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Assisted Living as a Long-Term Care Option: Transition, Continuity, and Community

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research

EXECUTIVE SUMMARY



Report of research funded by the AARP Foundation through a
subcontract from the Assisted Living Research Institute.

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May 2004

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The objectives of this special study are: to determine how assisted living settings affect continuity of meaningful resident roles and activities; and to identify facilitators, barriers, and best practices in maximizing resident involvement with community and family; and identify mechanisms that promote continuity of meaningful activity.

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Acknowledgements

The Assisted Living Research Institute wishes to thank the AARP Foundation for its support of this important project. We also want to acknowledge the innovative work that Dr. Rosalie Kane and her team at the Division of Health Services Research, Policy & Administration, School of Public Health, University of Minnesota, have been doing in the field of assisted living and community-based care for more than two decades.

This report is the second publication by the Assisted Living Research Institute (formerly the International Assisted Living Foundation). Without the support of our volunteer Board of Directors, and of the Assisted Living Federation of America's Judy Hagaman and Geoff Camphire, who continue to provide exemplary administrative support, this report would not have been possible. We are confident that this research will add to the growing body of knowledge available to consumers and providers as assisted living seeks to continue meeting the needs of older Americans.

Respectfully submitted,

Joan Hyde, Ph.D.
Chair, Board of Directors
Assisted Living Research Institute





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INTRODUCTION

Assisted living could open the door to achieving what is possible and desirable in the daily lives of people receiving long-term care. In this monograph we report on studies that help us understand the circumstances surrounding moving in and out of assisted living and about consumers' preferences in that regard. We also report on efforts to establish vibrant communities within assisted living while enhancing individuality for assisted living residents.

Assisted living programs are feeling their way as to how assisted living can create internal communities and what they can do to assist residents to be part of their community of origin. Little is known about how residents themselves think about their relationships with either the internal or external community after they move to assisted living and about how providers view possibilities for enhancing community in either sense. Do residents want to leave the assisted living premises and take more vigorous part in communal and family life? Do residents want to create a new society of friends and activities in the assisted living setting? How highly does the resident value continuity, and how possible is it for him or her to achieve continuity with past interests and preferences? If, as one might suspect, resident preferences vary, what affects a resident's attitude? If opportunities vary from one assisted living program to another, what can we learn about the successes and imaginative efforts made by programs in some communities?

We perceive that issues of transition, continuity, and community are all linked with each other and together deal with basic questions about what kind of entity an assisted living setting is and what life in an assisted living setting can and should be. With funding from the Andrus-AARP Foundation, we were able to use a variety of quantitative and qualitative techniques to explore this topic.

ABOUT THE STUDY

This report is based on data collected from executive directors of assisted living residences about what they do as well as secondary analysis of data during other studies done at the University of Minnesota. Together these studies answer some questions that we think are particularly important to assisted living consumers and providers about what assisted living residents need and want to foster continuity and community, what they are doing to meet those needs, and the obstacles they face in doing so.

ANALYSIS OF EXISTING DATA

First we looked at what the data from prior studies tells us about how residents and providers think about continuity and community. In one of our prior studies, 60 assisted living directors and 337 residents were asked open-ended questions about the kinds of things their assisted living residence does to promote continuity and community. This kind of survey is important because it gives us information about how people think about their experiences so that we can ask more focused questions in the future.

RESIDENTS

As expected, residents made a range of comments about their experiences in assisted living. Those who moved from nursing homes had many more positive comparisons to make than those who moved from their own home. Also relevant was whether the resident had moved to a new town or city concurrently with moving to assisted living. Moves to new communities often occurred when residents moved to be closer to family.

Negative changes related to the move to assisted living tended to center on the smaller size of the new home and reduced freedom. Those who moved to a new town, in particular, experienced losses in friendships. Residents referred to loss of freedoms as well, and many of their verbatim quotations were variants of the comment that “there’s



no place like home,” meaning their former homes. Some residents had as a frame of reference homes that they had occupied, sometimes with a spouse, for many years.

Positive changes because of the move to assisted living included the increase in companionship, the availability of visits with family and friends, increased sense of security, and availability of help with housekeeping and daily tasks. In terms of continuity, many residents referred to things they had brought with them to the assisted living building. Said one resident, “A lot of memories on my walls here. This is all my furniture. It is just like my home was. Home is where you are.” One male resident, who felt life was much better in the assisted living setting, said, “Everything is much better. Meals are prepared, and I don’t have to cook anything.”

Answers about continuity in activity and pastimes and starting new activities and interests varied a great deal. Some residents previously had extensive recreational and community interests, including civic involvement, religious leadership, and traveling. Residents often had given up activities and interests important to them for health reasons well before moving to an assisted living setting. A few residents had identified new interests, and some continued with old interests, especially solo hobbies. Some residents, especially men, connected their loss of career with their loss of community. One resident said, “It is difficult [now] to see my friends. I was a pharmacist, and I owned my own pharmacy. So, I had lots of socialization attached to the profession.”

We did summary ratings of whether residents felt part of the assisted living community based on their responses to all questions. Almost half (49%) of residents who gave responses suggested that they did feel very much a part of the assisted living community, 29% suggested they felt alienated from or not a part of the community, and the remaining 22% gave answers that were mixed and did not fall neatly into categories.

On the negative side, sometimes residents themselves kept away from the community as a self-protection. For example, one said, “I don’t always try to make new friends here because they either die or go to a nursing home.” Those who were positive often cited very particular topics. For example, one resident who perceived she experienced life continuity and felt a part of the assisted living community said, “I am a button collector. I used to go to button shows. Now the activities director comes and

asks me my opinion on the art activities because I was an artist. I appreciate that.” Other residents discussed the dining experience as a positive social time that brought their community together. As a resident said, “I have friends in the dining room. They are so nice. I sit with them all the time. It makes me feel good that they like me. I like it here.” But some residents had less positive feelings and spoke of being excluded or left alone.

Similarly, we made summary ratings of residents’ ability to maintain relationships with family and the greater community. We rated 59% as believing they readily were able to maintain meaningful external relationships; 21% were rated as feeling they were unable to maintain those relationships; and 20% gave responses that were mixed. Perceived barriers to maintaining community networks included distance from family and friends, transportation problems for family and friends, and residents’ own health or that of members of their social network. One resident said, “It is easy because we live close, one mile. That is why we selected this place.” Another resident said, “It is easy because all of my family are close, very fortunate. I am a lucky guy. I have lots of money, and I need it to take care of myself.” One resident talked about the frequency with which his son visits, and how important this is to him. He said, “[It is] easy because my son visits me daily, sometimes only for 10 to 15 minutes, but every day.” Family was overwhelmingly the focus for meaningful social relationships and community connections.

Executive director responses in early studies were quite consistent in the way they articulated ideal roles for families. They tended to perceive that families have a responsibility to visit, take residents out for meals and appointments, and run errands for residents. By and large, administrators wanted to encourage family interaction and communication at the outset and throughout the stay. Assisted living providers located in retirement areas were more challenged to help residents maintain contact with some long-distance family members.



Executive directors' main approach to community involvement was to bring community groups, particularly youth groups and religious groups, into the assisted living setting. Less emphasis was given to helping individual residents maintain their own contacts in the community. Group outings for shopping and seasonal community events were common. Volunteer activity tended to be at a low level. Sometimes administrators provided a setting for community meetings, but this tended to be done to foster community awareness of assisted living rather than benefit residents by identifying groups they might attend. These limited data helped the research team develop more in-depth questions for the Andrus-funded study.

Respondents believed that an understanding of how assisted living and nursing homes differ was an important precursor to community involvement. As part of this, some respondents commented that members of the community need to know not only how the assisted living program serves elders, but also how it can serve the community at large.

ANDRUS-FUNDED SURVEY OF ASSISTED LIVING ADMINISTRATORS ADMINISTRATOR SURVEY

We undertook a special survey of assisted living administrators to obtain a broader view of the way programs create community within residences' boundaries and become integrated into the larger community. The main objectives of this special study were to determine how assisted living settings affect continuity of meaningful resident roles and activities and to identify facilitators, barriers, and best practices in maximizing resident involvement with community and family and continuity of meaningful activity.

Building on the findings reported from the national study, which included resident responses, the Andrus survey sought to determine the extent to which residents in responding facilities were integrated into the facility community and into the larger community, respondents' perceptions of what facilitated or impeded such integration, and strategies that respondents used to increase community involvement of both types.

For this research, a sample of 64 assisted living settings was selected from the membership list of the Assisted Living Federation of America (ALFA), based on

discussions with ALFA and experts on state assisted living policy: we sought states that reflected some variety in assisted living policy and that were evolving rapidly in terms of increasing ALFA membership.



DESCRIPTION OF SAMPLE

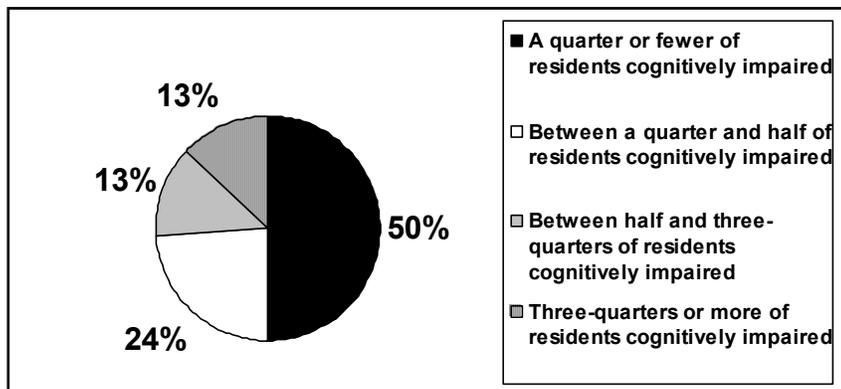
Length of time that the residence had been in operation	<ul style="list-style-type: none"> • 39 years to just opened (less than 1 year)
Length of time the executive director had worked at the residence	<ul style="list-style-type: none"> • 96 months to 5 months
Location of residence	<ul style="list-style-type: none"> • 50% Urban • 20 % Suburban • 30% Rural
Number of units per residence	<ul style="list-style-type: none"> • 8 units to 183 units (mean of 62 units)
Number of residents per residence	<ul style="list-style-type: none"> • 7 residents to 365 residents (mean of 63 residents)
Type of residence	<ul style="list-style-type: none"> • 80% For-profit • 70% Part of a chain
Activities staff	<ul style="list-style-type: none"> • 95% had dedicated activities staff (average 45 hours/week of activities staff time)

About half (51%) of the assisted living residences were comprised of a majority of private rooms with their own bathrooms not shared unless by clear choice, and 22% had a preponderance of shared rooms and bathrooms. None were comprised solely of shared rooms and/or bathrooms. Five percent had some different configuration, including private rooms without baths, shared houses where each resident had his or her

own room and common areas such as the kitchen and family room were shared, and private studio apartments with bathrooms but very minimal kitchenettes.

Administrators were asked to estimate what share of their current residents were cognitively impaired, a factor that we thought would be related to the results. About 50% said that a quarter or fewer were cognitively impaired, about 24% estimated that the proportion was between a quarter and half of residents, about 13% estimated between half and three-quarters of residents, and about 13% said three-quarters or more were cognitively impaired.

Chart 1: Share of Administrators Reporting Residents Cognitively Impaired



FINDINGS

Respondents were asked to rate the likelihood of their residents using a variety of ways to remain involved with activities and relationships with the outside community. *Table 1* shows these results. The top three responses for this question (calculated by combining the top likelihood ratings of 4 and 5) were having family or friends as visitors (92%), going out with family or friends for day trips (81%), and having family or friends as guests for meals (72%). Rarely seen were other choices such as residents continuing active participation in their own church or civic organizations, residents participating in volunteer activities outside the assisted living setting, residents taking walks in the neighborhood, Internet or email communication, vacations and travel away from the assisted living residence, political or social action beyond voting,

and maintaining some paid employment. Occasionally, respondents gave examples of such activities, but they were the exception for their residents.



Table 1: Ways Residents Maintain Relationships with the External Community

Ways residents might maintain relationships with external community	Unlikely<<<<>>>>Likely Percent of Administrators (N=64)				
	1	2	3	4	5
Having family or friends as visitors at the residence.	0	0	7	22	70
Going out with family or friends for day trips.	0	2	16	22	59
Having family and friends as guests for meals at the facility.	0	8	21	18	54
Phone communication with people outside the facility.	5	10	22	24	40
Going on community trips arranged by assisted living.	6	6	24	25	38
Active participation in outside church or religious organizations.	14	10	37	21	19
Taking walks in neighborhood.	11	22	38	14	14
Internet/e-mail communication.	59	21	8	3	10
Active participation in clubs or organizations in the community.	21	22	33	21	3
Participating in volunteer activities outside.	43	30	13	11	3
Being involved in political or social action activity (beyond voting).	60	29	3	3	3
Participating in work activities outside.	86	13	0	2	0
Traveling/vacation away from assisted living facility.	32	29	21	18	2

Note: Responses may not add exactly to 100% because of rounding.

Using the same five-point scale, the top three ways that residents form ties with the internal community, in the view of respondents, were socializing at congregate meals (97%), forming friendships with residents and staff members (86%), and participating in organized activities at the residence (83%). Resident-initiated socialization with other residents outside meals was less likely (see *Table 2*). Respondents were asked to rate the importance of barriers to involvement in the external (*Table 3*) and internal (*Table 4*) communities, then rank the top three barriers, including any additional barriers they might suggest. The most frequently cited barrier to involvement in the larger community was lack of resident interest. Respondents did not



believe that residents being new to the area and without community ties figured largely as a barrier. They also discounted liability concerns as a relevant barrier. The most frequently cited and most highly ranked barrier to resident involvement in the internal community was that residents have many individual interests and stay busy in their own rooms or apartments. Respondents did not often say that residents might feel they had little in common with other residents, rating that possibility low as a barrier.

Table 2: Ways Residents Might Be Integrated into Internal Assisted Living Community

Ways residents might be integrated into internal assisted living community	Unlikely<<<<>>>> Likely % Administrators (N=64)				
	1	2	3	4	5
Socializing at congregate meals at the assisted living residence.	0	2	2	24	73
Participating in organized activities at (name of facility).	0	2	16	33	50
Participating in religious services at the assisted living facility.	5	3	14	30	48
Forming friendships with residents and staff members at (name of facility).	0	2	13	46	40
Individually initiated socializing with other residents (not previously closely known to the resident).	3	8	40	29	27
Socializing with family or friends who also live at (name of facility).	11	6	33	30	19
Becoming active in assisted living community governance, such as resident councils, committees, and the like.	16	19	37	16	13
Having other residents as guests in resident's rooms or apartments.	6	19	38	25	11
Being a volunteer for the assisted living community.	24	27	30	16	3

Note: Responses may not add exactly to 100% because of rounding.

Table 3: Administrator Perception of Barriers to Resident Involvement in External Community

Perceived barrier to involvement with outside community	Not a Major Barrier <<<>> Major Barrier % Administrators (N=64)				
	1	2	3	4	5
Transportation problems.	35	22	14	11	18
Resident not interested.	6	16	37	25	16
Resident too sick or frail.	8	27	40	13	13
Resident too cognitively impaired.	21	22	35	11	11
Family unavailable or unwilling to assist.	21	35	19	18	8
Liability concerns.	67	14	14	0	5
Resident severed community ties.	33	19	27	18	3
Resident new to geographic area.	54	25	18	3	0

Note: Responses may not add exactly to 100% because of rounding.

Table 4: Administrator Perception of Barriers to Resident Involvement in Internal Community

Perceived barrier to community involvement inside residence	Least Important<<<>> Most Important % Administrators (N=64)				
	1	2	3	4	5
Resident has individual interests.	14	11	29	30	16
Resident too sick or frail.	19	40	30	5	6
Resident too cognitively impaired.	25	33	30	8	3
No interest in group activities.	8	25	30	33	3
Resident feels other residents are too impaired or nothing in common with them.	22	32	27	18	2

Note: Responses may not add exactly to 100% because of rounding.

Administrators also were asked about strategies used in their residence to promote external involvement for residents (**Table 5**) and resident involvement in the internal community (**Table 6**). The top three actions providers used (chosen from our list of actions that providers used “a lot”) to assist their residents in participating in the external community were encouraging families to visit at any time (97%), assessing resident interests and making care plans concerning interests (89%), and organizing events that include residents’ families or friends (81%).



Table 5: Policies and Practices to Foster Involvement with External Community

Strategy to promote resident involvement with external community	Extent used (% administrators)			
	Not at all	A little	Some	A lot
Encourage families to visit at any time.	0	0	3	97
Assess residents' interests and make care plans to help them continue with these interests.	2	2	8	89
Provide events that include residents' family or friends.	5	0	19	81
Inform residents via newsletter and/or discussion about current events and issues in the larger community.	5	8	18	68
Provide residents with transportation to shopping areas.	14	5	22	59
Encourage outside groups to meet at (name of facility).	8	8	31	52
Make community involvement a strong part of your mission statement and training of personnel.	5	11	41	43
Have a bookmobile or library for larger community co-located on premises.	32	3	22	43
Provide transportation to community events.	10	16	33	41
Provide/arrange non-medical transportation on an individual basis.	13	21	40	27
Organize enjoyable spaces and things for children who visit.	5	16	54	25
Encourage residents to use public transportation.	51	13	18	19
Use a negotiated risk process so residents can take informed risk in apartment and other locations to pursue their own interests.	45	15	23	15
Have preschool, after-school, or youth groups meet on premises.	19	25	43	13
Use residents as a group to do community projects or fund-raising.	35	33	21	12
Provide escort on one-to-one basis for residents to go into the community.	18	37	35	11
Learn and build on residents' former employment.	18	51	21	11
Encourage residents to become volunteers.	26	26	37	11
Affiliate with universities, community colleges, or other education programs for resident adult education.	66	8	18	8
Use the assisted living facility as a polling station.	87	5	2	3

Note: Responses may not add exactly to 100% because of rounding.

Providing transportation to the outside community was a fairly common strategy, though only 59% provided transportation to shopping areas “a lot,” and only 41% provided transportation to community events “a lot.” Less common strategies were escort provided for one-on-one community activity, affiliation with college or educational programs to provide stimulation, and negotiated risk process to allow residents to pursue interests in the community. The latter finding is consistent with the earlier reported finding that respondents did not perceive liability concerns as a barrier to community participation (see *Table 4*).

The top two actions that providers reported using to assist their residents in participating within the assisted living setting were assessing individual resident interests and preferences and tailoring the individual’s plan to those preferences (87%) and using newsletters, posters, and other communications to inform residents of upcoming activities (83%). For the third-ranking strategy, 57% said that they tried a lot to foster friendships among residents whom they thought might be congenial with each other. Much less attention was given to other possible strategies, such as facility-initiated efforts helping residents entertain in their own room or apartment and arranging for groups with which a resident is affiliated to meet at the facility so the resident could be involved. We also asked respondents to indicate the extent to which they agreed or disagreed with five philosophical statements about assisted living (*Table 7*). Respondents very strongly endorsed the statement that assisted living should foster an internal community of residents because the assisted living setting is now their community; 67% strongly agreed, and the rest agreed.



Table 6: Policy and Practices to Foster Resident Involvement with Internal Community

Strategy to promote resident involvement with internal assisted living community	Extent used (% administrators)			
	Not at all	A little	Some	A lot
Assess individual resident interests and preferences and tailor the individual's plan to those preferences.	2	0	11	87
Use newsletters, posters, and other communications to inform residents of upcoming activities.	0	3	14	83
Deliberately help residents become acquainted with other residents who might be particularly congenial.	0	5	38	57
Plan group activities around specific interests and skills of current resident(s).	2	5	43	51
Do individualized reminders of upcoming activities and encourage residents to participate.	2	2	46	51
Encourage community groups to use space in facility for meetings likely to be of interest to some residents.	16	21	35	29
Facilitate residents' entertaining in own room or apartment (e.g., helping guests get there or with set up).	21	65	30	14

Note: Responses may not add exactly to 100% because of rounding.

Table 7: Respondents' Personal Philosophy on Assisted Living and Community

Statement presented to respondents	Percentage Agreeing or Disagreeing				
	Strongly Disagree	Disagree	Neither	Agree	Strongly Agree
To assist in continuity for residents, assisted living programs must communicate clearly how they differ from nursing homes.	0	0	3	24	73
Assisted living should try to foster an internal community of residents because this is largely a resident's community.	0	0	0	33	67
An assisted living community should develop a program with volunteers from outside the assisted living program.	0	0	5	44	51
Assisted living programs should try hard to encourage residents to get or stay involved in outside community.	2	3	10	36	49
Assisted living staff should emphasize achieving individual resident goals and preferences more than establishing an internal community.	0	11	18	48	24

Note: Responses may not add exactly to 100% because of rounding.

Respondents were more guarded about their opinions though still in favor of the proposition that the assisted living setting should try hard to encourage resident involvement in the external community, with 49% strongly agreeing, 36% agreeing, 10% neutral, and 5% disagreeing. One of the statements dealt with the tension between individual and group goals within assisted living. To the statement that the assisted living should emphasize achieving individual resident goals and preferences over and above establishing an internal community in the assisted living residence, 72% agreed, and a third of those agreed strongly. The respondents strongly endorsed the idea that an assisted living community needs to clearly establish its differences from nursing homes to promote continuity for the resident.

OPEN-ENDED RESPONSES

Responses to open-ended questions on assisted living programs and their larger communities varied widely in focus as well as specific content. About half of respondents discussed key elements that they felt promote continuity for residents who live in an assisted living residence. The other half provided specific details about what they saw as positive practices that work well with their assisted living programs.

We identified six categories under which we classified open-ended responses: staff or administration; family or friends; resident interest or choice; public and professional awareness; geographic location; and safety concerns. The quotations provided in each section are illustrative rather than a complete list of comments.

Respondents shared their ideas about practices to maintain continuity that worked well for their assisted living programs. One respondent mentioned that residents typically choose their assisted living setting to remain near home. Community is important for some individuals' identity, and remaining in the community where they may have raised their children or worked provides security and continuity in their lives, even when their living arrangements might be changing. However, many respondents also remarked on older people who move across the country when moving into an assisted living residence to be closer to family, especially adult children. Such people have obviously severed their community ties and literally changed their community

before moving to the facility. Thus, it is more difficult to involve them with the external community when they have no roots in that community. Therefore, it could be possible that internal community becomes more salient to the people who have few or no ties to the nearby outside community. Respondents did not seem hopeful about stimulating such ties if they did not arise out of a long history. One respondent spoke of residents who were bound to meet a friend whenever they went on a shopping excursion, but such experiences flowed from being a part of the community over a period of time.

Administration and Staff

The role of the administrator and other staff in establishing community connections was emphasized. An issue mentioned several times was that one or more people needed to take responsibility for continuing the community relationship between the residents and their community. Respondents either commented that they had taken on or assigned that responsibility or reflected the problem in having it be “nobody’s job”:

- “A staff that makes community connection a priority is key.”
- “Administrators and staff must be involved in community, looking for connections and opportunities.”
- “It is the administrator’s job to make contacts and stay connected in the community. If we are good citizens, then people and organizations will be more likely to include us.”
- “Longevity of staff is key. Staff is then more apt to bring in their church or social groups or invite residents out to events.”
- “Management and staff just need to be very conscious of residents’ backgrounds and cultural elements of the community. Christian traditions are very strong, so we organize a lot activities around church groups who come in.”
- “Management must do their homework about the community and stay connected with leaders, clergy, business owners, etc. That keeps program staff involved and helps residents stay connected.”

- “[It is] very important that staff make the effort to keep residents connected to groups they were previously involved with. We can also accomplish a lot by reminding outside groups to check in on members who are now living here.”
- “It is primarily the director’s job to promote relationships with the community so they know who we are and residents can stay involved. This is a big part of maintaining quality of life.”

Family and Friends

In the view of administrators, family and friends have an important role with continuity and external community interactions of assisted living residents:

- “Involving family and friends needs to be stressed. That is the key to success — changes the feeling of the place, makes it home. Our families are as important as our residents.”
- “Very important that residents understand how we differ from nursing homes, so they are willing to be involved in activities. Also, support from families is critical.”

This emphasis was so strong that it raised questions about the fate of those residents with no engaged family or friends.

Resident Choice

Respondents commented on how residents should have a voice or choice as to what they do and be able to decline participation in both internal and external programs. For example, one provider stated, “I believe that activities are important both inside and outside [the assisted living residence]. However, I have found most are not interested in going out and would rather stay inside the facility. I try to bring the community in to them because they are more comfortable with that.” Another provider commented that the individuality of residents is important with maintaining activities. She said, “We find that most of our residents are happy doing their own thing. Those who were active

in outside activities before coming to the assisted living program continue to maintain those connections on their own.”

Inside the Assisted Living Residence

- “Every day at 2:30 p.m., we have a coffee social. Residents get coffee and get together to visit. It has been very successful. [As the activities director] I know exactly what residents want in their coffee. Residents also like community rides.”
- “A band comes to play once a month. The library comes to read to [the residents]. . . . Pet therapy, visiting employees can bring pets in. The residents like to be involved with the daily routines of the house.”

Outside the Assisted Living Setting

- “Art classes in the outside community, physical therapy/wellness program, casino trips, trips to mountains, meals on wheels, and nursing homes. Help run exercise program, cooking classes, and crochet class. Most interests are already part of the program.”
- “These, like other issues, are only important if residents are interested. We are not here to make choices for them.”

Community Awareness

Respondents believed that an understanding of how assisted living and nursing homes differ was an important precursor to community involvement. As part of this, some respondents commented that members of the community need to know not only how the assisted living program serves elders, but also how it can serve the community at large. Several respondents felt education about assisted living is necessary for the community to understand and accept the building as a space in the community and recognize what that building and staff can offer to the greater community. Many of the

comments here are rather general, although some responses emphasize what people in the community need to understand about assisted living rather than what it can offer:

- “Community awareness is very important. It is the program’s responsibility to make the program a known entity that is connected to the community.”
- “In Oregon [where respondent previously ran an assisted living facility], we had a grant to take residents to schools to care for babies while the mother works on her high school degree. Another location has set up programs where college students would come in to get stories about the depression.”
- “We need to make sure the community as a whole understands what [assisted living] is. Especially the professional people [such as doctors and social workers] about the abilities and capabilities of the assisted living and its roles for the elderly population.”
- “Enhance the education of the general public on how the public should interact with dementia. Everyone thinks this disease is terrible, but [residents with dementia] can benefit from and enjoy normal activity with minimal changes on the part of normal people in the community. For example, people ask questions to dementia people they really wouldn’t ask someone who doesn’t have an illness. Don’t ask, ‘Do you remember me?’ More education on assisted living in all realms. Health professionals and the general public need to understand what assisted living can do and provide. People don’t want to think about aging. They don’t want to discuss it or plan for it.”
- “Education of residents, facilities, communities of differences from nursing homes. More assisted living needed for 18-55 population. Additional federal funding, escalating healthcare, high medical needs of residents has exceeded expectations.”

Location

The rural or urban location of the assisted living program and other local variations made a difference in what could be done to facilitate community involvement. Many of our respondents had worked in assisted living settings in a variety of localities and were able to draw comparisons. Also, respondents at some facilities that were part of a campus felt that the grounds and amenities of the campus were so superb that a resident would not need or want to take a walk outside its boundaries or seek out community experiences:

- “Easier in the urban area or metropolitan area. Harder in rural area, there are less opportunities to continue what they did. But in rural there is more personal touch. [Assisted living] communities need to be customized to the clientele.”
- “In a small rural community like this, there is not a great deal to choose from in terms of community activities. They revolve around church and school for the most part, and we already have a strong relationship there.”
- “[There is a] nature reserve in our backyard, [and] deer come onto the property. Independent living has been around since 1910 for various reasons, it was a TB solarium therefore, it’s part of the community.”
- “Philadelphia [has] lots of transportation, volunteers and activities. A lot of donations in the form of tickets. Residents have AIDS. Many are addicts, poor, and have never had jobs. Some have never even seen the ocean before.”
- “That is one of the reasons residents choose a program close to home, so they can stay connected to their community.”

Safety Concerns

Although safety issues were not emphasized in the closed-ended ratings, comments did show that safety was not too far from respondents' thoughts:

- “The first responsibility is to make residents feel safe and comfortable in a homelike environment, then to encourage them to maintain community ties.”
- “Secured building, significant impairment is quite limiting in what they can offer. Residents can't go out on their own. They don't remember their community ties.”

CONCLUSIONS

The findings reviewed here suggest that assisted living is fulfilling some of its promise in optimizing normal life for its often highly disabled elderly residents.

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The findings also offer suggested approaches that assisted living providers might undertake to meet the needs of their residents. In particular, it appears that individualization of social programming for all residents would be helpful. And those residents who have relocated geographically to be near family may need additional opportunities for involvement in the external community. Moreover, a wider range of strategies is available than are generally used to promote community involvement within assisted living and in the larger community, so as to promote individual fulfillment for assisted living residents.

The multiple components of this study suggest that residents are selecting assisted living, or their families are selecting it on their behalf, with a desire to achieve a normal life experience while getting necessary help, care, and protection. Family and friendship configurations for assisted living are varied but tend to be present; and most assisted living residents have a lot of contact with family members.

Community involvement, we conclude, is a rather vague concept in assisted living. It is sometimes blurred with family involvement, a related but different topic. The development of a vigorous internal community is sometimes at odds with an emphasis on the individual and his or her own interests. Certainly, the data from both prior studies and this one suggest that residents are not highly interested in organized activities, and this finding supports an individual emphasis.

From an executive director's perspective, it appeared that developing cohesion and integration into the internal community was a more important goal than maintaining resident contacts with the external community. Moreover, a high respect for individual preference was reflected in the responses. On the other hand, the activities reported by administrators in the Andrus study, with few exceptions, did not involve very much individualized programming. Individualized programming was relegated to family, and facilities did make efforts to keep families engaged.

Some residents' comments suggested that little things meant a lot to them, that the ability to carry on their previous interests or have their things around them made them happy, and that they were very saddened by losses (such as loss of gardening privileges or the inability to keep a cat). It is possible that assisted living programs can be more active in promoting these positive effects and avoiding negative ones. It seems that the development of partnerships between assisted living programs and other entities in the community is in its infancy. Administrators believe such collaboration is impeded by lack of popular understanding about assisted living, though ways to best define and present assisted living were not really suggested. This entire arena seems a fruitful one for continuing research.

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