This report presents findings from interviews with current and prospective participants in Portable Assisted Living Services (PALS)—an assisted living program in northern New Jersey. PALS provides support that is typically only available in assisted living facilities to residents in need within independent senior housing. Examples of services include medication assistance, light housekeeping, and coordination of healthcare. To better understand how PALS operates from the perspectives of consumers, 18 interviews were conducted with residents and family members who differed in their enrollment status with PALS (i.e., enrolled, were in the process of enrolling, or not currently pursuing enrollment). Results indicated participants’ strong perceptions of the influence of PALS on residents’ ability to age in place, such as by preventing the escalation of problems and enhancing residents’ functioning. Findings also indicated the program’s perceived effects on family members, such as reduced anxiety around the care of their loved ones. Participants identified several key influences on enrollment in PALS, including perceptions of clinical need, costs, and Medicaid Managed Long-Term Services and Supports enrollment issues. Findings can be used to inform efforts to further develop PALS at the Westwood House and beyond.

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Background

Aging in place refers to people’s ability to remain in their own homes and communities safely and comfortably, for as long as they so choose and especially when faced with challenges that become more common in later life.\(^1\) With rapid population aging—and given that the vast majority of adults report a preference to age in place—supporting people in their own homes and communities has become an increasingly valued social goal.\(^2\)

Health conditions and frailty associated with later life, especially at very advanced ages, are major threats to aging in place. Without adequate supports, older adults can be at risk for undesired relocation to care-based residential settings, repeated falls and hospitalizations, and self-neglect. Long-term services and supports, a service category that refers to assistance with activities of daily living for people who have long-term health conditions that limit their ability to perform such activities on their own,\(^3\) can protect against such negative aging in place outcomes. Nevertheless, in general, the United States lacks a comprehensive system for funding and delivering long-term services and supports to those in need. This gap leaves many reliant on family caregivers or managing as best they can without the additional needed support.

Although recent efforts to re-design long-term care at the national level have been met with frustration,\(^4\) developments at more local levels continue to emerge. One such example is assisted living programs (ALPs). ALPs are designed to offer many of the benefits of assisted living facilities without older adults having to move from independent housing into care-based residences. ALPs offer comprehensive in-home services to older adults, most typically targeting those who have daily needs for care. Assisted living services often include assistance with activities of daily living, meal preparation, social and recreational activities, as well as other ancillary health and social services, such as care coordination.\(^5\)

ALPs have developed specifically in the context of publically subsidized housing. Research has found that compared to their peers, older adults who reside in public housing face more health problems, have greater rates of disability, are more likely to live alone, and are more likely to be women—all factors that are associated with greater risk of nursing home placement.\(^6,7\) ALPs have been introduced as one way to provide more adequate support to residents in need of greater care than is typically provided within affordable senior housing.

Despite relatively vibrant national discourse on other innovative approaches to delivering long-term services and supports,\(^8\) there has been relatively little discussion of ALPs to date. ALPs have been “on the books” since before 2001, at which time the AARP Foundation conducted a study of 17 ALPs across nine states.\(^9\) Focusing on New Jersey specifically, according to the AARP report in 2002, there were 14 licensed ALP providers serving 37 distinct subsidized housing projects in the state. New Jersey also had developed licensing procedures and regulations, as well as had made assisted living programs reimbursable through the New Jersey Medicaid program. Currently, the State of New Jersey’s Department of Health website lists 13 licensed ALP providers.\(^9\)
**The Westwood House**

This report focuses on the development of an ALP—Portable Assisted Living Services (PALS)—in Westwood, New Jersey. Westwood is a community of approximately 11,000 people in Bergen County, located in the northeast corner of the state in the greater New York metropolitan area. According to the 2014 American Community Survey, Westwood residents are predominantly White (just over 80%), and approximately 18% of residents are ages 65 years and older, compared to 14% for New Jersey as a whole.

According to the AARP livability index, Westwood scores in the top third of communities nationwide on a variety of indicators, including personal safety, neighborhood quality, access to different types of places (e.g., retail, health care, grocery store), convenient transportation options in terms of local transit and walkability, as well as social engagement. It scores in the bottom third on housing affordability, both in terms of absolute housing costs and housing cost burden.

Located near the center of the municipality, the Westwood House is a mid-rise building with 182 rent-assisted units. All units are one-bedroom and have a kitchen and private bath. The building is managed by Emerald Management Corporation, a private property management group. As Section 202 housing under the U.S. Department of Housing and Urban Development, households must have at least one person who is at least 62 years old at the time of initial occupancy or at least age 18 and disabled with a mobility, hearing, or sight impairment. Households must also have annual gross incomes no greater than $32,450 for a single applicant and $37,100 for a couple. Similar to the few other federally subsidized senior housing properties in Bergen County, there is a long waiting list for residence in the Westwood House.

Although the Westwood House does not have a designated service coordinator through federal or state programs, the building does have an on site senior center, which provides a hot lunch program on weekdays, informational seminars, recreational activities, exercise classes, and linkages to resources outside of the building. Westwood House facilitates other supportive services, including arrangements with the county transportation provider. The regional home-delivered meals provider is also headquartered on site.

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**PALS at the Westwood House**

Senior Housing Services, Inc. (SHS), which is a private not-for-profit organization, operates PALS. The mission of SHS is “to provide affordable housing and support services that respond to the changing needs and preferences of older adults and offer choice, promote dignity, and ensure safety and comfort.” SHS is the only assisted living services operator in Bergen County that accepts Medicaid outright, with few other providers in the region offering affordable assisted living.

PALS developed at the Westwood House as part of SHS’s work on a parallel project to develop a new federally subsidized senior housing property in a neighboring community. As part of planning for the new building, SHS staff visited the Westwood House. Through conversations with the property managers there, SHS learned of the building’s interest in more on site supportive services. Together, SHS and building management developed plans for the implementation of PALS at the Westwood House upon receiving approval from the Westwood Senior Housing Corporation Board of Trustees, as well as grants from The Brookdale Foundation Group and The Henry and Marilyn Taub Foundation.

SHS received its ALP license from the State of New Jersey in December of 2014, and the program at the Westwood
House enrolled its first participant in February of 2015. In addition to funding from The Henry and Marilyn Taub Foundation and The Brookdale Foundation Group, PALS has received revenues from program fees and grants from the Bergen County Division of Community Development and the Bergen County Area Agency on Aging.

PALS staff members are housed in an office suite on the first floor of the Westwood House, and enrolled residents live throughout the building. The core staff consists of a program director, a nursing supervisor, nurses, and aides. SHS currently contracts with two local home health organizations for staffing several of the aides, and there is a partnership with a local family service organization to assist prospective participants with Medicaid enrollment. Table 1 summarizes the program details for PALS.

The current fee structure for PALS is based on a monthly fee per participant. The minimum fee is the New Jersey Medicaid rate of reimbursement for ALPs, which is currently just over $1,600 per month. People who do not clinically or financially qualify for Medicaid pay for PALS privately. (For more information about Medicaid eligibility, see http://www.state.nj.us/humanservices/dmahs/clients/medicaid/abd.)

Table 2 (next page) presents the number of residents enrolled in PALS during its first year of operations. A total of 14 people had enrolled through January of 2016, with four people exiting the program due to death or a need for a higher level of care. Of the 14 people, six people were paying privately, and the others were receiving PALS through Managed Long-Term Services and Supports (MLTSS) as part of New Jersey Medicaid.

<table>
<thead>
<tr>
<th>CATEGORY</th>
<th>HOW PROVIDED</th>
</tr>
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<tbody>
<tr>
<td>Activities and Recreation</td>
<td>PALS provides some activities, and assists residents to participate in activities already at the Westwood House</td>
</tr>
<tr>
<td>Apartment and Building Maintenance</td>
<td>Part of participants’ rental agreement with the Westwood House</td>
</tr>
<tr>
<td>Assistance with Personal Care</td>
<td>PALS provides</td>
</tr>
<tr>
<td>Coordination of Health Care Services</td>
<td>PALS provides</td>
</tr>
<tr>
<td>Light Housekeeping, Laundry, and Linen Services</td>
<td>PALS provides</td>
</tr>
<tr>
<td>Meals</td>
<td>PALS provides assistance with meal preparation</td>
</tr>
<tr>
<td>Medication Administration and Management</td>
<td>PALS provides</td>
</tr>
<tr>
<td>Non-Skilled Nursing Care</td>
<td>PALS provides</td>
</tr>
<tr>
<td>Rent</td>
<td>Participants pay rent to the Westwood House</td>
</tr>
<tr>
<td>Staffing</td>
<td>PALS staff on site 12 hours per day and seven days per week, with a registered nurse on call 24/7; Westwood House staff on site 24/7</td>
</tr>
<tr>
<td>Transportation Services</td>
<td>PALS helps to arrange municipal, county, and taxi services</td>
</tr>
</tbody>
</table>

A PALS enrollee leaves her unit to participate in an on site activity.
Overview of the Research Project

To better understand consumers’ experiences with PALS, Emily Greenfield, Associate Professor at Rutgers, The State University of New Jersey, partnered with PALS to conduct an in-depth interview study of residents and family members. The study’s aim was to learn from current and prospective consumers about their experiences with PALS, with particular attention to how to support the development of PALS within the Westwood House and at future sites. More specifically, the project aimed to address the following questions:

1. What do current and prospective consumers perceive as the purpose of PALS?
2. What influences people’s ability to enroll in PALS?
3. What ideas do consumers have for strengthening PALS in the future?

A total of 18 interviews were conducted from September through November of 2015. The project intentionally recruited individuals and families with different degrees of involvement with PALS, although all people included were identified as having potential need for the program. Table 3 summarizes key characteristics of the participants in the research project.

Interviews were conducted in people’s homes, workplaces, a conference room at the Westwood House, or by telephone. As part of the university-approved human subjects protocol, all participants provided informed consent before participating. With support from The Henry and Marilyn Taub Foundation, participants were provided $40 as a token of appreciation for their time. Interviews were approximately one hour in duration. Similar questions were asked of all participants, although questions were customized somewhat to explore particular themes in more or less depth with particular participants. Some examples of interview questions included:

- How would you explain the purpose of PALS to somebody completely new to the community?
- Describe how you first learned about PALS and what led you to enroll (or not enroll) in it.
- How might receiving assistance from PALS be different than receiving home care as usual?

All interviews were audio-recorded, transcribed, and then analyzed within qualitative data analysis software. Preliminary results were presented to program staff, funders, and residents at the Westwood House in January of 2016. Feedback from this session helped to ensure that results accurately capture predominant perspectives on PALS.

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Number</th>
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<tbody>
<tr>
<td>Interviewee</td>
<td></td>
</tr>
<tr>
<td>Resident alone</td>
<td>4 out of 18</td>
</tr>
<tr>
<td>Family member alone</td>
<td>12 out of 18</td>
</tr>
<tr>
<td>Resident and family member</td>
<td>2 out of 18</td>
</tr>
<tr>
<td>PALS Enrollment Status at the Time of the Interview</td>
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</tr>
<tr>
<td>Enrolled*</td>
<td>6 out of 18</td>
</tr>
<tr>
<td>Pursuing enrollment</td>
<td>6 out of 18</td>
</tr>
<tr>
<td>Not enrolled but potentially clinically eligible</td>
<td>6 out of 18</td>
</tr>
<tr>
<td>Receiving or Pursuing Funding through MLTSS (versus private pay)</td>
<td>9 out of 12 enrolled or pursuing enrollment in PALS</td>
</tr>
</tbody>
</table>

* One of the six was recently discharged by the time of the interview.

<table>
<thead>
<tr>
<th>Table 3. Characteristics of Interviewees</th>
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<tbody>
<tr>
<td><strong>CHARACTERISTIC</strong></td>
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<tr>
<td>Interviewee</td>
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<tr>
<td>Resident alone</td>
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<tr>
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<td>Receiving or Pursuing Funding through MLTSS (versus private pay)</td>
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* Because of death or need for a higher level of care
Results

Findings from the interviews are presented in three parts. The first part addresses the perceived effects of PALS for individuals, families, and communities. The second part addresses themes concerning how people access PALS. The third part highlights themes suggesting future directions for the development of PALS.

I. What are the perceived effects of PALS for individuals, families, and communities?

PALS and Aging in Place

Interviewees overwhelmingly emphasized that PALS allows residents in need to remain living at the Westwood House and to age in place safely and comfortably. As one family member stated:

I don’t think there’s any question that if PALS didn’t exist, my (loved one’s) time in the Westwood House would probably not be that long. She loves Westwood House, loves her apartment, loves to stay close. So this is a true blessing that the services have come around, that the powers that be have come around to putting something like this in place.

Themes from the interviews described two primary ways in which PALS was perceived to promote aging in place. First, people described how services through PALS improve residents’ overall physical, cognitive, and social functioning, thereby allowing them to remain in independent housing longer. Second, participants described how PALS staff are positioned to prevent the escalation of problems that would otherwise undermine residents’ ability to remain at the Westwood House. These themes are described further below.

Improved functioning. Family members and residents alike described how services from the nurses and aides, in particular, enhanced various aspects of residents’ health and functioning. One predominant theme addressed how PALS promotes people’s physical functioning. By accepting help with some activities of daily living, people perceived themselves as better able to maintain independence with other tasks. For example, one resident explained that before PALs, she would oftentimes just make herself a sandwich for lunch, and as a result become very tired: “I would think of having dinner, and I would just say ‘I don’t want to bother.’ Being on my feet a little too much, my back is just impossible after a little while.” The resident continued to explain how receiving help with cooking nutritious meals from the PALS aides helps to improve her overall stamina and to conserve energy for other tasks. Participants also described the value of PALS for helping them to access physical therapy and assisting residents with mobility limitations to take walks outside of their apartment units.

In addition to physical functioning, family members of residents with dementia discussed the cognitive benefits of PALS, largely through the daily social contact with the staff. As one family member explained:

(PALS) keeps (my loved one) more on a schedule. She has more of a sense of the time of day. I was getting a little concerned about that because (before PALS) she would fall asleep in her recliner in the evening into the next morning. That’s not a terrible thing, but she was unaware of how long she was sleeping. So I think this is very good for her. It keeps her awake and communicative throughout the day.

Interviewees further described how the staff provided meaningful social contact for residents, especially among those otherwise relatively homebound and socially isolated. As an example, one family member remarked how much her loved one enjoys the company of the staff and observed how she seems “peppier” after they visit. In addition to the direct social contact with the staff, family members also described how PALS has indirect effects on their loved ones’ social relationships. By supporting them in place, family members perceived PALS as helping their loved ones to maintain their existing social networks at the Westwood House.

Preventing the escalation of problems. PALS was seen as especially important in catching problems before they escalated into full-fledged crises. Participants discussed how PALS prevents catastrophic health events—such as falls and medication errors—that could have grave health consequences undermining people’s ability to remain at the Westwood House. PALS was also valued for attending to changes that appear minor at first, but that could escalate quickly, such as a low-grade fever or a rash.
PALS’ ability to prevent the escalation of problems was attributed to several programmatic features. First, many participants described the significance of having PALS on site seven days a week. The staff’s on site presence was perceived as facilitating their daily contact with residents—observing to make sure that everything is okay and responding to potential problems in a timely fashion. One caregiver of a loved one in the process of enrolling stated, “I have friends in assisted living, and they get checked on each day. I don’t think (the PALS staff) are going to sit there and chat with her, but she would see a face, and they would see her. So…we wouldn’t find her on the floor two days later.” Participants also described the significance of having more customized and flexible times at which the nurses and aides can provide care “compared to just having (an aide) come in three or four hours a day.” Participants described the value of flexible, on site services, especially in the context of healthcare needs that require care at multiple times per day, such as putting on stockings early in the morning and taking them off at night.

Participants further noted the importance of the wide range of services that PALS can provide beyond simply assisting with activities of daily living. One particular program component of value was through the nursing staff—to monitor the residents’ daily health more comprehensively than an aide alone. Family members, in particular, also identified the value of PALS staff liaising with other healthcare providers, especially physicians and pharmacists, and communicating regularly with the family when concerns arose. Many family members of residents already enrolled in PALS relayed stories of how PALS staff contacted them out of concern for their loved one and then connected with other parties to help ensure the resident’s health and safety. As an example, one family member said:

My (family member) had an allergic reaction on her chest one time...PALS recognized there’s a problem here that needs medical attention. They would call me, explain what’s going on, and I would say ‘absolutely, let’s get a hold of [primary care physician].’ They would hang up with me, and they’d be on the phone with [primary care physician]. And then it would go from there. If [primary care physician] prescribed something, he would send the prescription to the pharmacy. PALS would call the pharmacy to make sure they got the prescription, (find out) when it’s getting delivered, and then deliver it to (my family member) as needed based on the prescription. So (my family member) medically was just simply getting better treatment than she was without PALS.

Finally, participants overwhelmingly expressed their appreciation for the high quality care of the PALS staff. Participants spoke of the program director as being consistently responsive, knowledgeable, and eager to help. They also described the nurses and aides as being patient, compassionate, friendly, respectful, and in some cases, better engaging residents in accepting assistance compared to prior experiences with home health aides.

Alternatives to PALS
Many caregivers further expressed how much they valued PALS when considering the alternatives. As one family member summarized, “If you had a dream what the ideal situation would be, this would be it, and the others are just nightmares.”

One alternative that caregivers discussed was skilled nursing facilities, which was perceived to be far worse for participants’ health, to likely place more burden on family members, and in some cases, to be more expensive. Another alternative that caregivers identified was having their loved one stay put at the Westwood House, managing the best they could, and simply waiting for a catastrophic health event that would effectively force the resident to move. As an example, one caregiver said, “We would probably have to, unfortunately, let her fall down and have her go to the hospital because of a fall injury. She would then get admitted after the ER for three days and then from that, she would be forced into any nursing home that would take her.”

Some family members also discussed the possibility of having their loved one move in with them, but quickly noted conditions that would undermine their loved ones’ quality of life, such as inaccessible dwelling spaces and social isolation from the broader community. Interviewees also identified assisted living residences as another alternative, but realized that it was most likely to be financially out of their reach.

Outcomes for Family Caregivers
While the overwhelming majority of interviewees addressed the significance of the program for residents, nearly an equal number of participants discussed the
benefits of the program for family caregivers as well. In nearly all cases, family caregivers had been providing intensive care for their loved ones prior to PALS. Although PALS did not eliminate their carework, it was perceived as making their efforts more manageable, less burdensome, of higher quality, and in some cases, more enjoyable. Most prominently, family members described how PALS lessened their anxiety around their loved ones’ health and well-being—giving them greater peace of mind in this aspect of their lives.

First, caregivers described how PALS staff could do specific tasks that family members were more anxious about. For example, a son of a resident described his discomfort with helping his mother with her shower, making him especially appreciative of the aides’ assistance with this task. Many caregivers also identified the relief of having PALS staff assist with medication management, especially with certain medications that needed to be administered multiple times per day (e.g., insulin) and that required specialized knowledge.

Participants also described the value of having staff on site, whom they trust will notify them if there were any problems. As one caregiver summarized, “Knowing that someone’s going to see her first thing in the morning who knows us and knows her definitely give us peace of mind.” Several family members specifically mentioned the value of having a consistent team of people involved in their loved ones’ daily care. One family member said, “They know her medical history. They know who she is, and she knows she has somebody who’s there to care for her with us.”

Family members also derived a greater sense of peace of mind by knowing that PALS would be there if residents’ health status changes. For example, one family member stated that her loved one currently does not need help yet with showering or cleaning her apartment. “But when’s the next stroke happening?” she asked, indicating the significance of PALS as an anticipated source of support. In general, interviewees commented on the value they found in PALS offering diverse and flexible levels of support, readily allowing for modulating services as residents’ need fluctuated.

PALS also provided family caregivers with more flexibility and choices around their carework by serving as back-up when family caregivers became less immediately available to assist. This further reduced caregivers’ anxiety concerning their loved ones’ care. Several family members described putting their own plans on hold—be it their daily routine (e.g., where they would go after work) or their life goals (e.g., relocating to a different state, taking a long awaited vacation, or looking for work)—because of their carework. They described how PALS gave them more freedom to pursue these plans without feeling like they were placing their family members’ health and well-being at risk as a result.

Community– and Society-Wide Benefits
A handful of participants commented on how the benefits of PALS extend beyond the individual residents receiving services and their family members. For one, residents not enrolled, as well as family members of such residents, referenced the peace of mind that they derive from knowing that PALS is on site if they should need it in the future. As one resident stated, “This (is a) service that they will give you in the apartment instead of going into a nursing home, which a lot of people used to have to do. I don’t think most of us would like that. I’m glad (PALS) is available in case I need it.” Other interviewees described the benefits of having PALS on site to address health emergencies, as well as having a go-to place within the community to figure out next steps if a loved one’s health status changes.

Several family members of residents not enrolled described how the presence of PALS, as well as PALS staff, helped them to become more engaged about planning for the future and to learn about other sources of
supports that they had not yet considered or learned about. In some cases, caregivers met with PALS staff and partners to initially consider services through PALS, and in the process, learned about other resources that could address their family’s needs. More broadly, leaning about PALS motivated some family members to more actively look into additional sources of support. As one caregiver described:

When PALS gave their presentation over a year ago, my mother didn’t really need anything, (but) it triggered the thought that, if my mom’s going to stay here, she’s going to need help…That triggered me to look for some outside services as well.

More generally, interviewees expressed their overwhelmingly positive regard for the Westwood House and the ways in which PALS makes the building even better by providing services across a broader spectrum of care. Some residents expressed how they moved to Westwood House because of its being a supportive community for residents and that they feel “lucky that PALS picked to spearhead their program there” to allow residents to enjoy this supportive environment for even longer.

Some interviewees also described how PALS has benefits for people and organizations outside of the building, such as physician offices and hospitals. For example, one family member described the benefit of PALS after his loved one was discharged from a subacute rehabilitation center. “(The facility) feels secure in the fact that she’s going to get the care she needs. They’re going to release her with a clear conscience and not call anyone for elder abuse because they know she’s getting proper care.” Others described how the program suggests an important direction for the delivery of long-term services and supports overall. Several interviewees contrasted what few options were available when caregiving for a parent or grandparent in the past relative to the options that PALS offers. As one participant stated:

There’s no question in my mind that having a system in place such as PALS is so much better for the people that need it… The people in authority should be looking at these numbers and saying this is a win all the way around. We’re doing what’s right for the patient, and we’re saving money. How could you go wrong with that type of an equation?

II. What influences enrollment in PALS?

The preceding section summarized the benefits that interviewees perceived from PALS, especially in terms of promoting aging in place for residents at risk. Why would not all residents with care needs who know about PALS enroll in PALS? This is the focal question of the following section—exploring interviewees’ perspectives on what influences enrollment in PALS after first learning about the program. Analysis of the interview data indicated the following three primary factors:

(a) perceived need, (b) costs and payment considerations, and (c) MLTSS enrollment experiences.

Perceived Need. A major influence on participants’ enrollment with PALS concerned their perceived need for its services. This theme applied both to residents’ and family members’ perceptions of whether a resident needed additional assistance beyond what they were already receiving. Many of the residents not pursuing enrollment in PALS described their lack of need on account of two factors: (a) their ability to manage without help, and (b) their receipt of help from other sources. Regarding the first theme, many residents not pursuing PALS described the strategies they employed to complete tasks of daily living without personal assistance. One woman, for example, stated that she does not need help getting in and out of the shower because she has long legs that allow her to step over the bathtub, and that there is a chair and extra bars in the shower to help her ambulate. Others described how they paid someone—or relied on family members, friends, and community members—to help them with their care needs. For example, one resident had aides outside of PALS, and others took advantage of meals provided by the senior center co-located within the building. At the same time, many of the narratives regarding participants’ ability to meet their own needs through their own efforts or those of their family members and friends referenced how these arrangements might change in the future. As one participant stated, “So far, I have no problem. And I do have family that (helps) a little bit. But they all work. So you can’t depend on them 24 hours a day.”

Residents and caregivers alike acknowledged how difficult it can be for people to accept services for activities that they themselves once were able to do independently. Many participants stated that they or their loved one would have to be completely unable to do a task on their own before accepting in-home services, especially those
who were described as fiercely independent. As one resident not enrolled in PALS explained, “(To) have somebody come in and make your bed and have someone else in the apartment... when you’re used to having the place by yourself, you’re not really into it that much. You don’t really like to have someone come in and do things.” Another resident not involved with PALS explained how receiving services from PALS might undermine her ability to do things on her own. For example, if she were to let somebody else manage her medications, and then lost that help, “I would have to go back, and then I couldn’t handle it. Once I’m dependent, I would stay dependent, and that’s where I have to be careful.”

Still others, especially among those enrolled, described how even though coming to terms with their needs for assistance and accepting services from PALS is not easy, it is necessary for them to maintain their independence. For example, one resident enrolled in PALS stated:

I know I need it. It’s the same thing as using a walker. People won’t use a walker. People that should. They don’t want to look old. Without the walker, I probably would be on the floor very often. You have to realize when you have a problem, and you can’t do something, that you have to do the next best thing.

Family members described their role in encouraging loved ones to consider services from PALS. For example, one caregiver stated:

When it first was announced, (my loved one) just put it to the side because she didn’t need it, but then I reminded her it was available and maybe it was a way for her to remain in her apartment. She took it seriously. I can’t say she is thrilled with people coming in and out at times of the day because she is a very private person. They are so kind and eager to help that it’s not an intrusion but something she had to get used to. In the beginning, it was very overwhelming for her, all of these people coming in, but now I think it’s settled down, and there is a routine to it, and she realized they are a big help.

Costs and Payment Considerations. Costs and payment considerations for the program constituted another primary theme regarding influences on PALS enrollment. Private paying clients stated the perspective that although the costs for PALS are significant, compared to alternative options, it is perceived as offering good value. At the same time, paying privately to spend down to MLTSS eligibility was described as psychologically difficult. As one family member described:

Even if it’s only $50 a day, that’s $350 a week. When people are on a limited income, that seems like a lot of money to people. I think it’s really unfortunate that it’s either feast or famine. You have to be on MLTSS. You have to be completely broke. Even now, we’re worried that my (loved one) isn’t broke enough. I think it’s really unfortunate that at that stage in the game, if you’re not broke enough, you’re not eligible.

Several interviewees expressed that if MLTSS could not cover the costs of the program, they would not be able to access it, especially when residents live on fixed incomes and Social Security alone. Several caregivers stated that if their loved one was not able to access PALS through MLTSS, they would continue doing what they were doing—managing as best they could and waiting for the next health crisis to force them into difficult decisions in the future. As one family member explained, without MLTSS to fund PALS, the family would “just continue to manage and cross our fingers, which isn’t ideal.”

A handful of interviewees described the difficulty of accepting services funded through Medicaid specifically. In these cases, participants referenced their upbringing as influencing their attitudes toward public programs. For example, one resident described how she was raised to not live beyond her means or to accept government assistance. She concluded, “It is unacceptable for me to go on Medicaid. No way.”

Experiences with MLTSS enrollment. Nine of the 12 interviewees who were active or enrolling members of PALS were involved with Managed Long-Term Services and Supports (MLTSS) to pay for services. Interviewees overwhelmingly expressed the arduous and time-intensive process of enrolling in MLTSS to access services through PALS. Participants described how the various phases of enrollment in MLTSS involves “a lot of stop and go,” including getting the initial paperwork from a physician, arranging for the clinical assessment, and then gathering the relevant paperwork to receive financial clearance for the program. There also were individual circumstances that made MLTSS enrollment more complicated, such as
III. What do consumers view as ways to develop the program in the future?

While participants were generally positive in their views about PALS, the interviews yielded two additional themes suggestive of how PALS could be improved in the future: (a) expanding the hours of on site staff, and (b) offering lower levels of services.

Expanding Hours of On Site Staff. Overall, residents and caregivers perceived how the services offered through PALS were quite comprehensive, as well as their appreciation for staff being on site for 12 hours a day, seven days a week, 365 days per year. Nevertheless, interviewees also expressed a desire to have at least one staff person on site for 24 hours a day. Participants described that although residents would not need help with certain tasks at night—such as meal preparations or getting dressed—they very well might need assistance with other tasks, such as safely getting to the bathroom or taking medications. As one family member explained:

It’s always more secure to know that somebody’s there 24/7. How realistic that is with the cost, I don’t know. My mother actually has the (emergency response) necklace; if she was to have an issue, 911 comes really fast. But if everybody had their opinion, they would say that it would be great if somebody were there at all times, right?

Offering Lower Levels of Services. Some interviewees expressed interest in PALS offering more a la carte services, or being able to sign up for PALS services on a per diem basis rather than per month. These suggestions were made to make the program a better fit for people with fewer care needs, as well as for people who could not afford daily care. One family member, for example, expressed interest in paying for PALS to assist with medications a few times per week “to make it more affordable...to get some services, but maybe not all.” Other families similarly stated that they would be able to pay for some services on behalf of their loved ones, but were not in a position to pay for the full program cost.
Conclusion

In summary, participants viewed PALS as helping residents to remain living safely and comfortably at the Westwood House despite their having increasing need for support. They described their perceptions that PALS promotes aging in place by enhancing residents’ physical, cognitive, and social health and by preventing problems from escalating in severity. Participants noted several program components, including having staff on site daily; offering a comprehensive team of providers; and attracting exceptionally competent and caring staff—that give “value added” to PALS beyond in-home assistance as usual. At the same time, findings indicated that not all individuals and families who likely would benefit from PALS necessarily engage with the program for reasons such as lack of perceived need, cost considerations, and MLTSS enrollment issues.

It is important to note that this report is based on the experiences of residents and family members at a specific place and time. Results are not intended to generalize to ALPs in all communities and at all times. For example, even within Westwood House, as the program enrolls more residents and potentially hires more staff, the overall “feel” of the program might change. As another example, the Westwood House is generally perceived as a desirable, safe, and clean place to live within a relatively well-resourced municipality. ALPs in buildings with more problems and in communities with fewer resources (e.g., local physicians to connect with in the case of health problems) might be perceived as less effective at promoting aging in place.

Nevertheless, insights from this study are useful for demonstrating the potential of ALPs such as PALS to powerfully promote aging in place, especially for people at immediate risk for needing higher levels of care. At the same time, the study demonstrates key factors that constrain some people’s ability to enroll in programs such as PALS, even when such services are located in their very own apartment buildings. Findings from this study can help to inform strategies to strengthen and expand PALS and ALPs more generally. They also further indicate the great importance, as well as grave challenges, concerning the uptake of new ways of doing old business in the realm of long-term services and supports.

Summary of Resident and Caregiver Perceptions of PALS

- PALS is perceived as promoting residents’ aging in place
  - Improves physical, cognitive, and social functioning
  - Prevents the escalation of problems
  - Few desirable alternatives to PALS
- PALS is perceived to benefit family members and friends who are caregivers for residents
  - Lessens their anxiety around their loved ones’ health and well-being
- PALS is perceived to be good for the Westwood House and society as a whole
  - Anticipated source of support for residents and families not yet enrolled
  - Sign of progress for long-term services and supports more broadly
- PALS is not necessarily utilized by all who could benefit from it at the Westwood House
  - Some families and individuals do not perceive a need for it
  - Program costs and Medicaid financial eligibility can be a barrier
  - People experience difficulty enrolling in Managed Long-Term Services and Support through Medicaid
- Participants would see value in PALS offering 24-hour on site staff and providing lower levels of services at less cost
References


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