

Aging in Place Partnerships:

A Training Program for Family Caregivers of Affordable Senior Housing Residents

Approximately two million low-income older adults live in subsidized senior housing properties across the country. Research shows these residents face a higher level of illness and disability than their homeowner counterparts. They often need assistance managing their health care and conducting daily activities. Yet, these individuals also face significant barriers to receiving help, including inadequate income to pay for services and limited availability of publicly funded services. For this reason, family caregivers often play a crucial role in helping residents meet their needs and remain safely in their apartments.

In a previous study of three affordable senior housing communities in Colorado, the Institute for the Future of Aging Services (IFAS) found that residents relied significantly on family caregivers. Interviews with housing staff at the Colorado properties reinforced the fact that family support was crucial to a resident's general well-being and an essential factor in allowing the resident to maintain his or her independence. Unfortunately, staff members observed that the uneven availability of informal care compromised the independence of some residents.

In 2009, IFAS and its partners set out to develop and test a program that would expand the capacity of family caregivers to assist residents in affordable senior housing properties. The project had three objectives:

1. Identify the specific needs and knowledge gaps of family caregivers to inform the development of a training program to help family caregivers and service coordinators collaborate more effectively in supporting residents.
2. Help housing properties and service coordinators recognize family caregivers as an integral part of the service network and offer property staff skills to train and interact with family caregivers.
3. Teach family caregivers about the role housing properties and service coordinators can play in helping residents remain safely in their apartments and how they can partner with property staff to facilitate their family members' independent living.



Project Activities

The project was conducted in three affordable senior housing properties located in the Washington, D.C. area. The program was initially conceived as a train-the-trainer model through which service coordinators working in the housing properties would deliver the caregiver-training workshop to family members of residents. Service coordinators were chosen to fill this trainer role because they had extensive knowledge of services and resources available locally. Because the project sought to enhance family caregivers' knowledge of services and to create a working relationship between family caregivers and the housing property, it seemed logical that service coordinators should conduct the workshops.

During the course of the project, IFAS team members interviewed service coordinators and conducted separate focus groups with and surveys of residents living in the participating housing properties and family caregivers who were recruited to participate in the project. In addition, family caregivers were randomly assigned to either an intervention or control group. Caregivers in the intervention group attended a caregiver-training workshop held in each of the housing sites.

Caregivers participating in both the intervention and control groups completed a survey prior to the caregiver-training workshops and approximately six months after the workshops. While these surveys attempted to gauge

the workshops' impact on attendees, a low response rate made it difficult for researchers to draw meaningful statistical conclusions. However, survey responses did provide insights into the value of the training and helped researchers identify aspects of the curriculum and format that should be revised.

Extent of Family Caregiving in Affordable Senior Housing Properties

As no study has focused specifically on the amount and scope of family caregiving taking place in affordable senior housing properties, the project team attempted to understand the level and intensity of caregiving occurring in the three pilot sites. The surveys and focus groups revealed a great deal of family involvement. Eight-five percent of residents responding to the survey said they receive a daily or weekly call from family members; 60 percent of older respondents reported visiting with family members either daily or weekly. By the same token, 62 percent of family caregivers responding to the survey said they assist their family member either daily or multiple times each week. Almost all family caregivers (95%) reported phoning their relative daily or multiple days each week.



One-quarter of respondents to the resident survey reported receiving considerable family assistance, most frequently with transportation, shopping or running errands; companionship; arranging medical care and communicating with doctors; and tracking bills or other financial matters. More than half of family caregivers said they help their family member with six or more tasks, the most common tasks involving socialization, transportation, running errands, monitoring medical care and managing bills and other paperwork. Findings from both the resident and family surveys were confirmed during the focus groups held with family caregivers. The extensive level of family support identified during those group discussions led researchers to perceive that many housing residents would be unable to remain in “independent” housing without continued support from their family caregivers.

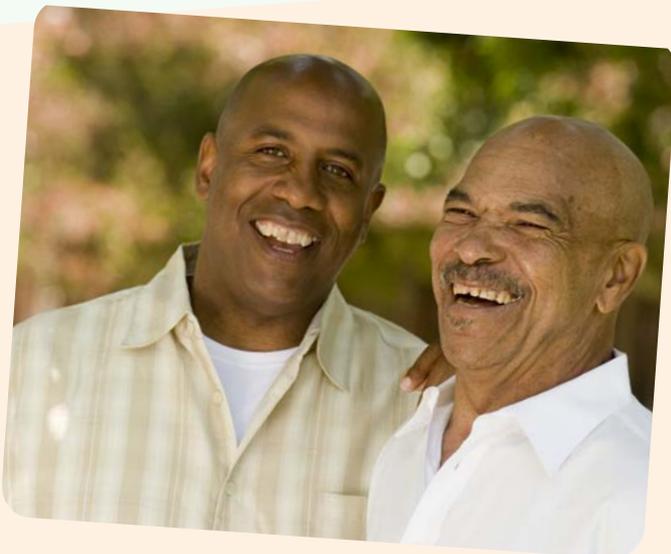
Developing the Workshop Curriculum

The project team used data and insights collected during family and resident surveys, focus groups and interviews with service coordinators to help inform the development of the family caregiver training curriculum.

Challenges in the Caregiving Relationship

Residents and family caregivers find themselves navigating a relationship that is marked by evolving roles, changing boundaries and occasional tension, especially when it comes to giving and receiving care. Some family caregivers are reluctant to step in and do things for their family member as his or her abilities decline. They are uncomfortable telling their family member how to act and are concerned about violating the older adult's privacy and sense of independence. Other family caregivers go to the other extreme, taking a more aggressive role in the relationship and often bringing about a parent-child role reversal.

The relationship between a family caregiver and an older resident is especially challenged by the fact that both parties are dealing with the resident's loss of independence. Some family caregivers are in denial about their family member's decline and do not understand how



day-to-day functioning changes with age. Service coordinators observed that family caregivers sometimes believe their family member is “just being difficult.” Often, family caregivers may not recognize that certain behaviors could signal a health-related problem. Other family caregivers are helping their family member come to terms with their loss of independence. Some residents may be in denial or embarrassed about his or her changing condition and unwilling to ask for or accept help or to change their habits. Several family caregivers said that they walk a fine line between empowering their family member to make his or her decisions and ensuring that relative’s safety and the safety of those around them.

Needed Skills and Knowledge

Generally, said service coordinators, family caregivers need a better understanding of the aging process and how it may affect a family member’s physical and/or mental health, functional status and behavior. These caregivers need additional skills to recognize when a behavior change could be a sign that a health-related issue needs to be addressed.

Service coordinators also suggested that family caregivers need education that would help them better handle a resident’s transition back to the housing community after a hospital stay. Family caregivers often do not know what questions to ask physicians and discharge planners to ensure their family member is, in fact, ready to return home and that the resident or the family caregiver have the necessary knowledge and resources to successfully

manage care post-hospitalization. Service coordinators also saw the need for more family caregiver training in the area of medication management. Specifically, family caregivers need the skills to provide better oversight of the resident’s medication regimen and to recognize that changes in a resident’s physical and mental health could be related to complications with medications.

Finally, service coordinators felt that family caregivers generally had limited knowledge of the services available in the community. The survey of family caregivers supported this perception. Sixty-two percent of family caregivers were only “somewhat aware” and 12 percent were “not aware at all” of community resources.

Family Caregivers’ Perceptions of their Caregiving Role and Experience

Some family caregivers participating in the project did not identify themselves as “caregivers” because their relatives lived in “independent” living properties. In fact, some participants wondered why the project team was asking them about the assistance their family members needed or they provided.

When asked how often they or their family members access services from the community, 61 percent said “rarely” or “never”. The top reasons given were: “I can take care of my family member’s needs on my own” (48 %); “My family member won’t let anyone other than me assist them” (33 %); “We can’t afford to purchase services” (24 %); “I’m not aware of available service” (24 %). During the focus groups, several family caregivers described their role in assisting their family member as their “duty.”

Caregivers who completed the survey indicated that they did not feel overwhelmingly stressed or burdened by their caregiving relationship, although a sizable proportion did indicate they were sometimes strained by their caregiving responsibilities. In addition, several family caregivers revealed during focus group discussions that they experienced frustrations and challenges in their caregiver relationship. Some also admitted that the rewards of caregiving became harder to appreciate over time as the interaction with older family members changed from a predominately social one to a relationship that revolved around caretaking. Some focus group participants said they worry about what will come next for them and their

family members. Survey participants shared this anxiety. About one-third said they are frequently or always afraid of what the future holds for their family member.

Significantly, most focus group participants admitted that they had never discussed their caregiving experiences with others. The focus groups seemed to provide these caregivers with a comfortable opportunity to reveal their thoughts and feelings.

Interaction Between the Service Coordinator/Housing Property and Family Members

Family caregivers were surveyed about their expectations of the housing property with regards to their family member's need for services and supports as they age. Almost two-thirds of caregivers who responded to the survey said they expected the housing property to alert them to services that might help their family member. Just over one-fourth of participants, however, had no expectations.

About three-fourths of respondents were aware of the service coordinator. However, 62 percent said they “never” or “rarely” approach the service coordinator for information or advice regarding their family member. Service coordinators confirmed the fact that many family caregivers do not use their services. They suggested that family caregivers see the properties as apartment complexes and do not expect staff to assist them with care-related issues. Several family caregivers in the focus group confirmed this observation, saying they did not expect assistance because their relative lived in “independent” housing.



Elements of the Family Caregiver Training Program

The project team developed curricula for both a train-the-trainer workshop for service coordinators and a family caregiver workshop. The eight-hour train-the-trainer workshop consists of two components:

1. **Awareness Training.** This component is designed to increase service coordinators' understanding of and empathy for family caregivers and their role. It also aims to help service coordinators recognize how families and the housing property can work together as partners to support residents.
2. **Workshop leader training.** This component is designed to prepare service coordinators to deliver the training program with family caregivers.

The family caregiver workshop is intended to be interactive, asking for input and incorporating role-playing activities that allow participants to practice the knowledge and techniques they are learning. The workshop consists of two, two-hour sessions, which can be delivered separately or combined into one workshop. These sessions include:

1. **Understanding Aging in Place.** This first session addresses the changes and associated needs that accompany the aging process, as well as the caregiver's changing role in relation to those needs. It also teaches self-care strategies that family members can use to cope with the stress of their caregiving role.
2. **Helping My Resident Age in Place.** The second session examines the role of the service coordinator and housing property and how they can assist family caregivers in supporting residents. It also helps the family caregiver learn about the services/resources available to help meet their family member's needs and improve their communication skills so they can have more positive interactions with their family member.



Piloting the Workshop

As originally planned, service coordinators from each of the housing properties attended a one day, train-the-trainer workshop aimed at preparing them to deliver the family caregiver training curriculum. It ultimately became apparent, however, that the participating service coordinators did not feel entirely comfortable in this teaching role. For purposes of the pilot, project team members instead delivered the family caregiver workshops in each of the three properties.

Service coordinators may feel uneasy delivering a training workshop for a variety of reasons. Although they may be knowledgeable about services and may perform one-on-one education with residents, service coordinators may not have prior experience working with family caregivers or delivering group trainings. In addition, service coordinators who manage a large number of residents may not feel they have time to take on an additional program, especially one not directly focused on residents. Finally, the service coordinators participating in the pilot project viewed themselves primarily as advocates for residents and expressed the concern that interacting with family caregivers in this way could conflict with that advocacy role.

Post-workshop evaluations indicated that participants were very satisfied with the family caregiver training curriculum. Two-thirds of participants rated the workshop as “excellent” and one-third described the workshop as “good.” Nearly all participants said they felt “well prepared” or “very well prepared” to help a family member age in place. All participants said they would recommend the workshop to others.

Only one participant said he felt only “somewhat prepared” to help a family member. However, this family caregiver also noted that he had acquired tools during the workshop that he was ready to try. Other workshop participants agreed, saying that the workshop had provided them with new ideas and techniques to address some of the challenges they face in assisting their family member. Caregivers also liked the workshop’s role-playing exercises, which gave them the opportunity to practice how they might apply what was taught in the workshop. Several participants said they appreciated the opportunity to talk with other family members and learning that they share common challenges and concerns and are not alone in their caregiver experience.

Conclusions

The input received from service coordinators, family caregivers and residents affirmed the need for a training program aimed at family caregivers of affordable senior housing residents. The project team observed the following during the course of the study:

- **Family caregivers provide a tremendous level of support and assistance to residents in affordable senior housing settings.** The amount of caregiving observed during this pilot project undoubtedly underestimates the magnitude and scope of family care being provided in affordable senior housing. Participation in the pilot was voluntary and many of the individuals who engaged in the project had been identified by the service coordinators. Undoubtedly, more family members are helping their relatives within these properties but are not engaged with the service coordinator or were uninterested in or unavailable to participate in the study.
- **Family caregivers appear to lack awareness of available services and resources.** Clearly, many caregivers feel they can take care of their family member’s needs on their own. However, a time may come when their family members will need additional assistance that is beyond the capacity of the family caregiver.
- **Family caregivers face challenges as they strive to accept and adapt to an older relative’s changing condition and abilities.** Equally challenging is the task of helping a family member make their own adjustment to age-related declines. Additional skills could help family caregivers handle these challenges.

- **Generally, family caregivers and service coordinators are not communicating with one another.** By working more cooperatively, caregivers and service coordinators could share their respective knowledge and resources, minimize the burdens they each carry and maximize their success in supporting residents.
- **Family caregivers could benefit from interacting regularly with one another.** The dynamic interaction between the family caregivers participating in the project was surprising. Several family members said they appreciated the opportunity to share with other caregivers during focus groups and workshops, even though such interaction may not have seemed valuable to them before the project began. During these discussions, many caregivers assumed peer-mentor roles, offering advice to others. Participants viewed the focus groups as an opportunity to discuss common challenges and to share with others the information and solutions they had learned through their experiences. When the focus groups ended, several participants wanted to know when the group would meet again. Others lingered afterwards and continued their sharing. Caregivers in one workshop noted that participants represented a natural support network because of the commonality they share of having a relative living at the property and a desire for that relative to remain there for as long as possible.

Next Steps

Nearly two million older adults currently reside in subsidized housing. Many of these residents receive some type of support from family caregivers. Given these statistics, it is clear that a family caregiver training program has the potential to reach a large group of caregivers and elderly residents. As affordable senior housing properties begin to witness the aging of their residents, they may find that supporting family caregivers, and building strong partnerships between those caregivers and service coordinators, could help make “aging in place” a reality for many older adults in communities across the country.

Given the hesitation of service coordinators in the pilot project to conduct the family caregiver workshop – and the absence of service coordinators in some housing properties – it may be advisable to identify other community partners that could deliver the family caregiver training program. One potential partner in this effort could be local area agencies on aging, which already have experience providing caregiver training and support programs. Other potential collaborators include community groups such as AARP chapters, Red Cross chapters, senior centers, social service organizations or care managers. Given the significant ethnic and cultural diversity among residents and family members, which IFAS researchers have observed in their examination of a number of senior housing-with-services models, community partners will need both multilingual and cultural competence expertise to address the needs of an increasingly diverse resident and family base.

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IFAS is a policy research institute whose mission is to create a bridge between the practice, policy and research communities to advance the development of high-quality health, housing and supportive services for America’s aging population. IFAS is the applied research arm of the American Association of Homes and Services for the Aging (AAHSA). AAHSA members serve two million people every day through mission-driven, not-for-profit organizations dedicated to providing the services people need, when they need them, in the place they call home. AAHSA’s commitment is to create the future of aging services through quality people can trust.