

The Ideal Assisted Living Alternative: What It Should Be and Why

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Introduction

Assisted living is not as easy to define in a precise and straight-forward manner as nursing home care. The concept covers a wide range of congregate living arrangements from room-and-board housing to adult foster care and assisted living residences, and numerous variations on each of these models, based on variables such as state regulations, property size, service provision, resident characteristics, and funding sources. In addition, the gap between assisted living and nursing homes may have begun to shrink. Some assisted living residences now have residents with serious cognitive and physical impairments and who meet nursing home eligibility criteria, while some nursing homes have begun to adopt the “homelike” features of the assisted living model such as the Eden Alternative and Nursing Home Pioneers’ models of care (Fagan, 2003; Thomas, 2003).

The number of assisted living residents has grown rapidly over the past several years and now numbers almost 1,000,000 (MetLife Mature Market Institute, 2004). This growth would indicate that assisted living has great appeal to many older persons who need assistance with the activities of daily living who cannot, or chose not to, live in their own home. There is also inferential evidence that assisted living is providing an alternative to nursing home care. The number of persons in nursing homes has declined since 1995, even as the population age 75 and

older has increased. It is reasonable to assume that part of the nursing home population decline is due to the growth of assisted living.

The research on assisted living has grown along with the industry. Although there are still major gaps in our knowledge about assisted living, we now have a good deal of information that can help us gain an informed perspective on the characteristics and perspectives of assisted living residents—why they choose assisted living and why they leave; the extent to which the values of assisted living have been achieved and the service needs of residents met; and, the relative affordability of assisted living. More broadly, this information can help us understand what we can realistically expect from assisted living in the future in regard to such issues as quality of life, appropriate regulation, and affordability.

This chapter describes the quality-of-life-oriented values that have guided the development of assisted living over the last 20 years; these values have been substantially achieved in practice, with major implications for regulatory policy. The core values of assisted living include resident autonomy and choice, privacy and dignity, and aging in place in the most homelike and least restrictive environment. We conclude with a description of what we think should be the major regulatory features of an “ideal” assisted living model that reflect the values of the original vision and are reasonably consistent with the information we now have from the assisted living research literature.

The fundamental message of this chapter is that the gap between the ideal model of assisted living, based on the original vision and actually existing assisted living, is not as wide as skeptics thought it would become nor as narrow as many consumers and their advocates would like and there are many challenges ahead. Policy makers and providers will be especially pressed to serve larger populations of residents with serious chronic conditions and impairments

while adhering to the values of assisted living. Meeting this challenge may eventually require the addition to the current array of assisted living options of a “hybrid” model with some of the health care features of a nursing home and new funding and regulatory strategies. Even this hybrid model, however, should be designed to maximize its potential of achieving the essential values of the original vision for assisted living.

The possible need for a hybrid model does not mean that qualitative changes should be made in the standard assisted living model that apparently works well for most residents. Assisted living should remain clearly distinct from nursing homes in their current form. Many advocates are concerned that, should the preponderance of assisted living residents approach the acuity level of those in nursing homes, then pressure to impose a nursing home regulatory system will become irresistible and assisted living residences will become essentially indistinguishable from nursing homes. This does not mean that nursing homes cannot become “cozier,” less institutionalized, more resident-centered, assisted living-like places while serving a qualitatively more impaired, high-need population. This is precisely what the Nursing Home Pioneers and Green House initiatives are trying to achieve. Maintaining this distinction will continue to generate significant differences between assisted living and nursing home population profiles, even though the number of more seriously impaired residents in assisted living will continue to increase in the future. Nursing homes serve a substantially higher percentage of seriously impaired residents (those with four or more activities of daily living impairments), which reflects the unique role of nursing homes in our long-term care system and the appropriate limits of assisted living as a substitute for nursing home care.

Although the impairment and health care needs profiles of assisted living and nursing homes are quite different, the substitutability of assisted living for nursing home care appears to

be fairly substantial. A recent analysis of Medicare data from 1992-1998, on beneficiaries over age 65, found that assisted living may be an alternative to nursing home care for some segment of the elderly population (U.S. Department of Health and Human Services (2003). The principle difference between the two populations was income; assisted living residents have significantly higher incomes than nursing home residents. An analysis of the dually eligible population (Medicare and Medicaid beneficiaries) in Florida found that those entering assisted living residences were 47% less likely to end up in a nursing home after controlling for a wide range of impairment, health status, and demographic characteristics (Andel, Hyer and Slack, 2005).

Assisted living's partial capacity, however, to provide alternative care and support aging in place is not grounds for arguing that it should become a comprehensive alternative for a substantial majority of those now admitted to nursing homes—at least not if the goal is to keep assisted living consistent with the values of the original vision for assisted living.

The industry is not perfect and some course corrections are in order. We are impressed, however, by the extent of progress achieved over the last 15 years. Prior to 1990, one of the biggest gaps in our long-term care system across the country was the absence of a congregate care program that would allow the frail elderly to “age in place” and offer them the same freedom (personal control, privacy) and level of service that many had been able to receive in their own homes since the 1970s. This kind of community-residential care has been substantially achieved through the growth of the assisted living industry for private-pay residents and is arguably the most positive development in long-term care in the last decade. Over the next several years, assisted living should become an increasingly available option for low-income persons who have largely been excluded from assisted living, which they cannot afford to pay for on their own. Making assisted living more affordable will depend on two major factors:

expanding public funding for assisted living, including Medicaid funding; and ensuring the survival and growth of small, lower cost facilities which now have a higher percentage of low-income residents than larger facilities (25 plus residents).

We have incorporated some of the recommendations and reflections of the Assisted Living Workgroup (2003) into our discussion. The Workgroup was formed in response to congressional concerns about assisted living regulation. The perspectives of the organizations that participated in the Workgroup constitute an informed commentary on current stakeholder views of assisted living policy. The recommendations and responses to them reflect philosophical differences among trade and professional associations and advocacy organizations about how to regulate assisted living. Although the workgroup was not of one mind in the formulation of regulatory guidelines, we think that the results of the workgroup are important in framing the debate over assisted living regulation and that most of the recommendations, including some that did not gain majority or two-thirds support, are largely consistent with the values framework of assisted living and available research findings on assisted living.

Core Values

The original vision for assisted living was largely a product of a philosophical commitment to the commonly recognized values of autonomy and choice, privacy and dignity, and to the deep preference of most impaired persons to “age in place” in the least restrictive environment. These values are deeply embedded in American culture and constitute an essential part of what might be called the American creed which was originally expressed in the U.S. Bill of Rights. These core values first emerged as guiding policy principles in the Independent Living Movement in the 1970s (Scala and Nerney, 2000) which affected primarily younger adults living with disabilities in their own dwellings and then, for older adults with disabilities, in

assisted living residences or through consumer-directed in-home long-term-care programs (Polivka and Salmon, 2003). Underlying these values was the distinction between a “medical model” of care that is typical of nursing home care, and a new, more “social model” of care that can be provided in settings with less regulation than nursing homes and are designed to be more homelike.

Autonomy and Choice

Autonomy, or self rule, is based on the societal values of freedom and choice and is the cornerstone of the foundation for democratic institutions (Kapp, 2000). Policy makers, however, have not historically prioritized autonomy as an achievable goal for frail older adults in long-term care (Polivka and Salmon, 2003). Autonomy is more than the power to keep others from intervening in an individual’s life without fully informed and non-coerced consent, or what is called negative autonomy (Collopy, 1988). Autonomy is also closely related to choice, privacy, and dignity. It is the power of an individual, however dependent, to communicate freely with others, to give and to receive affection, and to initiate actions that are consistent with the person’s sense of self. This positive autonomy is especially important in the development of an ethic for long-term care (Collopy, 1988). Positive autonomy preserves a person’s sense of self and extends the boundaries of his or her own volitional capacities (Polivka and Salmon, 2003).

To formulate an ethical standard for the care of people who are dependent, policy makers and caregivers need a concept of positive autonomy that is influenced by the realities of the day-to-day life of long-term care recipients. A conceptual framework, based on positive autonomy, requires policy makers and caregivers to view the world of long-term care from the frail elder’s perspective and support the person’s need to define and make a world that is consistent with her own preferences and identity.

Assisted living residences can offer the kinds of resources, especially staff services, transportation, and social activities, necessary to make the achievement of autonomy a more practical matter than may be possible in many in-home environments, where achieving the same level of opportunity to exercise personal control is beyond the financial means of many individuals or the public sector to provide, or too great a burden on the individual's informal care providers.

The significance of autonomy in determining quality of life in long-term care is just beginning to receive the level of attention in long-term care research and policy development commensurate with its role in shaping the philosophy of assisted living. Much of the current research on autonomy and choice provides important qualitative understanding of the meaning of these ideas for residents and staff (Ball, Whittington, Perkins et al., 2000; Carder and Hernandez, 2004; Utz, 2003); and supporting choice and control (Parker, Barnes, McKee et al., 2004; Yee, Capitman, Leutz et al., 1999). The importance of this research focus is demonstrated by a study of quality of life in nursing homes, assisted living residences, and in-home long-term care programs in Florida. We found that the major predictor of quality of life was the degree of personal control the respondent experienced (Salmon, 2001). Elders who were in assisted living and who had high levels of personal control experienced the highest levels of life satisfaction, compared to those with high levels of personal control in other settings.

The importance of personal control and autonomy is not limited to those who are cognitively intact. In a study of 427 residents in 15 Alzheimer's special care units, Zeisel, Silverstein, Hyde et al. (2003) found that privacy and control over environment, in addition to a homelike atmosphere, reduced aggressive and agitated behavior, and psychological problems. A varied ambience in the common areas and camouflaged exit doors also reduced depression,

social withdrawal, and hallucinations. The authors state that “the design features, by providing residents with greater control over their own lives, empower them, and thus reduce their tendency to withdraw and even to be situationally depressed” (p. 709).

The Assisted Living Workgroup (2003) recommended several principles for oversight of assisted living at the state level which strongly support resident autonomy and choice. They stated that the regulatory system for assisted living is responsible for abating harm while supporting the resident’s decision-making control and ensuring meaningful resident and family participation. Regulations should specify the practices, protocols, and methods by which services that are provided are respectful of, and responsive to, individual resident preferences, needs, and values.

Respecting and supporting resident autonomy entails allowing a resident to take risks that are inseparable from an acceptable quality of life. For example, a resident with diabetes may choose a less restrictive diet than has been prescribed for her in order to increase her dining pleasure and improve her quality of life, even though she risks shortening her life. Or, a physically impaired resident may choose to preserve her privacy and dignity by showering alone and increasing her risk of falling. Assisted living must be prepared to accommodate this kind of freely chosen risk taking. One potentially robust method of accommodating risk is through the recognition and negotiation of risk arrangements that articulate the nature of the risk(s); the rationale offered by the resident for choosing to run the risk; the acceptance of responsibility by the resident for the potential consequences; and the agreement of the facility administrator, or other responsible party, to abide by the expressed choices of the resident. Negotiated risk in assisted living is an evolving concept which is likely to become increasingly salient as the number of more seriously impaired residents who want to age in place with as much autonomy

as possible grows. This trend is likely to be associated with the emergence of statutory language and judicial decisions that will help clarify the appropriate boundaries and procedures of negotiated risk agreements. The idiosyncratic nature of negotiated risk, however, will never be completely eliminated, given the range and variety of circumstances under which agreements may be negotiated.

Privacy and Dignity

Privacy is virtually a necessary, if not always sufficient, condition for the effective exercise of autonomy and for maintaining interpersonal relationships. Privacy for many people is an essential resource in maintaining a modicum of control over one's personal space and time and in achieving a sense of self-efficacy and dignity, which are fundamental components of identity (Polivka and Salmon, 2003). Assisted living residents and potential residents place a very high priority on privacy as a quality-of-life value (Kane, Olson Baker, Salmon et al., 1998). Most fundamentally, this means a strong preference for private rooms and bathrooms and, to a lesser extent, kitchenettes.

The significance of privacy is evident from the finding that the vast majority (85%) of respondents in a national survey of assisted living residents in high-end residences providing relatively extensive services or private rooms reported that their top two priorities on entering the residence were the availability of a private bathroom and private bedroom. These priorities were stable even after they left the residence (Hawes and Phillips, 2000a). The majority of residents in the same study reported that they were treated with affection (60%) and dignity (80%), demonstrating the potential of assisted living to respect the dignity of the residents.

Many providers and policy makers believe this level of privacy is not affordable for many assisted living residents, especially those who are publicly supported. According to Kane, Kane

and Ladd (1998), however, the difference in construction costs between 39 private units versus 39 shared units ranges from \$3.20 to \$6.30 a day per tenant. These higher costs are offset by lower operational costs in private units. The greatest extra cost of shared space is from vacancies and roommate matching. The authors state: “If a unit is vacant for a week more because of the difficulty in finding a new occupant, a whole year’s savings on the development and construction costs are more than wiped out” (Kane et al., 1998, p. 182).

The debate between these two perspectives was illustrated in the Assisted Living Workgroup’s (2003) struggle over the role of private rooms in its definition of assisted living. A slight majority supported private rooms. Those in support stated that it was “critical to realizing the goals of assisted living—resident control, autonomy, and dignity” (p. 16). The opposition was concerned about regulatory language that would impact the marketplace, especially for residents who would choose shared rooms but only private rooms would be available if newly constructed residences were required to build private rooms.

Aging in Place in the Least Restrictive Environment

One of the principal reasons for the creation of home-based programs for the elderly in the late 1970s was that older people wanted to have their long-term care needs met in their own homes for as long as possible in order to preserve their quality of life. The home was the least restrictive environment. Prior to the development of assisted living, residents in congregate housing who required a substantial level of assistance with a number of activities of daily living could not be admitted to or remain in congregate housing. This meant that moderately impaired residents had to either enter a nursing home or find an unlicensed residence that would accept them. They were not allowed to “age-in-place” in their residence if the residence was congregate housing (Golant, 1999). Policy analysts and advocates concluded that the community-residential

part of the long-term care system was seriously handicapped by the absence of an assisted living program for those who could not remain in their own home, if they had one and who needed substantial levels of personal or home health care, but did not need the level of 24-hour skilled nursing care provided in nursing homes (Polivka, Sims and Salmon, 1996).

The rapid growth of assisted living as a long-term care option reflects the fact that many higher income elderly are willing to pay substantially (\$2,500 to \$5,000 monthly) to receive the services they need in an environment that supports their autonomy, dignity and privacy (i.e., most private-pay residents chose private apartments). Many residents remain in assisted living until they die, which reflects their desire to “age in place” to the maximum extent possible.

Capacity of assisted living to support aging in place. Frytak, Kane, Finch et al. (2001) found that assisted living residences and nursing homes in Oregon achieved comparable outcomes in terms of activities of daily living (ADL) trajectories, pain and discomfort levels, and psychological well-being, after controlling for differences in baseline conditions. Although nursing home residents were, on average, substantially more impaired than those in assisted living residences, these findings are encouraging in terms of the capacity of assisted living residences to accommodate aging in place by providing necessary health care services. It should be recognized that Oregon has a relatively mature assisted living industry in which regulatory policies and public funding strategies are designed to maximize the nursing home diversion potential of assisted living residences and the opportunity for assisted living residents to exercise choice, including the decision to age in place.

A study by Hedrick et al. (2003) on assisted living, adult foster care,¹ and adult residential care in Washington state found that persons at every impairment level, including the highest (limitations in all six ADLs), reside in assisted living, although the adult foster care

¹ These are small (five or fewer residents) facilities mostly operated by individuals in their own homes.

homes tended to have a higher percentage of more impaired residents and lower payment rates. The study also found very high levels of resident satisfaction in the assisted living and adult foster care programs, with 92% of the residents reporting that moving to the setting was a good decision, and they were very satisfied with every aspect of their care.

In Florida, about 25% of all assisted living residents in 1995 had three or more ADL impairments or had serious cognitive impairments (Polivka, Dunlop and Brooks, 1997). By 2003, the impairment levels were even higher among residents in Florida's Medicaid waiver-funded Assisted Living Program. These residents had a higher percentage of persons with no caregiver (87%) and with a dementia diagnosis than any other home- and community-based program and even higher percentages in each of these categories than in the nursing home population (Mitchell, Salmon, Chen and Hinton, 2003).

Zimmerman, Sloan and Eckert (2001) surveyed assisted living residences and nursing homes in New Jersey, North Carolina, Florida, and Maryland. They stratified their assisted living sample into small, traditional, and new model properties, which are, more recently, purpose built facilities which generally offer more services, amenities, and private apartments and tend to be part of multi-facility corporations. They surveyed a total of 233 residences in each state and found that state, ownership type, and age of the residence were significant factors in accounting for the ability of residents to age in place. Florida was more likely to discharge to a higher level of care, as were for-profit and older residences.

Hawes, Phillips et al. (1999, 2000a, 2000b) found that during a 12-month period, 19% of the residents in their national sample of high-end residences were discharged and 60% of those who moved, did so to receive a higher level of care—8% were discharged to nursing homes and 4% to other assisted living residences. Only 12% of those who moved indicated, through family

members, dissatisfaction with the care they had received in the residence they left. The most common reason for entering a nursing home was a decline in cognitive status or the lack of a full-time registered nurse on staff. They also found that 26% indicated they needed more help with toileting activities and 90% of the residents thought they could stay in their residence as long as they wanted to remain. Most, however, were not fully informed about policies governing retention and discharge from their residence.

The issue of full disclosure needs to be clarified at the state level, especially in the area of dementia care. The Assisted Living Workgroup's (2003) recommendations regarding disclosure for specialized programs provides an effective framework for developing regulations in this area. They recommended disclosure of the residence's dementia care program philosophy and placement process, individualized service plans and costs, staff training, and environmental support. This is especially important, given the growing number and proportion of assisted living residents who have cognitive impairments and the fact that program and environmental features can have positive outcomes for these residents (Zeisel et al., 2003).

There are a number of unresolved dementia care issues (separation of residents) and standards should be developed, implemented, and researched very carefully. Assisted living has great potential to serve residents with dementia and is already serving many people with moderate to serious dementia. There is a danger, however, that as a consequence of serving this cognitively impaired population, states will impose restrictive regulations that will unnecessarily limit the capacity of assisted living to serve this population. The significance of this issue is evident in Hawes et al. (2000a) findings that cognitive impairment is an important variable in accounting for movement to a nursing home.

Finally, Zimmerman et al. (2005) found that facilities with more restrictive admission policies, an affiliation with another higher level of care program, or have RNs or LPNs on staff are more likely to transfer residents to nursing homes. This latter finding conflicts with Hawes et al. (2000a) who found that the presence of a registered nurse protected residents from discharge to a nursing home. Zimmerman et al. (2005) also found, however, that residences providing more RN care hospitalized their residents less, which is consistent with a similar finding from the Hawes et al. (2000a) survey.

Regulation and the Ideal Model of Assisted Living

Our notion of the “ideal” assisted living model is based on a continuing commitment to a set of core values which we think the available research literature shows is achievable and should be embedded in the regulatory framework for assisted living. The ideal model can be applied across many types of congregate housing with services and supported by regulations explicitly designed to express the values of autonomy, privacy, and the capacity of assisted living to allow residents to age in place in an affordable setting. We suggest the following guidelines for a framework that is most consistent with the ideal model of assisted living.

- 1) *Disclosure.* Every potential resident and her family should be fully informed about the services the residence offers, how much they cost and how costs change in response to changes in resident need, aging-in-place policies, physical environments and other issues identified by the GAO (1999) as full disclosure problems in assisted living. This is an issue that probably needs to be clarified by state regulators, especially in the area of dementia care. Residents and their families should not be surprised by provider decisions.

Regulatory attention should focus on disclosure by requiring that residences clearly indicate what residents can expect in terms of services and the capacity of the residence to meet the needs of seriously impaired or sick residents. Even then, however, residences may decide to accommodate the desires of declining residents for many uniquely personal reasons (friendship bonds) and policy makers must be careful to avoid heavy-handed regulatory intrusion into the residence-resident relationship.

2) *Admission and retention criteria and staffing levels.* In order to maximize consumer choice and the preference of many residents to “age in place” as long as possible, admission and retention criteria should be as inclusive and flexible and staffing should be sufficient to meet the needs of each resident. Restrictive criteria would keep many frail elderly out of assisted living, diminish the quality-of-life conditions they want or force them into nursing homes, as would uniform staffing standards, by making assisted living less affordable. Staffing should be based on assessed resident needs and regulated accordingly.

Ball, Perkins, Whittingham et al. (2004) demonstrate the complex nature of aging in place in assisted living residences. They suggest that there may be as many ways of aging in place as there are assisted living residents. Regulations specifying the terms of retention very precisely are likely to end up displacing many residents whose quality of life is dependent on remaining in their assisted living residence. They conclude that resident pathways to aging in place are largely idiosyncratic and are influenced by a wide range of dynamic and interacting factors that determine “the ‘fit’” between the capacity of both the facility and the resident to manage resident decline” (p. 205).

There is no compelling evidence that requiring assisted living residences to staff at levels commensurate with resident needs, as recommended by the Assisted Living Workgroup and currently required by many states, jeopardizes resident safety or systematically threatens their quality of care. Staffing at assessed need levels is a more challenging regulatory approach than relying on simple, uniform staffing standards. The affordability benefits outweigh any downside risks at this point.

- 3) *Negotiated risk*. Negotiated risk contracts, if clear, non-coercive conditions are met, should be permitted on an expansive basis in assisted living. The use of risk contracts will continue to evolve in response to law and regulation over the next several years and may become an increasingly important vehicle for consumer choice and direction and aging in place. Special provisions will need to be made for those who are cognitively impaired.

The Assisted Living Workgroup's recommendation concerning shared responsibility agreements provides a workable framework for the future developing of equitable (no waiver liability) agreements between providers and consumers. Most of the recommendation provides a detailed outline for developing a process of negotiation, which the states can use as a guide. The recommended process specifies a provider's responsibility to determine the resident's choices and identify the associated risks. The process is also designed to recognize that some courses of action may not be realistically possible, but that the resident's choices should be honored, even when the provider thinks they are not in the resident's best interests.

- 4) *Dementia care*. The industry should develop a set of model guidelines for dementia care which could be used by states to develop regulatory standards designed to ensure an acceptable level of care for residents with dementia.

The Assisted Living Workgroup's recommendations regarding care for residents with cognitive impairment and the recently developed guidelines from the Alzheimer's Association provide an effective framework for serving this population. These recommendations are based on the proposal that assisted living residences serving residents with dementia be prepared to build on the strengths, values, and choices of these residents and that these preparations reflect the probability that the cognitive capacity of these people will change and deteriorate. These preparations should include: staff training about cognitive impairment and procedures for assessing and reassessing the resident's cognitive status, abilities, and needs; direct care staff with a focus on preparing to understand and respond effectively to residents' behavioral symptoms; specialized activities that are appropriate for residents with cognitive impairment/dementia; procedures for designating and working with a surrogate decision maker, if the resident is not capable of making decisions for him/herself; policies and procedures to protect residents who wander and/or are at risk of physical harm; regular monitoring to assure resident safety and health care status, consistent with impairment; and, policies and procedures for involving and supporting family members.

- 5) *Physical plant/environmental design.* Physical plant and environmental design regulations should be designed to create as homelike a living environment as possible, provide privacy, and enhance autonomy.

Many assisted living residents and potential residents place a high priority on privacy as a quality-of-life value (Hawes, 2000; Kane, 1998). Most fundamentally, this means a strong preference for private rooms and bathrooms and, to a lesser but still very significant extent, kitchenettes. The assisted living experience in Oregon and Washington, which requires these privacy provisions and where costs are within the industry norm, would seem to indicate that

these provisions for privacy are affordable. We should not forget that privacy may be a necessary condition for the exercise of autonomy, maintaining dignity and achieving an adequate quality of life among many residents, including those who are cognitively impaired, as found in the study of Alzheimer's special care units by Zeisel et al. (2003). A majority of the Assisted Living Workgroup's participants supported a provision for single occupancy rooms in their definition of assisted living.

- 6) *Training.* The industry tendency to have employees play multiple roles is generally positive in that it can help dilute the stifling effects of hierarchy and avoid the alienation and detachment of command and control structures and help maintain staff morale, creativity and commitment. The tendency toward "generalist worker" roles can also contribute to a more integrated, familial, homelike environment and help contain staff costs. It also creates a greater need for cross training, both pre- and in-services training, especially for workers in facilities serving more physically and cognitively impaired residents. The training should also be designed to focus on the values of assisted living in all phases of caregiving and interaction with residents. The industry can expect more regulatory activity in this area and should create guidelines in anticipation of state initiatives.
- 7) *Quality of life criteria.* Greater priority should be placed in the development and use of resident-oriented quality-of-life outcomes measures based on the fundamental values of assisted living—autonomy, privacy, dignity and the experience of a fuller life, however impaired one may be. This approach to performance accountability would emphasize systematic consumer feedback on such variables as enjoyment, meaningful activity, quality of relationships, spiritual well-being, autonomy, privacy

and dignity as well as the resident's sense of security and physical comfort (Kane, Bershadsky, Kane et al., 2004). Even in the current absence of regulatory requirements, assisted living providers should use these measures (as some already are) as essential components of an internal quality monitoring program.

- 8) *Nurse delegation and medication management.* Properly supervised by nurses, non-nursing staff should be allowed to assist in administering medications. There is no evidence that current nurse delegation acts in several states, including Oregon and Washington, are harmful to residents who, in fact, benefit from the capacity of these acts to help contain costs.

One of the principal purposes of nurse delegation² in assisted living is to create an effective balance between containing the cost and the risk of medication management. Three-fifths of the states provide some form of delegated nurse supervision of unlicensed staff or the use of trained aides to administer oral medications in assisted living, and some states also allow these staff to administer injections and as needed medications. Most informants from state boards of nursing report few consumer complaints in regard to nurse delegation, although there are no formal mechanisms for reporting errors (Reinhard et al., 2003).

Sikma and Young (2001; as cited in Munroe, 2003), found great enthusiasm among registered nurses for delegation because it brought a higher level of nursing into assisted living. However, Sloane et al. (2004) found that many assisted living residents with serious chronic conditions in four other states were under-medicated or were not receiving appropriate medications. This has been found in nursing home and home care settings as well (Munroe, 2003) and indicates a need for better regulations regarding medical assessments and protocols,

² Nurse delegation is “nurse-directed medication administration, involving direct training of unlicensed personnel to administer medications with ongoing RN oversight and supervision” (Reinhard, Young, Kane et al., 2003, p. 17).

including quarterly evaluations for certain residents by pharmacists or physicians. The Assisted Living Workgroup (2003) developed several medication management recommendations, most of which focus on the roles, training, and monitoring of medication management assistants working under the supervision of a nurse according to the provisions of nurse delegation acts.

- 9) *Regulating small facilities.* Policies, financing, and regulatory strategies should reflect our awareness of and support for the different forms of assisted living and the need to provide the consumers with as many options as possible to choose from, as long as they are consistent with the values of the assisted living philosophy and basic safety requirements. This means that small residences should not be held to precisely the same standards, which they are not as likely to meet as the larger, purpose-built, new paradigm properties. Zimmerman et al. (2002) note that if regulation and funding turns on adherence to the new facility paradigm's parameters, it may mean the demise of the smaller properties. This perspective will undoubtedly complicate the way assisted living is regulated, but if it results in supporting the expansion of the range of community-residential options available to consumers of housing with services, then it should be considered worth the additional complexity.

The value of small facilities is evident in the findings of two recently reported studies. Morgan, Eckert, Gruber-Baldini & Zimmerman (2004) found that the larger and newer properties are better able to provide services and meet the privacy and autonomy desires of residents, but small residences may provide more familial, homelike settings that many impaired elderly seem to prefer and are willing to give up some privacy, autonomy, and health services in order to live in such residences.

In a one-year follow-up study, based on data from 2,078 residents in 193 diverse assisted living residences across four states, Zimmerman et al. (2005) found that small properties (average bed size of 8.9 beds) fared as well as “new model” properties in terms of medical outcomes, nursing home transfers and better in terms of functional and social decline, and social withdrawal. Others have found that smaller or mid-size properties are often more willing to accept Medicaid and SSI-supported residents than larger properties (Salmon, 2003; Stearns, 2001), which has major implications for state long-term care policy and the use of Medicaid-waiver funds to expand community-residential alternatives to nursing homes.

Staffing issues generally, and nurse delegations in particular, are especially critical to the expansion or even the survival of small assisted living facilities. Staffing is a major cost factor for all assisted living residences and plays an important role in determining affordability. In the absence, however, of the economies of scale that benefit larger facilities, small facilities are especially vulnerable to the costs of regulation that prescribe staffing levels and preclude or greatly limit the delegation of certain nurse practices, including medication management.

In summary, the values of assisted living, which constitute the core of our “ideal” model, can best be achieved by a regulatory framework that:

- supports the use of inclusive admission/retention criteria
- requires full disclosure of information essential to informed decision-making by consumers
- permits flexible staffing based on accurately assessed resident needs and preferences, which providers can use to develop negotiated risk agreements with competent residents who prefer to age in place under conditions of clearly articulated risk

- specifies the kinds of care and activities provided to residents with dementia and the associated training requirements for residence staff
- establishes clear physical plant/environmental design criteria that reflect the values of assisted living, including provisions for a homelike environment like private rooms, at least for new construction properties
- incorporates quality of life measures into routine regulatory procedures, and allows the use of nurse delegation for a range of caregiving responsibilities. A regulatory framework for the ideal model of assisted living would also recognize the unique value of small residences through supportive initiatives designed to prevent abuse or neglect without imposing standards that would force the closing of residences favored by many consumers for their affordability and homelike features.

Conclusion

The best available information indicates that the assisted living industry, with the support of policy makers and the regulatory community, has built a sound foundation for serving residents with a wide range of long-term care needs and in a manner largely consistent with the values of the original vision for assisted living. A continuing skepticism about the capacity of assisted living to achieve these values in the future is probably in order in that it will help policy makers, providers, advocates, and residents keep their eyes on the prize. A sense of fatalism, however, about the practical ability of assisted living to achieve the original vision on a continuing basis is simply *not* justified by the documentary record which, we think, shows that the growth of assisted living has helped elevate the preferences and interests of consumers across the whole long-term care system.

The efforts of nursing homes across the country, with the assistance of advocacy groups like the Pioneers and the Green House initiative, to move toward the assisted living model and its quality of life values is more evidence of the need to keep regulation from undermining the original vision for assisted living which research now suggests is a largely achievable “ideal.”

The biggest problem with assisted living is not insufficient regulation, but rather the lack of availability of access for the less affluent elderly who require public support, have limited access to community resources, and want to avoid ending up in a nursing home. For many of these people, assisted living offers the optimal long-term care setting for not only receiving the physical care they need, but also for achieving a quality of life (autonomy, privacy) that may not be available in their own homes. Our primary goals for assisted living should be to expand access for publicly supported residents and avoid regulatory schemes that would undermine the quality of life features that constitute the fundamental appeal of assisted living as a long-term care program.

The Assisted Living Workgroup generated several recommendations designed to increase the affordability of assisted living for low-income persons, including expansion of the assisted living Medicaid waiver and HUD-funded programs related to assisted living. Oregon and Washington have used waivers to transform their long-term care system by expanding home- and community-based services, including assisted living, over the last ten years. The Assisted Living Workgroup also recommended an increase in SSI spending to cover assisted living room and board costs and allowing supplemental support by family members for assisting living residents.

Research findings demonstrate the importance of assisted living goals/values (privacy, autonomy, dignity, homelike ambiance) to residents and the apparent capacity of assisted living to achieve outcomes that reflect these values more often than not. Consumer advocates and

policy makers have a responsibility to recognize and respect these outcomes which reflect what we know about consumer preferences, and to resist regulatory interventions that would make assisted living significantly less affordable and less livable from a quality of life perspective.

Assisted living is a relatively fragile form of housing and long-term care that is largely sustained by the fact that many older people very much prefer it to nursing home care and may, in many cases, find it preferable to in-home care. It would not take the application of very many nursing home style regulations, however, to make assisted living substantially less affordable *and* far less attractive than it has proven to be over the last ten years. Every effort should be made to contain these risks by always assuming the perspective (her needs and preferences) of the consumer and by supporting rigorous research, the results of which can be used to guide policy and dilute the distorting influence of purely anecdotal accounts of bad *or* good outcomes.

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