

ASSISTED LIVING: EVOLVING MODEL FOR A NEW GENERATION
OF ELDERLY

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Good afternoon members of the commission, panelists, audience, and press. Thank you for the opportunity to share some of my thoughts about assisted living. My name is Keren Brown Wilson. Twenty-five years ago when I was working on my PhD, my mother was a stroke victim living in a nursing home. When I told her I had decided on a career in gerontology she asked me a question that changed forever the course of my life. She said: “Why don’t you do something to help people like me.” That question started me on a professional and personal quest to change the face of long-term care in the United States and around the world. In the ensuing years I have been focused on how to normalize the lives of those needing shelter and care. This has led me to a deep interest and involvement in the assisted living movement.

During that time I have been a researcher, university professor, provider of services in for profit and not-for-profit settings, developer of assisted living for more than 10,000 in 16 states, and policy advisor both nationally and internationally. I have also been a consumer of long-term care services in nursing homes, assisted living, and home care. This most recently includes care for my oldest sister who suffers from stroke

related dementia and paralysis. Thus, I have been examining issues associated with Assisted Living from a variety of perspectives for a number of years.

The timing of these hearings for the Federal Trade Commission and the Justice Department could not be better. They come on the heels of a long awaited report issued by the Assisted Living Work Group in April of 2003. This report was developed at the request of the Senate Special Committee on Aging and was the product of a large assortment of constituency groups. During the Senate hearings, testimony was heard regarding the Assisted Living Workgroup's final report. Despite valiant efforts, this report is not likely to provide many answers to questions asking how to help Assisted Living give consumers the kind of long-term care experience they want and deserve. My purpose here today, however, is not to discuss that effort to define and prescribe quality. Rather, it is to confirm that Assisted Living is at a critical crossroads in its development, to suggest some avenues for exploration in the quest for quality, and finally to comment specifically on the questions posed by the Commission.

Background

Assisted Living is at a crossroads (Kane, 2001; Kane & Wilson, 2001). Within a decade the Assisted Living industry has been characterized as both a highly regarded, promising option for long-term care, and publicly criticized as just a dangerous marketing ploy that gives frail elders false hope. Yet among consumers, the consensus remains clear: Assisted Living is an appealing option in the long-term care market that can help elders remain independent (Rosenblatt, 2001; Oser, 2001; AARP, 2003).

As I and others have recounted numerous times in the past 20 years, the philosophy of Assisted Living developed as a response to the desire of older people and their families to avoid nursing homes because they perceive them as place to die, not live. Assisted Living was conceived as offering an alternative environment in which to provide necessary care while acknowledging strongly held values associated with independence, privacy, dignity, choice, and the opportunity to live life as they normally would.

Although Assisted Living experienced rapid growth in a primarily private-pay market, states have begun to implement Medicaid waiver programs and other publicly funded mechanisms with which to make Assisted Living available to individuals eligible for Medicaid. As of 2001, approximately 800,000 persons reside in Assisted Living homes across the nation. Two-thirds of Assisted Living consumers are female, with an average age of 80 years; 81% experiences limitations with an average of 2.25 Activities of Daily Living. Ninety-three percent received help with housekeeping, while 86% received assistance with medications. Approximately half of Assisted Living consumers move into a building from their homes and 28% of Assisted Living residents terminate residency due to death. Estimates suggest that anywhere from 40 to 60% of residents have Alzheimer's disease, or another form of dementia (NCAL, 2001).

The rapid growth of the Assisted Living industry, combined with the growing involvement of Medicaid, have led some to argue that there needs to be greater federal and state and regulatory oversight. There does need to be oversight and I first argued for this in 1988 and later in a report for AARP (1994). But I have watched with increasing alarm the readiness of many to rely upon the

methods used to regulate quality in nursing homes– the very approaches that choked quality of life almost to death in those settings. Thus, I want to take this opportunity to suggest a different approach to address the questions raised before us today.

Challenges Embedded in the Industry

Central to this approach is recognizing and responding to the competing values prevalent in our society when we think about long-term care and Assisted Living (see Table 1). Chiefly among these is autonomy and safety. Noted expert on quality in long-term care, Dr. Robert Applebaum, summed up this dilemma quite nicely when he once said that what we wanted was autonomy for ourselves and safety for those we loved. Consumers and their families, advocates, researchers, policy makers, politicians and providers alike struggle daily with issues of additional safety gained at the risk of personal choice and privacy. Dr. Rosalie Kane, established authority on Assisted Living, has noted a second stressor: individual and community rights may be particularly strained in a collective setting. This is especially so if protecting or extending those rights negatively impacts on the quality of care or quality of life for others. A third area of conflict has been highlighted recently by the severe fiscal constraints states have faced and growing numbers of individuals without adequate resources to pay for needed health related care. Establishing standards and expectations for care in the context of the willingness and ability to pay for needed services is proving a bitter lesson for many. These conflicts are made more difficult by the debate still raging what Assisted Living actually is, and whom it should serve.

Table 1: Competing Societal Values Influencing the Assisted Living Industry In Need of Consideration

Safety vs. Autonomy
Individual Rights vs. Community Rights
Expectations of Standards vs. Ability To Pay
What Assisted Living Is, and Whom it Serves

These conflicting values have played a key role in slowing down the evolution of Assisted Living. Rather than getting caught in the tangled rhetoric of debate, we need a set of approaches that finds a balance within these conflicts. We need to recognize and address issues raised in the 1999 GAO report on Assisted Living that appear to have influenced the hearings today. To do this, we need tools that help us work with consumers, to empower them, and help them get what they want from Assisted Living, in a safe and realistic manner. I have five suggestions to describe for you today to initiate such an exploration.

Recommendations

1. Recognize the value of, and continue to develop, uniform consumer disclosure forms.

First, we should recognize that efforts taken to implement a strategy of using consumer disclosure forms have been a step in the right direction. These efforts were undertaken in response to the 1999 GAO report as it called for written information regarding cost, service agreements, discharge criteria, and grievance procedures provided to consumers before a contract is signed. Many states have developed instruments to assess this information. Industry trade associations such as the Assisted Living Federation

of America (ALFA), American Association Housing and Services for the Aged (AAHSA), and the National Coalition on Assisted Living (NCAL) have largely supported these efforts. I believe this tool can be useful for states to ‘weed out’ sites that are willingly engaging in fraudulent behavior, and help consumers think through their options in an organized manner. But disclosure is not likely to ensure consumers fully understand what they are buying, or answer questions about what will it really cost, how much control they will be able to exercise over their care and their environment, or when they will be told they cannot live any longer where they are.

2. Recognize the benefits of negotiated risk agreements, and continue to develop a mediation process for consumers and providers to address and reconcile disagreements in service delivery decisions.

A second strategy worth further exploration in relation to “aging with choice,” as some have begun to call attempts by consumers to assert their right to age in place and exercise greater decisional autonomy. This strategy calls for investigating the various forms of a negotiated risk process. States such as Michigan, Louisiana, and Texas adopted legislation designed to facilitate this negotiation at one level by saying that consensus reached between physicians, consumers, and providers about designated individuals remaining in Assisted Living could be legally honored. At least 28 states have incorporated negotiated risk language in their regulations governing Assisted Living, recognizing them as potential mechanism to facilitate discussions between consumers and providers when disagreement looms over what the consumer wants and what the provider feels can be accommodated in terms of both autonomy and individual rights.

This approach has been a topic of considerable debate. Some of my colleagues believe negotiated risk to be dangerous, misleading, and serves to protect providers of any liability if harm results from poor quality care. A recent article by Carlson (2004) highlights this anxiety. Unfortunately this article severely misrepresents the positions of persons such as myself and thus adds little to the policy discussion that should be taking place around negotiated risk. But to me what is truly dangerous is the categorical refusal to recognize that quality in the truest sense can never be achieved for frail, disabled and vulnerable consumers if we do not find ways to systematically explore and address how to achieve some sort of consensus about what to do in individual situations to balance conflict around autonomy, individual rights, and benefits as opposed to entitlements.

Some who have written about negotiated risk agreements have stressed underlying issues associated with legal issues (Burgess, 2001; Burgess & Hernandez, 2000; Carder, 2002). But I am more persuaded by Eli Cohen's ethical arguments (Wilson 1994; Cohen 1998) who sees negotiated risk as a process that facilitates systematic discussion of choices, options and consequences. Having a written signed agreement, in my view, should be a mechanism to remind parties of their discussions and agreements. These agreements are signed by both the provider and the consumer, in acknowledgement that a consumer has chosen to continue or discontinue a certain service or care plan even though doing so may result in negative consequences (Burgess, 2001). Consumers agree to accept some responsibility for outcomes that may occur under the agreement stipulations (Carder, 2002).

The guiding principal behind such written agreements is that risk is a natural element of adult life (Lustbader, 2000), and successful negotiations can occur to ensure a higher degree of autonomy for consumers as they exert their rights to make choices concerning their own health care and quality of life (Carder, 2002). This does *not* mean that providers are, or should be, exempt from providing high quality of care. Community standards of care still must be considered and efforts to reduce the likelihood of negative outcomes related to poor quality care must be taken (Wilson, Burgess & Hernandez, 2001).

3. Facilitate and encourage familial advocacy.

A third strategy to utilize is encouraging increased familial advocacy. In my experience nothing keeps providers more on their toes than those family and friends who come often and work collaboratively to address issues or concerns about the quality of care and life of those they love. Assisted Living has created a place that families are much more willing to encourage their elders to use based solely upon the environmental improvements (Kane & Wilson, 2001). What we need to do is make sure it stays that way. Research has shown that family involvement can have beneficial impacts on the quality of life for Assisted Living residents, and can also create positive experiences for the provider as well (Wonita, 2001; Mitchell & Kemp, 2000). By tapping into this resource, and finding ways to motivate and encourage the involvement of families and friends, we can address the controversies of negotiated risk agreements, and ensure a higher degree of quality both for individuals and for others who call Assisted Living home.

4. “Retool” the existing survey process to include Quality of Life measures, and to more accurately represent the findings of surveys.

A fourth strategy involves a “retooling” of the survey process to assess more meaningful, holistic measures of quality. Robert Mollica, in his review of state regulations for Assisted Living (Mollica, 2002), describes the overwhelmingly process-oriented nature of current state survey methods. While antidotal evidence abounds, little empirical information exists about what the actual survey results indicate for Assisted Living. In my own work, the evidence suggests that state survey results seldom address quality of life, and quality of care citations often focus on process measures such as food storage and records documentation (Wilson, 2003).

To complicate the issue even more, the integrity of the severity-rating systems, which classifies how “at-risk” consumers are based upon the citations issued during a survey, are compromised when restricted distribution of scores indicated such scales do not act to discriminate among providers. Further, many times surveys are done in a manner such that appeals of the citations levied against a building often are successful, and are ultimately removed from record. Many accessing such “public” records are not aware of how this process works and may place too much confidence in their accuracy. Yet, to my knowledge, nowhere are consumers made aware of the limitations of such information.

In my view the survey process should be restructured to more accurately measure quality of care and also account for quality of life. Particular attention should be paid to over-reliance on so called quality reports that do not establish more precise parameters.

States should be encouraged to evaluate rigorously the quality of the information they have gathered. Consumers should be encouraged to engage regularly in their own “sensory-test,” evaluating thoughtfully their observations about staff, the environment, and the opinions of those who consume the services.

5. Train family members, consumers, personal advocates, and surveyors to holistically assess quality measures, including quality of care and quality of life.

Finally, a fifth strategy involves more training made available to family members, consumers, personal advocates, and surveyors to more comprehensively assess quality of care and quality of life measures. Perspective residents and their families should have access to information that helps them to become better “sensory surveyors,” to help inform them of what is really happening in a residence. We need to recognize quality of life as an equal component to quality of care and general quality indicators, which means accepting that sometimes, providers will have to make a trade-off between safest procedure, yielding to the needs of consumers that they themselves feel are more important, and for which they are willing to share responsibility. The importance of this recommendation is in the training of consumer advocates and surveyors for a new generation of elders, who won’t be as accepting of regulations that ignore quality of life and their firm belief in the right to continued autonomy in later life.

Answering the Questions Raised

Now that I have expressed some of my views on Assisted Living, and the direction I think it needs to go in, I’d like to touch on the specific questions we were asked to address.

1. What is the nature of the information that is disclosed to such consumers about the cost and quality of the services they will receive?

As I mentioned earlier, many efforts have been made to develop standard consumer disclosure forms, on the behalf of states, as well as trade associations such as ALFA, AAHSA, and NCAL. In the format of a checklist or line-by-line fill-in sheet, these forms direct consumers to ask providers to supply the information included on the form. Form contents are generally focused on: the rate of basic service packages, rates and types of extra services offered, circumstances under which rates may (or will) change, resident rights and responsibilities, and termination or discharge policies. Many versions also include questions concerning staff background and qualifications, how medicine will be handled, and how residents will be monitored, as well as directing the consumer to ask for a copy of the contract before signing it, and suggesting it be reviewed by an elder law expert. Although this is a step in the right direction, there are limitations, as I mentioned before, and I highly advocate for contracts to be written in plain English, so consumers and their families can easily understand them.

Important sources of information for consumer include:

- Personal Referrals/Word-of-Mouth—potentially the most powerful information source influencing consumer decisions regarding Assisted Living
- Information contained within resident agreements/contracts provided by the Residence
- Trade Associations (ALFA, NCAL, AASHA, NAAAA, etc...)
- Quality survey information available to the public
- Advertising/Marketing materials from provider or media
- Better Business Bureau

- Ombudsmen program
- Web-sites

Consumers should recognize the value in consulting multiple sources of information and take advantage of the fact that they have the time to collect the information-if they are willing to do so.

2. Is the type and amount of the information that these facilities provide concerning quality adequate to allow consumers to make well-informed purchasing decisions?

3. If not, what additional information do consumers need or want to make such decisions and why are these facilities not already providing it in the marketplace?

It makes sense to tackle these questions together. To begin answering them, we must first identify what consumers need to make well-informed decisions about Assisted Living. Rosalie Kane suggests that consumers need information regarding the cost of all services and service options, under what conditions these change, when consumers may be asked to leave, and information on what it's *really* like to live in a residence. For example, what rules apply that may not be covered in the contract? Are housecoats prohibited in the dining room? Are pets only allowed within the bounds of a consumer's personal areas? Do direct care workers speak to the consumers when providing care? In other words, what will the daily routine of life look like for potential residents?

Following Kane's suggestions, again the disclosure forms are a step in the right direction. But, this area is where the personal recommendations of current residents become crucial, as do the skills of families and advocates acting as "sensory surveyors." Kane suggests developing a published comparison-chart providing different scenarios (i.e. Assisted

Living, Nursing Homes, Foster Care, etc...) and assessing the differences in what daily routines will be like in each.

In some cases, this information is available; however, many consumers will not or cannot take the time to pre-plan their decision. They may be restricted in options relating to geographic location or ability to pay, and thus, may be in 'crisis mode' thinking. All of these factors may play a part in the decisions that consumers make (for a detailed description, see Maloney, Finn, Bloom, & Andresen, 1996).

Many consumers may also have a preconceived notion of what they want in long-term care; one that just doesn't match the reality of the available options. Rosalie Kane identifies a problem when consumers are unaware of the context in which a specific group of providers exists, such as within the bounds of state regulations, their expectations are not always in sync with what the regulations dictate. For example, California mandates that a provider cannot retain a resident who is unable to leave the building without assistance (NCAL, 2003). Consumers need to be made aware of such stipulations in contracts, in order to ensure they fully understand the conflict between their needs or wants, and the mandated restraints relevant to them. .

Consumers may also ignore vital information that doesn't "fit" in their perception of Assisted Living, such as the rates for services outside of the basic package if they feel that they will never have a need for them. Many times, consumers and their families do not want to think about or plan for declines in old age and thus, are literally unable to comprehend information made available to them in advance. Service planning may be

utilized in conjunction with a form of residency contract negotiation addendums to mediate this situation. By beginning to plan for the future during the time when contracts are first signed helps the provider, consumer, and the consumer's family or personal advocate think about what might happen in the future, in terms of health or financially-related changes.

We should also continue to use existing structures to compile consumer-related issues in Assisted Living. For example, consumer complaint hotlines, Better Business Bureaus, and consumer aides such as Consumer Reports magazine all collect information that could be useful for potential Assisted Living residents. Asking the industry to suggest additional approaches to more effectively use disclosure forms, and steps to make to prevent incidents from occurring, rather than concentrating on what to do after an incident occurs, would also be useful. Perhaps the procedures used in Continuing Care Retirement Communities offer some clues.

4. Does the quantity and quality of the information that consumers would find helpful vary?

No empirical research has been done to assess the actual variance of information available to consumers; however, anecdotal evidence does tend to show a wide range in both the quality and quantity of information available to consumers. For example, a quick search on the internet for "assisted living" results in a barrage of provider homepages, each describing different aspects of their services, and some giving graphics of the residence. Searching a trade association-sponsored database yields similar results; each provider lists different degrees of information. The marketing materials provided by

Assisted Living companies is also varying; some offer detailed descriptions of rates and services available, while others are dominated by sales-pitch slogans aimed at getting consumers in the door to discuss the more detailed matters. According to Rosalie Kane, variation also exists in the information provided to consumers at the time of initial contract signing and what is provided later, as the needs of consumers change.

Minnesota serves as an example of one state that has developed a Task Force to address this issue.

5. What is the state of the art with regard to measures of nursing home and Assisted Living facility quality, whether structure, process, or outcome?

6. What are the risks of relying on (and disclosing) process-based measures of quality?

As I've mentioned before, quality measures in both nursing homes and Assisted Living facilities lack a holistic approach. Rosalie Kane argues that quality of life is not accurately assessed, and does not appear to be a concept of equal weight with measures of quality of care. Measures are overwhelmingly process-based (Mollica, 2002), and focus on issues often of little relevance to the consumer's day-to-day quality of life.

It can, indeed, be risky to rely on these measures. Kane warns of the dangers in disclosing process-based information, as the data can easily be misinterpreted. For example, a citation may be based on an isolated incident that has never before occurred in a residence, or, as previously suggested, the citation may be a mistake of the surveyors, such that people accessing the information have a skewed perception on the true nature of the home. The current survey process also does not identify the context within which the assessments are being done. This becomes a problem for the provider, if, for example, a

high number of residents are reported to have difficulty transferring from a chair to the bathroom; rather than resulting from poor care, the actual cause may be due to the provider's ability to offer services to this type of population, thereby drawing an increased percentage of residents with functional limitations.

Process-based outcomes do not focus on quality of life, nor do they allow for the differences in context and normalization of life. Disclosing information that may be inaccurate, measuring irrelevant issues, and ignoring the global conditions of where it was collected only threatens the ability of the consumer to make a well-informed, appropriate decision about an Assisted Living residence.

7. How would competition on quality measures affect costs, prices, and decisions by payers and customers?

On one hand, competition does often increase "quality" in some very specific ways. For example, the higher amenity level available in Assisted Living residences and the focus on accessibility are generally believed to have raised the environmental standard in general. On the other hand, however, many aspects of quality cost money, and we have a poor record of recognizing that simply calling for better quality without adjusting expectations about increased cost merely shifts attention from one area to another. In others words, *overall* quality doesn't necessarily increase, but we might see improvements in specific areas. Providers, as are many of us when overall capacity to respond is limited by available resources and perceived priorities, are likely to apportion attention in conjunction with where they receive the greatest positive reinforcement such as money and praise or the greatest negative reinforcement such as fines, bans on

admissions or conditions on their licenses. The state of the art related to quality measures is very mixed. Our ability to use them effectively is limited still.

Because many consumers tend to focus only on the services they feel they need, want, or have access to when investigating Assisted Living options, their decisions are likely to be little influenced with competition on quality measures. As providers focus on targeted areas to improve quality, if a consumer isn't interested in examining that particular area, competition information within the industry relating to that area will mean little. This is also likely to be true for consumers in rural settings who may only have one option for an Assisted Living residence or for persons without options due to financial reasons. When you have limited or no choice the only valuable information about what others have is to aid in demands that standards should be raised.

8. How does compensation affect quality?

Evidence throughout relevant literature indicates that increasing compensation to workers alone will not facilitate higher levels of quality. Rather, when used as one of many strategies to encourage staff retention, higher quality can more frequently be attained. More meaningful, however, are findings that indicate higher staff/resident ratios are directly related to quality (Chou, Boldy, & Lee, 2002; Yamada, 2002; Spector & Takada, 1991). Historically, it is difficult in third-party markets to obtain sufficient reimbursement rates to significantly raise wages within Assisted Living. So rather than focus on this one area, efforts should be targeted to investigate other factors associated with staff retention high quality care, and high quality of life.

9. Can compensation be harnessed to enhance the performance of nursing homes and Assisted Living facilities?

Dick Ladd, former head of Oregon's Senior and Peoples with Disability division, has indicated that despite many attempts, few programs aiming to enhance the performance of long-term care facilities have succeeded. One example he has noted is Quality Improvement Project (QIP), which was created in an attempt to focus providers on providing higher levels of quality in areas found to be less than desirable. But rather than achieving high quality, providers involved in the project viewed it more as a punishment, with no incentives to actually produce higher levels of quality. He noted some current efforts that have recently begun for which the results are not yet known.

One suggested approach for Assisted Living that might be worth exploring focuses on developing a targeting system that rewards buildings with public recognition, for providing outstanding work. This concept would reinforce prevention of poor quality experiences, and seek to combat the often-inaccurate information portrayed to consumers in the survey process.

Conclusions

We must recognize and address the competing values held in our society about long-term care. In Assisted Living, we need to strive for a balance within them, and acknowledge that in some cases, one or the other will be of more importance. We do this at the risk of sacrificing aspects in quality of care, for aspects in quality of life that really matter to holistic consumer satisfaction. Rather than repeating the mistakes of the past in trying to improve the quality of nursing homes, we should try new approaches, and

reinforce those that we know work, such as evolving negotiated risk agreements, encouraging familial advocacy, and restructuring the survey process. The challenges confronting Assisted Living cannot be reconciled through strict imposition of further process-oriented regulations, such as those developed for nursing homes; rather, we need to work to develop tools that center on the consumer, and what consumers were looking for as they have flocked to Assisted Living over the past decade.

Thank you for the opportunity to speak about these issues.

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