and food is poorly articulated, and rarely transparent to the consumer. Thus it is possible that the amount allocated in accounting to shelter and board is either more (as may be the case in many nursing homes) or less (as is the case in some assisted living) than consumers would pay in the market. Assisted living is expected and has held itself out as able to provide services in a normal, residential setting. The nature of the private and public residential environment and the choices around food and the dining experience are intrinsic to assisted living. Yet, states that cover assisted living under Medicaid waivers tend to set food and shelter rates at SSI levels; if comparable private apartments cannot be located for that shelter rate in the market area, the policy is surely somewhat cynical or disingenuous. It has the effect of encouraging providers to double up Medicaid clients (since the shelter rate for two persons might come closer to covering actual housing costs). States themselves are forced to use sleight of hand to transfer shelter into service costs. This problem of ignoring the cost of shelter has only grown worse as additional non-market driven care standards have been added. We do not argue here for a single standard for shelter just as any city has a variety of housing of styles and costs, so too should those who can afford it be entitled to buy what they want. However, "the fact on the ground" of apartment-style assisted living settings with a private room and bath standard does force consideration of the decent minimum that should be held out as a goal, and paid for at appropriate levels.  

The cost of shelter is related to the overall cost of housing in a given geographic area, special code requirements, building design, size, amenity level and location. (Wilson, Hernandez & Sheehy, 2001). It is affected by the amount of debt on a building (since few are without mortgages) and the type of financing used to finance that debt, as well as tax and utility rates of local municipalities. While impossible to put a specific price on the actual cost of privacy and other environmental amenities given all of these variables, we know that covering property-related costs typically consumes 35% to 45% of the national average private-pay rates in assisted living ($2202 a month in 1999). Even in assisted living residences tagged as affordable, this yields a shelter cost more between $500-$700 per month in low-cost-of-living areas, an amount well above what many private pay clients can afford for any extended period of time. A resident whose sole income is Social Security and SSI and who qualifies for Medicaid-waiver coverage, is almost certain to be unable to afford that amount out of income without additional public subsidization. The food budget allowance under SSI (which can be as low as $60 a month in some states and typically is no more than $120 a month) is also set unrealistically low. When food allowance substantially above those figures is criticized in the media as proof of cost-cutting, the distance between expectations and willingness to pay is further highlighted. Assisted living settings cannot provide three meals, choice of entrees, mandatory snacks, and special diets as required for $2 to $4 dollars per person per day. It is unclear what would be a reasonable expectation of value received for various prices, and the expected subsidy to Medicaid from the private-pay market is not made explicit.
Even without counting hidden subsidies to publicly-supported clientele, private pay residents and their families also harbor unrealistic notions of what portion of their monthly or daily rate is consumed by shelter and food related costs. In most communities, it is impossible to rent even a private room and bath, let alone with a kitchenette for $500 a month, even without the building-code requirements of specially constructed assisted living settings. The market rates for a studio apartment would be higher. Often a certain amount of service is incorporated into the base rate for the apartment (e.g. meals, housekeeping, laundry, care management, wellness services, and sometimes minimum amount of care) without residents having a breakdown of the literal price of the housing and meals.

Accepting Limitations and Sharing Responsibility

At the heart of all expectations is a vision of a good life towards the end of life. Assisted living has been successful in the market because seniors and their families seek a lifestyle different from a nursing home in a physical setting that is also different. It is unclear whether this commitment must be realized at the expense of health outcomes and quality of care, but it seems certain that orthodox views about how to provide that care based on the current nursing home model are ill advised. Certainly, residents who are in physical pain arguably experience a low quality of life, as do those who are anxious and depressed but receive no treatment or attention for those problems. Thus far, however, when tradeoffs are needed, orthodox views of quality of care take precedence over quality of life. This is an issue of importance in nursing homes, where authorities are trying to determine how they can measure and promote a better quality of life. It is certainly at issue in assisted living.

The rhetoric about the good life for long-term care consumers sometimes ignores the actual facts of later life for those who need care, mainly chronic disease, and frailty. Many consumers are ill or in pain, they have experienced physical and social losses that all the euphemistically named nursing homes and assisted living programs cannot gloss over. It is paradoxical that "the perfect drives out the good," and aspirations towards perfection can stand in the way of making life improvements for older long-term care consumers.

Some of the early concepts in assisted living may have already become lost in our quest to create a perfect life for frail and vulnerable older persons. Two important concepts were bounded choice and shared responsibility. It is truly ironic that older consumers themselves have proven more able to recognize these concepts as elements as a part of a more normal life than families, advocates, providers or regulators.

Bounded choice. As initially defined for assisted living (Wilson, 1993), bounded choice was described as identifying limits to choice and the costs (financial and otherwise). Put simply, bounded choice accepted the limits that occur in normal life and sought to recognize the right of actual consumers (as opposed to providers, advocates, regulators, and even family) to have the most powerful or
only voice in determining what tradeoffs should or could be made in order to assure that some, if not all, of their priorities for long-term care were met. This concept allowed for consumers' preferences (e.g. pet care) to take precedence over "needs" as defined by others (e.g. daily bed making) when financial considerations made it impossible to have both. It allowed for consumers to take risks (e.g., remain in residence if a needed service such as nighttime transfer assistance was limited in its availability and neither the provider, the resident, nor any other party could or would be responsible for extra costs. Bounded choice recognized the tension between individual and group rights, holding forth the notion that a woman’s home was her castle (ergo, few rules would be desirable regarding housekeeping standards or use of space). It also held that outside of one's personal space, respect for the rights of one's neighbors should prevail (ergo, residents would need to refrain from wearing bedtime clothing in public spaces, playing music at a volume guaranteed to be heard down the hall, or claiming a certain table in the dining room as one's own). Bounded choice implied that the tradeoff for establishing one thing as a priority might result in limitations in another area depending on the resources available (more privacy but fewer bedtime checks; more food choice and personal space, but fewer planned activities, for example). It also implied that residents had to accept consequences, including financial ones, if their demands exceeded established service or care boundaries.

What changed? Simply put, expectations were raised and subsequently not always met. These expectations were sometimes raised by the industry itself by lack of clarity in its marketing claims. The industry did an exceptional job appearing to promise a wonderful life with unlimited choice and a rather poor job of initially defining limits or costs for unlimited choice. Professionals turned out to be less comfortable with the idea of tradeoffs than consumers themselves. Moreover, families, providers, and regulators did not fully understand or embrace a "home-care philosophy" in a licensed long-term care setting. (By a home-care philosophy, we mean one that does not attempt to oversee every aspect of a resident's life nor be responsible for all outcomes.) Ultimately, when push came to shove, many stakeholders were unsure they approved of the consequences that such consumer empowerment might bring. They were more cognizant of their perceived responsibility to make sure such vulnerable people got what tradition said they needed, even if it wasn't necessarily what consumers themselves valued more. Why, except in a misguided attempt to make amends for the disability and disease that often accompanies later life, wouldn't we expect some limitations to the ability of care providers to solve problems? The answer is complex. The power to vote with their feet and change where they live is not a reality for many older people. It is also possible that, in our effort to protect the vulnerable person, professional and other stakeholders perceive the tradeoffs consumers themselves are asked and are willing to make are unfair. The undisputed paradox, however, is that the tradeoffs in quality of life (the double room or worse in nursing homes, the group tubs down the hall, the barracks-style daily routines, prohibitions of
beloved pets) were all accepted as an inevitable cost of giving people the health care they needed. Assisted living and the market response it generated challenges that assumption, but the idea of tradeoffs is hard to face.

**Shared responsibility.** The other concept, shared responsibility, has fared slightly better under the rubric of negotiated risk agreements, already discussed. Negotiated risk does not encompass the entire concept of shared responsibility, but does address an important dimension related to the tension inherent in the conflicting values of autonomy and safety. It should be noted, however, that cognitive impairment sends the most ardent supporters of negotiated risk into a maelstrom of caveats. Many are troubled by the idea that such a tool might be used to foster neglect, to excuse poor outcomes and to avoid liability for harmful acts. Moreover, despite the abstract acceptance of the gerontological truism that some loss of cognitive functioning does not mean loss of all capacity to exercise decisional autonomy in all areas of life, we are reluctant to take the risk that a poor decision will result in criticism, blame or additional liability. In a real sense the fear what others think of the "quality' of decision-making even when the decisions do not pose potential for demonstrated harm acts to motivates us to reduce or remove decisional autonomy in spite of an expressed desire to preserve and promote autonomy. It could be said that assisted living has done a great job of helping us recognize the importance of autonomy to older adults, regardless of impairment levels; however, it has not been as successful at helping to generate understanding that life, in spite of everything we might wish for, is seldom even close to being perfect.

The broader ideals embedded in the idea of shared responsibility have not been so well integrated into the thinking of families, providers, regulators and other advocates. A key concept is that life is, in part, about agreeing upon and setting priorities. Shared responsibility suggests a consensus that life is full of trade-offs and that lives are far from ideal. While in no way meant to condone neglect or abuse, the assumption, there is recognition that in normal life many spend their spare time watching television, few have unlimited choice about when (or what) they eat, and sometimes we wait in line to get help or even to go to the bathroom (consider the theater at intermission). In normal life not everything always happens we way we plan, nor do we do always get everything we need or want regardless of the price we pay. In other situations where expectations and the desire for perfection are high (for example, surgery or space launches), teamwork is demanded and everyone has a personal stake in achieving good results. Why should assisted living and long-term care not be more like ordinary life than like some superordinate time-limited mission or effort? Teamwork should not proceed along the lines of the space shuttle or the surgical suite. On the other hand, a way must be found to integrate a concept of some type of teamwork among consumers and their families and advocates, providers, and regulators to determine how to improve quality.

**Assisted Living at the Crossroads, page 32**
The current tendency in the press and in applications of regulations is to hold assisted living providers responsible for certain categories of adverse outcome, as though the more dramatic problems can be prevented and, if they occur, someone must be blamed. When something goes awry we feel that "payment" (whether public or private) allows us to lay all responsibility onto the provider of these services. If things go seriously awry, the line of first defense is a call for more requirements and rules that mandate a generic fix for specific situations. The tired scenario is played out by calling for familiar remedies such as staff ratios, additional certification of managers, and additional mandates or prohibitions.

In saying that responsibility needs to be taken by many parties, including residents and family, we are not negating the need for some standards. But the difficult issues of how these standards should be set and how to allocate responsibility requires the active, constructive, and ongoing involvement of those with a personal interest. The problems cannot be solved by promulgating more rules for providers as most familiar with the evolution of nursing home regulations would agree. The larger responsibility of families, friends and citizens to contribute more than negative involvement remains. It is easy to recognize a negative outcome. It is harder to define and promulgate positive outcomes, and decide what level and circumstances of negative outcomes are acceptable as part of life's chances.

Strategies for Action

General Approach
We have made the plea to avoid falling back on the familiar ways of quality control in nursing homes, or retreating from the ideals represented by the best assisted living can offer. What strategies, then, are available to maintain and improve the quality of assisted living without actually hurting the elements and values that attracted consumers in the first place? We are aware of the mounting pressure to act. Some residents appear to have been harmed by their assisted living care. An extensive process of deliberation, study, and testing would be needed to truly evolve and test a new approach to quality oversight in long-term care, and we urge this dialogue start. Short-term strategies will also be needed, and indeed quality monitoring and decisions based on presumed quality control are happening all the time. Going slow with prescriptive remedies for presumed problems would seem wise during this period of evolution.

The vehicles outside assisted living that shape its nature (which is another way of saying its quality) include: state and local licensing; state payment rules; the activities of publicly paid advocates such as state and local ombudspersons; the activities of care managers who may be involved in ordering and monitoring care for public and private payers; federal oversight when federal money is involved (which, so
far, is seldom); and the market itself. Within these possibilities, choices need to be made about how to direct quality standards and oversight efforts.

If we were to think of assisted living as home care, an earlier project identifying the forces for home-care quality may be instructive (Kane 1994). The following five factors were identified as influencing the quality of care at home: 1) consumer activism (which, of course, is fanned by information); 2) provider initiatives, such as continuous quality improvement and accreditation; 3) regulatory standards and oversight; 4) training (both basic, which takes a long time to affect results, and on the job); and 4) systemic and market factors. The present call is for regulatory efforts, but it is noteworthy that regulations can be used to improve the other categories. For example, standards could be established for consumer involvement and education, for provider quality improvement efforts, and for training. We are attracted to exploring the implications of considering assisted living as home care because of the assumption that people maintain freedom and control in their own homes. Merit may also be found in considering what kinds of regulations would increase consumer power and information, and what kinds of regulations would provide incentives for providers to become proactive in improving their own quality along the lines intrinsic to the goals of assisted living.

The nomenclature in assisted living needs to be examined for its underlying implications. What are the advantages or disadvantages of construing the consumers as "tenants" versus calling them "residents." Can tenant ever be accurate in terms of an expectation that residents have tenant's rights? Would tenant status make it impossible for regulatory bodies to specify criteria for who may live in the setting, and would this be a good thing? Is the language of "admission" and "discharge" desirable, or is the language of "move-in," "move-out," and "eviction" preferable? Is it possible that a resident (or tenant) could be discharged from the services, yet not evicted from or required to move out of the premises without due process. Many statements about assisted living shy away from terms that seem unduly medical. "Service planning" is substituted for "care-planning," and "facility" with all its ugly institutional connotations is replaced by "setting" or "community." Some commentators object to the term "home-like" as a goal of assisted living: people's own homes or apartments are not ordinarily described as home-like, but simply as home. In writing this document, we have struggled with choosing the words that allow for communication to readers (care-plan is better understood than "service plan," for example) and yet convey what assisted living could be. Some collective attention to word choice, especially around the distinction between tenant and resident, might be a helpful way of backing into clarifying the entity.

It appears evident that federal regulations would be premature, and possibly out-of-place given that assisted living falls outside the federal sphere. Developing a model statute that states would states be
urged to adopt (perhaps required to adopt if they accept federal money to subsidize any residents) also seems a mis-application of effort without prior resolution of some of the issues raised in this paper. Such a model statute is in danger of being so general that it lacks meaning and drives the field downward, or so prescriptive that it stifles innovation at a critical time.

Specific Suggestions
The 12 more specific recommendations below are couched as suggestions.

- Strive for approaches, guidelines and standards that pay significantly greater attention to quality of life. This means explicitly recognizing tradeoffs between quality of life and quality of care. It means using potential and actual consumers (of the services) to help at the front end in designing individual services and service programs, and in providing information about accomplishments at the back end. It means recognizing that the definition of quality of life may vary among consumers who actually use services, their families, advocates who speak for them, regulators of quality, or those who authorize use of public dollars, and that one should tread lightly when accepting definitions of quality proposed by others on behalf of actual users of service. Arguably, the further one gets from the primary consumer, the more likely it is that more attention will be given to safety than autonomy, resident preferences, and quality of life.

- Consider how regulations and monitoring could affect achieving the essential features of assisted living and resolving the major challenges described in this paper. Regulations could enhance or retard the development of the residential environments, the service capability, and the philosophy on which assisted living rests. They also can enhance or inhibit resolution of the challenges identified; namely, balancing safety with autonomy and quality of life; preferences and autonomy with safety; meeting residents' needs for individuality as well as for affiliation; encouraging individuality within the context of a community; permitting aging in place for those who wish it; avoiding the pitfall of too-high expectations; and maintaining affordability so some of these assisted living programs can be accessible to people with modest incomes and public subsidies. Related to aging in place, the approach evolving in Michigan seems worth examination.

- Critically examine state assisted living regulations and enforcement practices for their effects on the preceding goals. Assisted living is not unregulated; it is just not federally regulated. Going beyond mere cataloguing, the large number of state approaches now extant should be critically analyzed for their likely influences on the direction of assisted living. Materials prepared for a September 2001 Summit on Regulation sponsored by the Assisted Living Federation of America (ALFA) and the National Academy for State Policy made a helpful start by reviewing and
categorizing the range of state regulatory approaches to certain common issues. These included: the definition of assisted living itself, admission and retention standards, rules for management and administration of medications, policies for dementia care, staff training requirements, disclosure and admissions agreements, recording and documentation, and negotiated risk practices (ALFA, 2001). For most topics three or four characteristic approaches were identified. Such description and classification offers a starting point for considering how the various state stances affect the overall development of assisted living.

- Consider whether there has been unnecessary spillover of existing nursing home rules into assisted living, and at least for a time evolve assisted-living oversight as independently as possible from nursing-home oversight. Assuming that assisted living is meant to be different from nursing homes, it is necessary to create the conditions for that difference. (In time, we would prefer to see a level playing field created by offering nursing home residents freedoms similar to assisted living residents, rather than by restricting the latter). An example of spillover from nursing homes is found in abuse reporting requirement that some states have applied to assisted living, which define almost every negative result as neglect or abuse and level fines against those who report it. If there is to be a difference between nursing homes and assisted living in this developmental stage, it will be important that the licensing and survey personnel, and long-term care ombudsmen understand the thrust of what assisted living is meant to demonstrate. The habits developed in surveying nursing homes are hard to switch on and off, so that dedicated assisted living surveyors, trained for those positions, are optimal. If it is impractical to have separate inspection units for nursing homes and assisted living in sparsely populated areas, then perhaps some other entity could be assigned the assisted living portfolio.

- Develop actions that states can take to enhance consumer information and understanding of assisted living. This includes information about physical environments, services and care, aging-in-place policies, and prices so that they can more readily shop among assisted living programs. Efforts such as uniform disclosure and plain-English contracts are steps in the right direction and could be mandated through regulations.

- Determine how negotiated risk contracting and individualized care planning can be encouraged by and compatible with regulation. This includes reaching some consensus on the kinds of processes and results that are unacceptable and those that can be tolerated. It also entails a targeted research agenda that examines what we really know about how outcomes are associated with various behavior that professionals view as risky. Also necessary is some way of reconciling negotiated risk contracts with establishment of rates for various outcomes highly affected by those contracts. For
example, merely dropping individuals with negotiated risk contracts from the denominators when calculating relevant outcomes seems unwise, yet counting those outcomes against the assisted living program is also unfair. Perhaps, those with negotiated risk contract need to be tracked separately, though the numbers might be too small for viable rates. Perhaps the presence of a negotiated risk contract should be a modifying variable. The main point is that a mechanism needs to be developed to examine outcomes taking individualized care planning and negotiated risk into account.

- Keep the focus on the values inherent in assisted living with training and dissemination of "best practices" all geared to the developing competence in the promotion of those values. Make financial resources available to support the specialized training of professionals and para-professionals at every level to enhance their understanding of the physical, social, emotional and mental health of older adults needing assisted living and long term care. Resist efforts to artificially segment the work inherent in providing long term care redesign training programs at all levels of professionalism to encourage better communication and observational skills, as well as problem identification and solving techniques. Explore how to improve competency-based training, particularly for those involved in direct care, and to ensure that any state-mandated or state-conducted training is congruent with the service capacity that is essential. Given the cost of offsite training, it would be helpful to explore the use of interactive technology for some types of training, especially for mandated training for direct care staff. (Certainly if states mandate training, they should guarantee its availability at a frequency that allows providers to comply.)

- Find ways to address subsidies for shelter costs. Convene a group of finance and policy experts to examine the structure of SSI and other current programs to determine how the amount available for shelter might be raised for individuals. Explore new approaches involving tax and utility abatements, specifically for assisted living communities serving low and moderate income older adults. Review the tax credit program and explore how to make it more readily adaptable to assisted living. Continue, with renewed vigor, efforts to update thinking about fire codes and evacuation policies. Look at how broader use of universal design in construction, which could affect both the cost and the long-term usability of a building.

- Incorporate into any standard setting activity an analysis of impact on costs, resident autonomy, civil rights, and livability. This impact analysis should include not only financial cost to consumers and others, but the impact on quality of life, autonomy and civil rights of the consumer. Such analysis should also include the impact of any standard on the affordability and the livability of assisted living.
• Determine how to support active family involvement in care in assisted living. Family involvement, whether in the actual provision of physical care such as feeding assistance or bathing, social support through on-going communication and recreational opportunities or emotional support to workers should not be considered as filling in or making up for inadequacies on the part of the provider, but vital to the team effort. Such consideration should address the possibility of financial payment or training of families and cost reduction to the consumer. Such an approach would involve much more thoughtful discussion about coordination, shared authority and responsibility, particularly when things don't get done, go wrong, or the quality is perceived as poor. Family roles are integral to home care and, while assisted living should relieve some family responsibility, the home-care model evolving envisages a more vital role for family members than their Roles in nursing-home care.

• Refine ways to measure the outcome of assisted living and conduct research targeted at improving assisted living capabilities. The measurement development includes ways to measure outcomes using the residents' voices. Measures of satisfaction are particularly important but by no means easy to develop because of the well-known positivity bias in measuring satisfaction in all care settings. The targeted research should generate information about the strengths and limitations of the newer approaches intrinsic to assisted living: universal workers, delegation of nurse services, managed risk contracting, mainstreaming versus stratifying residents with cognitive impairment, aging in place, family roles, and the like.

• Encourage community dialogue and consensus building. All the suggestions made here require community dialogue at state and local levels, and addressing long-term care goals with a level of candor not typically undertaken. They need the thinking of professionals, organizational providers, advocates, and regulators, and also just ordinary citizens concerned about how they and their elderly relatives needing care will live out their lives. They would best be approached without too much certainty about what is right to do and some humility about how difficult the task is. The present crisis may be an opportunity to launch a truly fresh effort to think about the topic.
References


