The Hilltop Institute

analysis to advance the health of vulnerable populations

New Jersey Care Partner Support Pilot Program: Final Report

March 12, 2012

UMBC

AN HONORS UNIVERSITY IN MARYLAND

Suggested Citation: Woodcock, C., Tripp, A., Holt, B., & Reaves, E. (2012, March 12). *New Jersey Care Partner Support Pilot Program: Final report*. Baltimore, MD: The Hilltop Institute, UMBC.

Acknowledgements

The Hilltop Institute would like to acknowledge its partners in carrying out the New Jersey Care Partner Support Pilot Program: Susan Reinhard of the AARP Public Policy Institute for her professional commitment to supporting caregivers nationwide; Nancy Day of the New Jersey Department of Health and Senior Services (NJDHSS) and Pat Polansky, formerly with NJDHSS at the outset of the Pilot, and now with the AARP Public Policy Institute, for their unparalleled leadership and support for family caregiving in a state that has emerged as a leader in the field; Catherine Dailey, for her management of the project on behalf of NJDHSS; the care managers in New Jersey who work with caregivers every day and made this Pilot possible; Kathleen Kelly and Donna Schempp from the Family Caregiver Alliance, for their groundbreaking work in recognizing the needs of caregivers and providing them with needed supports; Rita Choula of the AARP Public Policy Institute, for her expert project management and guidance; and last but not least, Amy Berman of The John A. Hartford Foundation, for her vision and unwavering support.

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Executive Summary

The *New Jersey Care Partner Support Pilot Program* (Pilot) was conducted in four counties in New Jersey (Atlantic, Mercer, Monmouth, and Warren Counties) during the four-month period of March 14, 2011, to July 15, 2011, following orientation and training sessions on February 17 and 18, 2011. The goal of the program was to improve the knowledge and skills of family caregivers caring for adult family members and friends participating in New Jersey's Medicaid Global Options home and community-based services waiver (GO Waiver) and the state-only funded Jersey Assistance to Community Caregivers (JACC) program. The county-based agencies responsible for implementing the Pilot included two Aging and Disability Resource Centers (ADRCs) and two additional offices from which the Visiting Nurses Association (VNA) managed the contracts. During home visits with the care recipients, care managers offered caregivers the opportunity to complete a self-administered assessment that was designed to guide the care manager in providing the caregiver with information and referrals tailored to the specific needs of the caregiver. The assessment addressed the care needs and behaviors of the care recipient, asked the caregiver about her[1] physical and emotional health, and queried the caregiver about other family members and services available to help her with caregiving responsibilities. Based on the caregiver's responses to the assessment, the care manager provided a tailored package of written materials and referrals to the caregiver. The care manager later followed up with the caregiver by telephone. At the outset of the Pilot, care managers and supervisors participated in training sessions. In addition to assisting caregivers, the Pilot was intended to encourage care managers to be more aware of and responsive to the needs of caregivers and to better equip them to provide assistance.

The Pilot was one component of a larger initiative entitled *Professional Partners Supporting Family Caregiving* undertaken by the AARP Foundation with a grant from The John A. Hartford Foundation. The Administration on Aging (AoA) was involved in planning the Pilot and expressed interest early on in developing a prototype that might be replicated in other states. The Family Caregiver Alliance (FCA), based in San Francisco, California, developed and implemented the Pilot in New Jersey through a subcontract with the AARP Public Policy Institute. In New Jersey, the Division of Aging and Community Services (DACS) was the agency responsible for administering the Pilot in the four participating counties.

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[1] Because the majority (86 percent) of caregivers participating in the Pilot were female, caregivers will be referred to as female throughout this report.

Under a subcontract with the AARP Public Policy Institute, The Hilltop Institute at the University of Maryland, Baltimore County (UMBC) assessed the experience with the Pilot. Hilltop's assessment addressed the following questions:

> **Caregivers:** Who were the caregivers and how were they coping with caregiving responsibilities? How satisfied were the caregivers with the information and referral services that they received through the Pilot? Was their caregiving burden lessened in some way through participation in the program?
>
> **Care Managers:** To what extent were care managers experienced in and comfortable with assisting caregivers? Did the care managers feel that they were better able to provide assistance and guidance to caregivers after participating in the Pilot? How useful did they find the information and referral resources provided through the Pilot?

Data sources for the assessment included: Caregiver Questionnaires completed by the 86 participating caregivers during care managers' home visits; Caregiver Action Plans completed by the care managers after reviewing responses to the Caregiver Questionnaires; responses to a three-month follow-up mail survey of caregivers; care recipient assessment data; pre- and post-training questionnaires completed by care managers; logs in which care managers recorded telephone follow-up with caregivers; responses to a web-based survey completed by care managers six months after the Pilot began; and telephone interviews with New Jersey agency staff and representatives from AARP and FCA.

Assessment Findings

Profile of Care Managers: The care managers were experienced professionals, averaging 9.1 years of experience. Eighty percent were social workers and 20 percent were nurses. Half reported personal experience as a caregiver for a relative or friend. An overwhelming majority said that the role of care managers includes providing support to caregivers, but many said they did not have sufficient time and resources to devote to caregivers.

Profile of Care Recipients: Care recipients were enrolled in the Medicaid GO Waiver or JACC, so they had low incomes. All care recipients had functional deficiencies in at least three areas, 21 percent had deficiencies in seven areas, and 65 percent had cognitive deficits, so care recipients were in need of extensive supports.

Profile of Caregivers: The 86 caregivers ranged in age from 28 to 85 years and had been caring for their relative or friend on average for about 9 years. Eight-six percent were female and more than half were not working. While 70 percent of caregivers said they were in good or excellent health, 68 percent said that health issues got in the way of their caregiving duties. When asked about their help situation, 40 percent of caregivers reported receiving about the right amount of help from family and friends, 38 percent said they receive far less help than they need, and 19 percent said they receive no help.

Caregivers Three Months Later: Three months after they met with the care manager, 82 percent of caregivers reported that the care manager gave them information, advice, or referrals that were especially helpful; three-quarters said the information was very helpful; and a quarter said it was somewhat helpful. Nearly all of the caregivers reported that they were still the primary caregiver for the care recipient. When asked about the health of the care recipient, 28 percent said that the care recipient's health had gotten worse. Fifty-six percent of caregivers reported having paid help. Twenty percent said the relative or friend attended adult day care, 17 percent used a respite service, and 39 percent did not receive any support from community resources.

Care Managers' Views on the Pilot: Care managers generally viewed the Pilot training sessions to be helpful in preparing them to work with caregivers. Care managers reported that caregivers frequently asked for assistance in completing the Caregiver Questionnaire, which was intended to be self-administered. In designing the Pilot, one concern was whether care managers would have an opportunity to talk candidly with the caregiver during the home visit. Many care managers addressed this by talking with the caregiver in another room or telephoning her after the home visit. Almost half of the care managers said that administering the Caregiver Questionnaire and talking with the caregiver took an additional 31 to 45 minutes during the home visit; 18 percent reported an additional 46 to 60 minutes. Most caregivers said that caregivers welcomed the attention and support. Care managers said that more information and referrals for local resources for caregivers are especially needed.

Views of New Jersey Agency Staff: New Jersey agency staff emphasized that caregiver support is a priority for the state. However, they reported many competing priorities (e.g., the state's fiscal crisis, a new managed care waiver, launching Aging and Disability Resource Centers statewide, implementing an electronic client tracking system, and developing a partnership with the Veteran's Administration) when implementing the Pilot. The staff said that without funding or reimbursement, it was going to be difficult for the state to commit to expanding the Pilot.

Views of the Pilot Partners: The partners emphasized that the Pilot was intended to make care managers more aware of the needs of caregivers and to promote good professional practice; it was not intended to be an "intervention" that resulted in measurable behavior change in caregivers. The partners said it is important to integrate caregiver assessment into practice. Also there is a need for continuously updated local resource guides to provide care managers and caregivers with current information on community resources.

Summary and Recommendations

New Jersey is interested in expanding the Pilot. AARP and AoA are considering how it might be further developed and possibly replicated in other states. In moving forward, New Jersey, AARP, and AoA should consider the following:

- **Develop a system for providing up-to-date information on local resources for caregivers**. While the Pilot provided care managers with written materials and articles on direct care, behavior management, self-care, and informal supports, care managers voiced a need for referrals to local programs and services available to caregivers. A particular challenge is compiling and regularly updating information on relevant local programs and supports. States need a system for collecting, compiling, and continuously updating information on community resources that is easily accessible to professionals in the field and caregivers alike. New ways to use emerging media (e.g., online chat groups, support groups, and professional assistance) should be explored. States should also explore how to integrate these needs into one-stop and single-point-of-entry systems. It will be especially important to design systems and resources that meet the needs of caregivers with low incomes who are busy and stressed and may not be "plugged in" to new media. Focus groups with these caregivers may shed more light on their needs.
- **Target caregivers who are new to the system.** Caregivers of new Medicaid clients must learn to navigate the long-term services and supports (LTSS) system and how to care for their relative or friend. Targeting limited resources on these caregivers may be an effective strategy for states in the current budget climate. Caregivers of individuals with low incomes who do not qualify for Medicaid (e.g., JACC clients) are also in need of support. Providing this group with assistance could potentially delay nursing home placements and spend-down to Medicaid.
- **Incorporate caregiver assessment into the client assessment process.** As many states move to develop comprehensive standard assessment tools required by programs authorized under the Affordable Care Act (e.g., State Balancing Incentive Payments, §10202), states should be encouraged to incorporate caregiver assessment into these new tools. New Jersey could consider adding a caregiver module to NJ CHOICE and having assessors (instead of care managers) conduct the caregiver assessment. Assessors also have responsibility for options counseling, so they could be trained to counsel caregivers as well as clients. This could make the caregiver assessment process more efficient.
- **Position caregivers as clients and provide reimbursement for caregiver services.** New Jersey agency staff repeatedly stated that the lack of reimbursement for providing support to caregivers was a barrier to expanding the Pilot. This is likely to be a major issue for states across the country. New Jersey agency staff suggested a new paradigm in which caregivers are the clients and care managers are reimbursed for providing services to the caregiver. Working with the Centers for Medicare and Medicaid Services (CMS), states could explore providing services to the caregivers of Medicaid clients through Section 1915(c) home and community-based services waiver programs, through 1115 demonstration waivers, or as demonstration services under the Money Follows the Person program. Many states (including New Jersey with its Comprehensive Waiver) have or are developing Medicaid managed LTSS programs under 1115 demonstration waivers or concurrent 1915(b)(c) waivers. States could work with managed care organizations (MCOs) to find creative ways to provide services to caregivers, perhaps as value-added

services (i.e., additional services provided by MCOs under the capitation payment arrangement) or as a component of "service coordination," which is typically included in managed care administrative costs. Another option is for states to work with AoA to explore using Older American Act (OAA) Title IIIE funds for reimbursement for services provided to individual caregivers, especially now that the OAA is up for reauthorization.

In conclusion, the *New Jersey Care Partner Support Pilot Program* provided important insights into how states might provide support to caregivers. The effort in New Jersey warrants further development and expansion, and lessons learned from the Pilot can guide other states in pursuing caregiver initiatives.

Introduction

The *New Jersey Care Partner Support Pilot Program* (Pilot) was conducted in four counties in New Jersey during the four-month period of March 14, 2011, to July 15, 2011. The goal of the program was to improve the knowledge and skills of family caregivers caring for adult family members and friends participating in New Jersey's Medicaid Global Options home and community-based services waiver (GO Waiver) and the state-only funded Jersey Assistance to Community Caregivers (JACC) program. During a home visit with the care recipient, care managers offered caregivers the opportunity to complete a self-administered assessment that was designed to guide the care manager in providing the caregiver with information and referrals tailored to the specific needs of the caregiver. The assessment addressed the care needs and behaviors of the care recipient, asked the caregiver about her[2] physical and emotional health, and queried the caregiver about other family members and services available to help her with caregiving responsibilities. In addition to assisting caregivers, the Pilot was intended to encourage care managers to be more aware of and responsive to the needs of caregivers and to better equip them with relevant information and resources.

The Pilot was one component of a larger initiative entitled *Professional Partners Supporting Family Caregivers* undertaken by the AARP Foundation with a grant from The John A. Hartford Foundation. The Family Caregiver Alliance (FCA) based in San Francisco, California, developed and implemented the Pilot in New Jersey through a subcontract with the AARP Public Policy Institute. In New Jersey, the Division of Aging and Community Services (DACS) was the agency responsible for administering the Pilot in the four participating counties. Under a subcontract with the AARP Public Policy Institute, The Hilltop Institute at the University of Maryland, Baltimore County (UMBC) assessed the experience with the Pilot.

Additional background on the vision for and development of the Pilot can be found in the following pages, as well as a description of the assessment research questions, design, and methodology; assessment findings; and recommendations for future efforts to assist caregivers. All evaluation materials can be found in the appendices.

Background

On February 11, 2009, The John A. Hartford Foundation and the AARP Public Policy Institute hosted a meeting in Trenton, New Jersey, to explore New Jersey's interest in developing a prototype for a program to educate nurses and social workers to assess and train family

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[2] Because the majority (86 percent) of caregivers participating in the Pilot were female, caregivers will be referred to as female throughout this report.

caregivers. The prototype was to be developed as part of the Administration on Aging's (AoA's) Nursing Home Modernization and Diversion (NHMD) program.[3] New Jersey was one of 20 states that had received a 2007 grant from AoA for a NHMD initiative. AARP and AoA expressed interest in a partnership with New Jersey because of the state's commitment to funding caregiver support programs since the 1980s; the state's strong leadership and expertise in leveraging federal initiatives to shape system transformation; the state's exemplary record in developing and expanding ADRCs; and the state's commitment to a paradigm shift from a focus on the individual to a system of family-centered services. If the prototype proved successful, AoA intended to promote replication of the program nationwide. Invited attendees at the meeting included representatives from AoA, FCA, the Jacob & Valeria Langeloth Foundation, the New Jersey Department of Health and Senior Services, and The Hilltop Institute.

Following this meeting, AARP, FCA, Hilltop, and New Jersey DACS collaborated on the design of a prototype program. What later became known as "the Pilot" was incorporated into the AARP Foundation's grant proposal to The John A. Hartford Foundation for a larger initiative entitled *Professional Partners Supporting Family Caregivers—Phase II*. The aim of this initiative is to improve the capacity of nurses and social workers to meet the needs of family caregivers. Phase II is an outgrowth of an earlier Hartford Foundation grant to AARP (Phase I) that culminated in simultaneous publication of identical issues of the American Journal of Nursing and the Journal of Social Work Education entitled *State of the Science: Professional Partners Supporting Family Caregivers*.

The John A. Hartford Foundation approved the Phase II grant to the AARP Foundation in June 2009. In addition to the New Jersey Pilot, the grant supported development of standards of practice for supporting family caregivers by the National Association of Social Workers, initiatives to inform public policy about the needs and importance of family caregivers, and efforts to raise consumer expectations for caregiver support in order to drive demand for changes in professional practice and public policy.

Implementation and Assessment of the Pilot

The Pilot was conducted in four New Jersey counties: Atlantic, Mercer, Monmouth, and Warren (Figure 1). The county health departments were the agencies responsible for carrying out the Pilot. Atlantic and Warren Counties are fully operational ADRCs, whereas the Mercer and Monmouth ADRCs are still under development. Caregivers of GO Waiver and JACC clients in the four counties were enrolled, assessed, and provided with information and referrals over the four-month period of March 14, 2011, through July 15, 2011. Follow-up with caregivers (explained below) continued through October 15, 2011.

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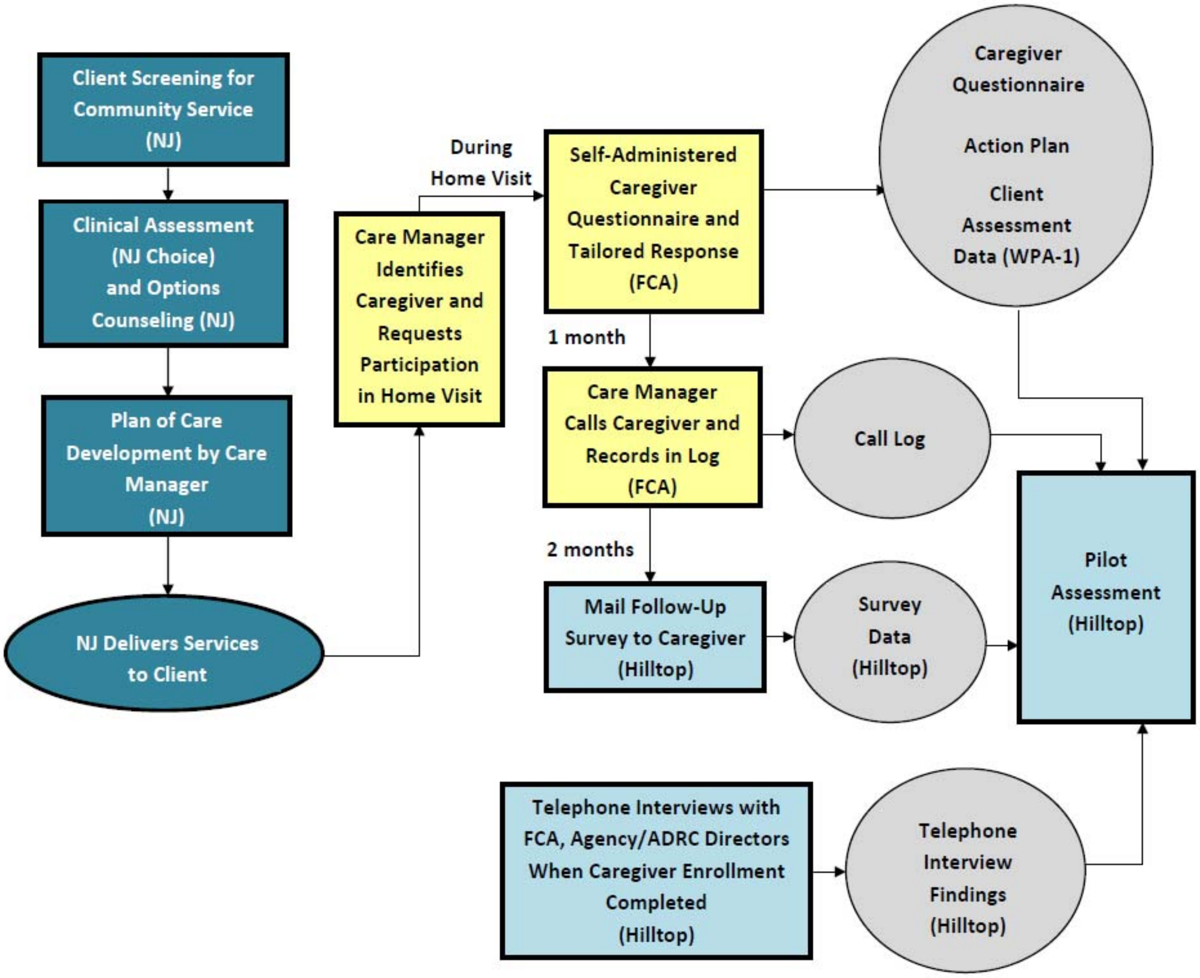
[3] AoA later changed the name of this program to the Community Living Program.

Figure 1. Participating New Jersey Counties

Figure 2 illustrates how the Pilot was conducted. The rectangles on the left of the flowchart (lavender in color) illustrate New Jersey’s process for screening, assessing, and enrolling clients in the GO Waiver and the JACC program. When a client calls the county health department, the county administers a “Screen for Community Services” by telephone. This screen asks pertinent information about the individual’s demographics, functional and health status, living arrangements, and finances to determine whether the client might be in need of and eligible for publicly financed LTSS. If the client is determined to be potentially in need of and eligible for LTSS, a county assessor visits the home and conducts a comprehensive assessment using a tool called NJ CHOICE and then provides options counseling for the client. The next step is for a care manager—nurses and social workers employed by the county—to visit the client in a subsequent home visit to develop a plan of care. Services commence shortly thereafter. Care managers make periodic home visits to monitor service delivery and the client’s status. On an annual basis, care managers reassess the client’s functional and health status and LTSS needs.

Figure 2. Schematic of New Jersey Pilot



In Figure 2, implementation of the Pilot is represented by yellow rectangles. FCA was responsible for developing and implementing these processes. Caregivers of care recipients enrolled in either the GO Waiver or JACC were eligible to participate. The care recipients could be new GO Waiver or JACC clients (i.e., receiving their first home visit by the care manager) or existing GO Waiver or JACC clients (i.e., receiving a periodic home visit or an annual reassessment home visit). First, care managers identified clients with family caregivers who had primary caregiving responsibility for the client and were likely to be in the home during the home visit. In some cases, the care managers telephoned the caregivers ahead of the home visit to ensure that they would be present. During the home visit, the care manager asked the caregiver to sign a consent form and complete a self-administered questionnaire (Appendix A). The questionnaire asked the caregiver about her age, education level, employment status, and relationship to the care recipient; direct care concerns; ability to manage troublesome behaviors;

self-care; and the availability of other informal and formal supports. In addition, the questionnaire included the screening version of the Zarit Burden Interview.[4]

Based on the caregiver's responses to the questionnaire, the care manager completed a Caregiver Action Plan (Appendix B) and shared it with the caregiver. Then the care manager provided the caregiver with informational materials and referrals relevant to the caregiver's needs. FCA provided links to brochures, articles, and other informational materials on a password-protected website available to care managers. In addition, care managers were free to access relevant information from other sources (e.g., other websites, materials available in the office, colleagues, and local programs). One month after the caregiver completed the questionnaire, the care manager telephoned the caregiver to see if she had any questions or concerns (see log for recording follow-up calls in Appendix C).

As shown in the light teal rectangles in Figure 2, Hilltop mailed follow-up surveys to each participating caregiver three months after the home visit (Appendix D). The follow-up survey asked about the caregiver's current situation, the information and referrals provided by the care manager, and the caregiver's current support network. In addition, the Zarit Burden Interview was included once again to see if caregivers reported any changes. To encourage caregivers to respond, Hilltop mailed surveys to non-respondents a second and third time. Survey mailings were spaced about two weeks apart. In addition, Hilltop asked care managers to remind caregivers to complete the questionnaires.

Also shown in Figure 2, Hilltop conducted telephone interviews with New Jersey agency staff, the care managers' supervisors in the four counties, and representatives from AARP and FCA to obtain their feedback on Pilot implementation. Interviewees are listed in Appendix E. These interviews were conducted in August and September 2011.

The gray ovals in Figure 2 depict data sources for Hilltop's assessment of the Pilot. These include the following items submitted to Hilltop by the care managers: caregiver questionnaire, action plan, and follow-up survey (Appendices A, B, and D); care managers' call logs verifying that one-month follow-up calls were made to caregivers (Appendix C); and care recipient assessment data (New Jersey WPA-1 Form; see Appendix F). In addition, findings from the telephone interviews with the individuals listed in Appendix E were used in assessing the Pilot.

Prior to implementing the Pilot in the four counties, FCA hosted trainings for care managers. Figure 3 illustrates the training process. Two six-hour trainings were convened: on February 17, 2011, in Hammonton, New Jersey, with care managers and supervisors from Atlantic, Mercer,

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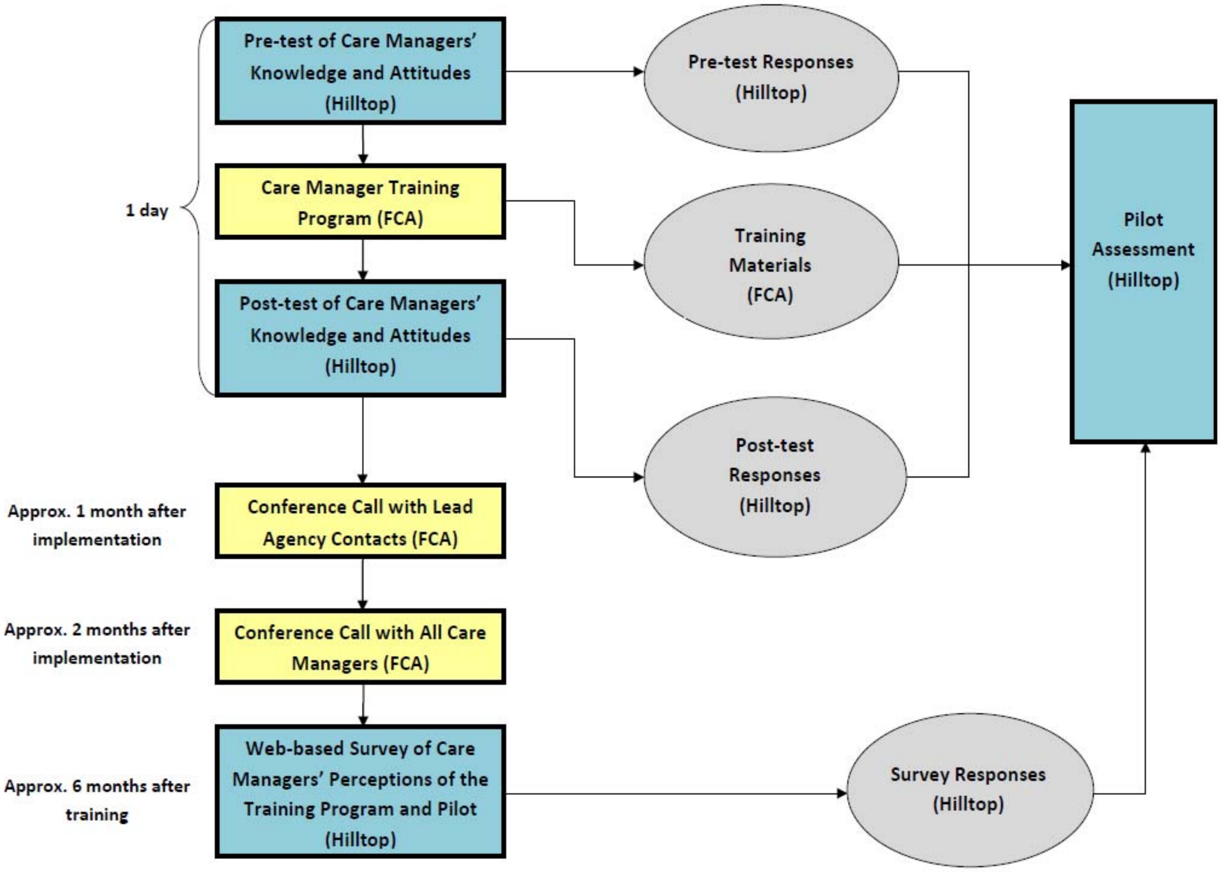
[4] The four-item version of the scale has shown strong correlation with the full interview and has been suggested for use in situations in which a quick assessment of burden is desirable. Bedard et al. (2001). The Zarit Burden Interview: A New Short Version and Screening Version. *Gerontologist,* 41(5): 652-657.

and Monmouth Counties, and on February 18, 2011, in Edison, New Jersey, with care managers and supervisors from Warren County. FCA developed a training curriculum that included an overview of caregiving, challenges caregivers face, caregiver stress and barriers, and caregiver assessment. In addition, FCA provided training on administering the Caregiver Questionnaire during the home visit, completing the Caregiver Action Plan, and providing a tailored response to each caregiver. Hilltop briefed care managers on the assessment methodology and follow-up surveys that would be administered to both caregivers and care managers to examine the experience with the Pilot. At the beginning and ending of each of the trainings, Hilltop requested that the care managers complete pre- and post-tests to gauge their knowledge of caregiving and query them about the usefulness of the training (Appendices G and H).

Figure 3. Schematic of Care Manager Training and Follow-Up



Also shown in Figure 3, FCA conducted a conference call with New Jersey agency staff and care manager supervisors on April 18, 2011—one month after the trainings—to discuss any issues in Pilot implementation, which began on March 14, 2011. On May 16, 2011, FCA conducted a conference call with all care managers, again to check in on any issues that may have arisen with Pilot implementation. Finally, Hilltop conducted a web-based survey of all care managers in August 2011—approximately six months after training—to learn more about their experience with the Pilot and to solicit suggestions for future programs targeting caregivers (Appendix I). The gray ovals in Figure 3 depict data sources for Hilltop's assessment, which include the care managers' pre- and post-tests from the trainings, FCA's training materials, and care managers' responses to the six-month follow-up survey.

Assessing the Experience with the Pilot

Research Questions

Hilltop conducted an assessment of the Pilot to address the following questions:

> **Caregivers:** Who were the caregivers and how were they coping with caregiving responsibilities? How satisfied were the caregivers with the information and referral services that they received through the Pilot? Was their caregiving burden lessened in some way through participation in the program?
>
> **Care Managers:** To what extent were care managers experienced in and comfortable with assisting caregivers? Did the care managers feel that they were better able to provide assistance and guidance to caregivers after participating in the Pilot? How useful did they find the information and referral resources provided through the Pilot?

Data Sources

As discussed in the description of the Pilot above, the assessment is based on the following data sources:

- Responses to self-administered caregiver questionnaire (Appendix A)
- Caregiver action plans (Appendix B)
- Responses to caregiver three-month follow-up mail survey (Appendix D)
- Care recipient assessment data (New Jersey WPA-1form; see Appendix F)
- Care managers' pre- and post-training questionnaires (Appendices G and H)
- Training materials for care managers
- Care managers' telephone logs (Appendix C)
- Web-based survey of care managers six months after Pilot enrollment began (Appendix I)
- Telephone interviews with New Jersey agency staff, care managers' supervisors, and representatives from AARP and FCA (Appendix E)

Data Analysis

The data were analyzed as follows:

- Profiles of care managers were produced from the pre- and post-training questionnaires
- Profiles of care recipients were produced from the New Jersey WPA-1 assessment form
- Profiles of caregivers were produced from the caregiver questionnaires completed during the initial home visit
- Completed caregiver action plans and care manager telephone logs were examined to assess compliance with the Pilot protocol
- Caregivers' responses in the initial caregiver questionnaire were compared to their responses in the three-month follow-up survey to determine the extent to which their caregiving situation had changed, the information and referrals provided through the Pilot had been useful, and their burden had lessened
- Responses to the web-based survey completed by care managers six months after the initiation of the Pilot were examined to determine the extent to which care managers found the Pilot helpful in providing support to caregivers and whether they had suggestions for future initiatives
- Transcripts from the telephone interviews with New Jersey agency staff, care managers' supervisors, and representatives from AARP and FCA were examined to assess satisfaction with the Pilot, identify lessons learned, and obtain suggestions for future initiatives

Response Rates

Response rates for assessment instruments are summarized in Table 1.

Table 1. Completion of Assessment Instruments and Processes: Response Rates

Instrument	Goal	Actual	Percentage of Goal
Care Manager/Supervisor Pre-Training Assessments Completed	20	20	100%
Care Manager/Supervisor Post-Training Assessments Completed	20	20	100%
Caregiver Questionnaires Completed at Home Visit	130	86	66%
Caregiver Action Plans Completed by Care Managers	86	86	100%
1-Month Telephone Calls to Caregivers Completed by Care Managers	86	86	100%
Caregiver 3-Month Follow-Up Mail Surveys Completed	86	49	57%
Care Manager 6-Month Follow-Up Web Surveys Completed	16	16	100%

Limitations

The Pilot was intended to test the feasibility of integrating into current practice 1) an awareness of caregivers' situations and needs on the part of care managers and 2) a limited set of supports for the caregivers of individuals receiving publicly funded LTSS. Lessons learned from the Pilot were intended to inform the development of new, low-cost models for providing support to caregivers that might be tested in New Jersey and other states. At the outset of this project, AoA expressed interest in the Pilot and supporting development, expansion, and replication of new models.

Because the Pilot was limited in scope, much of the data used in the assessment were self-reported and there was no comparison group. This must be taken into account in interpreting assessment findings. Additionally, because the caregiver supports were limited in strength and scope and the time from the initial caregiver assessment to completion of the caregiver follow-up survey was just three months, the Pilot was not expected to result in measurable changes in caregivers' attitudes or behaviors.

Unlike in many other programs that assess caregivers' needs, caregivers participating in the Pilot did not self-identify as needing support. Rather, they were identified by care managers through home visits to the care recipient and "drafted" (with their consent) to participate in the Pilot. The fact that these caregivers did not self-identify for services could have had a negative effect on the number who followed up on information and referrals provided by the care manager, as well as the number who completed the three-month follow-up mail survey.

Caregiver assessments and support were given within the confines of a standard home visit to the care recipient. No additional reimbursement was provided for what in most cases was an extended home visit by the care manager. The state of New Jersey was not compensated in any way for participating in the Pilot. This could have negatively influenced participation in the Pilot by care managers and the county health departments.

Care managers in Mercer and Monmouth Counties are employees of the Visiting Nurses Association (VNA) in those counties. The county contracts with the VNA for care management services for Medicaid and JACC clients. Because of this employment arrangement and the lack of reimbursement for participation in the Pilot, care managers employed by the visiting nurse services were unable to participate in the trainings hosted by FCA and Hilltop. Instead, their supervisors attended a training session and then trained the care managers. Even though each care manager in Mercer and Monmouth received training, this arrangement is likely to have reduced the effectiveness of that training.

Assessment Findings

Profile of Care Managers

Pre-Training Questionnaire

Sixteen care managers and four supervisors were trained prior to participation in the Pilot. Ten care managers and four supervisors participated in the February 17-18, 2011, training sessions. Six of the care managers were trained by their supervisors afterwards (Table 2).

Table 2. Care Managers and Supervisors Trained Prior to Participation in the Pilot

	County				Total
	Atlantic	Mercer*	Monmouth*	Warren	
Trained by FCA/Hilltop February 17-18, 2011	9	1	2	2	**14**
Trained by a Supervisor March 2011	0	3	0	3	**6**
Total	**9**	**4**	**2**	**5**	**20**

*Care managers in these counties are employed by the local visiting nurse service.

New Jersey's care managers are experienced professionals. Tables 3 to 8 provide data from the questionnaire administered to care managers and their supervisors prior to their participation in the Pilot training program. The average number of years of experience as a care manager was 9.1 (Table 3). Eighty percent of care managers and supervisors had bachelor's degrees and 20 percent had master's (Table 4). Eighty percent were social workers and 20 percent were nurses (Table 5). Seventy percent reported receiving prior training on caregiver supports (Table 6). Half reported personal experience as a caregiver for a relative or friend (Table 7). Eighty percent or more of care managers expressed confidence in assessing the abilities and needs of caregivers and recognizing caregiver burden (Table 8). While 95 percent of care managers agreed or strongly agreed that the role of care managers includes providing support to caregivers, far fewer felt that they had sufficient time and resources to help caregivers.

Table 3. Care Managers and Supervisors: Years Employed as a Care Manager

	Number of Years						
	0-5	6-10	11-15	16-20	20+	Total	Mean
Number	8	6	3	2	1	20	9.1
Percentage	40%	30%	15%	10%	5%	100%	--
Pre-Training Q1. How many years have you been employed as a care manager or in a care manager-like capacity (this may include employment outside of New Jersey)?							

Table 4. Care Managers and Supervisors: Highest Level of Education

	Bachelor's Degree	Master's Degree	Total
Number	16	4	20
Percentage	80%	20%	100%
Pre-Training Q4. What is your highest level of education?			

Table 5. Care Managers and Supervisors: Professional Background

	Social Work	Nursing	Total
Number	16	4	20
Percentage	80%	20%	100%
Pre-Training Q3. What is your professional background?			

Table 6. Care Managers and Supervisors: Prior Training on Caregiver Supports

	Number	Percentage (n=20)
Total Reporting Some Type of Prior Training	**14**	**70%**
In-Service at Work	10	50%
College Course	10	50%
Professional Training Program	7	35%
Other Training	2	10%
Pre-Training Q2. Prior to your participation in the pilot program, have you received any training on caregiver supports? Check all that apply.		

Table 7. Care Managers and Supervisors: Personal Experience as a Caregiver

	Yes	No	Total
Number	10	10	20
Percentage	50%	50%	100%
Pre-Training Q5. Have you been a caregiver for a relative or friend (that is, do you have a personal caregiving experience outside of your professional responsibilities)?			

Table 8. Care Managers and Supervisors: Self-Assessment and Views at Outset of Pilot

	Always	Often	Sometimes	Rarely	Never
Q6. I can assess a caregiver’s ability to provide direct care for their friend or relative.	5%	85%	10%	0%	0%
Q7. I am able to determine a caregiver’s circumstances and needs as they relate to their everyday care responsibilities.	5%	75%	20%	0%	0%
Q8. I can recognize the signs of caregiver burden.	15%	75%	10%	0%	0%
	Strongly Agree	**Agree**	**Neutral**	**Disagree**	**Strongly Disagree**
Q9. The role of the care manager includes providing support to caregivers.	30%	65%	5%	0%	0%
Q10. I feel care managers have the necessary resources to refer caregivers to community-based services and supports based on their individual needs and desires.	0%	70%	20%	10%	0%
Q11. In general, I have enough time during a client visit to consult with caregivers.	5%	45%	30%	20%	0%

Post-Training Questionnaire

As Table 9 shows, care managers and supervisors participating in the training on February 17-18, 2011, found the sessions helpful, with most agreeing or strongly agreeing to statements about usefulness of the training. As might be expected, the six care managers who were trained at the office by their supervisors did not rate the training as high.

After participating in the training, 70 percent of care managers and supervisors said they thought the Pilot could be implemented easily, whereas 25 percent were not certain (Table 10). Seventy-nine percent were looking forward to participating in the Pilot. Most agreed or strongly agreed that the Pilot would lead to improved outcomes for both the caregiver and the care recipient.

Table 9. Care Managers and Supervisors: Usefulness of Training

Care Managers and Supervisors Who Participated in Trainings, February 17-18, 2011 (n=14)	**Strongly Agree**		**Strongly Disagree**		
	5	**4**	**3**	**2**	**1**
Q1. The training met my expectations.	36%	57%	7%	0%	0%
Q2. The training topics were relevant to the theme of the pilot program.	64%	36%	0%	0%	0%
Q3. The training will be useful to me in the field.	57%	43%	0%	0%	0%
Q4. The presentations were targeted and informative.	64%	36%	0%	0%	0%
Q5. Adequate time was given to each topic.	57%	43%	0%	0%	0%
Q6. Adequate time was given for questions.	71%	29%	0%	0%	0%
Q7. The training materials were helpful.	57%	43%	0%	0%	0%
Q8. The meeting facilities were adequately equipped and comfortable.	43%	57%	0%	0%	0%
Q9. The directions to the meeting facilities were easy to follow.	50%	43%	7%	0%	0%
Q10. The trainer(s) and staff were knowledgeable and helpful.	64%	34%	0%	0%	0%
Q11. I would be interested in attending future trainings on caregiver supports.	50%	43%	7%	0%	0%
Care Managers Trained by Supervisors March 2011 (n=6)*	**Strongly Agree**		**Strongly Disagree**		
	5	**4**	**3**	**2**	**1**
Q1. The training met my expectations.	17%	66%	17%	0%	0%
Q2. The training topics were relevant to the theme of the pilot program.	17%	66%	17%	0%	0%
Q3. The training will be useful to me in the field.	17%	66%	17%	0%	0%
Q4. The presentations were targeted and informative.	33%	33%	33%	0%	0%
Q5. Adequate time was given to each topic.	33%	33%	33%	0%	0%
Q6. Adequate time was given for questions.	33%	50%	17%	0%	0%
Q7. The training materials were helpful.	17%	33%	50%	0%	0%

*A shortened post-training questionnaire was administered to care managers who were trained by supervisors.

Table 10. Care Managers and Supervisors: Views on Pilot Implementation

	n*	Agree	Disagree	Not Certain		
Q13. I anticipate that care managers will be able to implement this pilot program easily.	20	70%	5%	25%		
Q14. I am looking forward to participating in this pilot program.	14	79%	7%	14%		
		Strongly Agree	**Agree**	**Neutral**	**Disagree**	**Strongly Disagree**
Q15. I feel that this pilot will lead to improved outcomes for the caregiver.	14	29%	57%	14%	0%	0%
Q16. I feel that this pilot program will lead to improved outcomes for the care recipient.	14	21%	57%	21%	0%	0%

*A shortened post-training questionnaire was administered to care managers who were trained by supervisors (n=6), so this group did not respond to Q14, Q15, and Q16, making n=14 for these questions.

Profile of Care Recipients

As Table 11 shows, 72 percent of care recipients were enrolled in the Medicaid GO Waiver and 28 percent were enrolled in JACC, a program that provides LTSS to individuals with incomes slightly above the Medicaid eligibility level.

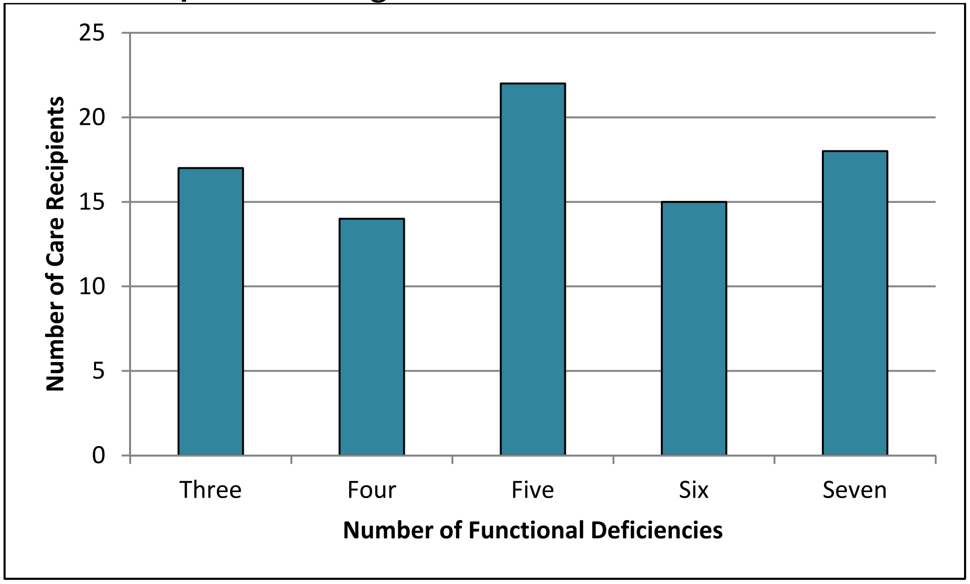
Table 11. Care Recipients of Caregivers in Pilot: LTSS Program Enrollment, by County

	County				Total	
	Atlantic	Mercer	Monmouth	Warren	Number	Percent
GO Waiver	31	7	10	15	63	72%
JACC	8	0	0	16	24	28%
Total	39	7	10	31	86	100%

Care recipients had a large number of functional deficiencies and many had cognitive deficits. Figure 4 shows the number of functional deficiencies recorded during each care recipient's most recent assessment using the New Jersey WPA-1 form. There are seven functional deficiencies listed on the WPA-1 form: bathing, dressing, toileting, transferring, locomotion, bed mobility, and eating. The assessor checks whether the care recipient requires "limited assistance" or "supervision/cueing" for each. Specifically, Figure 4 displays the number of functional deficiencies requiring "limited assistance" or "supervision/cueing." All care recipients had functional deficiencies in at least three areas. Nearly 21 percent had deficiencies in all seven areas.

Sixty-five percent of care recipients were reported to exhibit a cognitive deficit during their most recent assessment. The WPA-1 form defines a cognitive deficit as "exhibits short-term memory deficits, procedural memory deficits, and impaired decision-making and judgment."

Figure 4. Care Recipients of Caregivers in Pilot: Number of Functional Deficiencies



Source: New Jersey WPA-1 assessments.

Profile of Caregivers

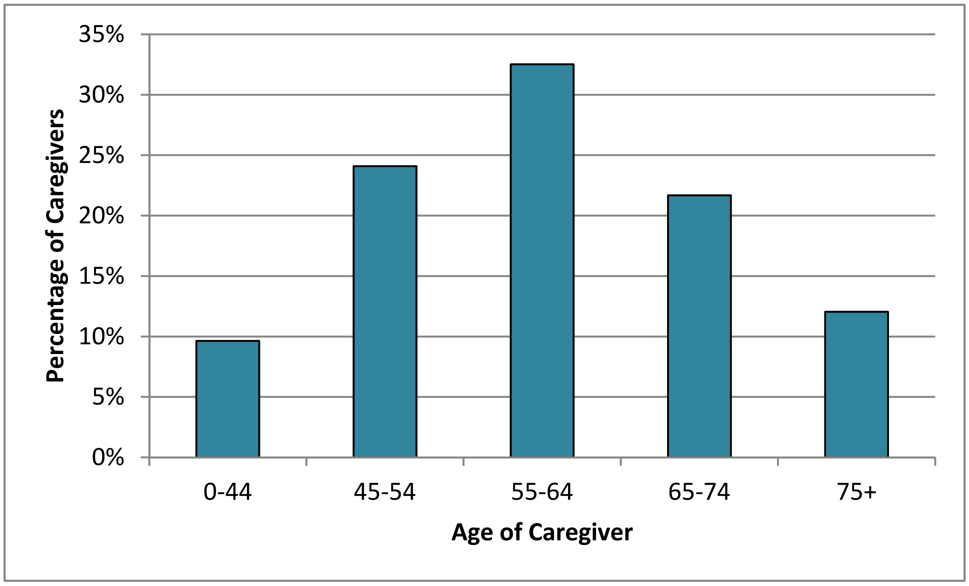
From March 14, 2011, to July 15, 2011, care managers in the four New Jersey counties asked caregivers to complete the Caregiver Questionnaire (Appendix A) during a home visit with the care recipient. Care recipients were receiving publicly funded home and community-based services through either the GO Waiver or JACC. Upon signing the consent form and completing this questionnaire, caregivers became participants in the Pilot.

Characteristics of Caregivers

The responses of the 86 caregivers who participated in the Pilot provide an unprecedented look at who caregivers are and the daily challenges they face in caring for their relative or friend. For example, 74 (86 percent) were female. The average age of caregivers was 60, but ages ranged from 28 to 85 years (Figure 5). Pilot caregivers were considerably older than the "average" caregiver in the United States, who is a 49-year-old woman working outside the home.[5] On average, caregivers had been caring for their friend or relative for nine years (Figure 6).

As Figure 7 illustrates, more than half of the caregivers were not working: 33 percent were retired, 22 percent were unemployed, and 2 percent were on a leave of absence. While 70 percent of caregivers reported that they were in excellent or good health (Figure 8), 68 percent said that health issues got in the way of their caregiving duties (Figure 9). For example, 27 percent reported arthritis, 22 percent reported back problems, and 22 percent cited sleep disturbance as interfering with caregiving.

Figure 5. Ages of Caregivers



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[5] National Alliance for Caregiving (NAC) and AARP. (2009, November). *Caregiving in the U.S. 2009*. Bethesda, MD: NAC; Washington, DC: AARP.

Figure 6. Number of Years Caring for Friend or Relative

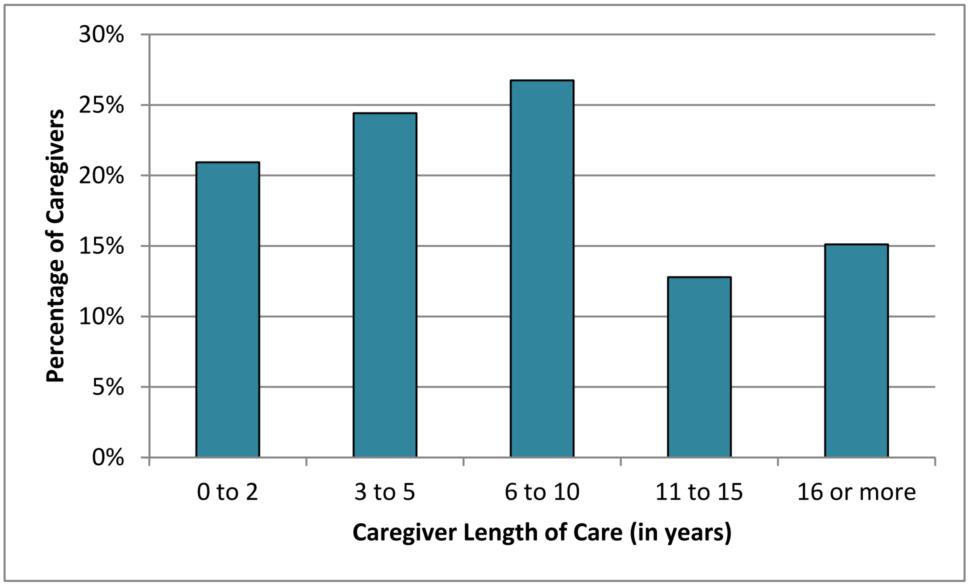


Figure 7. Caregiver Employment at Initial Assessment

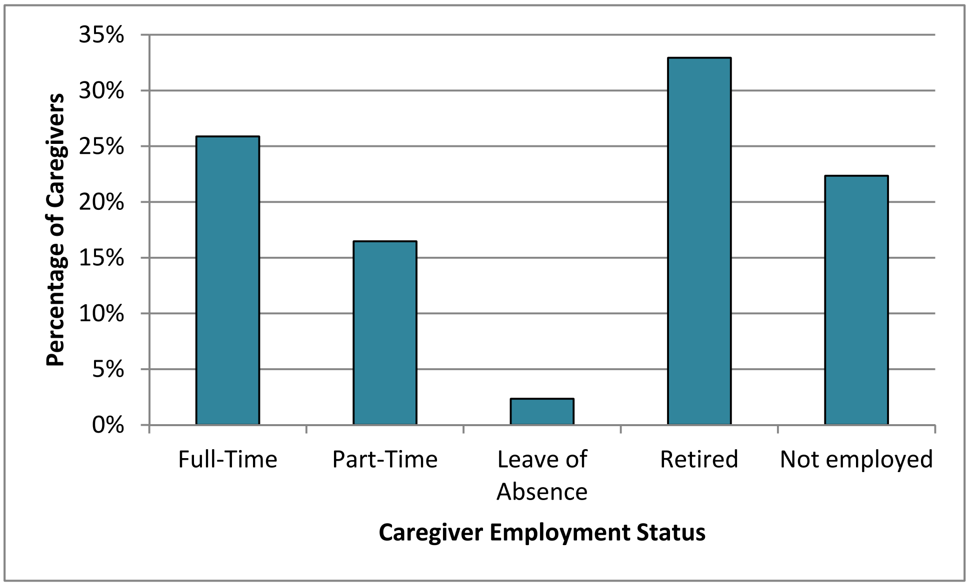


Figure 8. Self-Reported Health Status of Caregivers at Initial Assessment

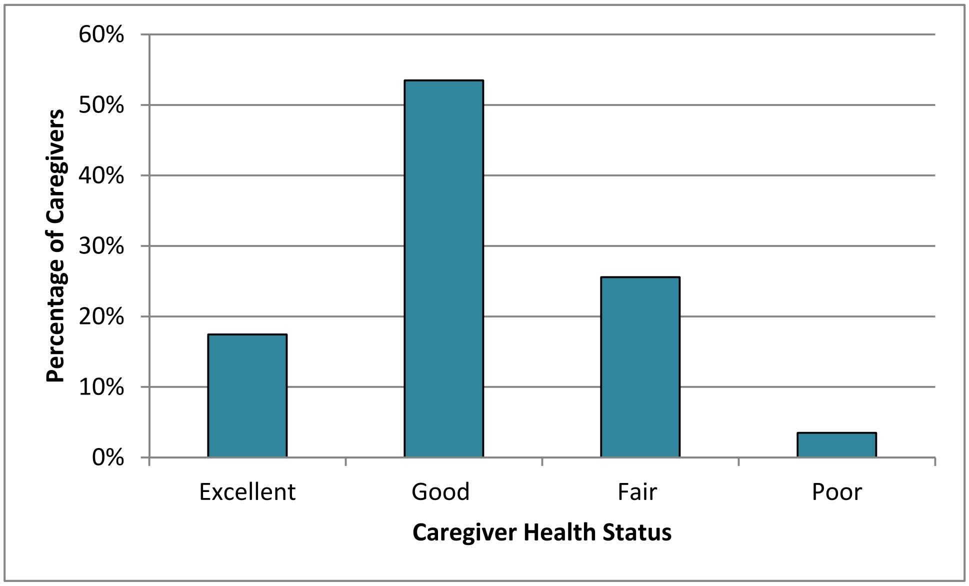
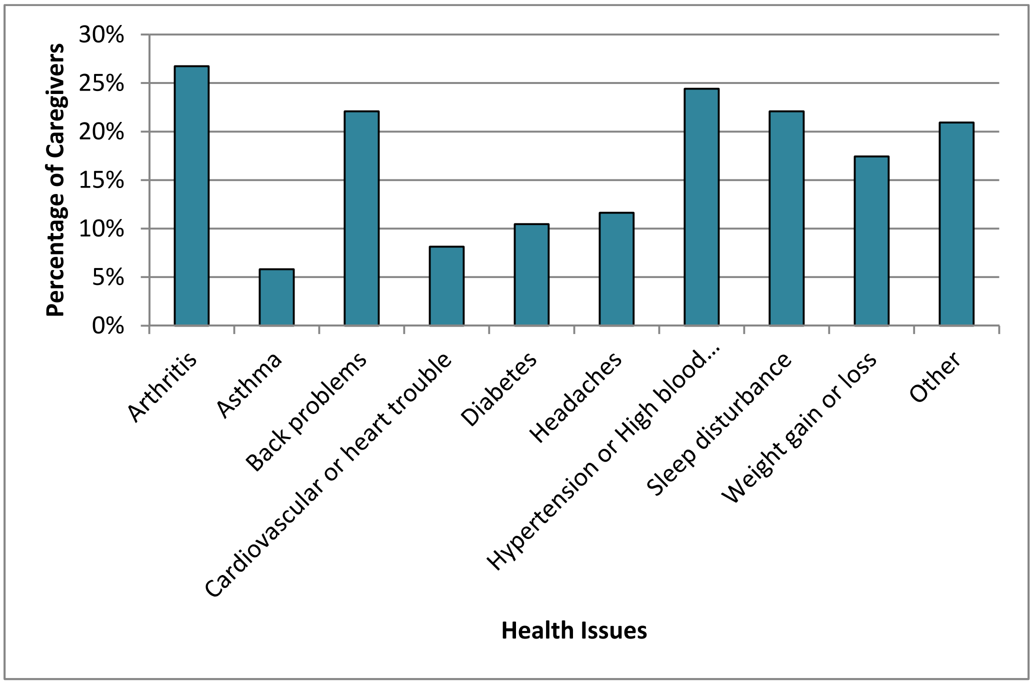


Figure 9. Health Issues Reported by Caregivers at Initial Assessment That Interfere with Caregiving



Direct Care Concerns

In the Caregiver Questionnaire (Appendix A), caregivers were asked about the direct care needs of their friend or relative and whether the caregiver was able to help.[6] Table 12 summarizes the caregivers' responses. For each of the direct care needs—except medical equipment—more than 70 percent of caregivers indicated that their friend or relative needed help.[7] Sixteen caregivers said that they were unable to help with bathing and 14 were unable to help with grooming. Caregivers most often said that they could benefit from training in order to help with managing symptoms (10 caregivers) and medical equipment (17 caregivers).

Table 12. Caregivers' Direct Care Concerns at Initial Assessment

Task	Frequency	Percentage	Task	Frequency	Percentage
Bathing			**Mobility***		
Doesn't Need Help	4	4.7%	Doesn't Need Help	13	15.3%
Help With Training	3	3.5%	Help With Training	1	1.2%
Help Without Training	63	73.3%	Help Without Training	66	77.7%
Unable to Help	16	18.6%	Unable to Help	5	5.9%
Dressing*			**Medication**		
Doesn't Need Help	9	10.6%	Doesn't Need Help	3	3.5%
Help With Training	3	3.5%	Help With Training	2	2.3%
Help Without Training	65	76.5%	Help Without Training	79	91.9%
Unable to Help	8	9.4%	Unable to Help	2	2.3%
Personal Hygiene*			**Managing Symptoms****		
Doesn't Need Help	24	28.2%	Doesn't Need Help	10	11.9%
Help With Training	1	1.2%	Help With Training	10	11.9%
Help Without Training	51	60.0%	Help Without Training	60	71.4%
Unable to Help	9	10.6%	Unable to Help	4	4.8%
Grooming*			**Medical Equipment**		
Doesn't Need Help	11	12.9%	Doesn't Need Help	46	53.5%
Help With Training	2	2.4%	Help With Training	17	19.8%
Help Without Training	58	68.2%	Help Without Training	21	24.4%
Unable to Help	14	16.5%	Unable to Help	2	2.3%

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[6] Questions in the Caregiver Questionnaire about direct care needs and managing troublesome behaviors were adapted with permission from www.nextstepincare.org. © United Hospital Fund.

[7] The caregivers did *not* report that the care recipient "doesn't need help," so one can imply that the care recipient needed help.

Task	Frequency	Percentage	Task	Frequency	Percentage
Toileting*			**Assistive Devices**		
Doesn't Need Help	24	28.2%	Doesn't Need Help	10	11.6%
Help With Training	2	2.4%	Help With Training	4	4.7%
Help Without Training	50	58.8%	Help Without Training	68	79.1%
Unable to Help	9	10.6%	Unable to Help	4	4.7%
Transfer			**Coordinating Care**		
Doesn't Need Help	24	27.9%	Doesn't Need Help	2	2.3%
Help With Training	1	1.2%	Help With Training	3	3.5%
Help Without Training	55	64.0%	Help Without Training	81	94.2%
Unable to Help	6	7.0%	Unable to Help	0	0.0%

*Frequency missing = 1
**Frequency missing = 2

In the Caregiver Questionnaire, caregivers were also asked about managing any troublesome behaviors displayed by their friend or relative. Table 13 summarizes caregiver responses. Among the 12 behaviors caregivers were queried about, short-term memory loss, trouble with decision making, and communicating with friend/relative were the most common.[8] Least common were smoking and physically abusive behavior. Caregivers most often said that they could benefit from training in managing these behaviors: anxiety (18 caregivers), short-term memory loss (12 caregivers), sadness or depression (12 caregivers), anger (11 caregivers), and agitation (10 caregivers). For each of the 12 behaviors, no more than 3 caregivers said that they were unable to manage the behavior.

Table 13. Managing Troublesome Behaviors in Care Recipients at Initial Assessment

Task	Frequency	Percent	Task	Frequency	Percent
Short-Term Memory Loss			**Anxiety*** **		
Doesn’t Have Behavior	14	16.3%	Doesn’t Have Behavior	35	42.2%
Manage With Training	12	14.0%	Manage With Training	18	21.7%
Manage Without Training	59	68.6%	Manage Without Training	28	33.7%
Unable to Manage	1	1.2%	Unable to Manage	2	2.4%
Trouble with Decision Making			**Withdrawal from Social Contacts***		
Doesn’t Have Behavior	21	24.4%	Doesn’t Have Behavior	32	37.7%
Manage With Training	5	5.8%	Manage With Training	8	9.4%
Manage Without Training	59	68.6%	Manage Without Training	43	50.6%
Unable to Manage	1	1.2%	Unable to Manage	2	2.4%

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[8] That is, few caregivers indicated that the care recipient “doesn’t have behavior.”

Task	Frequency	Percent	Task	Frequency	Percent
Communicating with Friend/Relative			**Mood Decline*** **		
Doesn’t Have Behavior	14	16.3%	Doesn’t Have Behavior	34	41.0%
Manage With Training	8	9.3%	Manage With Training	9	10.8%
Manage Without Training	62	72.1%	Manage Without Training	37	44.6%
Unable to Manage	2	2.3%	Unable to Manage	3	3.6%
Smoking **			**Agitation***		
Doesn’t Have Behavior	73	86.9%	Doesn’t Have Behavior	44	51.8%
Manage With Training	1	1.2%	Manage With Training	10	11.8%
Manage Without Training	7	8.3%	Manage Without Training	28	32.9%
Unable to Manage	3	3.6%	Unable to Manage	3	3.5%
Sadness or Depression			**Verbally Abusive** **		
Doesn’t Have Behavior	36	41.9%	Doesn’t Have Behavior	55	65.5%
Manage With Training	12	14.0%	Manage With Training	7	8.3%
Manage Without Training	35	40.7%	Manage Without Training	19	22.6%
Unable to Manage	3	3.5%	Unable to Manage	3	3.6%
Anger*			**Physically Abusive*** **		
Doesn’t Have Behavior	37	43.5%	Doesn’t Have Behavior	73	88.0%
Manage With Training	11	12.9%	Manage With Training	2	2.4%
Manage Without Training	34	40.0%	Manage Without Training	8	9.6%
Unable to Manage	3	3.5%	Unable to Manage	0	0.0%

*Frequency missing = 1

**Frequency missing = 2

***Frequency missing = 3

Formal and Informal Supports

The Caregiver Questionnaire asked caregivers about the number of hours they spend helping their relative or friend, other paid and unpaid help the care recipient receives, and other resources available to support the caregiver. Fifty caregivers (58 percent) said they received help with their caregiving responsibilities from other family members. The same number said that their friend or relative received help from a paid attendant (Figure 10). Twenty-six caregivers (30 percent) said that their relative or friend attends adult day care, and 33 caregivers (38 percent) reported taking advantage of other community resources, such as transportation programs, meals services, and senior centers (Figure 11). However, 23 caregivers (27 percent) reported that they have not received any help.

When asked about their help situation, 34 caregivers (40 percent) reported receiving about the right amount of help from family and friends, 33 (38 percent) said they receive far less help than they need, and 16 (19 percent) said they receive no help (Figure 12).

Figure 10. Sources of Help Reported by Caregivers at Initial Assessment

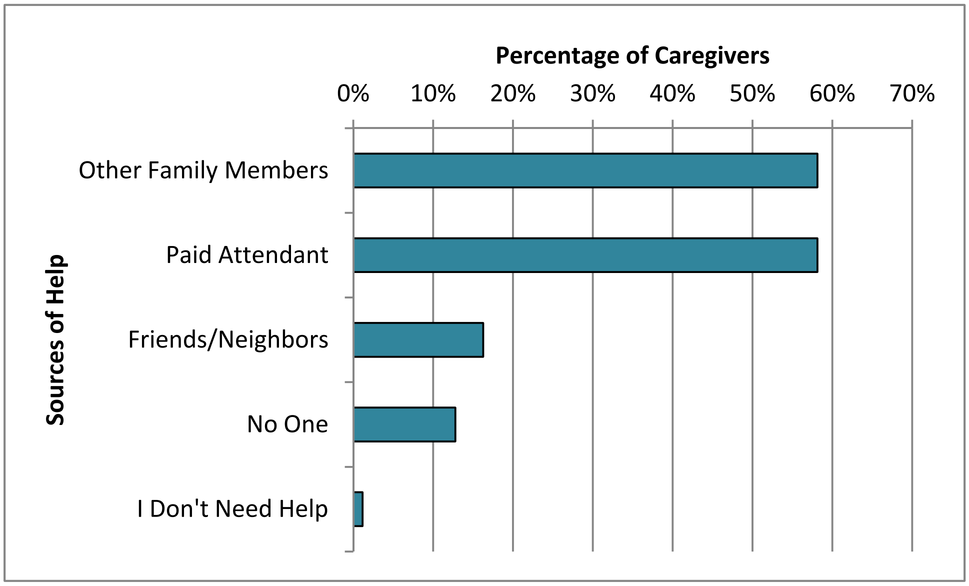


Figure 11. Community Resources Available to Caregivers at Initial Assessment

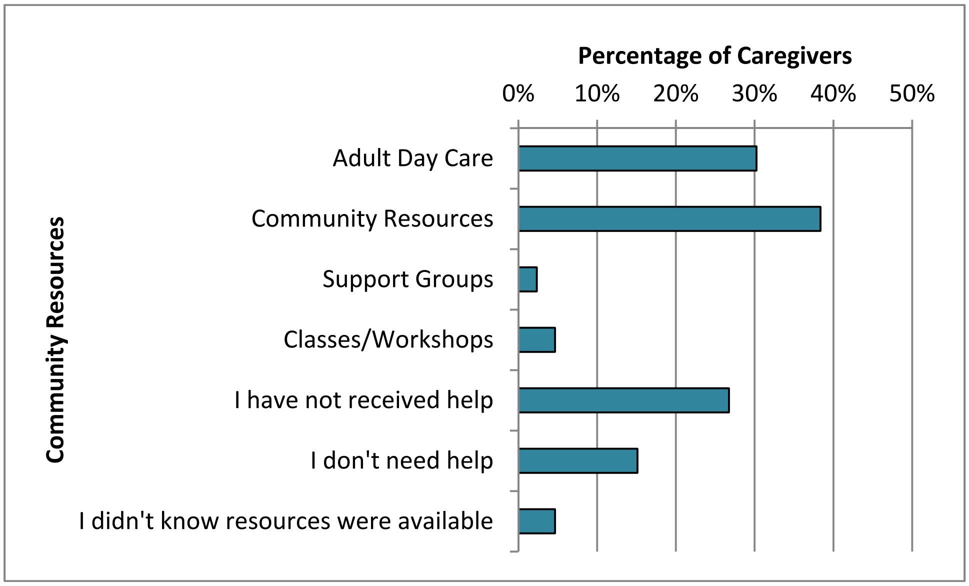


Figure 12. Caregivers' Views on the Amount of Help They Receive at Initial Assessment

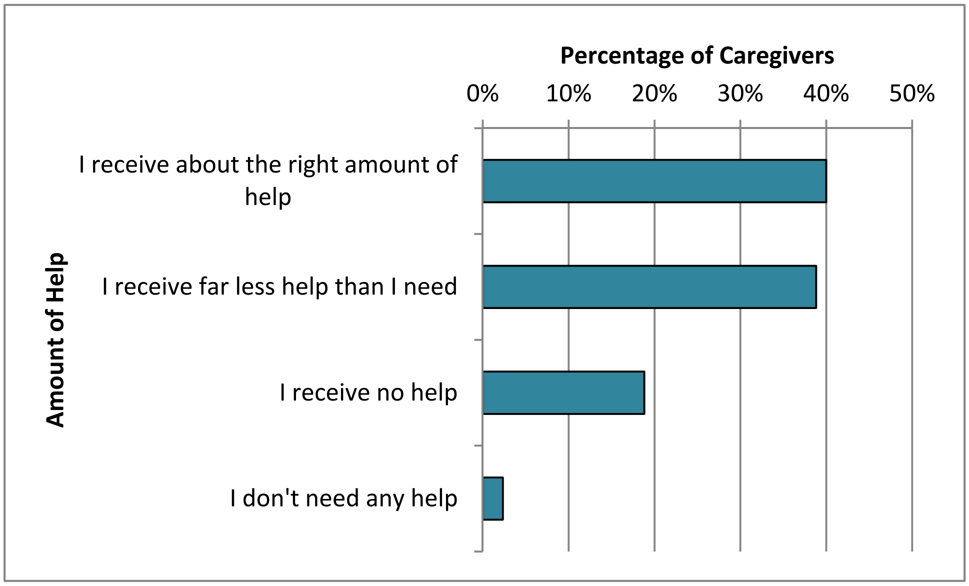


Figure 13 shows the number of hours of care per week that caregivers report providing to their relative or friend. As expected, caregivers who live with the care recipient provide far more care. Figure 14 shows hours of paid care per week provided to the care recipient. Figure 15 shows hours of unpaid care per week provided by family, friends, and volunteers other than the caregiver. Figure 16 provides caregivers' sources of emotional support.

Figure 13. Hours of Care per Week Provided by Caregivers at Initial Assessment

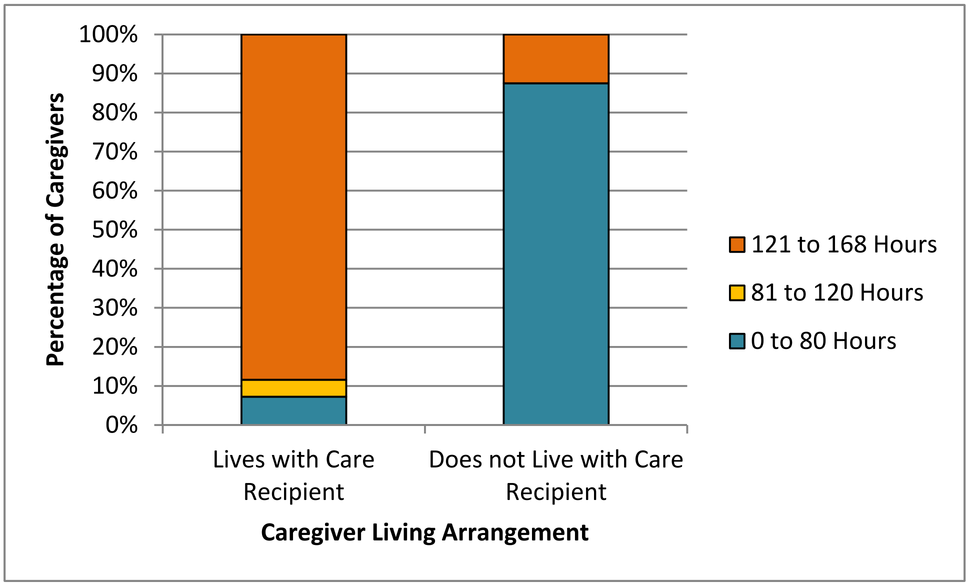


Figure 14. Hours of Paid Help per Week for Relative or Friend at Initial Assessment

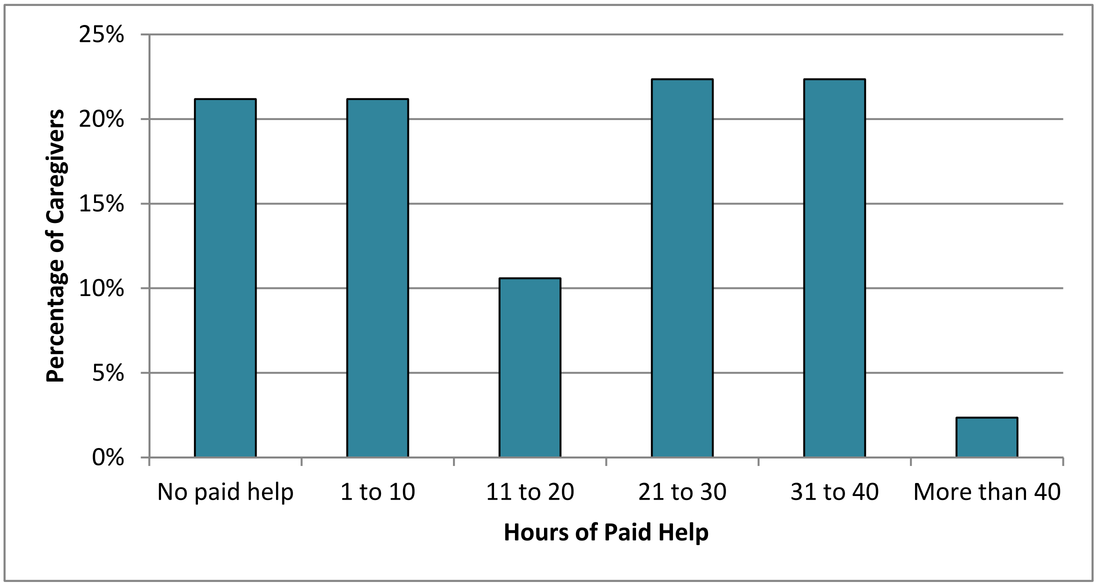


Figure 15. Hours of Unpaid Help per Week from Family, Friends, and Volunteers at Initial Assessment

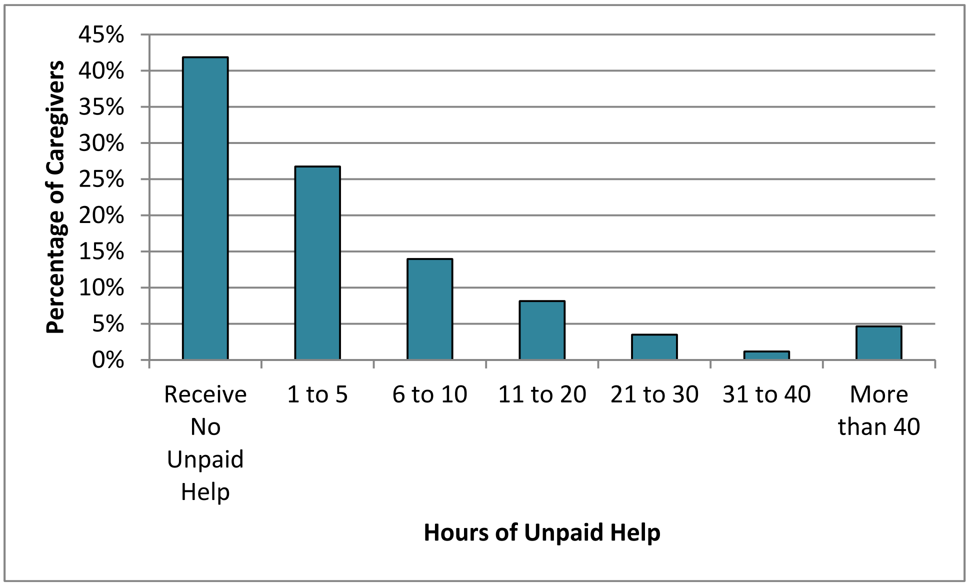
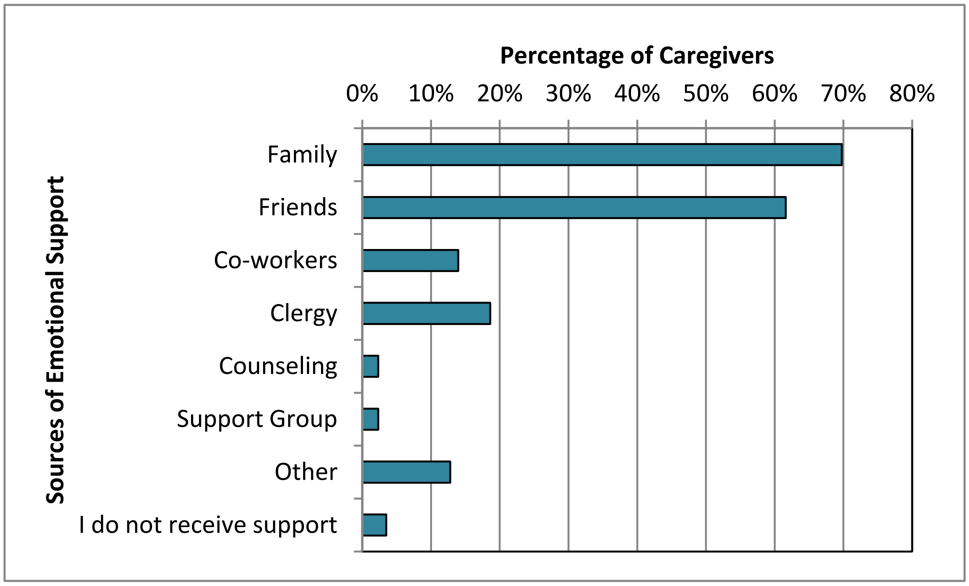


Figure 16. Sources of Emotional Support for Caregivers at Initial Assessment



Caregiver Burden

Caregivers' average score on the four-item Zarit Burden Interview was 7, but many scores were significantly higher (Figure 17).[9] Four caregivers had scores of 13 to 16. Table 14 shows caregivers' responses to each of the four questions on the Zarit Burden Interview, as well as the mean score for each question. Caregivers were more likely to report burden on the first two questions (time for oneself and stress from responsibilities) than on the second two questions (strain when around the relative or friend and not knowing what to do about the relative or friend).

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[9] To see the Zarit Burden Interview, refer to Question 8 in the Caregiver Questionnaire (Appendix A).

Figure 17. Caregivers' Composite Scores on Four-Item Zarit Burden Interview at Initial Assessment

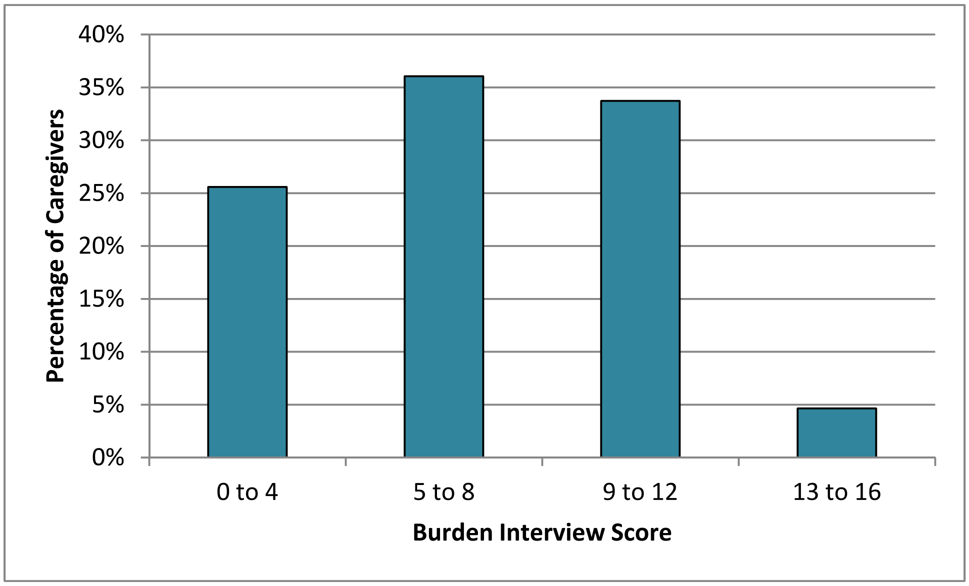


Table 14. Caregivers' Responses on the Four-Item Zarit Burden Interview at Initial Assessment

	Never	Rarely	Sometimes	Quite Frequently	Nearly Always	n	Mean Score
Number of Points	0	1	2	3	4	--	--
How often do you feel:							
That because of the time you spend with your relative or friend that you don't have enough time for yourself?	12 (13.9%)	12 (13.9%)	33 (38.4%)	19 (22.1%)	10 (11.6%)	86	2.0
Stressed between caring for your relative or friend and trying to meet other responsibilities (work/family)?	14 (16.3%)	6 (7.0%)	30 (34.9%)	25 (29.1%)	11 (12.8%)	86	2.2
Strained when you are around your relative or friend?	22 (25.6%)	18 (20.9%)	34 (39.5%)	10 (11.6%)	2 (2.3%)	86	1.4
Uncertain about what to do about your relative or friend?	26 (30.2%)	25 (29.1%)	22 (25.6%)	9 (10.5%)	4 (4.6%)	86	1.3

Caregivers Three Months Later

Three months after caregivers completed the Caregiver Questionnaire during a home visit by the care manager for the GO Waiver or JACC program, Hilltop mailed a second questionnaire to the caregiver's home. This questionnaire (Appendix D) asked about the caregiver's current situation and whether she had found the information and referrals provided by the care manager during the initial home visit helpful. Table 15 shows the number of questionnaires that were returned.

Table 15. Number of Caregiver Follow-Up Questionnaires Returned

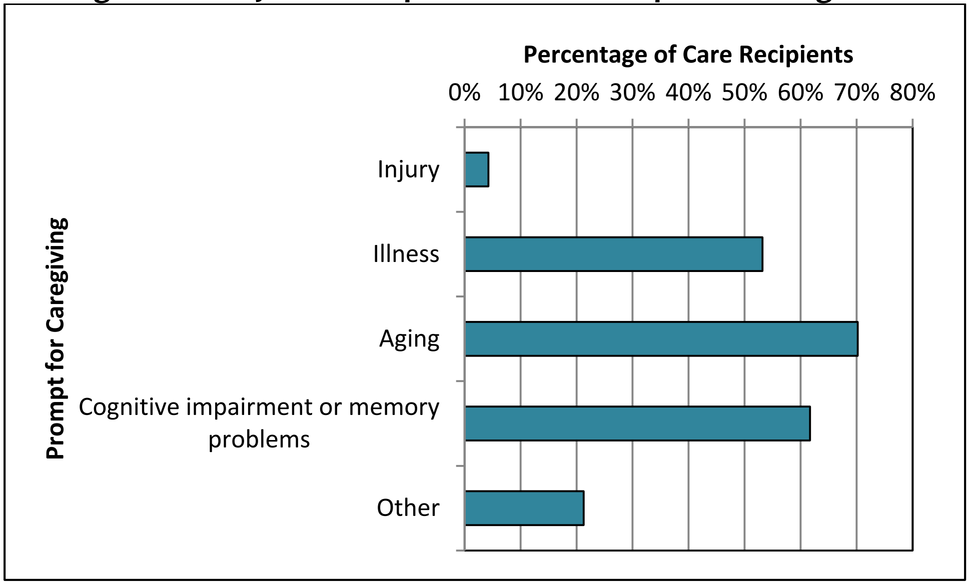
	County				Total	Response Rate
	Atlantic	Mercer	Monmouth	Warren		
GO Waiver	13	5	9	8	35	56%
JACC	4	0	0	10	14	58%
Total	17	5	9	18	49	
Response Rate	44%	71%	90%	58%	57%	

The follow-up questionnaire asked some of the same questions asked in the initial Caregiver Questionnaire to determine any change in caregiver status over the three-month period. Statistical tests were completed, comparing participants who responded to the follow-up questionnaire and those who did not. No significant differences were found between the two groups. Findings from the follow-up questionnaire are discussed below.

Caregiving Situation

Caregivers were asked what initially prompted the need to provide care to their relative or friend. Many caregivers gave multiple reasons. As Figure 18 shows, 70 percent cited aging, 62 percent said cognitive impairment or memory problems, and 53 percent said illness.

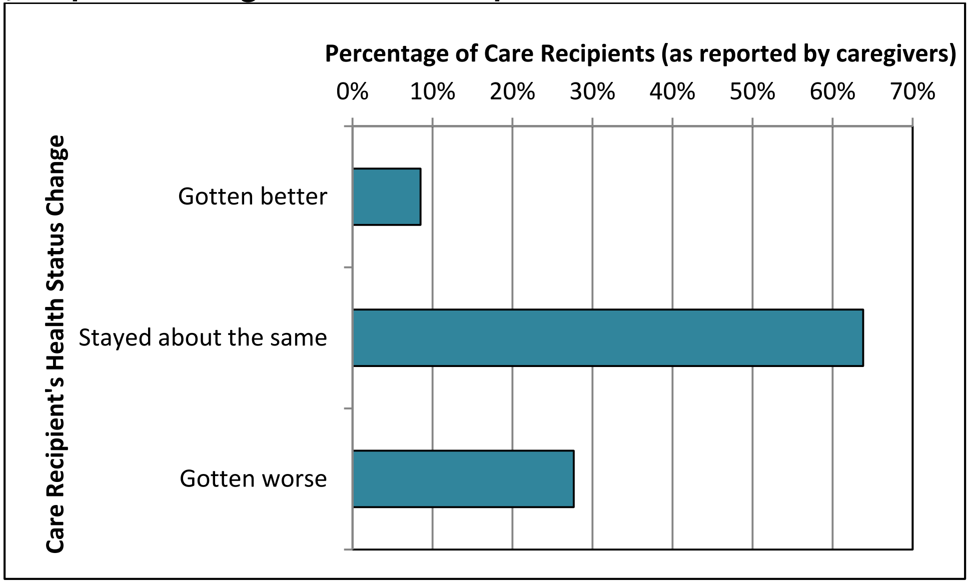
Figure 18. Why Care Recipients Needed Help from Caregivers



Caregivers were asked if they were still the primary caregiver for their relative or friend. Forty-five (96 percent) said “yes.” Thirty-seven caregivers (79 percent) reported that they live with the care recipient.

When asked about the health of the care recipient and whether it had gotten better, gotten worse, or stayed about the same over the last three months, 13 caregivers (28 percent) said the care recipient’s health had gotten worse, 30 (64 percent) said it was about the same, and 4 (9 percent) said it had gotten better (Figure 19).

Figure 19. Reported Change in the Care Recipient's Health over the Past Three Months

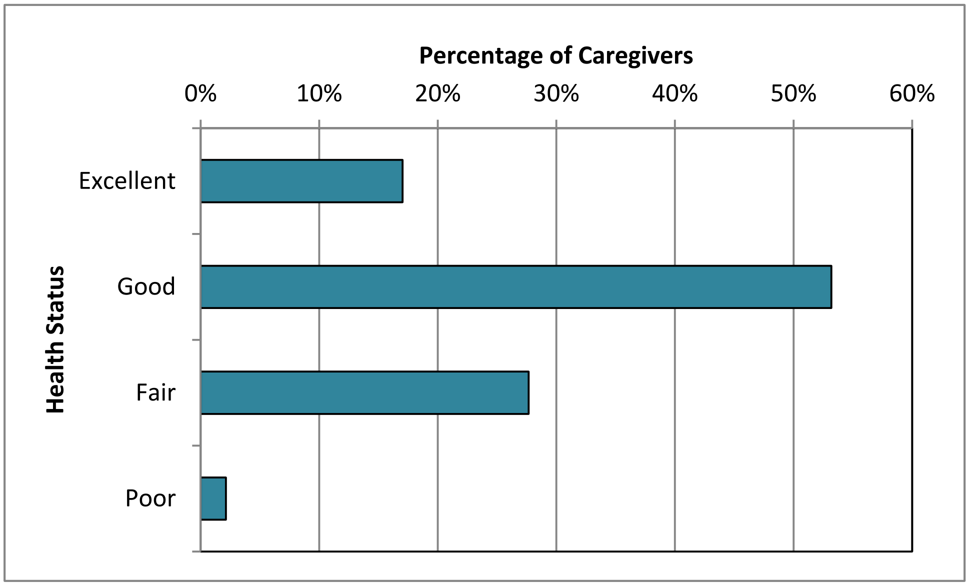


When asked about their current employment situation, 24 caregivers (51 percent) reported that they were not employed (Figure 20).

Figure 20. Caregiver Employment Three Months Later

Caregivers were also asked about their current health status. Thirty-three (70 percent) said that their health was good or excellent (Figure 21).

Figure 21. Caregiver Self-Reported Health Status Three Months Later



Direct Care Concerns

Caregivers were asked about the kinds of assistance they provided to their relative or friend over the past 30 days. Table 16 shows the wide array of tasks that caregivers performed for care recipients. Caregivers were also asked if their relative or friend had memory or behavior problems and, if so, how they would rate their ability to manage the behaviors over the past 30 days (Table 17). Among caregivers citing the following eight behaviors in their relative or friend, 50 percent or more rated their ability to deal with the behavior as “fair” or “poor”:

- Smoking (50 percent “fair” or “poor”)
- Prolonged period of sadness or depression (73 percent)
- Unrealistic fears or anxiety (50 percent)
- Mood decline (60 percent)
- Agitation, such as pacing or restlessness (55 percent)
- Verbal abuse (50 percent)
- Socially or sexually inappropriate behavior (100 percent)
- Resists care (such as refusing help with bathing or dressing) (53 percent)

Table 16. Tasks That Caregivers Assisted Care Recipients with over the Past 30 Days

Task	Relative or Friend Needs Assistance?	Looking back over the past 30 days, how often did you provide assistance with these tasks?			
	% (n)	% (n)			
Bathing (shower, bath, or sink)	Yes: 87% (41)	Frequently	Sometimes	Rarely	Never
	No: 13% (6)	66% (27)	27% (11)	0% (0)	7% (3)
Dressing	Yes: 85% (40)	Frequently	Sometimes	Rarely	Never
	No: 15% (7)	65% (26)	28% (11)	5% (2)	3% (1)
Personal hygiene (such as brushing teeth)	Yes: 60% (28)	Frequently	Sometimes	Rarely	Never
	No: 40% (19)	61% (17)	32% (9)	4% (1)	4% (1)
Grooming (such as cutting nails)	Yes: 87% (41)	Frequently	Sometimes	Rarely	Never
	No: 13% (6)	68% (27)	25% (10)	5% (2)	3% (1)
Toileting (going to the bathroom or changing diapers)	Yes: 57% (27)	Frequently	Sometimes	Rarely	Never
	No: 43% (20)	70% (19)	19% (5)	11% (3)	0% (0)
Transfer (such as moving from the bed to a chair)	Yes: 51% (24)	Frequently	Sometimes	Rarely	Never
	No: 49% (23)	58% (14)	33% (8)	8% (2)	0% (0)
Mobility (includes walking)	Yes: 68% (32)	Frequently	Sometimes	Rarely	Never
	No: 32% (15)	56% (18)	34% (11)	9% (3)	0% (0)
Medication (ordering, organizing, giving medications)	Yes: 96% (45)	Frequently	Sometimes	Rarely	Never
	No: 4% (2)	98% (44)	0% (0)	0% (0)	2% (1)
Managing symptoms (such as pain or nausea)	Yes: 83% (39)	Frequently	Sometimes	Rarely	Never
	No: 17% (8)	46% (18)	44% (17)	10% (4)	0% (0)
Medical equipment (such as oxygen, IV, or infusion)	Yes: 21% (10)	Frequently	Sometimes	Rarely	Never
	No: 79% (37)	100% (10)	0% (0)	0% (0)	0% (0)
Assistive devices (such as wheelchairs, walkers, shower chairs)	Yes: 83% (39)	Frequently	Sometimes	Rarely	Never
	No: 17% (8)	67% (26)	31% (12)	3% (1)	0% (0)
Coordinating your relative's care (includes talking with doctors, nurses, social workers, and others)	Yes: 98% (46)	Frequently	Sometimes	Rarely	Never
	No: 2% (1)	89% (41)	7% (3)	2% (1)	2% (1)

Table 17. Caregivers' Ability to Manage Memory or Behavior Problems over the Past 30 Days

Behavior	Relative or Friend Has Behavior?	If your relative or friend has memory or behavior problems, looking back over the past 30 days, how would you rate your ability to manage these behaviors?			
	% (n)	% (n)			
Short-term memory loss	Yes: 78% (36)	Excellent	Good	Fair	Poor
	No: 22% (10)	22% (8)	50% (18)	22% (8)	6% (2)
Trouble with decision making	Yes: 72% (33)	Excellent	Good	Fair	Poor
	No: 28% (13)	44% (14)	38% (12)	13% (4)	6% (2)
Trouble communicating with me	Yes: 54% (25)	Excellent	Good	Fair	Poor
	No: 46% (21)	28% (7)	32% (8)	40% (10)	0% (0)
Smoking	Yes: 9% (4)	Excellent	Good	Fair	Poor
	No: 91% (42)	0% (0)	50% (2)	25% (1)	25% (1)
Prolonged periods of sadness or depression	Yes: 48% (22)	Excellent	Good	Fair	Poor
	No: 52% (24)	14% (3)	14% (3)	64% (14)	9% (2)
Anger with self or with others	Yes: 50% (23)	Excellent	Good	Fair	Poor
	No: 50% (23)	17% (4)	39% (9)	30% (7)	13% (3)
Unrealistic fears or anxiety	Yes: 40% (18)	Excellent	Good	Fair	Poor
	No: 60% (27)	6% (1)	44% (8)	50% (9)	0% (0)
Withdrawal from social contacts or reduced socializing	Yes: 50% (23)	Excellent	Good	Fair	Poor
	No: 50% (23)	5% (1)	50% (11)	41% (9)	5% (1)
Mood decline	Yes: 56% (25)	Excellent	Good	Fair	Poor
	No: 44% (20)	12% (3)	28% (7)	56% (14)	4% (1)
Agitation, such as pacing or restlessness	Yes: 39% (18)	Excellent	Good	Fair	Poor
	No: 61% (28)	6% (1)	39% (7)	44% (8)	11% (2)
Verbally abusive	Yes: 30% (14)	Excellent	Good	Fair	Poor
	No: 70% (32)	14% (2)	36% (5)	36% (5)	14% (2)
Physically abusive	Yes: 4% (2)	Excellent	Good	Fair	Poor
	No: 96% (44)	0% (0)	50% (1)	50% (1)	0% (0)

Behavior	Relative or Friend Has Behavior?	If your relative or friend has memory or behavior problems, looking back over the past 30 days, how would you rate your ability to manage these behaviors?			
	% (n)	% (n)			
Wandering off or getting lost	Yes: 13% (6)	Excellent	Good	Fair	Poor
	No: 87% (40)	50% (3)	33% (2)	17% (1)	0% (0)
Losing, misplacing, or hiding things	Yes: 44% (20)	Excellent	Good	Fair	Poor
	No: 56% (25)	15% (3)	60% (12)	15% (3)	10% (2)
Not recognizing familiar people	Yes: 38% (17)	Excellent	Good	Fair	Poor
	No: 62% (28)	24% (4)	41% (7)	35% (6)	0% (0)
Asking the same question over and over	Yes: 50% (23)	Excellent	Good	Fair	Poor
	No: 50% (23)	22% (5)	39% (9)	35% (8)	4% (1)
Socially or sexually inappropriate behavior	Yes: 7% (3)	Excellent	Good	Fair	Poor
	No: 42% (93)	0% (0)	0% (0)	67% (2)	33% (1)
Resists care (such as refusing help with bathing or dressing)	Yes: 33% (15)	Excellent	Good	Fair	Poor
	No: 67% (30)	20% (3)	27% (4)	33% (5)	20% (3)

Formal and Informal Support

In the three-month follow-up questionnaire, caregivers were asked again about the sources of help available to them. There were no statistically significant differences between the amount of support caregivers received before the assessment and the amount reported in the three-month follow-up questionnaire. Figure 22 shows the kinds of help caregivers received in the last 30 days. Twenty-five (56 percent) of the 45 responding caregivers reported receiving paid help and 8 (18 percent) reported receiving no help. As Figure 23 shows, 9 responding caregivers (20 percent) said their relative or friend attended adult day care and 8 (17 percent) used a respite service; 18 (39 percent) said they did not receive support from community resources. When asked about the amount of help they received in the last 30 days, 23 caregivers (50 percent) said they received about the right amount of help, 12 (26 percent) said they received far less help than they need, and 8 (17 percent) said they received no help (Figure 24).

Figure 25 displays the hours of care per week that caregivers reported providing three months later, showing hours provided by caregivers who live with the care recipient separately from hours provided by caregivers who do not live with the care recipient. Figure 26 shows hours per week of paid help and Figure 27 shows hours per week of unpaid help.

Figure 22. Source of Help Reported by Caregivers in the Past 30 Days

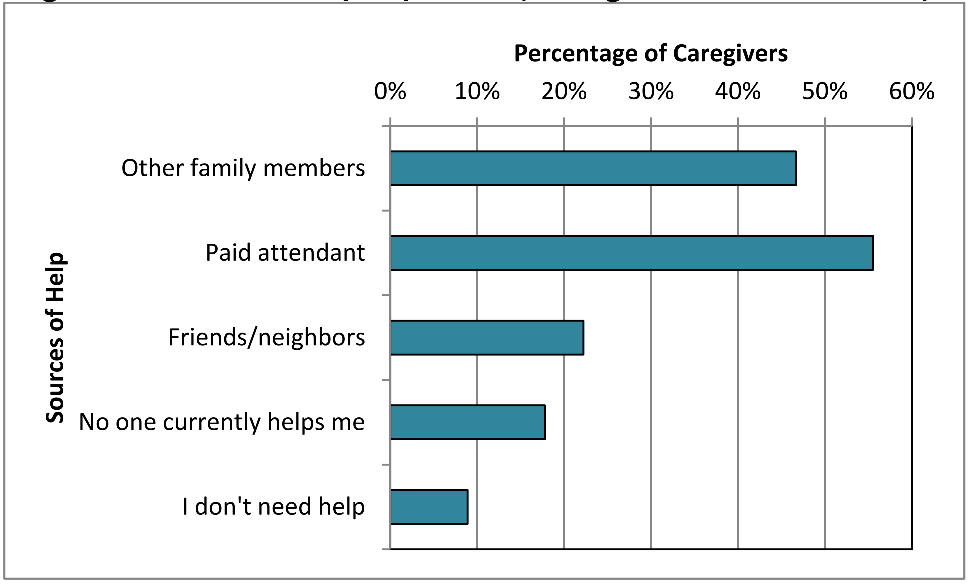


Figure 23. Community Resources and Supports Used by Caregivers in the Past 30 Days

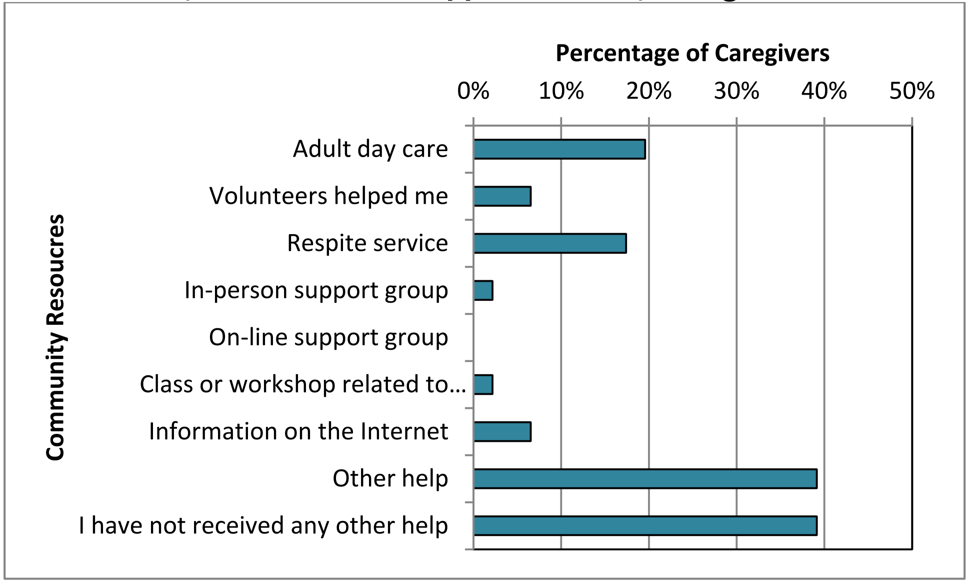


Figure 24. Caregivers' Views on the Amount of Help They Received in the Past 30 Days

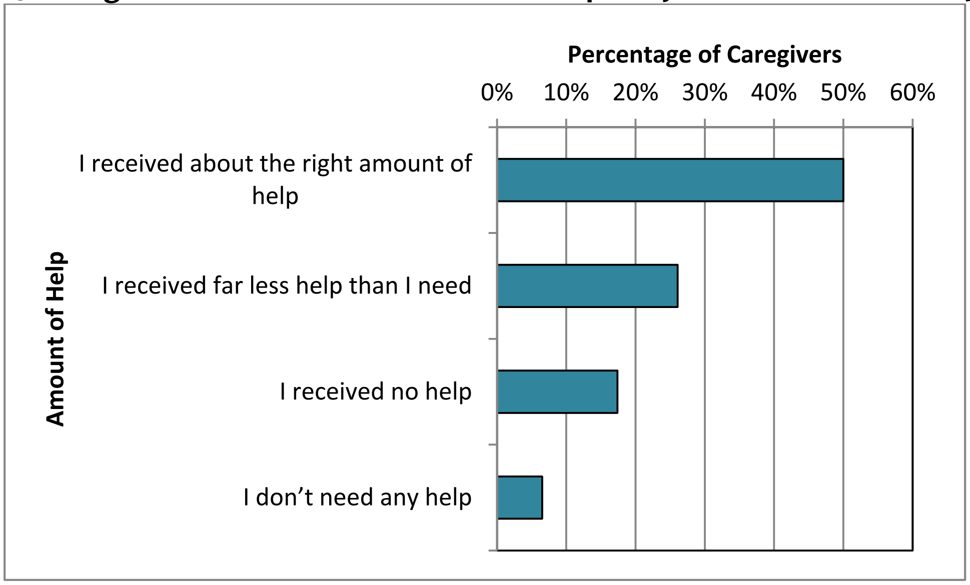


Figure 25. Hours of Care per Week Provided by Caregivers Three Months Later

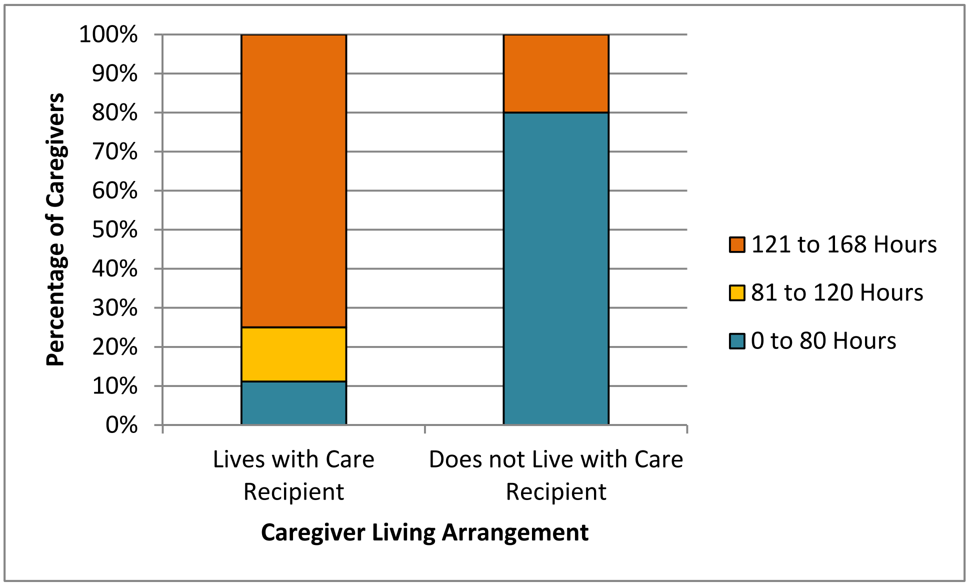


Figure 26. Hours of Paid Help per Week for Relative or Friend Three Months Later

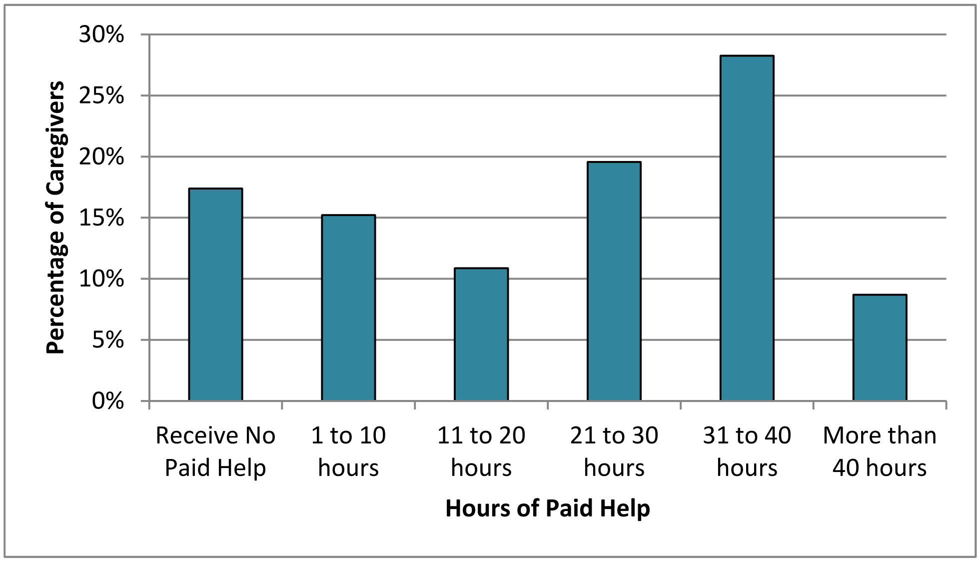
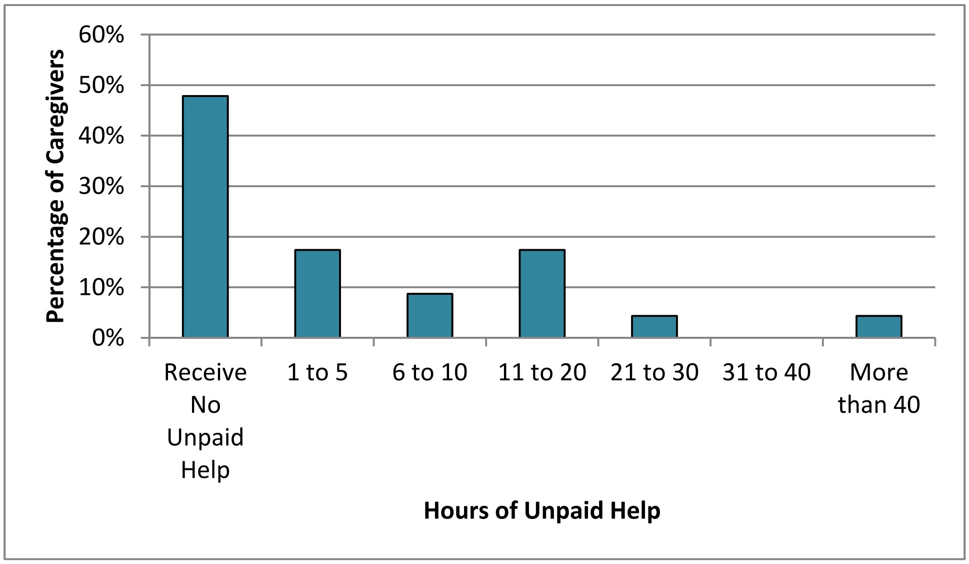


Figure 27. Hours of Unpaid Help per Week from Family, Friends, and Volunteers Three Months Later



Caregiver Burden

In the three-month follow-up questionnaire, caregivers were asked once again to complete the four-item Zarit Burden Interview. The average score was 7.4, and 4 (9 percent) of the 47 responding caregivers had scores between 13 and 16 (Figure 28).

Figure 28. Caregivers' Composite Scores on Four-Item Zarit Burden Interview Three Months Later

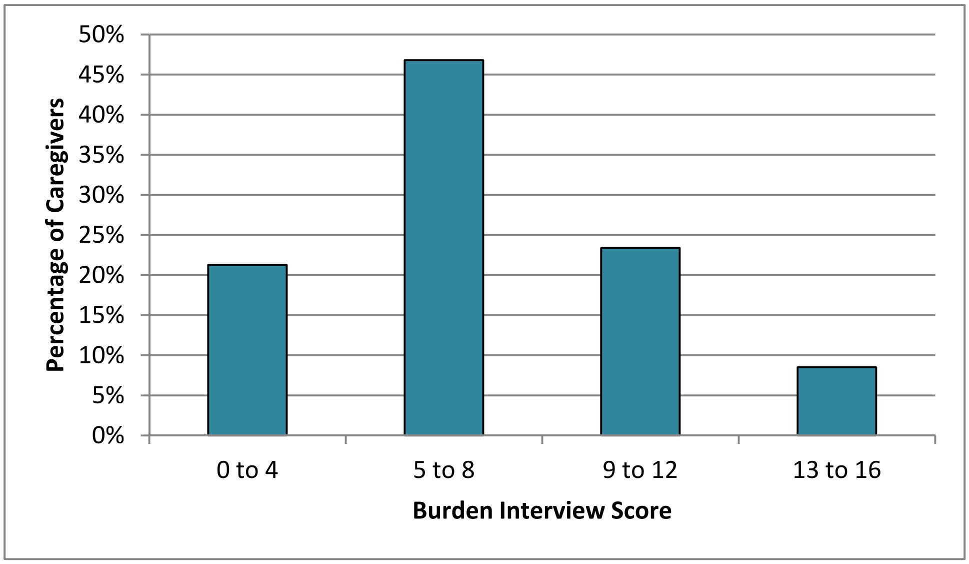


Table 18 shows caregivers' responses to each of the four questions on the scale, as well as the mean score for each question. Caregivers were more likely to report burden on the first two questions (time for oneself and stress for responsibilities) than on the second two questions (strain when around the relative or friend and not knowing what to do about the relative or friend).

Table 18. Caregivers' Responses on the Four-Item Zarit Burden Interview Three Months Later

	Never	Rarely	Sometimes	Quite Frequently	Nearly Always	n	Mean Score
Number of Points	0	1	2	3	4	--	--
How often do you feel:							
That because of the time you spend with your relative or friend that you don't have enough time for yourself?	1 (2.1%)	9 (19.1%)	30 (42.5%)	11 (23.4%)	6 (12.8%)	47	2.3
Stressed between caring for your relative or friend and trying to meet other responsibilities (work/family)?	3 (6.4%)	9 (19.1%)	16 (34.0%)	10 (21.3%)	9 (19.1%)	47	2.3
Strained when you are around your relative or friend?	11 (23.4%)	14 (29.8%)	15 (31.9%)	4 (8.5%)	3 (6.4%)	47	1.4
Uncertain about what to do about your relative or friend?	15 (31.9%)	9 (19.1%)	15 (31.9%)	4 (8.5%)	4 (8.5%)	47	1.4

Usefulness of Information and Referrals

After the caregiver completed the Caregiver Questionnaire during the care manager's home visit with the care recipient, the care manager completed a Caregiver Action Plan and then provided information and referrals to the caregiver tailored to her needs. Table 19 lists the kinds of information caregivers remember receiving three months after the home visit. Ninety-six percent remember talking with the care manager about caregiving and 94 percent said the care manager telephoned later to see how the caregiver was doing. Most caregivers also remember receiving various kinds of information on caring for themselves and caring for others.

Table 19. Care Manager Actions during the Home Visit as Reported by the Caregiver

Did the Care Manager:	n	Yes	No	I Don't Remember
Talk with you about caregiving?	47	45 (96%)	0 (0%)	2 (4%)
Give you written materials on **how to care for your relative or friend**?	47	42 (89%)	3 (6%)	2 (4%)
Give you written materials on **how to manage the behavior of your relative or friend**?	46	33 (72%)	5 (11%)	8 (17%)
Give you written materials **to help you better understand your relative or friend's condition or illness**?	46	37 (80%)	7 (15%)	2 (4%)
Give you written materials on **how to care for yourself** while you're caring for your relative or friend?	47	34 (72%)	6 (13%)	7 (15%)
Give you any written materials on **how to involve the entire family** in caring for your relative or friend?	48	31 (65%)	6 (13%)	11 (23%)
Call you at a later time to see how you were doing?	47	44 (94%)	2 (4%)	1 (2%)

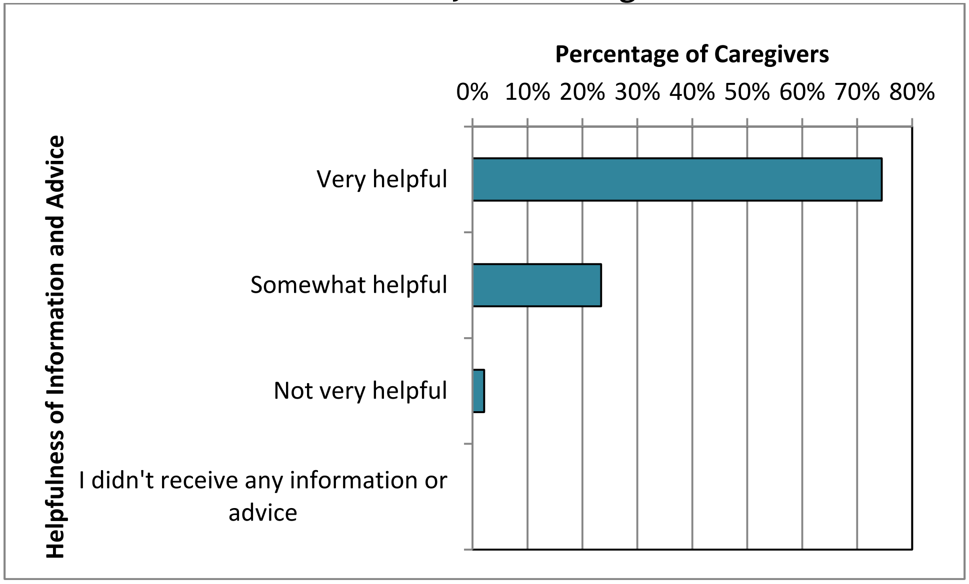
Care managers also provided caregivers with referrals during the home visit. Table 20 lists the kinds of referrals caregivers remember receiving and whether they acted on them. In most cases, about half the caregivers reported following up on the referral. Eighty-two percent of caregivers said that the care manager gave them information, advice, or referrals that were especially helpful, such as information on dementia and Alzheimer's disease, legal assistance, respite care, adult day care, hospice services, handyman services, advocacy groups, support groups, and the Veteran's Administration.

When asked how helpful the information and advice was that they received on caregiving, 74 percent of caregivers said the information was very helpful and 23 percent said it was somewhat helpful (Figure 29).

Table 20. Care Manager Referrals during the Home Visit as Reported by the Caregiver

The Care Manager Referred Me to:		Have I Contacted the Referral?	
	% (n)	% (n)	% (n)
Health care providers *(e.g., doctor, nurse, psychologist, social worker, clinic)*	Yes: 43% (20)	Yes: 44% (7)	No: 56% (9)
	No: 57% (26)		
Service organizations *(e.g., senior center, county health department)*	Yes: 65% (30)	Yes: 46% (12)	No: 54% (14)
	No: 35% (16)		
Support groups *(e.g., in-person or on-line groups of caregivers who share experiences and support one another)*	Yes: 38% (17)	Yes: 14% (2)	No: 86% (12)
	No: 62% (28)		
Respite services *(e.g., help with your relative or friend while you take time off)*	Yes: 65% (30)	Yes: 44% (12)	No: 56% (15)
	No: 35% (16)		
Websites *(e.g., hotlines, information on aging and caregiving, listings of agencies and services)*	Yes: 53% (24)	Yes: 48% (10)	No: 52% (11)
	No: 47% (21)		

Figure 29. Caregivers' Ranking of Information and Advice about Caregiving Provided by Care Manager



Care Managers' Views on the Pilot

In August 2011—six months after initiation of the Pilot—care managers were asked to complete a web-based survey on their experience with the Pilot (Appendix I). Seventeen care managers completed the survey (100 percent response rate).[10] Findings are discussed below.

Care Manager Training

As shown in Table 21, care managers generally agreed that the training they had participated in at the outset of the Pilot was useful in preparing them to work with caregivers.

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[10] Only care managers who worked in the field with care recipients and caregivers and were responsible for recruiting caregivers into the Pilot were asked to participate in the survey. Supervisors without field responsibility were not asked to complete the survey.

Table 21. Care Managers' Views on the Pilot Training Six Months Later*

	Strongly Agree	Agree	Somewhat Agree	Somewhat Disagree	Disagree	Strongly Disagree
The training provided useful information on the challenges caregivers face.	1 (6%)	12 (71%)	4 (23%)	0 (0%)	0 (0%)	0 (0%)
The training provided useful information on how care managers can support caregivers.	0 (0%)	9 (53%)	8 (47%)	0 (0%)	0 (0%)	0 (0%)
The training prepared me to work with caregivers in the pilot.	0 (0%)	9 (53%)	8 (47%)	0 (0%)	0 (0%)	0 (0%)
The training prepared me to administer the *Caregiver Questionnaire.*	1 (6%)	12 (71%)	4 (24%)	0 (0%)	0 (0%)	0 (0%)
The training prepared me to complete the *Caregiver Action Plan*.	1 (6%)	11 (65%)	5 (29%)	0 (0%)	0 (0%)	0 (0%)
The training prepared me to select appropriate resource materials for caregivers.	0 (0%)	8 (47%)	8 (47%)	1 (6%)	0 (0%)	0 (0%)
The training provided adequate instructions on how to submit documents to the evaluators at The Hilltop Institute.	1 (6%)	14 (82%)	2 (12%)	0 (0%)	0 (0%)	0 (0%)
My questions and concerns were addressed during the teleconference with my colleagues and Pilot partners about 2 months after training	2 (12%)	11 (65%)	4 (24%)	0 (0%)	0 (0%)	0 (0%)

*n=17. Percentages may not add up to 100 due to rounding.

Experiences in the Field: Caregiver Questionnaire and Action Plan

To recruit caregivers into the Pilot, most care managers (88 percent) telephoned the caregiver prior to the home visit and 12 percent sent a mailing to the caregiver prior to the home visit (Figure 30). Most care managers (94 percent) used the Program Description provided by FCA to familiarize caregivers with the Pilot during the home visit (Figure 31).

Figure 30. How Care Managers Approached Caregivers about Participating in the Pilot

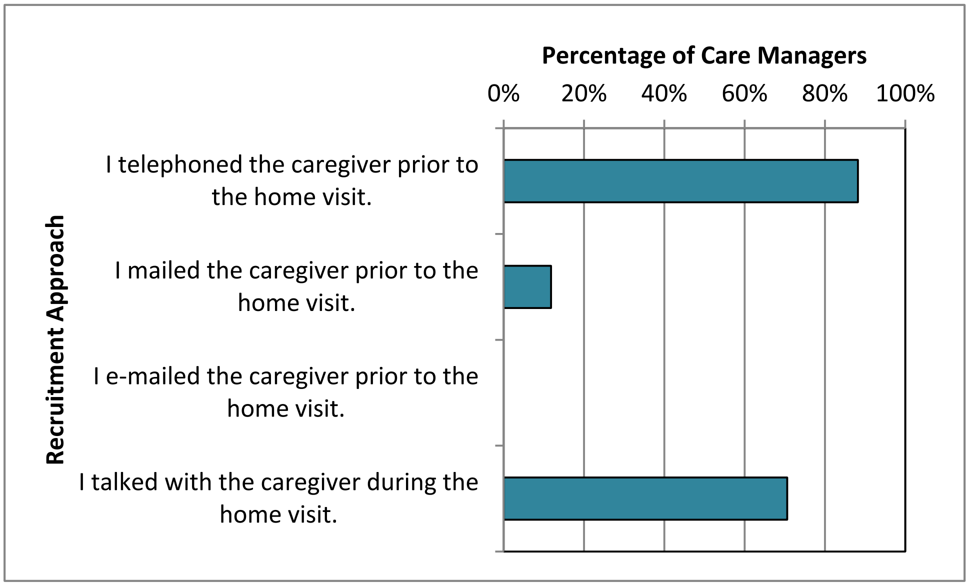
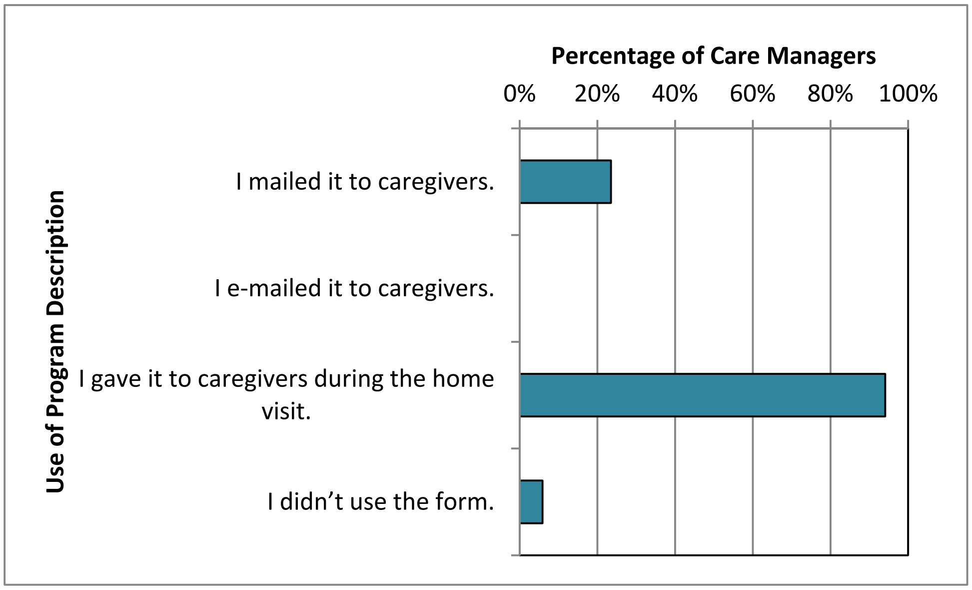


Figure 31. How Care Managers Used the *Program Description* to Introduce Caregivers to the Pilot



The survey asked each care manager how many caregivers that they had approached refused to participate in the Pilot. Six care managers (35 percent) had no refusals; three (18 percent) reported one refusal; four (23 percent) reported two refusals; and four (23 percent) reported three refusals (Figure 32).

The Caregiver Questionnaire (Appendix A) was designed to be self-administered by the caregiver. When care managers were asked how often caregivers requested assistance in completing the questionnaire, care managers reported a number of requests (Table 22). The most frequently cited reason for requesting assistance was "did not understand a specific question(s)" (88 percent) (Figure 33). Twenty-nine percent of care managers cited the "low literacy level" of the caregiver and 23 percent said that the caregiver was "concerned about relative/friend's feelings or reaction." Other reasons cited by care managers were caregivers feeling overwhelmed by paperwork and the questions were not clear.

Figure 32. The Number of Caregivers Approached by Each Care Manager Who Refused to Participate in the Pilot

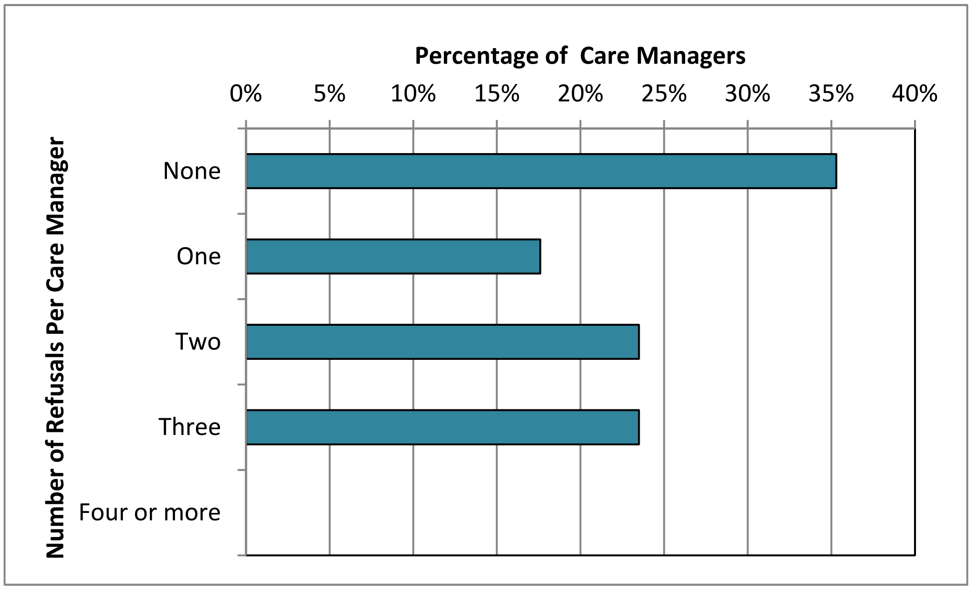
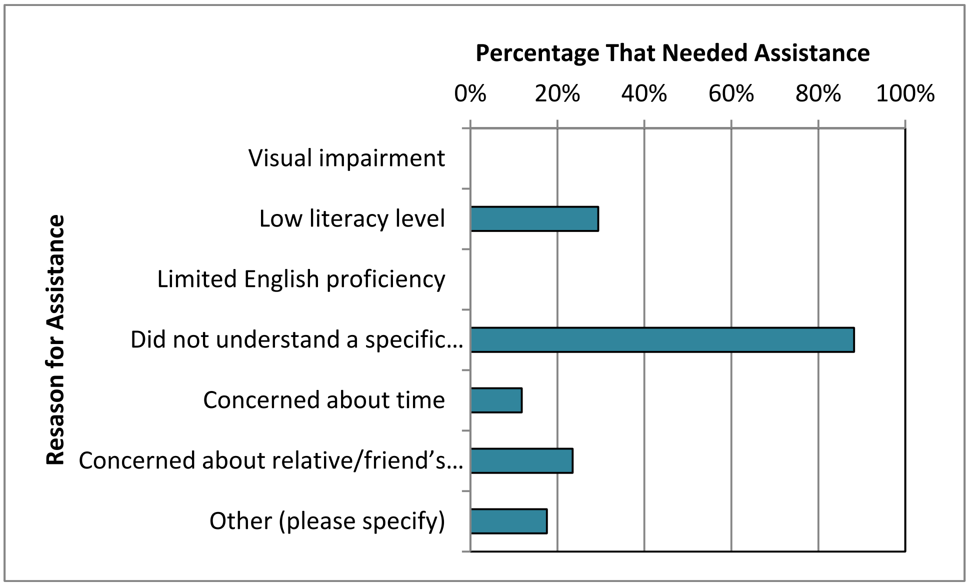


Table 22. Assistance Provided to Caregivers in Completing the *Caregiver Questionnaire**

	Always	Frequently	Sometimes	Rarely	Never
How often did you assist caregivers in completing the *Caregiver Questionnaire*?	1 (6%)	7 (41%)	4 (24%)	5 (29%)	0 (0%)

*n=17. Percentages may not add up to 100 due to rounding.

Figure 33. Reasons Caregivers Asked Care Managers for Assistance in Completing the *Caregiver Questionnaire*



After the caregiver completed the Caregiver Assessment, the care manager completed the Caregiver Action Plan (Appendix B). As shown in Table 23, most care managers agreed that completing the Caregiver Action Plan was straightforward and it served as a useful guide, although three (18 percent) disagreed about the plan's usefulness.

Table 23. Care Managers' Views on the *Caregiver Action Plan**

	Strongly Agree	Agree	Somewhat Agree	Somewhat Disagree	Disagree	Strongly Disagree
I understood how to interpret a caregiver's responses to the *Caregiver Questionnaire* in order to complete the *Caregiver Action Plan*.	5 (29%)	10 (59%)	2 (12%)	0 (0%)	0 (0%)	0 (0%)
The *Caregiver Action Plan* was a helpful guide in my discussions with caregivers.	0 (0%)	12 (71%)	4 (24%)	1 (6%)	0 (0%)	0 (0%)
The *Caregiver Action Plan* was a helpful guide in deciding what kind of resource materials to share with a caregiver.	1 (6%)	8 (47%)	6 (35%)	1 (6%)	1 (6%)	0 (0%)

*n=17. Percentages may not add up to 100 due to rounding.

Resource Materials Provided to Caregivers

Table 24 shows the sources used by care managers to obtain resource materials for caregivers. Sixty percent of care managers said they always or frequently used the website maintained by FCA. Eighty-five percent of care managers said they sometimes, frequently, or always consult with other care managers. When asked about resources other than what were listed in the survey question, care managers said they used information from the Pilot training, articles and other resources that they had collected themselves, and resources available in the office.

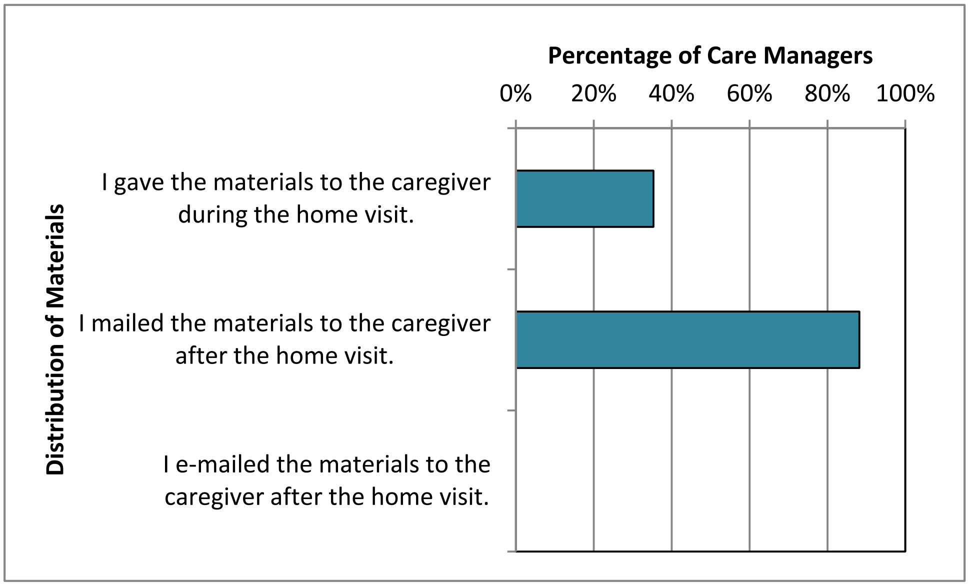
Also shown in Table 24, care managers reported giving caregivers resource materials on behavior management, direct care, informal supports, and self-care. Most care managers (88 percent) reported mailing materials to the caregiver after the home visit. Thirty-five percent said they gave materials to the caregiver during the home visit (Figure 34).

Table 24. Sources of Resource Materials Used by Care Managers and the Kinds of Materials Given to Caregivers*

	n	Always	Frequently	Sometimes	Rarely	Never
Where did you find resource materials to give to care managers?						
Pilot Project Website Maintained by Family Caregiver Alliance	15	5 (33%)	4 (27%)	1 (7%)	3 (20%)	2 (13%)
Other Websites	12	2 (17%)	1 (8%)	4 (33%)	2 (17%)	3 (25%)
Office Supervisor	11	1 (9%)	0 (0%)	5 (45%)	3 (27%)	2 (18%)
Other Care Managers	13	1 (8%)	2 (15%)	8 (62%)	0 (0%)	2 (15%)
New Jersey DACS Staff	12	0 (0%)	0 (0%)	2 (17%)	1 (8%)	9 (75%)
Other (*please specify*):	10	2 (20%)	1 (10%)	2 (20%)	0 (0%)	5 (50%)
How often did you give caregivers resource materials on the following topics?						
Behavior Management (e.g., dementia, anger, sexuality)	17	1 (6%)	9 (53%)	6 (35%)	1 (6%)	0 (0%)
Direct Care (e.g., assistive technology, incontinence, dressing, grooming)	17	2 (12%)	3 (18%)	6 (35%)	5 (29%)	1 (6%)
Informal Supports (e.g., hiring in-home help, family participation)	17	2 (12%)	4 (24%)	6 (35%)	3 (18%)	2 (12%)
Self Care (e.g., stress management, depression)	17	4 (24%)	11 (65%)	2 (12%)	0 (0%)	0 (0%)

*Percentages may not add up to 100 due to rounding.

Figure 34. How Care Managers Gave Resource Materials to Caregivers



When asked if there were additional resource materials that they would have liked to have had on the FCA website, care managers listed: information on caregiver support groups and other local resources that assist caregivers; information on encouraging siblings to participate in caregiving; less information on Alzheimer’s disease and dementia and more information on other topics; and information on traumatic brain injury, multiple sclerosis, and cerebral palsy. One care manager suggested condensing the materials because caregivers are pressed for time and often feel overwhelmed with too much information. Another care manager said that many caregivers have been caring for their relative or friend for many years and have settled into a routine; receiving information and referrals when one first becomes a caregiver is when caregivers are likely to appreciate the help the most.

In designing the Pilot, one of the concerns was the care manager being able to talk candidly with the caregiver during the home visit while the care recipient was present. In the survey, care managers were asked if they experienced difficulty in talking with the caregiver. Forty-two percent said “frequently” or “sometimes,” while 59 percent said “rarely” or “never” (Table 25). When asked about strategies they used to talk with the caregiver, most said they talked with the caregiver in another room or followed up after the home visit by telephone, mail, or e-mail.

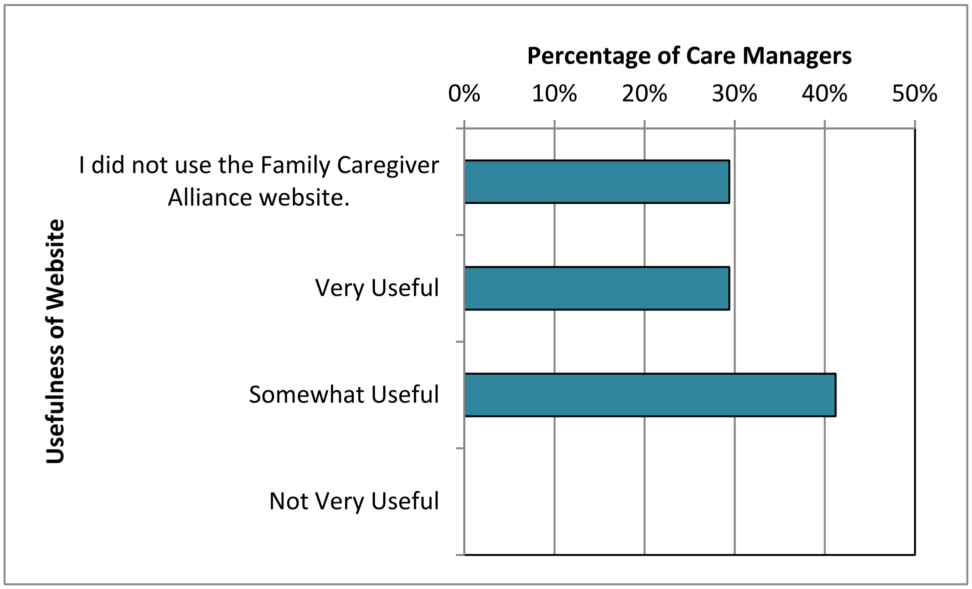
Table 25. Care Managers' Strategies for Talking with the Caregiver in the Care Recipient's Presence*

	Always	Frequently	Sometimes	Rarely	Never
During the home visit in which you administered the Caregiver Questionnaire, how often did you encounter difficulty in talking with the caregiver?	0 (0%)	3 (18%)	4 (24%)	9 (53%)	1 (6%)
When you encountered difficulty in talking with the caregiver in the care recipient's presence, what strategies did you use?					
I asked the caregiver to complete the *Caregiver Questionnaire* in another room.	0 (0%)	4 (24%)	4 (24%)	2 (12%)	7 (41%)
I talked with the caregiver in another room.	2 (12%)	7 (41%)	4 (24%)	2 (12%)	2 (12%)
I followed up with the caregiver by phone after the home visit.	4 (24%)	9 (53%)	3 (18%)	0 (0%)	1 (6%)
I followed up with the caregiver by mail or e-mail after the home visit.	2 (12%)	4 (24%)	3 (18%)	1 (6%)	7 (41%)

*n=17. Percentages may not add up to 100 due to rounding.

A website maintained by FCA provided care managers with links to written materials on behavior management, direct care, informal supports, and self-care. When care managers were asked how useful they found this website, 29 percent said it was very useful, 41 percent said it was somewhat useful, and 29 percent said they did not use it at all (Figure 35).

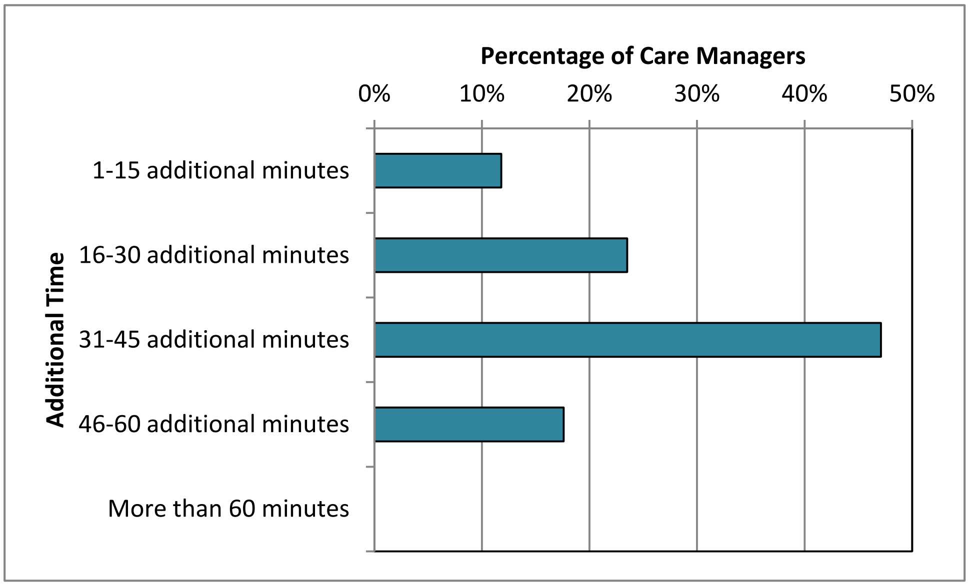
Figure 35. Care Managers' Views on the Usefulness of the Pilot Website



Care Managers’ Experiences with the Pilot

In designing the Pilot, an important consideration was the amount of additional time that would be required during the home visit for administration of the Caregiver Questionnaire, completing the Caregiver Action Plan, and developing a tailored response for each caregiver. In the survey, care managers were asked how much additional time was typically needed to carry out these tasks. Almost half of care managers (47 percent) reported 31 to 45 additional minutes and 18 percent reported 46 to 60 additional minutes (Figure 36). One care manager commented that the additional time during the home visit, plus the time spent afterwards in selecting and forwarding resource materials, was very resource-intensive; the process needs to be more sensitive to the care manager’s time.

Figure 36. Additional Time Needed During the Home Visit to Administer the Caregiver Questionnaire, Complete the Caregiver Action Plan, and Talk with the Caregiver



Finally, when queried about their experience with the Pilot, most care managers reported that caregivers welcomed the attention and support (88 percent strongly agreed, agreed, or somewhat agreed) (Table 26). There was less agreement on the extent to which caregivers found the resource materials helpful. On each of the other questions listed in Table 26 about the extent to which the Pilot helped the care managers assist caregivers, 77 percent of care managers agreed or somewhat agreed, while the remainder (24 percent) somewhat disagreed or disagreed.

Table 26. Care Managers' Views on Their Experience with the Pilot*

	Strongly Agree	Agree	Somewhat Agree	Somewhat Disagree	Disagree	Strongly Disagree
Caregivers welcomed the attention and support	2 (12%)	7 (41%)	6 (35%)	2 (12%)	0 (0%)	0 (0%)
Caregivers found the resource materials helpful	0 (0%)	2 (12%)	10 (59%)	5 (29%)	0 (0%)	0 (0%)
The pilot helped me to recognize the signs of caregiver burden	0 (0%)	2 (12%)	11 (65%)	2 (12%)	2 (12%)	0 (0%)
The pilot helped me to better understand the needs of caregivers	0 (0%)	3 (18%)	10 (59%)	2 (12%)	2 (12%)	0 (0%)
The pilot gave me practical tools to help caregivers	0 (0%)	3 (18%)	10 (59%)	3 (18%)	1 (6%)	0 (0%)
The pilot increased my knowledge of services and supports available to caregivers in my area	0 (0%)	4 (24%)	9 (53%)	2 (12%)	2 (12%)	0 (0%)
Overall, participating in the pilot was a positive experience for me	1 (6%)	3 (18%)	10 (59%)	3 (18%)	0 (0%)	0 (0%)

* Percentages may not add up to 100 due to rounding.

When asked for suggestions about how the program model could be improved to simplify implementation at the county level, care managers offered these suggestions: survey local areas to determine needs and provide national and local resources that address those needs; provide information and resources on more topics; caregivers are most interested in learning about additional home care services and respite services, as this is their primary need; some of the reading materials were long and caregivers may benefit from briefer written materials; and provide funds for CPR/first aid classes and respite care.

Perceptions of Agency Staff and Pilot Partners

In August and September 2011, Hilltop conducted telephone interviews with New Jersey agency staff and partners to obtain their views on Pilot implementation. Interview findings are discussed below. Interviewees are listed in Appendix E.

New Jersey Agency Staff

Caregiver Support is a Priority. Leadership of New Jersey DACS has had a longstanding commitment to rebalancing and innovation in the delivery of LTSS. The state's ADRCs are nationally recognized and state supports caregivers through options counseling, the *CaregiverNJ* website (http://www.nj.gov/caregivernj/), and other programs. The leadership recognizes that care managers want to do as much as they can for caregivers and works to support them in this endeavor. From the outset, the leadership enthusiastically supported New Jersey's participation in the Pilot. They believed the Pilot would support the state's rebalancing efforts, broaden the mission of the aging network, and help educate nursing and social work professionals.

Competing Priorities. From the beginning, the state encountered many competing priorities in implementing the Pilot. The state had a new governor and was dealing with a major budget crisis. Gradual reductions in state and county staff had been underway for a number of years. Meanwhile, state and county staff were engaged in launching ADRCs statewide; implementing the NJ CHOICE Care Management Assessment tool; developing the Social Assistance Management System™ (SAMS) electronic client tracking system to automate the ADRC processes (this involved training more than 1,000 users and 300 providers throughout the state); launching the Community Living Program which included a partnership with the Veteran's Administration; and consolidating three waivers into the GO Waiver. When the Pilot was finally underway in the first half of 2011, the state was engaged in planning for its new Comprehensive Waiver, an 1115 waiver that will bring LTSS into managed care.

It took more than a year to recruit a group of counties willing to devote the staff and other resources (including travel) required for participation in the Pilot. There was push-back from many counties because of the other demands on them and because no additional reimbursement was being provided under the Pilot. The original plan was to involve only counties with fully-implemented ADRCs, but because an insufficient number expressed interest, non-ADRC counties were invited to participate. The original plan also called for enrolling only care recipients who were new to the GO Waiver or JACC, but the counties said this was not feasible if they were to meet Pilot enrollment goals. Thus, a decision was made to enroll caregivers of both new and existing GO and JACC clients.

Too Early to Tell. DACS staff reported limited feedback from the counties during the Pilot, which generally implies that the counties do not have strong feelings one way or the other about the program in question. DACS staff also reported feeling "left out" of the Pilot because the activity was at the county level, with feedback bypassing the state level and going directly to Pilot partners. They were anxious to be informed of findings from the surveys of care managers and caregivers.

Thoughts on the Pilot. DACS staff said that care managers always want to do as much as possible for clients and their caregivers and looked forward to participating in the Pilot. However, administering the Caregiver Questionnaire, talking with the caregiver, and sharing informational materials significantly extended the time required for a home visit and related follow-up work.

DACS staff provided positive remarks about the training provided to care managers and supervisors. However, they said that the training did not specifically cover the resource materials that were to be provided to caregivers, and that care managers could have benefited from having materials on additional topics. A number of staff said the materials were too focused on Alzheimer's disease and dementia. It might be helpful to focus on topics that are not included in options counseling and that are pertinent to the caregiver's needs, such as family medical leave. Some care managers reported that it was tedious to download materials from the FCA website to take into the field.

In New Jersey, assessors are typically responsible for options counseling, so providing options counseling to caregivers is a new role for many care managers. Care managers are by nature very interactive with their clients, and providing only written materials may seem impersonal to some. Some of the limited feedback received by DACS staff indicated that caregivers may not have gotten what they needed and that the care managers were looking for "more" to give to caregivers, although the "more" was not clearly defined. DACS staff also voiced a need for more information on local resources to share with caregivers.

In New Jersey, there is no waiting list for the GO Waiver, but JACC has a long waiting list. Individuals eligible for JACC are those who might otherwise "fall through the cracks," in that they have functional deficits but do not have incomes low enough to qualify for Medicaid. Services provided to JACC clients are also more limited than Medicaid waiver services. Targeting the caregivers of JACC applicants who are on the waiting list and not receiving any services may be an effective use of limited resources.

DACS staff said that in order for the counties to commit long term to continuing the Pilot, it will be important for the counties to receive positive feedback from the caregivers. In addition, counties would also insist on funding for the program. There is never much enthusiasm from the counties when their responsibilities are increased with no additional reimbursement. The ideal situation would be figuring out how to position the caregiver as the client (instead of the care recipient) and reimbursing care managers for services provided to the caregiver. This has obvious challenges under a Medicaid waiver program, but perhaps Title IIE funds could be used. Some Area Agencies on Aging (AAAs) have a caregiver specialist; maybe this position could be used to provide direct support to caregivers.

There is uncertainty and fear surrounding implementation of the new 1115 Comprehensive Waiver. In the new managed care environment, it is possible that managed care organizations (MCOs) will take over care management responsibilities from the counties and the county workers may lose their jobs. If MCOs become responsible for LTSS in New Jersey, they will likely implement proprietary program models for care management.

Pilot Partners

The Pilot Promotes Good Professional Practice. The Pilot was intended to make care managers more aware of the needs of caregivers and to promote good professional practice; it was not intended to be an "intervention" that resulted in measurable behavior change in caregivers. It is good practice to ask questions of the caregiver, and the Caregiver Questionnaire provides a good tool for formalizing this process. The Pilot partners reported an enthusiastic response to the Pilot from the New Jersey leadership.

The NJ CHOICE instrument is an excellent assessment tool, but it focuses on the care recipient and does not collect information on caregivers' needs. By using both NJ CHOICE and the Caregiver Questionnaire, care managers can obtain a comprehensive profile of both the client and the caregiver and respond to the needs of both. The Caregiver Assessment is believed to be far more comprehensive than any other assessment used by states. A next step related to Pilot expansion might be to survey the states to see exactly what kind of caregiver assessments they are now using. Also, in New Jersey, administering the Caregiver Questionnaire electronically and integrating it into the SAMS client record would be beneficial if the Pilot is expanded.

The Pilot partners were surprised by the high number of functional deficiencies in the care recipients and responded that this reinforces the need for caregiver supports.

However, "if you assess it, you must address it." Pilot partners expressed concern about whether there are sufficient resources available to meet the needs of caregivers. Also, technical assistance will be required for any expansion of the Pilot, particularly in implementing it in diverse settings.

Local Resource Guides are Needed. Each county needs a local resource guide that is updated regularly and easy to access. Care managers need to know what services are available; without centralized communication, they can easily be out of the loop. The guides should include services targeted at both the care recipient and the caregiver. Resources should specifically target Medicaid clients and their caregivers, who typically have low incomes and more limited education. For example, web-based resources may not be accessible to this population. The guides should take into account that care manager knowledge may reflect the mission and priorities of the employing agency (e.g., Medicaid, AAA, visiting nurses service) and may be focused more on medical services than social services and supports. It is important for the resource guide to include services outside the county's borders; counties can be very parochial, thinking not much is accessible to them outside their borders.

Pilot partners emphasized that in developing resource materials, it is important to be sensitive to language. For example, many caregivers are frightened by terms such as "dementia" and "Alzheimer's disease" even though their relative or friend may have such a condition.

Who are the Caregivers? The Pilot has been beneficial in that it has provided an opportunity to better understand who the caregivers in New Jersey are and the kinds of help they are (or are not) receiving. There is not currently much information on the caregivers of Medicaid clients. The Pilot partners said some care managers mentioned that caregivers may have been reluctant to participate in the Pilot, fearing that services for the relative or friend may be affected.

Training Care Managers. The training conducted as part of the Pilot was intended to bring about a "mind shift" among care managers, teaching them to view caregivers as clients. Care managers should receive regular training on assisting caregivers. Perhaps those who exhibit this "mind shift" could be recruited to train other care managers.

Pilot partners reported some disappointment with the training sessions in that a number of the care managers tended to be passive and not actively engaged in the subject matter and discussions. Generally the care managers from the larger counties were more engaged. The lack of engagement may have been caused by care managers feeling pressured by their responsibilities or perhaps not realizing the extent of caregiver burden.

FCA Website. Pilot partners expressed interest in expanding the Pilot website to include articles on more topics, training scenarios or mini-case studies, and links to more detailed information. As the Pilot was ending, the staff member responsible for the website left the sponsoring agency and resources were not available to reactivate the site.

Other Training Opportunities. Video content could be developed for care managers to share with caregivers. DVDs on self care could be distributed to caregivers. Online support groups are an efficient means for providing support services and may meet the needs of busy caregivers. Webinars and teleconferencing could be used to train care managers.

Summary and Recommendations

The *New Jersey Care Partner Support Pilot Program* aimed to 1) improve the knowledge and skills of family caregivers caring for relatives and friends enrolled in the GO Waiver and JACC and 2) increase awareness among care managers of the needs of caregivers and provide these professionals with practical tools to assist the caregivers of their clients. Twenty care managers and supervisors from four New Jersey counties participated in training sessions that provided an overview of caregiving, challenges caregivers face, and caregiver stress and barriers. Care managers received instruction on how to administer a specially designed Caregiver Questionnaire during a home visit to assess the caregiver’s situation and needs and to provide a tailored package of information and referrals. Care managers recruited 86 caregivers to participate in the Pilot over a four-month period. In contrast to most prior caregiver support demonstrations, these caregivers did not actively seek support, but were instead sought out by the care manager. Follow-up surveys with both the care managers and caregivers, as well as telephone interviews with New Jersey agency staff and Pilot partners, assessed the experience with the Pilot.

The 86 caregivers ranged in age from 28 to 85 years and had been caring for their relative or friend on average for about 9 years. Care recipients were enrolled in the Medicaid GO Waiver or JACC, so they had low incomes. All care recipients had functional deficiencies in at least three areas, 21 percent had deficiencies in seven areas, and 65 percent had cognitive deficits, so care recipients were in need of extensive supports. Eighty-two percent of caregivers reported that the care manager gave them information, advice, or referrals that were especially helpful; three-quarters said the information was very helpful; and a quarter said it was somewhat helpful. Clearly caregivers welcomed the attention and assistance received from care managers.

The care managers were experienced professionals, averaging 9.1 years of experience. Eighty percent were social workers and 20 percent were nurses. Half reported personal experience as a caregiver for a relative or friend. An overwhelming majority said that the role of care managers includes providing support to caregivers, but many said they did not have sufficient time and resources to devote to caregivers.

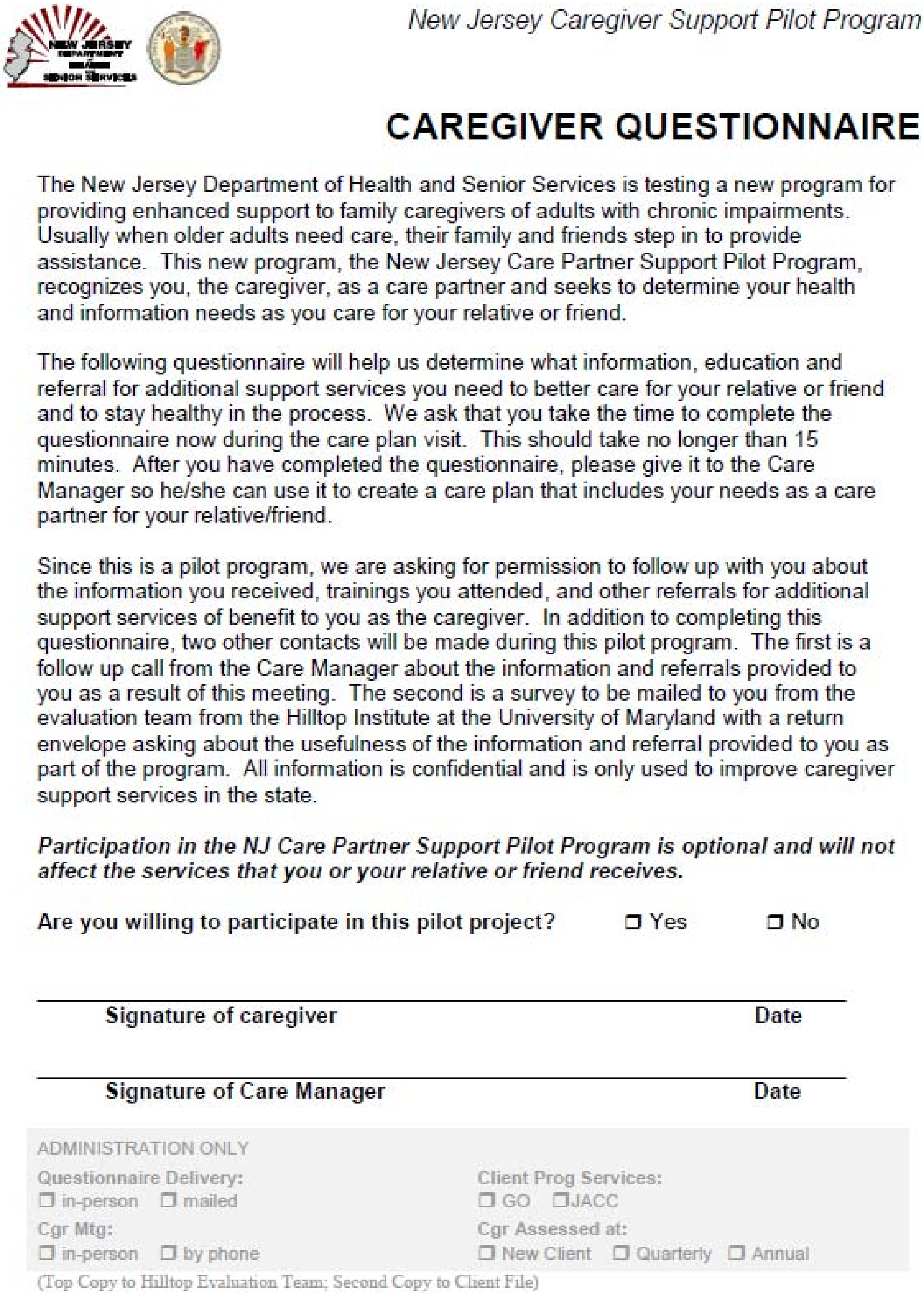
New Jersey is interested in expanding the Pilot. AARP and AoA are considering how it might be further developed and possibly replicated in other states. In moving forward, New Jersey, AARP, and AoA should consider the following:

- **Develop a system for providing up-to-date information on local resources for caregivers.** While the Pilot provided care managers with written materials and articles on direct care, behavior management, self care, and informal supports, care managers voiced a need for referrals to local programs and services available to caregivers. A particular challenge is compiling and regularly updating information on relevant local programs and supports. States need a system for collecting, compiling, and continuously updating information on community resources that is easily accessible to professionals in the field and caregivers alike. New ways to use emerging media (e.g., online chat groups, support groups, and professional assistance) should be explored. States should also explore how to integrate these needs into one-stop and single-point-of-entry systems. It will be especially important to design systems and resources that meet the needs of busy and stressed caregivers with low incomes who may not be "plugged in" to the new media. Focus groups with these caregivers may shed more light on their needs.
- **Target caregivers who are new to the system.** Caregivers of new Medicaid clients must learn to navigate the LTSS system and how to care for their relative or friend. Targeting limited resources on these caregivers may be an effective strategy for states in the current budget climate. Caregivers of individuals with low incomes who do not qualify for Medicaid are also in need of support (e.g., JACC clients and their caregivers). Providing this group with assistance could potentially delay nursing home placements and spend-down to Medicaid.
- **Incorporate caregiver assessment into the client assessment process.** As many states move to develop comprehensive standard assessment tools required by programs authorized under the Affordable Care Act (e.g., State Balancing Incentive Payments, §10202), states should be encouraged to incorporate caregiver assessment into these new tools. New Jersey could consider adding a caregiver module to NJ CHOICE and having assessors (instead of care managers) conduct the caregiver assessment. Assessors also have responsibility for options counseling, so they could be trained to counsel caregivers as well as clients. This could make the caregiver assessment process more efficient.
- **Position caregivers as clients and provide reimbursement for caregiver services.** New Jersey agency staff repeatedly stated that the lack of reimbursement for providing support to caregivers was a barrier to expanding the Pilot. This is likely to be a major

issue for states across the country. New Jersey agency staff suggested a new paradigm in which caregivers are the clients and care managers are reimbursed for providing services to the caregiver. Working with the Centers for Medicare and Medicaid Services (CMS), states could explore providing services to the caregivers of Medicaid clients through Section 1915(c) home and community-based services waiver programs, through 1115 demonstration waivers, or as demonstration services under the Money Follows the Person program. Many states (including New Jersey with its Comprehensive Waiver) have or are developing Medicaid managed LTSS programs under 1115 demonstration waivers or concurrent 1915(b)(c) waivers. States could work with MCOs to find creative ways to provide services to caregivers, perhaps as value-added services (i.e., additional services provided by MCOs under the capitation payment arrangement) or as a component of "service coordination," which is typically included in managed care administrative costs. Another option is for states to work with AoA to explore using Older American Act (OAA) Title IIIE funds for reimbursement for services provided to individual caregivers, especially now that the OAA is up for reauthorization.

In conclusion, the *New Jersey Care Partner Support Pilot Program* provided important insights into how states might provide support to caregivers. The effort in New Jersey warrants further development and expansion, and lessons learned from the Pilot can guide other states in pursuing caregiver initiatives.

Appendix A. Caregiver Questionnaire



New Jersey Caregiver Support Pilot Program

CAREGIVER QUESTIONNAIRE

The New Jersey Department of Health and Senior Services is testing a new program for providing enhanced support to family caregivers of adults with chronic impairments. Usually when older adults need care, their family and friends step in to provide assistance. This new program, the New Jersey Care Partner Support Pilot Program, recognizes you, the caregiver, as a care partner and seeks to determine your health and information needs as you care for your relative or friend.

The following questionnaire will help us determine what information, education and referral for additional support services you need to better care for your relative or friend and to stay healthy in the process. We ask that you take the time to complete the questionnaire now during the care plan visit. This should take no longer than 15 minutes. After you have completed the questionnaire, please give it to the Care Manager so he/she can use it to create a care plan that includes your needs as a care partner for your relative/friend.

Since this is a pilot program, we are asking for permission to follow up with you about the information you received, trainings you attended, and other referrals for additional support services of benefit to you as the caregiver. In addition to completing this questionnaire, two other contacts will be made during this pilot program. The first is a follow up call from the Care Manager about the information and referrals provided to you as a result of this meeting. The second is a survey to be mailed to you from the evaluation team from the Hilltop Institute at the University of Maryland with a return envelope asking about the usefulness of the information and referral provided to you as part of the program. All information is confidential and is only used to improve caregiver support services in the state.

Participation in the NJ Care Partner Support Pilot Program is optional and will not affect the services that you or your relative or friend receives.

Are you willing to participate in this pilot project? ☐ Yes ☐ No

Signature of caregiver **Date**

Signature of Care Manager **Date**

ADMINISTRATION ONLY

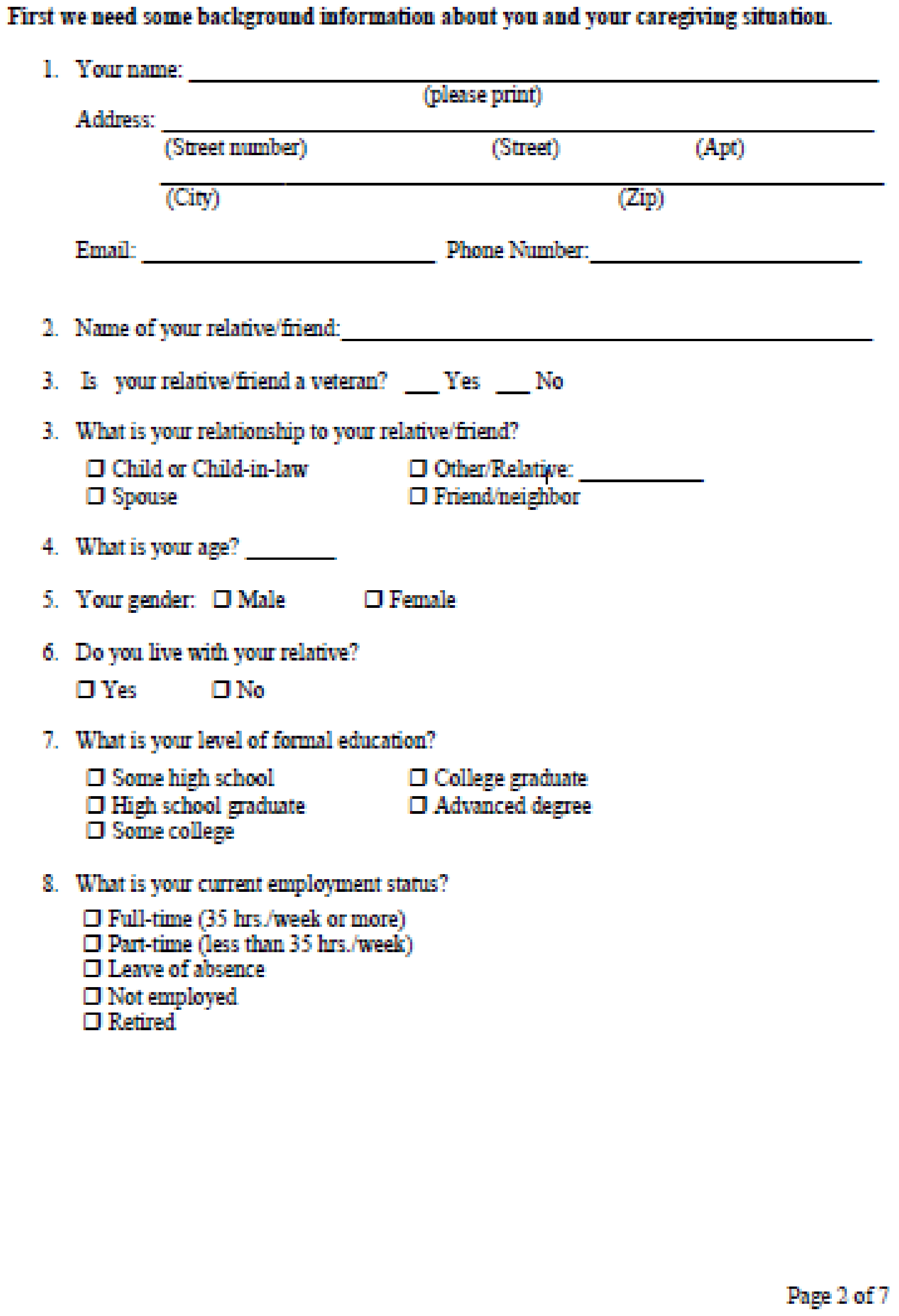
Questionnaire Delivery:
☐ in-person ☐ mailed

Cgr Mtg:
☐ in-person ☐ by phone

Client Prog Services:
☐ GO ☐JACC

Cgr Assessed at:
☐ New Client ☐ Quarterly ☐ Annual

(Top Copy to Hilltop Evaluation Team; Second Copy to Client File)



First we need some background information about you and your caregiving situation.

1. Your name: ____
   (please print)

   Address: ____
   (Street number) (Street) (Apt)

   ____
   (City) (Zip)

   Email: ______________________ Phone Number: ____________________

2. Name of your relative/friend: ____

3. Is your relative/friend a veteran? ___ Yes ___ No

3. What is your relationship to your relative/friend?

   ☐ Child or Child-in-law
   ☐ Spouse
   ☐ Other/Relative: __________
   ☐ Friend/neighbor

4. What is your age? _______

5. Your gender: ☐ Male ☐ Female

6. Do you live with your relative?

   ☐ Yes ☐ No

7. What is your level of formal education?

   ☐ Some high school
   ☐ High school graduate
   ☐ Some college
   ☐ College graduate
   ☐ Advanced degree

8. What is your current employment status?

   ☐ Full-time (35 hrs./week or more)
   ☐ Part-time (less than 35 hrs./week)
   ☐ Leave of absence
   ☐ Not employed
   ☐ Retired

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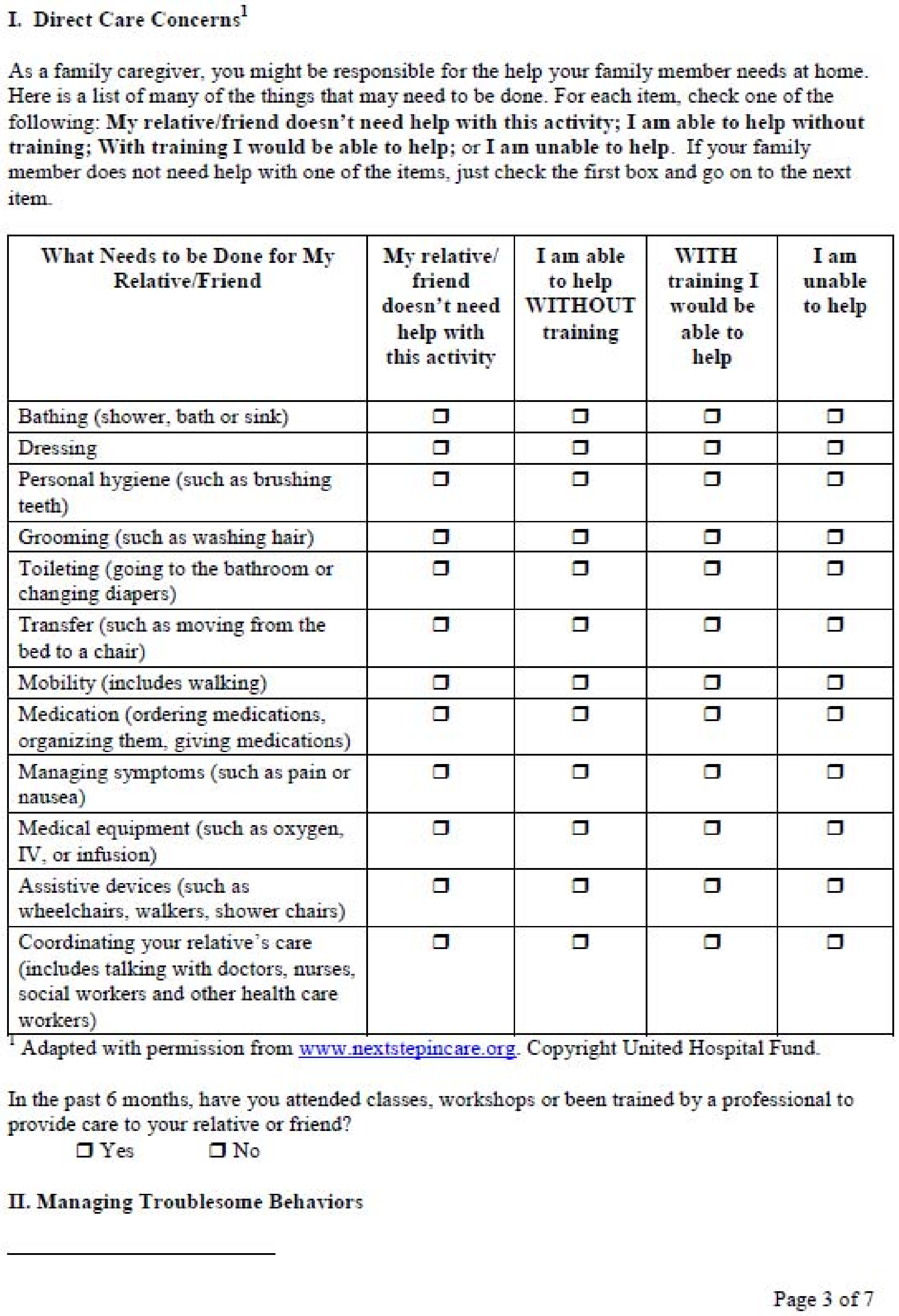


I. Direct Care Concerns[1]

As a family caregiver, you might be responsible for the help your family member needs at home. Here is a list of many of the things that may need to be done. For each item, check one of the following: **My relative/friend doesn't need help with this activity; I am able to help without training; With training I would be able to help;** or **I am unable to help**. If your family member does not need help with one of the items, just check the first box and go on to the next item.

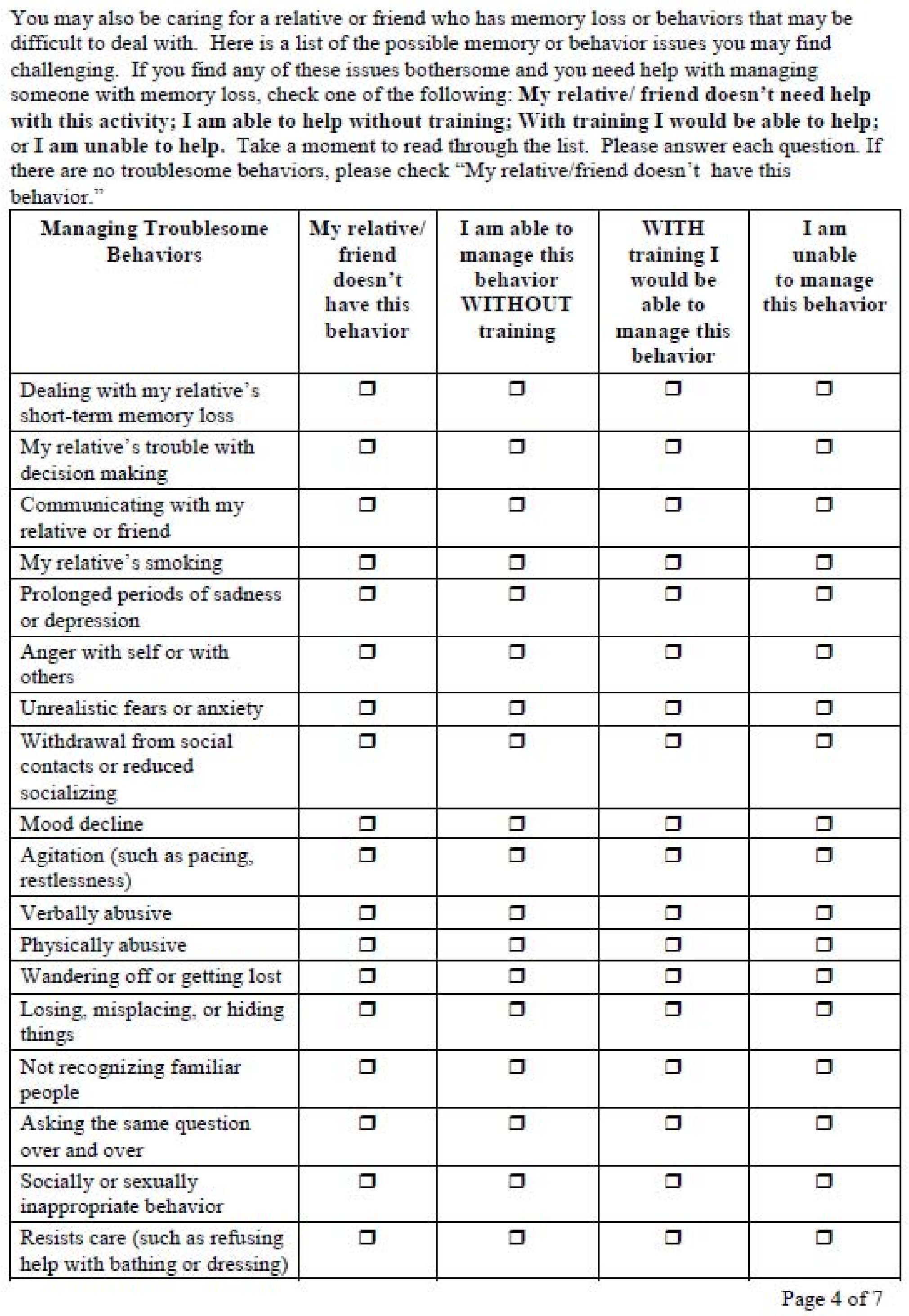
What Needs to be Done for My Relative/Friend	My relative/ friend doesn't need help with this activity	I am able to help WITHOUT training	WITH training I would be able to help	I am unable to help
Bathing (shower, bath or sink)	☐	☐	☐	☐
Dressing	☐	☐	☐	☐
Personal hygiene (such as brushing teeth)	☐	☐	☐	☐
Grooming (such as washing hair)	☐	☐	☐	☐
Toileting (going to the bathroom or changing diapers)	☐	☐	☐	☐
Transfer (such as moving from the bed to a chair)	☐	☐	☐	☐
Mobility (includes walking)	☐	☐	☐	☐
Medication (ordering medications, organizing them, giving medications)	☐	☐	☐	☐
Managing symptoms (such as pain or nausea)	☐	☐	☐	☐
Medical equipment (such as oxygen, IV, or infusion)	☐	☐	☐	☐
Assistive devices (such as wheelchairs, walkers, shower chairs)	☐	☐	☐	☐
Coordinating your relative's care (includes talking with doctors, nurses, social workers and other health care workers)	☐	☐	☐	☐

[1] Adapted with permission from www.nextstepincare.org. Copyright United Hospital Fund.

In the past 6 months, have you attended classes, workshops or been trained by a professional to provide care to your relative or friend?

☐ Yes ☐ No

II. Managing Troublesome Behaviors



You may also be caring for a relative or friend who has memory loss or behaviors that may be difficult to deal with. Here is a list of the possible memory or behavior issues you may find challenging. If you find any of these issues bothersome and you need help with managing someone with memory loss, check one of the following: **My relative/ friend doesn't need help with this activity; I am able to help without training; With training I would be able to help; or I am unable to help.** Take a moment to read through the list. Please answer each question. If there are no troublesome behaviors, please check "My relative/friend doesn't have this behavior."

Managing Troublesome Behaviors	**My relative/ friend doesn't have this behavior**	**I am able to manage this behavior WITHOUT training**	**WITH training I would be able to manage this behavior**	**I am unable to manage this behavior**
Dealing with my relative's short-term memory loss	☐	☐	☐	☐
My relative's trouble with decision making	☐	☐	☐	☐
Communicating with my relative or friend	☐	☐	☐	☐
My relative's smoking	☐	☐	☐	☐
Prolonged periods of sadness or depression	☐	☐	☐	☐
Anger with self or with others	☐	☐	☐	☐
Unrealistic fears or anxiety	☐	☐	☐	☐
Withdrawal from social contacts or reduced socializing	☐	☐	☐	☐
Mood decline	☐	☐	☐	☐
Agitation (such as pacing, restlessness)	☐	☐	☐	☐
Verbally abusive	☐	☐	☐	☐
Physically abusive	☐	☐	☐	☐
Wandering off or getting lost	☐	☐	☐	☐
Losing, misplacing, or hiding things	☐	☐	☐	☐
Not recognizing familiar people	☐	☐	☐	☐
Asking the same question over and over	☐	☐	☐	☐
Socially or sexually inappropriate behavior	☐	☐	☐	☐
Resists care (such as refusing help with bathing or dressing)	☐	☐	☐	☐

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III. Care of Yourself

1. How is your health?

   ☐ Excellent ☐ Good ☐ Fair ☐ Poor

2. Do you have any on going health issues that stand in the way of your caring for your relative or friend?

   ☐ Yes ☐ No

   If yes, what health issues do you have? (Check all that apply):

Arthritis	☐
Asthma	☐
Back problems	☐
Cardiovascular or heart trouble	☐
Diabetes	☐
Headaches	☐
Hypertension or High blood pressure	☐
Sleep disturbance	☐
Weight gain or loss	☐
Other: ________________	☐
Other: ________________	☐

3. How long have you provided care to your relative or friend?

   ________ years

IV. Increasing formal and informal supports

1. Who currently provides you with help caring for your relative?

   (Please check all that apply.)

   ☐ Other family members
   ☐ Paid attendant
   ☐ Friends/neighbors
   ☐ No one currently helps me care for my relative
   ☐ I don't need help

2. What types of community resources have you used to help care for your relative?

   (Please check all that apply.)

   ☐ Adult day care
   ☐ Community resources (such as transportation, meal services, senior center, friendly visitor, and so on)
   ☐ Support groups
   ☐ Classes/workshops
   ☐ I have not received help from community resources
   ☐ I don't need help
   ☐ I didn't know these resources were available

3. Think of the help you get from all your family and friends in looking after your relative/friend. Please check the one response that most closely identifies your help situation:

   ☐ I receive no help from family and friends
   ☐ I receive far less help than I need from family and friends
   ☐ I receive about the right amount of help from family and friends
   ☐ I don't need any help from family and friends

4. How many hours per week do you provide care, assistance, supervision or companionship to your relative or friend? From 0 (no hours) to 168 hours (7 days/week 24 hours/day):

   _______ hours

5. On average, how many hours per week of paid help do you currently receive (including adult day care, home attendant, etc)? From 0 (no hours) to 168 hours (7 days/week 24 hours/day):

   _______ hours

6. On average how many hours per week of unpaid help do you currently receive from family, friends, or volunteers? From 0 (no hours) to 168 hours (7 days/week 24 hours/day):

_______ hours

7. From whom do you receive emotional support? (Please check all that apply.)

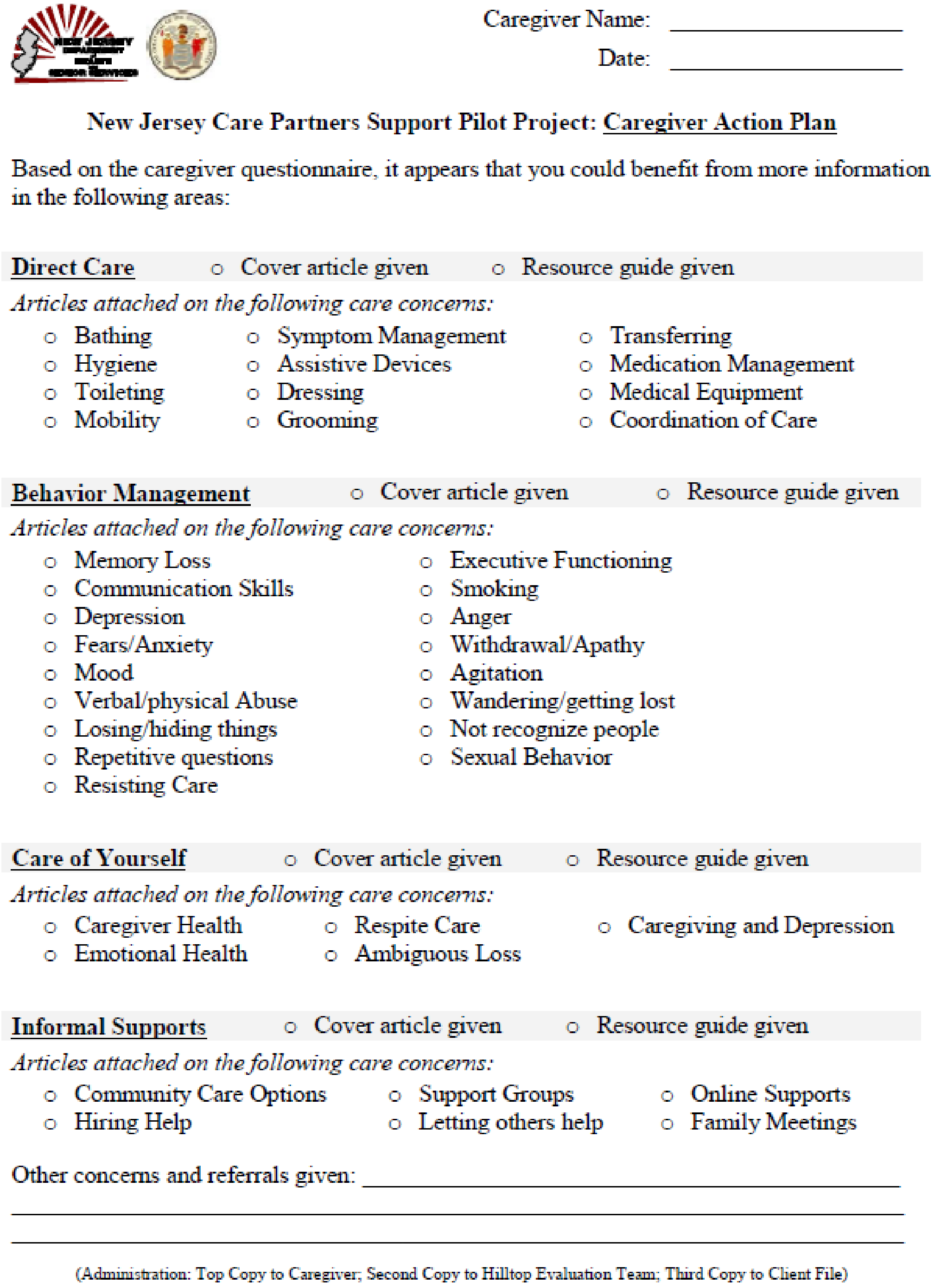
- ☐ Family
- ☐ Friends
- ☐ Co-workers
- ☐ Clergy
- ☐ Counseling
- ☐ Support group
- ☐ Other: ______________________________
- ☐ I do not receive emotional support from any source

8. How often do you feel:

	Never (0)	**Rarely (1)**	**Sometimes (2)**	**Quite Frequently (3)**	**Nearly Always (4)**
That because of the time you spend with your relative or friend that you don't have enough time for yourself?	☐	☐	☐	☐	☐
Stressed between caring for your relative or friend and trying to meet other responsibilities (work/family)?	☐	☐	☐	☐	☐
Strained when you are around your relative or friend?	☐	☐	☐	☐	☐
Uncertain about what to do about your relative or friend?	☐	☐	☐	☐	☐

The New Jersey Care Partner Support Pilot Project is project under the Professional Partners Supporting Family Caregivers Consortium funded by The John A. Hartford Foundation. The principle partners on this project are the National Center on Caregiving, Family Caregiver Alliance, the Hilltop Institute at the University of Maryland and the AARP Public Policy Institute, 2011.

Appendix B. Caregiver Action Plan



Caregiver Name: ____________________

Date: ____________________

New Jersey Care Partners Support Pilot Project: Caregiver Action Plan

Based on the caregiver questionnaire, it appears that you could benefit from more information in the following areas:

Direct Care ○ Cover article given ○ Resource guide given

Articles attached on the following care concerns:

- ○ Bathing
- ○ Hygiene
- ○ Toileting
- ○ Mobility
- ○ Symptom Management
- ○ Assistive Devices
- ○ Dressing
- ○ Grooming
- ○ Transferring
- ○ Medication Management
- ○ Medical Equipment
- ○ Coordination of Care

Behavior Management ○ Cover article given ○ Resource guide given

Articles attached on the following care concerns:

- ○ Memory Loss
- ○ Communication Skills
- ○ Depression
- ○ Fears/Anxiety
- ○ Mood
- ○ Verbal/physical Abuse
- ○ Losing/hiding things
- ○ Repetitive questions
- ○ Resisting Care
- ○ Executive Functioning
- ○ Smoking
- ○ Anger
- ○ Withdrawal/Apathy
- ○ Agitation
- ○ Wandering/getting lost
- ○ Not recognize people
- ○ Sexual Behavior

Care of Yourself ○ Cover article given ○ Resource guide given

Articles attached on the following care concerns:

- ○ Caregiver Health
- ○ Emotional Health
- ○ Respite Care
- ○ Ambiguous Loss
- ○ Caregiving and Depression

Informal Supports ○ Cover article given ○ Resource guide given

Articles attached on the following care concerns:

- ○ Community Care Options
- ○ Hiring Help
- ○ Support Groups
- ○ Letting others help
- ○ Online Supports
- ○ Family Meetings

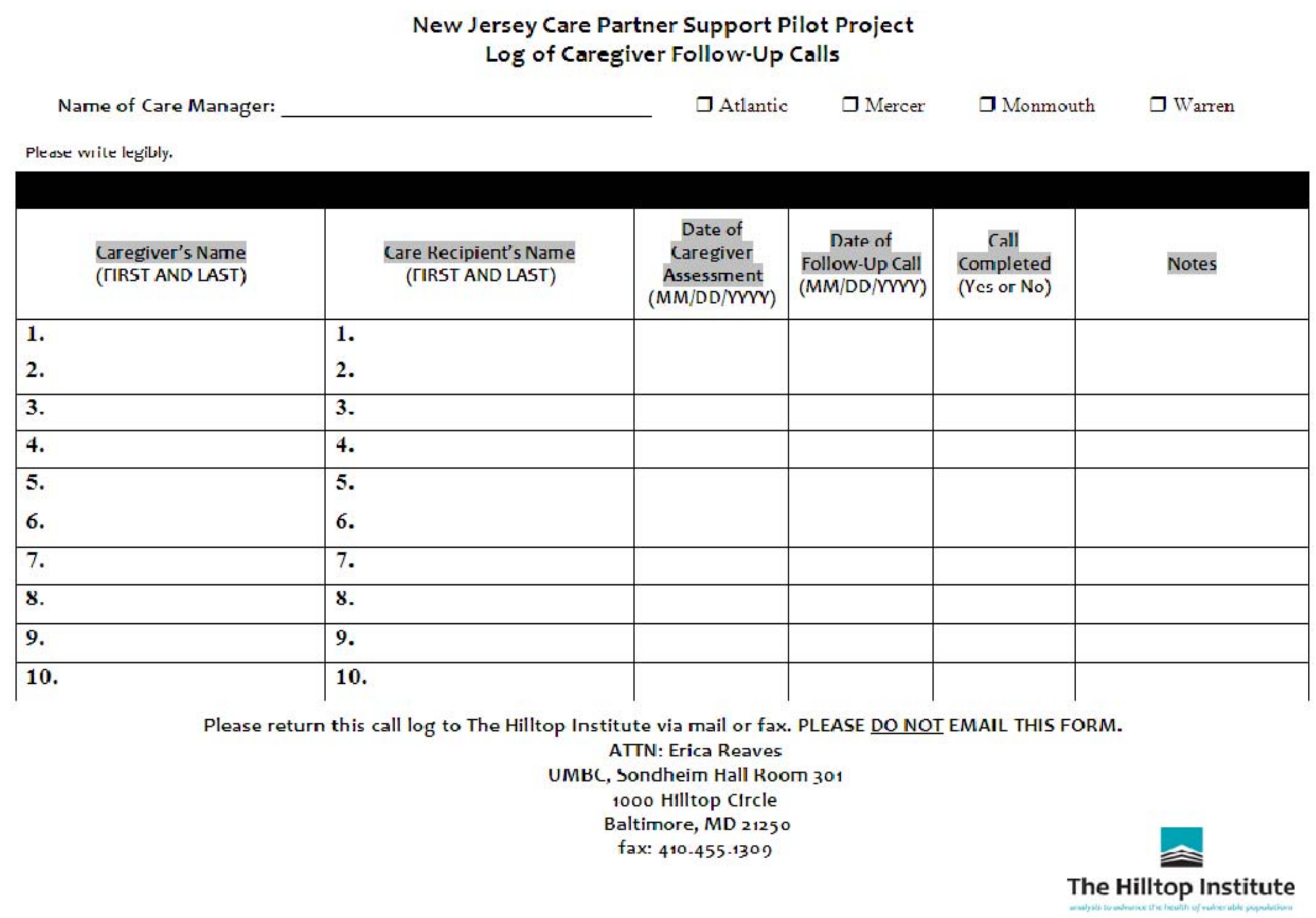
Other concerns and referrals given: ______________________________________

____

____

(Administration: Top Copy to Caregiver; Second Copy to Hilltop Evaluation Team; Third Copy to Client File)

Appendix C. Log of Caregiver Follow-Up Calls



New Jersey Care Partner Support Pilot Project
Log of Caregiver Follow-Up Calls

Name of Care Manager: ______________________ ☐ Atlantic ☐ Mercer ☐ Monmouth ☐ Warren

Please write legibly.

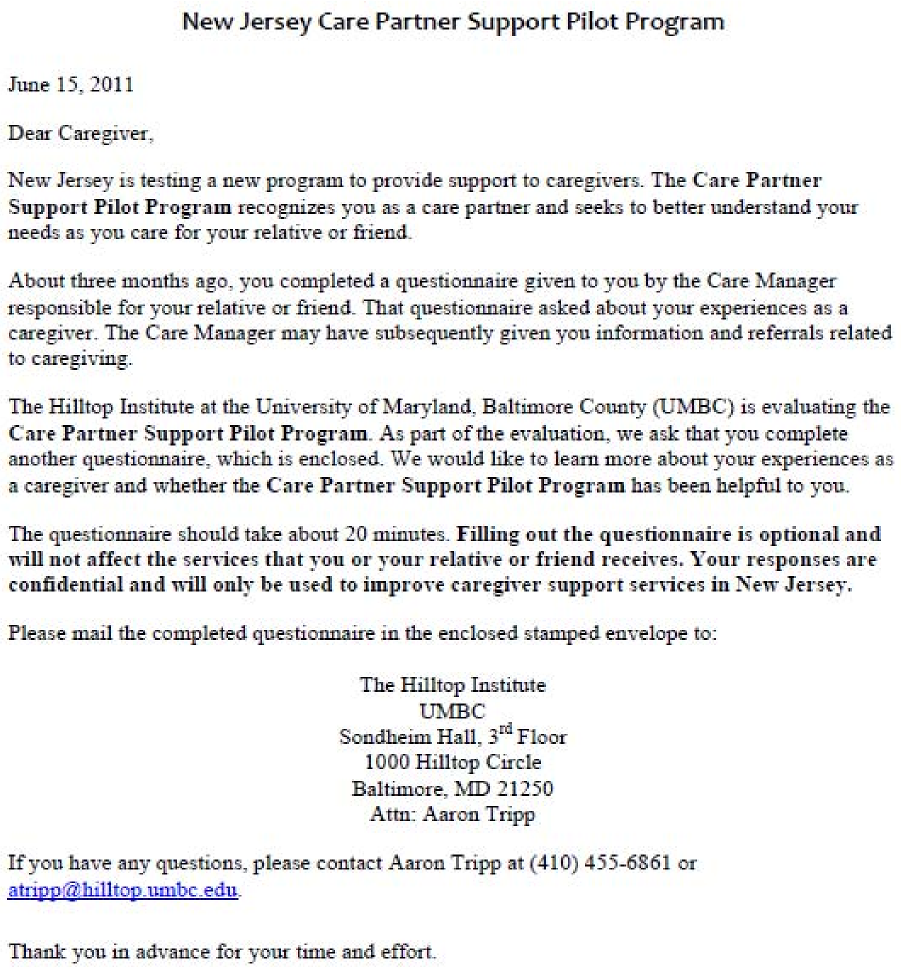
Caregiver's Name (FIRST AND LAST)	Care Recipient's Name (FIRST AND LAST)	Date of Caregiver Assessment (MM/DD/YYYY)	Date of Follow-Up Call (MM/DD/YYYY)	Call Completed (Yes or No)	Notes
1. 2.	1. 2.				
3.	3.				
4.	4.				
5. 6.	5. 6.				
7.	7.				
8.	8.				
9.	9.				
10.	10.				

Please return this call log to The Hilltop Institute via mail or fax. PLEASE DO NOT EMAIL THIS FORM.

ATTN: Erica Reaves
UMBC, Sondheim Hall Room 301
1000 Hilltop Circle
Baltimore, MD 21250
fax: 410.455.1309

The Hilltop Institute

Appendix D. Caregiver Three-Month Follow-Up Questionnaire



New Jersey Care Partner Support Pilot Program

June 15, 2011

Dear Caregiver,

New Jersey is testing a new program to provide support to caregivers. The **Care Partner Support Pilot Program** recognizes you as a care partner and seeks to better understand your needs as you care for your relative or friend.

About three months ago, you completed a questionnaire given to you by the Care Manager responsible for your relative or friend. That questionnaire asked about your experiences as a caregiver. The Care Manager may have subsequently given you information and referrals related to caregiving.

The Hilltop Institute at the University of Maryland, Baltimore County (UMBC) is evaluating the **Care Partner Support Pilot Program**. As part of the evaluation, we ask that you complete another questionnaire, which is enclosed. We would like to learn more about your experiences as a caregiver and whether the **Care Partner Support Pilot Program** has been helpful to you.

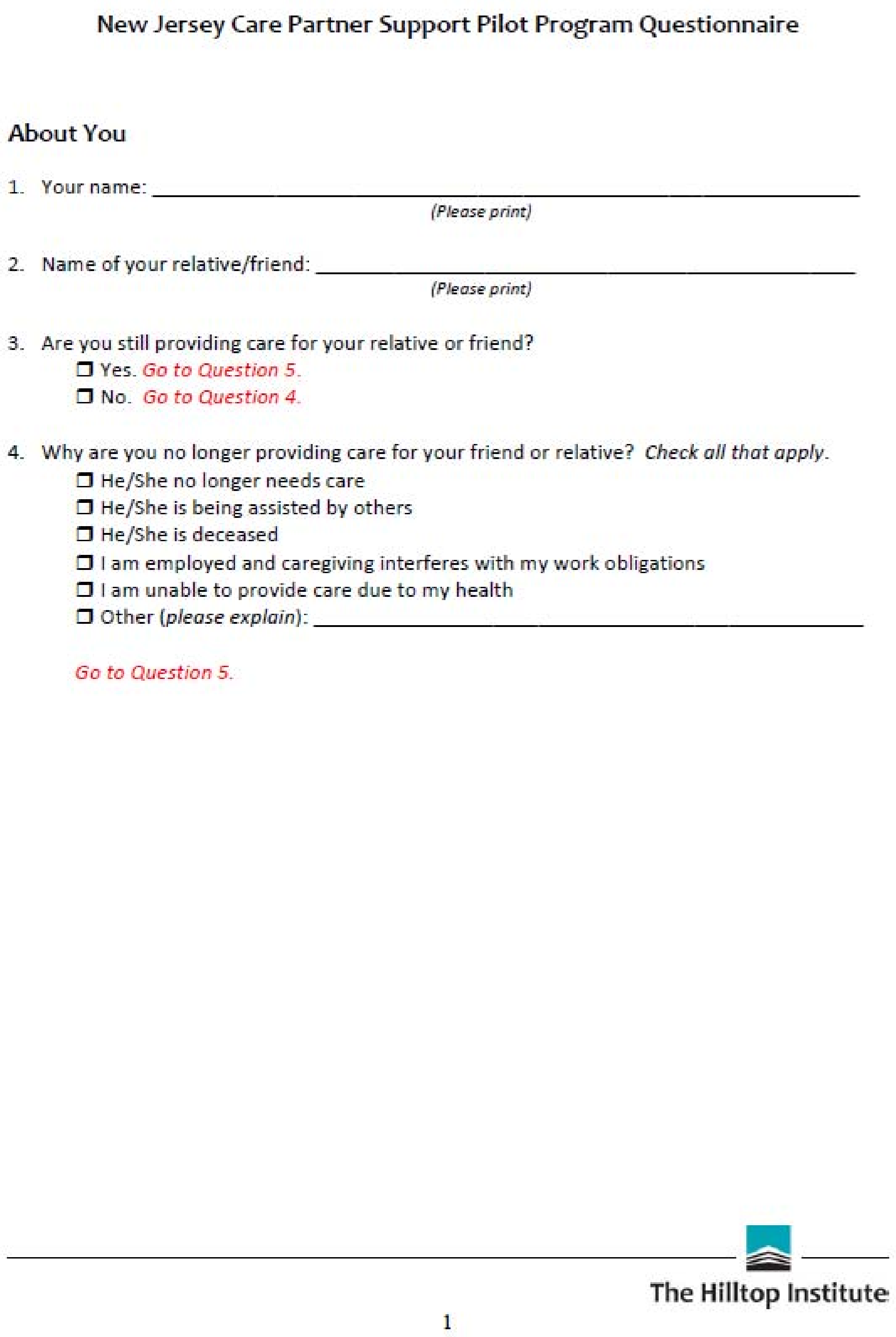
The questionnaire should take about 20 minutes. **Filling out the questionnaire is optional and will not affect the services that you or your relative or friend receives. Your responses are confidential and will only be used to improve caregiver support services in New Jersey.**

Please mail the completed questionnaire in the enclosed stamped envelope to:

The Hilltop Institute
UMBC
Sondheim Hall, 3rd Floor
1000 Hilltop Circle
Baltimore, MD 21250
Attn: Aaron Tripp

If you have any questions, please contact Aaron Tripp at (410) 455-6861 or atripp@hilltop.umbc.edu.

Thank you in advance for your time and effort.



New Jersey Care Partner Support Pilot Program Questionnaire

About You

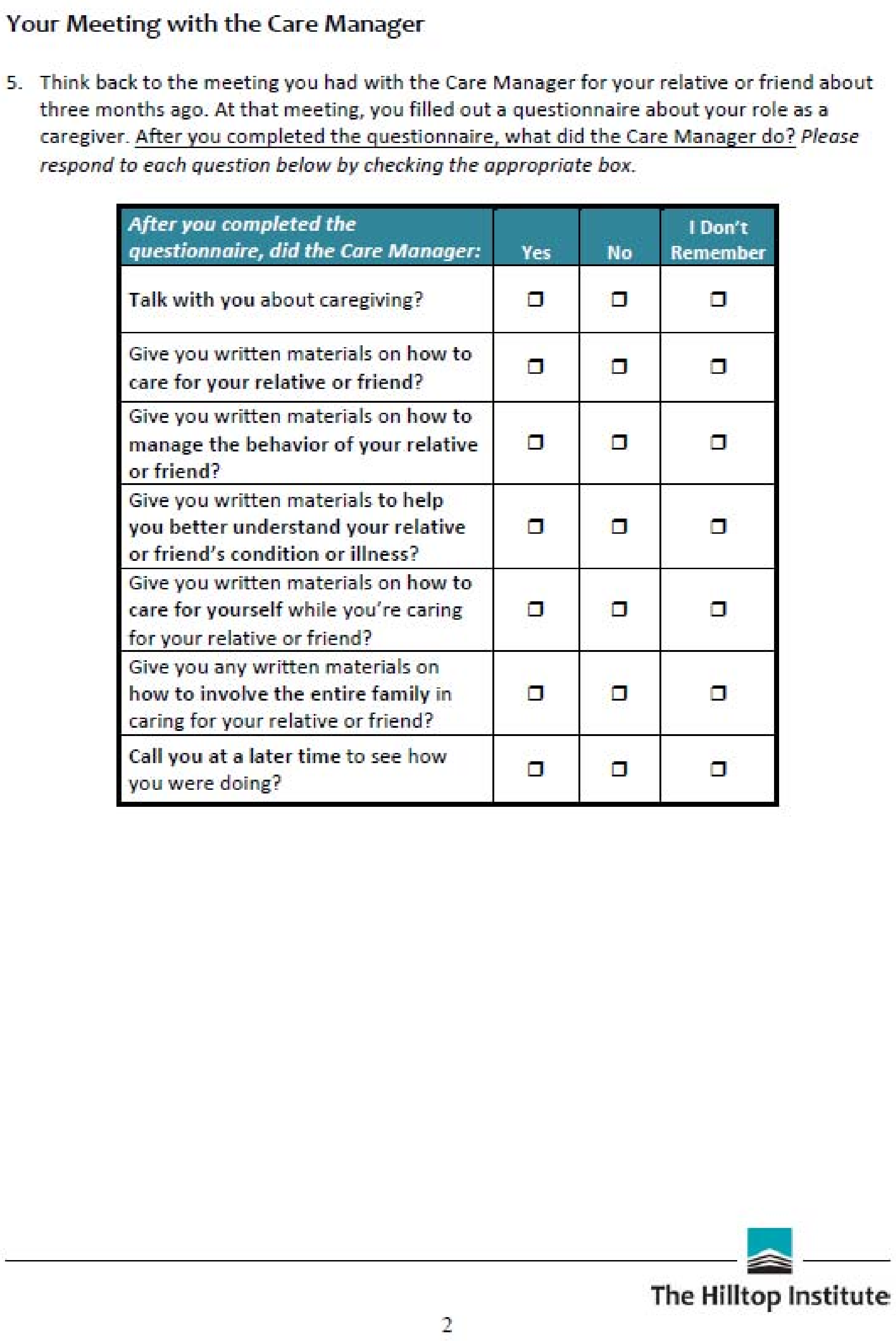
1. Your name: ______________________________
(Please print)

2. Name of your relative/friend: ______________________________
(Please print)

3. Are you still providing care for your relative or friend?
   - ☐ Yes. *Go to Question 5.*
   - ☐ No. *Go to Question 4.*

4. Why are you no longer providing care for your friend or relative? *Check all that apply.*
   - ☐ He/She no longer needs care
   - ☐ He/She is being assisted by others
   - ☐ He/She is deceased
   - ☐ I am employed and caregiving interferes with my work obligations
   - ☐ I am unable to provide care due to my health
   - ☐ Other (*please explain*): ______________________________

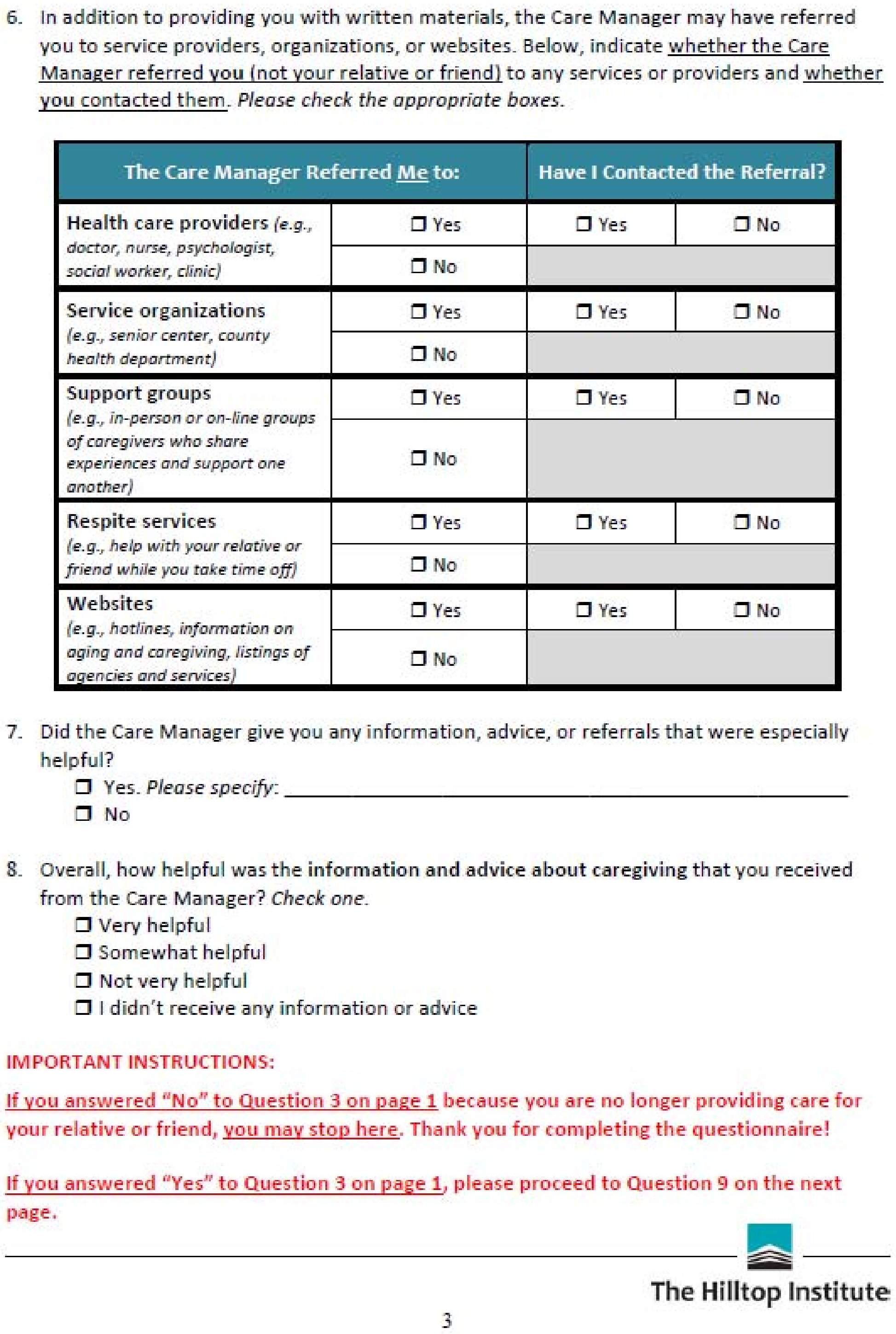
   Go to Question 5.



Your Meeting with the Care Manager

5. Think back to the meeting you had with the Care Manager for your relative or friend about three months ago. At that meeting, you filled out a questionnaire about your role as a caregiver. After you completed the questionnaire, what did the Care Manager do? *Please respond to each question below by checking the appropriate box.*

After you completed the questionnaire, did the Care Manager:	**Yes**	**No**	**I Don't Remember**
Talk with you about caregiving?	☐	☐	☐
Give you written materials on how to care for your relative or friend?	☐	☐	☐
Give you written materials on how to manage the behavior of your relative or friend?	☐	☐	☐
Give you written materials to help you better understand your relative or friend's condition or illness?	☐	☐	☐
Give you written materials on how to care for yourself while you're caring for your relative or friend?	☐	☐	☐
Give you any written materials on how to involve the entire family in caring for your relative or friend?	☐	☐	☐
Call you at a later time to see how you were doing?	☐	☐	☐



6. In addition to providing you with written materials, the Care Manager may have referred you to service providers, organizations, or websites. Below, indicate whether the Care Manager referred you (not your relative or friend) to any services or providers and whether you contacted them. *Please check the appropriate boxes.*

The Care Manager Referred Me to:		**Have I Contacted the Referral?**	
Health care providers *(e.g., doctor, nurse, psychologist, social worker, clinic)*	☐ Yes	☐ Yes	☐ No
	☐ No		
Service organizations *(e.g., senior center, county health department)*	☐ Yes	☐ Yes	☐ No
	☐ No		
Support groups *(e.g., in-person or on-line groups of caregivers who share experiences and support one another)*	☐ Yes	☐ Yes	☐ No
	☐ No		
Respite services *(e.g., help with your relative or friend while you take time off)*	☐ Yes	☐ Yes	☐ No
	☐ No		
Websites *(e.g., hotlines, information on aging and caregiving, listings of agencies and services)*	☐ Yes	☐ Yes	☐ No
	☐ No		

7. Did the Care Manager give you any information, advice, or referrals that were especially helpful?
   - ☐ Yes. *Please specify*: ____
   - ☐ No

8. Overall, how helpful was the **information and advice about caregiving** that you received from the Care Manager? *Check one.*
   - ☐ Very helpful
   - ☐ Somewhat helpful
   - ☐ Not very helpful
   - ☐ I didn't receive any information or advice

IMPORTANT INSTRUCTIONS:

If you answered "No" to Question 3 on page 1 because you are no longer providing care for your relative or friend, you may stop here. Thank you for completing the questionnaire!

If you answered "Yes" to Question 3 on page 1, please proceed to Question 9 on the next page.

Caring for Your Relative or Friend

9. What prompted the need for you to provide care for your relative or friend? *Check all that apply and please explain.*
   - ☐ Injury
   - ☐ Illness
   - ☐ Aging
   - ☐ Cognitive impairment or memory problems
   - ☐ Other

   Please explain: ____

   ____

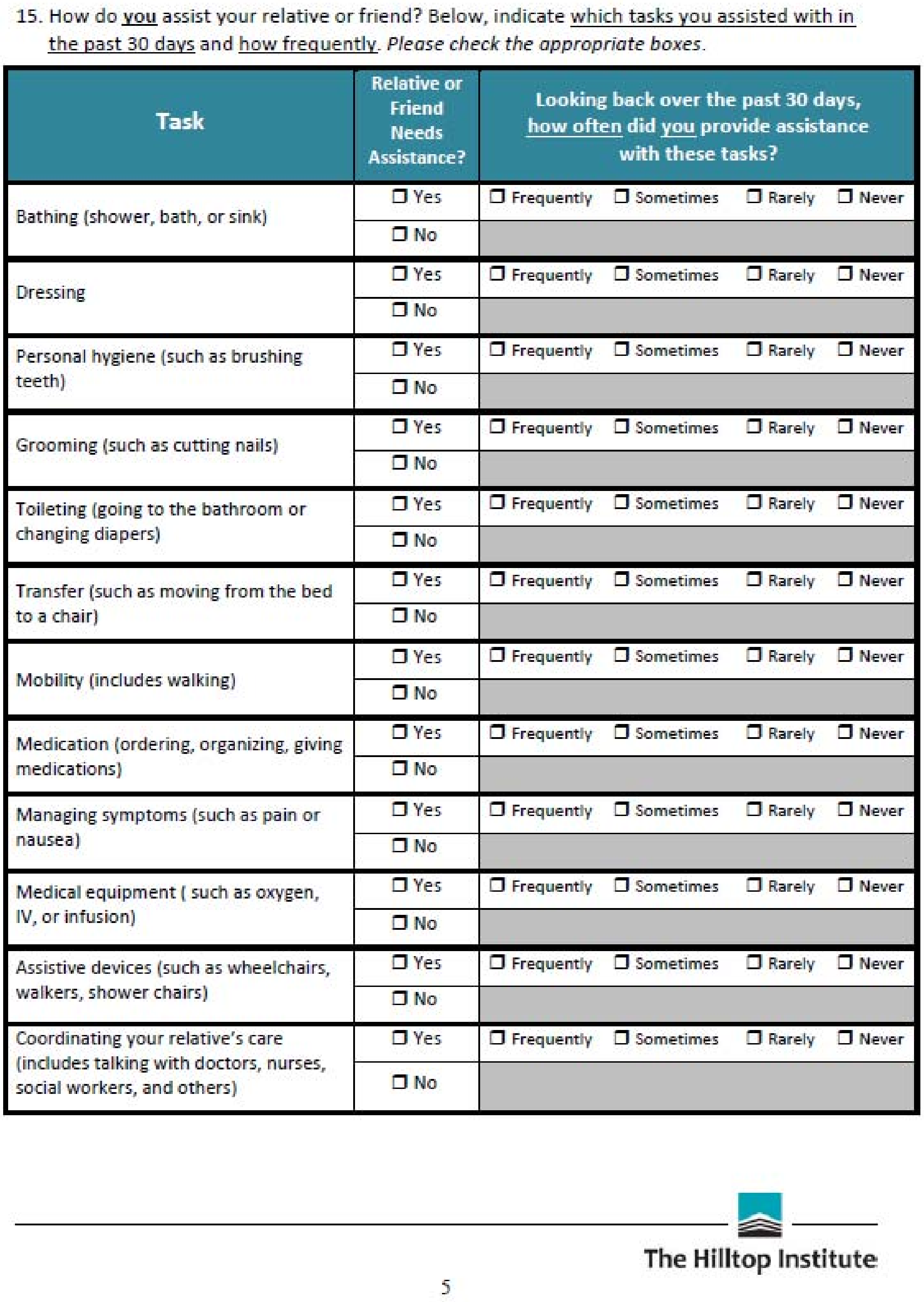
10. Are you still the primary caregiver for your relative or friend?
    - ☐ Yes
    - ☐ No

11. Do you and your relative or friend live together?
    - ☐ Yes
    - ☐ No

12. Has the health of your relative or friend changed or stayed about the same over the last three (3) months? *Check one.*
    - ☐ Gotten better
    - ☐ Stayed about the same
    - ☐ Gotten worse

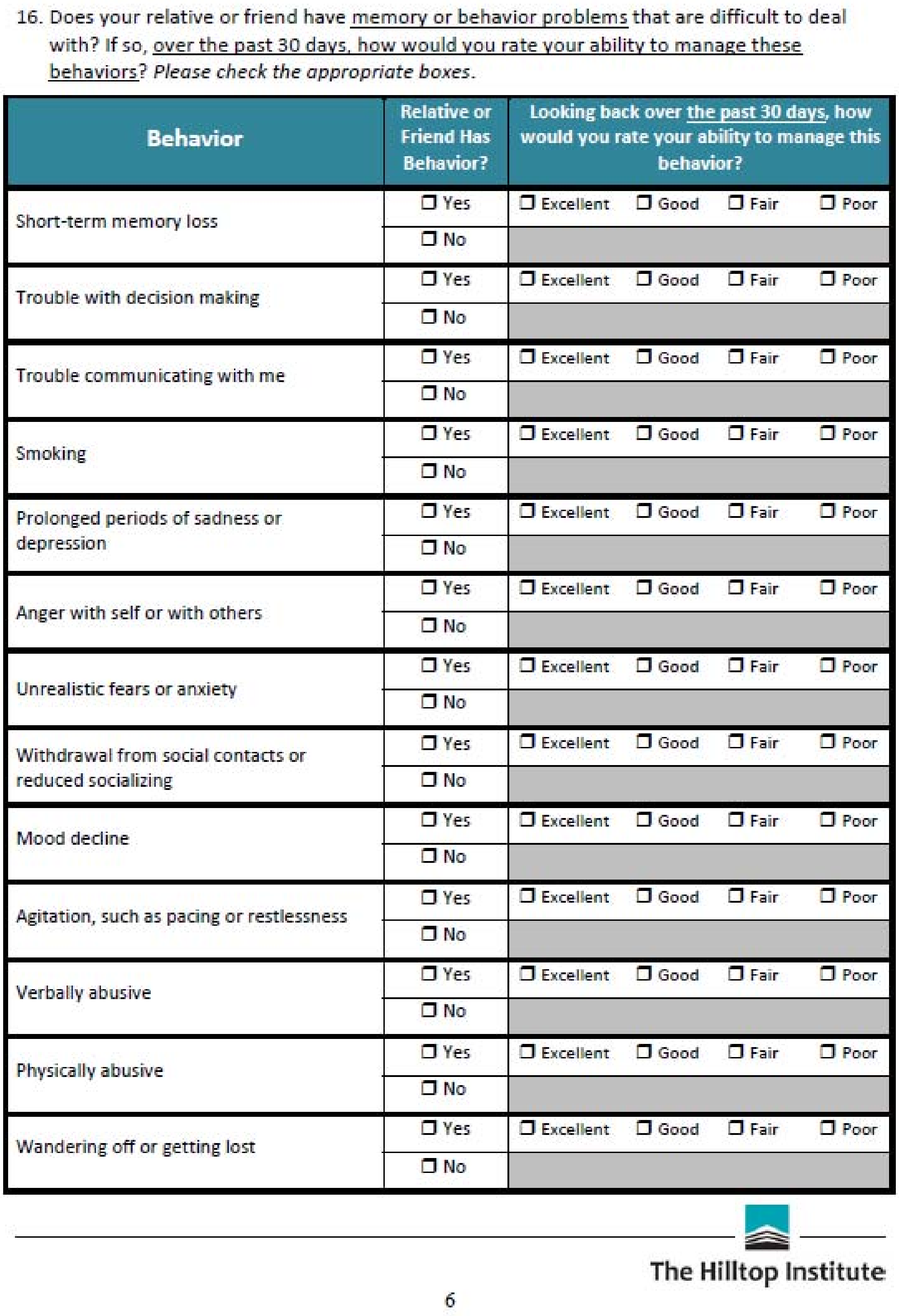
13. What is your current employment status? *Check one.*
    - ☐ Full-time (35 hours/week or more)
    - ☐ Part-time (Less than 35 hours/week)
    - ☐ Leave of Absence
    - ☐ Not Employed
    - ☐ Retired

14. How is your health?
    - ☐ Excellent
    - ☐ Good
    - ☐ Fair
    - ☐ Poor



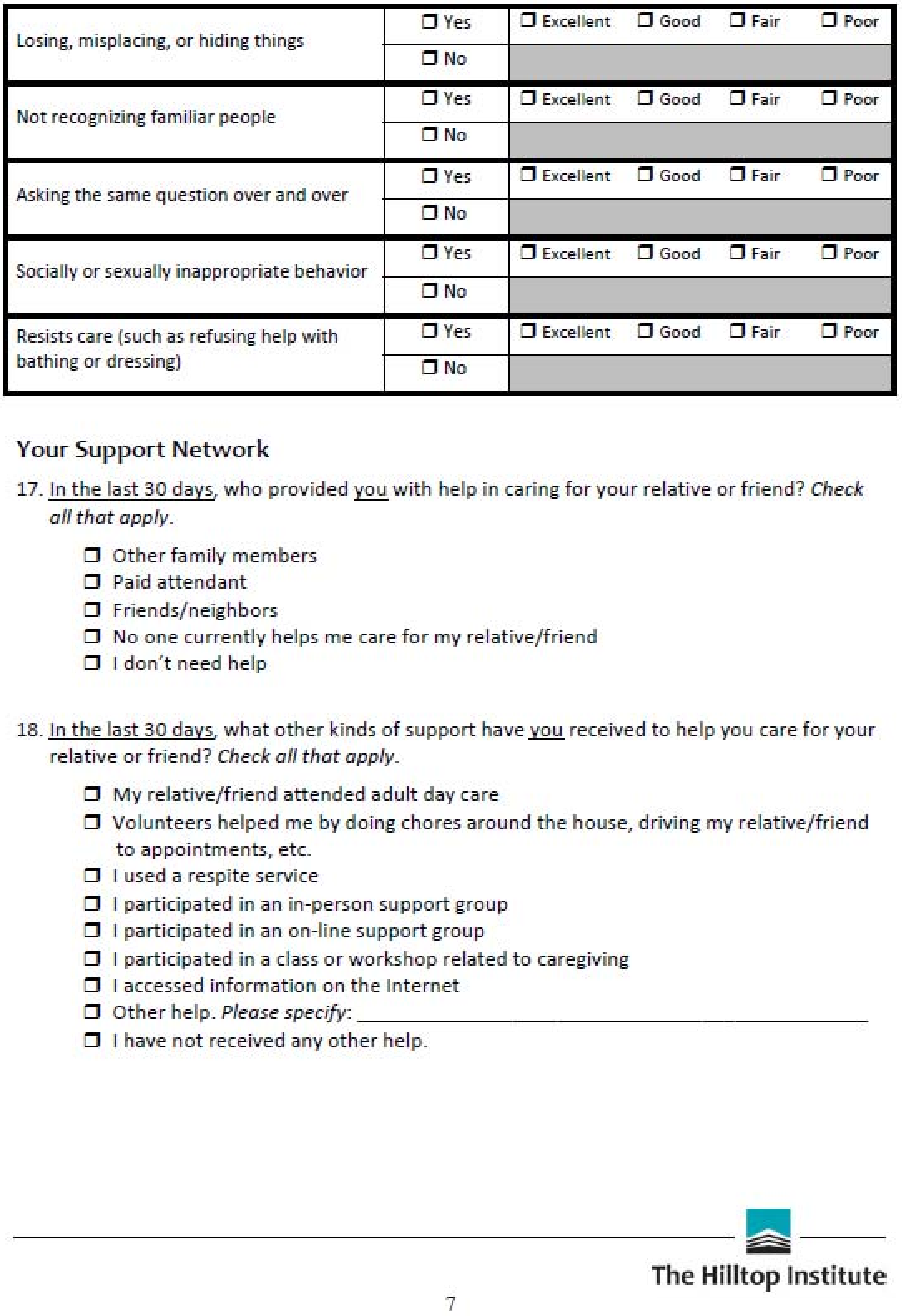
15. How do you assist your relative or friend? Below, indicate which tasks you assisted with in the past 30 days and how frequently. *Please check the appropriate boxes.*

Task	**Relative or Friend Needs Assistance?**	**Looking back over the past 30 days, how often did you provide assistance with these tasks?**
Bathing (shower, bath, or sink)	☐ Yes	☐ Frequently ☐ Sometimes ☐ Rarely ☐ Never
	☐ No	
Dressing	☐ Yes	☐ Frequently ☐ Sometimes ☐ Rarely ☐ Never
	☐ No	
Personal hygiene (such as brushing teeth)	☐ Yes	☐ Frequently ☐ Sometimes ☐ Rarely ☐ Never
	☐ No	
Grooming (such as cutting nails)	☐ Yes	☐ Frequently ☐ Sometimes ☐ Rarely ☐ Never
	☐ No	
Toileting (going to the bathroom or changing diapers)	☐ Yes	☐ Frequently ☐ Sometimes ☐ Rarely ☐ Never
	☐ No	
Transfer (such as moving from the bed to a chair)	☐ Yes	☐ Frequently ☐ Sometimes ☐ Rarely ☐ Never
	☐ No	
Mobility (includes walking)	☐ Yes	☐ Frequently ☐ Sometimes ☐ Rarely ☐ Never
	☐ No	
Medication (ordering, organizing, giving medications)	☐ Yes	☐ Frequently ☐ Sometimes ☐ Rarely ☐ Never
	☐ No	
Managing symptoms (such as pain or nausea)	☐ Yes	☐ Frequently ☐ Sometimes ☐ Rarely ☐ Never
	☐ No	
Medical equipment (such as oxygen, IV, or infusion)	☐ Yes	☐ Frequently ☐ Sometimes ☐ Rarely ☐ Never
	☐ No	
Assistive devices (such as wheelchairs, walkers, shower chairs)	☐ Yes	☐ Frequently ☐ Sometimes ☐ Rarely ☐ Never
	☐ No	
Coordinating your relative's care (includes talking with doctors, nurses, social workers, and others)	☐ Yes	☐ Frequently ☐ Sometimes ☐ Rarely ☐ Never
	☐ No	



16. Does your relative or friend have memory or behavior problems that are difficult to deal with? If so, over the past 30 days, how would you rate your ability to manage these behaviors? *Please check the appropriate boxes.*

Behavior	**Relative or Friend Has Behavior?**	**Looking back over the past 30 days, how would you rate your ability to manage this behavior?**			
Short-term memory loss	☐ Yes	☐ Excellent	☐ Good	☐ Fair	☐ Poor
	☐ No				
Trouble with decision making	☐ Yes	☐ Excellent	☐ Good	☐ Fair	☐ Poor
	☐ No				
Trouble communicating with me	☐ Yes	☐ Excellent	☐ Good	☐ Fair	☐ Poor
	☐ No				
Smoking	☐ Yes	☐ Excellent	☐ Good	☐ Fair	☐ Poor
	☐ No				
Prolonged periods of sadness or depression	☐ Yes	☐ Excellent	☐ Good	☐ Fair	☐ Poor
	☐ No				
Anger with self or with others	☐ Yes	☐ Excellent	☐ Good	☐ Fair	☐ Poor
	☐ No				
Unrealistic fears or anxiety	☐ Yes	☐ Excellent	☐ Good	☐ Fair	☐ Poor
	☐ No				
Withdrawal from social contacts or reduced socializing	☐ Yes	☐ Excellent	☐ Good	☐ Fair	☐ Poor
	☐ No				
Mood decline	☐ Yes	☐ Excellent	☐ Good	☐ Fair	☐ Poor
	☐ No				
Agitation, such as pacing or restlessness	☐ Yes	☐ Excellent	☐ Good	☐ Fair	☐ Poor
	☐ No				
Verbally abusive	☐ Yes	☐ Excellent	☐ Good	☐ Fair	☐ Poor
	☐ No				
Physically abusive	☐ Yes	☐ Excellent	☐ Good	☐ Fair	☐ Poor
	☐ No				
Wandering off or getting lost	☐ Yes	☐ Excellent	☐ Good	☐ Fair	☐ Poor
	☐ No				



Losing, misplacing, or hiding things	☐ Yes	☐ Excellent	☐ Good	☐ Fair	☐ Poor
	☐ No				
Not recognizing familiar people	☐ Yes	☐ Excellent	☐ Good	☐ Fair	☐ Poor
	☐ No				
Asking the same question over and over	☐ Yes	☐ Excellent	☐ Good	☐ Fair	☐ Poor
	☐ No				
Socially or sexually inappropriate behavior	☐ Yes	☐ Excellent	☐ Good	☐ Fair	☐ Poor
	☐ No				
Resists care (such as refusing help with bathing or dressing)	☐ Yes	☐ Excellent	☐ Good	☐ Fair	☐ Poor
	☐ No				

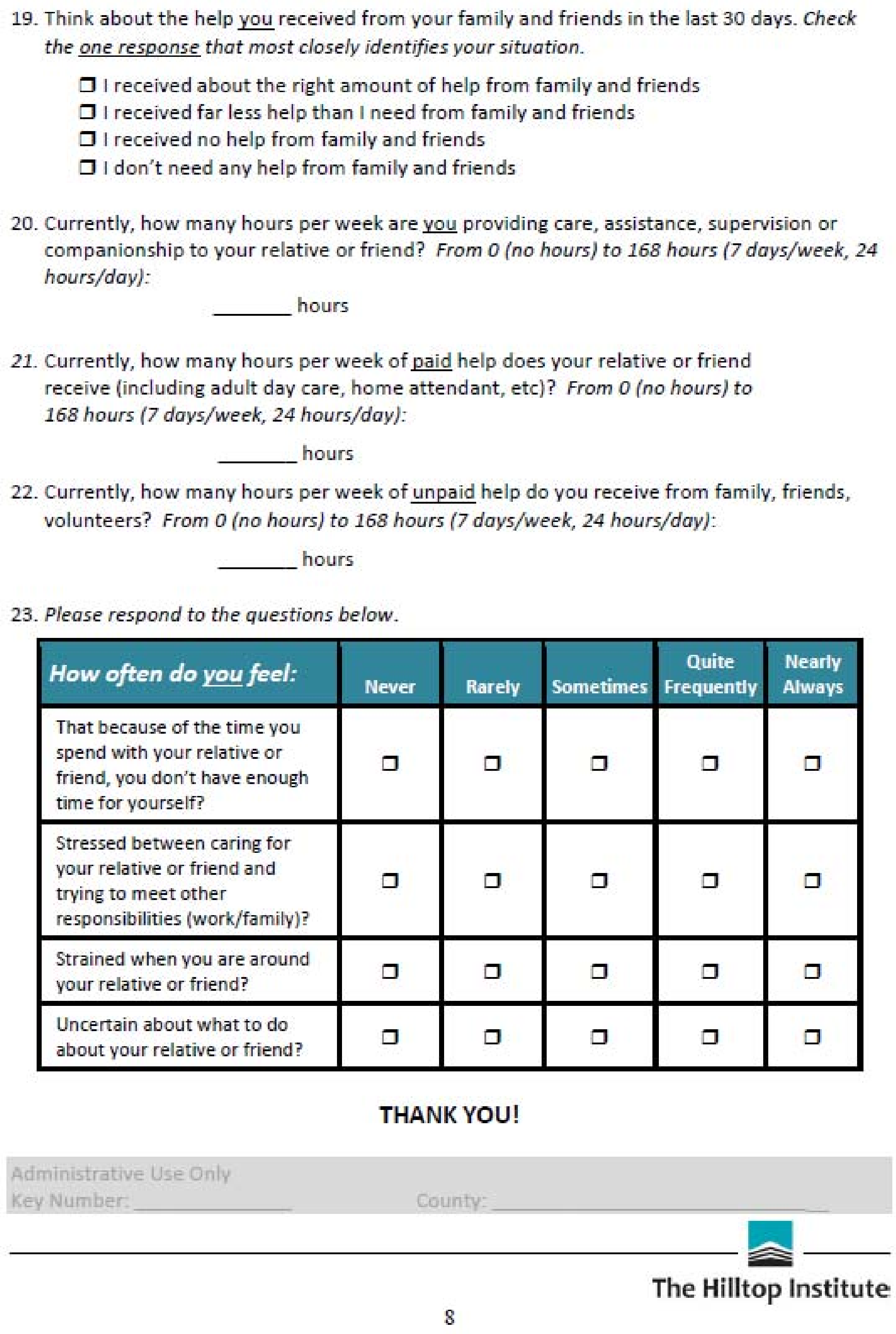
Your Support Network

17. In the last 30 days, who provided you with help in caring for your relative or friend? *Check all that apply*.

- ☐ Other family members
- ☐ Paid attendant
- ☐ Friends/neighbors
- ☐ No one currently helps me care for my relative/friend
- ☐ I don't need help

18. In the last 30 days, what other kinds of support have you received to help you care for your relative or friend? *Check all that apply*.

- ☐ My relative/friend attended adult day care
- ☐ Volunteers helped me by doing chores around the house, driving my relative/friend to appointments, etc.
- ☐ I used a respite service
- ☐ I participated in an in-person support group
- ☐ I participated in an on-line support group
- ☐ I participated in a class or workshop related to caregiving
- ☐ I accessed information on the Internet
- ☐ Other help. *Please specify*: ______________________________
- ☐ I have not received any other help.



19. Think about the help you received from your family and friends in the last 30 days. *Check the one response that most closely identifies your situation.*

- ☐ I received about the right amount of help from family and friends
- ☐ I received far less help than I need from family and friends
- ☐ I received no help from family and friends
- ☐ I don't need any help from family and friends

20. Currently, how many hours per week are you providing care, assistance, supervision or companionship to your relative or friend? *From 0 (no hours) to 168 hours (7 days/week, 24 hours/day):*

_______ hours

21. Currently, how many hours per week of paid help does your relative or friend receive (including adult day care, home attendant, etc)? *From 0 (no hours) to 168 hours (7 days/week, 24 hours/day):*

_______ hours

22. Currently, how many hours per week of unpaid help do you receive from family, friends, volunteers? *From 0 (no hours) to 168 hours (7 days/week, 24 hours/day):*

_______ hours

23. *Please respond to the questions below.*

How often do you feel:	**Never**	**Rarely**	**Sometimes**	**Quite Frequently**	**Nearly Always**
That because of the time you spend with your relative or friend, you don't have enough time for yourself?	☐	☐	☐	☐	☐
Stressed between caring for your relative or friend and trying to meet other responsibilities (work/family)?	☐	☐	☐	☐	☐
Strained when you are around your relative or friend?	☐	☐	☐	☐	☐
Uncertain about what to do about your relative or friend?	☐	☐	☐	☐	☐

THANK YOU!

Administrative Use Only
Key Number: _______________ County: ________________________________

The Hilltop Institute

8

Appendix E. Agency Staff and Partner Interviewees

AARP Public Policy Institute

Susan Reinhard
Senior Vice President, Public Policy Institute

Rita Choula
Project Administrator

Family Caregiver Alliance

Kathleen Kelly
Executive Director

Donna Schempp
Consultant

New Jersey Department of Health and Senior Services
Division of Aging and Community Services

Patricia Polansky
Former Assistant Commissioner

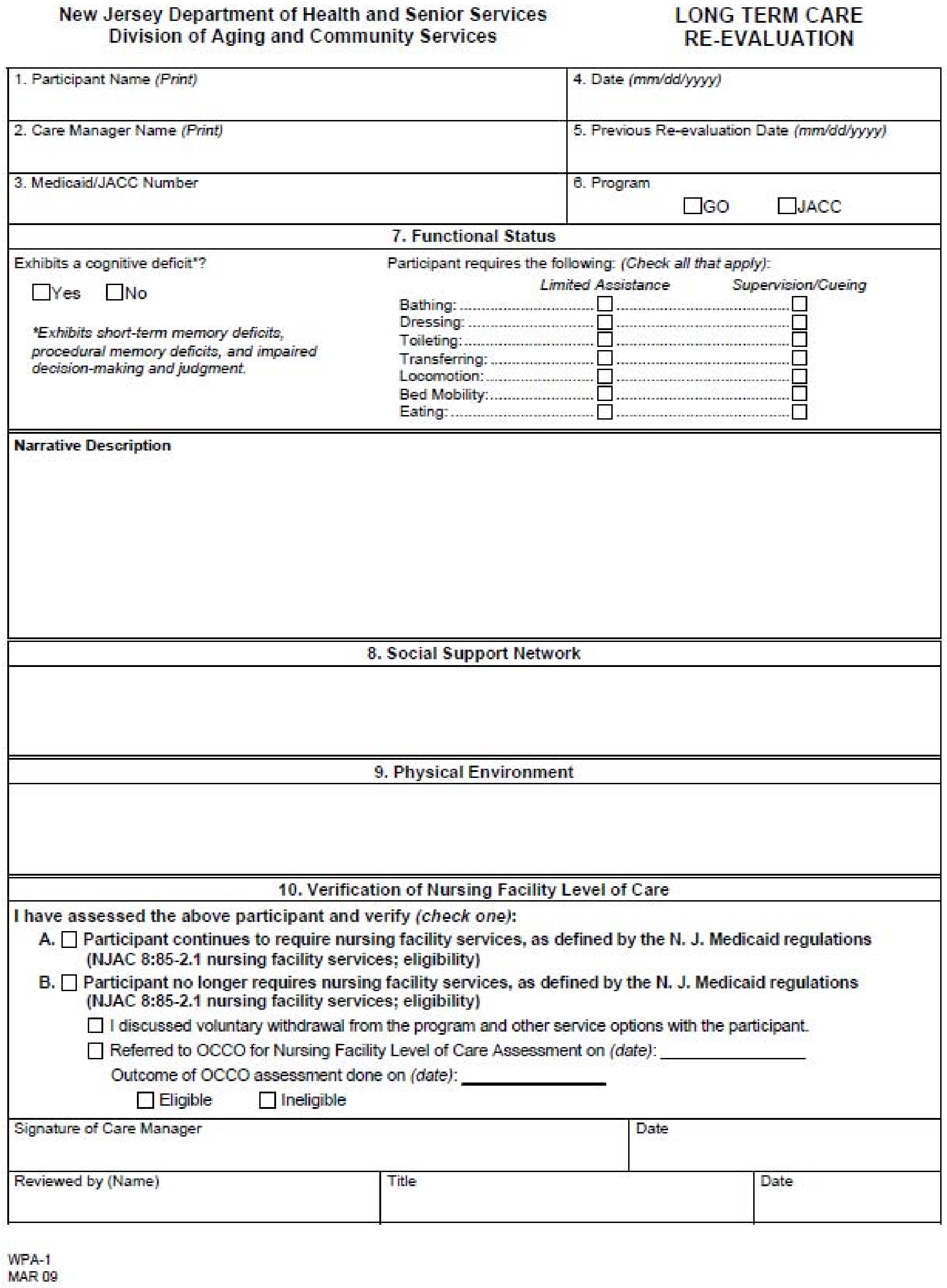
Nancy Day
Acting Assistant Commissioner

Catherine Dailey
County Liaison/Quality Assurance Specialist

Alice Obelleiro
County Liaison/Quality Assurance Specialist, Supervisor

Deanna Freundlich
Nursing Consultant for ADRC

Appendix F. New Jersey Form WPA-1



New Jersey Department of Health and Senior Services
Division of Aging and Community Services

LONG TERM CARE
RE-EVALUATION

1. Participant Name *(Print)*	4. Date *(mm/dd/yyyy)*
2. Care Manager Name *(Print)*	5. Previous Re-evaluation Date *(mm/dd/yyyy)*
3. Medicaid/JACC Number	6. Program ☐GO ☐JACC

7. Functional Status

Exhibits a cognitive deficit*?

☐Yes ☐No

**Exhibits short-term memory deficits, procedural memory deficits, and impaired decision-making and judgment.*

Participant requires the following: *(Check all that apply)*:

	Limited Assistance	*Supervision/Cueing*
Bathing:	☐	☐
Dressing:	☐	☐
Toileting:	☐	☐
Transferring:	☐	☐
Locomotion:	☐	☐
Bed Mobility:	☐	☐
Eating:	☐	☐

Narrative Description

8. Social Support Network

9. Physical Environment

10. Verification of Nursing Facility Level of Care

I have assessed the above participant and verify *(check one)*:

A. ☐ **Participant continues to require nursing facility services, as defined by the N. J. Medicaid regulations (NJAC 8:85-2.1 nursing facility services; eligibility)**

B. ☐ **Participant no longer requires nursing facility services, as defined by the N. J. Medicaid regulations (NJAC 8:85-2.1 nursing facility services; eligibility)**

☐ I discussed voluntary withdrawal from the program and other service options with the participant.

☐ Referred to OCCO for Nursing Facility Level of Care Assessment on *(date)*: ________________

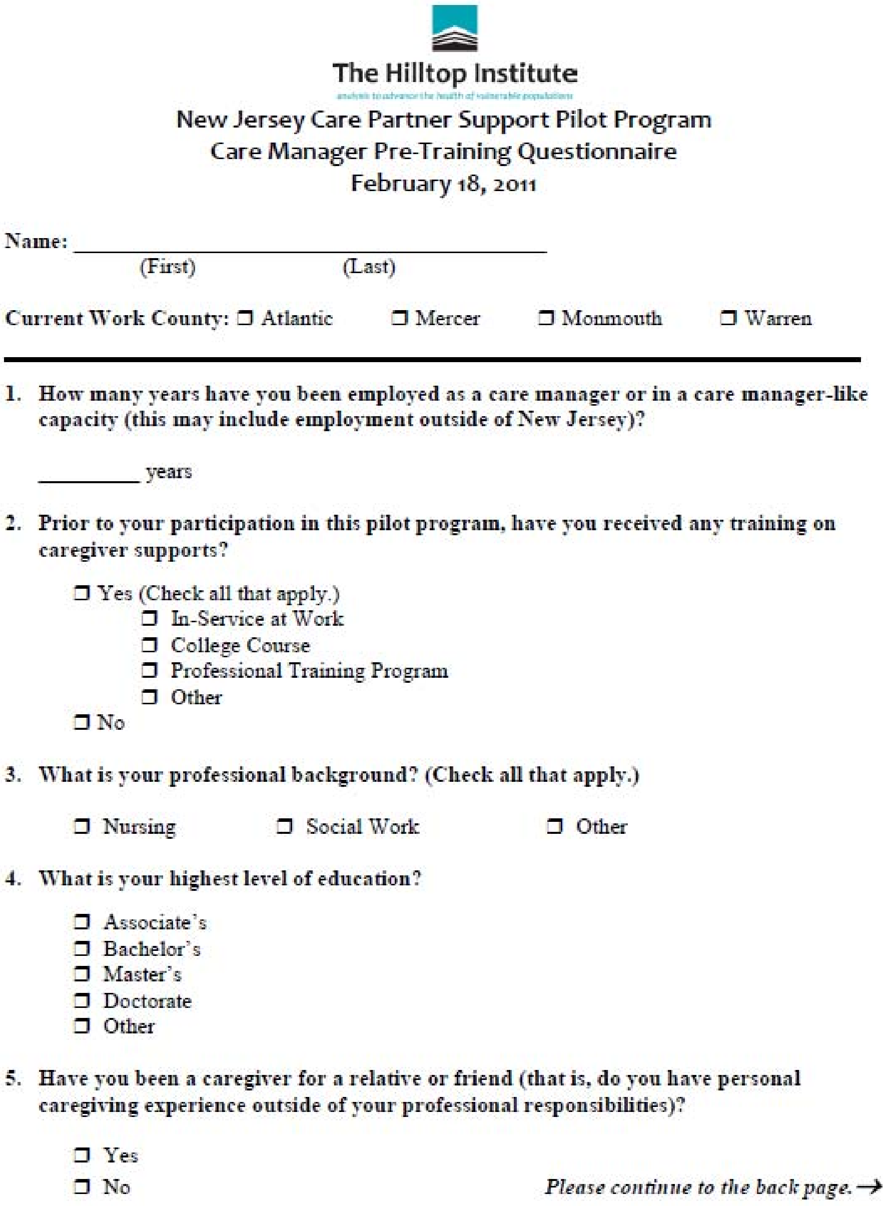
Outcome of OCCO assessment done on *(date)*: ________________

☐ Eligible ☐ Ineligible

Signature of Care Manager		Date
Reviewed by (Name)	Title	Date

WPA-1
MAR 09

Appendix G. Care Manager Pre-Training Questionnaire



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analysis to advance the health of vulnerable populations

New Jersey Care Partner Support Pilot Program
Care Manager Pre-Training Questionnaire
February 18, 2011

Name: ______________________________________
(First) (Last)

Current Work County: ☐ Atlantic ☐ Mercer ☐ Monmouth ☐ Warren

---

1. How many years have you been employed as a care manager or in a care manager-like capacity (this may include employment outside of New Jersey)?

_________ years

2. Prior to your participation in this pilot program, have you received any training on caregiver supports?

- ☐ Yes (Check all that apply.)
  - ☐ In-Service at Work
  - ☐ College Course
  - ☐ Professional Training Program
  - ☐ Other
- ☐ No

3. What is your professional background? (Check all that apply.)

☐ Nursing ☐ Social Work ☐ Other

4. What is your highest level of education?

- ☐ Associate's
- ☐ Bachelor's
- ☐ Master's
- ☐ Doctorate
- ☐ Other

5. Have you been a caregiver for a relative or friend (that is, do you have personal caregiving experience outside of your professional responsibilities)?

- ☐ Yes
- ☐ No

Please continue to the back page.→

Please respond to the following questions using the scales provided.

6. I can assess a caregiver's ability to provide direct care for their friend or relative.

☐ Always ☐ Often ☐ Sometimes ☐ Rarely ☐ Never

7. I am able to determine a caregiver's circumstances and needs as they relate to their everyday care responsibilities.

☐ Always ☐ Often ☐ Sometimes ☐ Rarely ☐ Never

8. I can recognize the signs of caregiver burden.

☐ Always ☐ Often ☐ Sometimes ☐ Rarely ☐ Never

9. The role of the Care Manager includes providing support to caregivers.

☐ Strongly Agree ☐ Agree ☐ Neutral ☐ Disagree ☐ Strongly Disagree

10. I feel Care Managers have the necessary resources to refer caregivers to community-based services and supports based on their individual needs and desires.

☐ Strongly Agree ☐ Agree ☐ Neutral ☐ Disagree ☐ Strongly Disagree

11. In general, I have enough time during a client visit to consult with caregivers.

☐ Strongly Agree ☐ Agree ☐ Neutral ☐ Disagree ☐ Strongly Disagree

Thank you for completing the questionnaire!

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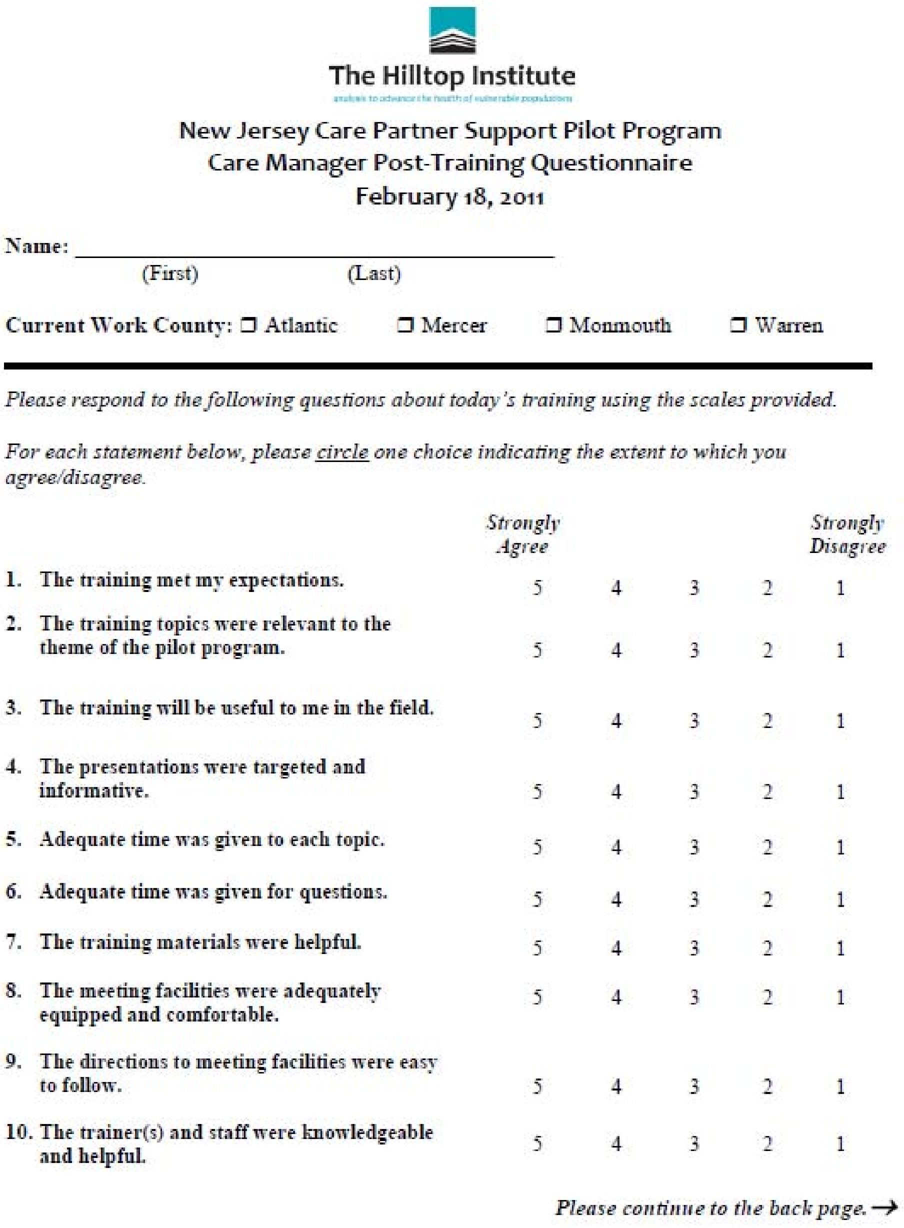
Appendix H. Care Manager Post-Training Questionnaire



The Hilltop Institute

New Jersey Care Partner Support Pilot Program
Care Manager Post-Training Questionnaire
February 18, 2011

Name: ____
(First) (Last)

Current Work County: ☐ Atlantic ☐ Mercer ☐ Monmouth ☐ Warren

Please respond to the following questions about today's training using the scales provided.

For each statement below, please circle one choice indicating the extent to which you agree/disagree.

	Strongly Agree				*Strongly Disagree*
1. The training met my expectations.	5	4	3	2	1
2. The training topics were relevant to the theme of the pilot program.	5	4	3	2	1
3. The training will be useful to me in the field.	5	4	3	2	1
4. The presentations were targeted and informative.	5	4	3	2	1
5. Adequate time was given to each topic.	5	4	3	2	1
6. Adequate time was given for questions.	5	4	3	2	1
7. The training materials were helpful.	5	4	3	2	1
8. The meeting facilities were adequately equipped and comfortable.	5	4	3	2	1
9. The directions to meeting facilities were easy to follow.	5	4	3	2	1
10. The trainer(s) and staff were knowledgeable and helpful.	5	4	3	2	1

Please continue to the back page. →

11. I would be interested in attending future trainings on caregiver supports.	5	4	3	2	1

12. Do you feel that there were topics missing from the training curriculum?

☐ Yes. I have these suggestions for additional topics:

1. ____

2. ____

3. ____

☐ No

Please respond to the following questions about the New Jersey Care Partner Support Pilot Program training using the scales provided.

13. I anticipate that care managers will be able to implement this pilot program easily.

☐ Agree ☐ Disagree ☐ Not certain at this point

If you disagree, please list your concerns below:

1. ____

2. ____

3. ____

14. I am looking forward to participating in this pilot program.

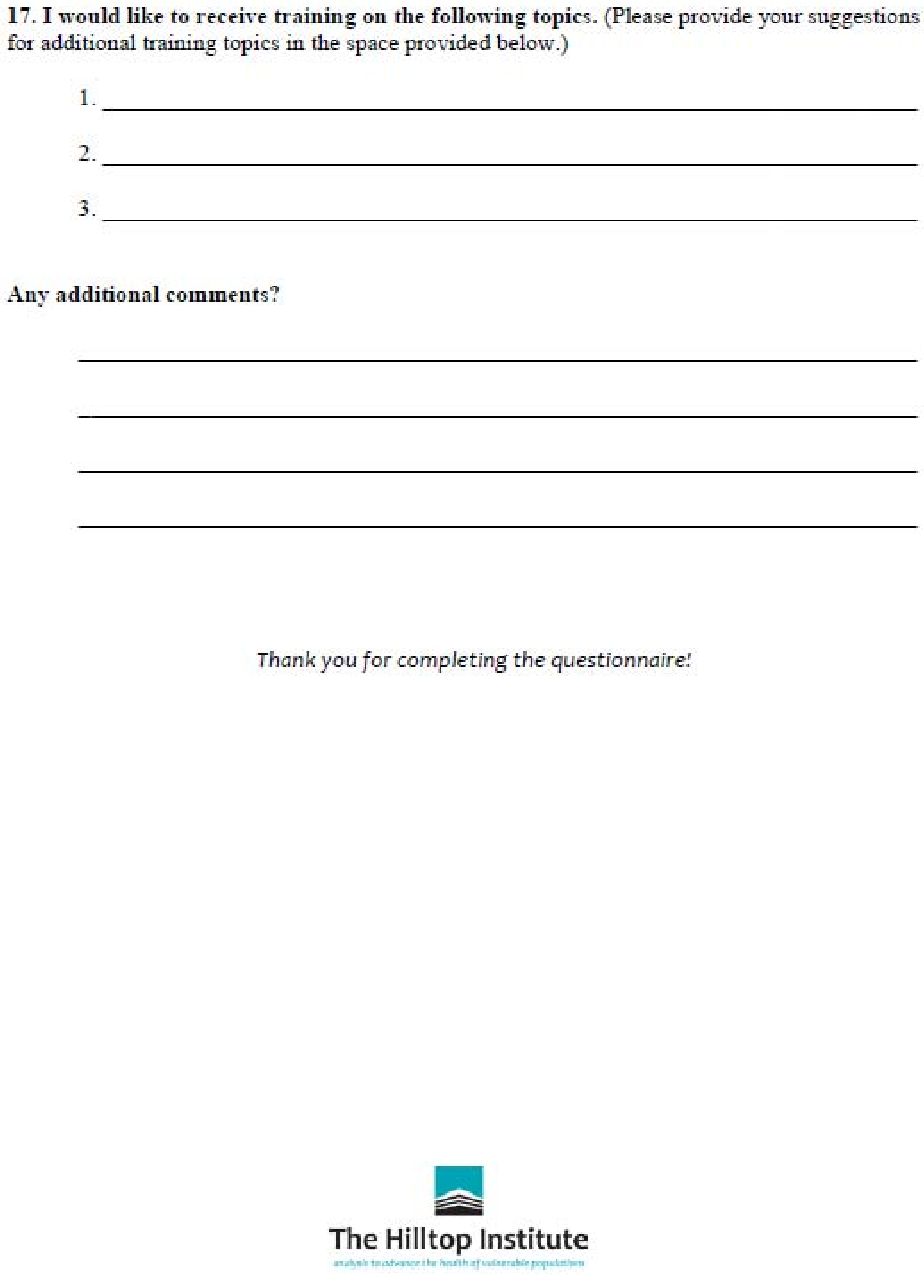
☐ Agree ☐ Disagree ☐ Not certain at this point

15. I feel that this pilot will lead to improved outcomes for the caregiver.

☐ Strongly Agree ☐ Agree ☐ Neutral ☐ Disagree ☐ Strongly Disagree

16. I feel that this pilot program will lead to improved outcomes for the care recipient.

☐ Strongly Agree ☐ Agree ☐ Neutral ☐ Disagree ☐ Strongly Disagree



17. I would like to receive training on the following topics. (Please provide your suggestions for additional training topics in the space provided below.)

1. ____________________

2. ____________________

3. ____________________

Any additional comments?

____

____

____

____

Thank you for completing the questionnaire!

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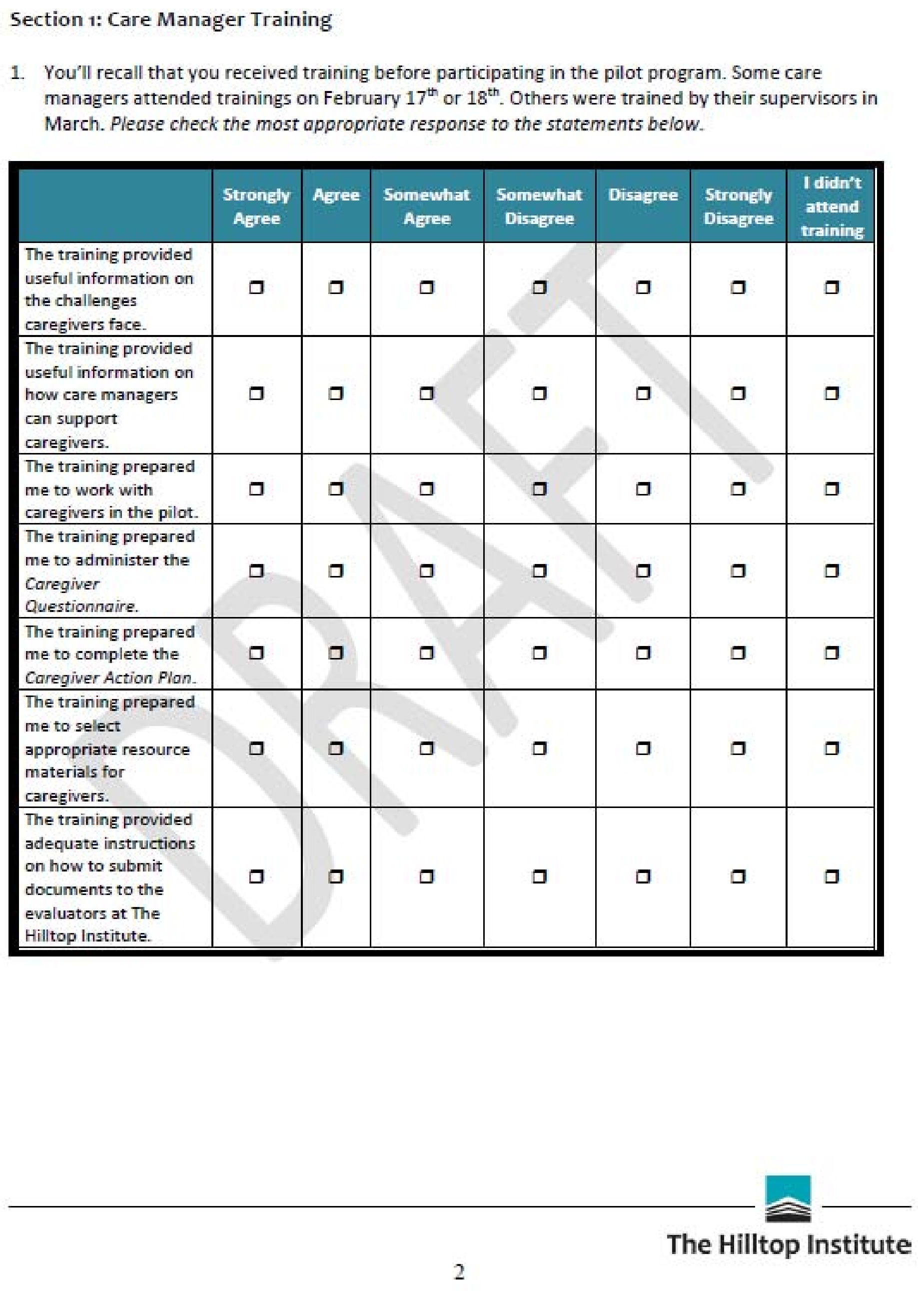
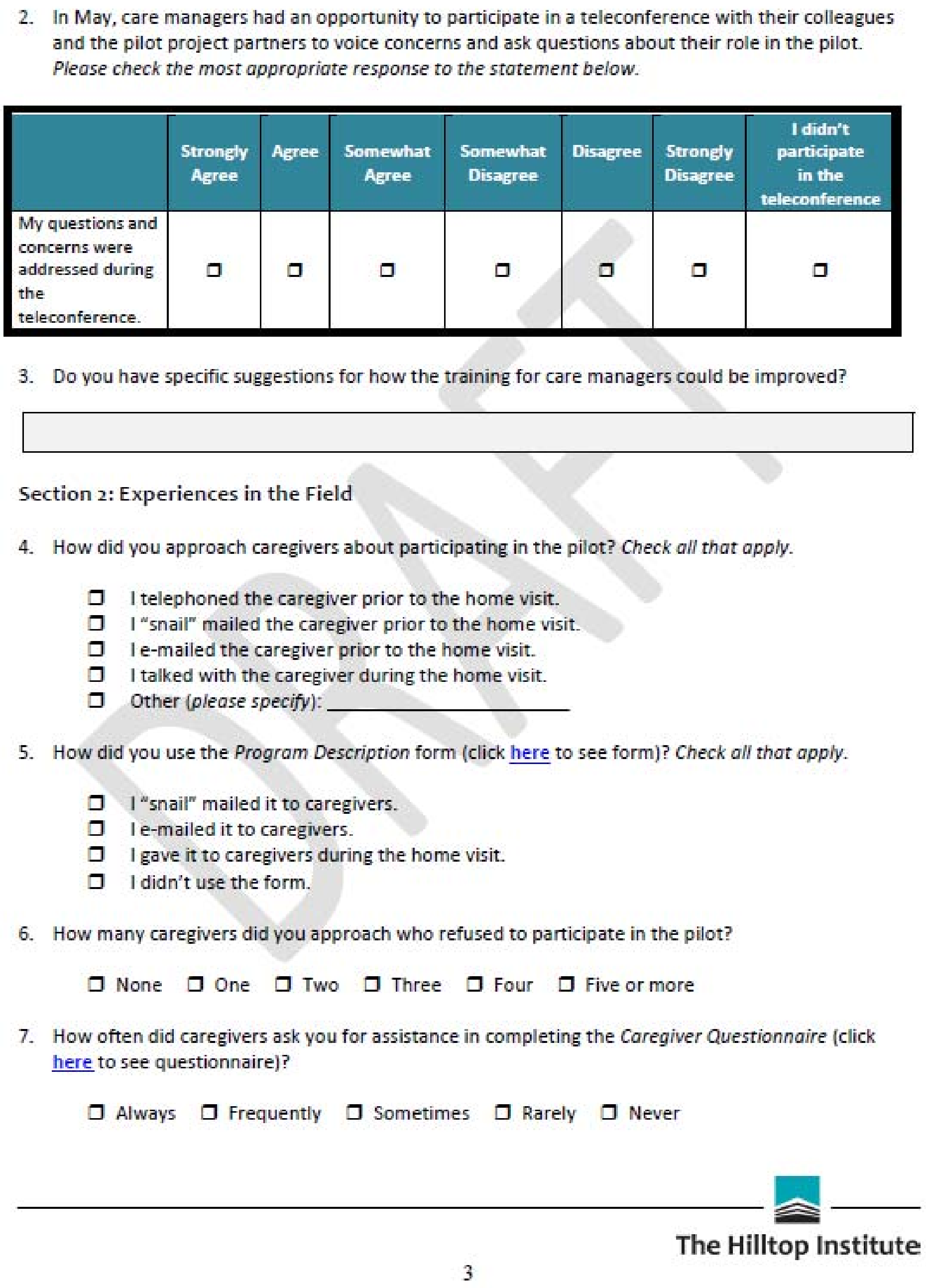
Appendix I. Care Manager Six-Month Follow-Up Questionnaire



Section 1: Care Manager Training

1. You'll recall that you received training before participating in the pilot program. Some care managers attended trainings on February 17th or 18th. Others were trained by their supervisors in March. *Please check the most appropriate response to the statements below.*

	Strongly Agree	Agree	Somewhat Agree	Somewhat Disagree	Disagree	Strongly Disagree	I didn't attend training
The training provided useful information on the challenges caregivers face.	☐	☐	☐	☐	☐	☐	☐
The training provided useful information on how care managers can support caregivers.	☐	☐	☐	☐	☐	☐	☐
The training prepared me to work with caregivers in the pilot.	☐	☐	☐	☐	☐	☐	☐
The training prepared me to administer the *Caregiver Questionnaire*.	☐	☐	☐	☐	☐	☐	☐
The training prepared me to complete the *Caregiver Action Plan*.	☐	☐	☐	☐	☐	☐	☐
The training prepared me to select appropriate resource materials for caregivers.	☐	☐	☐	☐	☐	☐	☐
The training provided adequate instructions on how to submit documents to the evaluators at The Hilltop Institute.	☐	☐	☐	☐	☐	☐	☐



2. In May, care managers had an opportunity to participate in a teleconference with their colleagues and the pilot project partners to voice concerns and ask questions about their role in the pilot. *Please check the most appropriate response to the statement below.*

	Strongly Agree	**Agree**	**Somewhat Agree**	**Somewhat Disagree**	**Disagree**	**Strongly Disagree**	**I didn't participate in the teleconference**
My questions and concerns were addressed during the teleconference.	☐	☐	☐	☐	☐	☐	☐

3. Do you have specific suggestions for how the training for care managers could be improved?

Section 2: Experiences in the Field

4. How did you approach caregivers about participating in the pilot? *Check all that apply.*

   ☐ I telephoned the caregiver prior to the home visit.
   ☐ I "snail" mailed the caregiver prior to the home visit.
   ☐ I e-mailed the caregiver prior to the home visit.
   ☐ I talked with the caregiver during the home visit.
   ☐ Other (*please specify*): ____________________

5. How did you use the *Program Description* form (click here to see form)? *Check all that apply.*

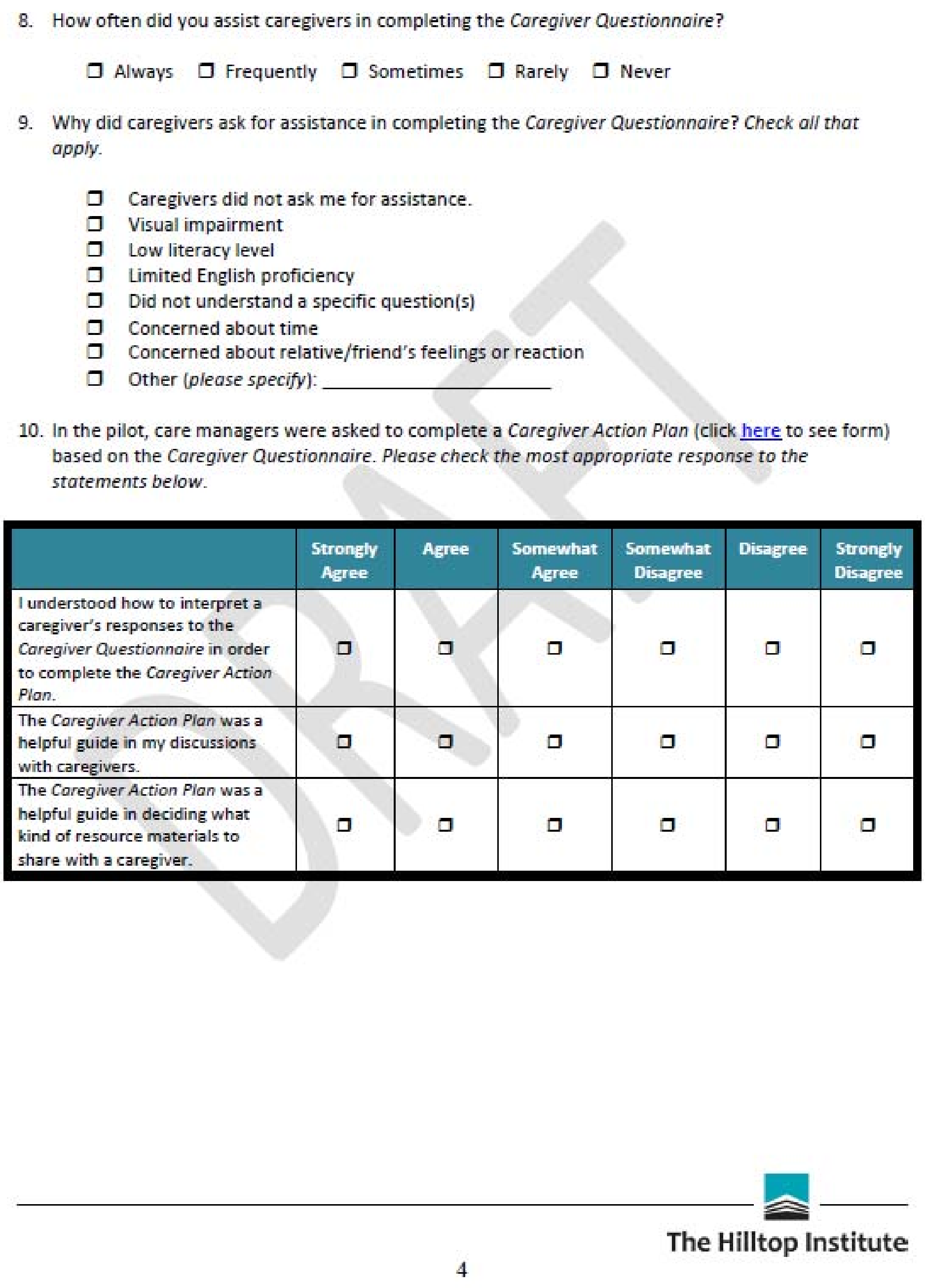
   ☐ I "snail" mailed it to caregivers.
   ☐ I e-mailed it to caregivers.
   ☐ I gave it to caregivers during the home visit.
   ☐ I didn't use the form.

6. How many caregivers did you approach who refused to participate in the pilot?

   ☐ None ☐ One ☐ Two ☐ Three ☐ Four ☐ Five or more

7. How often did caregivers ask you for assistance in completing the *Caregiver Questionnaire* (click here to see questionnaire)?

   ☐ Always ☐ Frequently ☐ Sometimes ☐ Rarely ☐ Never



8. How often did you assist caregivers in completing the *Caregiver Questionnaire*?

   ☐ Always ☐ Frequently ☐ Sometimes ☐ Rarely ☐ Never

9. Why did caregivers ask for assistance in completing the *Caregiver Questionnaire*? *Check all that apply.*

   - ☐ Caregivers did not ask me for assistance.
   - ☐ Visual impairment
   - ☐ Low literacy level
   - ☐ Limited English proficiency
   - ☐ Did not understand a specific question(s)
   - ☐ Concerned about time
   - ☐ Concerned about relative/friend's feelings or reaction
   - ☐ Other (*please specify*): ______________________

10. In the pilot, care managers were asked to complete a *Caregiver Action Plan* (click here to see form) based on the *Caregiver Questionnaire. Please check the most appropriate response to the statements below.*

	Strongly Agree	Agree	Somewhat Agree	Somewhat Disagree	Disagree	Strongly Disagree
I understood how to interpret a caregiver's responses to the *Caregiver Questionnaire* in order to complete the *Caregiver Action Plan*.	☐	☐	☐	☐	☐	☐
The *Caregiver Action Plan* was a helpful guide in my discussions with caregivers.	☐	☐	☐	☐	☐	☐
The *Caregiver Action Plan* was a helpful guide in deciding what kind of resource materials to share with a caregiver.	☐	☐	☐	☐	☐	☐

11. Where did you go to find resource materials to give to caregivers? *Please check the most appropriate response to the statements below.*

	Always	Frequently	Sometimes	Rarely	Never
Pilot Project Website Maintained by Family Caregiver Alliance	☐	☐	☐	☐	☐
Other Websites	☐	☐	☐	☐	☐
Office Supervisor	☐	☐	☐	☐	☐
Other Care Managers	☐	☐	☐	☐	☐
New Jersey DACS Staff	☐	☐	☐	☐	☐
Other (*please specify*):	☐	☐	☐	☐	

12. How often did you give caregivers resource materials on the following topics? *Please check the most appropriate response to the statements below.*

	Always	Frequently	Sometimes	Rarely	Never
Behavior Management (e.g., dementia, anger, sexuality)	☐	☐	☐	☐	☐
Direct Care (e.g., assistive technology, incontinence, dressing, grooming)	☐	☐	☐	☐	☐
Informal Supports (e.g., hiring in-home help, family participation)	☐	☐	☐	☐	☐
Self Care (e.g., stress management, depression)	☐	☐	☐	☐	☐

13. Were there topics that you would have liked to have had resource materials on, but didn't? *Please specify the topic(s).*

14. How did you give resource materials to caregivers? *Check all that apply.*

- ☐ I gave the materials to the caregiver during the home visit.
- ☐ I "snail" mailed the materials to the caregiver after the home visit.
- ☐ I e-mailed the materials to the caregiver after the home visit.
- ☐ Other (*please specify*): ________________

15. Some care managers voiced concern about talking with caregivers about caregiver burden in the presence of the client. During home visits in which you administered the *Caregiver Questionnaire*, how often did you encounter difficulty in talking with caregiver?

☐ Always ☐ Frequently ☐ Sometimes ☐ Rarely ☐ Never

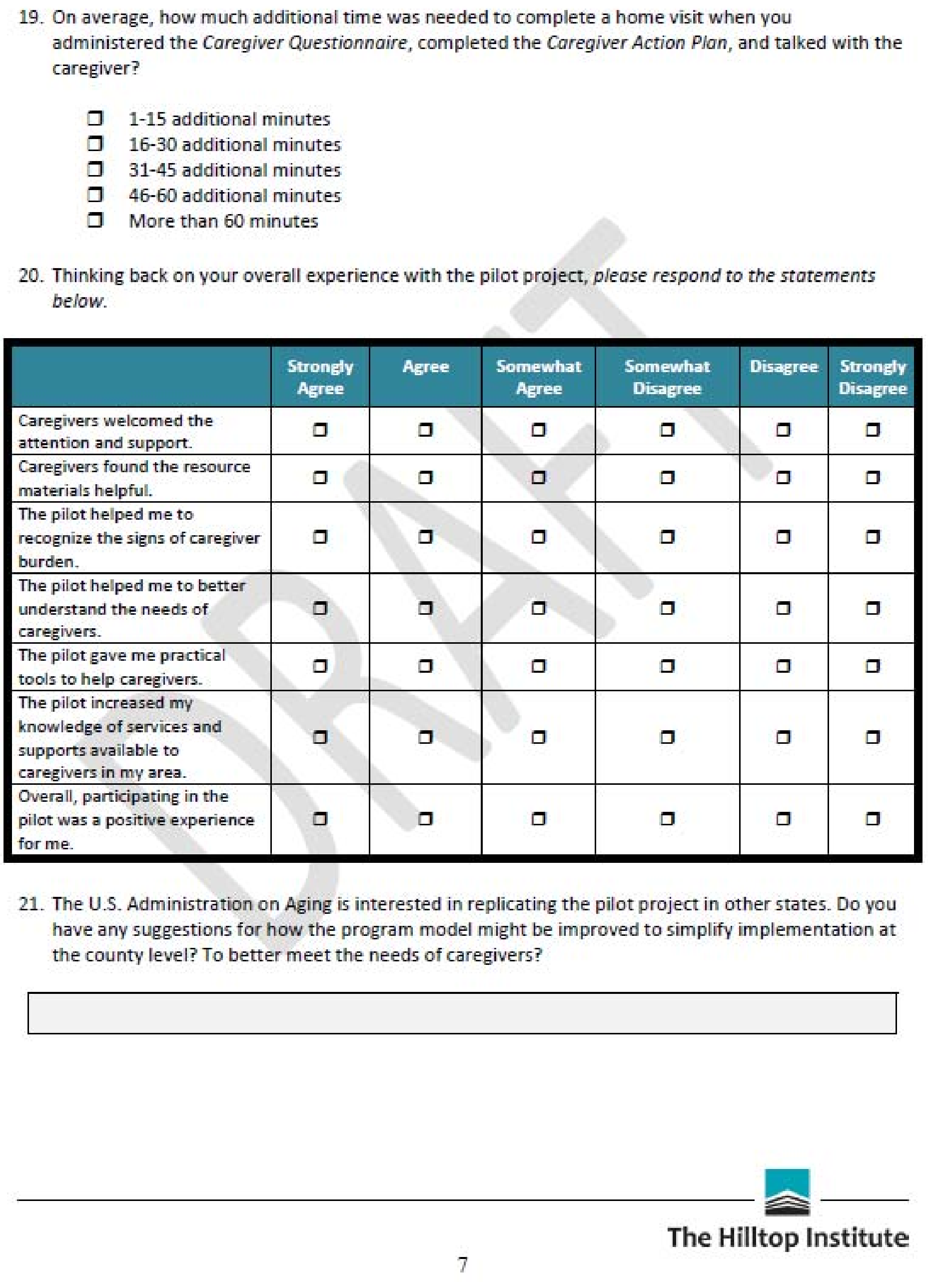
16. When you encountered difficulty in talking with the caregiver in the client's presence, what strategies did you use? *Please check the most appropriate response to the statements below.*

	Always	Frequently	Sometimes	Rarely	Never
I asked the caregiver to complete the *Caregiver Questionnaire* in another room.	☐	☐	☐	☐	☐
I talked with the caregiver in another room.	☐	☐	☐	☐	☐
I followed up with the caregiver by phone after the home visit.	☐	☐	☐	☐	☐
I followed up with the caregiver by mail or e-mail after the home visit.	☐	☐	☐	☐	☐
Other (*please specify*):	☐	☐	☐	☐	☐

17. Overall, how useful was the pilot project website maintained by Family Caregiver Alliance?

- ☐ I did not use the Family Caregiver Alliance website.
- ☐ Very Useful
- ☐ Somewhat Useful
- ☐ Not Very Useful

18. Do you have suggestions for improving the pilot project website maintained by Family Caregiver Alliance so that it can be a useful resource for care managers like yourself?



19. On average, how much additional time was needed to complete a home visit when you administered the *Caregiver Questionnaire*, completed the *Caregiver Action Plan*, and talked with the caregiver?

- ☐ 1-15 additional minutes
- ☐ 16-30 additional minutes
- ☐ 31-45 additional minutes
- ☐ 46-60 additional minutes
- ☐ More than 60 minutes

20. Thinking back on your overall experience with the pilot project, *please respond to the statements below.*

	Strongly Agree	Agree	Somewhat Agree	Somewhat Disagree	Disagree	Strongly Disagree
Caregivers welcomed the attention and support.	☐	☐	☐	☐	☐	☐
Caregivers found the resource materials helpful.	☐	☐	☐	☐	☐	☐
The pilot helped me to recognize the signs of caregiver burden.	☐	☐	☐	☐	☐	☐
The pilot helped me to better understand the needs of caregivers.	☐	☐	☐	☐	☐	☐
The pilot gave me practical tools to help caregivers.	☐	☐	☐	☐	☐	☐
The pilot increased my knowledge of services and supports available to caregivers in my area.	☐	☐	☐	☐	☐	☐
Overall, participating in the pilot was a positive experience for me.	☐	☐	☐	☐	☐	☐

21. The U.S. Administration on Aging is interested in replicating the pilot project in other states. Do you have any suggestions for how the program model might be improved to simplify implementation at the county level? To better meet the needs of caregivers?

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