

Chapter 2

Research and Regulation in Assisted Living: Achieving the Vision

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This book is about frontline workers in assisted living (AL), a residential care setting that is not easy to define. The concept of AL covers a wide range of congregate living arrangements which vary by facility size, service provision, regulatory standards, funding sources, and resident characteristics. This variation has made it difficult to generate a broad consensus in support of a common definition of AL, which could be used for organizing research or developing a universally acceptable regulatory framework. The range of difference within AL is probably just as great as the difference between AL and the other long-term care settings, home care and nursing homes. In fact, the difference between AL and nursing homes may have begun to shrink in that some AL facilities (ALFs) now have highly impaired (cognitively and physically) residents who meet nursing eligibility criteria and some nursing homes have begun to adopt some of the “homelike” features of the AL model as advocated by Eden Alternative and Green House supporters, and the Nursing Home Pioneers (Pioneer Network, 2007) group. These trends have important implications for hiring, training, and retaining a quality workforce.

Although a rigorously precise definition of AL has yet to emerge, most states have regulatory standards that require ALFs to provide or arrange for personal and supportive services 24 hours a day, meals, social activities, some level of health care, and housing in a group residential setting. The states vary considerably, however:

The intensity of services, the range of disabilities for which services are provided, the type of living arrangements, and many other aspects vary a great deal, often within, as well as between states. Most AL residences provide private rooms or apartments, a communal dining area, and common areas for socialization and activities. Although most residences have from 11 to 50 beds, two-thirds of

residents live in larger residences (those with more than 50 beds). The majority of AL residences (55%) are free-standing. The remainder shares a campus with some other type of residential setting, such as a nursing home, rehabilitation center, board and care home, independent living apartments, or continuing care retirement community. About half are non-profit, and about half are for-profit; very few are government-run. (Wright, 2004, p. 3-4)

Most states now have AL definitions and regulatory standards that include provisions designed to emphasize the significance of such quality-of-life values as resident choice, autonomy, dignity, and the protection of privacy. The role of these values also is beginning to be addressed in the regulation of nursing homes.

Because of differences in how AL is defined, it is difficult to pinpoint the number of residents living in these types of facilities. According to a recent report (Mollica, Sims-Kastelein, & O'Keefe, 2007), based on information from 50 states and the District of Columbia, approximately 38,000 licensed residential care facilities with about 975,000 units/beds in the United States currently fall under the rubric of AL. Monthly costs for AL care vary considerably by geographic location, type of accommodation (private versus shared room), and number and types of services and amenities provided. Data from a recent national marketing survey of 1,518 ALFs located in both metropolitan and non-metropolitan areas in the United States (ranging in size from 3 to 344 beds, with an average size of 60 beds) show that based on state averages, monthly base rates per resident range from approximately \$1,980 to \$4,700, with a national average of \$3,000 (Metlife Mature Market Institute, 2008). Residents and their families cover most (86%) of AL costs, and only about 8% receive Medicaid payments compared to approximately 69% of nursing home residents who receive this support (Redfoot, 2007).

This review of the literature on AL is selective in that I focus on the research that, in terms of scope and findings, I think is most relevant to the debate over how these programs

should be regulated in order to provide adequate quality of care and life for residents, which includes developing and maintaining a quality workforce. Many gaps exist in the research literature on these programs, and substantial methodological limitations, especially in the scope and size of resident and facility samples, are evident in most of the completed research. Nevertheless, enough findings of sufficient scientific quality are available to justify their use in offering provisional assessments of the relative merits of alternative regulatory policies and funding strategies.

The rapid growth of the AL population over the last decade is clear evidence of the appeal of this long-term care option and of what the industry describes as its core values of privacy, autonomy, dignity, and a homelike environment. However, the AL industry also has received intermittently negative media attention over the last several years. Most of this attention has focused on the quality of care received by some residents. A report prepared by the U.S. General Accounting Office (1999) found that many facilities do not provide residents, or potential residents, with enough information about costs, services, and retention policies, and some facilities may not be accurately representing their services and facility rules in their advertising.

Although such reports are not evidence of extensive quality of care problems in the industry, they have sparked discussions in some quarters about the possible need to regulate AL more stringently. This emerging discussion in turn has raised concern within the AL industry about potential political support for a regulatory approach based on current nursing home regulation. Some policy analysts and consumer advocates argue that as the population of more seriously impaired residents and those with acute medical conditions in ALFs grows, the regulatory scheme should become medically oriented and more stringent in terms of who is allowed to enter and remain, what kinds of services can be delivered and by whom, qualifications needed for staff, and how the quality of services will be defined and monitored.

The potential for significant regulatory changes makes it imperative that policy analysts, policy makers, and advocates gain a clear understanding of the currently available research findings on AL, and pay careful attention to the results of research as they are reported over the next several years.

This chapter is divided into four sections. The first section includes a selective review of the research literature on AL, including research on small family-model homes, which are referred to in the literature by a variety of names (e.g., adult foster care, board and care, and domiciliary care homes) and typically house 16 or fewer residents. In the second section, I discuss the implication of the findings from this research for several regulatory issues and alternative approaches to providing adequate quality of care and quality of life for residents in AL, including ensuring a quality workforce. The third section is a brief discussion of AL affordability issues, and the fourth section presents concluding comments and a suggested AL research agenda.

What Do We Know About Community-Residential Care?

The research on AL has grown along with the industry over the last 10 years with the most extensive and significant findings becoming available since 2000. Prior to the publication of this book, few studies have focused specifically on staffing in AL. Although major gaps in our knowledge of AL still exist, and important questions remain largely unanswered, we now have a good deal of information that can help us think constructively about the future of the AL industry.

The research of Hawes, Rose, and Phillips (1999) provides among the most important early AL information. Their study using a national sample of ALFs estimated to be about 40% (4,300) of all ALFs across the country in the mid-1990s was the first to provide a relatively comprehensive, empirically oriented view of AL. This study included homes with more than 10 beds, served a primarily elderly population and self-identified as AL or offered basic services

such as ADL assistance, meals, and 24-hour oversight. Close to two-thirds (70%) of facilities surveyed had either a full-time or part-time registered nurse (RN) on staff and close to half (40%) had a full-time RN.

In a subsequent report based on a subset (41%) of the larger sample comprised of 300 facilities designated as either “high service” or “high privacy” that included 1,500 residents and 569 staff members, Hawes, Phillips, and Rose (2000) reported several findings that are especially relevant to regulatory and other policy issues in AL. With regard to resident admission, discharge, and retention, findings showed that during a 12-month period, 19% of the residents in the sample facilities were discharged; only 8% were discharged to nursing homes; and almost 4% to other ALFs. Overall, 60% of those who moved did so in order to receive a higher level of care. Only 12% of those who moved indicated, through proxy respondents (family members), dissatisfaction with the care they had received in the facility they left. A decline in cognitive status was the only resident variable that significantly increased the likelihood of entering a nursing home. The researchers also found that when facilities had a full-time RN involved in direct care, residents were half as likely to move to a nursing home. The vast majority (85%) of residents reported that their top two priorities on entering the ALF were the availability of a private bath (#1) and private bedroom. Among those who had left an ALF (19% over 12 months), a majority (65%) continued to identify these same privacy-oriented priorities.

Hawes and her colleagues (2000) also found that resident assessments of their facilities were generally positive, with a majority of residents reporting that they were treated with affection (60%) and dignity (80%). Twenty-six percent of residents, however, indicated that they needed more help with toileting activities, and 90% thought they could stay in their facility as long as they wanted to remain, although most were uninformed about policies governing retention and discharge from their facility. Other major concerns reported by residents (and their family members) were inadequate staffing levels and staff turnover.

The Hawes et al. (2000) study also provided the first extensive data on AL staff. Findings showed that staff were predominately female (97%), more than half (68%) were white, and most (85%) had completed high school. Only 61% worked full-time, and half had worked in the facility for 2 or more years. Slightly over half (51%) were resident care assistants, and 20% were licensed professionals. The median ratio of direct-care staff to residents was 1:14. Overall, staff reported positive views regarding their work environment, although more than half (55%) indicated dissatisfaction with pay, and 70% reported that they did not have good opportunities for advancement. Assessments of staff knowledge and training showed that, overall, staff had inadequate understanding regarding various health conditions and what constituted normal aging. Although 80% of staff had received training in dementia care, most (88%) believed that symptoms (e.g., memory loss and confusion) were a normal part of aging.

Earlier research conducted in Oregon that included a sample of ALFs and nursing homes found that both types of facilities 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 (Kane, Olsen Baker, Salmon, & Veazie, 1998). Although nursing home residents were substantially more impaired than those in ALFs, these findings are encouraging in terms of the capacity of ALFs to accommodate “aging in place” by providing necessary health care services (Frytak, Kane, Finch, Kane, & Maude-Griffin, 2001). It should be recognized that Oregon has a relatively mature AL industry, regulatory policies and public funding strategies designed to maximize the nursing home diversion potential of ALFs. The state also provides AL residents the opportunity to exercise choice, including the decision to “age in place.”

In a more recent study of quality of life in nursing homes, ALFs, 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. Those in ALFs expressed the greatest

satisfaction with their quality of life and the level of personal control they experienced.

Respondents in the home care programs expressed a clear preference for home care over nursing homes, but they also reported less satisfaction with both their quality of life and personal control than the AL respondents. Another recent study of community-based programs in Florida found that AL residency reduced nursing home utilization by 47% compared to the other in-home services programs (Andel, Hyer, & Slack, 2007).

A recent study of the Veterans Administration AL Pilot Program (ALPP) (Hedrick, et al., 2007) found that adult family homes enrolled residents needing more assistance with ADLs than the larger AL and residential care facilities, which tended to employ more staff with professional health training. The researchers described several potential benefits for residents of small facilities, such as the family-like environment, where residents may receive more individualized care, and potentially lower costs, which could allow for program expansion.

Sheryl Zimmerman and her colleagues (Zimmerman, Sloane, & Eckert, 2001; Zimmerman, et al., 2005) have conducted extensive survey research in ALFs and nursing homes in New Jersey, North Carolina, Florida, and Maryland. Their sample included 233 facilities stratified into three types: small (under 16 residents), traditional (16 and over residents and built before 1987) and new model facilities (16 and over residents, built in or after 1987 and having two or more private-pay rates, at least 20% of residents needing transfer assistance, at least 25% of residents with incontinence, or an RN or LPN on duty at all times.). Among their more interesting policy relevant findings was that type of facility made no difference with regard to likelihood of resident discharge based on functional status. Variables found to affect discharge included the state in which the facility was located and facility profit status and age. Findings also showed that new-model facilities scored higher on policy choice, privacy and policy clarity than other facility types, and that traditional and new-model types provided more health and social services compared to small facilities. Zimmerman and colleagues (2005) also found that

facilities in continuing care environments, or that had a registered or licensed practical nurse (RN or LPN) on staff were more likely to transfer residents to nursing homes. On the other hand, residents were less often hospitalized when facilities provided more RN care. In addition, they found that small facilities (average 8.9 beds) fared as well as new-model properties with respect to medical outcomes and nursing home transfers, and better in terms of functional and social decline and social withdrawal (Zimmerman, et al., 2005).

These findings indicate that the larger and newer ALFs are better able to provide services, and meet the privacy and autonomy desires of residents. It should be noted that privacy is often a necessary, if not always sufficient, condition for the effective exercise of personal control and autonomy and for maintaining interpersonal relations (Polivka & Salmon, 2003). Small facilities, however, may provide more familial, homelike settings that many impaired elders seem to prefer, despite fewer opportunities for privacy and autonomy. Many elders may also prefer to age in place in small facilities, even in the absence of privacy and some of the health services offered by larger facilities. The major point is that potential residents should have an array of facility types, including small, less-sophisticated facilities, to choose among. Other studies have found that small or mid-size facilities frequently are less expensive than larger facilities and are often more willing to accept Medicaid and SSI-supported residents than are larger properties (Ball, et al., 2005; Salmon, 2003; Stearns & Morgan, 2001), a finding that has major implications for state long-term care policy and the use of Medicaid-waiver funds to expand community-based alternatives to nursing homes. A significant factor affecting operation of these homes is their ability to pay for quality staff (Perkins, Ball, Whittington, & Combs, 2004).

Morgan, Eckert, Gruber-Baldini, and Zimmerman (2002) suggest that researchers, policy makers, and regulators exercise caution in defining and comparing facilities for purposes of descriptive and evaluative analysis and for regulating the range of facilities that may be

described as AL. Small facilities, for example, may not be able to offer the same level of control and autonomy or service as larger, purpose-built facilities, but residents, as noted above, may well find them more homelike, more affordable, and accommodating enough in terms of autonomy and control, especially in comparison to nursing homes or even their own homes. In sum, the advantages and shortcomings of the whole range of AL options should be recognized without claiming that one style of AL is necessarily superior to another or better designed to meet everyone's needs, preferences or ability to pay. As this book will show, a variety of staffing issues and the experiences of frontline workers varies across facility size and type.

Findings from Morgan, Eckert, and Lyon's (1995) study of small board and care homes in Baltimore and Cleveland also support the view that small facilities have the capacity to serve a wide range of residents, including those with serious impairments. The authors point out, however, that the popularity of small facilities could increase the perception among policy makers that they need to be more rigorously and conventionally regulated, which they think could eventually lead to their extinction, or at least substantially reduce their affordability and overall appeal.

The importance of small facilities from a quality-of-life perspective is evident in findings from a qualitative study by Ball, et al. (2005) of both large and small facilities in Georgia. The researchers found that the quality of internal social relationships, including those between residents and staff, was commonly better for residents in the small, family-model facilities, especially for those without routine contact with family members. The importance of internal social relationships is supported by the results of a study by Street, Burge, Quadagno and Barrett (2007), who found that they were the major predictor of the overall quality of life for residents.

Community-residential care is not for everyone requiring long-term care assistance, especially for those who develop extensive and complex medical care needs. For many AL residents, however, a substantial amount of "aging in place" is already

occurring in ALFs and the number of residents who “age in place” without ever entering a nursing home is likely to increase in the future, as AL providers become more confident of their ability to accommodate the changing needs of residents in a relatively flexible regulatory environment. Findings from a study by Ball and colleagues (2004) demonstrate the complex and often idiosyncratic nature of “aging in place” in ALFs: there may be as many ways of “aging in place” as there are AL residents and overly precise regulations specifying the terms of retention precisely are likely to end up displacing many residents whose quality of life is largely dependent on remaining in their ALF. Ball, et al. (2004) conclude that residents’ ability to age in place is a “balancing act” that is influenced by multiple community-, facility-, and individual-level factors that are complex, dynamic, and interactive. Of key importance is the “fit” between the capacity of both the facility and the resident to manage resident decline. Obviously, staff qualifications and staffing levels are key factors affecting aging in place.

These are important “facts on the ground” that have major implications for the future of AL regulation and its role in the long-term care system. Although many of these studies are based on relatively small samples and much more research is needed, we can speculate about the significance of their findings for long-term care policy generally and regulation more specifically. For example, to the extent that personal control and autonomy are important determinants of quality of life in long-term care, AL may be the optimal setting of care, including for many now receiving care in their own homes. That is, AL may be for many frail elderly persons the best setting for achieving an effective balance between autonomy and supportive services, including health care and more human interaction to combat loneliness.

ALFs can offer the kinds of resources, especially staff services, transportation, and social activities, necessary to make the achievement of personal control and autonomy a far 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 most individuals or the public sector to provide, or too great a burden on the individual's informal care providers. These possibilities should be kept firmly in mind as we think about AL regulation and how to achieve the full potential of AL as a long-term care program.

Policies, funding, and regulatory strategies should reflect our awareness of and support for the different forms of AL and the need to provide consumers with as many options as possible, as long as they are consistent with the basic values of the AL philosophy and basic safety requirements. This means that small facilities should not be held to precisely the same standards, which they are not likely to meet, as the larger, purpose-built, new paradigm ALFs. Other researchers note that if regulation and funding turn on adherence to the new paradigm's parameters, it may mean the demise of the smaller facilities (Ball, et al., 2005; Zimmerman, et al., 2002). This perspective will undoubtedly complicate the way AL is regulated, but if it results in maintaining, or 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 findings reviewed here indicate that, overall, AL is often an optimal environment for residents as they age in place, including many residents with cognitive impairments and medical needs. There is a danger, however, that as a consequence of serving an increasing number of cognitively and physically impaired residents, states will impose restrictive regulations that will unnecessarily limit the potential of AL to serve this population (Chapin & Dobbs-Kepper, 2001).

Implications of What We Know For Regulating Assisted Living

The vast majority of older people and their families strongly prefer home- and community-based alternatives to nursing home care (Ball et al., 2004a; Mollica, 2009). The primary reasons for this strong preference are the desire to maintain a modicum of personal

control and to preserve their privacy and dignity to the maximum extent possible (Ball et al., 2004b; Ball et al., 2005). This consumer preference is the fundamental rationale for creating a far better balanced system of long-term care than is currently available to the frail elderly, particularly those dependent on public support. Both AL and home care should be vastly expanded in response to the deep preference among the elderly for alternatives to nursing homes. At this point, however, AL is probably the most under-developed alternative program in the public sector. Most of the AL growth since 1990 has occurred in the private sector, and states, on the whole, are just beginning to develop and expand their AL programs, primarily through Medicaid waiver initiatives. Medicaid Home and Community Based Services (HCBS) waiver programs (authorized under Section 1915(c) of the Social Security Act) enable states to waive certain Medicaid requirements in order to cover home and community-based services, such as assisted living, and may include case management and skilled nursing services. Despite growth in funding for HCBS, expenditures for nursing homes remain considerably higher. In 2007, Medicaid spent \$47 billion on nursing homes versus \$17 billion on HCBS-waiver programs for older people and adults with physical disabilities, although expenditures for HCBS vary considerably by state, ranging from 1% to 61% (Houser, Fox-Grage, & Gibson, 2009).

The pervasive preference among the elderly for alternatives, including AL, to nursing homes should not be frustrated by excessive or inappropriate regulation. AL has demonstrated the capacity to serve seriously impaired residents effectively and regulations should be designed to maximize this potential through the use of flexible, inclusive admission and retention criteria. Providers can help maximize this potential by providing necessary care, including nursing care, for residents with health care conditions that require continuing care. The preservation and enhancement of AL's core values should be the top priority in the development of AL regulations.

As noted earlier, for many frail elders, AL is a more propitious setting for achieving these values than their own homes. The only sure outcome of imposing a nursing home mode of regulation of AL would be precisely what we have achieved in nursing homes—a rigid, institutional environment that restricts consumer-direction, resident autonomy, and privacy. We should pay more attention to reversing these outcomes in nursing homes and avoid creating a regulatory framework that could have the same results in AL.

The wide variance in AL regulation across the states represents a natural laboratory, and every effort should be made over the next 5-10 years to determine the relative costs and benefits of their regulatory strategies. We need this information before we prematurely decide to move to a single national regulatory framework. Researchers already are developing a useful body of knowledge for developing reasonable regulations over the next decade. Anecdotal accounts in the media should not lead to a “rush to judgment” and the implementation of conventionally stringent regulations that could kill the very thing we should be most committed to preserving—the fundamental values of AL.

Serious consideration, however, should be given to Hawes and Phillips’ (2000) findings concerning the impact of cognitive decline and the role of RN care in preventing movement to a nursing home or in facilitating aging in place. Providers should be prepared to use this information in the development and deployment of their services, and policy makers and regulators should monitor these areas carefully and consult closely with providers and advocates before deciding how they should be interpreted from a regulatory perspective. Clearly, however, the provision of sound dementia care and skilled nursing care are essential components of any efforts to maximize the aging-in-place potential of AL. In addition, better training is needed for direct-care staff in a variety of areas and interventions are required to improve staff satisfaction and increase retention, which has a direct effect on the quality and continuity of resident care.

I think we also could enhance the quality of care by requiring that residents taking more than four medications have their medication regimen evaluated by a consultant pharmacist at least annually. Pharmacists often are more knowledgeable than physicians or nurses about medications, and physicians usually are willing to listen to pharmacists and adjust prescriptions accordingly. As pointed out in Chapter 5 of this volume, direct care staff often assist residents with medications, a fact that has implication for staff training.

Management of medications is closely related to the issue of nurse delegation, which refers to training and permitting unlicensed personnel to administer medications with ongoing RN oversight and supervision (Reinhard, Young, Kane, & Quinn 2003). Nurse delegation can play an important role in making AL more affordable by limiting the cost of health care-related services. Three-fifths of states provide for some form of delegated nurse supervision of unlicensed staff or the use of trained aides to administer oral medications in AL, and some also allow these staff to administer injections. Most informants from state boards of nursing report few consumer complaints in regard to nurse delegation, although no formal mechanisms for reporting errors exists (Reinhard, et al., 2003).

Sikma and Young (2001) found considerable enthusiasm among registered nurses for supervised delegation. However, the fact that many AL residents who have serious chronic conditions have been found to be under-medicated, or not to be receiving appropriate medications (Sloane, et al., 2004) indicates a need for better medical assessments and medication management protocols. Regulation should address such concerns, which also arise in nursing home and home care settings (Munroe, 2003), including mandating periodic (e.g., quarterly) evaluations by pharmacists or physicians for certain residents. 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.

Every effort should be made to develop a greater quality of life focus in the regulation of ALFs. A focus designed to achieve the original vision for AL, especially the emphasis on resident choice, dignity, privacy, and a homelike environment conducive to the formation of close social relationships among residents and with staff members. For Ball and colleagues (2005), making quality of life a central feature of AL regulations will require training AL workers to provide the kind of personalized care that preserves the personality, identity, and will of the resident. This training would prepare workers to focus “much more attention on the socioemotional state of residents and concern itself with the person’s definition of quality of life (p. 266).” The authors believe that requiring this kind of quality-of-life oriented training would help redefine the work of AL staff as “professional and important and allow for a realignment of values (p. 266).”

Several other workforce-related issues will become increasingly important, from the regulatory and funding perspectives, as the number of ALFs grows and AL populations become more diverse in terms of health and functional assistance needs and socio-economic characteristics. Administrative and caregiving staff will need to receive gradually more extensive pre- and in-service training in physical health and dementia care related areas. Pre-employment qualifications also may need to be enhanced, which will raise the costs of staff turnover, which is now relatively high in many communities and set to increase further with demography-driven (population aging) tightening of long-term care labor markets over the next several years. We can develop more efficient methods of delivering training but retraining experienced, and dedicated staff will require higher salaries, better benefits, and improved work environments designed to empower workers, unleash creativity, and inspire a sense that caregiving is a highly valued career with a promising opportunity horizon. These workforce enhancements will be unavoidably expensive, which will make sensitivity to the cost and affordability implications of regulatory interventions in AL an increasingly important issue.

Finally, as Ball and colleagues (2005) noted earlier, regulatory policy should recognize the unique value and challenges of small facilities. Regulations, thus, should not be allowed to drive small facilities into extinction. Rather, they suggest that older persons of limited means are far better served by adjusting standards to fit the available resources than by raising expectations beyond the ability of that market to reach them.

States should continue to take a cautious approach to AL regulation. We need to learn more about the effects of the different regulatory schemes across the states, the impact of Medicaid-waiver funding on the demographics of AL and a wide range of outcomes, including the extent of AL's capacity to substitute for nursing home care and the capacity of AL to provide specialty care, especially dementia care. The already valuable body of research findings will grow substantially over the next few years and help us make far more informed decisions about regulation than we are prepared to make now.

Conclusion

The best available information indicates that the AL industry, with the support of policy makers and the regulatory community, has built a sound foundation for continuing success. The industry is not perfect and some course corrections are in order. I am impressed, however, by the extent of progress achieved over the last 15 years. As head of the Florida State Aging Agency in 1989, I felt that the biggest gap in the long-term care system 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 had been made available in their own homes through home care programs since the late 1970s. This kind of community residential care has been achieved primarily through the growth of the AL industry for private-pay residents and is arguably the most positive development in long-term care in the last decade.

The biggest problem in AL at this point is not insufficient regulation. The major problem confronting policy makers and those in need of long-term care is the relatively meager number of

AL beds available to 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, AL offers the optimal long-term care setting for not only receiving the physical care they need, but also for achieving a quality of life (e.g., autonomy and privacy) that may not be available in their own homes. Our primary goals for AL 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 AL as a long-term care program.

Medicaid waivers are essential to long-term care financing as demonstrated by the way they have been used to transform care for the developmentally disabled over the last 20 years and long-term care for the elderly in Oregon, Washington, and Arizona over the last decade. These examples indicate the capacity of waivers to change the fundamental nature of long-term care on a permanent basis and help address the fiscal crisis by containing overall long-term care costs. Most states need to make much more expansive use of Medicaid waivers to fund systemic long-term care changes, including increased availability of AL for impaired older people who are dependent on publicly supported services. Very few states have adopted the Oregon and Washington approach to funding the growth of affordable AL through the Medicaid program. Policy makers, AL providers and residents will continue to struggle for the foreseeable future with “a number of issues that require reconciliation of what appears to be inherently contradictory goals” (O’Keeffe & Wiener, 2005, p. 4).

At this point, I think the available research indicates that most of the state regulatory standards governing “quality of care” (standards setting minimally acceptable quality) and “aging in place” (standards allowing flexibility in terms of facilities deciding whom they will admit and retain) are generally sound, but that disclosure standards need to be more fully developed. We also need far more quality-of-life-oriented research and investigations such as is presented in this book that examine workforce issues, which will be used to inform regulatory

policy and prepare providers to care for an increasingly impaired AL population. The financing issues will remain problematic in terms of both funding levels and reimbursement rates and restrictions (no room and board coverage) until federal and state policy makers decide to make AL as available as institutional care in the publicly funded long-term care system.

AL is a relatively fragile form of housing and long-term care that is largely sustained by the fact that many older people prefer it to nursing home care and may, in many cases, find it preferable to in-home care. It would not take the application of very many nursing home style regulations, however, to make AL 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 (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.

Clearly, frontline workers in AL and other LTC settings are principal players in whether or not residents are able to realize the core AL values of autonomy, privacy, dignity, and the ability to age in place in the least restrictive environment. They must be trained in the importance of these values and how to incorporate them into their care regimens, and facility administrators must utilize staffing levels and policies that give direct care workers the time and freedom to respond to residents' individual needs and preferences. Findings presented in this book will provide valuable information to guide policy and practice regarding how best to incorporate frontline workers into the AL care mission and support them in their roles.

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