U.S. Department of Health and Human Services
Assistant Secretary for Planning and Evaluation
Office of Disability, Aging and Long-Term Care Policy

FAMILY MEMBERS' VIEWS:

WHAT IS QUALITY IN ASSISTED LIVING FACILITIES PROVIDING CARE TO PEOPLE WITH DEMENTIA?

February 1997

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FAMILY MEMBERS' VIEWS: What is Quality in Assisted Living Facilities Providing Care to People with Dementia?

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EXECUTIVE SUMMARY

Assisted living facilities are a rapidly expanding source of supportive housing with services that are increasingly being marketed as a source of long-term care for people with Alzheimer's disease and other dementias. In the view of many, such facilities represent a promising new philosophy and model of long-term care, one that blurs the sharp and invidious distinction between nursing homes and community-based long-term care and reduces the chasm between receiving long-term care in one's own home and an institution because of their emphasis on consumer-directed care.

For families with a loved one who has Alzheimer's disease or other dementia, assisted living facilities hold out significant promise. First, assisted living facilities are thought to provide oversight, supervision, and assistance with personal care for persons with cognitive impairment but to do so in a less regimented and more "normal" or homelike setting than is found in many nursing homes. Thus, residents may live in apartments or rooms in which they have their own personal furniture and other possessions and which look less like a traditional health care facility. Second, assisted living facilities may provide a more appropriate level of care than a nursing home would for persons with cognitive impairment who are still without significant limitations in the activities of daily living (ADLs). Thus, for example, elders who need help with medications, supervision for safety, and help with only bathing and dressing may be more appropriately cared for in assisted living facilities than in nursing homes which typically house residents who have greater levels of ADL limitations and who need daily nursing care or oversight. Third, assisted living facilities provide an environment in which family members could live with the loved one who requires more care and supervision than the family member could reasonably provide in their own homes. Finally, many assisted living facilities offer families the possibility that their loved one can "age in place." Thus, families often expect that the facilities will adjust their care patterns and service provision to meet the changing needs of the loved one with Alzheimer's or another dementia.

Despite this growing interest in and use of assisted living, relatively little is known about the role and performance of assisted living facilities and the degree to which they represent a viable option for family members and elders with dementia. In order to facilitate more effective studies of quality of care in assisted living facilities and to generate information that will help families and elders make more informed choices, the Alzheimer's Association authorized a study by Research Triangle Institute (RTI) of how family members define quality when a loved one with dementia is in an assisted living facility. In the **Executive Summary**, we summarize the major study findings. In the full paper that follows, we report greater detail on the study methods and provide more quotes from family members that illustrate the main points they made about what "quality" is in assisted living.

Study Goals

The report describes the implementation and findings of six focus groups conducted for the Alzheimer's Association. The focus groups consisted of family members of persons with dementia who were living in or had recently been discharged from an assisted living facility. Our goal in convening these groups was to use the information provided by family members to help define quality in assisted living from the consumer's perspective. Specifically, we wanted family members to share their experiences and insights about assisted living and quality. Using that information, we plan to generate a series of quality measures that will be used in a larger study of assisted living.

Study Methods

The focus group method, one well-known qualitative approach to collecting data, seemed best suited to our analytic needs. Focus groups were used in this project because of their ability to provide insight into family members' experiences and feelings, the group dynamics around quality and care issues, and social norms about caregiving for persons with dementia. Further, they allowed us to elicit feedback from participants about specific program features or elements of quality they might mention. Finally, as suggested by their widespread use in market research, focus groups are enormously effective in helping determine what a particular population wants or might like to have. This is precisely the situation that obtained in the Alzheimer's Association study.

We felt that it was appropriate to ask families to help us define quality for persons with dementia for several reasons. Family members are often regarded as the most appropriate informant about quality issues for persons who are unable (or presumed unable) to provide direct information about their care. While there is evidence which suggests family members' views about what is most important may differ from that of the direct care recipients, there is also recognition of the validity of family views and opinions.

- First, for persons with cognitive impairment, families have often provided care themselves and have knowledge about the challenges involved and what it takes to provide adequate care. Thus, they have a practical knowledge base for their opinions.

- Second, they typically make key care decisions for relatives with cognitive impairment, including placement decisions. Thus, their views of what is high or low quality helps determine which assisted living facility is selected for someone with dementia.

- Third, they are often in a position to observe both direct care provision and also the consequences of care. Thus, they have relevant information.

- Finally, most family members retain ties of affection and concern to the relative in a facility. Thus, they are typically regarded as a legitimate informant about the quality of the loved one's care.

Given these factors, we felt that family members' view about assisted living and quality were a valid starting point for developing improved quality measures. Thus, we conducted six focus group sessions with family members in five sites:

- Chicago, Illinois
- Northern Virginia
- Cleveland, Ohio
- Boston, Massachusetts
- Portland, Oregon

Participants were recruited by the local chapters of the Alzheimer's Associations, who also provided substantial additional assistance in setting up the meetings, communicating with participants, and making local arrangements, such as having a light supper catered for participants before the focus group sessions. They also helped RTI staff by reviewing and commenting on the proposed study protocols, the recruitment materials, and the moderator guidelines used to structure the focus group discussion.

Each focus group consisted of 6-8 family members and lasted approximately two hours. Staff leading the focus groups included a moderator and a note-taker. The moderator led the discussion, using a guide and series of supplemental "probes" to structure the group discussion. With the consent of the participants, the sessions were tape-recorded. In addition, we asked participants to complete a short survey that provided basic demographic and service use information about them and their loved one in an assisted living facility. We also used "flip charts" to foster discussion and record key issues or topics mentioned by the participants about key elements of quality. The result for each group was a 2-3 page list of elements of quality, from the families' perspective. At the end of the session, the moderator asked the participants to review the issues they identified as key to good quality in assisted living and to use round colored stickers ("dots") to indicate the two items or ideas they felt were the most important elements of quality.

The transcribed tapes were coded into major domains and sub-categories of topics or issues that were raised by the family members. Thus, we had three sets of data to analyze: the brief survey of participants, the transcribed tapes as coded, and the "dot" votes on which issues were most important. For the "dot votes," we simply tallied the results. For the survey, we calculated the proportion of respondents who choose each response for each question. The coded taped transcripts were entered into a text-oriented data base, *AskSAM*. We then used the software to sort the data by codes, with cross-referencing of text having multiple codes, and organized each coded comment into major domains and, within these, into major sub-categories. The resulting data were then presented by domain and sub-categories and analyzed for their content and meaning. The following section summarizes the key results.

Study Results

In this section, we describe the characteristics of the participants, their views on key elements of quality, and their "votes" on which aspects of quality are the most important.

Characteristics of the Focus Group Participants. The focus group participants were overwhelmingly women, Caucasian, and children of the loved one with dementia who was living in an assisted living facility. We also asked participants for some information about their loved one and the facility in which they resided. The survey showed that the range of monthly charges was from $1,400 to $5,000, with an average monthly charge of $2,930 per month by the assisted living facilities. This range and average rate was probably lower than one might find in a study that did not include Oregon, which provides Medicaid funding for the "service" component of assisted living charges. Thus, as might be expected, few of the elders residing in assisted living facilities were poor. More than 98 percent had annual incomes of more than $5,000; 95 percent had annual incomes higher than $9,000; 67 percent had incomes above $14,000 per year; and 39 percent had incomes greater than $25,000 per year. Given this, it is not surprising that most family members were providing emotional and physical support rather than financial support to the loved one in assisted living (i.e., only 11 percent of families provided financial support). We also found that most families and elders with dementia (75 percent) had some prior experience receiving long-term care services, while nearly one-third of the loved ones with dementia had been in another assisted living facility before the current facility.

We also asked a few questions about the loved one's experience in assisted living. We found that 61 percent of the loved ones resided in a private room or apartment; five percent in another arrangements, such as a studio apartment; and 34 percent were living in a shared room (semi-private). The average time the loved one had been in the current assisted living facility was nearly two years (i.e., 21 months). Finally, we found that family members were about evenly divided among those who expected their family member to be able to "age-in-place" and remain in the current facility indefinitely (54 percent) and those who expected that their loved one would eventually need to be moved to receive the level of care they would require (46 percent).

What Family Members Say About Quality. In this section, we present the specific results of the focus group discussions on the meaning of quality in assisted living. We have grouped these into four major topic areas identified by family members as important. These are: (1) facility staffing; (2) services; (3) environmental features; and (4) more general facility operational policies and practices.

Facility Staffing. In their discussion of quality, family members felt strongly about the key role played by staff. Within this general domain, they discussed what

quality was, from their perspective, with reference to seven topic area or sub-categories: (1) staffing type and level; (2) training; (3) knowledge (particularly care of persons with dementia); (4) attitude; (5) communication with the resident and family; (6) turnover; and (7) continuity. In the "dot voting" by participants, family members most frequently cited aspects of *staffing* as the most important quality domain in assisted living (28 of 111 votes). *Communication* (21 of 111 votes) with families and *respect for residents* (13 of 111), topics that were also discussed in relation to staffing, were rated as the second and their most important elements of quality. Thus, family members overwhelmingly identified the aspects of care discussed in this section as the core of what good care is in their view, with these elements gaining half of all the citations or "votes."

- *Staffing Level and Staff Qualifications.* The staff-to-resident ratio was brought up at each focus group, with high ratios being of greater importance as the disease advanced. Some family members also felt that it was important that the aides were certified because of the training and knowledge requirements associated with certification, and some wanted oversight or supervision by a licensed nurse, particularly if their loved one had health problems or as the loved one became more functionally impaired.

- *Training.* Across all focus groups, family members reported that training in Alzheimer's disease was very important for the direct care staff.

- *Attitude.* The major themes on the issue of attitude is that family members wanted staff to deal with the residents as individuals and treat them with kindness, respect, tolerance, and affection.

- *Communication.* Family members wanted facility staff to communicate with them about their loved one (how they were doing on a particular day, about any accident or change in health status, etc.) and to be receptive to feedback from family members. Some also felt that written documentation was essential. In addition, they wanted good communication between staff and the resident, that is at a level appropriate to the resident's expressive and receptive communication status and in English.

- *Staff Turnover and Continuity of Care.* A low turnover rate and continuity of staff (e.g., permanent aide assignment) were brought up at the majority of the focus groups as important prerequisites to and indicators of quality in an assisted living facility, particularly for care of persons with memory impairment.

- *Shared Sense of Responsibility and of Community Responsibility Among Staff.* Family members asserted that it was a sign of a good facility when the staff interacted well with each other and had a sense of shared responsibility. They sought staff who *all* cared about the welfare of the residents, not one in which people just performed discrete tasks. One family member referred to this concept as "*it takes a village…*"

> **The Importance of Staff Levels, Knowledge and Attitudes**
>
> I would take a really kind, loving care provider over how the place looked, smelled, anything." (*Northern Virginia family member*)
>
> I would place a higher priority [on staffing ratios]…at this point in time than I did earlier on. (*Northern Virginia family member*)
>
> [The] "it takes a village thing" is clearly something to think about when you walk into these Alzheimer's assisted living [facilities]. Is the guy who scrubs the floor willing to catch the [wandering] person that just went out the door? (*Chicago family member*)
>
> Of course, at the same time, she needs all of this [care and redirecting] to be done with a certain amount of respect for her as a person and not as if she's a child. (*Chicago family member*)
>
> The staff gives her the time and listens to her, you know, and that's real affirming for her even if her logic is messed up, the fact that someone will sit and listen to her. (*Chicago family member*)
>
> You know, [you want] a sense of the staff, some sense that they love these people,… that they view your person and the other residents as individuals and value them. I think eye contact, a lot of affection, hugging, physical touching…That's one of the reasons I chose where my mom is, because I know the staff….Everyone knows everybody, and they would always stop in the ball and put their arm around them [residents] or rub their back….To me that indicated they really know these people and …really care about them. But they're also preserving dignity, and this is important to me. (*Cleveland family member*)
>
> A respect issue to me is respecting the level that they are at. For example, when…[a resident] is pretty high functioning, I wouldn't want people to be talking to them in a way they would when they are not so high functioning…that in…activities…[and] also personal interactions that they be respectful of the stage of the disease. (*Cleveland family member*)

Services. Family members also felt strongly that the type of services provided and the manner in which they were provided were critical elements of quality. They specifically discussed seven topics within the "service" domain: (1) activities; (2) physical assistance; (3) Alzheimer's disease-specific services; (4) medications; (5) food; (6) transportation and other services; and (7) assessment and care planning. Across all the focus groups and discussion of various types of services, the underlying theme was the importance of having services that were targeted and appropriate to the individual needs, preferences, and strengths of the loved one with Alzheimer's or other dementia. What family members consistently sought was to have activities and services provided in a manner that helped the loved one maintain the highest possible level of physical, cognitive, and social functioning. In addition, several family members spoke of the importance of assessment of the loved one's customary routines, behaviors, preferences, and needs and an individualized plan of care or services.

- *Activities*. The need and importance of activities, and the impact of activities on the loved one's well-being was spoken about at every focus group. Indeed, the growing isolation of loved ones with Alzheimer's or another dementia who were

living at home was cited as a major reason that family members sought out an assisted living facility. In addition, they spoke of their perception that the activities need to be specifically adapted for persons with Alzheimer's disease, with the goal of meeting social and therapeutic needs.

- *Personal Care/Alzheimer's Specific Care*. Four basic themes emerged. First, family members wanted the appropriate level of services and personal care provided at each stage of the loved one's illness. Second, family members wanted facilities to recognize the impact of dementia when evaluating residents' needs for assistance, particularly among residents who appear physically intact and able to perform ADLs but who are memory-impaired. Monitoring, supervision, and cuing were cited as critical by family members. Third, family members want personal care performed in a way that maximizes the loved one's function and helps maintain it. Finally, many family members care very much about the assistance loved ones receive with bathing, dressing, and grooming. Cleanliness was especially important.

- *Medication Supervision*. Family members wanted staff to be sensitive to the impact of dementia on loved ones' needs for supervision which included follow-up to make sure the resident has taken the medication, monitoring for adverse effects, and being sensitive to behavioral indicators of problems (e.g., pain, constipation).

- *Meals/Food*. Family members wanted the food to be attractively prepared and presented, tasty, and served in appropriate amounts. They also liked attractive dining rooms. In addition, they wanted the facility to recognize the deficits associated with dementia. For example, they wanted staff to monitor the amount of food that their loved one actually ate to prevent unintended weight loss or gain. Also, some argued that it was important to determine whether a dietician and special diets were available.

- *Transportation & Other Ancillary Services*. Family members wanted transportation for social outings and to health care appointments. They also mentioned availability of other key services (e.g. hairdresser/barber, social worker, and health care providers (e.g., dentist, podiatrist, physician).

- *Assessment and Individualized Care Planning*. Many participants spoke of the importance of written records as a mechanism for recognizing changing needs, planning a resident's care, and communicating vital information to and from the family.

   Facility Environmental Features. In terms of the general space, family members wanted safety, with particular emphasis on the special safety needs for persons with dementia. In addition, families wanted their loved ones to have access to a pleasant and safe outside area. Also, they wanted sufficient space for a range of activities. In addition, many family members preferred single-story buildings and

emphasized the importance of avoiding either room or general facility lay-out that isolated residents. Further, they mentioned the importance of having an "Alzheimer's-friendly" environment, with safety for persons who wander, visual cues for persons with memory-impairment, good lighting, and so on. Finally, they discussed the importance of residents' personal space. Cleanliness, making the setting homelike, and allowing residents to bring their own furniture were cited as vital.

Meaningful Activities and Alzheimer's-Friendly Service Provision

They asked what kinds of things my mother did…so they could provide those activities for her…Or [they would] discuss with her [what] she wanted to do…She likes to sew and always did, so now they let her darn socks and things. (*Boston family member*)

There is a difference between keeping people busy -- entertaining people -- and having a really clearly defined therapeutic activity program that actually supports their remaining skills and encourages a certain sense of their independence and promotes a certain sense of self-esteem. (*Chicago family member*)

If you give her the toothbrush, help her put the toothpaste on, and show her the action, she can figure out that she needs to brush her teeth. But you can't just say go brush your teeth. She needs to be cued to understand. (*Chicago family member*)

And, like I said…it's important for me that he's clean, that he has on clean clothes. That would be more important to me than the quality of the food. (*Northern Virginia family member*)

She will put on my mom's make-up, and they will do her hair, and they will pick her out an outfit and it matches--it's how I like seeing my mother. (*Chicago family member*)

They hand her this little tiny cup with pills in it and say take your medicine, and she very calmly puts it in her purse or… - I find them everywhere. (*Cleveland family member*)

There were no medication aides on this…unit on the weekends or at night. It was very, very frustrating to me…[because] my mother was on 24-hour a day pain meds." (*Portland family member*)

One of the things I looked for was excellent food. I arrived at three different meal times, purposely unannounced. (*Portland family member*)

Something we were looking for was that…residents could go out in the van and just have a drive..We have to work for a living…so it was important to us, because my dad loves to get out. (*Northern Virginia family member*)

The whole point is, do they offer a full comprehensive health care package? I mean, do they make a dentist available to your loved one?...a podiatrist?...doctor? (*Northern Virginia family member*)

I think that's a very important consideration…[having] structured and timely and frequent evaluation, with the facility, with the [direct staff] caregiver, with the family -- concerning the person. I don't see that…[in the is facility], but I think that's…important. (*Cleveland family member*)

Change Over Time in Views of What Is Important. Throughout the discussion of what they thought was good quality, family members noted that over time, either their perceptions of what quality was or the relative importance they placed on various issues changed. Part of the change was associated with their becoming more expert about what actually matters in the day-to-day lives of residents with dementia. But the major factor in altering family members' perceptions of what factors were most important seemed to be changes in the loved one's condition and care needs, which shifted family member's views to focus more squarely on care issues. These issues also played out in the area of the facility environment, both the public and private spaces, in which safety and services appear to become more critical than physical amenities.

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Environmental Factors

Safety is the first thing. (*Northern Virginia family member*)

An environment that has been adapted to provide for [residents with] dementia. (*Chicago family member*)

They have an enclosed open area, which is also really nice..It's like an enclosed patio. It's a real plus….They've had some cookouts there. That's where they had the birthday party in May. They have tomato plants and flowers, and they have a path to stroll around…The exercise bike is out on the patio now in the summer time. (*Boston family member*)

One of the things that I don't think works well…is multiple floors. I would not choose that again. (*Boston family member*)

Avoid a [facility] lay-out that isolates residents. (*Northern Virginia family member*)

You have someone with Alzheimer's, and you want to place them in a unit, then you need to know that this unit is for Alzheimer's. [That they] have the facility constructed or at least modified to accommodate Alzheimer's…It's not just putting a corridor [of rooms in] and saying "This is for Alzheimer's." (*Cleveland family member*)

I would tell [a friend], use their noses…I have a very sensitive nose, and smells tell me cleanliness. (*Boston family member*)

The [furniture] arrangement is exactly like her room arrangement at home, if you came in the back door. At first, she was confused about that, and I told her, "It's just like at home, if you came in the back door." And at that time, she was still with it enough that she caught on, and [disorientation]…hasn't been a problem since then. (*Portland family member*)

The first place I was at was really nice. It was clean; it was new. It was your own furniture, the whole nine yards. I mean, it looked like…a hotel. The place he is now is very institutional. I mean he doesn't have his own bed. I brought -- for me -- in his dresser and a recliner chair, which he no longer uses because he's in…bed all the time. I would take a really kind, loving care provider over how the place looked, smelled, anything. (*Northern Virginia family member*)

I wanted to keep my mom in the surroundings of her own apartment, and I would go over there and we'd site and visit in the living room. And I would make lunch…I had buried my head, as I'm sure some people do, because it was what I wanted for my mother. It was not what my mother needed for herself. (*Chicago family member*)

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Facility Policies. Family members discussed several other topics that related more generally to facility policies and, to some degree, to public policies. First, there was considerable comment about whether family members expected their loved one to be able to stay indefinitely in assisted living or "*age-in-place*." While family members were divided on the issue of whether the loved one with dementia would be able to stay and receive more services as needs increase, the bulk of comments during the focus groups came from family members whose experience suggested the difficulties they had experienced. These difficulties centered on ensuring adequate care and experiencing increased costs. Second, expressions of *concern about cost* and how long families would be able to support the cost of assisted living were common across all focus groups. In addition, some family members reported difficulty in estimating monthly costs because of (a) unexpected costs for some services and (b) cost increases associated with increased level of care that were poorly understood by some family members. Finally, family members discussed the desirability of having *separate units for persons with Alzheimer's* or other dementias and of having multiple levels of care in an assisted living facility or having a facility be part of a multi-level campus.

Which Aspects of Quality Matter Most: Results of Family Members' Votes. As noted, we asked each of the focus group participants to review the list of topics and issues the members had identified as key quality components and "vote" for the two the family member considered the most important by planning "sticker dots" next to the statement to topics. Members of five of the six groups did so. (One group refused, with members saying that what was most important varied over time and across family members. Moreover, they argued that all the topics they listed were an essential part of a high quality facility.) Among those participants who "dot voted," issues related to staffing received the most votes (25 percent). Related topics of communication with families (19 percent of the votes) and an individualized approach to resident's strengths, preferences and needs (12 percent) ranked, respectively, second and third. Combined, these aspects of staff attitude and caregiving practices garnered 56 percent of the votes for the most important aspects of quality. Characteristics of the environment -- safety, security, and homelike environment garnered a total of 21 votes (19 percent of the votes). Family members also rated various aspects of care as important (activities, medical care, protective oversight, medication supervision, referrals, and hands-on physical care), with this domain receiving a total of 15 percent of the votes. When combined with individualized approaches to resident care, these care/service aspects account for approximately 27 percent of the votes.

Facility Policies

My mother is 81, and she's been in her present place for four years…Mother walked in and will not walk out, and they agreed to take care of her through the end. (*Portland family member*)

We knew up front [this facility]…was going to be able to provide that kind of care [aging in place]…That's their philosophy…So that the hope is that unless they really are not ambulatory that they can stay there until they die and won't have to go into nursing home care. We certainly pay a premium for these additional services. It's not part of the basic assisted living. (*Boston family member*)

There is no way. An assisted living facility is going to do certain services, and they're going to go so far and that's it. When my father got sick and went into a hospital the doctor said, "I cannot release him to go back there…He needs much more care than they are going to be able to give."….I think assisted living is great, but the families need to recognize earlier than I did when it's no longer appropriate. (*Portland family member of discharged resident*)

When they say they can handle incontinence, you need to know what that means… [They may mean]…if they are incontinent [and] can take care of it themselves, wear the appropriate thing, do their own laundry if there's problems with wetting the bed every night. You know, staff will do one laundry per week. They'll change the bed once a week. And so one lady had to…[move] because she couldn't do her own [sheets]. (*Portland family member*)

You know, that's why I like the idea of…[multiple] levels within the same facility that progresses with the disease…because it's very difficult [to move] them once they're in a facility…I wasn't sure how I was going to accomplish it. (*Northern Virginia family member*)

I mean, everybody's going to run out of money, you know, and then what? (*Chicago family member*)

Affordability has to be kind of up there too. I mean, you look for different things. You look for obviously the most you can that you can afford, but if you can't afford beyond that, you have to make certain compromises. (*Northern Virginia family member*)

Some…services [podiatrist, haircuts, incontinence supplies] are offered at a cost, and some of them are really expensive. I think you need to ask what are your services, and get a whole list of 25 services. Some of them have a flat fee, and some charge you for every little thing…But mostly they have a list of services available for level two or level three. But you need to know all this ahead of time. (*Portland family member*)

Hidden costs and the different costs increasing…there are some cockamamie concepts in terms of…what you pay…and its very hard to get a straight answer….If they need another level of care, whatever that means at that place, your cost just goes up, goes up 20 times. (*Chicago family member*)

The only thing that really…bothered me or I had questions about was that it seemed like she was six months in one [level of care and price category] and then the price went up. And she was in six months in another, and then the price went up. (*Portland family member of discharge resident*)

1. BACKGROUND AND PURPOSE OF THE STUDY

Assisted living facilities are a rapidly expanding source of supportive housing with services that is increasingly being marketed as a source of long-term care. In the view of many, such facilities represent a promising new philosophy and model of long-term care, one that blurs the sharp and invidious distinction between nursing homes and community-based long-term care and reduces the chasm between receiving long-term care in one's own home and institution (Kane and Wilson, 1993; Manard et al., 1991). In this model, consumer control and choice are central to the philosophy of "assisted living." Further, assisted living, at least conceptually, is distinguished by a flexible service arrangement, in which there is no set "package" of services but facilities provide services to meet scheduled and unscheduled needs of residents, according to a contract. Indeed, the ability of consumers of control both key features of the environment and to direct services, under a "negotiated" or "managed risk" model, and to receive care and supervision in a "homelike" setting are considered hallmarks of the philosophy of assisted living. Moreover, assisted living facilities are increasingly being seen as an important source of care for persons with Alzheimer's disease and other dementias.

Despite this growing interest in and use of assisted living, relatively little is known about the role and performance of assisted living facilities and the degree to which they represent a viable option for family members and elders with dementia. In order to facilitate more effective studies of assisted living and to generate information that will help families and elders make more informed choices, we conducted a study of how family members define quality when their loved one with dementia is in an assisted living facility. This paper reports on the results of that study. Section 1 presents the background and goals of the study. Section 2 describes the study methods. Section 3 presents a summary of what families said about quality and assisted living, as well as about other topics, such as what they perceived as barriers to care. Section 4 discusses our conclusions.

1.1 Role of Assisted Living in Providing Long-Term Care for Persons with Dementia

For families with a loved one who has Alzheimer's disease or other dementia, assisted living facilities hold out significant promise. First, they are thought to provide oversight, supervision, and assistance with personal care for persons with cognitive impairment but to do so in a less regimented and more "normal" or homelike setting than that found in many nursing homes. Thus, residents may live in apartments or rooms in which they have their own personal furniture and other possessions and which look less like a traditional health care facility. Second, assisted living facilities may

provide a more appropriate level of care for persons with cognitive impairment who are still without significant limitations in the activities of daily living (ADLs). Thus, for example, elders who need help with medications, supervision for safety, and help with only bathing and dressing, may be more appropriately cared for in assisted living facilities than in nursing homes which typically house residents who have greater levels of ADL limitations and who need daily nursing care or oversight. Third, assisted living facilities provide an environment in which family members could live with the loved one who requires more care and supervision that the family member could reasonably provide in their own homes. Finally, many assisted living facilities offer families the possibility that the loved one can "age in place." Thus, families often expect that the facilities will adjust their care patterns and service provision to meet the changing needs of the loved one with Alzheimer's or another dementia.

Available evidence suggests that many assisted living facilities are, in fact, providing care to substantial numbers of persons with cognitive impairment. Operators of assisted living facilities, even those that do not advertise themselves as having a specialized Alzheimer's care unit, estimate that between 30 and 40 percent of all residents have some level of cognitive impairment. A recently completed study of board and care homes, which included many assisted living facilities, provides evidence that supports this perception. The study of more than 3200 residents in 500 facilities in 10 States found that an estimated 40 percent of residents had moderate to severe cognitive impairment (Hawes et al., 1995).

Given the increasing importance of assisted living as a source of long-term care for persons with Alzheimer's and other dementias, it is important to learn how well these facilities perform and what role they play in the repertoire of long-term care services and settings. One of the first step in such an endeavor is determining what families and elders expect from assisted living and how the define "quality" in this setting. The Alzheimer's Association, therefore, provided support for study that examined the views of family members of loved ones with dementia who are current residing in assisted living facilities.

1.2   Purpose of the Study

This report describes the implementation and findings of five six groups conducted for the Alzheimer's Association. The focus groups consisted of family members of persons with dementia who were living in or had recently been discharged from an assisted living facility. Our goal in convening these groups was to use the information provided by family members to help define quality in assisted living from the consumer's perspective. Specifically, we wanted family members to share their experiences and insights about assisted living. Using that information, we plan to generate a series of quality measures that will be used in a larger study of assisted living. That study, a *National Study of Assisted Living for the Frail Elderly*, is currently being conducted by Research Triangle Institute (RTI) for the U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation

(ASPE). It will examine a variety of issues, including the quality of care and role of assisted living facilities, by collecting primary data on 2,200 facilities across the country, with on-site data collection in about 700 facilities, interviewing the operators, 1100 staff, and more than 3200 residents. We hoped that by interviewing family members we could better inform our selection of quality measures and improve the ASPE study's ability to generate useful information about assisted living and its role in providing care to persons with dementia.

In addition, we hoped the information we collected in the focus group interviews would generate useful information for the Alzheimer's Association and for families of persons with cognitive impairment about assisted living. Thus, in addition to developing valid measures of quality, we had several other specific objectives that guided the study. Thus, we structured the focus group discussions and analysis to achieve the following goals:

- To develop an understanding of the values, perspectives, experiences, and expectations of family members with respect to assisted living facilities and care of people with cognitive impairment;
- To arrive at an understanding of the issues people face in the process of selecting an assisted living facility for a relative with cognitive impairment;
- To learn more about the sources of information and types of information families use in selecting an assisted living facility;
- To determine what constitutes good and poor quality in assisted living facilities from the perspective of family members; and
- To determine whether family members' concepts of key elements of quality differ by the level of their loved ones' cognitive impairment or functional limitations and whether their definitions of quality when selecting a facility change after the loved ones have lived in a facility for a period to time.

2. STUDY METHODS

In this section of the report, we present information on the methods we used to collect and analyze the data on family members' perceptions about quality and other issues related to care of elders with dementia in assisted living. We present our rationale for selecting the focus group method for collecting the data and for choosing family members as respondents. In addition, we discuss how sites were selected and our criteria for family member selection. Further, we present the methods used to recruit participants, organize the sessions, and structure the focus group discussions. Finally, we report on the methods we used to organize and analyze the data.

2.1   Rationale for Using Focus Group Methodology

We concluded that a qualitative rather than a purely quantitative approach to collecting and analyzing data on families' perspectives on quality was appropriate for this study. Survey data, in which individuals are asked to respond to a series of questions, provides an anonymous "snapshot," or in the case of longitudinal studies, a series of "snapshots" of a person's responses to a given topic at a particular point in time. However, as Miles and Huberman (1994) note "Qualitative data, with their emphasis on people's 'lived experience,' are more fundamentally well-suited for locating the <u>meanings</u> people place on the events, processes, and structures of their lives…" Further, qualitative social research attempts to gather data from the perspective of those being studied (Strauss, 1987, Werner and Schoepfle, 1987 and Whyte, 1984). Because of the nature of the information we were attempting to collect and because we wanted family members' concepts of quality to be placed within the context of their experience and that of their loved ones, we concluded that a more formative, qualitative approach was called for. The focus group method, one well-known qualitative approach to collecting data, seemed best suited to our analytic needs.

Focus groups provide information generated in a natural environment and are particularly useful in exploring domains of meaning and social norms within a specified community or group of people with shared experiences, as Krueger (1994) notes:

> Focus groups produce qualitative data that provide insights into the attitudes, perceptions and opinions of participants. These results are solicited through open-ended questions and a procedure in which respondents are able to choose the manner in which they respond and also from observations of those respondents in a group discussion. The focus group presents a more natural environment than that of an individual interview because participants are influencing and influenced by others -- just as they are in real life. The researcher serves several functions in the focus group: moderating, listening, observing, and eventually analyzing using an inductive process. The inductive researcher derives understanding based on the discussion as opposed to testing or confirming a preconceived hypothesis or theory. (Krueger, 1994).

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Thus, for our purposes, focus groups were an ideal method. We wanted family members' discussion to generate our hypotheses and measures of quality for residents with dementia for the larger *National Study of Assisted Living for the Frail Elderly*. Focus groups were used in this project because of their ability to provide insight into family members' experiences and feeling, the group dynamics around quality and care issues, and social norms about caregiving for persons with dementia. Further, they allowed us to solicit greater detail from participants about specific program features or elements of quality they might mention. Finally, as suggested by their widespread use in market research, focus groups are enormously effective in helping determine what a particular population wants or might like to have. This is precisely the situation that obtained in the Alzheimer's Association study.

Last, but not least, we were drawn to the focus group method because of the explicit nature of the interaction among participants that a well-moderated group generates. As Morgan (1988) notes, the "hallmark of focus groups is *the explicit use of the group interaction to produce data and insights that would be less accessible without the interaction found in a group* (italics added)." These group discussions, organized around a topic and specific questions, yield a large amount of information over a relatively short period of time. While ideosyncractic and anecdotal information is revealed during focus groups, the group dynamic provides a window on social norms, values and customs regarding the focus group topic. However, reaching consensus is not usually the objective. Rather, focus group study aims to explore a broad range of views on a relatively limited and focused subject.

Finally, we want to note the context in which our focus group results are presented. Unquantitative research, such as population surveys, the sample used for qualitative research usually **not** representative. Thus results of data collected from qualitative approaches are statistically speaking, generalizable to some population. For this reason, generalization for qualitative data is necessarily tentative. Although qualitative research may provide some definitive answers (such as "*what vocabulary do people use when talking about assisted living facilities*") qualitative methods are more useful for providing an introduction to the issues, themes and meanings of life situations as lived by the participants. This information can then be used, as we plan to in *National Study of Assisted Living for the Frail Elderly*, to generate hypotheses, formulate measures (i.e., of quality), construct more focused items and relevant response categories instruments to be used in a population survey, and to help us interpret the findings from quantitative analyses.

2.2 Rationale for Focusing on the Views of Family Members

RTI conducted a prior study for ASPE, *Analysis of the Effect of Regulation on Quality Care in Board and Care Homes* (Hawes et al., 1995). As noted earlier, this study found that an estimated 40 percent of residents had moderate to severe cognitive impairment. Our study used only cross-sectional data, so analysis or resident outcomes

that are appropriate for elders with dementia was not possible. Further, since our study protocols called for use of staff members as proxy respondents for residents with moderate to severe cognitive impairment, we did not have measure of satisfaction or self-reports of unmet care needs from residents with dementia. Finally, while we could assume that our structural and process quality measures and operational definitions for these measures (e.g., safety, availability of social and recreational aids, cleanliness, staff knowledge, use of psychotropics) were as relevant to the care of persons with dementia as to persons with other illnesses and disabilities, we had no sound empirical evidence to support this assumption.

For cognitively intact residents in board and care, we had information from interviews with nursing home residents about how they defined quality in a residential long-term care setting to guide us (Spaulding, 1985). No similar data, however, were available for residents with dementia. In addition, we did not find evidence indicating a strong link between the process and structural measures selected and the outcomes of persons with dementia, a link that is generally thought to support the relevance or validity of the process and structural measures (e.g., Donabedian, 1968, 1990). Thus, at the end of the Board and Care study and start of the ASPE Assisted Living project, we decided to pursue mechanisms for developing cross-sectional quality measures for care of persons with dementia in which we could have greater confidence.

The development of quality measures relevant to care of persons with dementias is complicated by the perception that they are not good informants -- or at least that one cannot ask for self-reports and then depend on their responses to be reliable (e.g., consistent and related to the care received), particularly among persons with memory impairment. While some observers argue that many persons with cognitive impairment are capable of providing valid information about their status and experiences (e.g., Gurland et al., 1994), the operational methods for determining which persons and under what conditions have not been well-specified. As a result, one is left to make inferences about care from other data (e.g., the experience of cognitively intact residents) or to seek information from reliable informants.

Family members are often regarded as the most appropriate informant about quality issues for persons who are unable (or presumed unable) to provide direct information about their care. While there is evidence which suggests family members' views about what is most important may differ from that of the direct care recipients (e.g., DiBernardis and Gitlin, 1979; Bowers, 1996), there is also recognition of the validity of family views and opinions.

- First, for persons with cognitive impairment, families have often provided care themselves and have knowledge about the challenges involved and what it takes to provide adequate care. Thus, they have a practical knowledge base for their opinions.

- Second, they typically make key care decisions for relatives with cognitive impairment, including placement decisions. Thus, their views of what is high or

low quality helps determine which assisted living facility is selected for someone with dementia.

- Third, they are often in a position to observe both direct care provision and the consequences of care. Thus, they have relevant information.

- Finally, most family members retain ties of affection and concern to the relative in a facility. Thus, they are typically regarded as a legitimate informant about the quality of the loved one's care.

Given these factors, we felt that family members' views about assisted living and quality as a valid starting point for developing improved quality measures.

2.3   Site Selection

Site selection was a two-stage process. First, based on its work on the ASPE *Assisted Living* project, RTI identified those metropolitan areas with the highest known concentration of assisted living facilities, as of 1995. Second, we worked with the Alzheimer's Association to select all these potential sites. Our criteria were that (1) the local chapter had to be willing to provide considerable assistance in setting up the focus groups; (2) the local chapter had to be able to locate and make contact with family members of persons with dementia whose relatives were currently living in or recently discharged from an assisted living facility; (3) we would be able to participants whose family members were residing in several different assisted living facilities. On these criteria, the following local Chapters of the Alzheimer's Association were asked to participate and agreed to do so:

- Chicago, Illinois
- Northern Virginia
- Cleveland, Ohio
- Boston, Massachusetts
- Portland, Oregon

2.4   Criteria for Selection of the Family Member Sample

Because prior studies suggested systematic differences among family members in their role as caregivers and in their views about care and quality for a loved one with dementia, we wanted to recruit family members that represented this variability. In addition, we considered it likely concepts of quality and of which elements are most important might vary according to the age and type of care needed by the loved one. Thus, in recruiting family members, we focused on two primary dimensions: (1) type of family member and (2) level of the loved one's functional cognitive impairment.

- **Family Members**. Two types were considered: spouse and child/child-in-law.

We sought an equal representation of both; however, the demographics of long-term care resulted in a disproportionate number of children, as reported in Section 3.1. This is not surprising, since, as with nursing homes, most residents of assisted living facilities and board and care homes are among the older old (64% of board and care residents are aged 75 or older) and few have a living spouse (only 12% of residents of board and care homes are currently married) (Wildfire et al., 1995; Hawes et al., 1995).

- **Level of Care/Functional Impairment**. We defined this in terms of residents who could be classified as receiving one of two types of assistance: light care and heavy care.

  One category was defined as receiving a relatively low level of care. This meant that they received relatively little (or no) assistance with activities of daily living (ADLs). We defined this as a resident who receives no more than assistance with bathing and dressing. The second type of resident was defined as being "heavier care." This mean the resident received hands-on assistance with three or more ADLs on a daily basis (e.g., assistance with locomotion/walking, eating, toileting or transferring, as well as bathing and dressing).

  Again, we sought equal representation along this dimension; however, because of a variety of factors, we had good representation among families of residents with heavier care needs but not equal representation. Factors limiting this included: (1) the relative "newness" of assisted living facilities in many areas, which meant residents had not yet "aged in place" and become more dependent; (2) limitations on the level of resident impairment imposed on the population of assisted living facilities by either State licensure regulations or by facilities' policies. To address this, we added a focus group with family members of residents who had exited or been discharged from assisted living facilities. Thus, in Portland, Oregon, we held two focus group sessions: one with families of current residents and one with families of discharged residents.

In addition to seeking representation along these two dimensions, we developed other criteria for selection family members.

- **Representation of Different Assisted Living Facilities**: In each group, we sought to include family members from at least two or three different facilities. We were not seeking specific information about family member satisfaction with particular facilities, and we wanted to be sure that a particular focus groups's report on their concept of quality and experiences was not "colored" by their experience with only one facility. We achieved this goal in each of our sites.

- **Representation of Families and Residents with Sufficient Experience in Assisted Living Facilities**. We felt that families whose loved one had recently entered an assisted living facility might not have had sufficient experience to help

define key elements of quality. In addition, long-term care ombudsmen and consumer advocates report that often the factors which families and elders concentrate on in *selecting* a facility are not the same as the factors they identify as important after some months of experience in the facility (See also Spaulding, 1985). Thus, we sought to select family members with a relative who had cognitive impairment and had been living in an assisted living facility for at least six months.

Again, because of the relative "newness" of assisted living facilities, we did not achieve this goal in all focus groups. Thus in three of our sites, we had some family members whose relatives had been in an assisted living facility for less than six months. In general, however, we were successful in selecting focus group members with experience in receipt of long-term care and assisted living, since across the groups, (1) all but one resident had been in a facility for at least two months; (2) most residents had lived in a facility for at least six months (as reported in Section 3.1); and three-quarters of the family members and residents had prior experience with receipt of some type of long-term care services.

- **Representation of Families With Experience in Observing Facility Performance**. We also wanted to ensure that the family members selected to participate in the focus groups had first-hand knowledge of assisted living. Thus, we set as a criterion that the family member made regular visits to the assisted living facility so that they had a regular, on-going opportunity to directly observe conditions in the facility and the care their family member was receiving (i.e., visited at least 3-4 times a month). We achieved this goal.

2.5 Data Sources and Focus Group Methods

For this project, we held six focus groups. Five included family members of elders with dementia who were currently residing in an assisted living, and one group consisted of family members whose loved one had been recently discharged from an assisted living facility. In this section of the report, we describe the "mechanics" of the study: developing instrumentation, recruiting participants, and organizing and conducting the focus groups.

2.5.1 Instrumentation

We developed several types of study instrumentation, including recruitment materials, a consent form, a self-administered survey of participants, a moderator guide and structured note-taker forms.

Developing Recruitment Materials. After developing criteria for selecting sites and participants, our first step was developing recruitment materials. These included an explanation of the purpose of the study and what would be involved for the local Alzheimer's Association Chapters that chose to participate, a set of guidelines for the

Chapters that specified our recruitment goals and criteria, and a fact sheet for recruiting participants. We developed drafts of these, sought and received review of these from our project officers at the Alzheimer's Association, revised them, and sent them to the local Chapters in the five sites. We then held a conference call with representatives in the five Chapters, discussing the criteria and methods we proposed. Chapter representatives made several useful suggestions about both the forms and protocols, and we made further revisions. Copies of the study explanation, recruitment guidelines, and fact sheet may be found in Appendix A.

Developing Instrumentation. Our next step was to develop instruments and protocols that would allow us to achieve the study goals. These included: (1) a consent form for participants; (2) a short self-administered survey of focus group participants; (3) a moderator guide of general topics and follow-up probes designed to facilitate and structure the discussion; and (4) structured note-taker forms. These were reviewed by our project officers at the Alzheimer's Association and modified accordingly. The revised forms and a description of the study goals and protocols were then reviewed by RTI's Committee for the Protection of Human Subjects to ensure that nothing violated the family members' rights to privacy or placed them or their loved one in the assisted living facility in any jeopardy. A copy of the consent form can be found in Appendix B.

We also developed a two-page *self-administered Demographic Survey* for family members. This survey asked participants 14 questions covering basic demographics, their loved one's history of using long-term care services prior to entering the current assisted living facility, the length of their loved one's stay in the current facility, the facility room type, the monthly cost, whether they provided financial support to the loved one, the monthly income of the relative in the assisted living facility, and the family member's expectation about whether the loved one would be able to stay in the facility indefinitely (i.e., would be able to age in place). In addition, we asked the participation to provide their first name so that we could associate their comments during the discussion with the types of issues they raised. The data from this survey were used to describe participants and, in some instances, to compare the responses of participants across eligibility categories.

The key instrument we developed was a *Moderator Guide*. This guide was used as a framework for the focus group discussions and not as a scripted set of verbatim questions. It was developed to structure the discussion and illuminate the study questions and to ensure that key topics were raised with participants during the focus group session. This guide thus included both key topics and a set of topical "probes" that were used as needed to follow-up lines of inquiry suggested by the discussion or to clarify to topic and stimulate more focused discussion. The topics in the **Moderator Guide** included the following:

- The kind of help or supervision the loved one received in the assisted living facility;
- Why assisted living was chosen over other alternatives (e.g., a nursing home or board and care home);

- How they selected the current assisted living facility (e.g., information sources, what they looked for; how they decided on a particular facility);
- Whether there had been changes in the loved one's care needs over the course of the stay in the assisted living facility;
- How they define "quality" and what they would to tell a friend to look for in selecting a "good" assisted living facility;
- What they would tell a friend to avoid when looking for an assisted living facility;
- Whether (and if so, how) their perceptions about quality changed over time; and
- Whether the family members believed that the residents' concept of "good quality" matched that of family members.

A copy of the **Demographic Survey** and **Moderator Guides** are included in Appendix C.

In addition, we developed *structured note-taker forms* that were designed to facilitate our ability to capture not only what was said but also when and how it was said (the context), whether some questions did not elicit responses and required probes or clarification, and whether there were behavioral and verbal signs of agreement or disagreement among other participants to a point raised by one participant.

2.5.2 Recruitment of Focus Group Participants

Based on our experience and that of the local Chapters, we determined that the most effective process for identifying and recruiting family members for the focus groups was to work with the Chapters and give them primary responsibility for these activities. This would give family members a clear understanding of the purpose and sponsorship of the study and a local source of information and support for those families not already familiar with the local Alzheimer's Association Chapters. Some Chapters already had identified support groups for families of residents in assisted living facilities; others had many support groups but no way of identifying those members who had a relative in such facilities. Thus, for Chapters who wanted assistance, RTI staff provided them with lists of assisted living facilities and telephone numbers in their local area. In a few cases, we also made contact with administrators of local assisted living facilities to help identify potential participants.

As noted, some Chapters had a working knowledge of chapter members who were eligible for the study. Others contacted assisted living facilities they knew to identify potential participants. Once potential participants were identified by the Association Chapters, a lead letter and a fact sheet were mailed to them. In some instances a set of screening questions were also mailed to help determine whether they were eligible for the study. In other cases, the screening was done over the phone. For those contacted by mail, if the person qualified for the study they were asked to call a Chapter representative and notify him/her of their interest in participating in the group. Once eligibility was verified, and confirmation of attendance at the group was received,

Chapter representatives gave the participants details about such issues as the scheduled date, time and the location of the focus group session as well as the availability of reimbursement for transportation costs or other incentives. RTI provided a minimal payment to the local Chapters to help cover the costs they incurred in helping us with recruitment.

Recruitment Incentives for Participants. In many cases, particularly when focus groups are organized by marketing firms, financial incentives are offered to participants. Chapters felt that it was appropriate to offer participants reimbursement for transportation costs. One Chapter felt that it was also essential to offer participants an incentive payment, give the burden of travel in the large metropolitan area combined with the usual practice among other firms of providing incentives for focus group attendance. Thus, in one site we provided a $50 per person participant cash incentive. In other Chapters, they chose to give participants a gift certificate (valued at between $30 and $50). And in one Chapter, they felt offering any kind of financial incentive was inappropriate.

2.5.3 Organization and Operation of the Focus Groups

We considered appropriate organization and arrangements for the focus group sessions an important component of their success. First, it was important to hold the sessions in a place that was convenient and safe for participants and in which they would be comfortable. In four of the five sites, the Chapter offices provided conference rooms for the focus group sessions. In the fifth site, a centrally-located hospital provided a meeting room. Second, we sought the advice of the Chapters about the time of day that would be most convenient for family members. Since many worked, we started the sessions at 6:00 or 6:30 pm. In addition, we provided a light meal for all participants before the session. This gave participants time to get acquainted and time to complete the self-administered survey, as well as giving RTI staff (the moderator and note-taker) an opportunity to speak with the participants informally. They also asked each participant to read the informed consent form and complete the survey.

Each focus group consisted of 6-8 family members and lasted approximately two hours. Focus group staff included a moderator and a note-taker. The moderator led the session. She started by introducing herself and the note-taker, explaining the purpose of the study and how the focus group session would be conducted, and going over the material contained in the informed consent to ensure participants understood their rights and consented to having the sessions tape-recorded. She then asked the participants to introduce themselves and invited them to tell the group something about their loved one who was in an assisted living facility. The moderator then introduced the first topic, and group discussion began.

The sessions were tape-recorded, and the note-taker also recorded key comments, contextual notes, and so on. The recordings were used so that all important comments could be captured verbatim and coded for analysis. The notes of the note taker were used as a backup in the event the tape recording was unclear or the

recorder failed for some reason, as well as providing information the recording could not capture, such as the identity (by first name only) of the speaker so that the comments could be subsequently associated with demographic characteristics of the speaker or with the characteristics of the relative in the assisted living facility. The recordings were later transcribed and used to generate the summary reports from which the entire report is written. We also used "flip charts" to record key issues or topics mentioned by the participants. As participants raised topics and added responses to discussed lines of inquiry, the moderator created a list on the flip chart of what participants said. These mainly concerned the topics explicitly related to how participants defined quality of care. The result for each group was a 2-3 page list of elements of quality, from the families' perspective. At the end of the session, the moderator asked the participants to review the issues they identified as key to good quality in assisted living and, using round colored stickers ("dots") placed next to items on the list, to indicate the two items or ideas they felt were the most important.[1]

At the conclusion of the focus group session, we conducted a "debriefing" with staff of the local Chapter. This was done so that we could ask questions about any seemingly idiosyncratic issues or topics that were raised during the focus group session (e.g., several mentions in one site of a particular administrator and her philosophy of assisted living in the local community) and to place the group's discussion in context of any special situations or issues specific to a given site.

2.6   Analytic Methods

As noted, focus group data were collected in five forms: tape transcripts, structured notetaker forms completed during interviews, structured debriefing forms completed immediately after the focus group, "dot votes" on quality issues listed on flip charts during the focus groups, and a short survey completed by participants prior to the focus group interview. The use of such standardized data recording forms is critical for analysis of qualitative data.

All primary data from the focus group sessions were coded and entered into text-oriented analytic software. The short surveys completed by focus group participants were entered into a database that was analyzed using a software (i.e., Lotus) appropriate to producing simple descriptive statistics.

The initial lines of inquiry that guided our development of the moderator guidelines were based on a literature review also structured the general conceptual

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[1] It is important to note that one group refused to "dot vote" their lists. In both verbal and body language, they withdrew from this option. Their argument, vigorously presented, was that all the elements were important, even essential aspects of quality. Moreover, they noted that the relative importance of one element or another would change across time, as the loved one's needs changes, and would "rank" differently according to a range of issues. For example, location close to the family is important but only if one has a choice between two or more facilities that provide what the family member defines as "adequate" quality. If no good facility is nearby, location becomes a "non-issue" in selecting a facility. The group discussion on this topic was vigorous and provided other similar examples. Further, members explicitly stated their reluctance to quantify and rank their concerns.

framework we brought to analyzing the resulting focus group data. The first step in this process was the creation of categories of codes. Following the completion of all the focus group meetings, RTI's full project team[2] participated in a half-day meeting in which summaries of flip chart exercises and dot votes were presented and discussed. The team then used these lists to create the framework for the coding system used in qualitative analysis. The most commonly mentioned issues (and those that the focus groups gave the highest prior in their dot voting) were first divided into high level categories or domains, with sub-categories representing the full range of related issues raised by the groups. **Exhibit 1** presents those categories and sub-categories.

We also took advantage of advances in qualitative research that have resulted in more systematic analysis of qualitative data. These advances include computer software to archive and analyze qualitative data and standardized analytical approaches. Furthermore, computer technology facilitates intercoder reliability checks and iterative coding techniques, both designed to reduce the subjectivity previously associated with qualitative data analysis.

After creating a coding system of major domains and, within these, sub-categories of topics or key issues raised during the focus groups, the transcribed tapes of verbatim comments were coded into the domains and sub-categories. Initially, all members of the project team discussed how they would code particular comments in order to generate discussion and consensus about how various issues and topics should be coded. In particular, we reviewed the lists from each focus group on which participants' "dot votes" were recorded and discussed how each of us would code particular responses. Next, transcribed data from one session and the "dot votes" from two focus groups were independently "double-coded" by two staff members. Then they compared their coding for the same data to determine whether there were any discrepancies. If they found discrepancies in their coding, they brought these to the project director for resolution. This process for enhancing reliability was important to ensure that we had reliability across the coders, particularly since we report the results of "dot voting" not only in terms of the content but also the frequency with which specific items or topics were cited by participants as the most important elements of quality. Then, throughout the coding process, the two staff performing the coding maintained frequent communication to discuss and reach agreement on interpretation or coding of any ambiguous data.

RTI staff then entered the coded data into a text-oriented data base, *AskSAM*, and sorted the data by codes, with cross-referencing of text having multiple codes. Following preliminary review of the sorted data by the 29 codes shown in **Exhibit 1**, we used the software to organize each coded comment into the five major domains. The resulting data were then presented by domain and sub-categories and analyzed for their content and meaning. This report presents these summary analyses. In addition, to maximize our use of these rich qualitative data, we include verbatim quotes that illustrate the overall tone and content of comments in a particular area. (***It is important***

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[2] RTI's team consisted of four persons, and all team members participated in at least one focus group meeting. This increased familiarity with the data collection process and outcome.

to note that the number of quotes presented in a topic area do <u>not</u> signify the prevalence with which the topic or issue was raised. Rather they are used to illuminate the topic or clarify different perspectives.)

EXHIBIT 1. The Coding Scheme for Analyzing Comments on Quality	
Major Categories or Domains	**Sub-Categories of Topics**
Staffing Features	Training Attitudes Staffing levels/staff-resident ratios Staff turnover Communication with residents and family Consistency of caregivers
Services	Activities Transportation Personal care Alzheimer's specific services & approaches Management of medications Ancillary services Food and meal service
Facility Environmental Features	Safety Alzheimer's specific features Architectural lay-out Aesthetic qualities of shared spaces Room types Cleanliness Aesthetic qualities of personal space "Homelike" environment
Facility Policies	Aging in place Background checks on staff Issues related to cost of care Different levels of care Separate units for residents with dementia
Process of Shopping for a Facility	Sources of information Things to look for and to avoid

3. STUDY RESULTS

This section of the report describes the results of our analysis of the focus group discussion. It does not report all of the comments nor raise all of the issues discussed by family members. For example, much discussion was devoted to the characteristics, personality, and current physical and cognitive status of the loved one who was in an assisted living facility, as well, more generally, as to the consequences and trajectory of Alzheimer's disease. To the degree that the illuminated the specific topics under discussion, some have been included. However, our focus in the summaries is to identify and analyze those comments that specifically addressed our primary analytic concerns. These were to identify how families defined quality and to learn more about what they felt were successful techniques for shopping for a facility. Thus, in this section, we report on the characteristics of the focus group participants, what families said about quality and how they judged it, and which elements they identified as the most important aspects of quality. Finally, we present family members comments on some "miscellaneous" topics that arose, such as what they perceived as barriers to receiving appropriate care, the difficulty of identifying a good facility, including knowing what was meant by "assisted living," suggestions for how to shop for a facility, and family needs for support.

3.1   Characteristics of the Focus Group Participants

As noted in the methodology section, we asked focus group participants to complete a short self-administered survey. This section of the report presents the results of that survey.

As shown in **Exhibit 2**, the participants were overwhelmingly women, Caucasian, and children of loved ones with dementia who were residing in an assisted living facility.[3]

The participants also reported on the range of monthly charges ($1,400 to $5,000) and the average monthly charge ($2,930 per month) by the assisted living facilities. This range and average rate was probably lower than one would find in a study that did not include Oregon, which provides Medicaid funding for the "service" component of assisted living charges. Other states either provide no direct coverage of assisted living for low income elderly or provide limited coverage through Medicaid waiver programs.

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[3] While the focus group sample was not intended to be representative in a statistical sense, this distribution under-represents the proportion of the total population that is Hispanic or African-American. Whether it is representative of the more restricted population of families of persons residing in assisted living facilities is unknown, since there are no generalizable data on residents. However, our demographic distribution was not caused by refusals, since we had few. On the other hand, it is clear that achieving greater participation by spouses or securing participation by members of minority groups' would have required substantially different out-reach and recruitment strategies.

EXHIBIT 2. Results of Focus Group Participant Survey		
Characteristic		**Distribution[1]**
Gender	Male	15%
	Female	85%
Marital Status	Married	75%
	Widowed	5%
	Divorced	5%
	Never Married	15%
Race	Caucasian	98%
	African-American	3%
Ethnicity	Hispanic	0%
Relationship to Resident	Spouse	11%
	Child	74%
	Child-in-law	16%
Annual Income of Loved One in an Assisted Living Facility[2]	< $1,200	16%
	$1,200 - 4,999	2%
	$5,000 - 8,999	3%
	$9,000 - 13,999	28%
	$14,000 - 24,999	28%
	$25,000 - 49,999	17%
	$\geq$ $50,000	22%
Family Provision of Financial Support	Some provided	11%
	None provided	89%
Length of Stay in Current Facility	21.6 months	N.A.
Monthly Charge by the Facility	Range: $1,400 - $5,000	N.A.
	Average charge: $2,930	N.A.
Type of Unit in the Assisted Living Facility	Private apartment	24%
	Private room	37%
	Private room/shared bath	11%
	Semi-private room with bath	5%
	Semi-private room with communal bath	18%
	Other (e.g., studio apartment)	5%
Prior Use of Long-Term Care Services	*Use of any type of LTC services*	75%
	Home health	18%
	Home chore	26%
	Respite	9%
	Adult day care	5%
	Board and care home	18%
	Other assisted living	29%
	Nursing home	9%
	Other (e.g., retirement home)	16%
Family Expectations About Length of Stay in Current Facility	Expect loved one to stay indefinitely in current assisted living facility	54%
	Expect loved will have to move	46%
1. "Rounding" of percentages may lead to figures that combine to more than 100 percent.		
2. Five percent of the family members reported they did not know the relative's annual income; these data represent a calculation that excludes this missing data.		

Given the typical monthly charge, as might be expected, few of the elders residing in assisted living facilities were poor. More than 98 percent had annual incomes

of more than $5,000; 95 percent had annual incomes higher than $9,000; 67 percent had incomes above $14,000 per year; and 39 percent had incomes greater than $25,000 per year. Given this, it is not surprising that most family members were providing emotional and physical support rather than financial support to the loved one in assisted living (i.e., only 11 percent of families provided financial support). We also found that most families and elders with dementia (75 percent) had some prior experience receiving long-term care services, while nearly one-third of the loved ones with dementia had been in another assisted living facility before the current facility.

We also asked a few questions about the loved one's experience in assisted living. We found that 61 percent of the loved ones resided in a private room or apartment; five percent in another arrangements, such as a studio apartment; and 34 percent were living in a shared room (semi-private). The average time the loved one had been in the current assisted living facility was nearly two years (i.e., 21.6 months). Finally, we found that family members were about evenly divided among those who expected their family member to be able to "age-in-place" and remain in the current facility indefinitely (54 percent) and those who expected that their loved one would eventually need to be moved to receive the level of care they would require (46 percent).

3.2　What Family members Say About Quality

In this section, we present the specific results of the focus group discussions on the meaning of quality in assisted living. We have grouped these into four major topic areas: (1) facility staff; (2) services; (3) environmental features; and (4) more general facility operational policies and practices.

3.2.1　Facility Staffing

Staffing Features
Sub-Categories: (1) staffing type and level; (2) training; (3) knowledge (particularly care of persons with dementia); (4) attitude; (5) communication with the resident and family; (6) turnover; and (7) continuity.
"I would take a really kind, loving care provider over how the place looked, smelled, anything." (*Northern Virginia family member*) [The] "it takes a village thing" is clearly something to think about when you walk into these Alzheimer's assisted living [facilities]. (*Chicago family member*)
In the "dot voting" by participants, family members most frequently cited aspects of *staffing* as the most important quality domain in assisted living (28 of 111 votes). *Communication* (21 of 111 votes) with families and *respect for residents* (13 of 111), topics that family members also discussed in relation to staffing issues, were rated the number two and three most important elements of quality. Thus, family members overwhelmingly identified the aspects of care discussed in this section as the core of what good care is in their view, with these elements gaining half of all the citations or "votes."

Type & Level of Staffing

The staff-to-resident ratio was brought up at almost every focus group. When it was discussed, family members agreed that it was important that this ratio of staff to residents is very high. Ratios from 1 direct care staff for each 5 residents to 1:3 were mentioned as being optimal. Family members also discussed ratios as being of greater importance as the disease advanced and the resident's functional and cognitive limitations grew more pronounced.

> *I would place a higher priority* [on staffing ratios]...*at this point in time than I did earlier on.* (Northern Virginia)

Several family members stressed the importance of staff interaction and communication with residents and noted that with too few staff having too much work, those key elements of quality could be neglected. As one family member noted, for example, people with dementia often progressively lose the ability to communicate, that is to make themselves understood and to understand others. When staffing levels are too low, she argued, communication suffered.

> [Good communication is] *one thing that's tough to have -- to make time for these people [loved ones with dementia] to communicate clearly…In the first facility* [my father was in]*, they were so rushed…the staff had so much work to do that they could not get my father to respond well.* (Northern Virginia)

> *The third floor is for* [residents with] *advanced* [dementia] *and I had a lot of pressure put on me to have…[my relative] moved from the second floor to the third floor. And I fought it for…several months…*[I] *finally gave in for a couple of reasons, one is the ratio of staff to residents is much higher.* (Northern Virginia)

Some family members also discussed the importance of licensure requirements or certification of nursing assistants, which indicated to them that staff had a certain level of training and knowledge.

> *I mean, are you R.A.s* [ordinary resident aides] *or are you CNAs* [certified nursing assistants]*? If you're CNAs, you're in the state, you have a license here, you've go a card like RN's and LPN's. That hopefully saves us the heartache of abuse -- emotional and physical.* (Northern Virginia)

> *How many people are CNAs?* (Portland, discharged)

Finally, family members noted that if the loved one in an assisted living facility developed health problems in addition to Alzheimer's disease, nursing care and monitoring by a Registered Nurse (RN) might be needed. This was an issue that figured most prominently in the discussion of the one group of family members of residents who had been discharged from assisted living, mainly because their needs could no longer be met in the facility; however, it was a topic raised at each focus group.

If anyone's loved one had medical overlay [with] *their Alzheimer's, forget it unless there are RNS and lots of training.* (Portland, discharged)

Another participant in the same group of family members whose loved one had been discharged from assisted living echoed this theme.

I think I was distracted [when choosing the facility] *and didn't look at the ratio between staff and patient…*[or staff type]. *And I think having a LPN only for a…40-person Alzheimer's unit…I wouldn't every do that again.* (Portland, discharged)

Family members from other focus groups also felt supervision by an RN was important.

That's another reason I chose where my sister is. The head of the unit is an RN who is rather well-known in this area from people's contact with nursing home. (Northern Virginia)

A nurse on staff. At [this facility] *there was a nurse on staff, but I had an episode several weeks ago when I went over there* [and] *my mom wasn't well…I said, how long would it have taken for someone to call me? I made the decision to take her to the hospital at that point. It was a weekend, and that's an issue I've brought up with them. It's a weekend, there should be still be a nurse on duty, and the staff should be trained enough to call me and let me make a decision* [about] *whether she should go to the hospital.* (Boston)

There was a 24-hour RN on duty, three-shifts of RNS. [That's important] *because my mother has so many physical problems in addition to dementia.* (Portland, current)

Training & Knowledge

Across all focus groups, family members reported that training in Alzheimer's disease was very important for the staff that deal with their loved ones. Family members felt that without specialized training, staff would not understand key issues of the disease and its effects on residents. Thus, staff would have difficulty relating to residents with dementia, and it would be nearly impossible for them to manage behaviors appropriately. Thus, many family members said that staff training in and experience working with people with Alzheimer's was an important consideration for them when they were selecting a facility.

[That] *the staff is all trained in the disease…is absolutely critical as far as I'm concerned. It makes a significant difference because they* [people with dementia] *don't react the way a normal person would react to a suggestion or to a situation and if somebody -- if the staff -- doesn't understand the disease and how to, you know, redirect them or..distract them or whatever, it just become a brand…* (Boston)

Family members also noted that the issue of training become even more important as a loved one's disease progressed and its impact on decision-making and behaviors became more pronounced.

> *I think the training in Alzheimer's disease is more important to us than it was in the beginning because she's regressed so much.* (Boston)

Staff Attitudes

The major themes on the issue of *attitude* is that staff must deal with the residents as individuals and treat them with kindness and respect. Some optimal staff behaviors that were discussed by family members support the idea that respect for the resident is a key aspect of good care. These behaviors include learning about what is important to the resident, not treating residents like children, taking the time to listen to residents, and showing tolerance for any peculiarities. In addition, the nature of staff interaction with residents was also very important to family members. Positive types of interactions which family members discussed included gentle touching, eye contact and other behaviors that demonstrated affection and were affirming to the residents of their worth as people.

> *The criteria is, like you say, how they treat him…and what kind of care he receives…* (Northern Virginia)

> *Of course, at the same time, she needs all of this* [care and redirecting] *to be done with a certain amount of respect for her as a person and not as if she's a child.* (Chicago)

> *I think you need a facility that's pretty tolerant of peculiarities. Yeah, of the peculiarities of dysfunction that these folks shall have. You know, a sort of tolerance, some humor. And I don't mean laughing at these people, but just enjoying them.* (Cleveland)

Staff Interaction With Residents. Several family members noted that what they looked for was staff who interacted with residents in a positive and supportive manner rather than just performing the "body work" of bathing and dressing residents. In addition, they recommended avoiding facilities in which staff did not interact with residents.

> *The staff gives her the time and listens to her, you know, and that's real affirming for her even if her logic is messed up, the fact that someone will sit and listen to her.* (Chicago)

> *You talk about "what do people need." A respect issue to me is respecting the level that they are at. And…I think, it's not just related to activities but also to their personal interactions, that they be respectful of the stage of the disease.* (Cleveland)

The other things is, avoid homes where the staff is talking to each other about what they did on the weekend…They're just not engaged with the patients. They're engaged with each other…avoid that. That means that there's poor supervision. (Portland, discharged)

Another family member echoed this theme, noting that it carries over to how staff perform personal care, as well. She said that she cared about how staff treated her father in these activities, that is, not merely *whether* the assistance was provided but *how* it was provided.

[I notice], *you know, changing them* [a resident who was wet] *and if* [staff]…*are treating them with respect.* (Portland, discharged)

As a family member noted, agreeing with the discussion of other participants about the importance of having staff who take a personal interest in residents:

There's more to that human-being than clean teeth, clean bottom, clean clothing. (Northern Virginia)

Care and Affection. Family members also spoke, often movingly, of how positively they viewed kindness and affection being shown to their loved ones.

You know [you want] *a sense of the staff, some sense that they love these people,….that they view your person and the other residents as individuals and value them. I think eye contact, a lot of affection, hugging, physical touching…That's one of the reasons I chose where my mom is, because I know the staff…..Everybody knows everybody, and they would always stop in the hall and put their arm around them* [residents] *or rub their back. There's a lot of* [this] *that goes on, and to me that indicated they really know these people and…really care about them. But they're also preserving dignity, and this is important to me.* (Cleveland)

Staff caring, I would have to pick that one [as most important]. (Portland, discharged)

I think touch is key to most Alzheimer's patients…My husband was pretty easy to get along with. He loved to hug and found a girlfriend right away, and all this. But people [staff] *would touch him and hug him, and they would hold his hand. And that, to me, meant everything.* (Portland, discharged)

One family member noted the importance of staff being appreciative of receiving affection from the relative with dementia, how that signaled to her that staff cared about her mother as a person.

My mother…really can't make herself understood, and [when I'm in the facility], *one of the girls will say…"Oh, you mom gave me a hug this morning, and it was so neat." And you know, they are just so 'in' to her.* (Portland, current)

Administrative staff attitudes were also identified as important by family members.

> *The woman who runs the third floor is extremely caring…then I'd say the quality of management is extremely important.* (Northern Virginia)

> *What I'm saying is dedication, dedication of management, not just a job where they come in at…and leave at 5…but dedicated to the job…the work…I mean, she* [the administrator] *is the one when I* [went] *in unannounced, she had put her arm around my wife,* [was] *holding her hand, led her to the bathroom, helped her and so forth, -- very, very caring. And she imparts this to the people that work for her, which I think is wonderful.* (Northern Virginia)

A family member also noted how helpful it was to have someone on the staff who would help them plan for the future and care of their loved one as the care needs because greater than could be accommodated in the current facility.

> *Another thing I liked was the social worker…She really cares, and she's working with me* [to think about a new facility nearby]. *So that's like the future;…she's helping me wit the future.* (Northern Viriginia)

Communication

Staff communication was important to family members in two areas: (1) communication with families and (2) communication with residents. It involved communication with both direct care staff and also with supervisory staff.

The area that was discussed most often in the focus groups was staff communication with family members. First and foremost, family members wanted to know what is going on with their loved one. As one family member explained:

> *I had gone* [out] *to something one night, and* [one of the nurses] *kept calling and calling, and told me* [on the answering machine] *to call her no matter how late I got home. And she said, 'you have to know this." So, again, like you said, it depends on who the person is, how compassionate they are, if they care at all. The fact that she was determined to get hold of me to tell what was going on…really mattered.* (Northern Virginia)

In addition, family members said that if they call the facility, they want someone to talk to who knows how their loved one is doing and doesn't mind taking the time to tell them. Similarly, while they are visiting the facility, family member want someone to go to about any questions that they might have. They also wanted any medical decisions or health care information to be clearly explained to them by facility staff. Clarity and communication about billing was also discussed as an important aspect of the facility's performance, according to many family members. Many family members also wanted to have an established meeting schedule with caregivers and those in the facility who develop the resident's care plan. Further, family members noted that they

wanted the staff to solicit their views about the resident's care and how the facility was doing and to be receptive to feedback.

> *I think it's really important for them to be telling you what's going on. You can't be there…24 hours a day.* [But you want to know], *how's she doing?* (Cleveland)

> [I think it is important] *to have a quarterly meeting with the…primary caregiver.....*[because] *unless you ask the specific question, you don't get that feedback.* (Northern Virginia)

Some family members also spoke of the importance of written documentation as a source of information.

> *Our facility has what they call a well-plan. I don't know if it's required by law, but I know for Medicare patients* [in the nursing home unit] *it's required to have one of those care things.*[4] *So I guess* [they felt] *it might not be a bad idea to do it for all patients. So everyone…has* [one] *every three months…It's just…nice, and that bonds things between the nurse and me.* (Northern Virginia)

Other family members chimed in about the importance of getting reports.

> *I get a monthly report from the nurse on my sister.* [Another participant asks] *"A written report."* [The family member responds] *Yes, a written report.* [The other participant replies] *"That is great!"* (Northern Virginia)

Staff communication with residents was also important to family members. Family members want staff to communicate with residents at the highest level the resident can understand. For example, if the resident is intact in communication, family members want staff to speak in full sentences. In, on the other hand, the resident if more impaired, then staff should use simple sentences or directions.

> *For example, when somebody is pretty high functioning, I wouldn't want people to be talking to them in a way they would when they are not so high functioning.* [It's important] *that they be respectful of the stage of the disease.* (Cleveland)

Family members also felt it was important for the staff to be able to communicate with the residents in clear, easy-to-undersant English.

> [People with] *dementias -- they are robbed of their ability to communicate and understand* [over time]…*so there are added linguistic liabilities here. It's going to make it even harder for these people to understand the spoken word, and foreign accents were very difficult for my father.* (Northern Virginia)

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[4] In nursing homes, federal law requires use of a uniform resident assessment instrument (RAI) that is used on admission to the facility and at least annually thereafter to assess the resident's strengths, preferences and needs and to develop an individualized plan of care.

Staff Turnover

A low turnover rate was brought up at the majority of the focus groups as a important criterion when looking for an assisted living facility. Family members felt that a low turnover is important for several reasons. First, they noted that it is important to have staff who are familiar with the residents, that is, who know them as individuals and understand their needs and routines. Second, they noted that, particularly for residents with some memory impairment, having familiar faces around is important. Finally, they noted that low turnover may be an indicator that the facility is a good place to work.

> *One thing, it was very important to me is what their policies and procedures were and what the criteria for hiring their staff and what they expected to their staff, and of course, what the turnover was because I think it's very important that once you have an Alzheimer's patient, they start identifying with somebody…And then, the next thing you know, they [the familiar staff] are off* [and]*, well, here's somebody else…new help.* [And] *who's this? You know? I mean, I will talk to my mother about her care giver and she'll still say, "Who's that?"* (Cleveland)

> *And the other thing I would list* [as important]*…was consistency of staff…..She* [my mother] *has been there six years…and she has some of the same aides she first had…..We knew the reputation of the facility as* [having] *very stable staff. And for them to…know how she likes her dresses on and how she likes her hair done. And they could reaffirm who she was.* (Chicago)

Several family members states that turnover has been particularly high at the places where their loved ones had been residents or currently were residents and discussed the difficulties this caused. Further, they spoke about the possible causes -- that aides are faced with demanding work, often low ratios of staff to residents, and low pay. They showed enormous sensitivity to this issue, though they did not know how to remedy the problem. Finally, though they thought it was important, they felt it was difficult to obtain information about turnover when looking for a facility.

Staff Continuity

For some of the same reasons that a low rate of turnover was important to family members, the continuity of staffing was also important. This means that several participants mentioned favoring a system in which their loved ones were consistently cared for by the same aides, a system some facilities refer to as permanent aide assignment. These family members felt that this consistency created less confusion for residents and gave the staff the opportunity to get to know the residents. Family members felt this enabled staff to know how residents like things, what the residents' customary routines are, what "sets the residents off," and how to avoid or manage any behavioral symptoms.

> *I would list…consistency of staffing because I think that…memory-impaired people…need very consistent responses and as minimal confusion as possible.* (Cleveland)

I mean, they [staff] *really make an effort to find out about things that were important to people in their lives and to reinforce those things and to deal with them as individuals. And I think they learn what kind of space they need. They learn, you know, to let them alone when they want to be left alone and comfort them when they need comforting and they're just great.* (Boston)

Family members also noted the negative consequences when residents received care from staff who were not familiar with them.

[People with dementia] *panic easily…And weekends…is where staff are not consistent…Those weekend nurses don't know him…and one time* [the weekend nurse called] *"Oh, we called the ambulance. Your father's at the hospital. We were having a problem with him." I got there, and he's not having a* [health] *problem…*[he just became agitated and difficult and] *the girl just didn't know how to redirect him.* (Cleveland)

Family members also recognized that low staff turnover and consistency of direct staff caregivers was not always possible. However, they noted that the facility could use assessment information in the loved one's record and a process for ensuring that information was known to all caregiving staff could remedy many problems. As one family member noted of the failure:

I would watch people write things down, specific things -- when this happens, you need to [do the following], *need to call…such and such.* [But] *if that person left, it was if they burned everything* [they wrote in the record] *all the way down to* [zero]. *It was like, "Oh…are we supposed to know that?"* (Portland, discharged)

Shared Sense of Responsibility

Finally, focus group participants mentioned that good quality encompassed the performance of all staff, and that how these staff viewed their role, whether they were aides or housecleaning staff, was a key indicator of a facility's quality. Family members asserted that it was a sign of a good facility when the staff interacted well with each other and had a sense of shared responsibility. They sought staff who <u>all</u> cared about the welfare of the residents, not one in which people just performed discrete tasks. One family member referred to it as the concept "***it takes a village…***"

[The] "it takes a village thing" is clearly something to think about when you walk into these Alzheimer's assisted living [facilities]. Is the guy who scrubs the floor willing to catch the [wandering] *person that just went out the door?* (Chicago)

Family members also took other signals from staff behaviors about how well the facility would care for their loved one.

In addition to staff who like the job [being important]*…staff who know your name. Anytime I walked in,* [or] *any one of my family or my husband* [the resident] *walked in from outside, no matter who [the staff person] was in the assisted living*

section…they knew our names. I mean, like the janitor, the cleaning lady, everybody. (Portland, discharged)

Another family member recalls being told by the administrator that they would give her a tour but that she should also feel free to look around on her own and talk with anyone she wanted to. As she walked through the facility, observing the environment and staff interactions, she entered an area of resident rooms.

What convince me was totally unsolicited. This lady, she was pushing a cart…cleaning rooms. And she comes up to me and…says, "Are you thinking of placing someone here?" And I said, "Yes, my step-father." And she said, "Oh, they give wonderful care here. They are really wonderful here." And when you get an unsolicited comment from a cleaning lady…it was really great. (Portland, discharged)

Some family members felt that as assisted living facility that both emphasized the importance of all staff members and allowed greater flexibility among "jobs" and "tasks" would be beneficial not only for residents but also for staff.

[Having] *the same people serving the food* [being] *the same people* [doing] *activities…that was good for familiarity* [staff knowing residents and vice versa]. *If the caregiver has a variety of tasks, they feel a little more competent, you know, a little more resourceful…They're not just a person who makes all the beds. They're doing a lot of different things.* (Chicago)

Another family member saw the downside of having staff who did not regard resident care and safety as part of their shared responsibility.

Getting back to the wandering thing…The only exit [my father] *could get out* [was the front door]. *The people at the front desk…have no idea who the residents are…..My father is very young looking, and they thought that he was just a visitor…But…this went on over and over again. So* [you need] *staff familiarity with the residents.* (Northern Virginia)

3.2.2 Services

Services
Sub-Categories: (1) activities; (2) physical assistance; (3) Alzheimer's disease-specific services; (4) medications; (5) food; (6) transportation and other services; and (7) assessment and care planning.
They asked what kinds of things my mother did…so they could provide those activities for her…Or [they would] discuss with her [what] she wanted to do…They still do that with her now. She likes to sew and always did, so now they let her darn socks and things. (*Boston*) There is a difference between keeping people busy -- entertaining people -- and having a really clearly defined therapeutic activity program that actually supports their remaining skills and encourages a certain sense of their independence and promotes a certain sense of self-esteem. (*Chicago*) There were no medication aides on this…unit on the weekends or at night. It was very, very frustrating to me…[because] my mother was on 24-hour a day pain meds." (*Portland*) Something we were looking for…was that…residents could go out in the van and just have a drive..We have to work for a living…so it was important to us, because my dad loves to get out. (*Northern Virginia*)
Across all the focus groups and discussion of various types of activities, the underlying theme was the importance of having services that meet the individual needs, preferences, and strengths of the loved one with Alzheimer's or other dementia. In addition, several family members spoke of the importance of evaluation or assessment of the loved one's customary routines, behaviors, preferences and needs and the development of an individualized plan of care or services. One family member reported that the facilities called it a "*well plan*" rather than a "care plan."

Activities

The need for activities, the importance of activities, and the impact of activities on the loved one's well-being was spoken about at every focus group. Indeed, the growing isolation of loved ones with Alzheimer's or another dementia who were living in home was cited as a major reason that family members sought out an assisted living facility. In addition, they spoke of their perception that the activities need to be specially adapted for persons with Alzheimer's disease.

Family members mentioned that the purpose of activities is not merely to keep residents busy or to manage behaviors but also to provide mental, physical and social stimulation. Thus, activities were seen as having both social (quality of life) and therapeutic roles. Moreover, they argued that is was important that activities be structured to meet the individual needs, preferences, and level of functioning of the residents. For this reason, family members felt that it was good to have a range of activities, structured and unstructured, offered in groups of different sizes. With a range of activities offered, there is more of a chance that there will be activities at which their loved ones can succeed--activities which are appropriate for their functioning level--an issue that was important to family members. We also found disagreement among family

members which appears to be related to (1) their perceptions about the course of the loved one's cognitive impairment and (2) their perceptions about the role of activities more generally. Some feel that activities such as setting the table or folding napkins or activities that the loved one "used to do" are most appropriate. Other family members sought activities that helped residents maintain function. Still other family members thought that it was important to introduce new activities that are primarily social and interactive.

> *She's happier, participates…a lot with the regular seniors on the other side of the facility, and hopefully she can stay there as long as possible. So far, it's worked out fine. The decline is so much quicker…*[if] *they're not stimulated at all,* [if] *they just sit in chairs.* (Boston)

> *Look for activities that are engaging and still passive, like story-telling, nail painting, routine hands on projects for the men…or something to where their hyperactivity is being managed rather than ignored.* (Portland, discharged)

Families also noted that some activities fulfilled multiple needs for the loved ones in an assisted living facility.

> *I think it* [having her hair done] *covers a lot of things…I was there the other day and walked by a room where they have their hairdressing, and…the women are all sitting around, chatting…and the hairdressers talking about things. And it's a very social activity. And it's something they are all out* [of their rooms and off unit] *to do…And they always get positive feedback when they are back. And they just love that. They need it so much.* (Boston)

Several family members noted the importance of having a range of activities that was sufficient to meet the needs and interests of residents with very different interests and backgrounds.

> *Not always just painting or coloring. My mother never sat and colored.* (Boston)

> *My father…he gets very bored…and what we're finding with the assisted living facility is…"Oh, there's bingo tonight." Well, he…never liked bingo. He's not going to like it now.* (Cleveland)

In addition, family members noted that they believed activities could help maximize their loved one's physical and cognitive functioning and that they wanted that.

> *There is a difference between keeping people busy -- entertaining people -- and having a really clearly defined therapeutic activity program that actually supports their…remaining skills and encourages a certain sense of their independence and promotes a certain sense of self-esteem…..I thought* [this facility] *had gone very quickly into keeping them busy instead of thinking about…the therapeutic value of what they were doing.* (Chicago)

> *I think what I would hope for as the disease progresses…is that they wil try to provide activities that maximize whatever stage that…*[my mother-in-law] *is*

at…[She's] at a relatively early stage…so that now, I'm a little disappointed…that they're not taking her out more, because she's good enough to be going to activities outside the facility. (Cleveland)

Family members also recognized the importance of activities that were, in a sense, purely social. Thus, they spoke about a wide range of activities, with participants in most focus groups discussing the need for variety and choices in the types and location of activities. This includes "inside" activities and outside activities (e.g., gardening, taking walks) and activities at the facility and other places (e.g., bowling, playing golf, playing tennis). Others mentioned such activities as having a girl scout troop come to the facility once a month and put on a show. Pets, from a puppy to guinea pigs, fish and birds, were mentioned by individual family members as providing both entertainment for residents and a sense of a homelike environment. Thus, variety and individualized activities suited to the person were central themes. As one family member explained:

[You need] *a plan based on the specific needs to be met for the individual. This gentleman's need was to vacuum. Another person's need might be to be a member of the resident council.* (Chicago)

In addition, family members observed that they liked a facility in which staff took the time to speak with the resident and family members in an effort to understand the resident's preferences and customary routines.

[They asked] *what kinds of things my mother did…so they could provide those activities for her…Or* [they would] *discuss with her* [what] *she wanted to do…They still do that with her now. She likes to sew and always did, so new they let her darn socks and things.* (Boston)

Personal Care & Supervision: Alzheimer's-Friendly Care

In addition to growing isolation in the community among people with dementia, family members spoke of their loved one's growing need for assistance with personal care and their need for protective oversight and supervision as being major reasons for placing the loved one in an assisted living facility. Three basic themes emerged. First, family members wanted the appropriate level of services and personal care provided at each stage of the loved one's illness. Many family members spoke with despair about facilities' failure to recognize and address increasing needs among the loved ones with dementia. Second, family members wanted facilities to recognize the impact of dementia when evaluating residents' needs for assistance, particularly among residents who appear physically intact and able to perform ADLs but who are memory-impaired. Third, family members wanted personal care performed in a way that maximizes the loved one's function and helps maintain it. Many family members spoke of high quality in personal care as being specifically tailored to the unique needs and abilities of persons with Alzheimer's disease. Thus, set-up, verbal cuing, and task segmentation were considered essential elements in helping residents perform at the highest level of

independent functioning possible. Finally, many family members care very much about the assistance facility staff provide in the areas of grooming and personal hygiene.

Adequate and Appropriate Amount of Assistance. Many family members spoke about their loved one needing some kind of assistance with personal care, including the activities of daily living (ADLs). Some loved ones needed only reminders, such as reminders to change their clothes, go to the toilet, take their medicine, and so on. Others needed supervision or set-up help and cuing, such as laying out clothing and cuing about the order in which to put on the clothing. Others need "hands-on" help with ADLs, for example, help getting to the toilet and assistance with cleaning themselves. Family members had much to say about how they wanted the assistance to be provided. Family members also mentioned that as time passed, their loved ones' ADL limitations increase. For this reason, family members emphasized the importance of understanding the policy of the facility in terms of ADL assistance. Some family members have had to move their loved ones because facilities could not or would not care for their loved ones as their needs increased.

Want Staff To Understand Memory Impairment. It was important to family members that the facility staff understand the consequences of Alzheimer's disease and other dementias for memory and decision-making.

> *My mother really needs constant direction, so if there was no one there, she would never take a shower…She'd get dressed, but she'd be wearing two or three dresses, you know, at a time or wearing clothes inside out. And so there's direction in a facility…where, you know, things are laid out properly.* (Boston)

> *I can't believe they'd leave her laundry in a pile on her bed…She doesn't know to put it away.* (Boston)

Want The Facility to Recognize and Address Declines As They Occur. Family members also noted that as the loved one lives in the facility, over time, their limitations increase, as part of the on-going course of the disease. Because of this, many family members noted that it was important to them to know what the facility will actually do and whether the facility will adapt the services it provides to meet these changing resident needs.

> *He started to need assistance with eating, with dressing, and by the time he left assisted living, he no longer recognized what the telephone was for.* (Portland, discharged)

> *It starts out with little help and gradually progresses to the point where they need a lot of help, and you…need a facility that can offer than capability.* (Portland, discharged)

> *From about March until June…*[my mom] *had a siege of diarrhea problems…I finally took her to the doctor, and the doctor put her on…*[medicine] *and said to…*[put her on a scheduled toileting program]…*And I was going to her assisted living facility every two days, picking up all the soiled stuff…and there's stains on*

her carpeting from where she didn't make it from getting out of bed. And I'm over there scrubbing her carpeting, because they're not doing it; they're not even aware of it. And when I say something, it's, "Well, you know, we really don't take care of these kinds of people." (Cleveland)

Maintaining Function. As with activities, family members reported that they wanted ADL activities performed not only with kindness but also with a focus on helping their loved one perform at the highest level of independence possible. This, in turn, will help maintain function as long as possible. Thus, the desire for set-up help (laying out clothing or bathing items), cuing (verbal reminders and directions to help orient the person to the task), and task segmentation (breaking an ADL activity down into sequential component parts, with cuing as to how the resident should do them) figured prominently in family members' comments.

> *They'll help her with her bath, but if you would give her the wash cloth and the soap, she could do it herself. If you would lay out the clothes for her, she will get dressed herself. What it is…she does not remember to change her clothes and get into a nightgown at night, and then* [in the morning] *to get out of the nightgown, and so forth. So she needs that direction.* (Chicago)

> *If you give her the toothbrush, help her put the toothpaste on and show her the action, she can figure out that she needs to brush her teeth. But you can't just say go brush your teeth. She needs to be cued to understand.* (Chicago)

> *She can feed herself if somebody starts her out and puts her into the routine.* (Northern Virginia)

Cleanliness and Grooming. Family members also talked about the personal care and grooming of their loved ones. Cleanliness is of particular importance to family members. They want their loved ones smelling clean, looking clean, and in clean clothes. Family members mentioned that in many cases grooming and hair styling is important for their loved one to feel good about themselves. Other family members mentioned that their loved one may not know the difference but that it helps the family member to see their loved one looking good.

> *And, like I said, if the people that are taking care of him -- it's important for me that he's clean, that he has on clean clothes. That would be more important to me than the quality of the food.* (Northern Virginia)

> *It's really important to me to have her looking spotless, because that's how she always was…*[Being well-dressed] *was important to her…It she was not…*[impaired with] *dementia, she would be looking her best on her own.* (Chicago)

> *She will put on my mom's make-up, and they will do her hair, and they will pick her out an outfit and it matches--it's how I like seeing my mother.* (Chicago)

I like [to see her looking] *a certain way. I do that for myself. They do it so many days a week, but my mother always kept herself a certain way, so I go in three days a week, shower, shampoo and do my mother.* (Northern Virginia)

At the same time, family members recognized the difficulties of working with residents who have memory impairment and some limitations in decision-making. Indeed, they also recognized that there was sometimes a trade-off between loved one's looking his/her best in terms of grooming, particularly clothing selection, and allowing the loved one to make his/her own selections of clothing. They noted that allowing residents to make their own choices often gave the loved ones a tremendous sense of empowerment and affirmation but did not necessarily result in their looking their "best."

I've seen the different ways of working…..I have a personal preference of one over the other, but they both work very well…In terms of dressing, now, one of the staff "coaches" mom, but lets mom make her dressing choice,…and mom will put on…some of the strangest combinations of clothes…They're clean…but nothing I would chose…But I walk up to her, and she is so proud…She went through this process of picking these things out…[and she will say] *"I'm choosing my clothes and I'm dressing myself." She's so proud of herself. But, then…*[the other aide] *works differently. She will put on mom's make-up, and…do her hair and pick out an outfit, and it matches. And it's how I like seeing my mother. But each of those…*[approaches] *are important. One of the aides gave my mom that opportunity to express herself, and the other one makes my mom feel like a million bucks because she looks good.* (Chicago)

Family members themselves felt conflicted over this issue. Some really cared about how their loved one looked, wanting them to be dressed and groomed as they were before the onset of memory loss and impaired decision-making. Others felt that the sense of empowerment that came to their loved ones when they made choices was important to their well-being. The following exchange during one focus group illustrates the issue.

Family member #1.

But it's so sad…My mom was always so meticulous about herself, and she loved jewelry and was always so careful in selecting outfits and matching jewelry…And then I see her now, and she looks…well, I'll try to change her outfit, and she'd argue with me. And I'll say "Are you my mother?" She will say "Yes." And I'll say, "My mother would never go out in an outfit like that, so let's change it." (Chicago)

Family member #2.

Yes…my mother has been in some strange combinations, summer combinations…[but it's fall] *And when you get there, she's already dressed. Well, I just get her to put a sweater on, make sure she is comfortable…*[but don't try to make her change clothing]. *Her feelings are more important than what I think is right.* (Chicago)

Medication Management

Medication supervision was also a service which family members thought was an important aspect of good care; moreover, it was cited as one of the reasons that families sought out an assisted living facility. In most cases, the term medication supervision includes storing the medicine, administering the medication, and following-up to make sure that the resident has taken the medication.

> *I was still trying to manage her medication, and she wasn't living with me then. I would call her and say I had the pill box all set up and have you taken them. But that didn't work. No, it doesn't because they could just say, "Well, yes I have." Sometimes she'd go into the bathroom and she wouldn't be able to find the box and, you know -- they she'd come back to the phone 10 minutes later and say, "Now, what was it I was looking for?"* (Portland-current)

Thus, family members wanted their loved one's to receive assistance with medications. In addition, they emphasized the importance of the facility understanding what is really involved in providing appropriate care for residents with Alzheimer's or other dementias. They noted that people with cognitive impairment may need a different kind of medication supervision than that required by other residents.

> *They hand her this little tiny cup with pills in it and say take your medicine, and she very calmly puts it in her purse or… -- I find them everywhere.* (Cleveland)

A family members from Portland noted: "*Don't let them take the pills back to their rooms.*" Another added, "Yes, make sure they've taken them." A third family member noted:

> *My mother clears off the table* [at dinner]. *I mean, she loves to help, and she feels sorry for the person on the evening duty, so she clears the tables off. Well…she'd be just as likely to pick up somebody else's pills and take them.* (Portland, current)

Other family members mentioned several issues over and above passage of the daily medications. Other topics related to the need for medication management to include monitoring medication side-effects and the need for staff caregivers to be more sensitive to residents with dementia who have communication difficulties. In addition, family members noted the need for medication supervision on *all* days of the week.

> [My mother] *was on pain medications*…[and the facility] *didn't count whether or not she had had a bowel movement*…[and] *narcotics do cause constipation.* (Portland, discharged)

> *There were no medication aides on this…unit on the weekends or at night. It was very, very frustrating to me*...[because] *my mother was on 24-hour a day pain meds.*" (Portland, discharged)

Family members noted the difficulty of having pain adequately addressed when the loved one has memory or communication deficits. They also recognized that it affected the resident across various types of health care providers. However, they felt it was important that facility staff be trained to recognize and address the special needs of persons with dementia in terms of medication management.

> *I think it's difficult when you have to have medical things…*[M]*y husband went for quite a while before needing them* [pain medication]*…We had his own personal physician…and…it was so hard because he could not relate. He couldn't say what hurt, and…the doctor, bless his heart, he just said "I don't know how to help him because he can't tell me."* (Portland, discharged)

> *My mother-in-law's doctor said she could have…*[medicine as needed] *for pain, and she did have a lot of pain. But she didn't have enough* [cognitive function] *to ask them for...*[the medicine] *unless the nurse went to her and said, "Are you in pain?"…But if she was complaining of pain, they didn't have enough sense to give* [her] *the* [medicine] *unless she specifically asked.* (Northern Virginia)

Food

Good food was an important factor to many of the family members when choosing a facility for their loved one. Pre-prepared food and "junk" finger food were generally looked down upon. Family members want the food to be attractively prepared and presented, tasty, and served in appropriate amounts. They also liked having attractive dining rooms. Many family members also mentioned that it was important for the facility to recognize the deficits associated with dementia. For example, they wanted staff to monitor the amount of food that their loved one actually ate, since some family members would forget to eat and then lose weight. Also, some family members argued that it was important to determine if a dietician/nutritionist were available and if special diets were available.

> *Nobody has mentioned it yet, but food was just super important to my mother.* (Chicago)

> *One of the things I looked for was excellent food. I arrived at three different meal times, purposely unannounced.* (Portland, discharged)

Some family members also felt it was useful to have a dietician on staff or as a consultant and to ensure that special diets would be available, if needed.

> *Where mom is, there is actually a paid dietician/nutritionist, but the other questions to ask are do you have a 1,000 calorie or a 1,500 calorie diet? A salt-free diet or lower salt diets available? Do you have dietetic food for diabetics?* (Portland, current)

On the other hand, as with many things, families felt that you must do more than merely ask to in order to determine whether the facility is providing what it promises, such as a nutritionist.

She was in the dining room three or four times a day [but] *they didn't monitor her* [intake of] *food. And the food was pre-pared* [just had to be heated up] *and wasn't appetizing.* [And when I asked] *who the nutritionist is, in this particular case, he's not with the facility but…with the company that sells the food to the facility.* (Portland, discharged)

Families also thought that the type of assistance loved ones needed was as important as the quality of the food or meal service. In this regard, they mentioned again that the needs of persons with dementia are different from those of other residents and that facilities and staff need to be sensitive and responsive to these differences.

You think that because they're in a place [that's good] *and that serves three meals a day, that they're going to get decent meals. I don't know how long my sister ate two boxes of frosted flakes and two glasses of milk three times a day. Until, finally, somebody* [another resident] *says "Why does your sister eat allthat cereal?" So talked to them* [the facility staff] *and said I think she does it because it's easier to do that than* [for her] *to make a decision to order from the menu. When they have dementia, a lot of times, they are not capable of making decisions. And so they stared fixing a plate for her then…rather than asking her to make the decision. So she gets frosted flakes for breakfast now, and that's all.* (Portland, current)

Well, my husband is currently in a situation where they have to watch him…..He's gaining weight, and I say "Hey, you know, I have observed that when he goes to picnics or something, he doesn't realize, he doesn't remember he's eating something else…..If somebody gives it to him, he doesn't remember he's already had two desserts. (Portland, current)

One family member noted that sometimes the elegant place settings in dining rooms were confusing for loved ones with dementia, presenting so many options a family member with more severe cognitive impairment gets "lost" and forgets the most basic thing -- which is to eat.

She needs her food fixed for her…cut up her food and not put anything else around her place. And I come at meal time, and she's got two forks and a knife, and she's got [other] *stuff, cups, glasses,* [salad and dinner] *plate. But it's too confusing, and she's not eating…These things sound great, but they're not always.* (Boston)

In addition, family members spoke of the importance of ensuring that their loved ones got appetizing food, whatever their level of physical functioning. Thus, while finger foods might help people with cognitive impairment perform more independently, families still wanted a variety of appetizing and nutritious foods provided to family members.

After she moved into…[a different unit of the current facility] *the food turned into…fried fish patties, french fries…*[that] *kind of plate. It was very minimally prepared; it was mostly finger food. I asked for double portions at least every other month, but I never saw the portions change. So there was this huge*

difference between what they said and what they did and how food changed between units. I can understand they wanted to make it easy for the patients, but the quality wasn't there. And it's funny, because after mom left assisted living and went to a bonafidenursing home, the food was gorgeous. She ate a lot more and she gained 10 pounds. (Portland, discharged)

Other family members felt the same way about wanting nutritious meas but recognized that unless one was willing to "police" the loved once, he or she would continue to make his or her own choices.

I want my father to have access to all the right food groups, but I know the only thing my dad eats half of the time is the ice cream. Now see, I don't worry about that. As long as he keeps getting the proper food options, he's going to eat what he's going to eat. (Northern Virginia)

Transportation

Some family members also argued that it is important that some sort of transportation is available if residents want to go somewhere or just get out for a drive. They also mentioned the importance of having transportation available to take residents to health care appointments, including doctors and dentist appointments.

Something we were looking for -- and I get the sense that maybe my dad is not quite as far along as some, even though I guess he's the oldest -- we were looking for an avenue whereby residents there, if they wanted to go out, say, for a drive, that they could go out in the van and just have a drive. I have to work for a living…so it was important to us, because my dad loves to get out. (Northern Virginia)

His [facility] *had a van for the first six months. They went on trips in the afternoon. They went to the Dairy Queen and got a milk shake. They got out.* (Portland, discharged)

Ancillary Services

Many family members mentioned that having certain ancillary services available would be helpful. Among them were having a facility that arranged for or had on staff a physician, a social worker, a hairdresser, a barber, and a podiatrist.

Some [facilities] *have a podiatrist who comes..It's great because the people -- their toes, their feet have problems, and they have calluses and they can't bend over* [to tend to their feet]. (Portland, current)

Do they have a hairdresser who comes in and does hair and how often? Do they have manicurist that comes in and does nails? (Chicago)

A social worker, maybe one day a week, just to deal with family. (Chicago)

The whole point is, do they offer a full comprehensive health care package? I mean, do they make a dentist available to your loved one?...a podiatrist?...doctor? (Northern Virginia)

Assessment & Care Planning

As discussed in the section on communication between staff and family, many family members also spoke of the importance of written documentation as a source of information and as a mechanism for planning a resident's care and also for communicating vital information to and from the family.

> *Our facility has what they call a well-plan. So everyone…has* [an up-date] *every three months…It's…nice and…bonds things between the nurse and me.* (Northern Virginia)

> *I think that's a very important consideration…*[having] *structured and timely and frequent evaluation, with the facility, with the* [direct staff] *caregiver, with the family -- concerning the person. I don't see that…*[in this facility], *but I think that's…important.* (Cleveland)

Another family member noted the importance of written assessments that record key information about a resident with dementia, who can't communicate such information for themselves. Moreover, the family member emphasized the importance of information being shared among all staff and becoming part of the knowledge shared across all the resident's caregivers.

> *I would watch people write things down, specific things -- when this happens, you need to* [do the following], *need to call…such and such.* [But] *if that person* [who wrote down the information] *left, it was if they burned everything* [they know and wrote in the record] *all the way down to* [zero]. *It was like, "Oh…are we supposed to know that?"* (Portland, discharged)

Other family members chimed in about the importance of getting reports, while some felt that regular meetings with staff were more useful.

> *I get a monthly report from the nurse on my sister.* [Another participant asks] *"A written report!"* [The family member responds] *Yes, a written report.* [The participant replies] *"That's great."* (Northern Virginia)

> *I think one of the important things to find out is whether or not there is a meeting between the staff -- meaning the administrator, the RN, the dietician, the case worker, the resident and the family.* (Portland, current)

> *A care conference, yeah* [that's important]. *I have a friend who has someone in another facility, and they have a monthly meeting, and he told me that he definitely would want that monthly meeting.* (Portland, current)

3.2.3 *Facility Environmental Features*

FACILITY -- Environmental Features
Common Space Sub-Categories: (a) Alzheimer's-friendly feature; (b) Safety; (c) Architectural features; (d) Aesthetic qualities/amenities. **Personal Space Sub-Categories: (a) Personal room type; (b) Cleanliness; (c) Aesthetic features of the rooms; (d) Homelike qualities of the rooms.**
Safety is the first thing.. (*Northern Virginia family member*) An environment that has been adapted to provide for [residents with] dementia. (*Chicago family member*) One of the things that I don't think works well…is multiple floors. I would not choose that again. (*Boston family member*) Avoid a [facility] lay-out that isolates residents. (*Northern Virginia family member*)
In terms of the general or common space, family members wanted safety, with particular emphasis on the special safety needs of persons with dementia. In addition, families wanted their loved ones to have access to a pleasant and safe outside area. Further, family members in all focus groups spoke of the importance of the residents' personal space. The room's cleanliness, making the setting homelike, and allowing residents to bring their own furniture were cited as key components of good physical environments.

Common-Space Features

Family members want safety first and access to the outside second. Safety features most commonly mentioned included locked facilities, enclosed court-yards, and some type of "wander guard" alarm, so that staff will know when someone leaves the building. This highly expressed need among family members to keep the loved one with Alzheimer's disease from wandering off was almost always accompanied by a desire to have access to outside space, usually described as a patio or courtyard. The category of aesthetics, is relevant here as well, for family members wanted courtyard/patios that had flowers, walking paths, and sitting areas that are attractive.

Safety. Most of the things family members mentioned in terms of safety dealt with features that ensured the safety of loved ones with dementia who wandered. In addition, however, they noted that safety includes features that minimize risk for falls and addresses a variety of issues, including safe physical environments, proper nutrition, and, as discussed elsewhere, such things as background checks on staff.

> *Safety is the first thin. And…then you want comfort and… this and…that, but safety, you've got to have that before* [anything]. (Northern Virginia)

> *We needed him to be safe, first and foremost. And that encompasses proper nutrition, proper physical environment, just the basics of life. Beyond that, everything else is, you know, gets to be more of a luxury.* (Northern Virginia)

The [facility] *my dad* [was in] *was totally flat. In the building, there wasn't a step higher than this* [indicating with her hands]*…There were handrails. You would have to work hard to trip or fall.* (Portland, discharged)

I would favor an Alzheimer's-specific assisted living community over a mixed community because the Alzheimer's-specific community tends to have the protecting types of environmental…[features] *perhaps attractive fencing…that will allow people a certain amount of their "dependence" but freedom to go outside without getting lost.* (Chicago)

While family members were unanimous in all focus groups about wanting a safe environment for their loved ones with Alzheimer's disease and other dementias, they expressed different opinions about what constituted a "safe" environment. Some wanted locked units; others wanted units that loved ones could exit into a safe setting, such as an interior courtyard. Still others wanted units with alarms or doors that would open only with a code, which facilitated movement around the facility and grounds for residents who were accompanied by staff or family members. Yet, they recognized that not all solutions worked for all residents. For example, one family member realized that her father learned the new codes and frequently escaped the facility. Moreover, families noted that even good safety measures could be defeated by staff inattention. The following discussion from the focus group in Portland illustrates some of those issues.

They don't always turn the alarms on. My mom doesn't wander, but she likes to go for a walk occasionally [with the dog she has as a pet in the facility]. *And sometimes she gets turned around, gets confused…* [about] *where she is. Fortunately she knows that, so she asks for help finding her way home. She doesn't know where she lives, really, but the dog is licensed* [friendly laughter from the group] *and has a tag with the facility address.* (Portland, current)

My husband now has a dogtag! After he wandered away a few miles from the place, I got an ID tag…They leave the door open or something, and he's out and he will not be able to find his way [back]. (Portland, current)

One of the things I noticed just by visiting lately is that when the alarm goes off and the caregiver is in the kitchen, they can't hear it. [Portland, current)

Yeah, they're supposed to have the alarm on the door, but they don't. They get tired of it, so they turn it off. (Portland, current)

Attractive Outside Area. Family members in all focus groups mentioned wanting loved ones to have access to an outside area that is both safe and attractive and allows for a variety of outside activities. In fact, this desire was expressed in terms of multiple family goals. They wanted a safe area, an attractive area, and one that facilitated various types of activities. In addition, providing loved ones with access to an outside area was considered an essential component of having a homelike environment.

They have an enclosed open area, which is also really nice..It's like an enclosed patio. It's a real plus…..They've had some cookouts there. That's where they had

a birthday party in May. They have tomato plants and flowers, and they have a path to stroll around…The exercise bike is out on the patio now in the summer time. (Boston)

He had his own room and a bath, and he could go out….They had beautiful patios…..He loved to be outside, so I was looking at landscaping. (Portland, discharged)

Opposition to Multi-Floor Facilities. Another common theme among family members was opposition to multi-floor units. Several focus group participants spoke of the advantage of having a facility with multiple levels of care and wanted a secure, locked unit as their loved one's impaired orientation and decision-making skills worsened. However, only a few wanted that secure unit to be on a second or third floor. Most expressed the opinion that a ground-level unit was more homelike and allowed family members more access to enclosed outside areas for walking and more homelike scenes out the windows. Families also mentioned such negatives associated with multi-level facilities as safety, in case of fire, resident fear and confusion over operating elevators, and issues related to staffing levels and staff responsiveness for residents with dementia in a very spread-out facility. However, as noted, the multi-floor issue was also tempered by perceptions that loved ones with advanced Alzheimer's disease were perhaps better off with a separate floor -- that somehow this was more safe.

One of my mother's agitations is she always wants to get down [to the ground floor]. *She wants to go out or she wants to sit in a room where she can look out. You know, up in her room, you just have a little window….Everyday, she wants to just keep going down onto the first floor so she can sit outside or see out.* (Boston)

I made my decision on… [whether] *it was a high-rise or a first-floor level building. I had thought that she'd be safe if she was on the second floor and couldn't walk out the door. But our whole life has been one-story living, still is. So I have decided that a…*[one-story] *building is good. She can look out walk out on the patio, more like our house.* (Chicago)

One of the things that I don't thinks works well in the facility where we are is the multiple floors. I would not choose that again. Part of it's the elevator issue, part of it's -- the staff is too spread out….Ladies are always wanting a jacket…a coat…[or] *a sweater, and they* [the ladies] *are always downstairs. Somebody …has to go upstairs and get it.* [But] *they* [staff] *always get sidetracked they forget what they're doing…and it's so disorienting, you know, and* [the ladies], *they'll say "I want my sweater; I want my sweater," and then you get somebody who's agitated.* (Boston)

Other Alzheimer's-Friendly Features. Family members were quite knowledgeable about other things they viewed as "Alzheimer's-friendly features," and they wanted them in their loved one's assisted living facility.

You have someone with Alzheimer's, and you want to place them in a unit, then you need to know that this unit is for Alzheimer's. [That they] *have the facility*

constructed or at least modified to accommodate Alzheimer's…It's not just putting a corridor [of rooms in] *and saying "This is for Alzheimer's."* (Cleveland)

Family members mentioned features that included:

- Good lighting.

- Color-coding and other visual cues to locations within the facility.

  Outside of their rooms, there's a place where you put pictures, so they know where their room is. They look, they see themselves. They see a picture. Those are the kinds of things that I also looked for. What are the…visual <cues> that these people offer in this environment? (Chicago)

- Central nurses/administrative station "*so they can look around the perimeter and see all the* [resident] *rooms."* (Portland, discharged)

- Small eating areas to minimize sensory overload and allow for better supervision.

- A circular walk *"so that starting at point A…so they can walk around and not get lost and end up in the same place that they started."* (Cleveland)

- Separate activities area.

  I think also having an area for activities that is somewhat separate. I know a lot of [people with dementia] *and my husband's one…that got to a point where they couldn't stand to hear the music and didn't want to be around people…I mean he would become…agitated when the music was load.* (Portland, discharged)

Families also spoke of the need to avoid an environmental lay-out that contributed to isolation.

  [Avoid] *a facility that isolates the resident. And as I think you said, certainly* [you should look for]…*the layout of the facility that would encourage people to get out of their apartments or rooms or wherever they are.* (Northern Virginia)

For example, several family members spoke about seeking walking areas that encouraged residents to walk about and avoiding facilities with long hallways and "dead-ends" *"where they all gang up at the door, kind of like trapped bugs waiting to get out."* (Portland, discharged)

  One of the things I still think is important is the centrality of the rooms to…[the places] *they need to go, like where the nursing unit is, where they eat. They all have to…*[be] *real…accessible. The hallways have to lead to that* [common areas]…*not stairs, elevators.* (Northern Virginia)

  They don't live down a long hall…[like a nursing home or apartment building]. *They live in a house, and it promotes a sense of community,…a sense of*

family……They are in rooms and not in apartments but rooms that…[open] *right into the hall, so that people would come out for activities.* (Chicago)

My mom, like you said, they [residents with dementia on her unit] *like their area. It's two halls that converge around this gorgeous dining room area, and the nurse's station is there…My mother used to think it was a hotel -now I'm not sure, but she loved it.* (Northern Virginia)

Personal Space

The two most important things in this category for family members were that a facility be clean (have no unpleasant smell) and that their loved ones could take their own furniture to their room or apartment. In addition, a consistent theme across focus groups was the notion that a facility should be "homelike." Homelike included things like having their own furniture and their own rooms and bathrooms, but it also included activities and a structure that made day-to-day life in the facility seem like home. An example of structure was the physical layout and having personal possessions. Processes that were homelike, according to family members, included having staff call everyone by their first names. Homelike activities included setting the table, folding clothes, etc. An additional element of homelike for some was the ability to take a beloved pet to the facility.

This topic of personal space also generated information on how family members perceptions of quality changed as their loved one's needs a changed over time. That is, what was initially important to family members when they were selecting a facility often changed, with some elements becoming less important, as the resident's level of impairment and care needs increased. In particular, the issue of whether family members wanted a room or an apartment figured in this discussion, with no clear consensus other than the recognition that over time, family members' perceptions of what their loved ones needed changed as the disease progressed.

Cleanliness. Family members in all focus groups mentioned the importance of cleanliness -- which they judged by the facility's appearance, and as noted earlier, by the appearance of the residents. In addition, the "smells" in the facility were also a key indicator used by many family members to determine whether the facility was clearn.

Yeah, I think the problem from my standpoint was I was looking for something that was clean, neat and I thought it would be a nice place to move my mother. (Portland, discharged)

I would tell [a friend], *use their noses…I have a very sensitive nose, and smells tell me cleanliness.* (Boston)

I would avoid a facility that had caked-up food all over the floor…It's difficult at best to keep things perfectly clean, [but] *something that atrocious would be unacceptable.* (Northern Virginia)

Personal Furniture and Possessions. Almost all focus groups mentioned the desirability of being able to furnish the resident's room with the person's own possessions, including furniture, pictures, plants, and so on. Family members felt this helped "orient" the loved one, making it seem familiar, and that it also created a more pleasant and homelike environment.

> *It's her furniture in there and her bedspreads and her pictures on the wall and everything, so the independence of still having her space…She can get away from the group and be in her little place.* (Boston)

> *One of the things that was very important to us in choosing the facility was that she could take her own furniture because that was…how she knew who she was basically. By recognizing her belongings and not just her clothing or anything, but the embroidery she had down and, you know, all her pictures on the wall and just all the things that told her who she was because that was slipping away.* (Cleveland)

> *My mother's unit has her own bedroom, bath, living room, kitchenette…..so she could put her living room furniture, bedroom furniture,…and everything…That was important because when she was in the nursing home, she was sharing a room with their furniture. Here, she can go in and see all of her things, and…she thinks she's home.* (Boston)

> *The* [furniture] *arrangement is exactly like her room arrangement at home, if you came in the back door. At first, she was confused about that, and I told her, "It's just like at home, if you came in the back door." And at that time, she was still with it enough that she caught on, and it hasn't been a problem since then.* (Portland, current)

Homelike Environment. As noted, family members defined one key aspect of homelike as being able to furnish the loved one's unit with their own possessions. However, it consisted of other elements as well, including the overall environment of the facility (e.g., looks like a house, has an outside patio or courtyard) and the activities available to residents.

> *I think all of this keeps leading us back to that home-like environment* [is the] *second thing* [I looked for]. *Further things that, I think, summarize this very well is not just* [to] *provide the space when people can have their own furniture, but provide people with the kinds of things that you do with them in everyday situations. You go there around a meal-time for example, you have some people…setting tables, you know, folding napkins, putting them at each place or doing flower arrangements.* (Boston)

> *One of the reasons why I chose the particular assisted living facility that I did was…the fact that I wanted…my mother's life at this community to mirror her life in her home and her <original community> as close as possible. That she would have the similar kind of lifestyle and stimulation that she had in her home; however, she would be protected and…the environment would…meet her needs.* (Chicago)

She has a little dog and this dog is -- the two of them have been inseparable for 16 years, 17…[The facility] *said that they would allow my mother to have the dog, and so even though we're not totally satisfied with the facility, my mother has a very good friend* [there]*, Danielle, who are inseparable and she has the dog.* (Portland)

3.2.4 Facility Policies

FACILITY -- Policies and Practices
Sub-Categories: (1) age in place; (2) different levels of care; (3) separate units for people with dementia; (4) cost; (5) background checks on staff.
My mother is 81, and she's been in her present place for four years. [She] started out being able to assist with dressing and feeding herself…She's pretty much bedridden…Mother walked in and will not walk out, and they agreed to take care of her through the end. (*Portland family member*) There is no way. An assisted living facility is going to do certain services, and they're going to go so far and that's it. When my father got sick and went into a hospital the doctor said, "I cannot release him to go back there…He needs much more care than they are going to be able to give."….. I think assisted living is great, but the families need to recognize earlier than I did when it's no longer appropriate. (*Portland, family member of discharged resident*) I mean, everybody's going to run out of money, you know, and then what? (*Chicago family member*)
Family members discussed several other topics that related more generally to facility policies and, to some degree, particularly in terms of cost, public policies. First, there was considerable comment about whether family members expected their loved one to be able to stay indefinitely in assisted living and "age in place." While family members are nearly evenly divided on the issue of whether the resident would be able to stay in the current facility and receive more services as needs increase, the bulk of comments during the focus groups came from family members whose experience suggested the difficulties they had experienced with "aging in place," both in terms of ensuring adequate care and increased cost. Second, concern about price and how long families would be able to support the cost of assisted living were common across all focus groups. In addition, some family members reported difficulty in estimating monthly costs because of (a) unexpected costs for some services and (b) cost increases associated with increased levels of care that are poorly understood by some family members. Finally, family members discussed the desirability of having separate units for persons with Alzheimer's or other dementias and of having multiple levels of care at an assisted living facility. They also discussed the desirability of having the assisted living facility be part of a multi-level campus.

Family members discussed a variety of issues that, while touched on in previous domains, also related to facility policies and features they consider essential to their ability to secure high quality of care in assisted living. Some of these policies and practices relate to whether the resident can remain in the facility indefinitely ("age in place"), with the services provided by the facility changing to meet the increasing needs of the loved one. Other practices relate to how the facility is organized in terms of having multiple levels of care and separate units for persons with dementia. A major, but difficult to discuss issue for families, was the cost of assisted living. Finally, family members mentioned a few other miscellaneous issues, such as policies on visiting

hours, use of chemical and physical restraints, and the desirability of facilities ensuring they conduct background checks on staff.

Ability to "Age in Place"

One of the most problematic issues for family members in all the groups was the concept and practice of "aging in place." Family members spoke of coming to terms with compromises over what they wanted, what had been promised, and what they learned they could reasonably expect. As with other important issues, discussions about aging in place included considerations of change over time, and the facility's and family member's inability to predict the course of the functional and cognitive limitations associated with Alzheimer's disease. Moreover, there was considerable discussion of whether some facilities promised things they could not deliver because they had too little understanding of what was involved in providing care to meet changing needs.

As reported in the results of the demographic survey, more than half (54%) of the family members who participated in the focus groups felt that their loved one would be able to age in place in the current assisted living facility. Slightly fewer than half (46%) felt that their loved one would have to move, as their care needs increased. The experience of the families of discharged residents, as well as the experience of those whose loved one had been in the facility for some times and experienced a decline, suggests that this is an issue fraught with difficulties. Some of our best evidence of this comes from the group conducted with family members of discharged residents. However, we have included quotes from all the groups as illustrative of the diversity of the program.

> *We knew up front that* [this facility]…*was going to be able to provide that kind of care* [aging in place]*. They said to us at the beginning that's their philosophy… and that this would be their home until they die. So that the hope is that unless they really are not ambulatory, as you indicated that they can stay there until they die and won't have to go into nursing home care. We certainly pay a premium for these additional services. It's not part of the basic assisted living.* (Boston)

> *There is no way. An assisted living facility is going to do certain services, and they're going to go so far and that's it. When my father got sick and went into a hospital the doctor said. "I cannot release him to go back there. You must make other arrangements. He needs much more care than they are going to be able to give."…When I went to get him and move him out of assisted living, one of the little residents -- she's a sweet lady, totally with it, she comes up to me and she says, "This is really good for him" she said, "because you know they really don't have time for him." So I could see that, okay, things had changed a lot and he really did need…to leave there…I think assisted living is great, but the families need to recognize earlier than I did when it's no longer appropriate.* (Portland, discharged)

> *The do have this aging in place concept…..that as more care was needed, they would be able to provide that. And, truthfully, they did…but* [only] *…for a very few people. And one of the reasons that I wished I had acted sooner…*[is] *my dad*

wanted to walk less and less. He kept saying his legs were too tired, he couldn't walk, he couldn't walk. I did not realize, because I would see him sitting down all the time -- he had developed contractures…If that's starting, you can do something about it, [but] *he was already contracted…By the time he went to the hospital, they said physical therapy…isn't going to do a bit of good…And so, they say they can accommodate aging in place, but no. No. No. And that is something I feel dreadfully bad about…..his little knees are bent up to his chest. It's been really sad…But this aging* [in place] *-- I know it's a good concept, but I don't think it works…But, yeah, it's what they tell you.* (Portland, discharged)

My mother is 81, and she's been in her present place for four years. [She] *started out being able to assist with dressing and feeding herself…She's pretty much bedridden…Mother walked in and will not walk out, and they agreed to take care of her through the end.* (Portland, current)

Some family felt that part of the problem was communication. The facility said "aging in place" or that it would allow people with incontinence to remain in the facility, and family felt confident the loved one would be able to say throughout most changes. However, the reality of what the facility meant and what the loved one experienced and needed were different.

When they say they can handle incontinence, you need to know what that means…If they are incontinent [and] *can take care of it themselves, were the appropriate thing, do their own laundry if there's problems with wetting the bed every night. You know, staff will do one laundry per week. They'll change the bed once a week. And so one lady has to…*[move] *because she couldn't do her own* [sheets]. (Portland, current)

Ah, that's kind of like my mom. It's…more that they [the facility staff] *are finding that they don't have time to do. When you go into these places, they tell you that they're going to cue them and they're going to help them, and they're going to do all this. And she's there, and now they are telling me, "She requires too much"…because you can't just say "Mattie* [name changed], *put your shirt on." Some days Mattie will do that, and a lot of times, she'll just sit there and won't know what to do…..Brushing teeth. You can't say "Mattie go in the bathroom and brush your teeth. You have to go in with her, stand there, hand her the toothbrush…cue and remind her every step…..And they're telling me they don't have that kind of time.* (Cleveland)

Age in place…it's a philosophy that I don't believe can happen…I don't believe that was happening at this facility. So I have a lot of anger about how she was treated and the competency there. What they were saying was what they truly believed, [but] *the outcome was different.* (Portland, discharged)

Multiple Levels of Care & Need for Specialized Care Units

In many of the focus groups, family members expressed the opinion that people with Alzheimer's disease have unique needs and that they may need special facilities rather than being in a unit with a mix of cognitively impaired and cognitively intact

residents. Further, many argued that within Alzheimer's-specific facilities, different levels of care should be provided.

Desirability of Multiple Levels of Care. Although the discuss was not specifically focused on issues related to different levels of care, it appears that families thought about the issue in two ways. First, some families wanted different levels of care provided within the assisted living facility, tailored to the level of cognitive impairment and, it would appear, behaviors of the residents. Family members who discussed this expressed the opinion that the separation afforded by having multiple levels of care would be better for loved ones, particularly those in relatively early stages of physical and cognitive impairment.

> *She would be disturbed if she was in a building with nothing but Alzheimer's patients who had no control or had no kind of manners or anything like that, so in a sense it is good if there is a separation.* (Portland, current)

> *We…chose not to have her enter the Alzheimer's* [nursing home] *unit but enter the assisted living in this other building that had a number of mentally intact people…In our view, for her to have entered the Alzheimer's unit, where we heard a lot of yelling and a lot of much more aggressive behavior, would have been more frightening to her.* (Cleveland)

In addition, some family members felt that a facility with different levels of care within the assisted living facility would be able to allow their loved one to "age in place" at least in so far as they could stay in the same facility and merely move to a different floor or unit of that facility.

Other family members discussing multiple levels of care meant a multi-level campus that had independent or retirement apartments, assisted living, and a nursing home on the same campus. They tell this facilitated movement of their loved one from one setting to another, as needs changed, without the same type of burden other family members would face in finding an entirely new facility. Some also thought it might reduce the dislocation the loved one would feel if the setting (the campus) were still familiar.

> *But I think that…you need to know that they have…different levels of care,…level one, level two, and level three. That if they come in and they're pretty much okay, they are level one, and …they advance to level two…..But you need to know that if they get really bad, will they still keep them, and are they trained to take care of the Alzheimer's* [patient who is]*…totally…out of it.* (Portland, current)

> *You know, that's why I like the idea of…*[multiple] *levels within the same facility that progresses with the disease…because it's very difficult* [to move] *them once they're in a facility…I wasn't sure how I was going to accomplish it.* (Northern Virginia)

> *At least I know that he can move from…one floor to the other, which is easier, I think, to be in a facility where you can move within the facility.* (Northern Virginia)

One of the reasons why I chose [this facility]*…is that I did not want to have to move my mother again, which meant that I wanted a facility that as she became sicker, that could provide for her nursing home needs… There would be a continuity of care, and if she… had to go to the hospital, that she could go to the nursing home wing for that period of time that she had to be rehabilitated and then return and still stay in the same* [assisted living] *complex. (Chicago)*

At the same time that many family members expressed these opinions, the issue of disease progression was differentially experienced by family members, and thus their responses cover a range of perceptions about whether special care units and different levels of care were an essential part of quality. Thus, some family members did not feel that these were essential.

Need for Specialized Alzheimer's Facilities. In prior sections, we touched on what families identified as "Alzheimer's-friendly" environmental features, special needs of people with Alzheimer's, special care needs, and their perceived need for staff to have specific training in care of people with Alzheimer's disease. In addition, families discussed the need for the facility to have in place procedures for (1) determining the needs of the potential resident and whether the facility could meet those needs; (2) providing care tailored to the needs of their loved one; and (3) since these needs could be expected to change, that the assisted living facility must institutionalize a process for keeping up with changing needs. Many family members expressed the opinion that these elements of good care would be found in specialized Alzheimer's facilities. Other families felt that not all places calling themselves "Alzheimer's Special Care Units" (SCUs) actually had the environmental features and care practices they thought of as "Alzheimer's-friendly." Thus, some family members felt it was important to determine whether the facility was "Alzheimer's -friendly" by looking for specific environmental features and care practices -- rather than making assumptions based on whether a facility "called" itself an Alzheimer's SCU. The family members seemed to feel that the safety of locked units or units with other security features was the most important element missing from facilities that were not specialized for the care of persons with Alzheimer's disease or other dementias.

The Cost of Assisted Living

Family members also discussed cost issues, although there was initial reluctance to raise the topic. However, once one participant brought the topic up, the family members in the focus groups would look around the room, check each other out, and then jump into the discussion. The initial reluctance of family members to raise the issue of cost has implications for any population-based survey, since it seems that this is a case in which the group process allowed a topic to be discussed, whereas individual respondents on their own might not feel free to mention the issue.

Family member comments about cost included the topics of (1) lack of Medicaid reimbursement for assisted living (in four of the five sites); (2) feelings about spending down their loved one's money; and (3) facilities' policies about charging for services (i.e.

hidden costs). Cost issues were most often brought up at the end of the focus group, when we were looking over our lists to see if we left anything off. Often the discussion started with discussions about shopping for facilities and advice one would give a friend about what to avoid -- that is, facilities with hidden costs.

First, family members had concern about exhausting the resident's personal funds and what would then happen to the loved one in assisted living. They noted that assisted living was typically expensive; moreover, in most of the sites, Medicaid coverage was not available for assisted living. Families recognized that this probably meant that when the private funds were exhausted, the resident would have to move to a different type of facility, probably a nursing home. This was a topic of concern raised in each of the focus groups.

> *Another factor I think should be considered is…when the money runs out, what will the facility do?* (Portland, current)

> *Another issue that I looked at is the <long-term> potential for money. If mom had been there for a long period of time, what was the reality that if her money ran out, she would be able to stay there?* (Chicago)

> *Well, I mean, this cost factor is very important to most people…..*[You] *can never get any Medicaid help* [for assisted living]*….So you know, at $4,000 a month, most of us are not going to be able to continue that very long. And, you know, the savings are gone and everything… Let's face it, there's no way in most cases that can go on.* (Cleveland)

> *There are limited number of people who can afford assisted…when people ask me, you know, they see the facility and they say how nice it is and it's very homey, it's very comfortable and beautifully decorated and then they say "Well how much does it cost to have your mother there?" and you tell them. You know, they can't believe how much it costs on a yearly basis. And most cases, even if somebody's children are doing well financially, you know, there's no way that they could afford to maintain their family and a person in an assisted living complex. My mother's care is almost my entire salary.* (Boston)

> *Affordability has to be kind of up there too. I mean, you look for different things. You look for obviously the most that you can afford, but if you can't afford beyond that, you have to make certain compromises.* (Northern Virginia)

Family members also noted that just as it was important to understand what a facility meant by level of care, it was important but sometimes difficult to understand exactly which services were included in the price.

> *I didn't get answers, period. Now I would say, Alright now, so it's so much a day at such and such a level. Now what does that include?"* (Northern Virginia)

> *Yeah, the fee. What does that include? This was assisted living you know, and it's ah, "Ok everything you need, everything you need, everything you need." And I said, "Well, now does it include shampooing? Does it include--" "Everything you*

need." Never go a "Yes." Never got a "No." "Everything you need. Everything you need." She opens the door and shows me their gorgeous exercise equipment. I said, "Of course, that's extra." "Everything's included. Everything's included." Well, you know, she lied through her teeth. She knew she was lying through her teeth. What am I supposed to do? (Northern Virginia)

Some of the other services [podiatrist, haircuts, incontinence supplies] *are offered at a cost, and some of them are really expensive. I think you need to ask what are your services, and get a whole list of 25 services. Some of them have a flat fee, and some charge you for every little thin…But mostly they have a list of services available for level two and level three. But you need to know all this ahead of time.* (Portland, current)

It is important to also note that for some family members, a major cost concern was the fact that costs increased as the services their family member needed increased. This was mentioned in relation to the ability of the loved one to age in place, as shown in some of the quotes presented earlier in that section. While this was generally expected, family members expressed some concern about the difficulty of understanding what types and amount of services were covered at a particular level of care and about the difficulty of estimating in advance when these cost increases would occur. In addition, as noted in the earlier section on communication, families wanted facility administrators to make these issues clear in the beginning and as their loved ones' needs changed and the price increased for additional services.

Hidden costs and the different costs increasing…there are some cockamamie concepts in terms of…what you pay…and its very hard to get a straight answer…..If they need another level of care, whatever that means at that place, your cost just goes up, goes up 20 times. (Chicago)

The only thing that really…bothered me or I had questions about was that it seemed like she was six months in one [level of care and price category] *and then the price went up. And she was in six months in another, and then the price went up.* (Portland, discharged)

We pay extra now. It's gone up…an extra $900 a month to get these extra services, and they don't do her medicines. (Boston)

Other Issues

Facility Policies on Communication with the Family. Although communication has its own code and discussion under "staffing", there were a number of communication issues relevant to policy. Family members wanted to make sure there are clear policies for communication with the family, and that the care being provided is clearly communicated, monitored and evaluated. Since they expected needs to change, family members wanted to have assurance that the facility would keep on top of changing needs and communicate that to the family. Some issues related to this were presented in Section 3.2 in which family members' views on the topic of assessment

and care planning is reviewed, but it also arises under the topic of facility policies and family views of facility responsibilities.

Other Topics. A variety of other topics were raised by individual family members, but did not generate the level of comment and discussion as the other issues and topics we presented. These included such topics or policy issues as visitation policies (*people thought they should be able to visit whenever they wanted to*), background checks (*family members thought that background of staff and volunteers should be carefully checked*), and policies on pets (*pets should be allowed, but that can create problems when the resident can no longer care for the pet*), and use of medications or restraints to deal with residents who wander or have other behavioral symptoms (*people thought this should not be done*).

3.2.5 Change Over Time in Views of What is Important

Throughout the focus groups and discussion of what they thought was good quality and what to avoid, family members noted that over time, either their perceptions of what quality was or the relative importance they placed on various aspects of quality changed. Part of the change was associated with becoming more expert about what goes on in assisted living and what actually matters in the day-to-day lives of residents with dementia. But the majority of altered perceptions seemed to rest with changes in the loved one's condition and care needs, which shifted family member's focus more squarely onto care issues. These issues also played out in the area of the facility environment -- both the public and private spaces.

Many family members felt strongly at first about the importance of their loved one having an apartment and as "normal" a living environment as possible. However, many of the features that seemed initially attractive to families about apartments became less important over time.

Our original thought of assisted living was an apartment for her…For us to make the decision to have her be in just room with a bath was really very hard for us. I mean, they kept assuring us that…she'll be happier, that most people [with dementia] *are happier when they can see all their stuff…And they were right, but it was very hard for us as family members to have her go from a big house to one room…..I'm happy with it* [the room] *now, but I still would like for her to have…her own little refrigerator or something, and that's probably my problem more than hers* (Cleveland)

I think there's something about the person putting a loved one in a place, you have to know that [the loved one] *is comfortable…I just knew that I wanted my husband to be comfortable and to be…in a place that he liked when he looked around and that I liked when I looked around. I don't think you know all this other stuff is so important* [when you first start looking]. (Portland-discharged)

She got to the point, well, she doesn't want to leave the apartment for fear of getting lost. She's very uncomfortable, so she became isolated in the apartment, not leaving it. (Chicago)

The same was true about having lots of personal furniture and possessions.

> *Even the old things, my mother doesn't remember anymore…At first it was important to have those things [furniture] that were familiar, but now, no.* (Portland-current)

Similarly, many of the amenities families found attractive and aesthetically pleasing at first became a source of difficulty as the loved one's condition worsened. Some family members noted, for example, that if any of the residents were incontinent, things like carpeting and upholstered furniture may become stained and contribute to unpleasant smells.

> *Upholstered furniture, wallpaper…see, those are all things that everybody looks for, looks nice…*[but are] *things to avoid…They went in for carpeting there, and then the carpeting just got saturated with urine.* (Portland, discharged)

As noted, some family members said that things they considered important when they first looked at facilities were different from what they subsequently viewed as essential. For example, they initially considered appearance (looked home-like, carpet, upholstered furniture) to be important but later came to recognize that function (flooring and furniture that can be easily cleaned) is also important. They originally wanted their family member to have a home-like apartment, but later those features became unwanted. For example, family members noted the following:

- Having doors on the bathroom was homelike, and even taken for granted, but they became a problem when the loved one didn't recognize that there was a bathroom behind the door.

- A kitchen sink seemed like a good idea, but when the person no longer knew how to remove the drain device, the sink would overflow.

- Having a television remote control was nice until the person could no longer operate it.

- Telephones seemed like an ordinary good thing to have until the person could no longer use it, or used it inappropriately.

- Having private space in one's own apartment seemed important, but family members noted a tendency for isolation.

Thus, different features became important as the disease progressed. Security became increasingly important, as were specialized activities, and the focus on the quality of care and staffing.

> *The first place I was at was really nice. It was clean; it was new. It was your own furniture, the whole nine yards. I mean, it looked like…a hotel. The place he is*

now is very institutional. I mean he doesn't have his own bed. I brought in -- for me -- his dresser and a recliner chair, which he no longer uses because he's in…bed all the time. I would take a really kind, loving care provider over how the place looked, smelled, anything. (Northern Virginia)

I wanted to keep my mom in the surroundings of her own apartment, and I would go over there and we'd sit and visit in the living room. And I would make lunch…I had buried my head, as I'm sure some people do, because it was what I wanted for my mother. It was not what my mother needed for herself. (Chicago)

3.3   Which Aspects of Quality Matter Most: Results of Family Members' Votes

"DOT VOTING" RESULTS
As noted, we asked each of the focus group participants to review the list topics and issues the members had identified as key quality components and "vote" for the two or three elements they considered the most important by placing "sticker dots" next to the statement or topics. Members of five of the six groups did so. (One group refused, with members saying that what was most important varied over time and across family members. Moreover, they argued that all the topics they listed were an essential part of a high quality facility.) This section presents those results.

For the participants that voted, 11 "dots" were recorded. The results are presented in **Exhibit 3**. As shown, issues related to staffing received the most votes (25 percent). Related topics of communication with families (19 percent of the votes) and an individualized approach to resident's strengths, preferences and needs (12 percent) ranked , respectively, second and third. Thus, issues related to staffing and care practices garnered a total of 56 percent of the votes. Characteristics of the environment -- safety, security, and homelike environment garnered a total of 21 votes (19 percent of the votes). Family members also rated various aspects of care as important (activities, medical care, protective oversight, medication supervision, referrals, and hands-on physical care), receiving a total of 15 percent of the votes. When combined with individualized approaches to resident care, these aspects of care account for approximately 27 percent of the votes.

EXHIBIT 3. Results of Focus Group Participant Voting on Most Important Aspects of Quality		
Domain	**Key Components of the Domain**	**Number of Votes**
Staffing	Quality, previous and ongoing training, understand Alzheimer, cooperate with each other, staff turnover, continuity, physical contact, attitude, tolerance, caring, flexibility, qualifications, staffing ratio, policies	28
Communication with Family	Helpful with orientation, have personal knowledge of resident, work with family, supportive of family	21
Care Responsive to Individual Resident Needs	Learn what people need, appropriately design space for residents with Alzheimer's disease, continued evaluation of needs	13
Safety and Security	Wanderguard, surveillance cameras, 24 hour supervision, locked unit, alarms, screening of staff	13
Homelike Environment	No smell, appearance homey, meals and snacks--flexible and easy access	8
Activities	Physical and mental, life, skills, home life activities, self-esteem (make-up, hair), social, pets, mixed activities, large or small groups, excursions, bus/van	7
Affordability	No hidden costs, availability of Medicaid, acceptable increases in rates overtime	5
Availability of Medical Care 24-hours a day		4
Location of the Facility		3
Medication Management		2
Facility Makes Appropriate Referrals		2
Physician Regularly Visits the Facility		1
Personal Care		1
Quality of Management		1
Resident Cleanliness and Personal Appearance		1
Policies and Practices that Prevent Isolation of the Resident		1

3.4   Family Members' Views on Other Topics

During the focus group sessions, family members mentioned other topics, either in direct response to an issue raised in the moderator's guide (e.g., "has your view of what was important and what is good quality changed over time?") or as a side issue that arose during discussion of specific topics (e.g., the difficulty of knowing what "assisted living" *means* in reference to a specific facility).

Assisted Living as a Concept: What Does It Mean?

Family members for the most part agreed that assisted living is a concept they like, and it is overwhelmingly preferred to nursing homes. At the same time, they recognized that there was tremendous variability among the places that call themselves "assisted living." Similarly, although some of the family members and their loved ones expressed dread of nursing homes, they often wanted the security, staffing levels, and staff competencies routinely offered by nursing homes.

Dread of Nursing Homes. One of the findings was, in fact, how fearful families and loved ones were of "nursing homes," even though they wanted many of the aspects of care that are routinely provided in many nursing homes and are specifically required by federal law. These features include such elements of quality family members strongly favored, including individualized assessment and care planning, trained nursing assistants or aides, nursing supervision, care that maximizes the functioning of the resident (e.g., cuing, verbal reminders, task segmentation), behavior management programs, and environmental security for residents who wander. Thus, one topic the Alzheimer's Association or others may wish to pursue is what, exactly it is that families and elderly so dislike or fear about nursing homes. For those residents who need more care than an assisted living facility provides and for families that have exhausted all personal funds in paying for care, nursing homes are a viable alternative, and research that would indicate how to make the nursing home environment or process of care less dreaded might be useful.

> [I knew my parents didn't want to be in a nursing home because] *25 years before they would always say, "I never want to go into a nursing home," and, you know, "Kill me before you send me to a nursing home."* (Portland, current)

> *He'll say, "Oh Sharon* [name changed] *dear, there's something going around with me, isn't there? It's Alzheimer's, isn't it?" And then you have to say "Yes, daddy." Well, this particular…*[facility] *has three buildings. He's in the assisted living…[and] there is a nursing facility…which is kind of up the hill…My dad always says, "Oh, Sharon dea, one of these days, I'm going to have to go up on the top of the hill, and I don't want to go."* (Northern Virginia)

Difficulty of Knowing What is Meant By "Assisted Living." There are many variations on the assisted living them. Indeed, one of the observations made by family members in nearly every focus group was that they had difficulty selecting facilities, since there was so much variability in what places were like and in the services provided among places that held themselves out as being "assisted living" facilities.

> *I think one of the real hindrances…is that the term assisted living is almost meaningless because it covers either minimal assistance or it covers the whole spectrum of possibilities.* (Cleveland)

> *It goes from the range of, if you need help turning on the water, that's fine, but if you need help with medication, it's all over. If you need, you know, meals served that's okay, but if you need them brought to your room, you're not assisted living anymore…Each facility has it's own definition of assisted living.* (Boston)

Family Members' Needs

Family members mentioned needing support groups for themselves, needing more consumer information about Alzheimer's disease and its progress, and needing more information about assisted living and other care options. They wanted both information about the options available and about how to make good decisions. In addition, they discussed wanting more advice on how to take medical information and

then make decisions about care. Finally, they wanted information on programs that will educate them about the disease, the care options available, and how to use this information in making decisions about the care of loved ones with Alzheimer's and other dementias.

Barriers to Care

During the focus group discussions, family members mentioned several factors they perceived as either barriers to securing assisted living for their loved ones or as barriers to making what they perceived as good decisions. First, in each focus group cost was perceived as a barrier to care. Family members noted that not everyone could afford assisted living. In addition, many expressed concern about exhausting their loved one's funds, the lack of Medicaid coverage for assisted living, and the implications for what would happen to their loved one when private funds were exhausted.

Family members also discussed the limited availability of assisted living facilities, particularly those specializing in the care of persons with Alzheimer's disease, long waiting lists are good facilities, lack of knowledge among some facility operators about Alzheimer's disease and its care implications, and their own lack of knowledge about how to evaluate facilities and, if evaluation criteria are known, how to determine during the selection process whether the facility meets those criteria.

4. CONCLUSIONS ABOUT MEASURING QUALITY

We explicitly asked family members whether their ideas about what they thought was important had changed over time, that is, whether they thought different things were important when they were selecting a facility compared to what they now knew. As we reported earlier, family members in each focus group reported that their views had changed as they gained more experience with assisted living, as their loved one's care needs changed, and as facilities changed their service mix and policies in seeking to be more responsive to the changing needs of residents.

These focus group discussions have several implications. First, it is not possible to generate a "static" list of quality measures. What constitutes "quality" for family members depends on (1) their own knowledge base and level of experience; (2) the loved one's level of cognitive and functional impairment and their care needs; and (3) what they can afford. Second, quality is multidimensional from the perspective of family members. Staffing levels and staff attitudes, care practices that promote and maintain function, safety, and environmental amenities all play a role in determining the "quality" of an assisted living facility. Third, it appears that as a loved one's needs change, the quality of the staff and the quality of the care the resident receives that precedence over some of the environmental amenities that were initially central to family members. Fourth, what matters to family members may not always match the needs and interests of the resident with dementia.

Thus, appropriate quality measures must be sensitive to the level and type of impairment of the residents. In addition, quality measures should be comprehensive, covering key environmental, staffing and service dimensions. Further, informed family members are a potentially useful source of information about quality for individuals with dementia and communication difficulties. Finally, even studies of quality must consider the policy and cost issues that are particularly relevant to families.

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APPENDIX A. STUDY FACT SHEET

FACT SHEET
MEASURING QUALITY IN ASSISTED LIVING FACILITIES

The local chapter of the Alzheimer's Association is participating in a focus group project designed to explore the issues related to the quality of care provided by assisted living facilities to persons with Alzheimer's disease or other dementias. The local chapters participating are in Boston, Chicago, Cleveland, northern Virginia, and Portland, Oregon.

The purpose of these discussions is to learn what to look for when we conduct an upcoming national study of assisted living facilities. We need to learn from focus group participants about indicators of good care and what we might look for as indicators of poor care or unmet care needs. In the focus group meetings, we would like people to treat us as they would a friend who was "shopping" for a good facility for her mother. What should we look for? What kinds of questions should we ask residents if we want to know whether this is a "high quality" facility? What should we ask family members? staff? operators?

A focus group is a discussion with a group of people about a particular topic. The discussion is led be a person called a moderator, who guides the discussion through a series of questions. Everyone in the group is encouraged to speak their mind, and tell about their experiences or opinions on the topic being discussed. The focus group you are being asked to participate in will be with 8-10 other family members in your area. The meeting will last for about 2 hours, during which you will be asked to share your thoughts with us about what constitutes good quality and what family members and others should look for when visiting a facility and trying to make a judgement about whether it is a "good" place.

There is no risk to your relative who is in an assisted living facility. Your participation is voluntary and confidential. Nothing you might say about a particular facility will ever be made public or reported in any way that would allow identification of either individual participants or facilities. While the meetings will be recorded, the recording is only to allow us to make sure we "hear" everything that is said. Only people working on the project will ever hear any of the recordings or read the notes we take.

This project is funded by the Alzheimer's Association. The study is being conducted by Research Triangle Institute (RTI). Questions can be directed to Candace Laska at Columbia/Wilamette Chapter of the Alzheimer's Association. Her number is 503-413-7115. You may also contact Angela Greene at Research Triangle Institute. Her number is 800-334-8571. If you have questions about being a participant in a research project, you can contact Dr. Wendy Visscher at 1-800-334-8571.

APPENDIX B. FAMILY MEMBER CONSENT FORM

CONSENT FORM FOR FAMILY MEMBERS
MEASURING QUALITY IN ASSISTED LIVING FACILITIES

This focus group is being conducted by Research Triangle Institute for a project funded by the Alzheimer's Association. In today's discussion we will be talking about your experiences and those of your loved ones who are in assisted living facilities. This meeting includes 6-8 other family members in your area. The meeting will last for about 2 hours, during which you will be asked to share your thoughts with us about what constitutes good quality and what family members and others should look for when visiting a facility and trying to make a judgement about whether it is a "good" place for a loved one with Alzheimer's disease or other dementia.

Your participation in the focus group is voluntary and confidential, and you may refuse to comment on any question that is asked.

Everything you say in this group is confidential. Nothing you might say about a particular facility will ever be made public or reported in any way that would allow you or your loved one or a particular facility to be identified. Your participation in today's group will not affect your family member's care, not will the information be released to the facility where they are living.

While the meetings will be tape recorded, the recording is only to help us make sure we "hear" everything that is said. Only people working on this project will ever hear any of the recordings or read the notes we take. The same thing goes for the questionnaire that you will be asked to complete. When we report our findings to the Alzheimer's Association, all identifying information from comments will be removed.

We will provide the local Alzheimer's Association chapter with copies of our findings, and you may have a copy if you'd like. Just let us or the Chapter representative know if you want a copy of the report.

If you have any questions after today, you may direct them to _____ [NAME OF LOCAL CHAPTER CONTACT] at the _____ [NAME OF LOCAL CHAPTER]. The telephone number is _____ [LOCAL PHONE NUMBER]. You may also contact Angela Greene at Research Triangle Institute (RTI). Her number is 800-334-8571. If you have questions about being a participant in a research project, you can contact Dr. Wendy Visscher of RTI's Committee for the Protection of Human Subjects at 1-800-334-8571.

APPENDIX C. SELF-ADMINISTERED DEMOGRAPHIC SURVEY FOR PARTICIPANTS AND MODERATOR GUIDES

**ALZHEIMER'S ASSOCIATION FOCUS GROUP
DEMOGRAPHIC SURVEY**

First Name_____   **Birth Date**_____

Confidentiality Statement. This survey will be used in combination with the focus group information. We realize that some people do not like talking about certain topics, like finances, in front of people they don't know. For this reason, we are asking you to answer the following basic demographic and economic questions. Answering these questions is purely voluntary, and refusing to answer any question will not affect your participation in the focus group. However, responding to these items will give us better information to go with the focus groups. It will also help us understand how different people feel about quality. Please include only your first name on this form. The form will only be used by people working on this research project. Your name and answers to these questions will never be available to any public or private agency.

The first few questions are about you and your background.

1.   Are you male or female?
         (1) Male
         (2) Female

2.   Are you married, widowed, divorced or never been married?
         (1) Married
         (2) Widowed
         (3) Divorced
         (4) Never married

3.   Which of the following best describes your race?
         (1) White
         (2) African American
         (3) Asian or Pacific Islander
         (4) American Indian
         (5) Alaskan Native

4.   Are you of Hispanic origin or descent?
         (1) Yes
         (2) No

5. Are you the spouse of child of a person in an assisted living facility?
   (1) Spouse ----->**Skip to Question 7**
   (2) Child
   (3) Son-in-law or daughter-in-law

6. Do you provide financial support to your family member who is in an assisted living facility?
   (1) Yes
   (2) No

The next questions are about your family member who lives in an assisted living facility.

7. Check all of the services your family member used before entering the assisted living facility.
   _____ Home health Care (e.g., nursing, physical therapy)
   _____ Respite Care
   _____ Home Chore Services (e.g., light housekeeping or Home Health Aide (e.g., help with bathing, dressing, etc.)
   _____ Units Attached to Nursing Homes
   _____ Residential Care Facility, Homes for Adults, or Assisted Living
   _____ Nursing Home
   _____ Other (describe) _____

8. How long has your family member lived in the current assisted living facility?
   _____

9. Do you think your family member will be able to stay in the facility indefinitely?
   (1) Yes
   (2) No

10. How much does your family member pay per month to live in the facility?
    $_____

11. What kind of room does this cover?
    (1) Private Apartment (with bath and full or partial kitchen)
    (2) Private room with private bath
    (3) Private room with shared bath
    (4) Semi private room with private bath
    (5) Semi private room with shared bath
    (6) Other (describe) _____

12. What kind of services does this monthly fee cover?
    _____
    _____

13. Did your family member live in any other assisted living facility prior to the one he or she currently lives in?
    (1) Yes
    (2) No

14. What is the yearly income range of your family member who lives in the assisted living facility? (If you are a spouse, what is your combined yearly income?)
    (1) Less than $1,200
    (2) Between $1,201 and $4,999
    (3) Between $5,500 and $8,999
    (4) Between $9,000 and $13,999
    (5) Between $14,000 and 24,999
    (6) Between $25,000 and $50,000
    (7) More than $50,000
    (8) I don't know

MODERATOR GUIDE:
MEASURING QUALITY IN ASSISTED LIVING FACILITIES

INTRODUCTION

(The introduction may be individualized as desired. Before to ask the things in bold. Things in italics are for the moderator's attention. Feel free to write on this guide as you go along.)

Thank you for coming.

We really appreciate your help; you are the experts here today; we want to give people a chance to tell us what their experiences have been

Confidentiality Statement: *(Read and make sure all have the Consent Form)* This focus group is being conducted by Research Triangle Institute for a project funded by the Alzheimer's Association. In today's discussion we will be talking about your experiences with assisted living facilities. Your participation in the focus group is voluntary and confidential, and you may refuse to comment on any question that is asked. Nothing you might say about a particular facility will ever be made public or reported in any way that would allow you to be identified. Your participation in today's group will not affect your family member's care, nor will the information be released to the facility where they are living.

While the meetings will be tape recorded, the recording is only to help us make sure we "hear" everything that's said. Only people working on this project will ever hear any of the recordings or read the notes we take. The same thing goes for the little questionnaire that you filled out. We will provide the local Alzheimer's Association chapter with copies of our findings, and you may have a copy if you'd like.

I am _____, and _____, is going to be taking notes so that I won't have to worry about it. *(Be neutral, non-threatening, familiar. You may want to say something personal about yourself, such as a story from your life or why this topic is important to you.)*

The purpose of this group meeting is to find out about people's perceptions and experiences with quality in assisted living facilities. We are going to use this information as part of a larger research project.

The entire session will be tape recorded. To protect everyone's privacy, we will use first names only in this room. This way, your responses will not be linked to you personally, so feel free to say what ever is on your mind.

There are no right or wrong answers. We want to hear what <u>you</u> think. I'm not planning to do most of the talking. I do have several things for us to talk about, though, so I'll try to keep moving things along.

We also want to know where your opinions differ from each other and from others we have already spoken to.

There is no need to raise hands. Speak right up, but please respect others when they are talking. When the discussion is over, please respect the privacy of your fellow group members.

This discussion will last about 2 hours. Is there anyone who can't stay? Any questions? Now lets begin.

Let's start by going around the room and each person introduce yourself, and say something about your family member in assisted living. (**10 minutes**)

1. Let's talk about what kind of help or supervision your family member needs. (**10 minutes**)

2. How did you decide on assisted living for your family member, instead of some other type of arrangement?

   (**This section, through #5, 35 minutes**)
   (Probe: did you consider other options such as a _____ [INSERT NAME OR B&C IN THE STATE] facility or nursing home? Why did you chose assisted living?)

3. What were you and your family looking for in a facility?
   Flipchart

4. What were your concerns about the type of care that assisted living provides?

5. How did you choose the facility?

   (Probes: Did you visit other facilities? Did you ask friends or family for recommendations? Was the distance from your home a factor?)

6. Have your family member's needs changed since they've been in the facility? (**10 minutes**)

7. If you had a friend in your situation who wanted your advice about what things to look for in choosing a good assisted living facility, what would you tell him or her? **Flipchart** (**20 minutes**)

8. For that same friend (the one in your situation), knowing what you know now what kinds of things would you tell him to look out for or avoid? **Flipchart** (**15 minutes**)

9. Have you changed your thinking about what is important to you in an assisted living facility? (**20 minutes**)

   (Probe: would you look for <u>different</u> things now? Are there problems you or your family member have had that would make you ask different questions?

Optional question, if there is time:

9. What do you think are the most important things **to your family member**? Do you think that your family member is **satisfied** with the quality of the assisted living facility? Are **you** satisfied? Can you tell me one good thing and one bad thing about the facility?

10. We are almost finished now. Let's look at all these things you've talked about. The things you were looking for when you first started looking, and the things that you know now. Is there anything else we need to add to the list? I have some colored stickers here and would like you to come up front and put your stickers on what you thing are the three most important things. Don't put more than one sticker on any one thing.

I want to thank you all for coming today and talking with us. What you have said will be very useful as we try to help policymakers better understand what people need and want in assisted living. **It is alright to talk to others about what we discussed here today, but please remember to respect each other's privacy, and don't mention anyone's name outside this room**.

MEASURING QUALITY IN ASSISTED LIVING FACILITIES MODERATOR GUIDE FOR SESSION OF PEOPLE WITH <u>DISCHARGED</u> FAMILY MEMBERS

INTRODUCTION

Thank you for coming.

We really appreciate your help; you are the experts here today; we want to give people a chance to tell us what their experiences have been

Confidentiality Statement: This focus group is being conducted by Research Triangle Institute for a project funded by the Alzheimer's Association. In today's discussion we will be talking about your experiences with assisted living facilities. Your participation in the focus group is voluntary and confidential, and you may refuse to comment on any question that is asked. Nothing you might say about a particular facility will ever be made public or reported in any way that would allow you to be identified. Your participation in today's group will not affect your family member's care, nor will the information be released to the facility where they are living.

While the meetings will be tape recorded, the recording is only to help us make sure we "hear" everything that's said. Only people working on this project will ever hear any of the recordings or read the notes we take. The same thing goes for the little questionnaire that you filled out. We will provide the local Alzheimer's Association chapter with copies of our findings, and you may have a copy if you'd like.

I am _____, and _____, is going to be taking notes so that I won't have to worry about it. *(Be neutral, non-threatening, familiar)*

(You may want to say something personal about yourself, such as a story from your life or why this topic is important to you.)

The purpose of this group meeting is to find out about people's perceptions and experiences with quality in assisted living facilities. We are going to use this information as part of a larger research project.

The entire session will be tape recorded. To protect everyone's privacy, we will use first names only in this room. This way, your responses will not be linked to you personally, so feel free to say what ever is on your mind.

There are no right or wrong answers. We want to hear what <u>you</u> think. I'm not planning to do most of the talking. I do have several things for us to talk about, though, so I'll try to keep moving things along.

We also want to know where your opinions differ from each other and from others we have already spoken to.

There is no need to raise hands. Speak right up, but please respect others when they are talking. When the discussion is over, please respect the privacy of your fellow group members

This discussion will last about 2 hours. Is there anyone who can't stay? Any questions? Now lets begin.

Let's start by going around the room and each person introduce yourself, and say something about your family member who was in assisted living. (**10 minutes**)

1. Let's talk about what kind of help or supervision your family member needs. (**10 minutes**)

2. How did you decide on assisted living for your family member, instead of some other type of arrangement?
(**This section, through #5, 35 minutes**)
(probe: did you consider other options such as adult foster care, residential care? Why did you chose assisted living?)

3. What were you and your family looking for in a facility?
Flipchart
*What were your **concerns** about the type of care that assisted living provides?*

4. Why was your family member discharged from the facility?

5. Did your family member's needs change while they were in the facility? (**10 minutes**)

6. What were your expectations about the facility continuing to meet your family member's needs as they changed?

7. If you had a friend in your situation who wanted your advice about what things to look for in choosing a **good** assisted living facility, what would you tell him or her?
Flipchart (**20 minutes**)

8. For that same friend (the one in your situation), knowing what you know now what kinds of things would you tell him to look out for or avoid?
Flipchart (**15 minutes**)

9. Have you changed your thinking about what is important to you in an assisted living facility?
(**20 minutes**)
(Probe: would you look for <u>different</u> things now? Are there problems you or your family member have had that would make you ask different questions?

Optional question, if there is time:

9. What do you think are the most important things **to your family member**?
Do you think that your family member was **satisfied** with the quality of the assisted living facility?
Were **you** satisfied? Can you tell me one good thing and one bad thing about the facility?

10. We are almost finished now. Let's look at all these things you've talked about. The things you were looking for when you first started looking, and the things that you know now. Is there anything else we need to add to the list? I have some colored stickers here and would like you to come up front and put your stickers on what you thing are the three most important things. Don't put more than one sticker on any one thing.

I want to thank you all for coming today and talking with us. What you have said will be very useful as we try to help policymakers better understand what people need and want in assisted living. It is alright to talk to others about what we discussed here today, but please remember to respect each other's privacy, and don't mention anyone's name outside this room.

NATIONAL STUDY OF ASSISTED LIVING FOR THE FRAIL ELDERLY

Reports Available

A National Study of Assisted Living for the Frail Elderly: Discharged Residents Telephone Survey Data Collection and Sampling Report
    HTML   http://aspe.hhs.gov/daltcp/reports/drtelesy.htm
    PDF   http://aspe.hhs.gov/daltcp/reports/drtelesy.pdf

A National Study of Assisted Living for the Frail Elderly: Final Sampling and Weighting Report
    HTML   http://aspe.hhs.gov/daltcp/reports/sampweig.htm
    PDF   http://aspe.hhs.gov/daltcp/reports/sampweig.pdf

A National Study of Assisted Living for the Frail Elderly: Final Summary Report
    HTML   http://aspe.hhs.gov/daltcp/reports/finales.htm
    PDF   http://aspe.hhs.gov/daltcp/reports/finales.pdf

A National Study of Assisted Living for the Frail Elderly: Report on In-Depth Interviews with Developers
    Executive Summary   http://aspe.hhs.gov/daltcp/reports/indpthes.htm
    HTML   http://aspe.hhs.gov/daltcp/reports/indepth.htm
    PDF   http://aspe.hhs.gov/daltcp/reports/indepth.pdf

A National Study of Assisted Living for the Frail Elderly: Results of a National Study of Facilities
    Executive Summary   http://aspe.hhs.gov/daltcp/reports/facreses.htm
    HTML   http://aspe.hhs.gov/daltcp/reports/facres.htm
    PDF   http://aspe.hhs.gov/daltcp/reports/facres.pdf

Assisted Living Policy and Regulation: State Survey
    HTML   http://aspe.hhs.gov/daltcp/reports/stasvyes.htm
    PDF   http://aspe.hhs.gov/daltcp/reports/stasvyes.pdf

Differences Among Services and Policies in High Privacy or High Service Assisted Living Facilities
    HTML   http://aspe.hhs.gov/daltcp/reports/2000/alfdiff.htm
    PDF   http://aspe.hhs.gov/daltcp/reports/2000/alfdiff.pdf

Family Members' Views: What is Quality in Assisted Living Facilities Providing Care to People with Dementia?

Executive Summary http://aspe.hhs.gov/daltcp/reports/1997/fmviewses.htm
HTML http://aspe.hhs.gov/daltcp/reports/1997/fmviews.htm
PDF http://aspe.hhs.gov/daltcp/reports/1997/fmviews.pdf

Guide to Assisted Living and State Policy

Executive Summary http://aspe.hhs.gov/daltcp/reports/1995/alspguidees.htm
HTML http://aspe.hhs.gov/daltcp/reports/1995/alspguide.htm
PDF http://aspe.hhs.gov/daltcp/reports/1995/alspguide.pdf

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Residents Leaving Assisted Living: Descriptive and Analytic Results from a National Survey

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State Assisted Living Policy: 1996

Executive Summary http://aspe.hhs.gov/daltcp/reports/96states.htm
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State Assisted Living Policy: 1998

Executive Summary http://aspe.hhs.gov/daltcp/reports/1998/98states.htm
HTML http://aspe.hhs.gov/daltcp/reports/1998/98state.htm
PDF http://aspe.hhs.gov/daltcp/reports/1998/98state.pdf

Instruments Available

Assisted Living Discharged Resident Telephone Interview

HTML http://aspe.hhs.gov/daltcp/instruments/ALDRTI.htm
PDF http://aspe.hhs.gov/daltcp/instruments/ALDRTI.pdf

Assisted Living Discharged Resident Proxy Respondent Telephone Interview
	HTML			http://aspe.hhs.gov/daltcp/instruments/ALDRPRTI.htm
	PDF			http://aspe.hhs.gov/daltcp/instruments/ALDRPRTI.pdf

Facility Screening Questionnaire
	HTML			http://aspe.hhs.gov/daltcp/instruments/FacScQ.htm
	PDF			http://aspe.hhs.gov/daltcp/instruments/FacScQ.pdf

To obtain a printed copy of this report, send the full report title and your mailing information to:

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Office of Disability, Aging and Long-Term Care Policy
Room 424E, H.H. Humphrey Building
200 Independence Avenue, S.W.
Washington, D.C. 20201
FAX: 202-401-7733
Email: webmaster.DALTCP@hhs.gov

NOTE: All requests must be in writing.

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