



**Report of the  
2008 Paid Family Caregivers Project**

**For**

**South Carolina DHHS**

**Bureau of Long Term Care & Behavioral Health**

**Survey conducted under contract by the**

**Center for Social Welfare**

**Research and Assessment**

**Winthrop University**

**Department of Social Work**

This survey was a collaborative effort of the Center for Social Welfare Research and Assessment of the Winthrop University Department of Social Work and staff of the Bureau of Long Term Care & Behavioral Health.

Center for Social Welfare Research and Assessment

Ronald K. Green, J.D., Executive Director

Sue Lyman, Ph.D., MSW

Lead Investigator, Paid Family Caregivers Project

Alex Wagaman, MSW, Director of Operations

Michael D. Bremseth, MA, Director of Research

## Table of Contents

<b>Background and Introduction</b> .....	<b>1</b>
<b>Project Objectives</b> .....	<b>3</b>
<b>Review of the Literature</b> .....	<b>3</b>
<b>Sample</b> .....	<b>5</b>
<b>Methodology</b> .....	<b>5</b>
<b>Key Findings</b> .....	<b>6</b>
<b>Who is receiving paid family care?</b> .....	<b>6</b>
<b>How satisfied are they with the caregiving situation?</b> .....	<b>9</b>
<b>Program Impact</b> .....	<b>11</b>
<b>Discussion and Implications</b> .....	<b>14</b>
<b>Appendix</b> .....	<b>16</b>
<b>References</b> .....	<b>16</b>
<b>Unstructured Interview Script</b> .....	<b>19</b>
<b>Unstructured Interview Questions</b> .....	<b>20</b>
<b>Stakeholder Questions</b> .....	<b>21</b>
<b>Introductory Script</b> .....	<b>22</b>
<b>Survey Questions</b> .....	<b>23</b>

## **Background and Introduction**

Some researchers have examined the presence of informal caregiving in the United States. In 1997, researchers found that 24 to 27 million people in the United States were caregivers (Arno, Levine, & Memmott, 1999). It has been estimated that on average, each of these caregivers spent nearly 18 hours a week caregiving to equal approximately 22 to 26 billion hours nationwide. Based on a midrange rate of formal caregivers' earnings of \$8.18 an hour, the economic value of informal caregiving in 1997 was \$196 billion. If that estimate was added to the national healthcare spending totals, healthcare in the United States would cost nearly \$200 billion more.

Our nation has been actively moving in the direction of supporting the aging population and adults with disabilities to stay at home as long as possible. This movement has drawn attention to the under-recognized resource of family caregivers. As states grapple with re-balancing their nursing home and home care dollars, and with how to implement high quality programs of care for home and community-based waivers through the Medicaid system, it is apparent that family caregivers are crucial to the success of these programs. As such, many states have begun to implement service options that create opportunities for family members to become paid caregivers. In many cases, this is preferred by the care recipient who seeks a sense of familiarity and comfort with their caregiver while experiencing a loss of independence. In addition, families often prefer to rely on someone who can be trusted to care for their loved one. With this comes a certain peace of mind in what can often be a stressful time (Angus, J., Kontos, P., Dyck, I., McKeever, P., & Poland, B., 2005).

South Carolina has been on the cutting edge of home and community-based services in the United States for a number of years. In 2000, South Carolina began discussing what soon became the SC Choice program under the Elderly/Disabled waiver in 2003. This consumer-directed waiver used less restrictive federal funds and only restricted spouses and legal guardians of minor children from being paid caregivers. In 2004, the option to hire family members to provide traditional Community Long Term Care (CLTC) services began to be offered in other waiver programs. In 2006, SC Choice was rolled in with the Elderly/Disabled waiver, giving all participants the option to hire a family member to provide personal care through CLTC. As of August 2007, Community Long Term Care has 1,114 attendants (or consumer-selected and directed personal care providers) authorized to provide services. Of those, nearly 50% (520) are reported family providers. UAP, the University of South Carolina program that oversees attendant matches for CLTC, reported that they saw a huge increase in the number of family members being hired as attendants when the policy changed to allow it in 2004.

A first phase of this study was conducted in 2007 looking at the experiences of family members providing paid care to Community Long Term Care participants. This second phase of the study was aimed at exploring the other half of this relationship – those participants who are receiving paid care through CLTC from a family member. The researchers wanted to identify the factors associated with participant satisfaction. Because the literature associates satisfaction with health-related services and better health outcomes, this data would be beneficial to the Community Long Term Care program. A significant number of questions from the first phase of the study were kept in the instrument for the second phase. This allows for comparison of the experiences between the two populations. Leading up to this study, South Carolina's Community Long Term Care program was aware that the option to pay family caregivers had benefits and successes, such as limiting the number of changes a family had to undergo once they are in need of home-based long term care services. However, CLTC had also become aware of barriers and challenges to offering such an option.

One challenge is related to supervision. If a participant has selected to supervise a family member to provide her/his care, that participant is responsible for all supervisory-related duties including disciplining and firing the family member if necessary. The case manager, from a programmatic perspective, is told to have limited involvement in the relationship other than monitoring the quality and consistency of care as they would with an agency-based provider. This leaves the care relationship with very little, if any, oversight and support while the dynamics associated with having a business relationship with a family member has the potential for complications and conflict. In some cases, the question has also been raised about the potential these relationships have for fraud and abuse.

Another challenge for CLTC is around the expectations and needs of family members. As the literature shows, many caregivers give up paid employment to care for a family member (Wolff & Kasper, 2006). This loss of income can be very difficult for a family to manage. While CLTC currently approves hours for paid family caregivers at the same level that an agency provider would be approved, many families want more in order to supplement or make up for the lost income. In addition, the service costs are called into question when a family member who is being paid to provide care requests respite or other support services.

Additional challenges to the option being provided by CLTC to pay a family member include identifying a back-up caregiver, and identifying inconsistencies with how case managers use the attendant option.

## **Project Objectives**

With these and other barriers and challenges in mind, South Carolina CLTC decided to have Winthrop University look at the paid family caregiver program from a participant perspective with particular interest in how the attendant option is going overall, satisfaction issues, and issues related to quality and impact of care. Two key questions that Community Long Term Care hoped to answer through this study are what positive impact the attendant option is having on participants and their families, and what kinds of policies need to be developed to maximize the benefits of the attendant option while minimizing the potential for misuse.

## **Review of the Literature**

The number of elderly and adults with disabilities needing long term care is steadily increasing (Friedland, 2004). As many as 78% of those receiving long term care rely on family and friends to provide that care on a volunteer basis (Thompson, 2004) and many family members gain peace of mind in a very stressful time from having their loved one cared for at home by someone that they know and trust (Angus, Kontos, Dyck, McKeever, & Poland, 2005). As much as it is clear that family home care is a valuable and desirable option for many families (Angus, Kontos, Dyck, McKeever, & Poland, 2005), there have been mixed findings regarding the impact of family home care on family dynamics and satisfaction with the long term care arrangement. In a study of mother daughter eldercare relationships, Hollis-Sawyer (2003) found that 30% viewed the situation as negative and identified personality traits and communication patterns as influencing factors. Dyeson (2000) found that burden self-perception was a mediating variable of depressive symptoms among family care recipients. On the other hand Dwyer, Lee and Jankowski (1994) found no relationship between reciprocity and satisfaction of the care recipient. In addition, strain on the caregiving relationship may be influenced negatively by grief and loss issues (Rando 2000; Doka and Aber, 2002) and positively by level of spirituality (Doka, 2003).

Newsom and Schulz (1998) suggest that the family caregiving relationship may have a negative impact on the care recipient and that “perceived control, feelings of fatalism, self-esteem, and relationship factors may be important predictors of negative reactions to assistance from caregivers, because these factors are known to be associated with well-being or negative responses to helping” (p.172). According to the results of the study, almost 40% of the care recipients reported stress related to having assistance with daily tasks. Half of the care recipients indicated receiving unnecessary care, while another 28% stated that they did not receive adequate help with basic activities. The care recipient’s indication of inadequate assistance was associated with negative

feelings toward the caregiving relationship, however these negative feelings were inversely related to the extent of control the care recipient reported. An important finding from the study is that distress experienced by care recipients was a significant predictor of the presence of depression in the care recipient up to a year after the report of negative feelings.

It seems that just the fact that one needs to rely on others for care can have negative effects. McPhearson, Wilson & Murray (2007) found that the idea of depending on others for daily activities brought out feelings of hopelessness and self-perceived burden. These participants also feared a loss of respect because of their inability to provide for their families or fulfill their roles in society. From an administrative perspective, more control by families in the management of their respite/personal assistance has been associated with higher satisfaction and increased community involvement of people with developmental disabilities (Caldwell, J., & Heller, T. 2003). Direct payment schemes have been found to be positively perceived because of the wide range of flexibility but both care recipients and caregivers often experienced difficulties managing the dual relationship of employer/employee and caregiver/care recipient (Glendinning, Halliwell, Jacobs, Rummery and Tyrer, 2000). Incongruence in role expectations can also impact satisfaction for both the caregiver and the care receiver (Zweibel and Lydens 1990, Lyons, Zarit, Sayer and Whitelatch, 2002). In one study, difficulty managing employer responsibilities emerged as one of the reasons that recipients of paid family care voluntarily withdrew from the program. (Schore, Foster, & Phillips, 2007).

It would seem that reciprocity is an important factor in the caregiving/receiving dynamic. In typical caregiving relationships of those with physical illness, as the care recipient begins to lose self-care abilities, reciprocity between them and their caregiver also begins to decline (Reid, Moss and Hyman, 2005). When reciprocity does occur, it is demonstrated in the form of love, information, advice, and money (Walker, Pratt, and Oppy, 1992). Dwyer, Lee, and Jankowski (1994) conducted a study which illustrated that in times when the care recipient is able to assist in different tasks, no matter what size, levels of stress and burden among caregivers was significantly lower. It has been found that when a caregiver is satisfied, this feeling is translated onto the care recipient, building a more stable relationship. In a study looking at the relationships between people who are mentally ill and their family caregivers, recipients of care “identified ways in which they acted as caregivers. Caregiving practices were described by 14 of the 21 people interviewed.” (Williams and Mfoafo, 2006)

It also seems that culture and ethnicity influence the caregiving/receiving dynamic. Lockery (1991) suggests ethnic and racial differences impact caregiving patterns, which includes reciprocity.

Informal support was more frequently cited among African-American elderly people. Lockery (1991) also suggests that older adults from the American Indian population who live on reservations depend on relatives to provide caregiving. These older adults are also more involved in childcare responsibilities for younger generations. Reciprocal caregiving has been shown to be a major part of American Indian, specifically Navajo, culture. The same study found very different caregiving patterns among Asian Americans. Many Asian Americans must depend on formal support for caregiving, despite the cultural expectation that younger generations are responsible for providing care for older adults. In the Hispanic community while caregiving patterns differ according to the subpopulation, family as a priority is typically a theme, and Hispanic older adults tend to rely on caregiving support from family members.

With all of the attention given in the literature to caregiving and family caregiving it is interesting that there is very little literature on the differences in relationship dynamics and recipient satisfaction when the family caregiver is paid versus unpaid to provide care.

## **Sample**

It was determined that this phase of the study would focus on one specific population of participants who were receiving paid family care – those who were supervising their own care. Pulling in other groups would add an additional variable that may skew the data. Therefore, those participants who had been deemed unable to supervise their own care and those who were capable but had chosen someone else were not included in the sample.

One-hundred and twenty-nine people were identified through Community Long Term Care's computerized case management system as meeting the criteria for the study population.

## **Methodology**

In order to focus the information gathered through the literature review and provide data that would be most useful to South Carolina, key stakeholder interviews were conducted to gain a better understanding of the attendant option within CLTC more specifically, as well as the issues that had been raised by staff and participants around the option. Based on recommendations from state-level CLTC staff, three interviews were conducted – Linda Motley (UAP), Maria Patton (CLTC) and Debra Stevens (CLTC). Feedback from these interviews was incorporated into the survey instrument as appropriate.

Based on the literature and the stakeholder interviews, a set of questions was developed to be used in

conducting a series of unstructured phone interviews with a few randomly selected participants in the identified population. These questions created an opportunity for the research team to identify whether they were on target with the areas and issues that had been identified as important for this population, to identify areas and issues that had been missed by the research team, and to assist in the quantification of the questions for the final survey instrument. In addition, this process assisted with training tips and methodology development for the larger survey. A total of 8 unstructured interviews were conducted. The information and feedback gathered were used to finalize the instrument (see Appendix).

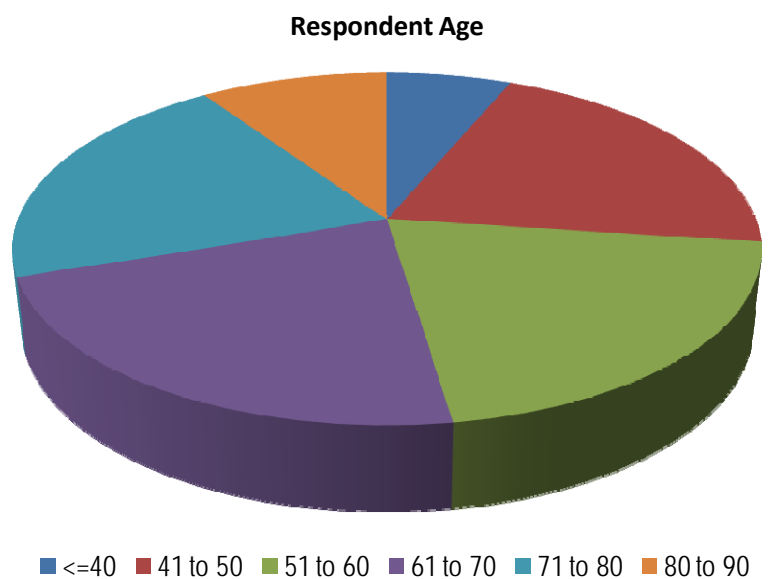
The final survey was conducted by the Social and Behavioral Research Lab at Winthrop University. From the total identified population of 129 self-directing participants, 65 phone interviews were completed.

### Key Findings

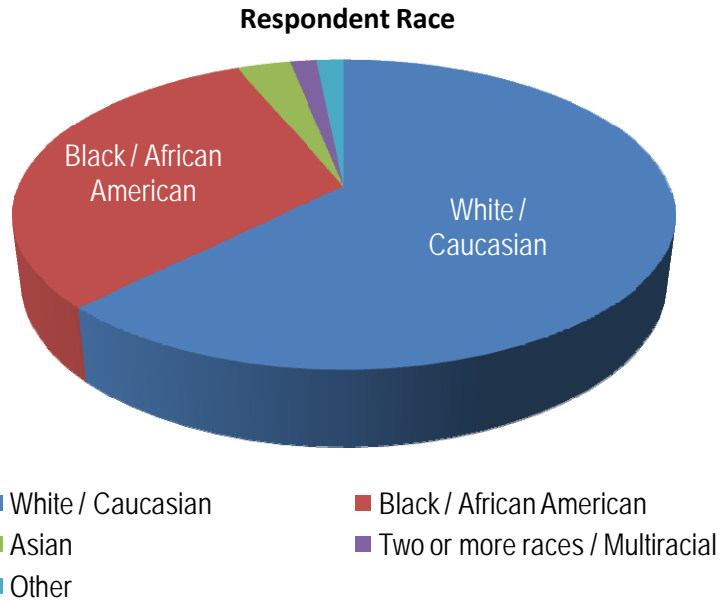
The following findings are those that seem to be of relevance for this study and of particular interest to the research team and Community Long Term Care.

#### ***Who is receiving paid family care?***

The majority of these care receivers (79%) are female, while only 21% of the care receivers are male. While the cause for this **3.5 to 1** difference is unclear, these numbers reflect what would be typically expected. As shown, the age of care receivers is fairly evenly distributed across age categories, which would not necessarily be expected. The 41-50, 51-60, 61-70, and 71-80 age groups each account for approximately 20% of the care receivers. Care receivers under the age of 40 make up about 6% of the respondents, while care receivers falling in the 81-90 range account for 9% of the respondents.

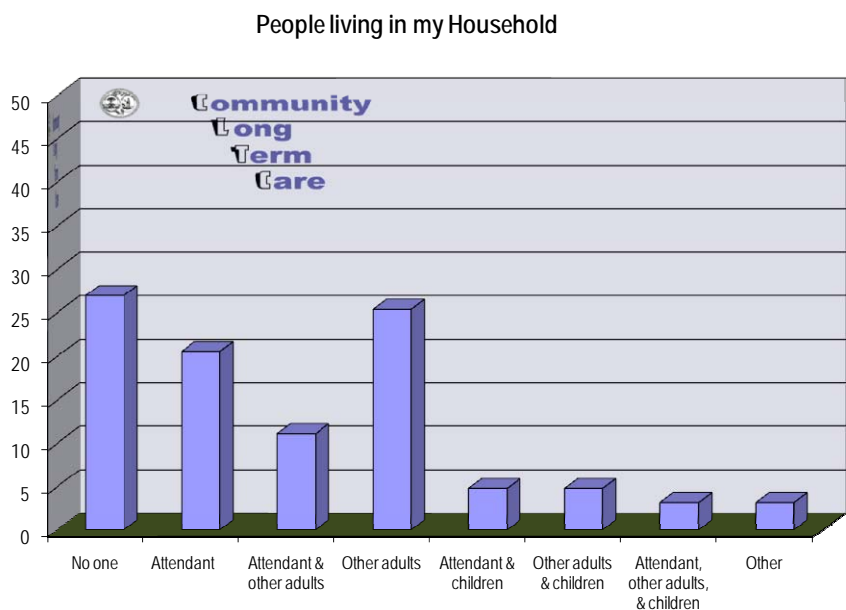


Finally, the racial distribution is not distributed in the way that would be expected. Caucasian care receivers make up 63% of respondents, while African-American care receivers make up only 31% of respondents. This distribution presents the reverse of the racial distribution of the whole population of those in the Community Long Term Care



program. The reasons for this unexpected distribution is unknown, but future research may want to investigate whether cultural factors impact the receptiveness of those in the African-American community to be paid for providing care to a family member, or whether race is a factor in who is offered the option to receive paid family care.

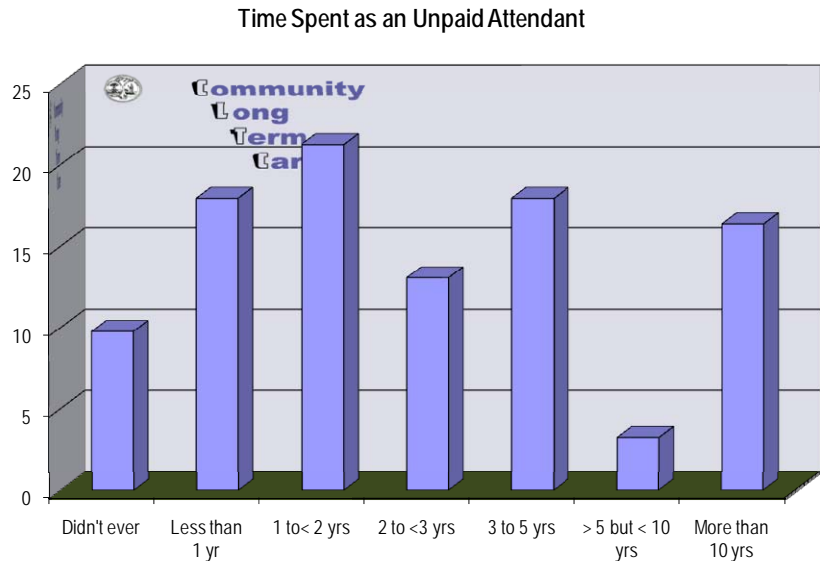
Nearly half of the respondents live alone or live only with their attendant. In other words, these care receivers rely on the attendant as the primary means of care and support. A smaller number, about 25% of respondents, live with other adults, such as a spouse. Approximately 10% of respondents live with the attendant and other adults.



Children are present in only a small percentage of households.

In contradiction to the perception held by some states struggling with whether to offer a paid family caregiver option, the respondents in this study have primarily been receiving care informally by the same caregiver that they now pay.

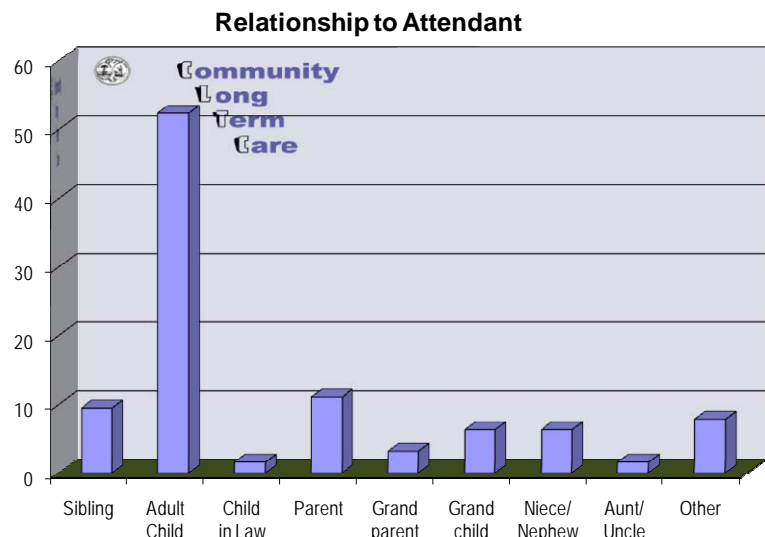
This figure depicts the length of time that the caregiver had provided care prior to being paid. In fact, well over half (63%) had the same attendant for more than a year prior to paying them and less than 10% did not provide care to them prior to being paid. There has been discussion nationally about families, particularly



extended family members, taking advantage of the opportunity to be paid with little to no accountability, and in some cases engaging in fraudulent behavior. These data seem to show otherwise. These caregivers would be, and have been, providing the care anyway. The financial opportunity merely serves as a source of support for a role that they already are in. This is consistent with our assumption that family members do not assume the role as caregiver as a means to earn money. Similarly, this is consistent with the findings from Phase I of this study.

It is interesting to note the dip in the number of caregivers who had provided care informally between 5 and 10 years. This may simply be a product of the sample size, but begs the question – Is there something that happens once someone has been able to get through 10 years of providing care or receiving care that then creates a stability? Is there something that happens for caregivers, receivers or to the caregiving relationship between 5 and 10 years that becomes a breaking point in terms of stress or other areas related to retention? This may be an area to explore in future phases of the study.

The relationship that the paid family care participant in the study has with the caregiver is represented in this figure. The most prevalent relationship of the paid family caregiver to the care recipient in the study's population is adult child. The role reversal that occurs has



implications for the impact of caregiving on the family dynamic. Over half (52%) of the attendants are adult children. This is closely followed by a significant number of caregivers who are parents (11%) and siblings (9%). Grandparents, grandchildren, nieces/nephews, and aunts/uncles are also found among the paid attendants. This is an important piece of the puzzle because of the closeness of the relationship potentially between those who are providing care and those who are receiving it.

It is significant to point out that there was a small portion of the population (8%) that identified as being “unrelated” or “other” in terms of their relationship to the care recipient. As in Phase I of the study, the research team aimed to broadly define family for this study, while understanding the confines of the federal and state restrictions on who can serve as a paid caregiver. This may be an area for further exploration as this population may include partners of gay or lesbian care recipients, or non-blood related family. While there is no consensus on a formal definition of family, laypersons tend to define who is included in their circle of “family” varies by region, culture, class, etc. (Weigel, 2008). The consideration of this is significant because a non-blood familial relationship can many times bring the same complications and needs as a blood-related one based on the depth of the relationship.

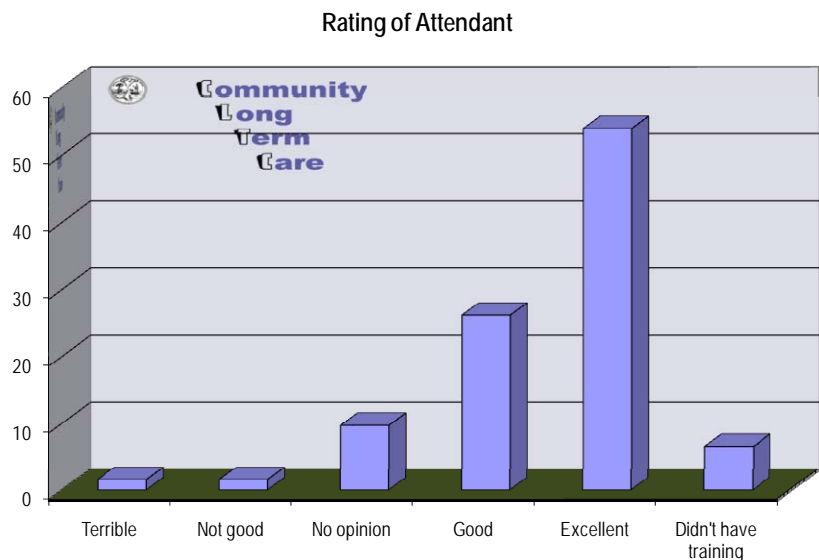
**Quotes from consumers: Continuity of care.**

*“My daughter has ALWAYS taken care of me. She knows what to do for me. Nobody else can do that for me.”*

*“My brother understands and he has been helping me for years. He did research, talked to doctors and helped diagnose my condition. He also puts his life on hold to take care of me.”*

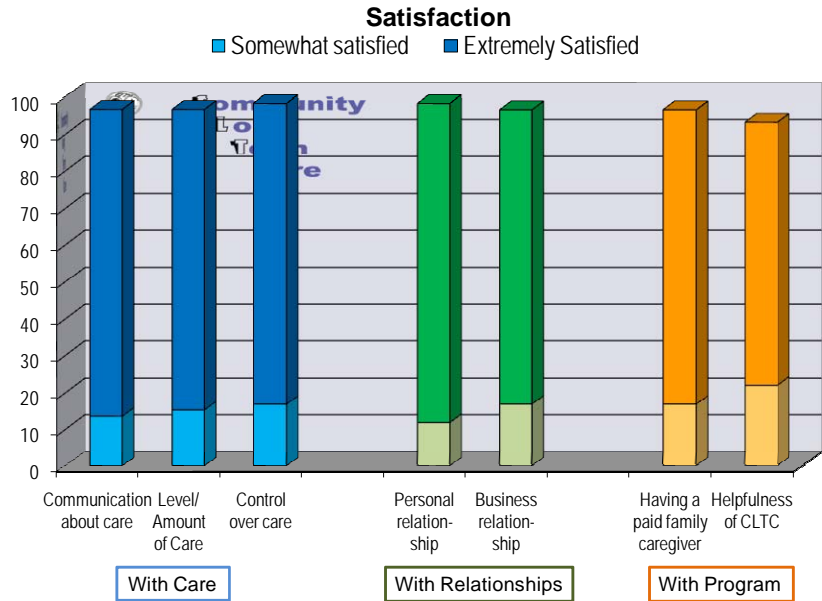
**How satisfied are they with the caregiving situation?**

Care receivers are generally satisfied with the training and knowledge of their attendant. Nearly 100% of care receivers view their attendants’ knowledge and ability as good or excellent, and over 70% of care receivers view their attendants’ training as good or excellent. A significant relationship was found



between perceived quality consistent care and overall satisfaction with the program.

This figure illustrates reported participant satisfaction on a series of aspects related to the care that they were receiving, the relationship that they had with the caregiver, and with the program in general. Participant satisfaction with the care that they were receiving was further divided into three areas;



communication about care, the

level/amount of care, and the control over care. About 95% of care receivers were either somewhat satisfied or extremely satisfied with all three areas of care. Because this is in part a business arrangement the relationship aspect was divided into personal and business. Approximately 95% of care receivers were somewhat satisfied or extremely satisfied with both the personal and business relationship with their attendants. Finally, participants were asked to rate their satisfaction with being in the program and with the helpfulness of the CLTC staff. About 95% of care receivers were extremely satisfied or somewhat satisfied with having a paid family caregiver; while just over 90% of care receivers expressed that they were extremely satisfied or somewhat satisfied with the helpfulness of CLTC.

**Quotes from consumers: Trust, dignity & value of being cared for by a family member.**

*“A family member is always with you, someone you love. It’s better than someone you don’t know.”*

*“That it would be somebody that I would get along with that would take care of my needs. She wouldn't have any other agenda besides taking care of my needs. My prior help had other things to do.”*

*"This is on the clock time, this is mommy-daughter time."*

*“Wouldn't have to be naked in front of strangers, people I didn't know, people that were in and out of my house.”*

*“I just think that I am a quiet person and I'd rather have my family members come in and help me take a bath than the nurse.”*

## Program Impact

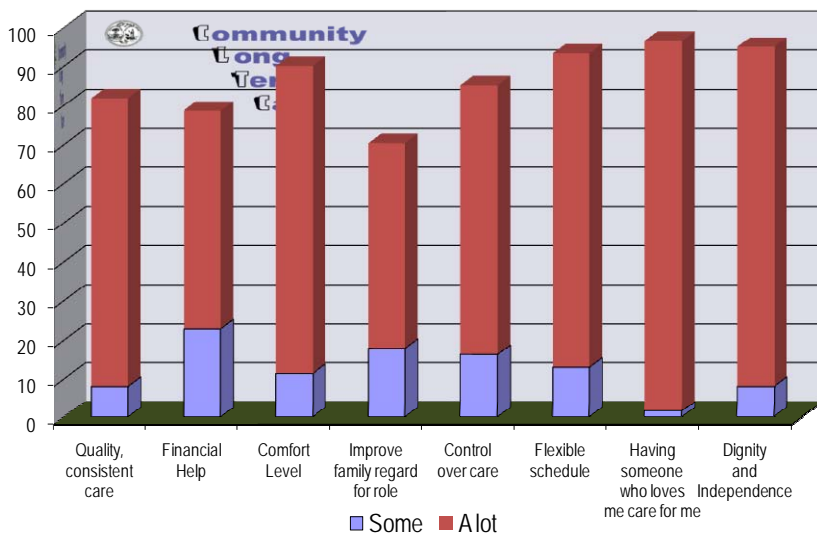
In general, the results showed that care receivers perceived few challenges with the program as well as a high level of benefits.

Findings revealed that over 90% of care receivers reported a lot or some benefit from the attendant option in terms of having a flexible schedule, having someone who loves them to care for them, and in maintaining dignity and independence. Furthermore, over 80% of care receivers perceived a lot or some benefit

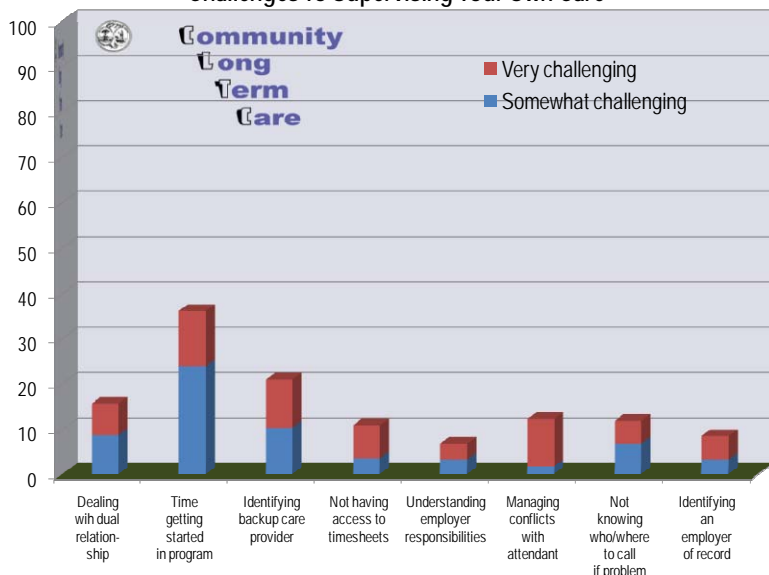
from the program in having quality and consistent care, in being comfortable with the caregiving situation, and in having control over care. Approximately 70% of care receivers reported some or a lot of benefit from having an improved family regard for the caregiving role, and over 75% of care receivers reported financial help as being of some or a lot of benefit.

On the other hand, less than 10% of care receivers perceived any aspect of care as very challenging. The most frequently reported challenge to the program was the time getting started on the program with approximately 30% of care receivers reporting this as somewhat challenging or very challenging. Only about 10% perceived this issue as very challenging.

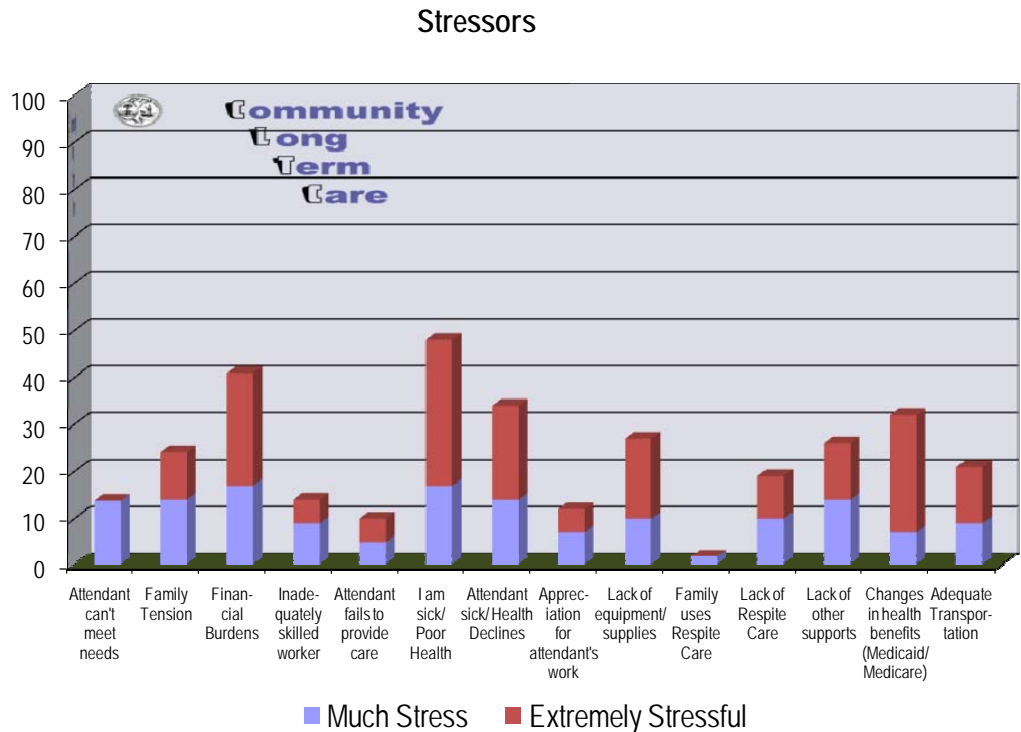
Benefits of Program



Challenges To Supervising Your Own Care

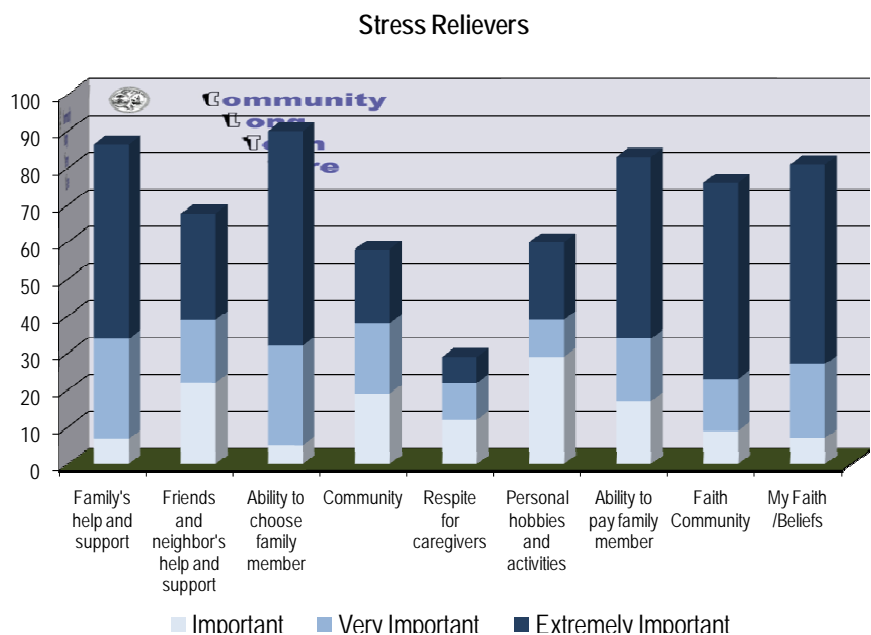


As shown in this figure, the vast majority of participants did not experience high levels of stress. The stressors were not mutually exclusive and not ranked. Clients were asked to identify them independently. The stressor that is most



prevalent, reported by almost 30% of the participants, is the participant them self being sick. This is closely followed by financial burdens, changes in health care benefits and the caregiver being sick. Taking into consideration some of the issues discussed earlier, this is no surprise. Other stressors were reported relatively infrequently. It is interesting to note that those variables that were least stressful were those related to the direct care such as the attendant's skill level, the attendant's ability to provide care and the actual care that was provided. It is also interesting to note that the use of respite care was not a stress. This may be because respite was not perceived as necessary by the participant indicating that they may not be aware of the stress experienced by their caregivers.

In addition to exploring what creates or exacerbates stress for the participants, the research team also wanted to find out what helps them cope. Shown here is the percentage of participants who identified each source of support either helpful/ supportive or very helpful/very supportive. As was the case with stressors, the



stressor reducers/sources of support were not mutually exclusive and not ranked. Clients were asked to identify them independently. The most frequently reported stress reducer among care receivers was the ability to choose a family member to provide care, with almost 90% of respondents citing this as important, very important, or extremely important. Over 80% of care receivers also perceived family help and support as an important, very important, or extremely important stress reducer. Over 70% of care receivers indicated that the faith community, faith/beliefs, and the ability to pay a family member were important, very important, or extremely important stress reducers. Other important but less significant stress reducers that were reported included: help and support from friends/neighbors, the community, respite for caregivers, and personal hobbies/activities. The stress-reducing impact of being able to pay a family member and being able to choose a family member to provide care offers support for the attendant option of Community Long Term Care.

**Quotes from consumers: Impact on health and stress**

*“It makes me feel safe and secure and comfortable with a family member.”*

*“I gained a lot. I get to go out of the house more and see family more often and my health is better than it was.”*

*“I’ve gotten to be with my family and I know they won’t let anything bad happen to me. It doesn’t matter if they are on the clock or not I can count on them.”*

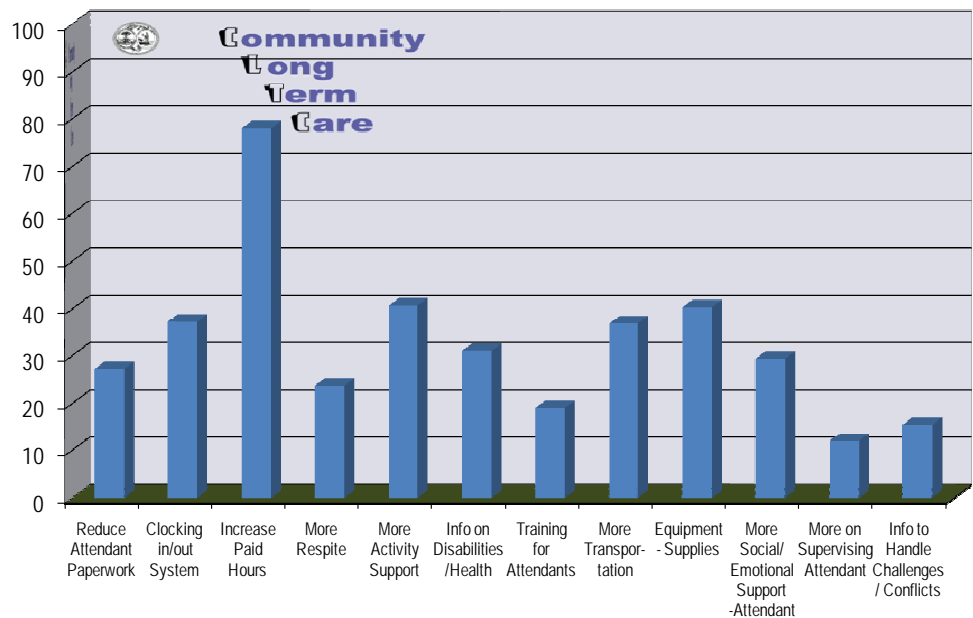
*“To be as self sufficient as I can, to do as much as I can for myself.”*

**Changes Recommended by Participants**

When asked what they would change regarding the program, the participants had few recommended changes.

**Recommended Changes**

The most commonly recommended change was that caregivers should receive more hours, with over 60% of respondents suggesting this change. Another frequently recommended change was the provision of more equipment, with



over 30% of respondents indicating this as a need. It is interesting to note that the least recommended change was to provide more information on handling difficult situations and conflicts. Given that the participant is supervising their caregiver it was expected that they would want more support in that area. Results indicate that was not the case.

## **Discussion and Implications**

Based on these findings, it is clear that the participants receiving paid family care through the CLTC attendant option are very satisfied. The low rate of recommended changes is consistent with the high reported satisfaction in all aspects of the experience. Low perceived challenges and high perceived benefits indicate that it is a fairly easy to manage program that is considered a valuable resource by participants.

Low perceived stressors and high perceived stress reducers indicate that participants are able to cope well with the family home care situation. It is interesting to note that being able to select a family member to provide care and to be able to pay the family member to provide care both emerged as prominent stress reducers. This supports Caldwell et al's (2003) findings that more control by families in the management of their respite/personal assistance is associated with higher satisfaction as well as Williams et al's (2006) findings that reciprocity reduces the perception of burden which in turn reduces stress. The ability to pay for care is a form of reciprocity. The participants' recommendation that the hours of paid care be increased may also reflect a desire to increase this reciprocity. This is an even more pertinent point considering that most of the family members that were providing care for these participants were providing care before they began being paid; some for many years and for many hours each day. In addition the participants' reported high satisfaction with both the personal and the business relationship with the caregivers is interesting given the findings from Zweibel et al (1990) and Lyons et al (2002) that incongruence in role expectations can impact satisfaction. The ability to pay for care may mediate the negative effect of relying on family for care and clarify the role expectations. The high levels of satisfaction may also be linked to the number of participants who have been receiving care from the designated family member informally in which a routine and agreement has been established for a number of years. The pay may, in fact, be the only change that the caregiver and receiver undergo when signing on with the attendant option. The role itself is not perceived as having changed.

The combination of low perceived challenges with low perceived stressors may mean decreased cost for case manager support and turnover in personal care providers. Additionally, low perceived stressors in combination with few recommended changes may lead to increased longevity in the

program, which results in lower cost to the state. An added benefit could be that the low stress of those in the program may actually lead to better health for care receivers.

## Appendix

### References

- Angus, J., Kontos, P., Dyck, I., McKeever, P., & Poland, B. (2005). The personal significance of home: Habitus and the experience of receiving long-term home care. *Sociology of Health & Illness*, 27(2), 161–187.
- Arno, P., Levine, C., and Memmott, M. (1997). The economic value of informal caregiving. *Health Affairs*, 18 (2), 182-188.
- Arno, P. S. (2006). *Prevalence, hours and economic value of family caregiving*. Kensington, MD: National Family Caregivers Association and San Francisco, CA: Family Caregiver Alliance.
- Caldwell, J., & Heller, T. (2003). Management of respite and personal assistance services in a consumer-directed family support program. *Journal of Intellectual Disability Research*, 47, 352-366.
- Doka, K. (2003). The spiritual gifts and burdens of family caregiving. *Generations, American society on Aging, Winter*, 45-48.
- Doka, K., and Aber, R. (2002). Psychosocial Loss and Grief, in K. J. Doka, Ed. *Disenfranchised Grief: New directions, Challenges and Strategies for Practice*. Champaign, Ill.: Research Press.
- Dwyer, J., Lee, G., and Janowski, T. (1994). Reciprocity, elder satisfaction and caregiver stress and burden: The exchange of aid in the family caregiving relationship. *Journal of Marriage and the Family*. 56, 35-43.
- Dykeson, T. B. (2000). Burden self-image: a mediating variable of depressive symptoms among chronically ill care recipients. *Journal of Gerontological Social Work*, 33(1), 17-33.
- Friedland, R. B., (2004). Caregivers and long term care needs in the 21<sup>st</sup> century: Will Public policy meet the challenge. *Report of the Long Term Care Financing Project*. Georgetown University. <http://ltc.georgetown.edu/pdfs/caregiversfriedland.pdf>
- Glendinning, C., Halliwell, S., Jacobs, S., Rummery, K., and Tyrer, J. (2000). New kinds of care, new kinds of relationships: How purchasing services affects relationships in giving and receiving personal assistance. *Health and Social Care in the Community*, 8, 3, 201-211.

- Hollis-Sawyer, L. A. (2003). Mother-daughter eldercare and changing relationships: a path-analytic investigation of factors underlying positive, adaptive relationships. *Journal of Adult Development, 10*, 1, 41-52.
- Lockery, S. (1991), Caregiving among racial and ethnic minority elders. *Generations, 15*, 4, 58-62.
- Lyons, K., Zarit, S., Sayer, A., and Whitelatch, C. (2002). Caregiving as a dyadic process: Perspectives for caregiver and receiver. *Journal of Gerontology: Psychological Sciences, 57B(3)*, 195-204
- McPherson, C., Wilson, K., and Murray, M. (2007). Feeling like a burden to others: a systematic review focusing on the end of life. *Palliative Medicine, 21*, 115-128.
- Newsom, J and Schulz, R., (1998). Caregiving from the recipient's perspective: Negative reactions to being helped. *Health Psychology, 17*, 2, 172-181.
- Rando, T. A. (2000). *Clinical Dimensions of Anticipatory Mourning*, Champaign, Ill.: Research Press.
- Reid, C., Moss, S., and Hyman, G. (2005). Caregiver reciprocity: The effect of reciprocity, caregiver self-esteem, and motivation on the experience of caregiver burden. *Australian Journal of Psychology, 57*, 3, 186-196.
- Schore, J., Foster, L., & Phillips, B. (2007). Consumer enrollment and experiences in the Cash and Counseling program. *Health Services Research, 42(1)*, 446-467.
- Thompson, L. (March 2004). Issue Brief, long term care: Support for family caregivers. *Report of the Long Term Care Financing Project*. Georgetown University.  
<http://ltc.georgetown.edu/pdfs/caregivers.pdf>
- Walker, A., Pratt, C. and Oppy, N. (1992). Perceived reciprocity in family caregiving. *Family Relations, 41*, 82-85.
- Weigel, D. (2008). The concept of family: An analysis of laypeople's view of family. *Journal of Family Issues, 29*, 11, 1426-1447.
- Williams, C. and Mfofo-M'Carthy, M. (2006). Caregiving, receiving, and meaning in the context of mental illness. *Psychiatry, 17*, 1, 172-181.

Wolff, J., & Kasper, J. (2006). Caregivers of frail elders: Updating a national profile. *The Gerontologist*, 46, 344-356.

Zweibel, N. and Lydens, L. (1990). Incongruent perceptions of older adult/caregiver dyads. *Family Relations*. 39, 63-67

## Unstructured Interview Script

Hi, my name is \_\_\_\_\_ and I am with Winthrop University. How are you today? [Respond appropriately.] Earlier this year, you took a telephone survey on your experiences with and opinions about the Community Long Term Care program. As part of that survey you told us two things:

1. That you have a family member paid through Community Long Term Care to care for you.
2. That we could contact you again if we had more questions.

Is this correct? [If not, thank them for their time and go on to the next call.]

We are doing a study on Community Long Term Care participants who have chosen a family member to be paid to provide their care. We want to learn more about this opportunity – the attendant program – so that we can help more people benefit from it, and help the program strengthen this option.

Do you have a few minutes to talk with me? [If not, see if they will schedule a day and time for you to call them back.]

Right now, we are in the process of finalizing our survey and we found that we had some questions we couldn't answer. We were wondering if you might be willing to help us. Your feedback will not be part of the study, but will help us develop a survey that asks the questions that are important for us to understand.

Does this make sense? Do you have any questions? [Respond appropriately.]

Before I begin asking our questions, I want to be sure that you understand a few things about our discussion today.

First, I want to be sure you understand that you do not have to talk with me or answer any of the questions. Also, if you do decide to talk with me, your feedback and answers will only be used to help us develop our final survey, which you may be contacted at a later date to participate in. Finally, nothing that you tell me today will be shared with Community Long Term Care staff. It is completely confidential and your name will not be on any answers you give me.

The great thing is that your feedback will help us to give advice to people at the state level about how to strengthen the attendant program through Community Long Term Care.

Do you have any questions about this? Is it OK to get started?

Great! Please stop me at any time if you have any questions.

## **Paid Family Caregiver Study**

### **Phase Two: Participant Perspective**

#### ***UNSTRUCTURED TEST INTERVIEW QUESTIONS***

1. How did you first hear about and get involved with hiring a family member to provide your care?
2. What was it about the option to hire a family member to provide your care that sounded good to you?
3. Was there anything that was difficult about getting things set up to have your family member provide your care? Please tell me about that.
4. Why did you want to hire your own caregiver? What made you decide to choose a family member?
5. Have you faced any challenges to supervising your own care? If so, how did you handle them?
6. If you had a problem with your care, who would you call?
7. What are the benefits (**for you**) to having a family member provide your care?
8. What does your attendant/caregiver look to you or rely on you for?
9. How do you show or express your appreciation to your attendant?
10. How would you describe the relationship between you and your attendant?
11. What are the things that make it stressful to have a family member providing your care?
12. Where does your support come from? What decreases or relieves your stress?
13. Talk a little bit about respite. Have you used it? Why or why not? What would make you and your family more comfortable using it in the future?
14. What are the things that are most important to keeping you satisfied with the Community Long Term Care program?
15. Is there anything else that you think it would be important for us to know or understand for this study?

**Paid Family Caregiver Study  
Phase Two: Participant Perspective**

***Stakeholder Questions***

1. Discuss use of language – What are the terms and phrases that are used with the participants and caregivers that they will be familiar with? For example: attendant/attendant care
2. What do you think are the key things that make the attendant option attractive to CLTC participants?
3. What do you think are the key things that make the attendant option difficult or challenging for them to take on?
4. What seem to be the biggest reasons that people hire their own attendants? Why do you think they choose a family member to serve in this role?
5. What challenges do you think participants face in supervising their own care? What is in place to help them overcome or manage these challenges? What are other strategies you have seen participants or families use to overcome these challenges?
6. What do you see as the benefits for participants to having a family member serving as an attendant?
7. What measures are in place to ensure that the care provided in these situations is quality care? How are family members who are attendants held accountable?
8. What issues does CLTC face in maintaining accountability for these caregivers?
9. Describe some of the key relationship dynamics that you have witnessed between family member attendants and the participants they care for (both positive and negative).
10. What factors do you think increase stress for participants who have family members as their attendants?
11. What factors or outside sources do you think decrease stress for participants who have family members as their attendants?
12. What role does respite play in this relationship/component of the program?
13. Is there anything else that you think it would be important for us to know or understand for this study?

**Paid Family Caregiver Study – Phase II  
Attendant Program Participant Survey**

***Introductory Script***

Hello. My name is \_\_\_\_\_ and I am calling from **Winthrop University** for a research project sponsored by the South Carolina Department of Health and Human Services. You should have received a letter telling you that we would be calling. If you were not contacted, or if you do not remember what it said, I will gladly share with you what it said. Do you want me to go over the letter?

**If not, continue, else read the letter.**

Your name was **randomly selected** from a list of all Community Long Term Care participants who have selected a family member to provide their care through the attendant program, and have chosen to direct their own care. The term “family member” could include those who are related by blood, marriage, or some other significant relationship. We know that “family” means different things to different people. With this in mind, are we correct that you have a “paid family caregiver”?

**If not, thank them and apologize for the mistake, and go to the next call.**

As you may know, the attendant program is fairly new in South Carolina, and Winthrop would like to get your feedback to help make it stronger. How does this sound?

Good. We would like you to take a couple of minutes to talk with us about having a paid family caregiver. We know that your time is precious and appreciate your willingness to share your opinions and experiences. There are no right or wrong answers to the questions I will ask you. Your information will help the Medicaid CLTC program better prepare to provide needed care in the future. **Your participation is very important and your feedback is very valuable.**

Of course, it is your choice whether or not you participate in the survey, and you can quit at any time. We estimate that it will take about 30 minutes to complete the survey.

This survey is **confidential**. Your answers are recorded and stored in such a way that Medicaid staff **can not** know what you said or be able to connect you with your answers.

If you understand that and are interested in participating, let’s begin. If at any time you have a question, please stop me. If I can not answer your question, I will put you in touch with someone who can.

**Paid Family Caregivers Study: Part II  
Participant Perspective**

***Survey Questions***

**Q1. ID number**

**Q2: Race**

- |                          |                                     |                                      |
|--------------------------|-------------------------------------|--------------------------------------|
| 01. White / Caucasian    | 02. Black / African American        | 03. Hispanic                         |
| 04. Asian                | 05. Pacific Islander                | 06. American Indian /Native American |
| 07. Arab/ Middle Eastern | 08. Two or more races / Multiracial | 09. Other                            |

**Q3: Gender**

- |            |          |                 |
|------------|----------|-----------------|
| 01. Female | 02. Male | 03. Transgender |
|------------|----------|-----------------|

**Q4: Year of birth**

**Q5. What is your relationship to the person (or persons) that is paid to care for you through CLTC (your attendant)? My primary attendant caregiver is my:**

Read as many responses as necessary:

- |                    |                   |                        |
|--------------------|-------------------|------------------------|
| 01. Sibling        | 02. Adult child   | 03. Child in-law       |
| 04. Parent         | 05. Parent in law | 06. Grandparent        |
| 07. Spouse/partner | 08. Niece/nephew  | 09. Grandchild         |
| 10. Cousin         | 11. Aunt/Uncle    | 12. Friend             |
| 13. Neighbor       | 14. Other         | 15. No other caregiver |

**Q6. My next most important family caregiver is my: (Same scale)**

**Q7. My next most important family caregiver is my: (Same scale)**

**Q8: Who else lives in the household with you?**

- |                  |                                        |                              |
|------------------|----------------------------------------|------------------------------|
| 01. No one       | 02. Just me and my attendant           | 03. Attendant & other adults |
| 04. Other adults | 05. Attendant & children               | 06. Other adults & children  |
|                  | 07. Attendant, other adults & children | 08. Other                    |

**Q9. How long did your attendant serve as an informal caregiver to you prior to getting paid?**

- |                   |                      |                        |
|-------------------|----------------------|------------------------|
| 01. Didn't ever   | 02. Less than a year | 03. 1 to < 2 yrs       |
| 04. 2 to < 3 yrs. | 05. 3 to 5 yrs       | 06. >5 but < 10 yrs.   |
|                   |                      | 07. More than 10 years |

**Q10. How did hear about the opportunity to have a family member as your attendant through CLTC?**

- 01. Another CLTC participant or paid caregiver told me / my family about it.
- 02. My CLTC worker told me / my family about it.
- 03. Another social worker / medical provider told me / my family about it.
- 04. I / my family inquired about paying a family member to provide my care.
- 05. Other

**Q11. When did you hear about the option through Community Long Term Care to have a family member as your attendant?**

- 01. Before becoming a CLTC participant
- 02. When I first became a CLTC participant
- 03. Soon after becoming a CLTC participant
- 04. A long time after becoming a CLTC participant.

**Q12. What was it about the attendant option that you liked most when you heard about it?**

**Q13. Under the attendant option through CLTC, you can hire anyone of your choosing. What made you decide to hire a family member?**

**Q14. How long did it take from the time you expressed an interest in having an attendant until your family member started as a paid attendant?**

- 01. A week or less
- 02. More than a week but less than a month.
- 03. 1 to almost 2 months
- 04. 2 to almost 5 months
- 05. 5 to almost 6 months
- 06. 6 months or more

**Q15. How would you rate the training that your attendant has had through CLTC to prepare them to care for you?**

- 1. Terrible
- 2. Not good
- 3. No Opinion
- 4. Good
- 5. Excellent
- 6. Didn't have training

**Q16. How would you rate your attendant's knowledge and ability to care for you? (competence...)**

- 1. Terrible
- 2. Not good
- 3. No Opinion
- 4. Good
- 5. Excellent
- 6. Didn't have training

For the next set of questions, please answer using this scale.

- 01. Not Applicable
- 02. Unimportant Reason
- 03. Important Reason
- 04. Very Important Reason
- 05. Extremely Important Reason

How important were each of the following in encouraging you to have a family member work as your attendant?

**Q17. Previous caregivers were poor or inadequate.**

**Q18. The family member wanted to do it.**

**Q19. I wanted my caregiver to be paid.**

**Q20. Other family members wanted the caregiver to do it.**

**Q21. Social worker or medical professional encouraged me to do it.**

**Q22. I felt obligated to do it.**

**Q23. Inconsistent care from agencies previously, including lack of back-up care staff.**

**Q24. I was nervous about having care provided by an unknown person.**

For the next set of questions, please answer using this scale.

**01. Only change is family member now gets paid    02 None    03. Some    04. A lot**

As a CLTC participant, how much have each of the following been a benefit to you and/or your family since you started with the attendant program.

- Q25. Having received quality, consistent care.**
- Q26. Helping me/my family financially.**
- Q27. Being more comfortable being cared for by a family member.**
- Q28. Made family take my caregiver's role more seriously**
- Q29. Increased control over my care.**
- Q30. Being able to negotiate a flexible schedule with my attendant.**
- Q31. Having someone care for me who I know really cares about/loves me.**
- Q32. Maintaining my dignity and independence as much as possible.**
- Q33. Other:                    Q34. Specify \_\_\_\_\_**

For the next set of questions, please answer using this scale.

- 01. Not Applicable    02. Very Unhelpful / Unsupportive    03. Unhelpful / Unsupportive
- 04. No Effect            05. Helpful / Supportive                    06. Very Helpful / Supportive

**In your role as a CLTC participant with a paid family caregiver, how would you rate the help and support you get from each of the following:**

- Q35. CLTC Case Manager**
- Q36. Other CLTC staff**
- Q37. Other unpaid caregivers who are NOT family members**
- Q38. Support groups**
- Q39. Other medical provider**
- Q40. Other family members**
- Q41. Your faith community**
- Q42. Your personal faith**
- Q43. Friends and/or neighbors**
- Q44. Other                    Q45. Specify \_\_\_\_\_**

For the next set of questions, please answer using this scale.

- 01. Things got much worse            02. Things got worse    03. Nothing changed
- 04. Things got better                    05. Things got much better

Please tell me what happened on each of these family issues when your family member started as a paid caregiver / attendant.

- Q46. Family attitude toward the paid caregiver.**
- Q47. Family attitude toward me.**
- Q48. Consensus of family about the caregiving arrangement.**
- Q49. The support other family members provide to me.**
- Q50. The family attitude about the legal implications/changes that had to be made.**
- Q51. Other.                    Q52. Specify \_\_\_\_\_**

To what extent have the following been challenges to supervising your own care through CLTC?

- |                                             |                                |                                          |
|---------------------------------------------|--------------------------------|------------------------------------------|
| <b>1. Not a challenge at all</b>            | <b>3. Somewhat challenging</b> | <b>5. So challenging I cannot do it.</b> |
| <b>2. Occasionally a bit of a challenge</b> | <b>4. Very challenging</b>     | <b>6. N/A</b>                            |

**Q53. Being clear about the difference between my family relationship and my business relationship with my attendant.**

**Q54. The length of time it takes to get started in the attendant program.**

**Q55. Identifying someone to provide back-up care if my attendant is unable.**

**Q56. Not having access to Care Call or information about when my attendant clocks in and out.**

**Q57. Understanding my responsibilities as an “employer”.**

**Q58. Knowing how to handle conflicts with my attendant.**

**Q59. Not knowing who or where to call if I have a problem or question.**

**Q60. Identifying someone to be the employer of record**

**Q61. Other**            **Q62. Specify**

**Q63. What strategies have you used (what have you done) to overcome these challenges?**  
[Open Ended]

**Q64. Who do you call when you have a problem with your care?**  
[Open Ended]

[Note: If they give a name, find out who it is – get job title – relationship, etc.]

[Note: If respondent does not call anyone – Find out why not.]

For the next set of questions, please answer using this scale.

- |                                  |                      |                               |
|----------------------------------|----------------------|-------------------------------|
| <b>1. Extremely Dissatisfied</b> | <b>3. No Opinion</b> | <b>4. Somewhat Satisfied</b>  |
| <b>2. Somewhat Dissatisfied</b>  |                      | <b>5. Extremely Satisfied</b> |

How would you rate the following aspects of the care your attendant provides?

**Q65. Communication about care and how it is provided**

**Q66. Level and amount of care**

**Q67. Amount of control you have over when and how your care is provided**

**Q68. Overall, how would you rate your personal or family relationship with your attendant?**

- |                                  |                      |                               |
|----------------------------------|----------------------|-------------------------------|
| <b>1. Extremely Dissatisfied</b> | <b>3. No Opinion</b> | <b>4. Somewhat Satisfied</b>  |
| <b>2. Somewhat Dissatisfied</b>  |                      | <b>5. Extremely Satisfied</b> |

**Q69. Overall, how would you rate your business or work-related relationship with your attendant?**

- |                                  |                      |                               |
|----------------------------------|----------------------|-------------------------------|
| <b>1. Extremely Dissatisfied</b> | <b>3. No Opinion</b> | <b>4. Somewhat Satisfied</b>  |
| <b>2. Somewhat Dissatisfied</b>  |                      | <b>5. Extremely Satisfied</b> |

**Q70. What does your attendant look to you or rely on you for?**  
[Open Ended]

**Q71. To what extent has this changed, if at all, since your family member began getting paid to provide your care?**

- |                                   |                                   |                      |
|-----------------------------------|-----------------------------------|----------------------|
| <b>01. Decreased considerably</b> | <b>02. Decreased some</b>         | <b>03. No change</b> |
| <b>04. Increased some</b>         | <b>05. Increased considerably</b> |                      |

For the next set of questions, please answer using this 5 point scale, where **1 is ‘No Effect’**, and **5 is ‘Completely Stresses Me Out’**.

In your role as a CLTC participant with a paid family caregiver, how much does the following effect your stress level:

**Q72. Those times when I feel my attendant can’t meet my needs.**

**Q73. Family tension.**

**Q74. Financial burdens**

**Q75. Those times when I feel my attendant is inadequately skilled/prepared to provide specific aspects of care.**

**Q76. Those times when my attendant fails to provide care.**

**Q77. When I am sick or my health is poor.**

**Q78. When my attendant is sick or their health declines.**

**Q79. Trying to show my appreciation for the work that my attendant does.**

**Q80. When the program doesn’t provide the equipment or supplies my attendant needs to provide care.**

**Q81. When my family uses respite care.**

**Q82. When my attendant needs respite (a break) but can not get it.**

**Q83. Lack of other supports.**

**Q84. Changes in the health benefits I receive (Medicare or Medicaid).**

**Q85. Getting adequate transportation.**

**Q86. Other**    **87. Specify** \_\_\_\_\_

**Q88. What do you think would make your attendant and caregiver/s more comfortable using respite?**

**[Caller: ‘Respite’ means having someone come in and give caregiver or attendant a break from their duties.]**

**Q89. Overall how would you rate your satisfaction with the CLTC option to have a family member serve as your attendant?**

- |                                  |                              |                               |
|----------------------------------|------------------------------|-------------------------------|
| <b>1. Extremely Dissatisfied</b> | <b>4. A Bit Dissatisfied</b> | <b>7. Somewhat Satisfied</b>  |
| <b>2. Quite Dissatisfied</b>     | <b>5. No Opinion</b>         | <b>8. Quite Satisfied</b>     |
| <b>3. Somewhat Dissatisfied</b>  | <b>6. A Bit Satisfied</b>    | <b>9. Extremely Satisfied</b> |

**90. Overall, how would you rate your satisfaction with the helpfulness of CLTC in supporting you and your attendant to provide and supervise your care?**

- |                                  |                              |                               |
|----------------------------------|------------------------------|-------------------------------|
| <b>1. Extremely Dissatisfied</b> | <b>4. A Bit Dissatisfied</b> | <b>7. Somewhat Satisfied</b>  |
| <b>2. Quite Dissatisfied</b>     | <b>5. No Opinion</b>         | <b>8. Quite Satisfied</b>     |
| <b>3. Somewhat Dissatisfied</b>  | <b>6. A Bit Satisfied</b>    | <b>9. Extremely Satisfied</b> |

**Within the last month:**

**Q91. About how many social activities did you participate in, at or outside your home?**

**A “social activity” is any time you are meeting or talking with others for enjoyment.**

**Q92. Other than for medical reasons, how many times last month did you get out of house?**

**Q93. About how many times did you communicate with others using a telephone, cell phone, email, or internet?**

Please use this scale to answer the following questions.

**Read it to the respondent as often as necessary**

**01. Never 02. Rarely 03. Sometimes 04. Always**

**How often do you feel:**

Q94. You lack companionship.

Q95. Isolated from others.

Q96. That you have a lot in common with the people around you.

Q97. That there are people who really understand you.

Q98. Close to people.

Q99. That people are around you but not with you.

Q100. Left out.

Q101. That there are people you can talk to.

Q102. That no one really knows you well.

Q103. That there are people you can turn to.

For the next set of questions, please answer using this scale.

01. Do Not Use It 02. Unimportant 03. Important 04. Very Important 05. Extremely Important

How important are each of the following in helping you relieve your stress?

**Q104. Family's help and support.**

**Q105. Friends' and neighbors' help and support.**

**Q106. Being able to choose a family member to provide my care.**

**Q107. Community organizations' programs, activities, and/or resources for me.**

**Q108. Respite for my caregiver/s.**

**Q109. My own personal activities or hobbies.**

**Q110. Being able to pay my family member to care for me.**

**Q111. A faith community.**

**Q112. My faith / beliefs.**

**Q113. Other.**

**Q114. Specify \_\_\_\_\_**

For the next set of questions, please answer using this scale.

01. Don't Know 02. No Change 03. Possibly Change 04. Probably Change

05. Absolutely Change

Based on your experience as a CLTC participant with a paid family caregiver, what would you change about the way this system works?

**Q115. Reduce amount of routine paperwork required for the attendant.**

**Q116. Change clocking in and out system to better reflect all the hours the attendant works.**

**Q117. Increase the number of paid hours.**

**Q118. Provide more available and quality respite.**

**Q119. Provide more activity support for me / CLTC participant based on specific needs.**

**Q120. Provide resource information regarding specific disabilities and health conditions.**

**Q121. Provide better access to appropriate training for attendants.**

**Q122. Provide more transportation for me.**

**Q123. Provide more equipment/supplies for my care.**

**Q124. Provide more social / emotional support for my attendant / caregiver's issues and needs.**

**Q125. Provide more help or support to know how to supervise my attendant.**

**Q126. Provide more help or support to handle challenges or conflicts that come up with my attendant.**

**Q127. What would you say to someone considering hiring a family member through CLTC to provide their care?**

**Q128. If you were talking directly to the people who make the policies and rules about paying family caregivers for CLTC, what would you want them to know?**

**CLTC Number**