

**“Assisted Living: What Do We Know, What Should We Do?”**

By:

Larry Polivka, Ph.D., Executive Director

Jennifer Salmon, Ph.D.

Lisa Rill, Ph.D.

Claude Pepper Center  
Florida State University  
636 West Call Street  
Tallahassee, FL 32306-1124  
(850) 644-9311

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### Preface

This latest draft of the Claude Pepper Center Assisted Living Literature Review and Policy Analysis Paper draws on far more sources of information (over 50) than were included in the 2006 version sent to the Work Group last summer. The additional information may be of value to Work Group members in preparation for meetings and in gaining a more informed perspective on the larger context in which our discussions about Assisted Living (AL) regulations are occurring. Some of the more salient findings that emerge from the review include the following:

- The values most associated with AL (autonomy, choice, privacy and home-like environment) are, in fact, extremely important to AL residents, and AL providers have, for the most part, done an adequate or better job of achieving these values. This does not mean that the provider community can assume that the task is done and what they have achieved cannot erode if sufficient effort is not maintained. In fact, threats to this achievement may be inherent in two other major findings from our review.

First, aging in place in AL is occurring and probably increasing as the number of more impaired persons living in AL continues to grow. Aging in place has been part of the AL mission for almost two decades and is an important aspect of achieving the vision for AL as a major part of the long-term care (LTC) system.

Second, a substantial percentage of residents who are remaining in Assisted Living Facilities (ALFs) as they experience increasing impairment (aging in place), are persons living with dementia, the most common form being Alzheimer’s disease. The research literature indicates that AL has the capacity to accommodate this growing segment of the population and may be, for many, a more propitious place to age in place than their own homes or nursing homes.

This does not mean however, that AL should become a massive substitute for nursing home level of care for very seriously impaired (physically or cognitively) persons.

- Policymakers should be careful and avoid relying excessively on what Rosalie Kane has referred to as the over utilization of AL. As noted in several articles and reports reviewed for this paper the typical profile of long-term residents in AL compared to residents in nursing homes is still substantially different and should probably remain so. Regulatory (less restrictive placement/retention criteria) and funding (higher costs for increased staffing) changes designed to create a convergence of profiles would in all likelihood turn AL into a slightly less regulated and slightly, if at all, less expensive version of the nursing home model. This would undermine the very characteristics (more autonomy, privacy and choice) that have made AL such an attractive option in the long-term care continuum over the last 20 years. This would be an unfortunately ironic development given the current efforts in several states by the Nursing Home Pioneers and Green House

movements to create smaller, less regimented, more home-like nursing home environments.

AL has gradually developed the capacity to serve a more impaired resident population but may now be approaching the threshold of resident impairment (functional and medical needs) that must be preserved in order to maintain its qualitatively distinct difference from living in a nursing home. This issue would remain even if ALFs were evenly available across geographical areas and equally willing to take the Medicaid rate for ALF residents. Neither of these conditions currently exists in most states.

Furthermore, the current regulatory framework for AL in Florida underwent a major change in 1990-1991 with the passage of legislation establishing the ECC License and has evolved since then to accommodate changing perceptions of the proper role of AL in the LTC system. The research literature and expert opinion largely support the perspective that Florida's ALF regulatory framework would have to undergo substantial modification to accommodate a qualitatively more impaired population that is more comparable to the typical nursing home resident.

The current ALF regulatory framework is allowing many older people and younger people with disabilities, who would have been in nursing homes 20 or even 10 years ago to live in ALFs without turning them into poorly resourced nursing homes. Any regulatory changes that might put this carefully constructed balancing act at risk should not be undertaken lightly.

- With the huge growth in the number of persons living with dementia in AL, the need to pay much closer attention to their service needs and quality of care and life has grown as well. More research focusing on these issues is showing up in the literature but far more is needed, especially research on the quality of life of residents with dementia. AL has clearly demonstrated its capacity to serve this population, but, as it grows, policymakers, providers and the public need to know more about what should be required in dementia specific units, what kinds and amounts of training should be provided to administrators and caregivers, what type of living arrangements and activities are best for residents as they progress through the stages of dementia and what might be needed in terms of regulatory changes to improve the quality of care and life for this population.
- AL has been a major source of housing and services for persons living with mental illness for several years in Florida and many other states, without a clear consensus emerging about what AL for this population should be expected to provide and be held accountable for beyond the requirements of the Limited Mental Health License. This lack of consensus includes the relationship between ALFs and the larger mental health provider community and the proper roles and responsibilities of each, the qualifications and training requirements for administrators and staff in ALFs with residents needing mental health services and many other important regulatory issues that have been debated for years without consensus being reached.

The absence of research findings related to these issues greatly hampers the ability of policymakers, advocates, providers and the public to obtain the breadth and depth of information needed to generate a consensus on what should be done and what it might cost. This does not mean, however, that efforts to more systematically address the housing and services needs of persons living with mental illness in the community should continue to be delayed until more research information becomes available. Public officials, housing and mental health experts and advocates should conduct a collaborative initiative to develop a range of housing and services models including cost estimates, funding strategies and regulatory systems, for this population (based on the best available information).

- Cost, of course, is a major challenge for AL generally and for all the populations living in ALFs. Although the research literature has increased steadily over the last several years, AL cost studies are still rare and the few that have been done are far from adequate. As the need for more AL capacity increases with the growth of the 75+ population over the next three decades, and economic pressure continues to be felt in both the public and private sectors, policy makers, the public and private providers are going to need far more accurate information than what is currently available about AL costs and the financial impact of possible regulatory changes.

The monthly cost of AL for residents paying from private sources has been increasing by 5-10% annually for several years and now average about \$3,200 a month (\$38,000 annually). This rate of increase is unlikely to abate over the next several years as the demand for AL increases with the growth of the 75+ population. This trend is likely to put AL increasingly beyond the reach of those who need a residential alternative to their own home, but who do not require nursing home level care. This trend is also likely to perpetuate and possibly increase the current gap between the amount charged to private pay residents and what state and federal governments will pay for Medicaid supported residents or for residents supported by other public sources.

Resolving these discrepancies between the demand and need for AL and its affordability will be one of the nation's major long-term care challenges over the next several years and will keep the need to balance the relationship between cost and regulation permanently on the policy agenda along with the need to achieve greater efficiencies in service delivery and facility financing. Regularly conducted cost and outcome evaluation studies should help policymakers and providers identify potential efficiencies on a continuing basis.

These kinds of policy oriented analyses, however, will depend on the routine collection of resident characteristics and service cost data. This will require the development of resident and services information systems similar in design to those now administered by nursing homes, but requiring the collection of less data at less frequent intervals.

- In our view the AL research completed since the 2003 national AL Work Group is generally consistent with the findings from the pre-2003 literature in providing evidence supportive of the vast majority of regulatory recommendations made by the Work Group

and addressed at length in this paper. The Work Group did not address every regulatory issue and others have arisen since they released their report. On the whole, however, the 2003 Work Group report still provides a solid framework for the formulation of regulatory models for AL and the identification of gaps.

It would probably be helpful to all affected parties to reconvene the Work Group in 2013 to review the 2003 report in terms of new knowledge and 10 years of experience across the states in the management of AL growth and change.

### *1) 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 and culture change (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

(<http://www.ahcancal.org/ncal/resources/Pages/ResidentProfile.aspx>, 2012). 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. A recent study on ALFs found that fifty-four percent of residents are aged 85 and over (Caffrey, Sengupta, Park-Lee, Moss, Rosenoff, Harris-Kojetin, 2012). 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 about 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.

The fundamental message of this paper 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 likely 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. An analysis of Medicare data from 1992-1998, on beneficiaries over age 65, found that assisted living has become 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.

As mentioned above, ALF residents are more likely to have higher incomes when compared to the nursing home population (Hernandez, 2012). Among the private-pay residents, over 84 percent report that they are the primary payer by themselves, either with current income or combining their income with spending down their savings and/or assets (Coe and Wu, 2012). Approximately 40 percent of residents in the Independent Living (IL) portion of IL/ALs reported that they rely mostly on their personal resources, such as Social Security, pensions, and private annuities to cover *all* of their expenses (Coe and Wu, 2012; Hernandez, 2012).

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. A key factor that has made ALFs inaccessible to most low-income individuals is the unwillingness of many ALFs to become contracted Medicaid providers (Hernandez 2012). ALFs are reluctant to accept Medicaid because it is associated with higher operating costs and inadequate reimbursements. More specifically, Hernandez (2012) suggests, “The wider the gap between a provider’s private monthly rates and the state’s reimbursement, the less likely a provider will serve any Medicaid residents...Some providers may also choose to terminate their Medicaid contracts” (123). 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).

The number of persons needing LTC services and who are likely to be Medicaid eligible is set to increase. Meeting these challenges will require the States to create a more balanced long-term care system which is both more affordable and better designed than the current system to meet the growth in long-term care needs (Mitchell, Polivka, Rill, and Stivers, 2011). Changes, however, in staffing and regulatory oversight of ALFs will need to be considered if there is an increase of higher acuity residents cared for in an ALF setting.

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.

This paper begins with a discussion of 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, social engagement, privacy and dignity, and aging in place in the most homelike and least restrictive environment. Although we have incorporated many of the recommendations and reflections of the National Assisted Living Workgroup (2003)

into our discussion, we make most extensive use of these valuable materials in section IV on regulatory issues.

The National 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. Generally speaking, participants divided into three groups with the majority supporting a regulatory approach based on the assisted living principles of resident choice, autonomy, and privacy. The second group supports a substantially more prescriptive approach based on safety and quality of care priorities and a third, smaller group, felt that many of the recommendations were too prescriptive on regulatory issues that should be left to the states. Although the workgroup was not of one mind in the formulation of regulatory guidelines, we think that the results of the workgroup remain relevant 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. In addition, the recommendations, on the whole, provide a workable framework for the development of state regulations – they provide a clear direction without being burdensomely prescriptive.

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. A summary of the final report from the Assisted Living Phase I Workgroup in Florida (2011) is

provided in the appendix. This report contains specific policy recommendations for ALF administration and regulation and can be used to illustrate the range of ideas about what can be done to help ensure the well-being of the residents without imposing excessively burdensome or expensive new regulation on ALFs.

## *II) Core Values of Assisted Living*

The original vision for assisted living was largely a product of a philosophical commitment to the commonly recognized quality of life values of autonomy and choice, social engagement, 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.

### *1) Autonomy and Choice*

Researchers have identified autonomy and choice as two important factors affecting ALF residents’ quality of life. 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). Researchers have found that residents in ALFs, compared to residents in nursing homes or residential homes, reported higher levels of autonomy and privacy, and lower levels of depression and boredom (Robison, 2010). 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. Salmon (2001) found that the major predictor of quality of life was the degree of personal control the respondent experienced. 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.

Other recent studies report similar findings. Chen and colleagues (2008), examined 1,098 residents living in ALFs in Florida, Maryland, New Jersey and North Carolina, and found that the residents were less depressed when they were more involved in influencing facility policy. The same study also found that a greater degree of resident control (e.g., having a say in selecting décor, new residents, hiring/firing staff and menus) was associated with fewer sleep disturbances and lower levels of agitation. Similarly, Jang and colleagues (2006) examined depressive symptoms in ALFs and discuss the importance of fostering and empowering residents feeling of control. They suggest the staff implement ways to improve the resident's self-mastery skills by allowing as many decisions to be made by the resident as possible. Some examples include, allowing the resident to choose their feeding and bedtime schedules and teaching the resident new skills to increase self-efficacy (Jang, Bergman, Schonfeld, Molinari, 2006). In another study of 74 Adult Foster Homes (AFH), Residential Care Facilities (RCFs) and ALFs,

Thomas and colleagues (2011) found that although ALFs provided more resident autonomy than the other two settings, they were also less likely to admit those who needed a high level of care. The researchers concluded that all three settings provide a trade-off between autonomy and care.

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).

Autonomy and control are also important for the intellectually and developmentally disabled (ID/DD) living in ALFs because most of them have very limited choice-making opportunities. Kozma and colleagues (2009) did a systematic review of multiple studies from 1997-2007 that examined the outcomes for different residential settings for people with ID/DD. After reviewing 21 studies, they found smaller, more personalized community based services offered more individual control and opportunities for autonomy than the larger congregate facilities. They also found staff practices and empowerment were central in promoting choice (Kozma, Mansell, Beadle-Brown, 2009). Overall, the degree to which residents have control and autonomy in ALF settings is related to their quality of life, although there may be a tradeoff that residents consider when weighing control and autonomy against a higher level of care.

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.

## *2) Social Engagement and Quality of Life*

Social engagement refers to an individual's choice to connect socially and emotionally with other people and the community (Park, 2009; Park, Zimmerman, Kinslow, Jung Shin, Roff, 2010). Researchers have examined the role of social engagement between resident-resident and staff-resident relationships. The findings illustrate that social engagement is an important factor because of the positive effects it has on AL residents' quality of life, morale, life satisfaction, and wellbeing (Kemp, Ball, Hollingsworth, Perkins, 2012; Park, 2009; Street, Burge, Quadagno, Barrett, 2007).

Social relationships between AL residents are influenced by community, facility, and resident factors (Burge and Street 2010; Kemp et al., 2012). Community factors exist outside the facilities and can operate on federal, state, and local levels (Kemp et al., 2012). The Health Insurance Portability and Accountability Act (HIPAA) is a federal policy designed to protect the individual's privacy; however, Kemp and colleagues (2012) found that HIPAA hindered co-resident relationships in times of illness-related relocation due to the withholding of information during the residents hospitalization. AL regulations at the state level often allow for relocation, which can hinder an individual's ability to maintain relationships with other residents and age in place (Kemp et al., 2012). In a study of residents in 10 large facilities and 12 small facilities in Maryland, Tilly and colleagues (2008) found that residents who spent more hours engaged in activities remained in the facility longer than those who spent fewer hours engaged in activities, net of other factors including health, mobility, and level of cognitive functioning. On the local level, certain community characteristics can influence ALF activity programs. Kemp and colleagues (2012) found that a large Jewish community in one area helped shape an activity program that was organized around Jewish culture.



Facility factors that influence AL residents' social relationships include various organizational characteristics, such as size, physical and social environment, the quality of staff, and types of activity programs (Burge and Street 2010; Kemp et al., 2012). Mealtime in ALFs is a key factor affecting co-resident relationships. In a study of 384 residents in various Florida ALFs, Street and colleagues (2007) found that life satisfaction was associated with food quality along with internal social relationships (positive feelings towards staff and friendships with other residents). Similarly, in a study of 82 residents in 8 southern ALFs, Park (2009) found that the enjoyment of mealtime and residents' perceived friendliness of staff and other residents were associated with psychological well-being, and that these factors had a greater influence on psychological well-being than perceived social support, social activities and relationship reciprocity. Kemp and colleagues (2012) found that mealtimes "structured daily routines, offered social venues, and were essential to relationship building" (p. 496).

The designs of common spaces in ALFs and the types of activities offered are also important factors that influence social interaction. The physical design can impede or enhance relationships depending on the amount of usable space that is available to residents. Kemp and colleagues (2012) examined three AL facilities and found the design of one facility was not suitable for frail elders, and the other two had usable spaces, however, one facility did not take advantage of the spaces available. In another study of 171 residents in four Maryland ALFs, researchers found that life satisfaction was associated with the social support of friends and staff who encouraged physical activity (Resnick et al., 2010). The researchers concluded that the improvement in life satisfaction was less about the activity itself, and more about the social engagement that the activity provided. Activities provide opportunities for interaction; however, activity programming should not be a "one size fits all" approach, but rather reflect the range of

residents' interests and abilities in each ALF (Kemp et al., 2012; Park et al., 2010). Overall, the social environment can facilitate social engagement by “providing opportunities for resident-initiated activity groups, designing well-planned seating arrangements for dining, and offering special events to break the monotony of the AL routines” (Park et al., 2010: p. 16).

Residents' individual characteristics, family relationships, and health and functional status also influence relationships with other residents (Burge and Street 2010; Kemp et al., 2012). Resident characteristics, such as age, race, gender, and culture were found to influence co-resident relationships (Kemp et al., 2012). Residents with supportive family members experience more positive relationships with other co-residents and staff compared with residents more isolated from or lacking family (Burge and Street 2010; Kemp et al., 2012; Port et al., 2005; Street and Burge 2012). The findings for health and functional status are mixed. Some researchers found that social bonds are not only formed on the basis of similarity, but also because of individuals' wish to reach out and be kind to others more in need (Kemp et al., 2012; Park et al., 2010). However, others have found that individuals with cognitive impairments or behavioral problems are often socially isolated (Burge and Street 2010).

Social relationships between AL residents and staff are also influenced by community, facility, and resident factors; however, in different ways than between co-residents (Ball, Lepore, Perkins, Hollingsworth, Sweatman 2009; Burge and Street, 2010; Kemp, Ball, Hollingsworth, Lepore, 2010). These factors directly and indirectly influence the quality of staff-resident relationships, care outcomes, and staff satisfaction/retention (Kemp et al., 2010). Community factors, such as size, location, and culture can affect staff-resident relationships. In small towns and rural areas, residents and staff are more likely to have similar backgrounds and may also have prior connections to each other due to the small size of the community. In larger, urban

areas there is a greater chance that the resident and staff have different backgrounds, which can lead to relational barriers (Kemp et al., 2010).

Facility factors that influence staff-resident relationships include: size, ownership, staff, physical layout, and workload (Kemp et al., 2010). Smaller, family-owned ALFs are more likely to have a homelike feeling where staff are more familiar with the residents and can build relationships with them, in contrast to a larger facility with multiple floors or buildings, which can inhibit interactions with residents. High amounts of workload and rotation of staff can hinder staff-resident relationships due to the lack of time spent with the resident.

Residents' individual characteristics, family relationships, and health and functional status also influence staff-resident relationships (Burge and Street 2010; Kemp et al., 2010). Out of all the demographic characteristics, the race and class of both the staff and resident tends to influence their relationship the most (Kemp et al., 2010). In terms of family relationships, Burge and Street (2010) found that individuals with family contact on a regular basis were significantly more likely to report positive perceptions of staff relationships than those without family contact. Health and functional status is also a key factor in establishing staff-resident relationships. Kemp and colleagues (2010) found that some staff felt it was easier to connect with residents who were frail or had cognitive impairments because they needed more care, while others felt it was more difficult. They also found that it was most difficult for the staff to build relationships with residents when they had poor attitudes and behaviors (Kemp et al., 2010).

Overall, the research literature clearly indicates a social climate that promotes active social engagement is associated with residents' quality of life; therefore, it is important for ALFs to provide residents with a variety of opportunities to develop meaningful activities and relationships within the facility.

### *3) 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. In a study of residents in ALFs in four states, Morgan and colleagues (2004) found that smaller facilities were rated as being lower on measures of privacy, tolerance for problematic behaviors, resident choice, providing services, and having RNs on staff. However, in the same study, the researchers found that residents rated smaller facilities as being more homelike than larger facilities.

States vary in how they interpret what it means to ensure an adequate level of privacy and dignity. The "Assisted Living State Regulatory Review" (2008) highlights this variation in how

minimum requirements for meeting these values are interpreted in terms of the physical facility requirements (e.g., occupancy, room size, and bathroom requirements). A few examples of state variation include the following:

- Washington State stipulates that rooms must be at least 80 square feet (70 per resident for shared occupancy), that there must be one toilet and sink for every eight residents and a bath/shower for every 12, and residents under AL contract with DSHS/ADSA have a private bathroom.
- Oregon has multiple stipulations including that newly constructed facilities create rooms that are at least 220 square feet include a kitchen and bathroom, residents units must be at least 80 square feet, and that unit doors must not open into another resident's bedroom.
- In Florida, a minimum of 80 square feet of usable floor space is required (60 square feet for shared occupancy), an additional 35 square feet of living and dining space per residents, only two residents max are permitted in newly built or remodeled multiple occupancy units, and shared bathrooms are allowed with the stipulation that there is one toilet and sink per six residents (plus one bathing facility per eight residents).
- Minnesota simply stipulates that facilities must comply with state and local building codes.
- Georgia policy requires a minimum of 80 square feet per resident (regardless of whether the room is private or shared), no more than four residents per room, and that common bathrooms are permitted.

Many providers and policy makers believe that the single occupancy 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. For instance, the maintenance and housekeeping costs are higher with shared rooms due to issues such as wear and tear from frequent roommate switches, increase need for staff to provide behavior management, and more demand for tray service in the rooms to be assured some alone time

while the roommate is in the dining room. 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). Given the deep preference of residents for single occupancy rooms, the state should pay careful attention to Kane’s argument for their financial feasibility, at least in the case of regulations governing new developments. Oregon and Washington have operated with single occupancy provisions in their publicly assisted living programs for the past several years and have found them affordable and consistent with their long-term care cost containment priorities.

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.

#### *4) 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 \$9,500 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.

### *III) 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,<sup>1</sup> 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 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 a study of ALFs in Florida, researchers found that admission, discharge, and licensure type differed across the facilities (Street et al., 2009). They found that behavioral facilities are less likely than traditional and high-frailty ALFs to admit (and more likely to discharge) those who are incontinent or frail. High-frailty and behavioral ALFs were more likely than traditional ones to admit those who have a history of mental illness or behavioral problems (high-frailty tended to especially accept those with mental problems relating to age, such as dementia; behavioral ALFs tended to accept those with mental illness). With regard to licensure type, Street and colleagues (2009) found that because high-frailty facilities have a more specialized license than the behavioral or traditional ALFs, they admit and are better able to provide specialized services to frail individuals.

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

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



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.

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.

*1) Capacity of assisted living to support aging in place for people with Dementia.<sup>2</sup>*

The prevalence of dementia is high among the long-term population. In one study of residents in seven Assisted Living Facilities in Nebraska, researchers estimate that approximately

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<sup>2</sup> This section prepared by Lori Moore, Ph.D.

33 percent of the residents had dementia (Magsi and Malloy, 2005). In another study of 198 residents living in ALFs in Maryland, Rosenblatt (2004) found that 66 percent of the study participants had dementia (81 percent in small facilities, 63 percent in large ones). 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). A national study of ALFs found that forty-two percent of residents have Alzheimer's and other dementias (Caffrey et al. 2012). Because age-related cognitive impairment is so common in long-term care facilities and because of the rise in popularity of ALFs for long-term care, it is important to understand how cognitively impaired residents fare in these settings.

State policy varies in terms of regulating ALFs that care for dementia or Alzheimer's residents. Some states have many stipulations while others have none. New Jersey, for example, requires facilities that care for residents who have Alzheimer's to have written policies and procedures relating to discharge and admission, staff training, safety, and a list of activities (Polzer, 2008: 130). In Florida, facilities that advertise special care for aging-related cognitively impaired residents must provide activities designed for these residents, ensure their safety and welfare, have staff who have received an eight-hour training course, and have 24-hour staffing ability (2008: 37). In Washington, residents meeting the dementia criteria must receive additional assessments and those with Alzheimer's or dementia must either give consent or have

someone legally authorized to give consent for them before being admitted to the ALF.

Additionally, the ALF must ensure fire safety and make provisions for a secured outdoor area, provide activities, and provide specialized training to staff that will be working with dementia residents (2008: 212). Finally, Georgia has no specifications for ALFs that serve Alzheimer's residents (2008: 40).

A dementia diagnosis, risk factors associated with dementia (e.g., risk of falling), or the type of facility can trigger ALFs to discharge residents. In a study of 198 residents living in 2 ALFs in Maryland, Lykestsos and colleagues (2007) found that those who were diagnosed with dementia had shorter times to discharge, compared to those without a dementia diagnosis. The researchers also found that among those residents with a dementia diagnosis, lack of dementia treatment and more serious co-morbidity were the two most significant predictors of a faster discharge. In another study (Kenny et al., 2008) of residents living in a dementia specific ALF, researchers found that residents who scored low on a balance test were more likely than others to be transferred to a nursing home. The researchers concluded that ALFs should take into consideration fall risk upon admission to reduce high transfer rates of dementia residents. In a comparison of consumers living in the community (Home Care Based Services or HCBS; n=1630) to those living in an ALF (n=836) in Florida, Temple and colleagues (2010) found that those with dementia in the home based care were significantly more likely than those with dementia in ALFS to be transferred to nursing homes. The researchers concluded that ALFs allow those with dementia to age in place better than those receiving in home care.

The research literature has also identified several factors that improve the quality of life for dementia residents, including the physical environment and staff training. In a literature review of 72 studies of dementia in ALs and nursing homes published between 1994 and 2003,

scholars found that the familiarity of staff with residents, environments that incorporate nature scenes, and environments that were more home-like increased residents' happiness and reduced stress (Tilly and Reed, 2008). In a study of 326 residents living in 21 ALFs, Bicket and colleagues (2010) found that positive ratings of the environment were associated with lower psychiatric problems, with higher quality of life scores for those with Alzheimer's, and with fewer falls. In a study of dementia specific facilities, Zisel and colleagues (2003) found that varied ambience and the camouflaging of exit doors decreased depression, social isolation, and hallucinations.

Another study of 421 residents living in 35 ALFs and 10 nursing homes, found that specialized staff training and activity participation were associated with positive quality of life outcomes (Zimmerman et al., 2005). They also found that the setting (ALF versus nursing home) did not affect residents' quality of life. A similar study (Sloane et al., 2005) of 1,252 residents with dementia in 106 ALFs and nursing homes across 4 states found that quality of life indicators such as behavioral problems, depressive symptoms, social function, activities of daily living, and social withdrawal did not differ between the two settings. Additionally, they found no difference when comparing dementia special care units to non-specialized settings in the quality of life indicators. Hospitalization rates, however, did differ between the two settings with ALFs having higher rates than nursing homes, a finding that could indicate that ALFs are not as well equipped to handle residents with dementia or who have significant medical needs (Sloane et al., 2005). This research shows that improvements in the physical environment and well-trained staff can improve the quality of life for residents in long-term care setting who have dementia.

Overall, 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.

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).

## *2) Mental Health in Assisted Living Facilities.*

Research has shown that it is common for persons with severe mental illness, such as schizophrenia, to reside in ALFs. A recent study found that 26.3 percent of traditional ALF residents have a current psychiatric disorder (inclusive of mood, anxiety, and psychotic disorders), 34 percent exhibit one or more behavioral symptoms associated with dementia or psychiatric illness per week, and two-thirds have some indicator of a mental health problem (Dakin, Quijano, McAlister, 2010). However, even with the increase in ALF residents with

mental illness, there have been relatively few published studies about the association of living environment and quality of life, particularly among mentally ill residents in ALFs.

Auslander and colleagues (2001) compared older out-patients living independently with those in assisted-care facilities. They found that residents living in assisted-care facilities had “higher levels of negative symptoms, worse cognitive impairment and a poorer health related quality of wellbeing compared to those living independently” (p.384). In addition, the assisted-care living group had a greater likelihood of being never married, and having an earlier age at onset and longer duration of illness. However, severity of positive and depressed symptoms was similar between the two groups. Mausbach and colleagues (2008) compared the functional capacity and community responsibility between independent and AL settings. They found that although residents in both settings were similar in terms of demographic, clinical, and functional characteristics, those residing in the community engaged in more community responsibilities (ie. work, school, volunteer, caregiving) than those living in ALFs. In a study that only focused on residents living in ALFs, Mares and colleagues (2002) report the following three findings: 1) Supportive social environments enhance resident satisfaction, 2) residents of larger ALFs and residents living in lower-income neighborhoods reported more frequent contact with friends and significant others than residents of smaller homes, and 3) individual characteristics – mostly combined psychiatric symptoms – explained much of the variation in quality of life.

The findings above support the importance of continued attention and treatment by ALF staff, case managers, and others who treat psychiatric symptoms of the mentally ill residents. However, studies have shown that the rates of detection and treatment of mental illness in ALFs are quite low. Mental disorders are more likely to go undetected by untrained staff and are often misdiagnosed by attributing symptoms of mental illness to other age related conditions (Becker,

Schonfeld, Stiles, 2002). In addition, without sufficient training it is possible for both administrators and direct care staff to confuse mental illness and dementia (Dakin, Quijano, McAlister, 2010).

A study on mental health treatments in ALFs found that 42 percent of residents with mental illness go completely untreated and 27 percent of facilities do not provide or require mental health training for their staff (Gordon, Dobbs, Molinari, 2011). The findings suggest:

Mental health issues are not always adequately addressed in ALFs due to inadequate staffing, insufficient support and involvement from community resources, the minimal number of interactive activities provided for residents in the facility, the lack of a mental health screening process upon admission to facilities, and the lack of aid with the transition process (p.22).

However, one study by Cadena (2006) found, of those residents with schizophrenia who reside in ALFs and receive treatment, the most frequent mental health treatment was attendance at a community mental health center. In addition the average resident had five inpatient psychiatric hospitalizations, was never in a state psychiatric facility, and took an average of four psychiatric medications (Cadena 2006).

Insufficient detection and inadequate treatment also remain considerable barriers in the management of late-life depression in ALFs. Researchers have found that depression among ALF residents is common and often untreated (Dakin, Quijano, McAlister, 2010; Watson et. al 2003; Watson et. al 2006). Estimates of depression rates among ALF residents range from 13% to 24% (Dakin, Quijano, McAlister, 2010; Stefanacci, 2008; Watson et. al 2003; Watson et. al 2006).

Watson and colleagues (2003) examined a large and geographically diverse sample of residents age 65 and older from 193 assisted-living facilities across four states (Florida, Maryland, New Jersey, and North Carolina). They found that 13 percent of the baseline sample

were depressed and 5 percent had more severe depression. Of the depressed residents, only 18 percent received an antidepressant the week prior, and only 38 percent of residents with the most severe depression were given antidepressants. Depressed residents were 1.5 times more likely to be discharged to nursing homes than non-depressed residents.

In another study, Watson and colleagues (2006) examined the prevalence of depression, its associated factors, and rates of treatment among residents of ALFs in central Maryland. They found that 24 percent of the sample were depressed and 8 percent had more serious depression. Of the residents with depression, 43 percent were receiving antidepressants, and of those with more severe depression 40 percent were given antidepressants. When looking at the total sample, 33 percent were receiving antidepressants, and of the non-depressed sample, 30 percent were receiving these medications. Residing in a larger facility was the major predictor of receiving antidepressants, with 51 percent being treated versus 17 percent of those living in a smaller facility. Sixty percent of depressed residents did not have a regular source of psychiatric care, and of the remainder, 17 percent received psychiatric care on site and 23 percent away from the facility (Watson et. al, 2006). Overall, the above studies found that depression was common, frequently untreated, and related to an increased rate of nursing home placement and mortality.

If left untreated, depression can cause physical, cognitive, and social impairments, and may contribute to morbidity, all of which can make it difficult for residents to age in place (Stefanacci 2008).

Currently there is no mandated oversight for the screening and treatment of depression or other mental disorders in AL settings. Only a few states require AL staff to be trained in information about mental health disorders such as depression. Currently, very few AL facilities screen residents for mental health problems besides dementia, and few states require that information about emotional and mental health be included in training programs for AL staff. (Stefanacci: p. 31)



Research indicates that long-term care recipients with depression are themselves frustrated with their professional caregivers' limited ability to recognize and communicate about depression (Miller & Kuruvilla, 2008). Stefanacci (2008) suggests that AL staff can proactively assess for symptoms of depression rather than rely on the resident to report mood changes, which will lead to higher rates of diagnosis and better response to therapy. In addition, unlike skilled nursing facilities, state licensing regulations typically do not require ALFs to employ social workers. However, given the valuable role of social workers providing the majority of community mental health services in the United States, the social work profession has a uniquely important role to play in developing and providing training concerning the management of resident mental illness within ALFs (Dakin, Quijano, McAlister, 2010).

#### *IV) 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.

The Assisted Living Workgroup recommendations regarding disclosure for specialized programs of care provides a useful framework for developing regulations in this area:

At a minimum, the Assisted Living Residence (ALR) shall disclose the following information to each prospective resident prior to admission: the philosophy of the special care program; the process and criteria for placement in, and transfer or discharge from, any specialized unit and/or the ALR; the process for assessing residents and establishing individualized service plans; additional services provided and the costs of those services relevant to the special care program; specialized (condition-specific) staff training and continuing education practices relevant to the special care program; and how the physical environment and design features are appropriate to support the functioning and safety of residents with the specific conditions (p. 274).

The importance of these provisions is highlighted by the fact that a large portion of the assisted living population is cognitively impaired and is likely to rapidly increase in the future. In fact, if current trends continue and confidence in assisted living's capacity to provide optimal care for the cognitively impaired increases across the country, assisted living may well become the long-term care setting of choice for most persons with significant cognitive impairment. Currently, the Medicaid waiver-supported assisted living program in Florida has a far higher percentage (50-73%) of residents who have been diagnosed as cognitively impaired than are among the populations of any other waiver-supported program.

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 and colleagues (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).

The Assisted Living Workgroup’s recommendations regarding reasons for resident transfer or move-out provides guidance in determining when a facility’s staffing and other resources may no longer be sufficient to provide adequate care:

...Following a documented assessment, ALR is no longer able to care for the resident due to his/her physical, or mental/cognitive status or behavioral issues based on the scope of services offered or coordinated by the ALR as disclosed to the resident upon move-in and as required by, state licensing requirements; and, wherever practical and except in an emergency, the ALR had attempted to work with the resident so that move-out or transfer would be unnecessary and this attempt has been unsuccessful (p. 128).

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 however, appear to 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.

Opponents of the recommendation feel that:

The rationale emphasizes that the 'shared responsibility' process is to be employed when the assisted living residence disagrees with decisions made by the resident, even if the only person affected is the resident himself or herself. This raises the inference, confirmed by the debate within the Workgroup, that shared responsibility agreements are

designed almost exclusively to protect the facility from regulatory requirements and legal action (p. 154).

This concern, however, must be weighed against the desire of the consumer to enter or remain in a facility under terms of negotiated exception to facility rules and procedures and at some recognized risk to the consumer; precluding such agreements would seem to place an undue restriction on resident choice.

- 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.

Resident needs related to cognitive impairment/dementia differ depending on the severity of the cognitive impairment. An ALR should have procedures and services in place that are appropriate for the severity of cognitive impairment of its residents. The Workshop recommends the following:

For ALRs that choose to serve only individuals with cognitive impairment/dementia or to establish a special dementia unit or units should define precisely the purpose of the unit(s) and develop admission and discharge criteria, staff training activity programs, and physical design features that are consistent with that purpose (p. 145).

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 and Staff Development.* 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.

Staff in ALFs are charged with the care and well-being of residents, have emotionally and physically taxing jobs, and are among some of the lowest paid workers in the U.S. (Ball et al., 2009). Staff in ALFs tend to be white, female and have at least a high school degree (Hawes et al., 2000). Depending on the type of license that a facility has, staff can provide anything from a low level of care (e.g., providing meals or help with light housekeeping) to a high level of care (e.g., administer feeding tubes). States also vary in terms of their staff requirements. The literature has focused on both staff’s perspectives on care giving and on residents’ experiences with staff.

In Florida, the number of staff hours required in a given facility depends on the total number of residents in that facility. Also, at least one employee who is certified in first aid must be present at all times, staffing must be sufficient enough to meet residents’ need, and in facilities that have residents with dementia, staff must have specialized training (Polzer, 2008: 37). In Washington State, policy stipulates that an administrator must be responsible for the 24 hour operation of the facility, that staff provide services stipulated in the negotiated service agreement, and that staff are to ensure the safety of the facility including maintaining fire and

disaster plans (Polzer, 2008: 212). In Alabama, staff must be trained in first aid and CPR, trained to the level of service in accordance with the facility's license, have three months of health-related experience, and the state also specifies the number of hours of training based on the staff level (Polzer, 2008: 10). In Georgia, staff must receive work-related training within 60 days of employment in several areas (e.g., CPR, First-Aid, emergency procedures, social needs, etc.). Direct care staff are also required to complete 16 hours of continuing education each year. Additionally, Georgia ALF policy stipulates that there must be a staff member present at all times and that there should be one staff member to every 15 residents during awake hours and one staff person per 25 residents during sleeping hours (Polzer, 2008: 40). In sum, state requirements vary in terms of staff training and certification, the number of staff that must be on duty, and when staff members must be present.

The research literature has largely focused on factors that make caregiving in ALFs more satisfying for the staff, which is important in recruiting and retaining competent employees, as well as factors that lead to residents' satisfaction with the care they receive. Studies have found that there are several factors that lead to job satisfaction for ALF staff. In one study (Chou and Robert, 2008) of 984 direct care workers, job satisfaction was positively associated with emotional support from supervisors and coworkers, instrumental support from supervisors, and institutional support. The same study found that care workers were less satisfied with their jobs when they experienced role overload. Another study (Ball et al., 2009) found that the types of relationships that staff formed with residents were related to job satisfaction. Specifically, the study found that the more that staff were able to affirm their values for helping the elderly through relationships with residents, develop close ties, engage in positive social interaction, and complete tasks that improved residents' quality of life, the higher their job satisfaction. In a



study of 644 Direct Care Workers (DCWs) in 49 long term care facilities, Ejaz and colleagues (2008) found that compared to nursing home workers, DCWs in ALFs and in home care settings were more satisfied with their jobs. They also found that low job satisfaction was related to lower pay, high turnover, depression, and poor interactions with others. In a study of 3,468 DCWs, Kemper and colleagues (2008) found that home care staff who were interviewed about what could increase their job satisfaction cited increased compensation, decreased hours and better benefits. In the same study, staff in ALFs cited better compensation and supervision. In sum, the research literature indicates that staff job satisfaction could improve with more emotional and instrumental support, better supervision and with increased compensation and benefits.

The research literature has also examined ALF residents' experiences with staff. In a study of 429 residents in 12 ALFs in Florida, Burge and Street (2009) found that residents' ability to receive quality care and to form positive social networks was dependent on being able to pay privately (although the researchers surmise that it's probably because private pay facilities are better able to hire or pay for quality staff) and having control over the initial move into an ALF. In addition, the researchers found that external social support (e.g., family) may buffer some of the negative consequences of poor staff-resident relationships. Another study of 5 ALFs and 5 hospice facilities in Oregon, found that the longer that residents were in the facility, the better their relationship with staff and the more familiar staff were with residents (Cartwright et al., 2009).

The availability of mental health care in ALFs allow facilities to take better care of their residents, which can in turn improve the residents' psychological well-being, physical health, and quality of life (Gordon, Dobbs, Molinari, 2011). In the study by Dakin and colleagues

(2010), both administrators and direct care staff indicated that staff would benefit from mental health-related training, such as managing difficult behaviors, understanding the difference between dementia and mental illness, appropriately addressing conflicts between residents with mental health issues, and redirecting residents with mental health concerns. Ultimately, the most important outcome measure in ALFs is resident quality of life, whether or not the resident is a person who suffers from mental illness. Effective staff training in topics relevant to residents with mental illness is one important means of promoting a strong quality of life for all ALF residents (Dakin, Quijano, McAlister, 2010). Greater effort should be made to detect and treat mental health issues in assisted living, both to reduce suffering and prolong the residents' ability to remain in their preferred environment (Watson et. al, 2003).

Many of the Assisted Living Workgroup's direct-care recommendations either directly or indirectly address training issues. Opponents of the recommendations felt that some of the recommendations required too little training or were too prescriptive and preempted the role of the state in setting training requirements. Our literature review clearly suggests that ALFs need greater capacity to increase their staffs' compensation and benefits in order to increase job satisfaction. The literature also suggests that ALFs provide staff with more training, institutional support and supervision. Finally, facilities should promote residents aging in place as the research shows that the longer staff know and interact with residents, the better their staff-resident relationship.

- 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.

The following is a brief summary of the quality of life guidelines for policy development and program accountability that have emerged over the last 40 years in the ID/DD community. It provides a robust framework for the continuing improvement of services for persons with ID/DDs in the future (Polivka 2009).

- A. Consider that quality of life for persons with ID/DD is composed of those same core dimensions that are valued by all of a nation's citizenry.
- B. Regardless of age, an enhanced quality of life is experienced when a persons' basic needs are met and when he or she has the same opportunities as anyone else to pursue and achieve goals in the major life domains and settings.
- C. Focus evaluation activities on both consumer outcomes and system performance.
- D. Stress that continuous quality improvement is a fundamental aspect of an organization's culture.
- E. Integrate subjective and objective quality of life indicators into a unified concept of the core dimensions of quality of life, and use multivariate statistical and research designs to determine the effectiveness and efficiency of quality of life—focused education and rehabilitation programs.

These guidelines have guided advocates, policy makers, and program administrators in the development of ID/DD policy and practice for over two decades and should continue to be valuable in addressing the many challenges confronting the ID/DD community in the future as the need for services increases and fiscal resources come under growing pressure.

- 8) *Nurse delegation and medication management.* Properly supervised by nurses, non-nursing staff should be allowed to assist in administering medications.

Medication management and nurse delegation are important issues in ALFs because they relate to cost or expense of care, risk, and residents' autonomy and independence. The National Center for Assisted Living (2010) estimates that 81 percent of individuals living in Assisted Living Facilities need assistance with taking their medication. On average, ALF residents have been estimated to take 6.2 different medications and 25% take nine or more medications (Armstrong, Rhoads, & Meiling, 2001). In one study of 78 residents in several Assisted Living Facilities in New Jersey, Wizwer & Simonson (2006) found that needing assistance with taking medication was the most significant reason for moving to the facility, even more so than age, depression, number of falls, cognition, and function. The need for medication management and issues related to nurse delegation is also critically related to residents' safety, dignity, independence and ability to age in place.

The research literature on safety, medication management, and nurse delegation in ALFs offers an increasingly informed perspective on these issues. In a study of 1,335 ALFs in Arizona, Woods and colleagues (2010) found that almost 62 percent (n=1,335) received a medication-related citation between 2007 and 2008. In another study of 45 facilities in Georgia, scholars found that although there were few problems overall with medication management and safety, there were some problems relating to miscommunication and medicine (Kemp et al.,

2010). Mollica and colleagues (2005) found in a study of licensing officials nationwide that the officials believed that medication errors in ALFs were frequent. In a study of 29 ALF employees who handled residents' medication, researchers examined the role of staff training and licensure in making medication errors (Zimmerman et al., 2011). They found that licensed practical nurses (LPNs) and medication aides have similar medication error rates, but that others who were responsible for medication management handled the medication considerably more than medication aides or LPNs and made more errors than either aides or LPNs (Zimmerman et al., 2011). The researchers concluded that staff who are responsible for medication management should at least be trained to the level of a medical aide in order to reduce errors. In sum, the research literature shows that medication errors in ALFs are not uncommon. It also suggests, however, that better communication between staff about medication administration, and requiring staff to receive training that is equivalent to at least the level of a medical aide could reduce these errors.

Policy surrounding medication management and nurse delegation also affects consumers at the individual level in terms of their dignity, maintaining some level of independence, and being able to age in place. Carder and colleagues' (2009) ethnographic study of 6 ALs in Maryland is particularly useful in highlighting these issues in medication management. The ALs in the study varied in terms of their medication management policy and in terms of how residents experienced medication management. Some residents felt that the facilities policies were too stringent and that it infringed on their dignity and independence. For example one resident who lived in a facility where all medications were required to be administered by staff said, "...I find that very disconcerting. Because... before you came in here, you had a brain, and you left your

brain at the door when you arrived... So that takes away independence on my part, you know, it makes me more dependent” (Carder et al., 2009: 466-467).

In the same study, another resident who was diagnosed with dementia, wanted to keep an over-the-counter pain reliever in her room but was forbidden to do so because of the facility’s medication management policy. She felt that being unable to control OTC medication made her feel “belittled” (Carder et al., 2009: 469). Other residents in different facilities were encouraged to maintain their independence and mental sharpness through participating in their own medication management. The study also found that for residents who truly need help with taking their medications, medication management in ALFs helps them to age in place. The researchers concluded that there was a mix of both high and low congruence between residents’ needs and policy. They suggest that a one-size-fits-all approach does not work for medication management and individual residents’ choices, needs and preferences. They also suggest that reflexivity between the organizations, policy and consumers is likely to achieve best results (Carder et al., 2009).

States and AL facilities within each state vary in terms of their medication management and nurse delegation policy. As of 2008, 14 states require that nurses administer medication to residents and 32 states allow designated care workers (DCW) to either fully administer medication or to help residents self-administer medication (Mitty et al., 2010). In Alabama, for example, Assisted Living facilities are required to help residents self-administer their medications (Polzer, 2008: 92). By contrast, Georgia policy requires that the resident administer their own medications, except when they need to be supervised by a staff person (Polzer, 2008: 39). In Florida, medication can be self-administered, administered by unlicensed staff (who have had at least four hours of training) or administered by a registered nurse or pharmacist (Polzer,

2008: 36-37). Washington State perhaps has the most varied policy. In that state, medication can be administered by unlicensed staff without nurse supervision, via nurse delegation, self-administered by residents, administered by family members, or the residents can refuse to take medications if they chose (Polzer, 2008: 209-210). In addition, residents in Washington State are allowed to store their own medications (Polzer, 2008: 210). Other states have policy that requires a review process. In Oregon, for example, medication can be administered by unlicensed trained staff, although a registered nurse or pharmacist must review all medications every 90 days and document any problems (Polzer, 2008: 162). In sum, some states have specific restrictions on who can administered medication and whether or not nurses can delegate tasks, while other states have more inclusive and less restrictive policy.

One of the principal purposes of nurse delegation<sup>3</sup> in assisted living is to create an effective balance between containing the cost and the risks associated with 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,

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<sup>3</sup> 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).

2003) and indicates a need for better regulations regarding medical assessments and protocols, 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. Many of these recommendations were opposed by organizations that supported a generally more restrictive, medically oriented regulatory approach and greater involvement of nurses (RNs and LPNs) in all aspects of caregiving in assisted living facilities, including medication management, that are generally required by nurse delegation acts.

The experience of states with nurse delegation in assisted living and adult foster care suggests that delegated medication management is achieving an adequate balance between costs and risks. Oregon and Washington, which have extensive community-residential programs, have more than a decade of successful experience with delegated medication management. There is no evidence that current nurse delegation acts in these states are harmful to residents who, in fact, benefit from the capacity of these acts to help contain costs. This experience offers evidence that the proper delegation of medication management as defined and operationalized by the Assisted Living Workgroup's recommendations are sound and can be confidently used by states as a framework for legislation and rulemaking.

- 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 delegation 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 based on the following criteria:

- 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.

## V) 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 meet 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 National 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 twenty 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. The application of many nursing home style regulations, however, would 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. This kind of careful approach to assisted living regulation, however, does not mean that public officials, advocates, or residents and their families should ignore regulatory issues or fail to respond to the need for changes as assisted living grows, populations change and research and other sources of information provide evidence of the need for improvements. This is precisely the approach adopted by the Florida Assisted Living Workgroup in the development of phase I recommendations designed to improve administrative capacities, the quality of training, to increase the frequency and rigor of surveys and inspections, and to empower residents. The Workgroup will also identify several other issues and potential recommendations for consideration during phase II of the Workgroup, which will meet in the summer of 2012.

## APPENDIX A

### The Florida Assisted Living Workgroup

In 2011, the governor of Florida directed the Agency for Health Care Administration (AHCA) to examine assisted living facilities across the state. In response, the Assisted Living Workgroup (AL Workgroup) was created with the objective to “make recommendations to the Governor and Legislature that will improve the monitoring of safety in assisted living facilities to help ensure the well-being of residents” (2011: 1). The AL Workgroup made their recommendations based on three meetings held across the state, public testimony, and presentations from more than seventy-five people from various backgrounds – residents, family members, AL administrators and owners, provider associations, advocates and state agency representatives. The discussions focused on regulation, consumer information and choice, and long-term care services and access.

There were two phases to the workgroup. Phase I included recommendations that they felt could be addressed immediately, and Phase II allowed an additional 6-12 months of evaluation and dialogue prior to being considered as formal recommendations. The recommendations received approval by a majority of the members. Based on the AL Workshop deliberations, the following recommendations were made with the intention to strengthen oversight and reassure the public that ALFs are safe places for their residents<sup>4</sup>:

#### *Phase I Recommendations*

- Provide better integration of information on existing consumer resources,
- Raise the standards to become an ALF administrator and expand the CORE training curriculum for other staff,

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<sup>4</sup> This is just a brief summary of the recommendations, for detailed descriptions of the recommendations please refer to the original report.

- Improve the initial and ongoing continuing education/training for all staff, especially for Limited Mental Health (LMH) facilities,
- Increase survey/inspections and reporting, focusing on ALFs with poor track records,
- Initially create rigorous ALF license requirements to prevent unprepared individuals or facilities from providing care,
- Provide a systematic appeal process for residents who want to contest eviction,
- Assist people with their choices in order for them to make the best decision for their situation,
- Create a permanent policy review and oversight council with members representing all stakeholder groups,
- Require all facilities with at least one resident receiving mental health care to be licensed as a LMH facility.

Overall, these recommendations address the following topics: consumer information, administrator qualifications, training/staffing, surveys and inspections, licensure, resident discharge, information and reporting, enforcement, mental health, multiple regulators, and home and community based care.

### *Phase II Recommendations*

- Develop an electronic guide to ALFs, including a rating system and an ALF watch list,
- Increase administrator requirements and create an ALF administrator licensure with a Department of Health to track and monitor discipline and core training,
- Revise regulations to include specific persons served in an ALF, such as individuals with serious mental illness,

- Hold hospitals accountable for discharge planning that matches the individual's needs using a pre-admission screening process,
- Enact legislation that provides ALF residents a formal appeal process for disputed discharge,
- Increase amount and quality of activities, and allow for proper staffing ratios in order to promote resident participation,
- Create online reporting for cost effective methods of collecting, reporting, and analyzing client information,
- Revocation or denial of renewal license for certain violations, such as resident death due to neglect on the part of the facility,
- Require more education and experience for LMH facility administrators and staff,
- Improve coordination between various federal, state and local agencies with any role in LTC facilities oversight,
- Ensure an anonymous method of regularly seeking input from ALF residents about care received,
- Reevaluate the ALF fee structure as it relates to paying the cost of regulation and require licensure fees for certain types of beds,
- Eliminate waiting lists for waiver programs and have open enrollment for MCD waiver providers.

The additional topics in Phase II of the AL workshop include the following: resident admission, resident safety and rights, funding, and resident advocacy. The topics revisited from Phase I with more detailed recommendations include: consumer information, administrator



qualifications, licensure, resident discharge, information and reporting, mental health, multiple regulators, and home and community based care.

To summarize, the AL workgroup suggest:

Regulations governing ALFs must be flexible enough to allow facilities to adopt policies that enable residents to age in place while accommodating their needs and preferences. When residents age in place, care becomes more complex. The challenge is balancing the provision of appropriate care without compromising the concept of a social or residential model (13).

As the growth of ALFs continue, we must continue to work together to reduce regulation in areas that are overly burdensome, while implementing safeguards and regulations that protect the ALF residents.

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