EXPLORING INFORMAL SUPPORT NETWORKS OF "IN SERVICE OF SENIORS: PITTSBURGH" PROGRAM PARTICIPANTS

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ABSTRACT

Across the United States the proportion of the population aged 60 and older continues to grow. American adults consistently express a desire to remain in their homes as they age, however the ratio of potential informal caregivers to potential older adult care recipients is shrinking. Both informal support from friends and families and formal support from private and public agencies play important roles in supporting older adults in their wishes to "age in place." The author worked with the leadership of the volunteer-based In Service of Seniors: Pittsburgh (ISOSP) program to design this explorative evaluation. The primary objective was to learn more about the formal and informal support networks of program participants. The project has public health importance, as the author provided program leadership with recommendations to provide more informed and coordinated services for their participants.

The author designed and administered questionnaires with 116 older adult participants of the ISOSP program and with 24 support people identified by those participants. Chi square and binary logistic regression analyses were conducted on questionnaire responses using SPSS statistical software. Results indicate that, compared to the older adult population across Allegheny

County, ISOSP participants were older, lower income, more likely to live alone and have lower self-rated health, more limited in ability to perform routine tasks but less likely to have informal support, and less satisfied with their quality of life. The only factor significantly correlated with receipt of informal support was race, with African Americans being more likely to report receipt of practical assistance from family members and friends. The only factor significantly correlated with granting permission to contact a support person was receipt of practical support from family members and friends. Program participants receiving assistance from formal support sources but not from informal sources were less likely than other participants to receive emotional support from family members and friends. The author recommends that ISOSP staff members continue to ask participants about their support networks, to provide resources to support people, and to pay special attention to participants who receive formal services but may lack safety net support from family members and friends.

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PREFACE

Acknowledgements are due to all family members, friends, colleagues, advisors, and mentors who taught, encouraged, and listened to me throughout my academic journey. Thank you for your continued support!

1.0 INTRODUCTION

1.1 AGING IN PLACE

The concept of "aging in place" can be described as the experience of continuing to live in the same community-based residence as one grows older. Aging in place has been widely promoted as a preferable alternative to nursing home placement. This is evidenced at the federal level through the 2012 creation of the Administration for Community Living (Thomas and Blanchard, 2009; Black, Dobbs, and Young, 2012). Compared to older adults across the nation, Allegheny county older adults are more likely to stay in the same place and not move to a new location as they age (Musa, Beach, Briem, Schlarb, and Schulz, 2014).

Many people are now expanding on the concept of "aging in place" to promote "aging in community." Aging in community involves more than remaining at home; it promotes full integration of the older adult in their community through: opportunities for older adults to contribute to their community, provision of support to the older adult by fellow community members, and through accessible structures, transportation, sidewalks, and streets (Thomas and Blanchard, 2009). Examples of aging in community in action include co-housing arrangements and the Village model (www.vtvnetwork.org), a membership-based program that engages volunteers to provide neighborly support to older adults in their neighborhood and provides access to additional community-based services.

1.1.1 Benefits and Challenges of Aging in Place

Many positive outcomes can result from a person remaining at home in their community as they age. One benefit is simply the satisfaction and comfort of achieving one's wishes. As Thomas and Blanchard (2009) note, most people want to stay at home as they age and have a strong fear of being placed in a nursing home or other institutional facility. Research has shown that aging in place supports improved health outcomes, as older adults' health suffers with each change in residence, and that aging in place conserves health care dollars since it is less expensive than providing care in institutional settings (Marek and Rantz, 2000; Rantz et al, 2011). Several researchers argue that the aging in community approach also "enhances well-being and quality of life" (Thomas and Blanchard, 2009), and facilitates dignity, independence, community integration, access to information, and health maintenance (Black, Dobbs, and Young, 2012).

Despite the many benefits, there are also challenges presented by aging in place. For example, staying at home without sufficient practical support, emotional support, and community engagement can actually decrease health and well-being. As Thomas and Blanchard (2009) note, "feeling compelled to stay in one's home, no matter what, can result in dwindling choices and mounting levels of loneliness, helplessness, and boredom." In addition, few communities are currently designed to support aging in place or aging in community. Public transportation systems, pedestrian safety, and "age-friendly" home design are not sufficient in most communities to support successful aging in place (Farber and Lynott, 2011). This can be changed, but it will take time, and until then barriers exist to full community integration for all older adults. Throughout this process, older adults may take advantage of their existing social support networks as well as formal support through public and private agencies to aid in their efforts to remain independent in the community.

1.2 SOCIAL SUPPORT IN OLDER AGES

Social support is an important factor impacting overall health and quality of life. Greater number, higher quality, and accessibility of relationships have all been shown to be correlated with lower risk of premature death, lower likelihood of engaging in risky health behaviors such as problem drinking, and higher likelihood of better health and well-being (Musa, Beach, Briem, Schlarb, Schulz, 2014). Social networks give a sense of belonging and self-worth, foster trust and mutual support, and offer natural paths of exchange for information and resources. Older adults are also more likely than younger adults to volunteer and be involved in religious communities, which are both beneficial for health, and are also more likely to interact with their neighbors (Cornwell, Laumann, and Schumm, 2008).

Social networks tend to shrink as people age due to numerous factors including a preference to focus on fewer but more meaningful relationships, death of spouse or other relatives and friends, not seeing coworkers after retiring, less discretionary income for recreation, and moving to a new neighborhood, city, or state. Looking to other relationships to substitute and compensate for lost ones, as well as reframing expectations and adapting to new conditions are all common forms of coping (Rook, 2009). However, during these transitions, people are vulnerable to becoming isolated. In addition to experiencing higher risk for premature mortality and adoption of risky health behaviors, individuals who are socially isolated are also more likely to develop dementia, to fall, to be re-admitted to a hospital after release, and to be admitted to a nursing home (Nicholson, 2012). Older adults are more likely to become socially isolated if they have disabling health conditions, reduced sensory capacity (i.e.: hearing and sight loss), incontinence (Nicholson, 2012; Simonsick, Kasper, Phillips, 1998), are grieving the death of a close friend or relative

(Nicholson, 2012; Cornwell, Laumann, and Schumm, 2008), or are embarrassed about their physical image (Nicholson, 2012).

Though the potential consequences of isolation are substantial, most older adults are not severely socially isolated. A study of over 1000 older women with disabilities found that only 3% of participants were so isolated that they lived alone without leaving the house or seeing another person in a typical week. While 23% of participants did not see friends or relatives in a typical week, nearly one-fifth of participants did see someone on a daily basis (Simonsick, Kasper, Phillips, 1998). As older adults age into their late 70s and early 80s, they also socialize more often. Frequency of contact with social network members has a U-shaped curve across older ages, being lowest for individuals in their late 60s and early 70s, but highest for adults in their earlier 60s and adults in their later 70s and beyond (Cornwell, Laumann, and Schumm, 2008).

1.3 CAREGIVING FOR OLDER ADULTS

When a person experiences increasing levels of frailty and requires additional assistance to maintain independence, friends and family members may take on the role of an informal caregiver, and become critical members of that older person's support network.

1.3.1 Defining Caregiving

There is no single agreed-upon definition of what constitutes caregiving. A caregiver can be defined by any or all of the following parameters: the type of caregiving activities they perform, the amount and frequency of support they provide, and the health and age of the person they care

for (Stone, 1991; Bastawrous, 2013). Examples of caregiver definitions include: "the person who helps you the most but who is not paid to do so" (Bugge et al, 1999); "a friend, partner, or family member who does chores for someone who needs assistance with them, schedules medical appointments, provides personal care (bathing, dressing, etc.), or is "on call" for family problems" (Family Caregiver Alliance); "the person who spends the most time with the elder, whom the elder describes as their main caregiver or carer, and who is not part of a formal care organization" (Van Durme et al, 2012); and "an individual who provides help to someone needing assistance due to age-related difficulties" (Bureau of Labor Statistics, 2013). Some authors define caregiving even more broadly, blurring the lines between "caregiving" and the more inclusive term "social support." Chappell and Funk (2011) distinguish between social support as an umbrella term that includes emotional support, informational support, and practical support, and caregiving as a term that should be used more narrowly to describe provision of practical support provided to a person who is becoming frailer.

The Bureau of Labor Statistics (2013) reported that between 2011 and 2012, 16% of Americans provided informal (uncompensated) care to an older adult. According to the same report, most caregivers are women providing daily care for a single person they do not live with. Although provision of informal support is widespread, the proportion of potential caregivers (between 45 and 64 years old) to potential participants (aged 80 and older) is fast declining (Redfoot, Feinberg, and Houser, 2013). According to the AARP, in 2010 the "caregiver support ratio" was seven potential caregivers for every one potential participant and projections indicate that the ratio may drop to 4:1 by 2030 and to below 3:1 in 2050. Fewer potential caregivers for each potential recipient of care is likely to lead to greater reliance on paid and subsidized support programs, as well as greater levels of stress for those individuals who are providing care (Redfoot,

Feinberg, and Houser, 2013). Changes to normative family structures and social roles are also expected to impact caregiving. For example, there are greater numbers of older adults who are unmarried and/or who do not have children than in the past, but the incidence of non-related older adults cohabitating is on the rise (Chappell and Funk, 2011). Public and private service providers will need to prepare an increase in demand for in-home services as well as supports for caregivers.

Caregiving often looks different depending on race and ethnicity as well. Previous research shows that minority caregivers are more likely to be younger, unmarried, and lower income than White caregivers, and are also more likely to be providing more care and have more unmet caregiving needs than White caregivers (Navaie-Waliser et al, 2001). In a study on daughters who are caregivers, results indicated that compared to White caregivers, African American caregivers were less likely to have good health, and were more likely to provide care to parents with more functional limitations (Lawton et al, 2000). According to another study, African American and Latino(a) caregivers are more likely than White caregivers to report experiencing increased religiousness and spirituality as a result of caregiving. The study authors hypothesized that this increased faith helps the caregivers cope with the stress of providing care. African American and Latino(a) caregivers are also less likely to feel depressed, stressed, and burdened than White caregivers (Navaie-Waliser et al, 2001), and to have a broader support network than Whites, including family, friends, and neighbors (Dilworth-Anderson, Williams, and Gibson, 2002).

1.3.2 Effects of Caregiving

Providing care for another person can have both beneficial effects on the caregiver, such as increased life satisfaction and increased closeness with the care recipient, as well as negative effects such as decreased levels of physical and emotional health and even premature death.

Considering the serious risks these effects can place on the caregiver, it is important to explore the various positive and negative consequences of caregiving. Numerous study results suggest that caregivers are at greater risk than non-caregivers for adverse health outcomes, especially related to stress (Chappell and Funk, 2011). Research also suggests that caregivers experiencing stress are at elevated risk of premature death compared to both non-caregivers and caregivers who are not experiencing high levels of stress (Schulz and Beach, 1999). Women are especially vulnerable to these risks since they are both more likely than men to (1) become caregivers and subsequently experience "role overload" as they negotiate their competing responsibilities, and (2) to provide emotional support, which has been shown to increase risk of stress (Bastawrous, 2013). One example of competing roles is the potential impact caregiving can have on employment. People committed to caregiver roles may need to turn down promotions that require relocation, and may also face unique challenges if they are self-employed and don't have coworkers to cover for them if they need to take time off (Thompson, Tudiver, and Manson, 2000).

Caregiver burden has been a topic of much research as well, although the lack of a universally accepted definition of caregiver burden has made it difficult to compare studies examining burden (Bastawrous, 2013). And while some people understand burden as a negative experience, several researchers have pointed out that experiencing burden is not necessarily synonymous with poor well-being (Chappell and Funk, 2011; Lawton et al, 2000). The degree to which burden is experienced is also related to numerous factors. The following variables are correlated with increased feelings of burden among caregivers: caring for someone with dementia (Colatonio et al, 2001), poorer health of caregiver (Bugge, Alexander, and Hagen, 1999), increased independent activities of daily living (IADL, includes routine tasks like shopping and housekeeping) and activity of daily living (ADL, includes personal care tasks like bathing and

eating) deficits in the recipient of care, caring for a spouse (Kim, Chang, Rose, and Kim, 2012), cohabitating with the recipient of care (Kim et al, 2012; Lawton et al, 2000), and spending more hours per week caregiving (Bugge et al, 1999; Kim et al, 2012). Interestingly, Butterworth et al (2010) found that when examining mental health status among a sample of Australians, having poorer mental and emotional health was primarily explained by having low levels of positive support from and high levels of conflict with their family. Duration of caregiving career, number of hours per week spent caregiving or the health status of the care recipient did not have any impact on caregiver mental health in this same study. Considering the importance of positive support from family members, the recent trend of reduced support may result in greater challenges for caregivers in the future.

Despite documented negative effects of caregiving, there are numerous powerful positive effects of caregiving as well. In various studies, caregivers have reported feeling a sense of "accomplishment" at keeping the care recipient at home and out of institutional care (Thompson, Tudiver, and Manson, 2000), feeling "self-affirmation and enjoyment" from caregiving (Chappell and Funk, 2011), experiencing greater intimacy with the recipient of care, experiencing increased life satisfaction, feelings of strength, and increased sensitivity to disability issues (Chen and Greenberg, 2004). In some circumstances, providing help and care for others has even been shown to reduce risk of premature mortality (Brown, 2007).

1.3.3 Caregiver-Care Recipient Relations

Relationships between caregivers and care recipients, like any relationships, are complex and vary person to person. Smerglia et al (2007) note that social networks can be helpful or harmful depending on a person's relationships with the members of their networks, and that social networks

may not be helpful to a person if that person doesn't receive the support they actually need from those networks. Other researchers have stressed the importance of considering and measuring the strength of the bond between caregiver and care recipient because pairs with a stronger bond who feel more interdependent may be more able to weather stress and even experience an enhanced relationship, as opposed to pairs with a weaker bond who may feel a loss of interdependency (Brown, 2007; Carpenter and Mak, 2007).

Most caregivers are children caring for aging parents, and while all caregiving relationships involve adaptation, the shift for children and parents can be particularly challenging. Many caregivers supporting parents have noted that the shift from being dependent on a parent to caring for a parent who has become dependent on them is very challenging (Thompson, Tudiver, and Manson, 2000; Bastawrous, 2013), though children tend to have a strong sense of obligation to care for their parents (Dellmann-Jenkins, Blankemeyer, and Pinkard, 2000). Adapting to becoming dependent on others is also very challenging for some people, who may struggle with feelings of powerlessness when they can no longer independently meet their own needs, and feelings of guilt that they need to ask others to make time in their schedules to assist them (Brown, 2007).

For siblings, deciding who will provide care for aging parents can also be challenging. Baby Boomers are in the unique situation of being more likely than both their parents and their children to have large (and surviving) sibships, which may result in situations where siblings must negotiate care of a parent together. The Within Family Differences Study found that mothers have clear expectations, even long before they need care, of who they expect to provide care for them when they need it. These expectations may not correlate with their children's views on who will provide help, and can even create conflict between their children, who may view their mothers'

expectations as favoritism. Looking ahead to when these Boomers will need help themselves, there are conflicting thoughts on whether they are more or less likely than their parents to receive support from their children. Some evidence indicates that Boomers have closer relationships with their children than did previous generations, and so their children may be more likely to care for them. However, the Boomers also have much higher divorce rates than their parents, and children of split families may feel less obligation to care for parents and step-parents (Fingerman et al, 2012).

1.4 VOLUNTEER-BASED PROGRAMS SERVING OLDER ADULTS

Volunteer-based programs play an important role in supplementing the care and support older adults may receive via fee-based programs and informal caregivers. Although exact estimates vary, there are a large number of volunteer-based programs serving older adults wishing to age in place across the United States. The National Volunteer Caregiving Network lists 525 programs across the United States that provide volunteer-based practical and social support services for older adults and adults with disabilities (National Volunteer Caregiving Network, 2014). The National Volunteer Transportation Center counts 940 volunteer-based transportation programs across the United States that provide rides to older adults and/or individuals with disabilities who may need more assistance than other transportation sources such as buses or taxis can provide (Kerschner and Rousseau, 2008; National Volunteer Transportation Center, 2014).

1.4.1 Benefits of and Challenges Faced By Volunteer-Based Programs

Evaluations have shown that volunteer-based programs help alleviate stress and anxiety felt by older adult participants, provide reassurance that help is available, provide appreciated opportunities to get out of the house, and improve overall quality of life (Butler, 2008; Martin, 2010; Trickey, Kelley-Gillespie, and Farley, 2008; Wilson, 2012). In evaluating the FriendshipWorks program in Boston, Massachusetts, Martin (2010) found that elder participants reported that they did not have to cancel any appointments due to lack of transportation since their enrollment in the program. Another study involving a small, convenience sample of caregivers of individuals with dementia found that these caregivers also experienced benefits from having their care recipient enrolled in a volunteer program. Reported benefits include feelings of "renewal," knowledge gain, and satisfaction with services provided to their care recipient (Winslow, 2003).

Volunteers experience personal gains from engaging in service as well. In 2007, the Corporation for National and Community Service reported that compared to non-volunteers, people who volunteer experience lower mortality rates, better physical health, lower levels of depression, and increased feelings of purpose, accomplishment, and satisfaction in life. These benefits are strongest in older volunteers (Grimm, Spring, and Dietz, 2007). In addition, volunteers report feeling that their service is important and impactful, they felt enjoyment from getting to know new people, and enjoyed "feeling needed" (Butler, 2008; Kerschner and Rousseau, 2008).

Despite the benefits of volunteer-based programs to the direct care recipients, caregivers, and volunteers, these programs also face challenges. Volunteer recruitment is a common and chronic challenge for programs worldwide. Data from the United States Bureau of Labor Statistics shows that the most common reasons that people do not volunteer are that they (1) feel that they do not have enough time, (2) are not interested in available opportunities, and (3) have poor health

(Sundeen, Raskoff, and Garcia, 2007). Overcoming these barriers, whether real or perceived, can be a great challenge for programs needing to attract volunteers. Additionally, volunteer-based programs sometimes struggle with volunteer supervision, satisfaction, and retention issues. In Butler's evaluation of the Senior Companion Program (2008), volunteers reported sources of dissatisfaction as seeing older adult participants in pain; death of older adult participants; older adult participants who are aggressive, have dementia, or exhibit other "challenging" behaviors; and sometimes overextending themselves, leading to volunteer burnout.

1.4.2 In Service of Seniors: Pittsburgh

In Service of Seniors: Pittsburgh is a program that uses a "neighbors helping neighbors" approach to match volunteers with community-dwelling older adults to provide neighborly services at no charge. The program is in the Community Partnerships division of Family Services of Western Pennsylvania, a Pittsburgh area non-profit agency with a mission to "empower people to reach their full potential." In Service of Seniors: Pittsburgh's volunteers are community members who give time weekly, monthly, or annually to provide transportation to medical appointments; assistance with grocery shopping; friendly visits; help reading and sorting mail; outdoor home maintenance such as mowing grass, raking leaves, and shoveling snow; and home safety inspections.

In Service of Seniors: Pittsburgh was founded in 1993 with seed money from the Jewish Healthcare Foundation and is part of a national network of similar grass roots volunteer programs called the National Volunteer Caregiving Network. In 2007 In Service of Seniors: Pittsburgh joined Family Services of Western Pennsylvania (FSWP) and became one of 42 distinct programs

operated by FSWP. During 2013, In Service of Seniors: Pittsburgh volunteers reported nearly 17,000 hours of service and provided assistance to over 1400 older adults.

Pittsburgh, Pennsylvania is located in Allegheny County, home to over 200,000 adults over age 65. With nearly 17% of the county population over age 65, Allegheny County has an older population than the average American county, which has an over-65 population of 13%. The history of the local economy has had a strong influence on the current age distribution of county residents. The collapse of the local steel industry in the 1980s prompted many younger residents to leave in search of employment, resulting in a demographic shift towards older adults. In fact, in the 1990s Allegheny County had one of the highest proportions of older adults in the entire United States. In the late 1990s and throughout the first decade of the 21st century, the local economy diversified and grew, younger people moved to the city, and the proportion of the county population over age 65 fell. Although the over-65 segment of the population shrank during this period, it still remained several percentage points higher than the national average. Currently, the percentage of county residents over age 65 is growing again, and over the next several decades is predicted to stabilize around 20%, similar to predictions for the national average. In 33 Allegheny County municipalities, the proportion of residents over age 65 is already 20% or higher (Musa, Beach, Briem, Schlarb, and Schulz, 2014). With a growing older adult population, particularly within the 85-plus age group, programs like In Service of Seniors: Pittsburgh will likely see a rise in demand for services in the coming years.

1.5 CONCEPTUAL FRAMEWORK

This particular project focused on the support networks of the older adults served by the In Service of Seniors: Pittsburgh program. To date, the extent to which the In Service of Seniors: Pittsburgh program has interacted with the informal support networks of its participants has been (a) to coordinate volunteer services for a person whose caregiver is the primary point of contact, and (b) by asking participants to pass along a brief mail-return survey to a caregiver for the caregiver to fill out and return. The In Service of Seniors: Pittsburgh program leadership worked with the author to develop an evaluation project to learn more about participant support networks. The motivations of this evaluation project included the recognition that many caregivers and other support people could likely benefit from program services (e.g. information and referral), that program participants have complex support networks, and that the program could be doing more to learn about and engage caregivers and other support people. This evaluation of the In Service of Seniors: Pittsburgh program is based on the following conceptual framework, which was developed by the author:

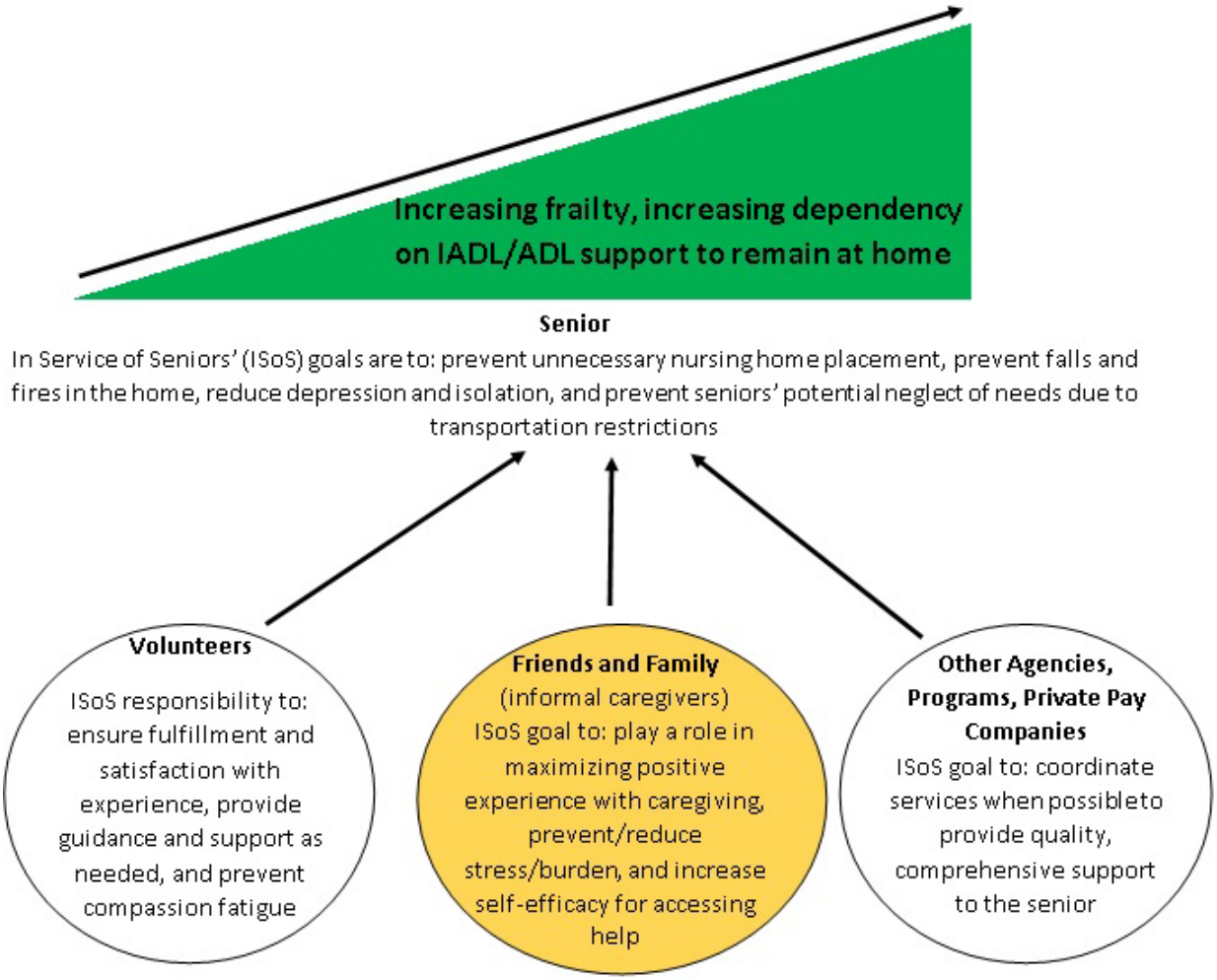

Figure 1: Conceptual Framework

As illustrated above, In Service of Seniors: Pittsburgh's primary goal is to support older adults who wish to remain at home as they age and inevitably need assistance. In Service of Seniors: Pittsburgh accomplishes this by engaging community volunteers, to whom the program in turn has a responsibility to support. In order to provide informed and cohesive services across programs and agencies, In Service of Seniors: Pittsburgh also has a responsibility to communicate and coordinate with other service providers as appropriate. This particular project focuses on In Service of Seniors: Pittsburgh's relationship with the family members and friends of the older adult

participant. The goal of the program in this arena, as stated above, is to maximize positive caregiving experiences, reduce levels of caregiving-related stress, and increase levels of caregiver self-efficacy by providing high quality information/referral assistance and light respite (through direct services such as grocery shopping and visiting for the older adult).

1.6 EVALUATION QUESTIONS

Despite the expansive research and published results on social networks of older adults, aging in place, and caregiving, little attention has been given to older adults relying on volunteer-based programs and those adults' support networks. With this knowledge gap in mind, the following evaluation questions were developed to increase understanding of In Service of Seniors: Pittsburgh participants' support networks and how they compare to other older adults in the region.

- Questions
    - How do the participants of In Service of Seniors: Pittsburgh compare to the county-wide population of older adults in terms of demographics, health, and social support?
    - What factors are correlated with the likelihood that an In Service of Seniors: Pittsburgh participant will give permission for the program to contact a caregiver or other support person?
    - Are there any demographic factors that correlate with receipt of informal and formal practical support?
    - What are the descriptors of In Service of Seniors: Pittsburgh participants' caregivers? For example, age, employment status, health, level of burden.
    - How much concordance is there between what program participants report their caregivers help them with and what the caregivers report they assist with?

2.0 METHODS

This evaluative project utilized questionnaires to gather descriptive data on In Service of Seniors: Pittsburgh participants' support networks. The questionnaires were administered to a sample of In Service of Seniors: Pittsburgh participants and their caregivers or other support people. In some cases, the identity of the primary caregiver or support person was known because they acted as the primary (and sometimes sole) point of contact with In Service of Seniors: Pittsburgh staff members. However, in most cases, In Service of Seniors: Pittsburgh program staff knew very little about the extent of the participants' support networks and who, if anyone, provided care and support to them. To address this issue, the author designed one questionnaire to conduct with participants to assess the sources of their support and obtain permission to contact a support person, and a second questionnaire to conduct with the identified support people. The evaluation rationale and protocol was reviewed by the University of Pittsburgh Institutional Review Board and granted exemption from further oversight and review (See Appendix A).

2.1 METHODS: PARTICIPANT QUESTIONNAIRE

The participant questionnaire was developed for the purposes of: (a) describing and assessing the number and type of formal and informal sources of support identified and utilized by In Service of Seniors: Pittsburgh's participants, and (b) gaining access to people providing support on an informal basis to learn more about their experience as a support person (see section 2.2: Support

Person Questionnaire). The final version of the questionnaire administered to In Service of Seniors: Pittsburgh participants and the accompanying script is in Appendix B.

2.1.1 Questionnaire Development and Pre-Testing

The participant questionnaire was developed in the spring of 2014 and was based on observations and conclusions from previous efforts to learn more about the supportive relationships of In Service of Seniors: Pittsburgh participants. For example, in the fall of 2013 the author contacted individuals receiving volunteer services through In Service of Seniors: Pittsburgh and asked these participants to identify someone who they would consider to be a caregiver or support person for them. The author observed that many participants were unclear about the question and needed further clarification about the definitions of "caregiver" and "support person." For example, some individuals easily identified a person who fell into a traditional definition of "caregiver" and provided hands-on practical support such as housecleaning and personal care. However, many individuals had a person in their lives who provided some level of practical support such as occasional rides to the store, but who they did not consider as a "caregiver." Other participants did *not* have a person providing practical help but *did* have one or more people who provided some other type of important assistance such as emotional support.

Based on these observations, the author decided that the script for the next iteration of these calls needed to be more explicit about the definitions of "caregiver" and "support person." The author identified three levels of informal support that a person may receive from others, and recognized that a person may identify the same or different people for each level. The first level of support most closely aligned with traditional definitions of caregiver: practical help such as assistance with cleaning, meal preparation, transportation, or personal care. The second level of

support was emotional: having someone who a person could call on to discuss personal matters or difficult decisions. The third level was defined by more rare but important needs for support: having a person or people that an individual could call in an emergency. The questionnaire contained items to gather information about how many and what type (e.g.: sibling, son/daughter/cousin, friend) of friends and family members (a) helped the participant with practical tasks [Independent Activities of Daily Living (IADLs) and Activities of Daily Living (ADLs)] in the home such as cooking, cleaning, bathing, dressing, etc.; (b) they could call or visit when they needed to talk about personal matters or difficult decisions; and (c) they could call in the event of an emergency. For (a) and (b) the questionnaire contained additional items regarding the frequency with which the friend or family member engaged in the specified activity with the participant. To gauge formal support, the questionnaire contained an item requiring the participant to identify (from a list) any formal supports they received such as care management, home delivered meals, housekeeping, and other related services.

If the In Service of Seniors: Pittsburgh participant identified any family or friends who were involved in a supportive role, the interviewer asked the participant for permission to contact that person to provide information about the program and administer a brief questionnaire. Google Forms was utilized for data entry. An online version of the script and questionnaire was designed so that the interviewer could enter responses in this online form live as they conducted the questionnaire calls. As Google Forms is not a secure application, no identifying information was recorded during the questionnaire administration. The In Service of Seniors: Pittsburgh database assigns an ID number to each participant, and these numbers were used in the questionnaire rather than names or other personal information.

As described above, the participant questionnaire was piloted in the fall of 2013 and revised accordingly. Minor changes in script wording were made following the first several calls in the summer of 2014.

2.2 METHODS: SUPPORT PERSON QUESTIONNAIRE

The support person questionnaire also went through several iterations prior to the author arriving at the final version used for this work. The final version of the questionnaire administered to support people identified by In Service of Seniors: Pittsburgh participants and the accompanying script is in Appendix C.

2.2.1 Questionnaire Development and Pre-Testing

The support person questionnaire was developed by consulting the literature on measures of informal caregiving to determine how to best address the objectives of the In Service of Seniors: Pittsburgh leadership. The questionnaire was pre-tested in April, 2014 with eleven individuals who were selected using convenience sampling. One respondent completed the questionnaire in person, two over the phone, and the remaining eight respondents completed an online version. Five respondents were known by the author to be current or very recent caregivers, one was known to be a past caregiver, and five were of unknown caregiver status. Upon completion of the questionnaire, respondents were asked to give feedback on the length of the questionnaire and on the wording and ordering of individual questionnaire items. Using this feedback, the questionnaire was revised into the final version that was used for this project

2.3 METHODS: SAMPLING FRAME

2.3.1 Participant Sampling Frame

For the purposes of this project, only individuals who were considered to be recently active with the In Service of Seniors: Pittsburgh program were contacted for a questionnaire. A list of individuals receiving at least one service from a staff person or volunteer between May 1, 2013 and August 31, 2014 was created using the In Service of Seniors: Pittsburgh database. The following inclusion and exclusion criteria were used to create the sampling frame of "recently active participants:"

Inclusion:

- Person received at least two services from a program volunteer during their tenure with the program, with at least one of those services being completed within twelve months of the date of the survey call
  OR
- Person received at least one volunteer service during their tenure with the program and was actively waiting for an additional volunteer service at the time of the survey call
  OR
- Person received an in home assessment from a program staff person after April 1, 2014 and received at least one confirmed volunteer service since that visit
  OR
- Person received an in home assessment within two months prior to the date of the survey call but may or may not have requested or received volunteer services at the time of the survey call

Exclusion:

- Person received snow shoveling assistance and/or a home safety visit but not additional volunteer based services
  OR
- Person was discharged from the program prior to the date of the survey call

One-hundred and sixty-two individuals met the inclusion criteria and were included in the sampling frame.

2.3.2 Support Person Sampling Frame

Sampling and selection of support people followed a network sampling design, as the support people were included in the sampling frame by virtue of their relationship with the participant. Any support person identified by the participant who the participant also gave permission to contact was included in the sampling frame. The interviewer used both the script and their discretion when deciding to ask for permission to contact a support person. For example, if the participant indicated that they had no friends or family offering practical or emotional support, or who acted as an emergency contact, then the interviewer did not ask to speak with anyone. However, the interviewer was permitted to use their discretion in situations that were not as well-defined. For example, if the participant identified an emergency contact only but admitted that they have very little contact with that person (e.g.: once per year), the interviewer did not ask to speak with the emergency contact person. Data from people with little contact with the participant would not address the evaluation questions about support people who have some regular level of involvement with and contribution to the participant's physical and/or emotional well-being. In total, thirty-four support people were included in the sampling frame and subsequently contacted to complete the questionnaire.

2.4 METHODS: QUESTIONNAIRE ADMINISTRATION

The scripts and full questionnaires for both participants and support people can be found in Appendices B and C, respectively. Questionnaires were completed over the phone when possible,

but print and online versions were made available upon the request of the respondent. Call dispositions and response rates are outlined below in Figure 2.

2.4.1 Participant Survey Administration

Calls to participants were made on weekdays and weekends between June and December, 2014. All but two calls were made by the author; the remaining two were made by a colleague of the author at the In Service of Seniors: Pittsburgh program. The interviewer used the final version of the questionnaire as found in Appendix B of this document. Some minor deviations from the script were made in order to make the calls conversational. If participants did not answer the phone, the interviewer left a voicemail asking the participant to call the author at her office phone at In Service of Seniors: Pittsburgh. If participants did not respond after three call attempts, they were removed from the call list.

2.4.2 Support Person Survey Administration

Contact to support people was made on weekdays, evenings, and weekends between June and December, 2014. In some cases, participants did not wish to provide direct contact information for their support person, and instead requested that a print copy of the support person questionnaire be sent to their home for the participant to pass on to their support person. In these cases, the author sent the questionnaire along with an introductory letter, stamped return envelope, and printed program information to the participant's home. In most cases, the participant provided a phone number for a support person and the author called that person directly. In cases where the

support person wanted to complete the questionnaire on paper, the same procedure outlined above was followed. In cases where the support person wished to complete the questionnaire online, the author sent an email with an introductory message and a hyperlink to the Google Form. In cases where the support person preferred to complete the questionnaire over the phone, the author went through all the questions as worded in Appendix C of this document. As with the participants, if support people did not answer the phone, the interviewer left a voicemail asking the participant to call the author at her office phone at In Service of Seniors: Pittsburgh, and if support people did not respond after three call attempts, they were removed from the call list.

2.5 DATA ANALYSIS

Questionnaire data were exported from Google forms to Excel and then into SPSS for analysis. Additional demographic information on participants was obtained from the In Service of Seniors: Pittsburgh database and added to the evaluation data set. Data from the University Center for Social and Urban Research's "The State of Aging in Allegheny County" report (Musa, Beach, Briem, Scharb, Schulz, 2014) were used to compare the In Service of Seniors: Pittsburgh sample to older adults county-wide. Chi Square analysis was used to investigate relationships between presence and absence of practical and emotional support and (a) likelihood of having adult children as supports, and (b) likelihood of giving permission for the author to speak with a support person. Logistic regression was used to investigate the relationship between support type (formal or informal) and demographic variables including age, sex, income, and living alone or with others. Due to the small number of completed support person questionnaires (n = 24), no statistical analyses were run on the data from the support person questionnaire. Rather, a descriptive

summary of results is presented below in Chapter 3, along with results of all participant questionnaire analyses.

3.0 RESULTS

3.1 QUESTIONNAIRE RESPONSE RATES

Out of the sampling frame of 162 program participants, 116 individuals completed the questionnaire, for a response rate of nearly 72%. The primary reasons participants did not complete the questionnaire were that no working phone number was available to the interviewer, or that the individual did not respond to the interviewer after three attempts to reach them. Out of the sampling frame of 34 support people, 24 completed the questionnaire for a response rate of nearly 71%. The primary reason for non-response was that the support person did not respond to the survey administrator after three attempts to reach them. A schematic diagramming call disposition and response rates can be seen below in Figure 2.

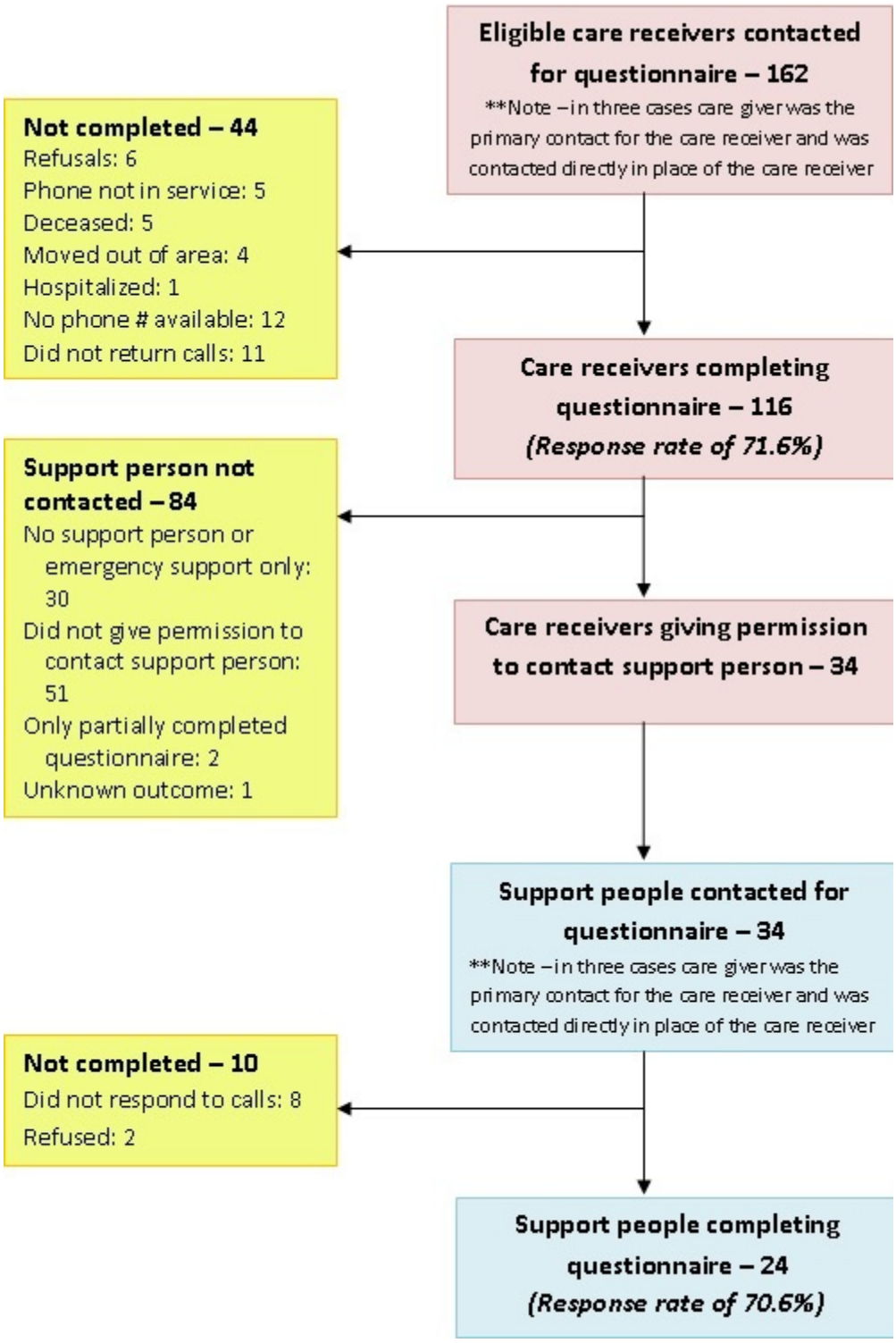

Figure 2. Questionnaire Response Rate and Call Disposition

3.2 DEMOGRAPHICS AND FEATURES OF PARTICIPANT RESPONDENTS

The 116 In Service of Seniors: Pittsburgh program participants who completed the participant questionnaire were primarily female, over age 75, White, living alone, and living on less than 150% of the 2014 federal poverty level (see Table 1, below).

Table 1: Participant Respondent Demographics

	Number	**% of Total**
Total Completing Survey	116	
Sex		
Male	17	14.7%
Female	97	83.6%
Missing	2	1.7%
Age		
60-64	10	8.6%
65-69	17	14.7%
70-74	22	19.0%
75-79	21	18.1%
80-84	18	15.5%
85-89	17	14.7%
90+	9	7.8%
Missing	2	1.7%
Race		
White	96	82.8%
African American	15	12.9%
Asian	2	1.7%
Hispanic	1	0.9%
Missing	2	1.7%
Income as a percentage of the Federal Poverty Level (FPL)		
≤ 100% FPL	29	25.0%
100-150% FPL	27	23.3%
150-200% FPL	17	14.7%
>200% FPL	4	3.4%
Missing	39	33.6%

Table 1 Continued

Lives Alone		0.0%
Yes	76	65.5%
No	23	19.8%
Missing	17	14.7%

Compared to the general older adult population in Allegheny County, the individuals surveyed were older and of lower income, were more likely to live alone and have lower self-rated health scores, had greater needs for assistance with routine tasks but were less likely to have informal support, and had lower satisfaction with their overall quality of life (Tables 2-3). Nearly eighty percent (78%) of In Service of Seniors: Pittsburgh participants with IADL data reported needing assistance with transportation, whereas county-wide over 80% of all respondents and 72% of respondents over age 75 report still driving at least once per month (Musa, Beach, Briem, Scharb, Schulz, 2014).

Table 2: Age Distribution of Sample vs County

	In Service of Seniors sample	Allegheny County
65-74	39 (37.5%)	95,684 (46.7%)
75-84	39 (37.5%)	74,259 (36.2%)
85+	26 (25%)	35,116 (17.1%)

Table 3: Characteristics of Sample vs County

	In Service of Seniors sample	Allegheny County
Lives Alone	65.5%	29.8%
At or below 100% Federal Poverty Level	25%	7.8%
At or below 200% Federal Poverty Level	63%	38.8%
Rates health as “fair” or “poor”	54%	26%
Need help with personal care tasks	12%	2.5%
Need help with routine tasks	79.5%	12.3%
Low levels of informal support	28.5%	12.6% - 14.4%
Average Quality of Life, on a scale of 0 to 1	0.45	0.79

Less than 40% of In Service of Seniors: Pittsburgh participants (38.8%) surveyed reported having practical support from a family and/or friend. Conversely, over 60% of participants surveyed reported having emotional support from a family member and/or friend (60.3%) and over 60% reported having practical support from an agency, company, program, or other formal source of aid (62.9%). When practical, emotional, and formal supports are looked at together, the most common combinations of support sources are: formal sources alone (21.6% of respondents), formal plus practical and emotional support from family and friends (20.7%), and emotional support alone (16.4%). A small percentage of participants (6.9%) reported receiving no support from any sources, other than In Service of Seniors: Pittsburgh (Table 4).

Table 4: Types of Support Reported by Participants

Type of Support	Number	Percentage
Formal only	25	21.6%
Practical + Emotional + Formal	24	20.7%
Emotional only	19	16.4%
Emotional + Formal only	15	12.9%
Practical + Emotional only	9	7.8%
No Support	8	6.9%
Practical + Formal only	7	6.0%
Practical only	4	3.4%

Participants who receive formal support but not informal practical support are much less likely to receive emotional support than participants with other patterns of support ($p<0.01$). As diagrammed in Figure 3 (below), 71 participants reported receiving formal supports and 40 reported not receiving formal supports. Those two groups of 71 and 40 are further broken down into those with and without informal practical supports and then into those with and without informal emotional support. Out of the four combinations of informal practical and formal

support, three combinations (no formal + no informal practical, no formal + informal practical, and formal + informal practical) had similar likelihood of also including emotional support, but those participants receiving formal but not informal practical were much less likely to receive emotional support.

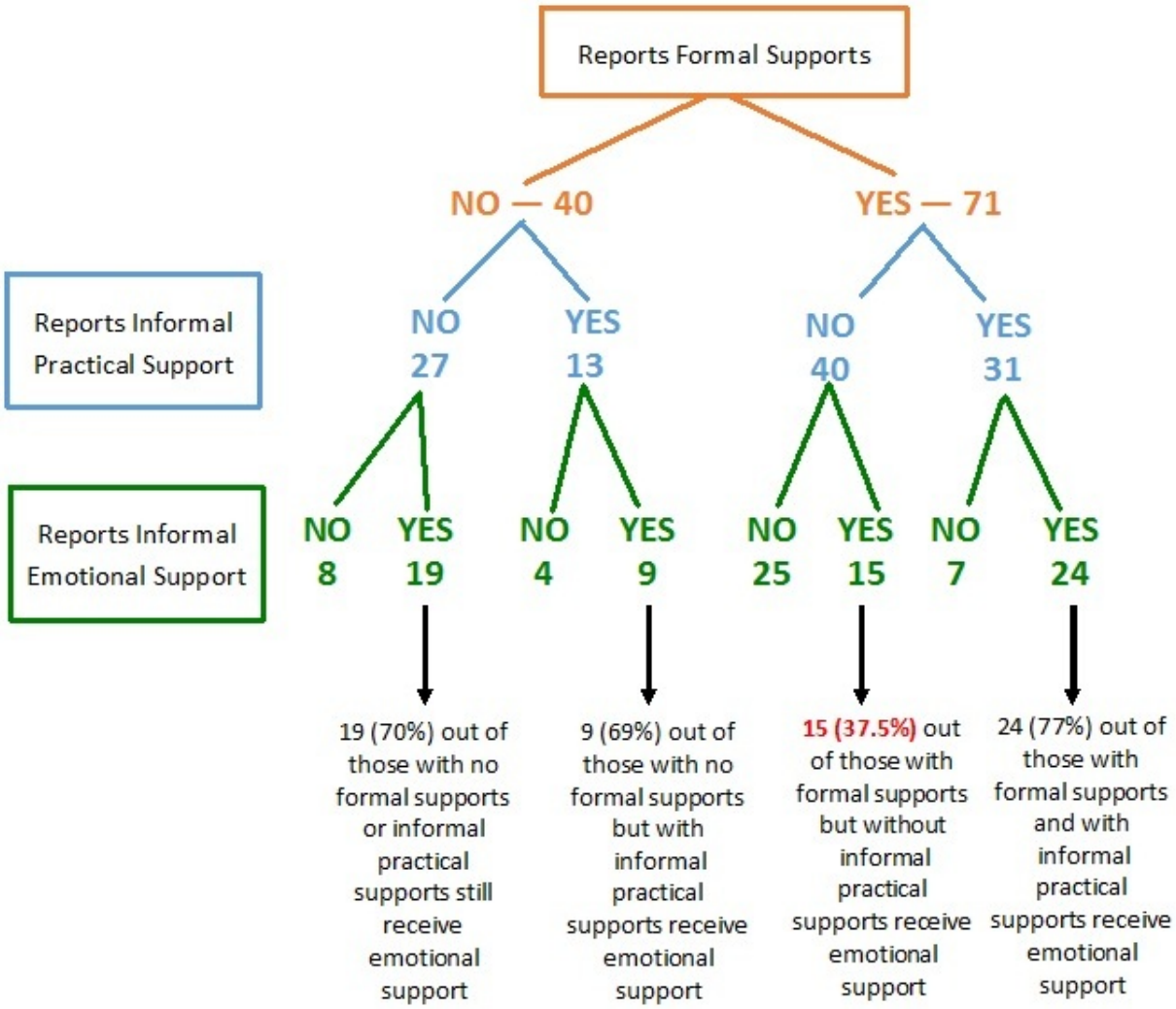

Figure 3: Distribution of Support Types

3.3 KEY PARTICIPANT OUTCOMES

The participant-related evaluation questions for this project were divided into two overarching themes: (1) factors associated with likelihood of granting permission to speak with a support person, and (2) demographic factors correlated with reporting receipt of support.

3.3.1 Factors Associated with Granting Permission to Speak with a Support Person

The only factor significantly associated with a participant granting the survey administrator permission to contact a support person was receipt of informal practical support, with those receiving practical support more than three times as likely to grant permission than those without informal practical support ($p = 0.015$). None of the other variables considered (receipt of emotional support and demographics) had any significant association with likelihood of granting permission to speak with a support person. Below, Figure 4 graphically represents the difference that reporting practical support has when compared with reporting receipt of emotional support.

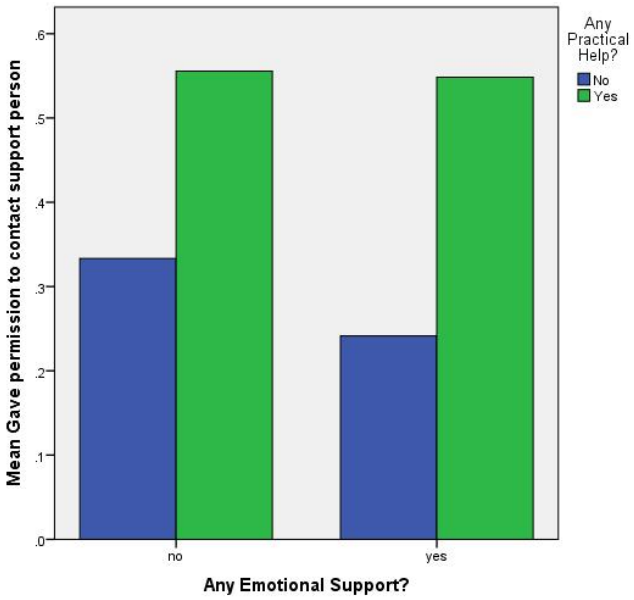

Figure 4: Type of Support and Likelihood to Give Permission

3.3.2 Factors Correlated with Reporting Receipt of Support

Questionnaire results indicate that adult children are important providers of both practical and emotional support. 48.9% of participants receiving practical support have an adult child providing that help, and 38.9% of participants receiving emotional support receive such support from an adult child. Out of all demographic factors tested, only race is significantly correlated with reporting receipt of practical help from family and/or friends (Table 5). Non-White participants were nearly five times as likely to report receiving informal support, however the number of non-White respondents in this evaluation is much lower than the number of White respondents. None of the factors tested are significantly correlated with reporting receipt of formal assistance (Table 5).

Table 5: Factors Correlated with Reporting Receipt of Help

	Odds Ratio (95% Confidence Interval)	
Variable	Receives Informal Practical Help	Receives Formal Practical Help
(Constant)	11.67	0.36
Sex (Reference = Female)	1.71 (0.31, 9.37)	0.28 (0.04, 1.76)
Race (Ref = White)	**0.19 (0.05, 0.76)****	2.09 (0.51, 8.52)
Age	0.98 (0.92, 1.04)	1.04 (0.97, 1.11)
Income (Reference = <100%FPL)	0.38 (0.12, 1.27)	1.51 (0.47, 4.84)
Lives Alone (Ref = No)	2.07 (0.51, 8.31)	0.28 (0.07, 1.05)
Receives formal help (Ref = No)	0.60 (0.18, 1.97)	--
Receives informal help (Ref = No)	--	0.66 (0.21-2.07)

Notes: *p<.05; **p<.01

3.4 DEMOGRAPHICS AND FEATURES OF SUPPORT PERSON RESPONDENTS

The results of the support person survey indicates that the support people surveyed are primarily in their 40s and 60s, are White, are children of the older adults they support, work full time (or more), provide over 11 hours per week of help to their care recipient, do not feel that they are familiar with caregiver resources, but also do not feel particularly stressed or burdened by their caregiving activities (Table 6).

Table 6: Support Person Demographics

		Number	Percentage
Total		23	
Age:	40-49	7	30.4%
	50-59	2	8.7%
	60-69	8	34.8%
	70-79	3	13.0%
	Did not share exact age	3	13.0%
Sex:	Female	17	70.8%
	Male	4	16.7%
	Not collected	3	12.5%
Race:	White	17	73.9%
	African American	5	21.7%
	Asian	1	4.3%
Work and/or volunteer		14	60.9%
Work/volunteer 41-50 hrs/week		4	28.6%
Work/volunteer >50 hrs/week		4	28.6%
Relationship to participant:			
	Participant is a parent	14	60.9%
	Participant is another relative	9	39.1%
Cohabitate with participant		6	26.1%
Hr/wk of help	0-10	8	34.8%
	11 to 20	3	13.0%
	21-30	5	21.7%
	Over 100	4	17.4%
	Did not share	2	8.7%
Familiarity with caregiver services			
	Not at all familiar	11	47.8%
	A little familiar	5	21.7%
Feels stressed balancing time			
	Not at all	4	17.4%
	A little stressed	6	26.1%
	Moderately stressed	9	39.1%
	Very stressed	3	13.0%
	Completely stressed	1	4.3%
Feels doesn't have enough time for self			
	Never	6	26.1%
	Rarely	6	26.1%
	Sometimes	7	30.4%
	Often	3	13.0%
	Always	1	4.3%

Compared with the over age 55 caregivers surveyed through the University Center for Social and Urban Research's State of Aging in Allegheny County (Musa, Beach, Briem, Scharb, and Schulz, 2014), In Service of Seniors: Pittsburgh caregivers are more likely to work outside the home (60.9% versus 25.6% county-wide). Like those surveyed at the county level, In Service of Seniors: Pittsburgh caregivers generally didn't feel overly stressed, but were more likely to feel stressed when they were providing both personal care (with ADLs) and routine care (with IADLs) as opposed to one or the other. The In Service of Seniors: Pittsburgh caregivers providing **both** personal and routine care provided more care per week than the general sample. Of the 8 caregivers providing both personal and routine assistance (35% of caregiver sample), all provided at least 20 hours per week of assistance and half provided over 100 hours per week of care. In the county-wide sample, caregivers providing both personal and routine care averaged 35.5 hours per week of care. However, the number of hours spent providing care dropped among In Service of Seniors: Pittsburgh support people providing only a single type of care, with 61.5% of those providing routine care only providing 10 or fewer hours of care per week.

3.5 KEY SUPPORT PERSON OUTCOMES

One of this project's evaluative questions specific to support people was: what is the discordance between which tasks the participant and the support person claimed the support person helps with? By comparing what the participants and the support people reported in their respective questionnaires, the average amount of disagreement over which tasks the support person assists with is 3.3 tasks, or 19.6% of the total possible 17 tasks included in the questionnaire. It is important to note, however, that in six cases, the support person completing their questionnaire

was not the sole provider of informal support for the participant, so it is possible that in those cases some discordance is attributable to the fact that other support people could be assisting with those tasks. Removing these six cases results in an average discordance of 15.3% or an average of 2.6 tasks. The tasks with the highest degree of discordance are: home maintenance and transportation (11 and 10 participant/support person pairs, respectively, had mismatched responses) followed by laundry, shopping, and social support (all at 6 pairs).

A second support person-specific evaluative question addressed by this project is: do support people with greater self-rated familiarity with caregiver resources experience lower levels of stress? This question is particularly relevant to the In Service of Seniors: Pittsburgh program because provision of information on and referral to other caregiver resources is a primary service that In Service of Seniors: Pittsburgh offers to support people. The support person sample for this project is too small to make statistically significant conclusions, but anecdotally, it seems that familiarity with resources has little correlation with stress levels. Of the seven support people who rated their familiarity with resources as moderate or greater, four (57%) rated their stress levels related to caregiving as moderate or higher and three (43%) rated their stress as little or none. Of the sixteen respondents who rated their familiarity as little or none, 9 (56%) rated their stress levels as moderate or higher and 7 (44%) rated their stress levels as little or none.

Finally, a third evaluative question relating to support people is: are any factors associated with greater confidence in the ability to get help for one's participant or oneself? This exploratory question is of interest to In Service of Seniors: Pittsburgh program leaders who would like to know if there are services that the program already does, or could in the future, offer to improve caregiver confidence. The factors included in analysis were: being able to rely on family for assistance vs not being able to rely on family for assistance, feeling familiar with caregiver resources vs not

feeling familiar with caregiver resources, feeling stressed vs not feeling stressed, and feeling burdened by caregiving activities vs not feeling burdened by caregiving activities. The responses from the support person questionnaire suggest that support people who report being able to rely on other family members for support for their care recipient or for themselves are more confident that they will receive assistance when they need it than support people who report not being able to rely on family members. Self-rated familiarity with caregiver resources had no discernable association with confidence in receiving assistance when needed. Feelings of stress and burden appeared to have no association with confidence in receiving help for oneself when needed, but responses suggest that support people who feel unconfident in receiving help for their care recipient when needed are actually less stressed and burdened than those who feel confident. However, the sample size of respondents was too small to conduct statistical analysis on these results.

4.0 DISCUSSION

4.1 INTERPRETATION OF PARTICIPANT RESULTS

Compared to older adults throughout Allegheny County, the In Service of Seniors: Pittsburgh participants are older, of lower income, have poorer health, have less support, and are more likely to live alone. These findings are in line with an understanding that younger, healthier people would not be in need of In Service of Seniors: Pittsburgh services. In addition, older adults with more informal support may have a greater variety of friends and family members to rely on for help, and wealthier individuals may prefer the greater dependability of paid services.

4.1.1 Types of Support Reported

Responses from participants regarding the types and combinations of support they receive suggest that while many participants do have a robust network of friends and family members providing practical support such as transportation, shopping, cleaning, and personal care, most program participants are not relying solely on friends and family members to provide practical support. Rather, participants are relying more heavily on formal sources of support such as care management, Aging Waiver services, Access transportation, and private pay services. This may be because older adults with support networks that are able to provide ample assistance would not have a need for a supplemental support program such as In Service of Seniors: Pittsburgh.

As described in Figure 3, participants receiving formal support but lacking informal support are less likely to receive emotional support when compared to other participants. A single

explanation of these results cannot be determined given the cross-sectional design of this evaluation and the limitations of the data collected. However, there are likely explanations to consider. Individuals receiving informal practical support likely receive comparable levels of emotional support since the informal support providers probably also provide emotional support. However, the group reporting no formal supports and no informal practical supports still has emotional support levels close to those of individuals receiving informal practical supports. The lack of practical support of any kind suggests that these participants have lower practical support requirements. Their friends and family members, who could also provide practical support if it were needed, are providing emotional support in this case. The participants in the group receiving formal supports but no informal practical supports may have a need for assistance (as indicated by their receipt of formal services), but not have family members or friends available to provide informal practical or informal emotional supports. Individuals with higher needs but lower levels of informal support, would need to be heavily reliant on formal services to meet their needs. Without a safety net or family members and friends to provide assistance, these individuals would rely on formal services being reliably available and accessible, and would be particularly sensitive to changes in formal services.

According to the University of Pittsburgh University Center for Social and Urban Research's (UCSUR) State of Aging report, there is a large unmet need for transportation services like those offered by In Service of Seniors: Pittsburgh. Although 36.4% of those surveyed by UCSUR reported using transportation services, 6.9% of those surveyed reported having unmet transportation needs. Of those reporting unmet needs, 21% (or 1.4% of entire sample) were not receiving necessary transportation services. Assuming a similar percentage of the adults over age 65 county-wide have unmet transportation needs, there are nearly 3,000 older adults who are not

accessing transportation services when they need them. This represents an opportunity for growth for In Service of Seniors: Pittsburgh and other similar programs.

4.1.2 Likelihood of Granting Permission to Speak with a Support Person and Factors Correlated with Receipt of Support

As noted in section 3.3.1, participants were significantly more likely to grant permission to speak with a support person if they report receiving informal practical assistance. One interpretation of these results is that participants consider relationships based on emotional or social support to be more private and intimate than relationships based on practical support and so are less likely to allow an outside party to contact that support person.

Non-whites (in this sample, primarily African Americans) were nearly five times more likely to report receipt of practical support from family and friends. Out of the 18 non-Whites in the sample, 10 reported receiving informal practical support. As noted in the introduction, previously published research suggests that African American caregivers have broader support networks than Whites (Dilworth-Anderson, Williams, and Gibson, 2002). At first, one might propose that because African American individuals may have broader support networks, these participants may have more individuals to rely on. However, out of the 10 non-Whites reporting informal support, only four reported receiving practical support from more than one friend or family member. So it is not necessarily the case that non-Whites are receiving help from a greater number of individuals. Nor is it necessarily the case that non-Whites report greater receipt of support because they have poorer health and are thus in need of more assistance. The proportions of Whites and non-Whites with "fair" or "poor" self-reported health are very similar, with 55% of non-Whites rating their health as "fair" or "poor" and 54% of Whites rating their health as "fair"

or "poor." It may just be the case that in this sample, non-Whites have friends and family members with greater availability or capacity to assist them.

4.2 INTERPRETATION OF SUPPORT PERSON RESULTS

The support people participating in this project were overall similar to the caregivers included in UCSUR State of Aging report in that most experience low levels of caregiving related stress unless they were providing more intense levels of care, such as both routine and personal care categories of support rather than one category or the other. In Service of Seniors: Pittsburgh support people were more likely to be working, but that could be explained by the fact that the UCSUR survey's sample was older (age 55 and older) and more likely to be retired, whereas 30% of In Service of Seniors: Pittsburgh support people were in their 40s.

4.2.1 Discordance in Types of Support Reported

The discordance between tasks participants reported receiving assistance with and tasks support people reported helping with was higher than expected. There are several potential explanations for the discordance. For example, some participants may have forgotten that they received assistance from others, particularly if they receive assistance infrequently or irregularly. Some participants may not have realized that their support person was providing assistance (for example, if an adult child discretely completed some housekeeping during a visit). Other participants may not have associated tasks their support person completed with the categories of tasks presented in the questionnaire. As described in section 1.3.3, family dynamics can be very complex, especially

during periods when roles are changing, such as parents shifting to become recipients of care and children shifting to become providers of care. Some participants' expectations for the amount of help they believed they should receive from caregivers and the amount of help they actually received could be different, and this mismatch could color the participants' recollection and description of actual care provided in a typical month. For example, it's possible that a participant didn't receive as much help as they think they should be getting, and as a result discounts the support they do receive.

4.2.2 Confidence in Receiving Support

The lack of correlation between familiarity with resources and confidence in receipt of support was different than expected. The author had hypothesized that high levels of familiarity with supportive resources would lead support people to feel more confident that they would receive help when needed. However, the results indicate that the support people in this sample rely heavily on family members for support, and that community-based supportive services aren't a strong factor in caregiver confidence.

4.3 LIMITATIONS

This evaluation does have several limitations that are important to recognize. One important point to note is that the author was employed full-time by the In Service of Seniors: Pittsburgh program throughout the duration of this evaluation. The author's employment creates a potential for bias both on the part of the author and the respondents. While the author's affiliation with the program

gave her recognition as a known entity and thus created entrée with the respondents, there is potential that she harbored some unconscious biases towards or against participants she was already familiar with, and towards or against certain outcomes. The author took great care to be very cognizant of her approach, thoughts, and words, and made every effort to introduce and go through the survey the same way with each respondent.

Another limitation of this evaluation is the broad time frame for data collection. The questionnaires were completed over a longer period of time than initially planned for, creating the potential for seasonal differences in responses that were not accounted for in analyses. For example, it is possible that some participants have more social interactions and receive greater levels of informal practical support over the summer, or during holiday seasons. Since respondents were surveyed during different times of the year, some were asked about supports during times of year that may be unusually busy or slow for them. The questions did ask about support in a typical month, but it is possible that there may still be some seasonal discrepancies that were not accounted for.

Finally, the sample size for this evaluation was too small to conduct anything more than simple statistical analyses on. This was due primarily to the restriction of the evaluation to a single program, and the strict inclusion and exclusion criteria within that program. As an exploratory project, this is not necessarily problematic, but is important to note.

5.0 CONCLUSION AND RECOMMENDATIONS FOR IN SERVICE OF SENIORS: PITTSBURGH

This evaluation is the first exploratory project investigating the support networks of In Service of Seniors: Pittsburgh participants and both offers useful information to the In Service of Seniors: Pittsburgh program and adds to the body of knowledge about participants of volunteer-based programs serving older adults. The author has several recommendations to the In Service of Seniors: Pittsburgh program to help staff members increase sensitivity to participant and support person needs.

In light of learning that there is a subset of participants with very little informal support, the author recommends that In Service of Seniors: Pittsburgh staff members incorporate questions about support networks into the participant intake process and pay extra attention to those individuals lacking informal supports who may be especially vulnerable to changes in and loss of formal supports. Staff members should direct these participants to additional formal support resources and assist them with enrollment when appropriate. Staff may also wish to prioritize matching these individuals who lack back-up support with volunteers. Considering the discordance between supports reported by participants and caregivers, it may also be necessary for staff members to experiment with how they ask participants about informal supports to see if they can get more accurate responses.

In Service of Seniors: Pittsburgh leadership has expressed that they would like to provide stronger supports to support people. Considering the limits of the program's current service capacity, In Service of Seniors: Pittsburgh staff can ask participants for permission to share the program's developed "support person information packet" with their friends and family members,

recognizing that they will only be able to reach a small percentage of support people, and will primarily be reaching support people of participants who receive practical assistance. Between November, 2014 and April, 2015 nine newly enrolled In Service of Seniors: Pittsburgh participants (out of 214 total new participants during that time period) accepted an informational packet of information and community resources designed for support people. Though support person survey results indicated that familiarity with caregiver resources may not be related to stress levels, support people nonetheless reported low levels of familiarity with resources available to them, and provision of information is a service that In Service of Seniors: Pittsburgh already does well. The In Service of Seniors: Pittsburgh program may wish to enlist the help of an additional student to explore what types of supports In Service of Seniors: Pittsburgh support people feel they need.

APPENDIX A: LETTER OF EXEMPTION FROM THE UNIVERSITY OF PITTSBURGH IRB

University of Pittsburgh

Institutional Review Board

3500 Fifth Avenue
Ground Floor
Pittsburgh, PA 15213
412-383-1480
Fax: 412-383-1508

Memorandum

To: Sarah Papperman

From: IRB Office

Date: 7/30/2014

Subject: Exploring informal support networks of In Service of Seniors: Pittsburgh participants

The University of Pittsburgh Institutional Review Board has conducted a facilitated review of the above proposal. This project is most appropriately defined as a Program Evaluation. This project does not meet the definition of research according to the Federal Policy Regulations, 45 CFR 46.102(d). Therefore, University of Pittsburgh IRB oversight is not required.

APPENDIX B: PARTICIPANT SCRIPT AND QUESTIONNAIRE

Hello, this is Sarah from In Service of Seniors: Pittsburgh, is [PARTICIPANT] available? I'm calling because you have received services from our program over the past year. From our records I see that you have received help from [VOLUNTEER], is that correct? How has that been going? *(Allow participant to describe experience and make notes on any positive or negative issues to follow up on)*

I'm calling today because we're conducting a brief survey with our participants to learn more about other sources of support for you. Do you have a few minutes to answer some questions for me?

(If refuses) No problem. Thank you for your time, and please feel free to call In Service of Seniors in the future if you have any further questions or need to request services.

(If it's a bad time) That's okay, I can call back. When is a good time to reach you?

(If yes) Great, thank you! This questionnaire should take just a few minutes. Remember you don't need to answer any question that you don't want to, so please let me know if there is a question that you don't want to answer for any reason and we'll skip it.

Record ID Number: _____

1. How many friends or family members do you have who help you with practical things like cooking, cleaning, bathing, or dressing?*(Estimates are okay, enter zero or one whole number)*

2. *(If >0 to question 1)* What is their relation to you? Are they your...

- ☐ Spouse
- ☐ Son/daughter
- ☐ Niece/nephew
- ☐ Grandchild
- ☐ Sister/brother
- ☐ Parent
- ☐ Friend
- ☐ Other: _____

3. On average, how often do they help you?

- ☐ Daily
- ☐ Weekly
- ☐ Monthly
- ☐ Less than once a month

4. Which of the following do they help with? *(Check all that apply)*

- ☐ Eating
- ☐ Bathing
- ☐ Dressing
- ☐ Walking
- ☐ Toileting
- ☐ Doing Laundry
- ☐ Preparing Meals
- ☐ Bills and Paperwork
- ☐ Housekeeping
- ☐ Home Maintenance
- ☐ Shopping
- ☐ Using a Phone
- ☐ Transportation
- ☐ Taking Medications
- ☐ Getting into/out of Bed
- ☐ Getting into/out of Chairs
- ☐ Other: _____

5. How many friends or family members do you have who you can call or visit with when you need to talk to someone about personal matters or difficult decisions? *(Estimates are okay, enter zero or one whole number)*

6. *(If >0 to question 5)* What is their relation to you? Are they your...

- ☐ Spouse
- ☐ Son/daughter
- ☐ Niece/nephew
- ☐ Grandchild
- ☐ Sister/brother
- ☐ Parent
- ☐ Friend
- ☐ Other: _____

7. On average, how often do you talk to or see them?

- ☐ Daily
- ☐ Weekly
- ☐ Monthly
- ☐ Less than once a month

8. How many friends or family members do you have who you can call in an emergency? *(Estimates are okay, enter zero or one whole number)*

9. *(If >0 to question 8)* What is their relation to you? Are they your...

- ☐ Spouse
- ☐ Son/daughter

- ☐ Niece/nephew
- ☐ Grandchild
- ☐ Sister/brother
- ☐ Parent
- ☐ Friend
- ☐ Other: _____

10. Do you receive additional help from any agencies, programs, or companies with any of the following tasks?

- ☐ Housekeeping
- ☐ Home Delivered Meals
- ☐ Personal Care (bathing, dressing, etc.)
- ☐ Medication Management
- ☐ Budgeting/Money Management
- ☐ Care Management
- ☐ Other: _____
- ☐ None (does not receive help from any agencies, programs, or companies)

Thank you, that was the last question! We have an additional survey for friends and family members of our participants to learn more about how they believe they are supporting you, how they are feeling, and if they know where to find assistance for themselves if they need it. Would it be okay with you if I contact your [FRIEND/RELATIVE] to see if they'd be willing to complete this survey for us?

(If yes, collect name and contact information for support person)

APPENDIX C: SUPPORT PERSON SCRIPT AND QUESTIONNAIRE

This questionnaire was designed with the option to be completed over the phone (with direct data entry into Google Forms), on paper (via postal mail with return envelope), or online (with a link sent via email). The introductory script is the basis for the postal and online versions.

Dear Family Member or Friend,

Thank you very much for taking a few moments to complete this questionnaire for In Service of Seniors: Pittsburgh. The purposes of this questionnaire are to learn more about support networks of our participants so we can provide the best services we can in the context of their individual situations, and to determine if there are additional ways we can provide better services to the community at large.

There are 25 questions. Remember as you go along, you don't have to answer any questions that you don't want to and you can skip to the end of the survey at any time if you wish. Your responses will be confidential and will help In Service of Seniors identify ways the program can improve and grow. If you provide help or support to more than one person, please answer these questions ONLY as they apply to the person who receives services through In Service of Seniors.

Record ID Number: _____

1. Prior to receiving this information packet, had you ever heard of In Service of Seniors or Interfaith Volunteer Caregivers (our former name)?

☐Yes
☐No
☐Not Sure

2. Do you believe that over the past six months, the services provided by In Service of Seniors: Pittsburgh have helped the program participant stay living at home?

☐Yes
☐No
☐Maybe/Not sure
☐I don't know enough about what In Service of Seniors does for the participant to answer this question

3. Which of the following best describes your relationship with the In Service of Seniors participant? ***They are my…***

☐Spouse
☐Parent
☐Grandparent
☐Sibling
☐Aunt/Uncle
☐Son/Daughter
☐Friend
☐Other: _____

4. Do you live in the same home as the In Service of Seniors participant?

☐Yes
☐No

5. In a typical month, do you provide any of the following types of assistance for the In Service of Seniors participant? Check the appropriate box for each item:

	Yes	No	Not sure
Eating Meals			
Bathing			
Getting dressed			
Walking in the home			
Using the toilet			
Doing laundry			
Preparing meals			
Paying bills and doing paperwork			
Housekeeping			
Home maintenance			
Shopping			
Using a phone			
Transportation			
Taking medications			
Getting into or out of bed			
Getting into or out of chairs			
Social support (e.g.: conversation, visiting, advice, social activities)			
"Checking In" (calling or visiting to make sure everything is okay)			
Acting as their emergency contact			
Lining up services (e.g.: arranging for housecleaning, scheduling medical appointments, etc.)			
Supervision for safety			

Please list any additional types of assistance you provide in a typical month.

_____

6. Think for a moment about all the types of support you just indicated you provide. About how long have you been providing all of these types of support?

☐Less than 1 year
☐1-5 years
☐More than 5 years
☐Not sure
☐Not applicable (I do not provide any support)

7. During the average or typical week, how many hours would you say you spend helping or supporting the In Service of Seniors participant? _____

8. Do you currently provide caregiving or support for any other adults?

☐Yes– How many other people? _____

☐No

☐Not sure

9. Are you currently the primary caregiver for any people under the age of 18?

☐Yes– How many children? _____

☐No

☐Not sure

10. How familiar are you with programs and resources to help you as a support person?

☐5– Completely familiar

☐4– Quite familiar

☐3– Moderately familiar

☐2– A little familiar

☐1– Not at all familiar

11. If you needed extra support for THE IN SERVICE OF SENIORS PARTICIPANT, who would you turn to?

	Yes	No	Not sure
Family within your household			
Other family members outside of your household			
Friend/neighbor			
Religious community			
Professional in-home service providers			
Social worker or support group			
Medical professional/doctor			
A volunteer program			

Please list any other people, groups, organizations, or agencies that you would turn to for support for the In Service of Seniors participant: _____

12. How CONFIDENT are you that you would receive the help for THE IN SERVICE OF SENIORS PARTICIPANT if you asked?

☐5– Completely confident

☐4– Moderately confident

☐3– Neither confident nor unconfident

☐2– Moderately unconfident

☐1– Completely unconfident

13. If you needed extra support for YOURSELF, who would you turn to?

	Yes	No	Not sure
Family within your household			
Other family members outside of your household			
Friend/neighbor			
Religious community			
Professional in-home service providers			
Social worker or support group			
Medical professional/doctor			
A volunteer program			

Please list any other people, groups, organizations, or agencies that you would turn to for support for yourself: _____

14. How CONFIDENT are you that you would receive the help for YOURSELF if you asked?

☐5– Completely confident

☐4– Moderately confident

☐3– Neither confident nor unconfident

☐2– Moderately unconfident

☐1– Completely unconfident

15. How would you rate your overall health at this time?

☐5– Excellent

☐4– Very Good

☐3– Good

☐2– Fair

☐1– Poor

16. How would you rate your overall quality of life at this time?

☐5– Excellent

☐4– Very Good

☐3– Good

☐2– Fair

☐1– Poor

17. How stressed do you feel from trying to balance your time spent providing care to the ISOS participant and meeting your other responsibilities (family, work, etc.)?

☐1– Not at all stressed

☐2– A little bit stressed

☐3– Moderately stressed

☐4– Very stressed

☐5– Completely stressed

18. Because of time spent with the ISOS participant, do you feel like you don't have enough time for yourself?

☐1– I never feel like this

☐2– I rarely feel like this

☐3– I sometimes feel like this

☐4– I often feel like this

☐5– I always feel like this

19. What is your zip code? _____

20. What is your age in years? _____

21. What race do you most consider yourself?

☐African American/Black

☐American Indian/Alaska Native

☐Asian

☐Latino/Hispanic

☐Middle Eastern

☐Multiracial

☐Native Hawaiian/Pacific Islander

☐White

☐Not Sure

22. What is your marital status?

☐Single/never married

☐Married

☐Divorced/Separated

☐Widowed

☐Not sure

23. Are you currently employed or self-employed?

☐Yes

☐No

24. Do you currently participate in any regular volunteer work?

☐Yes

☐No

25. Altogether, on average, how many HOURS PER WEEK do you spend engaged in paid and volunteer work? _____

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