

Community-residential care for the frail elderly: What do we know; What should we do?

by

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Introduction

Community-residential care (CRC) 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, assisted living and numerous variations on each of these models based on such variables as facility size, service provision and regulatory standards, funding sources, and resident characteristics. This variation has made it very difficult, if not impossible, to generate a broad consensus in support of a common definition of community-residential care, which could be used for organizing research or developing a universally acceptable regulatory framework. The range of difference within CRC is probably just as great as the difference between CRC and the other long-term care (LTC) settings—home care and nursing homes. The difference between CRC and nursing homes may have begun to shrink in that some assisted living 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 assisted living model as advocated by Eden Alternative supporters and the Nursing Home Pioneers group. In my judgment, these trends are not yet extensive enough to justify, on their own, qualitative changes in current regulatory standards for either CRC or nursing homes.

The focus in this paper is limited primarily to the assisted living model of community-residential care. We have also included a short discussion of adult foster care, which has received less research and policy analysis attention than assisted living and is a much smaller part of CRC in most states than assisted living. We think that adult foster care and the small assisted living facilities (5-10 beds), which are often hard to distinguish from adult foster care (1-6 beds) in any substantive fashion, have the potential to play a much larger role in the provision of community-residential care, especially for publicly supported and less affluent elderly persons who need access to a housing and services option. Although the research on adult foster care is even more limited than the relatively small amount of research available on assisted living, we think the findings from the research reviewed in this paper are sufficient to establish the potential benefits of adult foster care and to raise its profile in deliberations over the future of LTC policy.

This review of the literature on assisted living and adult foster care is selective in that we have chosen to focus on the research whose scope and findings we think are most relevant at this point, to the debate over how these programs should be regulated to achieve an adequate quality of care and quality of life and how they can be made more affordable for low-income persons. There are many gaps in the research literature on these programs; and there are substantial methodological limitations, especially in the scope and size of resident and facility samples, in most of the completed research. Nevertheless, we think there are now enough findings of

sufficient scientific quality to justify their use in assessing the relative merits of alternative regulatory and funding strategies. We consider our efforts in this respect to be preliminary and subject to revision as more findings become available.

We have incorporated the results (recommendations and rationales) of the Assisted Living Workgroup (2003) into our discussion of the policy (regulation and funding) implications of our literature review. The workgroup was not of one mind in the formulation of regulatory guidelines. We think, however that the results of the workgroup are important in framing the debate over assisted living regulation and that most of the recommendations, including some that did not gain majority support, are largely consistent with the available research findings on assisted living.

The paper is divided into four sections. The first section includes our selective review of the research literature on assisted living and adult foster care. In the second section we discuss the implication of the findings from this research for several regulatory issues and alternative approaches to ensuring an adequate quality of care and quality of life in assisted living. Our discussion of the results of the Assisted Living Workgroup is also included in this section. The third section is a brief discussion of assisted living affordability issues and the fourth section presents our concluding comments and a suggested assisted living research agenda.

The rapid growth of the assisted living population over the last decade is clear evidence of the appeal of this housing and services long-term care option and of what the industry describes as its core values of privacy, autonomy, dignity and a homelike environment.

However, the assisted living industry has received considerable negative media attention over the last two-to-three years. Most of this attention has focused on the quality of care received by some residents in a few facilities. A GAO study (1999) found that many facilities do not provide residents, or potential residents, with enough information about costs, services and retention policies. Some facilities may not be accurately representing their services and facility rules in their advertising.

Although these media 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 assisted living more stringently. This emerging discussion has raised concern within the assisted living industry that it could lead to growing political support for a regulatory approach based on the way we currently regulate nursing homes. Some policy 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; and how the quality of services will be defined and monitored.

The potential for significant regulatory reaction to these negative media reports makes it imperative that policy analysts, policymakers and advocates gain a clear understanding of the currently available research findings on assisted living and pay careful attention to the results of research as they are reported over the next several years.

This is an area where research can have an enormous impact on policy, given the nature of the dilemma facing policymakers. The tension between independence and safety, between a homelike environment and fire-safety, and between autonomy, privacy and the risk of medication errors must be carefully balanced. While no one wants to put assisted living residents at unreasonable risk, it is in defining and operationalizing “unreasonable risk” that the fundamental values of both assisted living and our commitment to protect the health, safety and welfare of vulnerable persons must be weighed and worked out.

What do we know about community-residential care?

The research on assisted living has grown along with the industry over the last ten years with the most extensive and significant findings becoming available in just the last few years. Although there are still major gaps in our knowledge of assisted living and important questions that remain largely unanswered, we now have a good deal of information that can help us think constructively about the future of the assisted living industry.

Among the most important sources of information are the three reports produced by Catherine Hawes, Charles Phillips and their colleagues since 1999. These reports, based on research funded by the office of the Assistant Secretary for Planning and Evaluation (ASPE) in the Department of Health and Human Services, have begun to give us a comprehensive, empirically sound view of assisted living, which addresses, directly or indirectly, many of the issues that are most integrally related to regulation.

In their first report, *A National Study of Assisted Living for the Frail Elderly: Results of a National Survey of Facilities*, Hawes, Rose and Phillips (1999) have focused their research on a national sample of high-privacy or high-service facilities or facilities that are characterized by both, which they estimate to be about 40% (4,300) of all ALFs across the country housing about 190,000 residents. Their sample consists of 1,500 residents drawn from 300 facilities.

The second report, *High Service or High Privacy Assisted Living Facilities, Their Residents and Staff: Results from a National Survey* (2000), contains several findings relevant to regulatory and other policy issues in assisted living. 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 authors also found that:

Residents in facilities with a fulltime RN involved in direct care were half as likely to move to a nursing home. When different formulations of staffing/service variables were used (any RN staffing, RN hours per resident, aide staffing, arranging for nursing care), the relationship between services and outcomes was not significant. It appears that these alternative staffing arrangements, or just better staffed facilities, are no substitute for a fulltime RN who does direct care. These findings, along with those about the effects of cognitive status, would seem to have major policy implications for aging in place.

In their third report, *A National Study of Assisted Living for the Frail Elderly: Final Summary Report*, Hawes and Phillips (2000) found that resident and staff assessments of their facilities were generally positive.

- The majority of residents reported that they were treated with affection (60%) and dignity (80%).
- They also, however, reported some level of concern about staffing levels and turnover rates; and
- 26% indicated that they needed more help with toileting activities.
- Ninety percent of the residents thought they could stay in their facility as long as they wanted to remain, but most were uninformed about policies governing retention and discharge from their facility. This supports the GAO findings and indicates a need for more public disclosure regarding these and other (service costs) policies.
- The vast majority (85%) of their respondents 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) most (65%) continued to identify these same privacy-oriented priorities. The other 35% of those discharged identified the presence of an RN or staff and the quality of the staff as their top two priorities.

Rosalie Kane and her colleagues (1998) found that ALFs and nursing homes in Oregon achieve 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 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 healthcare services. It should be recognized that Oregon has a relatively mature assisted living industry, regulatory policies and public funding strategies designed to maximize the nursing home diversion potential of ALFs and the opportunity for assisted living residents to exercise choice, including the decision to “age in place.”

We know that there are many seriously impaired residents in ALFs across the country and not just in Oregon. In Florida, about 25% of ALF residents in 1995 had three or more ADL impairments or had serious cognitive impairments (Polivka, Dunlop and Brooks, 1997). A recently completed study (Mitchell, Salmon, Chen & Hinton, 2003) found that Florida’s Medicaid waiver-funded Assisted Living Program (about 3,500) had a far 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.

A recently reported study by Hedrick, Sales, Sullivan et al. (2003) on assisted living, adult foster care and adult residential care in Washington state found that persons at every impairment level, including the highest (limitations in all six ADLs) residing 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. The residents also reported “very high levels of satisfaction with each aspect of care (p. 480).”

Payment rates (\$50-70 per day) in Washington's assisted living program are higher than the rate for adult foster care (\$40 per day in 1998), mostly because of state regulations requiring them to provide private rooms (single occupancy) and kitchenettes, which allow for greater resident autonomy and privacy. Hendrick and her colleagues note that:

. . . AL residents were significantly more satisfied with respectful treatment from staff and with their apartment or room, possibly indicating the influence of the stated AL philosophy of autonomy and privacy, and the required physical layout of separate apartments with lockable doors, kitchenettes, and the like (p. 481).

These are important "facts on the ground" that have major implications for the future of assisted living regulation and its role in the long-term care system. These studies are based on relatively small samples and much more research on these questions is needed. We can speculate, however, about the significance of these 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, assisted living may be the optimal setting of care, including many now receiving care in their own homes. This is optimal in the sense that assisted living may be for many frail elderly persons the best setting for achieving an effective balance between control/autonomy and supportive services including healthcare, and more human interaction to combat loneliness. For many frail elderly persons with thin or non-existent caregiver networks, assisted living may also be the best setting in which to achieve personal control and autonomy. Recently completed research in Florida highlights the significance of these values to long-term care consumers. In a study of quality of life in nursing homes, assisted living facilities (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. The respondents in the home care programs expressed a clear preference for home care over nursing homes, but they reported less satisfaction with both their quality of life and personal control than the assisted living respondents.

ALFs can offer the kinds of resources, especially staff services, transportation and social activities, necessary to make the achievement of control/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 assisted living regulation and the full potential of assisted living as a long-term care program.

Indirect, but compelling evidence supporting this perspective is provided in the third Hawes and Phillips (2000) report. The vast majority (85%) of their respondents 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) most (65%) continued to identify these same privacy-oriented priorities. The other 35% of those discharged identified the presence of an RN or staff and the quality of the staff as their top two priorities. The importance

of these privacy provisions indicates that many residents value the opportunities for privacy in assisted living very highly and expect to find these provisions in place. It should also be noted that privacy is often a necessary, if not always sufficient, condition for the effective exercise of personal control/autonomy and for maintaining interpersonal relations.

Privacy may be especially important for the quality of life for cognitively impaired residents. A recent study by Zeisel, Silverstein, Hyde et al. (2003) of 427 residents in 15 Alzheimer's special care units, ranging in size from 20 to 50 residents, found that:

The environmental features associated with both reduced aggressive and agitated behavior and fewer psychological problems include (privacy) and personalization in bedrooms, residential character, and an ambient environment that residents can understand. Characteristics of the environment associated with reduced depression, social withdrawal misidentification, and hallucinations include common areas that vary in ambiance and exit doors throughout the SCU that are camouflaged.

. . . 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.

. . .SCUs should strive to model their interior environments after homelike settings to reduce aggressive and other symptoms. Applied in design of SCUs, these findings will lead to more private and less shared rooms, variation in common room design within an SCU, common rooms for activities located at ends of hallways, and doors located along side walls whenever possible instead of at the end of hallways where they act as "attractive nuisances." (p. 709)

Sheryl Zimmerman and her colleagues (2001) have conducted extensive survey research in assisted living facilities and nursing homes in New Jersey, North Carolina, Florida and Maryland. They broke their assisted living sample into small (under 16 residents), traditional (16 and over residents) and new model facilities (purpose built and with 16 residents), and surveyed a total of 233 facilities in the four states. Among some of the more interesting, policy relevant findings, they found that:

. . . with the exception of a discharge policy related to the inability to walk, it makes no difference whether residents are in small, traditional, or new-model facilities in terms of whether the facility is likely to discharge them based on resident characteristics. Factors that do seem to make a considerable difference are the state in which the facility is located, who owns the facility, and the age of the facility. (p. 234)

For example:

Compared with facilities located in North Carolina, facilities in Florida are more likely to have a discharge policy for residents who are unable to get out of bed, who are unable to feed themselves, or who are unable to care for their appearance. . . . For-profit status is also associated with a greater tendency to discharge for ADL-related reasons, particularly an inability to bathe, dress, or maintain continence. Finally, as the age of the facility

increases, so does the propensity to discharge residents who are unable to walk, eat independently, or maintain urinary or fecal continence. (p. 234)

The new model facilities score higher on policy choice, privacy and policy clarity than the other facility types. The traditional and new-model types both provide more health and social services than the small facilities.

These findings indicate that the larger and newer facilities are better able to provide services and meet the privacy and autonomy desires of residents. Small facilities, however, may provide more familial, homelike settings that many impaired elderly seem to prefer and are willing to give up some privacy and autonomy in order to live in such facilities. Many may also prefer to age in place in small facilities, even in the absence of 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. It should also be noted that smaller facilities are often more willing to take Medicaid and SSI-supported residents than larger facilities, which has major implications for state long-term care policy, as Medicaid-waiver funds are increasingly used to expand congregate alternatives to nursing homes.

Morgan, Eckert, Gruber-Baldini and Zimmerman (2002) suggest that researchers, policymakers 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 assisted living. Small facilities, for example, may not be able to offer the same level of control and autonomy, or service as larger, purpose-built (new paradigm) facilities, but residents, as noted above, may well find them more homelike, more affordable and accommodating enough in terms of autonomy/control, especially in comparison to the nursing home setting or even their own homes. In sum, the advantages and shortcomings of the whole range of assisted living options should be recognized without claiming that one style of assisted living is necessarily superior to another or better designed to meet everyone's needs, preferences or ability to pay.

Policies, funding 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 basic values of the assisted living 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 facilities. Zimmerman, Eckert, Morgan et al. (2002) note that if regulation and funding turns on adherence to the new paradigm's parameters, it may mean the demise of the smaller facilities. This perspective will undoubtedly complicate the way assisted living 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.

Community-residential care may also be provided in adult foster homes, which are much smaller and less formal than conventional assisted living facilities. Adult foster care (Adult Family Care Homes) in Florida is provided in small group residential settings, usually private

homes, which, in Florida, are allowed to have up to five residents. Stark, Kane, Kane and Finch (1995) have described adult foster care homes as:

. . . a cottage industry of sorts. Typically, foster homes cannot make a profit unless they have a lean staff—perhaps limited to family members of the foster care provider and a few hired helpers for peak hours. Such foster homes obviously cannot use an elaborate division of labor; they depend on a flexible ability to handle whatever needs to be done. Ordinarily, they will be unable to care for Medicaid or low-income clientele with heavy levels of disability unless state regulation permits nursing functions to be done by foster care personnel without nursing licenses or unless (for Medicaid) reimbursement is high enough to permit contracting with nurses.

In a comparative study of adult foster homes and nursing home residents in Oregon, Stark et al. found that functional outcomes, controlling for a wide range of client health functional status and demographic characteristics, were comparable in the two settings and social and psychological outcomes have a propensity to favor foster care. These kinds of findings should help allay fears that adult foster care cannot serve seriously impaired persons and reduce nursing home utilization.

This type of long-term care setting may be especially appropriate for persons with early-to-mid-stage dementia who could benefit from the small scale and relatively intimate environment of foster care. Oregon made adult foster home care a major pillar of its home- and community-based long-term care system in the 1980s, and now has over several thousand foster home beds compared to fewer than 2,000 in Florida. Oregon covers adult foster homes under their home- and community-based Medicaid waivers, but 70% of the residents are paying their own way (private pay), which reflects both the affordability and consumer appeal of the program.

In short, adult foster care in Oregon has become a mainstream long-term care option available in both upscale, elaborate homes and in modest homes in less affluent neighborhoods. The Oregon experience demonstrates that Florida is absorbing considerable opportunity costs by not maximizing the potential of adult foster care. If Florida had the same ratio of foster homes in relationship to its 65+ population as Oregon, there would be as many foster home beds as Medicaid-supported nursing home beds—over 60,000.

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

Instead of trying to abolish risk through the imposition of extensive regulatory requirements, the authors recommend several policy initiatives designed to strengthen foster care and make it more available. They recommend:

- More financial support including increased per diem rates and more funded slots (beds).
- More case management services and advocacy for residents which could contribute more to the resident's quality of care and life from annual or even quarterly regulatory inspections.
- Policymakers should accept the notion that care cannot be given without some risk to the vulnerable. The authors note that:

. . . to eliminate risk beg the question of whether it is possible to achieve this goal in light of the severely and multiply impaired populations housed in board-and-care homes. It is unclear whether regulation simply provides the illusion of control in caregiving systems that are, at their core, reliant on the goodwill of workers to meet the desired goals.

The great majority of the homes that we saw were of good quality without regulation. They relied upon the altruism and motivation of their operators to guarantee that the needs of residents were met and that their safety was protected. If the personnel are key to ensuring care of high quality, then all of the emphasis on physical structure and recording of routine care is misdirected. Regulations would best be directed at initial screening of operators and ongoing observation of them during interactions with their residents, rather than checking for adequate hallway width and food storage. (p.205)

The authors also note that ensuring a high quality of care for residents is significantly dependent on policymakers and the general public acknowledging and respecting the work of caregivers.

- Finally, Morgan and colleagues' fundamental recommendation is "to preserve the small home." The authors' research revealed that:

Small size also permits flexibility, personalization, and building of more direct, ongoing linkages that characterized the best of the homes we visited in both of our locations. As the twin pressures of cost-containment and quality control push care toward an assembly-line, rationalized state, it was encouraging to us to see the personalization of care achieved in the small board-and-care homes. Attention to individual detail in planning meals and outings can, for example, separate adequate care from a more personal ideal to which many in American society would readily subscribe. (p. 204)

Community-residential care, whether in the form of assisted living or foster care, is not for everyone requiring long-term care assistance, especially those with extensive, complex medical care needs. As noted by Stephen Golant (2003), "ALFs will be neither the initial nor the final home for most frail older adults who seek alternatives to nursing homes."

Golant also points out, however, that ". . . older residents who are admitted to these facilities may be able to enjoy relatively long stays—on average as much as three years. Thus, although they probably will not age in place in their ALFs, they may receive sufficient benefits to justify their having to move again to a higher care facility."

I am a bit more optimistic in that I think 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. I also think that, unless the federal government expands its commitment to subsidized housing, assisted living will increasingly become the “by default” housing option for many low-income, impaired elderly persons over the next 20 years.

As the population of more highly impaired residents increases, the pressure to impose a more medical-model oriented regulatory scheme on assisted living is likely to grow. Some of these regulatory changes may be necessary on a facility-by-facility basis. On the whole however, I think they should be resisted in order to continue the effort to achieve the original vision of assisted living as a values-driven housing and services model of long-term care.

Implications of what we know for regulating assisted living

Before addressing assisted living policy specifically, we should recognize that the vast majority of older people and their families strongly prefer home- and community-based alternatives to nursing home care. They simply and understandably do not want to live in a highly regulated institutional environment. 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. 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. Over 80% of all public long-term care funds are spent on nursing home care in most states. Both assisted living 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, assisted living is probably the most under-developed alternative program, at least in the public sector. Eighty to ninety percent of the assisted living growth since 1990 has occurred in the private sector and states, on the whole, are just beginning to develop and expand their assisted living programs, primarily through Medicaid waiver initiatives.

The pervasive preference among the elderly for alternatives, including assisted living, to nursing homes should not be frustrated by excessive or inappropriate regulation. Assisted living has demonstrated the capacity to serve seriously impaired residents effectively (resident satisfaction, quality-of-care outcomes, etc.) and regulations should be designed to maximize this potential through the use of flexible, inclusive admission/retention criteria. Providers can help maximize this potential by providing necessary care, including fulltime RN care, for residents with healthcare conditions that require continuing care. Older people highly value autonomy, privacy and the opportunity to age in place and the preservation/enhancement of these values should be the top priority in the development of assisted living regulations.

As noted earlier, for many frail elderly, assisted living is a more propitious setting for achieving these values than even in their own homes. The only sure outcome of imposing a nursing home mode of regulation of assisted living would be precisely what we have achieved in nursing homes—a rigid, institutional environment that leaves little room for consumer-direction and resident autonomy, privacy and spiritual well-being. 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 assisted living. The wide variance in assisted living regulation across the states represents a natural laboratory and every effort should be made over the next five-to-ten 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 are already developing a body of knowledge that will be very helpful in the development of 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 assisted living.

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 policymakers/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 assisted living.

I think we could also 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 are more generally knowledgeable than physicians or nurses about medications, and physicians are usually willing to listen to pharmacists and adjust prescriptions accordingly.

Given these research findings and their policy implications, we think states should, for the most part, continue to take a very cautious approach to assisted living 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 assisted living and a wide range of outcomes, including the extent of assisted living’s capacity to substitute for nursing home care and the capacity of assisted living 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.

Our discussion of specific regulatory domains includes a review of some of the results of the Assisted Living Workgroup (2003). The Workgroup was formed in response to congressional concerns about assisted living regulation. The recommendations, rationale statements and responses of the several organizations that participated in the Workgroup constitute an informative commentary on current views of assisted living and long-term care policy in general. The recommendations and responses to them reflect basic 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 and programmatic flexibility, a second group supporting a substantially more prescriptive approach based on safety and quality of care priorities and a

third, smaller group which felt that many of the recommendations were too prescriptive on regulatory issues that should be left to the states.

In our view, the vast majority of these recommendations are sound in that they effectively reflect the philosophical framework that is the source of assisted living's value to residents and are consistent with the currently available research. 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 respectfully disagree with the several participating organizations in whose view:

. . . most of the recommendations from the Assisted Living Workgroup are not appropriate for adoption by the states. For states that have recently revised their assisted living regulatory approach, adoption of the recommendations in the Assisted Living Workgroup report would in nearly every case be a step backwards, increasing the risk of adverse outcomes to thousands of consumers. Rather than follow the report's recommendations, those states seeking to revise their current assisted living regulations should consider measures adopted by other states in recent years. (p. 31)

Limiting the risk of adverse outcomes is certainly a critical regulatory goal. Adverse outcomes, however, include more than healthcare related safety issues. They also include imposing regulatory standards that would undermine the qualities that make assisted living such an attractive housing and services option for thousands of cognitively and physically impaired people by implementing admission and retention criteria that eliminate assisted living as a choice for many people, safety-oriented regulations that would create a more regimented environment and diminish the freedom of residents, staffing standards and qualifications that would make assisted living even less affordable for both private-pay and publicly supported residents than it is now with rapidly growing waiting lists for potential residents who qualify for Medicaid waiver-supported assisted living programs.

Regulatory standards vary across the states, but the history of assisted living regulation in Florida does not support the opponents position that “adoption of the recommendations in the Assisted Living Workgroup report would in nearly every case be a step backwards . . . (Assisted Living Workgroup, 2003, p. 31).“ Florida began to make assisted living available to more impaired persons in 1991 with the development of a “values-based” assisted living licensure category called extended congregate care (ECC), which is referred to favorably by the opponents in one of their dissents. The evolution of ECC regulations over the last ten years can best be characterized as steady movement toward adopting the regulatory standards contained in most of the Workgroup's recommendations. This movement toward a less restrictive, medically oriented regulatory model has been motivated by a desire to accommodate consumer preference and increasing confidence on the part of regulators, policymakers and advocates that an effective balance between achieving the assisted living values (choice, privacy, dignity) and ensuring sufficient safety can be maintained. This confidence is based on ten years of experience (over 400 facilities now have an ECC license) and the research findings we discussed earlier, especially findings related to consumer preference, resident satisfaction and the relative cost-effectiveness of assisted living as a long-term care program. Regulatory vigilance is certainly necessary; but, at

this point, there is little reason to think this regulatory trajectory will be reversed in the future, given the popularity and demand for assisted living.

This division among workgroup participants is evident in responses to many of the most important, defining recommendations. The following excerpts from written responses to the recommendation on components of a state accountability and oversight system for assisted living are reasonably representative of the positions taken in support of and opposition to many other pivotal recommendations. The recommendation states that:

The regulatory system for assisted living is founded on these principles:

- A regulatory system for assisted living is responsible for abating harm and support the resident's decision-making control.
- The regulatory system ensures that there is meaningful assisted living stakeholder participation, especially resident participation, when defining regulatory standards.
- The regulatory system specifies that the practices, protocols and methods by which are provided are respectful of, and responsive to individual resident preferences, needs and values and that resident values guide care and service delivery decisions.
- Regulatory requirements should be periodically re-evaluated to determine whether or not they are achieving their intended effect (p. 36).

This approach seeks to combine elements of traditional regulatory systems having to do with deterrence and abatement of harm with other modes for monitoring and improving performance and quality of care. . . . This new approach would align the values associated with assisted living (autonomy, choice, dignity) with the outcomes to be accomplished and the means to evaluate the effectiveness of services within a system that encourages and rewards excellence while retaining traditional state responsibility for vigorous rule enforcement when necessary. (p. 38)

The Workgroup participants who oppose this recommendation and support a more healthcare and safety-oriented regulatory approach throughout the report take the position that although they support much of this recommendation, they do not support the assumption that:

. . . the most significant problem faced by AL regulators is ensuring that residents have enough decision making control. . . . The introductory principles, by elevating resident choice above all other concerns would be an impediment to an effective regulatory system. The majority diverts attention from the truly important issues. Ignoring the prevalence of care and safety problems in the assisted living setting, it directs regulators merely to make sure that residents have the right to make choices. This is neither useful nor rational as a response to the growing crisis in resident safety and well-being. (p. 39-40)

We discuss several more specific regulatory issues in the following section.

- 1) **Disclosure.** The Assisted Living Federation of America (ALFA) and other organizations have already moved to develop programs for fully informing (potential) residents and their families about what services facilities offer, 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 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.

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 ALR shall disclose the following information to each prospective resident prior to admission:

- The ALR's 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.
- How the physical environment and design features are appropriate to support the functioning and safety of residents with the specific conditions(s). (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 grow rapidly in the future. In fact, assisted living may well become the long-term care setting of choice for most persons with significant cognitive impairment, if current trends continue and confidence in assisted living's capacity to provide optimal care for the cognitively impaired increases across the country. Already in Florida, the Medicaid waiver-supported assisted living program 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) **Fire safety.** Appropriate fire protection provisions should be part of any regulatory scheme and there may be some need to standardize requirements across jurisdictions in order to ensure efficient approaches to a uniform level of safety, which does not unduly restrict access to and availability of community-residential care.
- 3) **Admission and retention criteria and staffing levels.** In order to maximize consumer choice, admission and retention criteria should be as inclusive and flexible as possible and staffing should be sufficient to meet the needs of individual residents. 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.

The failure of the Assisted Living Workgroup to provide two-thirds majority support for the recommendations promoting access to assisted living for individuals with personal healthcare needs is disappointing. No healthcare need treatable in a person's own home should be a barrier to admission to assisted living or an automatic trigger for discharge. As noted by supporters of the failed recommendation:

Many individuals with personal healthcare needs are capable to manage their care. Others have the ability to self-direct their care with occasional assistance from qualified caregivers or trained staff. These conditions can be easily managed in a home environment, and therefore are manageable in the ALR. It would be discriminatory to exclude individuals with personal healthcare needs from living in an ALR. (p. 156)

The failure of Recommendation D.14, by one vote, on March 4, 2003, represents a major setback for people with disabilities and other older Americans who may develop personal healthcare needs and wish to choose assisted living as an alternative to nursing home care. . . . Current state assisted living regulations prohibit many individuals with disabilities and other aging individuals who may acquire conditions later in life from admission to assisted living because these individuals require the use of a catheter, require oxygen, or have some form of medical ostomy. Additionally, current state assisted living regulations can also require a person with a disability to leave their assisted living home when they develop a temporary medical condition that requires bed rest, i.e., severe colds or Grade I or II pressure ulcers. (p. 157)

As an alternative to this recommendation, one group of opponents recommended:

. . . a system that would establish levels of care within assisted living—for example, the Florida system that licenses assisted living residences for either Limited Nursing Services or the more extensive Extended Congregate Services. (Florida Administrative Code Ann. R. 58A-5.030- 5.031). Such a system would help assure that an assisted living residence would be prepared to meet the needs of a resident with a significant health care condition. (p.158)

It is interesting to note here that the initial version of the Extended Congregate Care (ECC) licensure category included a number of healthcare procedures that could not be provided in ECC licensed facilities, restricting admission and retention to a much greater extent than intended by originators of the ECC proposal. Since then, however, prohibition on these procedures have been gradually removed and the only restriction now is the one contained in the Assisted Living Workgroup’s recommended definition of assisted living—that is, only those requiring 24-hour care are not allowed in assisted living. The Assisted Living Workgroup staffing recommendations state that:

The ALR shall ensure that the right number of trained and awake staff are on duty and present at all times, 24 hours a day, 7 days a week, to meet the needs of residents and to carry out all the processes listed in the ALF’s written emergency and disaster preparedness plan for fires and other natural disasters. (p. 313)

The evidence to date indicates that assisted living has a highly diverse population, including a large number of residents who are seriously impaired, both cognitively and physically. These “facts on the ground” should reassure policymakers and advocates that properly managed facilities have the capacity to serve the frail resident and support extensive “aging in place.” As noted elsewhere in this paper, we think that regulations and funding levels will probably have to be modified as the number/percentage of seriously impaired residents with substantial medical needs increases in the years ahead, especially in regard to the availability of RNs and training/retention of direct care workers. We also think, however, that experience and research, to date, indicate that these modifications can be made without

materially interfering with the pursuit of the goals (values) of assisted living or making it qualitatively less affordable. Imposing staffing standards like those required of nursing homes, however, would most certainly reduce affordability.

There is no compelling evidence that requiring assisted living facilities 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, but it can and is being done (in some states for several years) and the affordability benefits seem to outweigh any downside risks at this point. I think this recommendation takes us about as far as we need to go at this point in developing a regulatory standard for retention. 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 has attempted to work with the resident so that move-out or transfer would be unnecessary and this attempt has been unsuccessful. (p. 128)

Findings from a recent study by Ball et al. (2004) demonstrate the complex and often idiosyncratic nature of "aging in place" in assisted living facilities: there may be as many ways of "aging in place" as there are ALF residents and regulations specifying the terms of retention very precisely are likely to end up displacing many residents whose quality of life is entirely dependent on remaining in their ALF. Ball et al. conclude that resident pathways to "aging in place" are:

. . . influenced by multiple factors relating to the wider community outside the home, the physical and social environment of the facility, and the individual resident. The relationship between these factors was complex and dynamic, and the phenomenon of aging in place represented a balancing act that depended on how various factors acted and interacted in the context of each ALF. Central to a resident's ability to age in place was ultimately the "fit" between the capacity of both the facility and the resident to manage resident decline. (p. 205)

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

- 4) **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 ten years and are likely to 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 developing equitable (no waiver liability) agreements between providers and consumers, which are simply necessary if many persons are to be admitted or allowed to remain in an assisted living facility. As noted by several supporters of the recommendation:

Perhaps the most useful part of the recommendation is its detailed outline of a process for negotiating such agreements. Many states require negotiated risk or shared responsibility agreements without providing guidance on how they should and should not be developed. The process recognizes that the provider has a responsibility to identify the consumer's preferences as well as potential risks that may be associated with certain behaviors. The process also recognized that not all courses of action are possible or reasonable, but that resident preferences should be honored even when the provider does not believe them to be in the resident's best interest. (p. 153)

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 weighted 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.

5) End-of-life care. As the number of assisted living residents with serious healthcare needs grows and many of them with terminal conditions do not want to move to a nursing home or hospital, or return home, facilities will increasingly have to provide hospice care. There is little reason to think that assisted living cannot provide effective end-of-life care if sufficient accommodations are made. The Assisted Living Workgroup's recommendation for hospice care states that:

1. If the ALR is able to provide or arrange for the provision of hospice care, the ALR should inform terminally ill residents of the availability to receive hospice care at the ALR. The ALR should identify and make available to residents information about hospice services and the names and addresses of providers in the geographic vicinity.
2. When a terminally ill resident is receiving hospice care, transfer from the ALR may not be required, if the needs are being met.

3. The ALR and hospice communicate, establish, and agree upon a coordinated service plan that reflects the hospice philosophy and is consistent with regulatory requirements.
4. The service plan identifies the provider/caregiver/family members that is to be held responsible for implementing the service plan.
5. The ALR and hospice determine a process by which information from the hospice interdisciplinary team and the ALR interdisciplinary team will be exchanged when developing, and evaluating outcomes of care and updating the service plan. (p. 135)

6) 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. Initially, these standards should be applied only to providers who claim to provide specialty services. There are a number of unresolved controversies (separation of residents) in this area and standards should be developed and implemented very carefully and in close collaboration with the industry. Assisted living has great potential to serve residents with dementia, including those in advanced stages, and every effort must be made to prevent regulation from curtailing this potential unnecessarily. The significance of this issue is evident in Hawes et al. findings that cognitive impairment is an extremely important variable in accounting for movement to a nursing home. The Assisted Living Workgroup recommendations regarding care for residents with cognitive impairment provides an effective framework for serving this population. These recommendations include the following:

ALRs shall have in place procedures and services that 1) meet the needs of residents with cognitive impairment/dementia, 2) accommodate and balance concerns about safety and autonomy, 3) recognize and build on strengths, capacities, choices, and values of the resident, and 4) reflect the likelihood that the cognitive status of many of these people will change and deteriorate over time. Such procedures and services include:

Part 1: Care for People with Cognitive Impairment/Dementia

1. Staff training about cognitive impairment, dementia, and dementia care;
2. Procedures for assessing and reassessing the resident's cognitive status, abilities, and related care needs;
3. Procedures, including supervision, to help direct care staff understand and respond effectively to residents' behavioral symptoms;
4. Specialized activities that are appropriate for residents with cognitive impairment/dementia;
5. Procedures for working with the resident and the resident's family to define and clarify responsibilities of the resident, the family, and the facility;
6. Procedures for designating and working with a surrogate decision maker, if the resident is not capable of making decisions for him/herself;
7. Policies and procedures to protect residents who wander and/or are at risk of physical harm;
8. Regular monitoring to assure resident safety and health care status, consistent with impairment; and
9. 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 in place procedures and services that are appropriate for the severity of cognitive impairment of its residents.

Part 2: Dementia Special Care Units and Facilities

ALRs that choose to serve only individuals with cognitive impairment/ dementia or to establish a special dementia unit or units(s) 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)

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

Victor Regnier's (2003) defining criteria for assisted living requires that facilities appear residential in character and appear as small in size because these are essential features that contribute to a facility looking and feeling homelike. As one reviewer of Regnier's book on assisted living has noted, Regnier reports that:

. . . building design is one of the most important attributes consumers cite when describing why they moved to a particular assisted living building. The economics allow facilities to capitalize on this fact. Regnier points out that a \$300,000 reduction in the cost of a building translates into only a \$3 per day reduction in the overall cost and represents only a savings of 5% in a daily charge. This is not enough savings, he says, to justify the impact that such a cost reduction would have on the building's appearance, given how important design is in attracting residents. (Binstock, 2003, p. 594.)

We know from research by Kane, Hawes and others that assisted living residents and potential residents place a *very* high priority on privacy as a quality-of-life value. Most fundamentally, this means a strong preference for private rooms and bathrooms and, to a lesser but still very significant extent, kitchenettes. There seems to be a clear consensus in the industry and among policymakers that this level of privacy is not affordable for many assisted living residents, especially those who are publicly supported. 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 otherwise. This affordability vs. desirability issue is extremely important and is likely to grow in significance over the next ten years as quality of life becomes as important as quality of care in shaping the future of long-term care policy and practice and consumer preference and satisfaction become increasingly important factors in shaping long-term care policy. We should not forget that privacy is a necessary condition for the exercise of autonomy, maintaining dignity and achieving an adequate quality of life among 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 participants supported a provision for single occupancy rooms in their definition of assisted living.

Quality of life and privacy in assisted living

As stated above, we think states should also begin to address the fundamental issue of privacy in assisted living—of single occupancy units for those who prefer them. Rosalie Kane (2001) has noted that the case for privacy needs to be made on two levels—value and price. According to Kane, the case for intrinsic value can be easily established. Private-pay assisted living residents overwhelming (88%+) chose single occupancy units:

People not yet in a facility dread the shared space above most things, and people already in facilities say they would much prefer to have private rooms and baths, and would be willing to accept much less in the way of planned programs and activities in exchange. People with Alzheimer's disease are often unable to speak for themselves on this issue, but many of their advocates believe that they too would, in the whole, flourish better if not forced to share living space.

As noted earlier, recent research by Hawes and Phillips (2000) found that:

The vast majority (85%) of their respondents 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) most (65%) continued to identify these same privacy-oriented priorities.

The major issue then is not consumer preference, but rather price, which most providers think would be too high to be affordable for publicly supported residents. Kane (1998), however, thinks this may be true, at least in the case of new developments.

According to one analysis, modeled by considering a 39-unit building under more or less expensive construction and more or less favorable lending arrangements, the difference between building for 78 residents in 39 units versus 39 residents in 39 units would range from \$6.30 a day to \$3.20 a day per tenant. This slightly higher construction cost and, therefore, higher debt service was projected to be offset by sharply lower operational costs in the single-occupancy apartments.

Among the reasons for greater costliness in operating shared facilities were higher maintenance (since frequent roommate switches cause more wear and tear and more need for moving assistance; higher housekeeping costs (because higher needs or costs in maintaining common-use areas and more demand for entertainment; increased needs for highly paid staff to deal with conflict resolution and behavior management; higher demand for tray service in rooms since the time a roommate is in the dining room is the only time the other roommate can be assured of being alone; and greater dependence than residence-provided snacks. By far the greatest extra cost of shared space, however, relates to the costs of vacancies and the difficulties in roommate matching. 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.

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 containment priorities.

- 8) Training.** The industry tendency to have employees play multiple roles is generally positive in that it can help dilute the stifling effects of hierarchy and avoid the alienation and detachment of command and control structures and help maintain staff morale, creativity and commitment. The tendency toward “generalist worker” roles can also contribute to a more integrated, familial, homelike environment and help contain staff costs. It also creates a greater need for cross training, both pre- and in-services training, especially for workers in facilities serving more physically and cognitively impaired residents. The training should also be designed to focus on the values of assisted living in all phases of caregiving and interaction with residents. The industry can expect more regulatory activity in this area and should create guidelines in anticipation of state initiatives.

Many of the Assisted Living Workgroup’s direct-care recommendations either directly or indirectly address training issues, which are largely consistent with the approach suggested here. 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.

- 9) 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. Robert and Rosalie Kane’s research (2004) on the use of these measures in nursing homes should be carefully assessed for use in assisted living. Even in the current absence of regulatory requirements, assisted living providers should begin using these measures (as some already are) as essential components of an internal quality-monitoring program.
- 10) Certificate of need.** A certificate-of-need approach to containing the growth of assisted living would be, for the most part, ill advised at this point. Assisted living is overbuilt in some areas now, but market forces and the growth of the Medicaid waiver funded sector (and other sources of public funding) are likely to close the gap over the next five years.
- 11) Nurse delegation and medication management.** Properly supervised by nurses, non-nursing staff should be allowed to assist in administering medications. There is no evidence that current nurse delegation acts in several states, including Oregon and Washington, are harmful to residents who, in fact, benefit from the capacity of these acts to help contain costs. Universal workers will not be able to achieve their full potential without some form of nurse delegation and the training that delegation would require.

One of the principal purposes of nurse delegation is to create an effective balance between containing the cost and the risk of medication management. The Assisted Living Workgroup 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 which 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, than are generally required by nurse delegation acts. The available research on the effects of nurse delegation offers little guidance in the formulation of rules for medication modification. The experience of states with nurse delegation in assisted living and adult foster care, however, 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. 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.

A recent article by Sloane et al. (2004) found that many AL residents with serious chronic conditions are not receiving appropriate medications (under-medicated), which is a problem in all care settings. This may indicate a need for better regulations regarding medical assessments and protocols—role of physicians, nurses and pharmacists (quarterly evaluations for certain residents).

- Medication under-treatment in AL settings. Sloane et al. state:

This study demonstrates that older persons residing in RC/AL facilities have high rates of undertreatment, adding to existing reports from community, hospital, and nursing home settings. Among 328 RC/AL residents with CHF 62.2% were not receiving an ACE inhibitor; of 172 persons with a history of MI, 60.5% were not receiving aspirin, and 76.2% were not receiving a [beta]-blocker; of 435 persons with a history of stroke, 37.5% were not receiving any anticoagulant or antiplatelet agent; and of 315 with an established diagnosis of osteoporosis, 51.1% were not receiving treatment. Furthermore, the observed pattern of nonprescribing was not explained by age, race, or functional status of the residents. This gap in translating evidence-based medical treatment into practice may have a considerable adverse impact on the health of older persons. (p. 2036)

12) Resident assessment. We are not ready for a standard uniform resident assessment and case-planning instrument in assisted living à la the Minimum Data Set (MDS) now used in nursing homes. Maine's initiative in this area is interesting and may prove helpful in the future. But, we need more research and development and debate about tradeoffs before requiring a single instrument. This is another area where states are a natural laboratory and we need to learn much more about comparative results and allow time for the emergence of a consensus.

In addition to more conventional regulatory approaches to quality assurance described above, there are two other strategies that I think can be used that are more consumer (resident) oriented than conventional nursing home regulatory schemes.

13) Case management and case advocacy. I have long felt that the use of case managers as care advocates for publicly supported assisted living residents is as efficacious an approach to ensuring an adequate quality of care and life as annual or semi-annual surveys and episodic reporting to ombudsmen and Adult Protective Services, as important as these activities often are. This approach has been built into the Florida Assisted Living Medicaid Waiver Program. As long as caseloads are kept manageable (40:1) and the case managers are appropriately trained as care advocates and quality monitors, I think this approach has the potential to be an effective method of ensuring that the individual resident has an acceptable quality of life and receives sufficient care. This approach also helps avoid the adversarial, spot check approach to regulation by allowing the case manager (care advocate) to work with providers, residents and family members in a kind of continuous quality assurance manner based on common agendas and collaboration.

14) Consumer-direction. The Assisted Living Federation of America's call for making Medicaid "portable," so that recipients can choose where they will receive care and who will provide it, has considerable quality improvement potential. The Medicaid Consumer Account Program would reimburse the consumer (resident) rather than the provider and allow the states to determine the value of the consumer account based on the results of the functional and health assessment and the type of services required. This takes consumer-directed care from in-home care, which has been the major focus of advocates for consumer-directed care, into residential care and substantially expands opportunities for consumer empowerment. This program is a logical extension of the guiding values (autonomy and control) of assisted living. The evaluations of consumer-directed programs in California (Benjamin, Matthias, Franke, & Mills, 1998); Arkansas (Foster, Brown, Philips, & Schore, 2003); and in Europe (Wiener, Tilly & Cuellar, 2003) indicate that these programs generate high consumer satisfaction and are cost-effective. I also think that consumer direction of the kind proposed in the Medicaid Consumer Account Program represents an effective way of ensuring long-term care quality in all of its dimensions by giving the consumer and her family the ability to make choices and exercise power in the assisted living market.

The Assisted Living Workgroup was evenly divided over a recommendation for the creation of a consumer-directed federal long-term care program that would include assisted living. The rationale for the recommendation notes that:

In light of the various disability statutes and the recent Olmstead decision, the federal government and states should move to a long-term care funding system that provides funding in the least restrictive environment possible. To ensure consumer choice, the system should provide consumers the capacity to direct how and where their funding will be spent. This model of consumer directed care could be similar to the Cash and Counseling demonstration program currently being evaluated by HHS. (p. 56)

In explaining their opposition to this recommendation to give consumers qualitatively greater control over the use of long-term care resources, some of the opponents state that while they support expanding opportunities for consumer choice, they:

. . . object to the mythology about assisted living that pervades the rationale for this recommendation.

We support individuals' rights to live in the least restrictive environment possible. We cannot support a statement that implies that all assisted living facilities are always less restrictive than all nursing homes. Without a common and meaningful definition of assisted living, we cannot agree to this conclusion, which is more a statement of faith than a statement of fact. . . . We reject the majority's implication that innovation and good practices lie solely with assisted living. . . . Under current law, individuals have choice about where they will receive their healthcare. Consequently, the second sentence in the second paragraph of the Rationale states nothing unique. The distinction for purposes of these recommendations is that nursing facilities are entitlements under the Medicaid program, while assisted living is not. (p. 57)

Most of this rationale for opposing consumer-directed care reflects the opponents' hostility toward assisted living as it exists or might exist under provisions included in the Workgroup's recommendations. This hostility or deep suspicion of assisted living is evident in such phrases as "mythology about assisted living" and statement of faith rather than a statement of fact" about the reality of assisted living. They also claim that the nursing home entitlement does not restrict choice in deciding where care can be provided, which would come as a surprise to many people who cannot receive public support for any long-term care program but a nursing home. In my view, opponents of consumer-directed care have claimed far more than they can prove or use to convince consumers that consumer-directed care should not become at least as available as nursing home care.

Assisted living affordability

Most of the organizations opposing consumer direction are also opposed to all or most of the Workgroup's affordability recommendations, including expansion of the assisted living Medicaid waiver and HUD-funded programs related to assisted living. The recommendation to expand waiver funding is based on the fact that "in most states, waiver funding is quite limited and over-subscribed and that as an intermediate strategy to a fully implemented consumer-direct long-term care program, the federal government should encourage states to increase their waiver-funded programs (Assisted Living Workgroup, 2003, p. 58)." which might include incentives like increasing the federal share for waiver funds by 10%; this would build on the CMS Long-term Care Real Change and System Change grant initiatives. Oregon and Washington have used waivers to transform their long-term care system by expanding home- and community-based services, including assisted living, over the last ten years.

Most of the opponents of the funding for consumer-directed care recommendation also opposed this recommendation because expanding:

Medicaid funding of assisted living through home and community-based waiver is not good public policy in the absence of meaningful quality of care standards. In order to be eligible for home and community-based waivers, Medicaid beneficiaries have sufficiently significant health care needs to require a nursing home level of care. Nursing home-eligible individuals should not be placed in assisted living residences that are neither staffed nor otherwise prepared to meet their needs. The majority recommendations do little to guarantee a high quality of care in assisted living residences. (p. 59)

The Assisted Living Workgroup generated several more affordability/funding-related recommendations which included proposals to expand (HUD) programs for assisted living, increase SSI spending to cover assisted living room and board costs and allow supplemental support by family members for assisting living residents. Several organizations also opposed these recommendations because they support increased funding for a program (AL) they consider inadequately regulated and that other recommendations in the report failed to address sufficiently. Another group of participants supported most of the affordability/funding recommendations but qualified their support for the expanded Medicaid waiver recommendation by referring to it as a band-aid approach that:

. . .will not help to avert a growing crisis in long term care financing. It is important to understand that our current financing system, rooted in the Medicaid welfare program, will not withstand the huge influx of seniors in the coming decades. Therefore, it is imperative that a permanent comprehensive solution for the funding of the entire spectrum of long term care be developed. Research by the health policy experts at Abt Associates indicates that creation of an insurance-based public/private program offers a viable alternative to today's unsustainable financing system. Additionally, there must be recognition of the need for personal and family responsibility in the planning for future payment of long term care. State and federal governments, in conjunction with providers of care and services, consumers, researchers, actuaries and other stakeholders should meet and develop a strategy to reach a permanent, multi-faceted solution. (p. 59)

It is clearly a good idea to begin now the hard work of developing a comprehensive, multi-faceted proposal to address the looming fiscal crisis in long-term care. Absent the implementation of a long-term care benefit in Medicare or something similar, however, it is difficult to imagine a feasible alternative to Medicaid, especially as a source of funding for the extensive expansion of waiver funding for home and community services, including assisted living. Long-term care insurance is important but no plausible scenario for the future of long-term care funding, even with substantial public sector involvement, can depend primarily on long-term care insurance to resolve the emerging fiscal crisis. Medicaid waivers are far more than a band-aid approach 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. We should avoid dismissing the Medicaid waivers as a band-aid fiscal strategy when we have barely begun, in most states, to tap their potential to fund systemic long-term care changes, including increased availability of assisted living for impaired older people who are dependent on publicly supported services.

Conclusion and a research agenda

The best available information indicates that the assisted living industry, with the support of policymakers 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 ten years. As head of the Florida State Aging Agency in 1989, I felt that the biggest gap 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 had been made available in their own homes since the late 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.

The biggest problem in assisted living at this point is not insufficient regulation. The major problem confronting policymakers and those in need of long-term care is the relatively meager number of assisted living 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, 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 majority position on most of the Assisted Living Workgroup’s recommendations is consistent with both of these goals and represents a major advance in the continuing development of a consensus framework for the expansion and regulation of assisted living. The current body of research, as summarized in this paper, is also consistent with these goals, especially to the extent that it demonstrates 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 have a special responsibility here 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 or less livable from a quality of life perspective.

Policy makers, assisted living 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 and Wiener, 2004, p. 4). According to O’Keeffe and Wiener, these issues include:

- Meet expectations for privacy, amenities, and quality services that have been set by the private pay dominated model of “assisted living” when Medicaid cannot afford to pay private pay rates.
- Cover the actual costs of serving frail older individuals with chronic care needs in residential care settings, when Medicaid is not permitted to pay for room and board and the payment sources available to cover room and board are insufficient.

- Given consumers a sense of what they should reasonably be able to expect from a setting that calls itself “assisted living” or “adult foster care” or some other name, without imposing uniform definitions through state regulation.
- Assure a minimally acceptable quality of care without imposing rules that stifle improvements and without the regulated “floor” becoming the “ceiling.”

At this point, I think the available research indicates that most of the recommendations of the Assisted Living Workgroup and 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. The financing issues, however, 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 assisted living and adult foster care as available as institutional care in the publicly funded long-term care system.

Assisted living is a relatively fragile form of housing and long-term care that is largely sustained by the fact that many older people very much prefer it to nursing home care and may, in many cases, find it preferable to in-home care. It would not take the application of very many nursing home style regulations, however, to make assisted living substantially less affordable *and* far less attractive than it has proven to be over the last ten years. Every effort should be made to contain these risks by always assuming the perspective (her needs and preferences) of the consumer and by supporting rigorous research, the results of which can be used to guide policy and dilute the distorting influence of purely anecdotal accounts of bad *or* good outcomes. In the absence of advocacy in support of what older people want and research designed to identify how these preferences can most effectively be met, the combination of media attention on bad outcomes, however unrepresentative of assisted living as a whole, and the efforts of professional groups to assert their regulatory authority could eventually make assisted living indistinguishable from the impersonal, uniform and routinized environments and day-to-day life of most nursing homes.

In our judgment, the research agenda for assisted living should be as comprehensive as possible but with a focus on the following areas, most of which are related to the regulatory and financing issues addressed in this paper.

- We have suggested that assisted living may be an especially appropriate setting for the housing and care of cognitively impaired residents. It is also apparent, however, from the Hawes, Phillips et al. research that cognitive impairment is a major reason for discharge from assisted living and transfer to a nursing home. We need to know more about the kinds of assisted living settings and services that are most effective for the cognitively impaired and that have the greatest potential to allow them to age in place with an adequate quality of life. The research by Zeisel et al. on special care units represents the kinds of research (behavioral outcomes) that we need much more of on this issue. (p. 697)
- We also need much more research on the capacity of assisted living to serve residents with serious healthcare needs, including end-of-life care. This area of research overlaps

with the need to learn more about the utility of negotiated risk contracts and the limits (resident competence, facility capacities, etc.) within which they can be executed.

- Given the documented value of privacy to assisted living residents and the essential role it plays in the rationale for assisted living, we simply cannot accept the assumption that single occupancy is too expensive for the less affluent residents and those who are publicly supported. We need systematic research designed to determine the cost feasibility of private rooms and to identify methods that can be used to maximize their affordability.
- Although the results to date appear to be reassuring, we need more research on the effects of nurse delegation acts, especially in the areas of medication management and care for chronic conditions (colostomy care injections, etc.) that require training and routine supervision. These are contentious issues, as demonstrated by the debates in the Assisted Living Workgroup and they are likely to become increasingly salient as the population of assisted living residents with serious healthcare needs grows and tests the capacity of facilities to allow residents to age-in-place, as many residents would like to do as long as possible.
- In what ways does size matter in assisted living and adult foster care? Does the small size of adult foster homes and five-to-ten bed assisted living facilities provide enough quality-of-life benefits (as reported by residents) to compensate for diminished economies of scale and reduced (potentially) access to more sophisticated forms of healthcare? Should regulatory distinctions be made between larger, better-capitalized facilities and small (mom and pop) facilities?
- Within the next three-to-five years, quantitative quality-of-life measures, based on resident responses and extensive systematic research, need to be developed for use in assisted living and other long-term care programs. Quality of life is not likely to gain parity with quality-of-care regulatory criteria without the development of a set of widely recognized quantitative measures designed to operationalize assisted living goals/values.
- Research of case management demonstration projects should be conducted to determine the efficacy (cost-effectiveness) of case managers as a source of quality assurance (quality of care and life of residents) in assisted living. We have suggested that case managers (care advocates) can be more effective than regulatory surveys in assuring adequate quality in assisted living. This notion needs to be tested and its cost feasibility determined.
- Finally, assisted living should be part of comprehensive evaluations of all long-term care programs, especially those supported by public funds. This means conducting research comparing the risk adjusted (health characteristics, impairment levels, etc.) costs and outcomes (consumer satisfaction with quality of life and care, changes in health conditions and impairment levels, movement to more restrictive settings, etc.) of all home- and community-based programs, including assisted living, adult foster homes and nursing home care. This is difficult research to conduct given current data limitations,

but we can begin by using Medicaid claims data for waiver-funded programs, consumer data collected by states and by conducting surveys.

These are just some of the priorities that should be part of a comprehensive research agenda for assisted living, but they are critical to the development of a more informed debate about the nature and future of assisted living.

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