Developing a Research Agenda for Assisted Living

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**Purpose:** We describe an approach to identifying knowledge gaps, research questions, and methodological issues for assisted living (AL) research. **Design and Methods:** We undertook an inventory of AL literature and research in progress and commissioned background papers critiquing knowledge on selected subtopics. With an advisory committee, we identified a comprehensive list of researchable questions of potential utility to consumers, providers, and/or policy makers, which AL researchers then rated as to their importance. The preliminary work facilitated a structured working conference of AL researchers. **Results:** The top five priority topics identified as a result of the polling before the conference were consumer preferences, cost and financing, developing an information system for consumer decision making, developing quality measures, and resident outcomes. From conference discussion, conferees added other emphasis areas and refined the original ones. They flagged lack of standardized definitions and measures as barriers to building an empirically based AL literature. Conferences also identified distinctions between research on AL as a whole and research on interventions within AL. **Implications:** In an emerging area in which the literature cannot yet support rigorous comparisons, meta-analysis, or consensus conferences, the systematic approaches, including assembling researchers who use widely different methods, generated substantial agreement on a research agenda. **Key Words:** Research priorities, Working conference, Residential care, Personal care services, Physical environments
only or with a variety of health care holdings). AL came in all shapes and sizes, including small houses resembling private homes, larger developments resembling hotels or apartment complexes, and even in manufactured housing; the services available in the settings also varied widely. The bewildering array of settings and programs flying under the label AL has resulted in competing goals and visions, and confusion among government officials about how, if at all, they should regulate and reimburse services or try to shape the development of AL. The rapid development of a sector that did not quite fit within the usual long-term-care categories created a sense of urgency for officials to respond (Smith, 2003).

The confusion that characterizes the AL service sector also confounds the conduct of AL research. In 2003 when we began planning a working conference of AL researchers, the definition of the independent variable (AL) was contested in theory and varied in practice; the appropriate dependent variables (various outcomes for AL residents) were disputed; and, given the way AL has rearranged the usual health and social services, choosing the appropriate control groups to study AL was difficult. This article describes a process by which researchers invested in the study of AL deliberated on conceptual and methodological challenges, prioritized a research agenda, and discussed how to strengthen the AL research base.

Background

**AL Literature and Research up to 2000**

By the turn of the 21st century a cadre of gerontologists, social scientists, health services researchers, and policy researchers with substantial interest in study of AL had already emerged. Early on, the neophyte trade organizations commissioned descriptive studies of the industry (Assisted Living Federation of America, 1999, 2000; National Investment Conference, 1998; PricewaterhouseCoopers, 2000; Wylde & Zimmerman, 1999), and articles about the business side of AL began appearing in trade journals (e.g., Evans, 1994; Hogan, 1994; Moore, 1996, 1997; Wright, 1999). Also in the 1990s, AARP funded a general study to take stock of the new phenomenon (Kane & Wilson, 1993) as well as studies of particular topics related to AL, such as delegation authority in nurse practice acts (Kane, O’Connor, & Baker, 1995), the applicability of fair housing laws to AL (Edelstein, 1995; Vignery & Siemon, 1995), quality issues (Assisted Living Quality Coalition, 1996), and privacy in AL (Kane, Baker, Salmon, & Veazie, 1998). On the policy front, Mollica and colleagues gave attention to state regulatory and payment policies as early as 1992, issuing four reports before 2000 (Mollica, 1998; Mollica & Snow, 1996; Mollica, Ladd, Dietsche, Wolson, & Ryther, 1992; Mollica, Wilson, Ryther, & Lamarche, 1993). Other studies examined the appropriateness of AL for people with Alzheimer’s disease (Leon & Moyer, 1999). Those who had historically studied residential settings, sometimes called board and care homes, began considering AL in their work (Hawes, Wildfire, & Lux, 1991; Morgan, Eckert, & Lyon, 1995). Researchers primarily interested in physical environments also took note of AL in various monographs (e.g., Pastalan, 1990; Regnier, Hamilton, & Yatabe, 1995; Schwartz & Brent, 1999). Some early AL literature examined clinical or administrative practices such as management of medication (Edelberg, Shallenberger, & Wei, 1999; Garrard, Cooper, & Goertz, 1997; Hyde, 2001) and negotiated risk management (Kapp & Wilson, 1995).

During this first 15 years of AL research, various qualitative and case study reports appeared in journals and monographs (Cinelli, 1999; Frank, 1999; Heumann, 1998), and some research was directed at discerning preferences of residents (e.g., Salmon & Polivka, 1998; Yee, Capitman, Leutz, & Sceigaj, 1999). Asked to examine AL quality, the U.S. General Accounting Office (1999) concluded that consumers had inadequate information about services and costs that would certainly hinder effective exercise of consumer preferences in the market place.

Before 2000, the U.S. Office of the Secretary for Planning and Evaluation commissioned a study of a large representative sample of AL facilities (Hawes, Phillips, Rose, Holan, & Sherman, 2003); Hedrick began a longitudinal study of three types of AL in the State of Washington (Hedrick et al., 2003); Kane and colleagues began a longitudinal study of AL residents in Oregon compared to nursing home residents (Frytak, Kane, Finch, Kane, & Maude-Griffin, 2001); and Zimmerman and colleagues began a longitudinal study of AL and nursing homes in four states, Florida, Maryland, North Carolina, and New Jersey (Zimmerman et al., 2003). These longitudinal studies were each complex, mixed-methods studies with many substudies and spin-offs.

**AL Literature and Research, 2000–2004**

After 2000, the volume of research and publications on AL increased markedly, reflecting the culmination of work begun earlier as well as new work. The scale, scope, and foci of the research on AL were further diversified, and government and nonprofit organizations showed increased interest. The Agency for Healthcare Research and Quality (AHRQ), the National Center for Health Statistics, and the U.S. Census Bureau sponsored explorations of how to define residential places for national surveys and the census (Han, Sirrocco, & Remsburg, 2003), and the preliminary work was done to add AL to the AHRQ-funded system of Consumer Assessments of Health Programs and Services (Castle & Sonon, 2006). The Veterans Administration (VA) began a pilot demonstration of AL post-hospital coverage in several states, (Hedrick & Guihan,
2005). California began a demonstration of coverage of AL under its Medicaid program and under Robert Wood Johnson Foundation funding, and the National Cooperative Bank Development Corporation provided technical assistance to states in developing affordable AL in multiple states (Jenkins, Carder, & Maher, 2004). Various state governments contracted AL studies, for example, Florida (Street, Quadagno, & Burge, 2005; Vinton, 1999), New Jersey (Castle, Lowe, Lucas, & Crystal, 2004), and Kansas (Chapin & Dobbs-Kepper, 2001; Chapin, Dobbs-Kepper, & Oslund, 2001), and AARP conducted a series of state-consumer surveys on AL (Bridges, 2002; Bridges & Cicero, 2004; Cummins, 2001). The volume of qualitative research, some examining key concepts in AL such as autonomy, aging in place, and homey environments, greatly increased. Highly publicized newspaper and magazine critiques appeared at the turn of the century, ranging from negative to skeptical (Barnett & Walth, 2001a, 2001b, 2001c; Goldstein, 2001a, 2001b; Lieberman, 2001; Rosenblatt, 2002; Steinhauer, 2001); only a few exceptions (Bernstein, 2001; Shapiro, 2001) made the positive contributions and potential of AL a large part of the story. The Senate Committee on Aging held hearings on AL (U.S. Senate, 2001); and the Assisted Living Workgroup, a collection of organizations representing providers, consumers, and professionals, began convening to consider and report to Congress on elements of quality in AL (Assisted Living Workgroup, 2003). For several years, the Assisted Living Workgroup operated transparently with interim reports and decisions recorded on the Internet, illustrating how little the then-available research could be used by those struggling to identify best practices and minimum regulatory requirements.

The volume of research activity meant that a growing group of researchers had experience with the challenges of AL research; at the same time, the negative critique increased the urgency of meaningful research. Although in the first decades of AL researchers often participated at conferences geared toward AL policy in general, no major meetings had been dedicated to clarifying AL research issues and topics. With that in mind, in 2003 a group of AL researchers applied for and received a conference grant from AHRQ to further explore issues in AL research.

**Methods**

**Objectives**

The objectives of the conference and the associated pre- and post-conference activity were to (a) assess what could be learned from existing AL research and identify gaps; (b) identify and discuss methodological pitfalls inherent in AL study; (c) identify principles in AL research and its reporting that might make findings more interpretable and useful; and (d) forge a research agenda to address concerns of consumers, providers, and policy makers. For this project, we defined AL broadly as a group residential setting serving two or more people that was not licensed or certified as a nursing home and that provided or arranged for personal care and routine nursing services for people with functional limitations. The project focused on settings that serve older people, either exclusively or as part of their clientele.

**Stocktaking of Literature and Commissioned Papers**

As background, the conference organizers undertook a comprehensive review and classification of the literature on AL from 1989 until the Spring of 2004, drawing not only on published work in a wide variety of journals but also on conference abstracts, Web reports, and final project reports and classifying the resultant items by topic and method (for details, see Kane, Chan, & Kane, this issue). We also commissioned eight papers, all of which are published in this issue in revised and updated versions: (a) a historical overview (see Wilson), (b) a conceptual paper on how AL fits into a long-term-care service system and the extent to which it overlaps with or substitutes for other forms of care such as nursing home care and home care (see Stone & Reinhard), (c) AL for low-income and other special populations (see Hernandez & Newcomer), (d) AL for people with dementia (see Hyde, Perez, & Forester), (e) physical environments of AL (see Cutler), (f) roles and outcomes for family members of AL residents (see Gaugler & Kane), (g) classifications of AL (see Zimmerman & Sloane), and (h) defining and measuring AL outcomes (see Hawes & Phillips). We asked each author to consider empirical literature related to the topic and conclude with a discussion of knowledge requirements for consumers, practitioners, and policy makers and methodological challenges related to the topic. For some topics, the empirical literature directly on point was slim, and authors also extrapolated from work in nursing homes and other settings.

**Identifying Conference Participants**

From personal knowledge and by culling from lists of federal grantees and presenters at recent scholarly meetings, we identified almost 100 AL researchers. Because of both cost constraints and the need for a manageably sized group to ensure discussion, we aimed for a working group of no more than 50 people. We extended invitations sequentially to ensure a group of AL researchers that was balanced in terms of usual research method, research focus, and career stage; the participants included some new investigators whose doctoral
dissertations concerned AL. The 48 attendees included 32 active researchers in AL and a cadre of federal officials, many of whom both conducted and funded research. We identified nine federal organizations with an interest in AL: the AHRQ, the National Institute on Aging, the Centers for Medicare & Medicaid Services, the VA, the National Center for Health Statistics, the Census Bureau, the General Accountability Office, the U.S. Department of Health and Human Services Assistant Secretary for Planning and Evaluation, and the Administration on Aging. Ten federal officials attended the working conference, representing six of these agencies, and the other agencies were represented by researchers funded through the agencies or active on their advisory panels. The nongovernmental researchers reflected diverse disciplines (e.g., sociology, psychology, nursing, social work, medicine, economics, history, health services research, epidemiology, environmental studies, and gerontology) and used a wide variety of quantitative and qualitative methods. The conference also included six organizational stakeholders who represented provider or consumer organizations, some of whom were hands-on investigators.

Preconference Survey of Researchers

We generated a list of research topics on AL, phrased either as research questions or as “should” questions for which the desirable policy or practice to undertake could be informed by research but the specific research questions would need to be recast. These topics fell into 13 subcategories and 3 general areas. Topics closely related to residents and family fell into the following subcategories: resident characteristics, consumer perceptions and experiences, resident outcomes, family roles and outcomes, and transitions to and from AL (Table 1). Questions related to facilities and services fell into the following subcategories: service and program characteristics, service coordination (including coordination of outside services), price, staff qualifications and training, and dementia services (Table 2). Questions related to policy and values included the following: the nature of AL and its fit into the service system, autonomy and safety, regulations and quality assurance, and payments and service to low-income people (Table 3). All told, 71 separate potentially researchable topics were listed; we revised the draft list after a telephone conference with the advisory committee. In the preconference activity, AL researchers rated the importance of each of these topics plus any other topics they added on a scale of descending importance from 1 to 5 to indicate their view on whether each of consumers, providers, or policy makers might be interested in research on the topic. This resulted in three separate ratings for all topics, as well as additional comments by the raters. We e-mailed the questionnaire to 50 active researchers in AL.

Conference Process

Plenary Sessions.—The 2-day weekend conference was highly structured. The conference materials, sent in advance, contained a bibliography and the draft stocktaking of the AL literature, draft commissioned papers, and the result of the rating exercise on research topics. Plenary sessions dealt with the history and values undergirding AL, the state of existing AL research, and how good or bad outcomes of AL might be defined and studied. Over lunch, representatives of eight federal agencies briefly discussed their agencies’ perspectives on AL research, and after dinner a mediated speak-out session generated thoughts about the challenges of studying a moving target in the glare of politics and media. On the second morning, National Public Radio reporter Joseph Shapiro, who periodically had covered AL for National Public Radio and prior to that for U.S. News and World Report (Shapiro, 2001) and whose reporting on the disability movement had led to his award-winning book No Pity (Shapiro, 1994), provided a perspective on how AL and research about it appears to an informed journalist who might consult research as a source. The entire final afternoon was devoted to a plenary session to discuss promising hypotheses and research principles.

Breakout Sessions. — We designed the first breakout session, for which attendees divided into four heterogeneous groups all devoted to the same task, to further the setting of research priorities and consider together what the different knowledge needs might be for consumers, providers, or policy makers. The second breakout session was designed to allow like-minded researchers to work together on topics and issues that might be relevant to quantitative research, qualitative research, experimental and best practices research, and policy research. Groups were reconstituted around specific types of research (quantitative, qualitative, clinical/experimental, and policy oriented) and asked to consider the kind of investment they thought was most important for their type of research and whether principles could be enunciated to make the research more useful. Table 4 describes how the four research types were defined and lists the specific issues they were asked to address in addition to the general questions.

Results

Preconference Survey

By June 4, 2004, we had received 38 responses to our e-mail survey; we analyzed these to form part of
the conference material. Using mean ranking scores, we rank-ordered importance rating scores for each of the many questions listed in Tables 1 to 3, taking into account separately those deemed important for consumers, providers, and policy makers. The respondents strongly endorsed many of the questions, but averaging the mean ratings for all questions revealed that the five top-rated questions were the following:

1. How do AL setting characteristics and service characteristics (adjusting for resident characteristics) affect resident outcomes?

2. What outcomes are important for regulators to measure in quality assurance for AL? Do these differ from outcomes to measure in other long-term-care settings, including nursing homes, and, if so, how?

3. How far should AL residents be permitted to take risks in their daily lives? Which resident behaviors are most frequently perceived as “risky”?

4. What are the ranges of services and staffing patterns found in AL?

5. What if any guidelines do and should determine when residents move in to AL settings, and when they are asked to leave?
1. Service and programs in AL
   a. What types of staff are found in AL by AL facility size, sponsorship, and state of location?
   b. What intensity of staff coverage (as ratio to residents) is found in AL by size, sponsorship, and state of location?
   c. What extra services are most commonly provided over the base package for residents with higher levels of disability (e.g., with skilled nursing needs, unstable health conditions, or moderate-to-late-stage dementia)? To what extent are add-on service packages individualized or adhering to a predictable pattern of services that adhere to different “levels” of intensity?

2. Service coordination for AL services and services brought into AL
   a. What responsibilities do residents and family have for service coordination? What other arrangements are found?
   b. Do resident outcomes differ as a result of the way the total package is coordinated? Are services more effectively and efficiently delivered by AL providers themselves, or can services be more effectively and efficiently delivered with additional services from third parties (e.g., home care agencies or private duty nurses)? What are the effects of allowing or prohibiting residents to hire private-duty help in AL?
   c. Who monitors health care for quality? What internal capacity for do AL facilities have for quality management? What has been the effect and costs when states develop a care management capacity external to the AL facility at least for its publicly funded clientele?
   d. Have some AL facilities developed mechanisms for better coordination of health needs by primary care physicians (e.g., through medical directors, staff physicians, closed lists of doctors with attending privileges, or dedicated AL registered nurses to interact with primary care physicians). What are the advantages and disadvantages of these mechanisms?

3. Prices. What ranges of price for services are found within different AL types and in different states?
   a. To what extent and how are AL service prices bundled or disaggregated? What is the range of services included in base prices, and what mechanisms are used to price plans for additional services (e.g., rate tiers, unit pricing)? How do the price ranges and pricing mechanisms vary by AL characteristics and by state?
   b. What is the range (nationally and within states) for the price of the housing and board portion of AL, and what fraction of the entire price is attributed to rental and board?
   c. How can prices be presented in ways that permit consumers to make understandable comparisons?
   d. What is the prevalence of third-party coverage for AL services (Medicaid, Medicaid waivers, Veterans Administration, private insurance) and third-party coverage of “home care” services for AL residents (e.g. Medicare, Medicaid, insurance)? How well does each coverage correspond to actual prices charged to consumers or the AL facility’s costs?
   e. When an AL resident has increased needs for care, to what extent does his or her price rise? What is the typical change in price over the duration of a stay that is attributed to service intensity increases? How do third-party payers, especially Medicaid, recognize increases in care intensity in their reimbursement schemes?

4. Staff/personnel. What characteristics of staff, including technical skills, interpersonal skills, and communication skills, are most important for providing high-quality care and services to AL residents?
   a. How do these ideal characteristics vary, if at all, by job title or role?
   b. How do these ideal characteristics vary, if at all, by target population in the AL facility?
   c. Which skills can be effectively acquired with on-the-job training rather than as conditions of employment?
   d. What configuration of staff, including employees and contracted staff, is most effective for providing care and services in AL?
   e. To what extent is a flattened hierarchy with universal job descriptions helpful in cost-effective, high-quality services?
   f. What is the most effective way of delivering nursing services, including medication administration, nurse monitoring and evaluation, and health care treatments?
   g. What are the advantages and disadvantages of hiring direct caregiving staff with nursing home certified nursing assistant experience?

5. Dementia services. How has AL been structured to meet the needs of residents with varying levels of dementia? Have any best practices been identified?
   a. Should staff configurations differ for dementia units? Should staff in a nondifferentiated AL facility that serves people with dementia have special skills? Should activities be specialized for people with dementia in a nondifferentiated AL?
   b. What specifically are the extra skills and training needed to care for people with dementia in AL? Does the AL facility need to coordinate differently with primary care providers when the resident has dementia?
   c. What, if anything, should be different in the physical environment of a dementia-specific AL or a dementia care unit in an AL?

Note: AL = assisted living.

Differences emerged when we examined what raters thought were priorities for different research users (see Table 5). For consumers, the top five priorities included detailed questions about pricing and determinants of pricing for both the room and lodging and services, and ways of presenting price information that would permit consumers to make comparisons (the latter suggesting a research agenda that would test the effectiveness of various presentations to prospective residents and their family). Also judged of top importance for consumers were questions about expectations for family members and how family assistance affects price, and guidelines for when a resident may need to leave AL. Taking the perspective of providers, the top-rated questions dealt with consumer preferences, consumer
perceptions, definitions of quality both before and after the move, and, more particularly, the kinds of services they would most want to purchase in a package and the characteristics they would find most important in their private space and in the overall physical settings. Attendees thought that providers would be interested in research that would illuminate the best way to deliver nursing services, including medication, health monitoring, and health treatments; the practices that could mitigate risks to safety while preserving resident autonomy and choice; and whether the locus of monitoring health care quality should be internal to AL or external. Attendees considered policy makers’ top-rated interests to be research illuminating how AL residents differ from nursing home residents, the prevalence and adequacy of various third-party coverage for AL, whether and how outcomes of regulatory importance vary in AL compared to nursing homes and home-care settings, details of the AL services that should be covered under public funding and rate calculation, and the pros and cons of Medicaid

covering room and board directly (as it does in nursing homes) and whether any particular covered services might prevent discharge to nursing homes. As conferees discussed these results in early sessions, they noted that single studies might simultaneously address several of the interests attributed to all three or two of the user constituencies, but that the particular way the topic would be framed would differ by the user group considered.

Priorities and Related Approaches From First Breakout Groups

During the first heterogeneous small-group sessions, we asked each group to identify the most important AL research topics and to begin discussing the kinds of methods (e.g., quantitative, qualitative, experimental, or policy research) appropriate for addressing them. (Multiple methods were deemed appropriate for each of the 17 general topics discussed in one or more of the four subgroups.) Table 6 summarizes the deliberations of these groups based on the meeting notes. Conferees deemed quantitative studies best for research in resident outcomes, quality measurements, and resident transitions. They favored qualitative methods for exploring access issues, AL definition, AL typologies, consumer decision making, physical environments and how they are used and affect residents, information systems, and structure. Attendees recommended using clinical/experimental approaches to identify staffing models that achieve various outcomes and to describe consumer needs. They saw studies using administrative data and/or demonstrations as best for examining cost and financing, oversight process, and staffing.

Research Topics and Their Challenges

We scrutinized all of the meeting notes, particularly those from the plenary sessions, the second homogenous subgroups, and the closing session, to identify the research topics that received the closest attention and the issues identified in addressing them. We also identified some cross-cutting conceptual and methodological issues that participants emphasized.


**AL Residents’ Characteristics, Preferences, and Decision-Making Process.**—Participants argued that understanding residents’ characteristics (age, race, ethnicity, family structure, income and assets) and their needs (level of disability, health status, cognition) is the first step for developing a health-promoting living environment that truly allows elderly residents to be able to age in place. Specific studies could be designed (a) to illuminate the degree of overlap and the differences in residents cared for in various types of AL settings, compared to people cared for in their own homes and in nursing homes; and (b) to describe consumer preferences and perceptions regarding AL settings and services; the decision-making process by which consumers get to particular AL facilities; how residents and prospective residents perceive quality in an AL setting and the living conditions and service capacity they believe are most essential for their well-being and quality of life; and differences between resident and family members’ perceptions of these issues.

Despite the many studies conducted at state and national levels to describe AL residents, conference participants pointed to the following difficulties in using the work: (a) Inconsistent study findings may be due to variation in sample and definition of AL; (b) the information is often hampered by missing data, especially around the conditions precipitating

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**Table 5. Results of Preconference Exercise on Research Priorities**

<table>
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<tr>
<th>Rank</th>
<th>Consumers</th>
<th>Providers</th>
<th>Policy Makers</th>
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<tbody>
<tr>
<td>1</td>
<td>To what extent and how are AL service prices bundled or disaggregated? What is the range of services included in base prices, and what mechanisms are used to price plans for additional services (e.g., rate tiers, unit pricing)? How do the price ranges and pricing mechanisms vary by AL characteristics and by state?</td>
<td>What do consumers perceive as quality in an AL setting? What living conditions and services do they see as most essential for their well-being and quality of life? How, if at all, do consumer perceptions and preferences differ before and after move in?</td>
<td>How do AL residents differ from NH residents? What is the prevalence of third-party coverage for AL services (Medicaid, Medicaid waivers, Veterans Administration, private insurance) and third-party party coverage of “home care” services for AL residents (e.g., Medicare, Medicaid, insurance)? How well does such coverage correspond to actual prices charged to consumers or the AL facility’s costs?</td>
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<tr>
<td>2</td>
<td>How can prices be presented in ways that permit consumers to make understandable comparisons?</td>
<td>What do consumers perceive as important services to purchase as part of an AL package? What do they see as important characteristics of their private space and the overall setting?</td>
<td>What outcomes are important for regulators to measure in quality assurance for AL? Do these differ from outcomes to measure in other long-term-care settings, including NHs, and, if so, how?</td>
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<tr>
<td>3</td>
<td>What do AL providers expect of family in terms of direct care and management for a relative? What roles do family members prefer?</td>
<td>What is the most effective way of delivering nursing services, including medication administration, nurse monitoring and evaluation, and health care treatments?</td>
<td>What services in AL should be paid for under public programs? At what price? What method of reimbursement under Medicaid might best suit AL, and how should rates be calculated?</td>
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<td>4</td>
<td>How does direct family care provision affect price?</td>
<td>What practices, if any, can help mitigate risks to safety while preserving resident autonomy and choice?</td>
<td>Should public payers pay for rent in AL as room and board is paid for under Medicaid in NHs? What would be the policy advantages or disadvantages of Medicaid paying directly for room and board? What services can be paid by Medicaid or Medicare that would help prevent discharge to NHs?</td>
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<tr>
<td>5</td>
<td>What if any guidelines do and should determine when residents move in to AL settings and when they are asked to leave?</td>
<td>Who should monitor health care for quality? Should the AL facility be required to have an internal capacity for quality management, and/or should the state develop a care management capacity external to the AL facility at least for its publicly funded clientele? What experiences would shed light on these decisions?</td>
<td>Should public payers pay for rent in AL as room and board is paid for under Medicaid in NHs? What would be the policy advantages or disadvantages of Medicaid paying directly for room and board? What services can be paid by Medicaid or Medicare that would help prevent discharge to NHs?</td>
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**Note**: AL = assisted living; NH = nursing home.
move in; (c) comparable data are not available for nursing home residents or home care users; (d) studies inadequately consider the built-in variation among states due to state policy about who is permitted in AL and costs; (e) essential information at the national level, such as average length of stay, cost for stay, and discharge status, is lacking; and (f) longitudinal studies of long-term care users across settings beginning before entrance are needed to examine the decision-making process to enter AL versus choosing a different modality and the effects of that process.

**Service Capacity and Service Coordination in AL Settings.**—By service capacity we mean the range of services that an AL delivers or arranges for its residents. This topic generated strong opinions both about the kinds of clientele and services appropriate in AL settings and also about who should make that decision (consumers by deciding to move in and to stay, providers by choosing and disclosing what services they offer, or state or federal regulators by establishing parameters for required and prohibited services). Conferees sought empirical work on the actual service capacity of AL facilities, including the range and intensity of services and the balance between direct provision versus arrangement of services; how, if at all, AL staff and external agencies coordinate other health-related and social services needed by AL residents; whether external service coordination mandated by states for Medicaid clientele is a useful safeguard or a costly redundancy; and how consumers at move in react to settings in which large numbers of consumers have visible high-care needs.

Among the problems identified were the following: (a) Many studies are based on consumer self-report and may be inaccurate; (b) information from providers is often gathered by asking about the circumstances under which a resident would be discharged or whether any current resident is receiving a particular service; such data cannot be extrapolated to look at overall capacity because the capacity and willingness to serve a few residents with particular conditions differs from capacity to serve any resident with that condition; (c) information about services offered or provided gives few clues about the quality of those services; (d) longitudinal research is needed that links service capacity with resident outcomes, including the outcomes for residents remaining in the setting; (e) data linking service capacity to price are inadequate; (f) distinctions are not always made between service coordination and actual provision of services; and (g) standard data definitions are needed to make comparisons across care settings.

**Staffing Strategies.**—This topic overlaps with service capacity but was seen as an important area to consider separately. Staffing in AL is complex because of the mix of full and part-time personnel employed by AL settings, home care personnel from other agencies who provide services, private duty help paid for by the consumers, and family help. AL facilities also range from those whose service packages are almost entirely individualized even with respect to how many meals are included and those where the levels of help are completely packaged with the housing so that the AL can assume a certain level of revenue. If acceptance of and payment for services is largely a matter of individual choice for each resident, AL facilities are hard pressed to achieve economies of scale. Among the questions

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**Table 6. AL Research Priorities Identified in Four Small Groups of AL Researchers**

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<thead>
<tr>
<th>Research Topic Identified as a Priority</th>
<th>Small Group 1</th>
<th>Small Group 2</th>
<th>Small Group 3</th>
<th>Small Group 4</th>
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<tr>
<td>Access</td>
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<td>AL definition</td>
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<td>AL typologies</td>
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<td>Consumer preferences</td>
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<td>Consumer role in decision making process</td>
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<td>Cost/financing</td>
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<td>Differentiation between needs of consumers and family or representatives</td>
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<td>Effectiveness of public AL policy (e.g., Medicaid waiver programs)</td>
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<td>Environment design</td>
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<td>Determining the information system needed for consumer decision making</td>
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<td>Resident outcome studies</td>
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<td>Oversight of AL</td>
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*Note: AL = assisted living.*
were the following: (a) What are the differences in AL staffing patterns by state, and how does state policy dictate these patterns? (b) How are staffing patterns and strategies related to resident characteristics and outcomes? (c) What are the actual competencies of AL staff? (d) How much staff turnover and staff stability are present, and what recruitment and retention strategies are most effective? (e) What is the role of the registered nurse in AL (with the recognition that the ability of the registered nurse to delegate varies by state policy)? (f) What are the current and ideal roles of social workers? and (g) How do the outcomes and costs of strategies of hiring direct care staff and providing care through contracted outside agencies compare with the use of private duty personnel? The main methodological issue concerned a consistent framework on how to count staffing inputs.

**Specialized Services for Residents With Dementia.**—Important questions with policy significance concern what physical settings and services would allow people with dementia at various stages of severity to achieve good outcomes in AL. From a practice perspective, questions arise about the effects on people with dementia of being housed in segregated versus mainstreamed settings, the market preferences of prospective residents and their family members for settings and services for people with dementia, and the effects of mainstreamed versus segregated settings on residents without dementia in the same AL facility.

Conference participants pointed out problems in studying these issues: (a) Level of dementia needs to be clearly defined according to a commonly understood classification; (b) no agreed-upon outcomes measures; (c) difficulty of measurement; and (d) the large number of variables (including size and extent of private quarters) that would potentially affect the feasibility and desirability of mixing people with dementia in the general AL population.

**Cost and Financing.**—Attendees highly endorsed studies of the costs of care, the actual pricing patterns, and the payment mix as important for all groups—consumers, providers, and policy makers. Specific recommendations were (a) a regularly updated nationwide study on AL prices; (b) barriers to aging in place are different under bundled versus disaggregated (often called a la carte) pricing; (c) how price ranges and pricing mechanisms vary by AL characteristics and by state; (d) price ranges of the housing and board component alone, and examination of the cross-subsidization between the room and board and the service components of the costs; (e) development and testing (e.g., for comprehensibility, usefulness) of a standardized price information system for consumers; (f) the prevalence of third-party coverage for AL services, including Medicaid, Medicaid waivers, VA, private insurance; (g) variation in additional charges when residents have increased needs for care; and (h) the extent to which two-class systems of AL are emerging for low-income people, and whether low-income people are more likely to be offered nursing home care than counterparts with the same disability levels. Methodological problems include establishing common conventions for describing price structures and linking information on the individual resident’s care and the price billed for his or her services.

**Resident Outcomes.**—Conferees agreed upon outcome studies as crucial for measuring the effectiveness of AL settings, but they identified numerous difficulties in deciding how to measure outcomes and what outcomes should be measured. The relatively few existing longitudinal studies tend to use multiple outcomes, including mortality, morbidity, transitions to heavier or lower care settings, physical functioning, social functioning, psychological well-being, and satisfaction; there is little analysis of whether tradeoffs occur in outcomes or whether positive outcomes are linked. None of these candidate outcomes are easy to interpret; for example, death in an AL may be a good outcome in contrast to discharge of someone near death, whereas a preventable death in AL would be a bad outcome. All studies need to determine how to handle loss of sample because of mortality, discharge to a nursing home, or other kinds of discharge (to a different AL setting, perhaps to a dementia-specific setting, to home). If researchers use AL-specific outcome rates, they must develop a proper case-mix adjustment. Conferees thought all AL stakeholders would be interested in exploring tradeoffs between resident autonomy and resident safety as outcomes. Among the suggestions were (a) comparing safety outcomes between AL and nursing homes; (b) examining differences in the meaning of the concept of safety among residents, families, providers, and policy makers; (c) undertaking specific studies of negotiated risk management; and (d) undertaking studies to identify the practices that can help mitigate risks to safety while preserving resident autonomy and choice.

Conference participants identified the following problems in outcomes research: (a) Outcome measures sometimes are poorly defined; (b) mortality and morbidity is difficult to compare to those in nursing homes if case mix is drastically different; (c) ambiguity of measures that could signify a good, bad, or neutral outcome (e.g., mortality rate and transition to nursing home); (d) lack of consensus on which domains of social functioning to examine; (e) the need for much measurement work on social functioning and general well-being; (f) the difficulty of positive bias in satisfaction surveys; (g) variations in how consumers and professionals define psychological well-being; (h) the lack of linkage between...
environment factors and outcome measures; and (i) the lack of longitudinal studies of AL outcomes.

**Family Involvement in Resident Care.**—Specific suggestions here included the following: (a) Study the various type of roles families play in AL resident care, including what family members think their role should be, what they actually do, and how they feel about what they do; (b) examine AL providers’ expectations in terms of family involvement in direct care and management for the resident; (c) examine how, if at all, direct family care provision varies with AL pricing; (d) study family satisfaction about AL services; (e) examine the relationship between family and family care and decision making about moving to higher care settings; (f) examine family support within AL settings when spouses or siblings are in the same AL or share a living unit; and (g) study the extent to which AL residents relocate into communities where they have no local ties to live near family members.

**Transitions to and From AL.**—Relatively few studies have explored transitions to and, particularly, from AL in a dynamic way. Some specific topics suggested by conference participants were (a) develop research-based guidelines for determining when residents should be advised to move in or move out of AL settings of various types; (b) examine whether move out to nursing home is more likely to occur when ownership of nursing home and the AL facility is shared or located on the same campus; (c) study the dominant reasons why residents move out of AL, as well as how these reasons vary across states; (d) examine whether AL residents in AL portions of independent housing complexes have a different likelihood of moving to a nursing home than those in freestanding AL facilities; (e) study patterns of return to AL from hospitals, either directly or after a postacute nursing home stay; and (f) study whether postacute home health care for those who return to AL is associated with remaining in AL.

**Regulatory Oversight.**—The issue of oversight of AL, which was flagged as of great interest to policy makers, was prompted by the limited empirical information about regulatory and quality assurance strategies in AL even on a descriptive basis. Specifically, attendees thought that research was needed to guide (a) setting standards for AL in terms of staff qualifications and regulations, mandated admission and moving-out criteria, mandated programs, and mandated characteristics of the physical environment; (b) determining if special standards are needed for dementia care; (c) identifying ways that regulatory approaches could reinforce a philosophy of consumer control and choice; (d) determining types and timing intervals for inspections; and (e) identifying how regulators might measure and profile quality in AL settings.

**Broad Conceptual and Methodological Issues**

Although it is perhaps a truism to say, this conference reinforced the importance of a wide range of qualitative and quantitative methods and the interaction between researchers using both approaches. Many of the questions causing controversy in AL require in-depth observation and open-ended interviewing. At the same time, overgeneralization from small studies that may pertain only to a single state or even a single facility is a problem. Conferences endorsed longitudinal approaches for both qualitative and qualitative work. Attendees repeated discussed the lack of standardized definitions to classify AL or to examine outcomes as a barrier in AL research and in research comparing AL to other settings. Conferences saw the emergence of quasi-experimental and experimental studies of actual variations within AL as a positive development.

Conference participants were in accord that lack of a good information system hampers AL research, especially research that might compare AL programs to one another or to other types of long-term care. Consumers lack information for making informed decisions concerning AL entry and/or AL facility selection; providers require information to improve their service delivery, efficiency, and quality assurance; and policy makers need reliable information to initiate and develop effective policies that can both satisfy consumers’ needs and benefit long-term economic development. Although the need was expressed for a nationwide collection of data regarding AL settings and residents using common definitions in a way that would permit cross-walking with data on nursing homes and home care, sharply divided opinions were expressed on the utility of developing a mandated data collection form for AL or adopting versions of the nursing home Minimum Data Set, or on allowing definitions for AL to be constrained by already existing data sets for nursing home residents.

**Conclusions**

This article has described a process to help clarify and plan for an emerging area of research. We built the process around a working conference largely for and composed of individuals who actually do research in the area. We performed substantial front-end work to review existing literature, prepare commissioned papers, and identify the range of individuals and organizations then involved with AL research. An advance exercise in identifying and getting feedback on a long list of potential research topics helped focus the meeting itself, as did prior identification of streams of research: quantitative, qualitative, experimental, and policy oriented.
Participation in the conference was enthusiastic, and conferrees were deeply engaged, perhaps because no previous venue had brought actual researchers together to focus on their sometimes esoteric methodological issues. The research priorities that emerged during the conference were AL residents’ characteristics, preferences, and decision-making process; service capacity in AL; staffing strategies; specialized services for residents with dementia; cost and financing; resident outcomes; family involvement in resident care; transitions to and from AL; and regulatory oversight.

References


Received March 21, 2007
Accepted April 30, 2007
Decision Editor: Susan L. Hughes, DSW